REFLECTIONS

NARRATIVES of PROFESSIONAL HELPING

No Map for the Journey:
End of Life Caregiving

SPECIAL ISSUE

Volume 14, Number 3 Summer 2008

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REFLECTIONS: NARRATIVES OF PROFESSIONAL HELPING (ISSN 1080-0220)
is a refereed journal published quarterly by the Department of Social Work,
California State University Long Beach, 1250 Bellflower Boulevard, Long Beach, California, 90840-0902
Periodicals postage paid at Long Beach, CA.
POSTMASTER: Send address changes to Reflections: Narratives of Professional Helping, Department of Social Work, California State University Long Beach, 1250 Bellflower Boulevard, Long Beach, California, 90840-0902

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Special Issue

No Map for the Journey: Professionals Reflect on their Experiences with End-of-Life Caregiving

Guest Editor: Steve Wilson, Ph.D.

PRINTED QUARTERLY BY THE CSULB UNIVERSITY PRESS

Letter From the Editor

Jillian Jimenez, Ph.D.

This issue of *Reflections* is dedicated to those professional social workers who have offered caregiving to family members facing the end stages of their lives. The task of facing one of the greatest of life's challenges is not made easier by professional education and experience, as these narratives testify. Instead there is a bittersweet quality to the inversions experienced by those who have witnessed such passages from a safe professional distance. In the process of meeting the great challenge and opportunity offered by those who are dying, the authors in these narratives drew on their resources and their circles of support to sustain them, and found themselves in the roles of clients, perhaps for the first time.

Virtually all of us will have this experience at some point in our lives. While we are living it, the pain is searing; we feel as if we will die along with the one we love. Saying goodbye is the hardest thing we will ever do. Yet the real meaning of these experiences is felt only years later, when we can think about this time with calm reflection and realize that it has deepened our hold on life and diminished our fear of death.

Reflections would like to thank Steve Wilson for conceiving this issue, soliciting the narratives and performing the role of guest editor with great panache and intelligence. His contribution as a gerontologist is to have professionals reflect on their own first - hand experience with mortality. The universality of their experiences is refracted through their intellectual understanding of the themes embedded in end of life issues and their professional experience of witnessing these themes play out at a remove, for others. Steve Wilson has given us a great gift with this issue, one that *Reflections'* readers can share as their lives unfold.

Corrections:

We'd like to apologize for an error that was printed in our Winter Issue, Volume 14, #1. The narrative entitled "The Teacher's Task: Empowering the Student," by Paul Johnson and Brandi Fairchild has a mistake in the byline: Ms. Fairchild is listed as D.S.W., when it should have read B.S.W. We apologize to Ms. Fairchild for this error.

Introduction to Special Issue
No Map for the Journey:
Professionals Reflect on their Experiences with End-of-Life Caregiving

Steve Wilson, Ph.D., California State University, Long Beach

"Death is not extinguishing the light; it is putting out the lamp because the dawn has come."
- Rabindranath Tagore, Indian educator and Bengali poet (1861 - 1941)

This special edition of *Reflections* demonstrates that loss is universal, pervasive, profoundly heartbreaking, yet can still be a transformative experience. All the authors writing for this edition have a similar experience in common. We're all professional social workers and have all been the caregiver of a terminally ill family member. Contained within all our stories, in one form or another, is a common set of circumstances. After multiple visits to multiple hospitals, the doctor finally tells you that your loved one is dying. Though you knew the end of life would come eventually, you suddenly feel unprepared for what will follow—not the least of which is a willingness to let your loved one go. Literal life and death decisions follow. The next days, or weeks, or months come with all the confusing and contradictory emotions we've seen in our clients who have experienced similar losses over the years. But this time, it's our loss. We've supported the bereaved for years, but now the professional becomes very personal. Families rely on us for answers and resources, but we're frightened too. Who provides care for the family social worker? Shouldn't we know how to handle this situation? We've helped others countless times before.

Caregiving of a dying family member creates an internal conflict for professional social workers since our intellectual knowledge of death doesn't always assuage our feelings of loss. Rational explanations seldom ease feelings. Further, family members often rely on the social worker in the family as the rock of stability, which only complicates an already stressful situation. How can we be on the receiving end of sympathy and support from others when we've usually been the providers of care? However, within these narratives, you will see a personal transformation in the authors following the loss - a hope that triumphs after a loss, with our perception of social work changed. Out of the chaos of caregiving comes a clearer understanding of compassionate care at the end of life—perhaps the ultimate gift received from the trauma of our loss. Viktor Frankl said it best and quite simply: "Death gives life meaning."

Within these narratives there is a perspective on the distinction between sympathy and empathy. Sympathy is an expression of compassionate understanding of another's issue coupled with a sincere desire to help. So, although we might not have direct experience with another's tragedy, our compassion is extended through sympathy. Empathy calls on a deeper emotion. It is a literal sense that we can feel what another person has experienced. Thus, empathy is extended to those who have experienced a comparable pain to ours. However, as I reflected on these narratives, these definitions fall short. Empathy seems to be the ability to feel an emotion expressed by another person as if it were your own, *while maintaining your awareness that it is not your own*. Thus, empathy is less of an emotion and more of a capacity. It is the capacity to understand a person's subjective experience by vicariously sharing that experience with him/her, yet

keeping healthy objectivity. Sympathy seems to follow empathy; it is a sincere desire to support and/or comfort someone experiencing pain—most often emotional pain. After reading these narratives, I felt my own capacity for empathy and my willingness to offer heartfelt sympathy was expanded, which I believe will make me a better social worker. This was gift received as a by-product of guest editing.

The narratives contained within this issue are written by professional social work educators and practitioners who intellectually understand the phenomenon of caregiving stress and subsequent loss, yet they may be experiencing it from a new perspective as a client for the first time. These expressions of caregiving bravery and dignity in losing a loved one carry with them some important lessons learned. With these narratives we have the opportunity to answer some unique questions facing professionals who provide end-of-life care to a loved one. Does intellectual and academic preparation help us cope with family caregiving challenges? Does our professional experience buffer a personal loss? The themes that emerged from these narratives are perhaps not surprising: the resilience of the human spirit and the transformative power of experiencing the death of a loved one.

I hope you enjoy these narratives and are moved, as I was, by the lovingly written epitaphs to a significant person in the author's life. Beyond that, they are also a commentary on the resilience of humans and our capacity to go beyond self-imposed limits. We are much braver than we think. As social workers, we are witness to inconsolable grief and loss in one form or another as a daily occurrence. We understand that the loss of a loved one and the residual sorrow that follows can profoundly shape a client's views of the world. These narratives demonstrate that our own deep losses can also be reframed so as to shift our perception of our professional world.

A special "thank you" goes to *Reflections* Editor, Jillian Jimenez, and Assistant Editor, Wendi McLendon-Covey, for their support, encouragement, and patience in making this special issue possible. I would also like to acknowledge the anonymous reviewers for their valuable time and suggestions offered. Finally, my deep gratitude and appreciation goes to the authors in this issue for recounting their grief, loss, and transformation. Through your words, my hope is that we can all have a deeper appreciation of empathy in our daily social work practice.

The Legacy of Caregiving

Sally Hill Jones, Ph.D., Texas State University – San Marcos

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 (Hoefler, 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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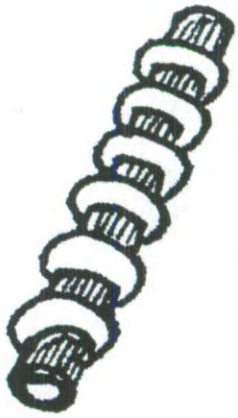

From Stillness to Dancing: The Journey from Caretaking of Another to Recovery of Self

Curt Paulsen, Ph.D., Augsburg College

Two years serving as his mother's caretaker left the author emotionally and physically exhausted. The invitation to reconcile grief and relief, in the aftermath of her death, pointed to other areas of his life requiring reconciliation. The accomplishment of this task, about which the author admits his ambivalence and potential lack of courage, is expected to expand his capacity for empathy beyond identification with those who suffer to a richer capacity to enter more deeply into their pain and joy.

After a two-year illness, my mother died early last year. I was her primary caretaker, a role that was as exhaustive as I had been told it would be. Within the various other dimensions of my life, I—with able assistance from my wife, children, and friends—managed to move my mother out of her home into assisted care and subsequently into a nursing home. Disposing of unneeded furniture and belongings was no less difficult than looking after her finances, managing medical appointments, attending to hospitalizations for recurring illnesses, and waiting through two surgeries and a broken pelvis, in addition to facilitating her relationships with family and friends. Perhaps most difficult of all was the constant reminder that this once proud, strong, and independent woman was reduced to almost total dependency on others, many she did not know. My sadness knew no bounds.

Exhaustion crept up on me; my efficiency declined; relationships, such as those with my wife, children, grandchildren, colleagues, and friends suffered; and my anxiety rose with respect to multiple unknowns, such as my fear that my mother would slip into a severe geriatric depression...or that I would.

Each time I entered the nursing home, virtually a daily occurrence, I became evermore aware of the pain and sorrow within the institution, as well as the humor that managed to find its way up out of the darkness, often rooted in incongruity. I vowed never again to drive by such a facility or hear a story of a nursing home resident without being more aware and more concerned for, and sensitive to, staff, residents, and their families.

I anticipated that one legacy of this experience would be increased sensitivity to others, including these remarkable people. This has become a reality. I did not realize, however, that real, genuine empathy would emerge, secondary to changes I would have to make within me, a journey I was not sure I had the courage to take because as Thompson (1991) suggests, creativity—which I think this grief journey is—involves "breaking apart existing combinations...combining of things or ideas into new combinations...[which] entails messing things up" (p. 43). I was not prepared for the 'mess.'

Death: The Door to Another Suffering

Difficult as these assisted care, hospital, and nursing home experiences were, I did not know that the worst was to come after my mother's death. Paradoxically, I would be led to see, and ever more fully understand, truths that would give me direction, though very paradoxical, inconsistent and, for me, difficult.

Mother slipped away early one afternoon. Even as I knew this profound event was approaching, I, too, felt like a 'dead man walking.' In a stunned state, I made the requisite phone calls, including the one to the mortician. Soon thereafter, I had the realization that the person who had birthed me, the person who was most always in my corner, was forever gone. There was a tremendous vacuum, a haunting and vacant space that could not be filled by anyone else. It hurt.

But lurking in the shadows, seeking an opening into my awareness, was a sense of relief, the lightness of being released from what had become heavy responsibilities that had taken their toll.

Subsequently, when people would ask how my mother's death was for me, I gave a variation of this reply: "Well, she did not wish to live any longer; she had little, if any quality of life left. And, though we miss her terribly, there is a measure of sweet relief for us." In other words, her death had negative and positive consequences for me. In response, however, many people latched onto the negative side with comments such as this: "You will grieve for at least a year; it's going to be rough." They seemed to imply that if this were not my experience, it would be indicative of a deficiency on my part.

Reflections on these conversations have left me perplexed. But, out of this struggle is forged, I believe, the seeds of my response to my mother's death that will offer greater personal creativity and passion and enlarge my professional work teaching and learning with students as well as my counseling practice with clients. I will, however, have to pay a price by relinquishing certain preconceived notions with particular reference to my tendency to lapse into a dualistic orientation.

When I have bi-polar feelings—as in grief and relief relative to my mother's death—I am tempted to think that if I have one feeling, I cannot simultaneously experience the opposite feeling toward the same person. To admit to this seems as if I am contradictory; I have learned over many years to hold a dualistic, *either-or* orientation consistent with many of the teachings to which I have been exposed throughout my lifetime. On the other hand, in the natural order everything co-exists in pairs of opposites, *both-and* dialectics, where each is needed for either to survive. Imagine fire without ice, land in the absence of sea, birth without death, everlasting day without night (or the reverse) and, the easiest to understand, female or male existing in the total absence of the other. Polar opposites in these instances are necessary for the survival of either.

Coming of Age: Accepting Realities

Given this reality of dialectics, it is reasonable to assume that I would experience both grief and relief in response to my mother's death. To accept this proposition is to simultaneously, however, be aware of other *both-and* dialectics, painful/wonderful realities, difficult to actualize, but full of promise for new life.

For the purpose of this paper, I will discuss two dialectics—intimacy and separation; and perfection and imperfection—that I have become more aware of as I struggle with my mother's death. They are consistent with my experiences of the dialectic of grief and relief.

Intimacy and Separation

The notion of dialectics suggests that strengths must co-exist with weaknesses; victories will stand alongside losses; freedoms will beget responsibility; acquisitions will inevitably lead to degrees of disillusionment; the other side of faith is doubt, and so on.

In my closest relationships, therefore, I must then acknowledge that intimacy will always be in balance with experiences of separation, and vice versa. This is contrary to a basic notion deep within me: If I truly love my wife, for example, I will get along, feel a constant sense of unity, and want to do most everything with her. This is consistent with the old adage that a strong, healthy relationship is associated with how close we are to one another, not how well we have achieved a balance between intimacy together and separation as individuals.

The truth is that contemplating losing my wife is unthinkable after having been together for forty-seven years. Words do not accurately describe this possibility, but those that come to mind include an amputation, a giant vacuum, a severe injury, or death to body and soul. On the other hand, there are times when I want to travel alone, sleep alone, have a sense of separation, experience disconnection for fixed, relatively short periods of time. Although I am conscious of this, I have never been totally comfortable with it. Yet, unity and separation are as natural as night and day or, in this context, grief and relief.

Johnston (1974) writes that "love is an exploration, a going out of self in quest of the mystery of the other; and in this search one goes endlessly on and on and on" (p. 160). In light of this statement, great intimacy can be achieved, but there is always an element of disconnection, mystery, and loneliness because our beloved can never be fully known. Yet this dialectic holds a paradoxical promise: Unity and separation in balance enable us to have more of each, not less. This promise, however, does not come naturally for me. My head comprehends; my heart is not so sure.

Perfection and Imperfection

Even though I often have been able to cleverly avoid my many foibles, I have known that they represent points of growth. And, I have known they fall into two categories: omission and commission. Interestingly, resolution for both is essentially the same.

Imperfections by Way of Omissions

From my earliest days, I have been given these admonitions, variations on a common theme: *If it is worth doing, it is worth doing well; Do the best you can; Effort in the direction of success will pay off*; and so on.

Implied in this orientation are messages of caution, for failure is to be avoided; it is downright dangerous. There is also the hidden admonition not to go out to the edge of one's abilities or experiences where failure might have a higher probability of occurring. To live within this protective, comfortable orientation, however, is to never know the outer aspects of our identities that hold seeds of our creativity and passion for living. We then engage in sins of omission and somewhere in conscious awareness lies this question: I wonder what would have happened if...?

When relationships live according to the principles of caution and perfection, there is opportunity for a deadly equilibrium that breeds the potential for boredom. If this is not changed consciously by allowing for more possibilities, even failures and mistakes, relationships are vulnerable to crises that may, paradoxically, serve the purpose of changing the relationship in such a way as to give it more possibilities, more creativity hence meaning, or the relationship may deteriorate to eventual dissolution.

To resolve my grief upon my mother's death—by acknowledging both grief and relief—is to simultaneously realize that I need to allow for failures as well as victories and that my wife and I—as well as my relationships with other family members and friends—need to continue to develop a language with which to have meaningful dialogue regarding such matters. Increased comprehension will facilitate the awareness of perspectives that can make sense of failures, mistakes, and hurtful expressions of disrespect, while reducing the probability of destruction.

O'Connor (1978) in her short story "A Good Man is Hard to Find" has her character, the Misfit, saying these words: "She would have been a good woman...if it had been somebody there to shoot her every minute of her life" (p. 133). Hopko (1987), in turn, reacts to those words of O'Connor: "To see things clearly, to realize....that even the virtues will be burnt up, very often requires an incredibly violent act. We often need to be shaken into that realization" (pp. 56-57). By way of this difficult journey, Hopko writes "There is a difference between improving ourself and being made whole, being brought to your true nature" (p. 57).

Imperfections by Way of Commissions

In contrast to errors of omission where we fail to execute our abilities, errors of commission relate to those dimensions of our lives that are destructive and that hurt others as well as ourselves. Regardless, they fall under a single category: a failure to be accountable, an avoidance of personal responsibility, a general orientation that leads to blaming others for one's shortcomings.

I am aware of having fallen into destructive ways of living in my history, stripping away the pretense I manifest in order to gain acceptance of others at the expense of my authenticity. As with errors of omission, however, it is in this state of brokenness, of being blown open, where change can occur. It is a matter of living in paradox, in this instance suffering in darkness as a way to the light, to new meaning. Wheatley (1999) quotes T. S. Eliot [East Coker III in *Four Quartets*): "So the darkness shall be the light, and the stillness the dancing" (p. 13).

Resolution: A 'Messy' Creative Process

During this period of my grief and relief, I have a much keener awareness of my separation and imperfection, as well as my capacity for intimacy and perfection; all parts of my wholeness are filled with positives and negatives. Even as I can be proud of strengths, the sting of my weaknesses cannot be ignored. It is a comprehensive, whole state, painful and exhilarating, implied in the poetry of Yevgeny Yevtushenko found in Whyte (1994):

> *Sorrow happens, hardship happens,*
> *the hell with it, who never knew*
> *the price of happiness, will not be*
> *happy*
> (p. 15)

Sorrow and hardship are inevitable parts of the process of living, certainly significant dimensions in grief. Whyte goes on to explain that in our contemporary society, people "wish to have power over experience, to control all events and consequences" (p. 17). The soul, on the other hand wishes "to have power *through* experience, *no matter what that may be*" (p. 17).

At the level of the soul, I take solace in knowing that I was a good caretaker of my mother through her death. But to constructively grieve, to be aware of the dialectics in my life—with particular reference to my unity and separation and perfection and imperfection—leaves me with an awareness of needing to be loved through a reconciliation of these wondrous strengths and stark weaknesses.

I was first brought to an awareness of this condition most clearly by way of my partnership with a native shaman on a South Dakota reservation. In the context of native ceremonies, I had my most telling experiences of how small I was relative to a higher spirit. Even as I felt I was undeserving, I knew that the first requirement, of two, was to accept the love and acceptance this spirit gave me.

First Requirement

Now, as I wrestle with these issues that surrounded my mother's death, I recall an experience with the shaman. He and I, along with two other native men, were deep in a forest, in the twilight of a low sun, preparing for a ceremony to call forth the spirit with reference to an illness of a daughter of one of the men. The shaman had built a fire to heat rocks, about the size of softballs, to red hot on which water would be poured to produce steam in a small igloo-sized structure with a bow frame. He was dressed in a faded blue chambray shirt, old jeans, and boots, all of which set off his bronze skin and black hair tied in a ponytail. Striking as he was, he showed vestiges of a hard life: deep, weathered wrinkles in his skin; a look of having experienced periods of malnourishment; but most difficult of all for me to witness, a badly infected eye, infected perhaps for a long time, surely now leaving him with little, if any, sight.

Still, he exuded a peaceful countenance, a sense that even though suffering abounded—not least of all related to the cruel racial bias I knew was prevalent toward him and his people—he was complete, whole, a living example of the dialectic between strength and weakness, life and death, perhaps not physically, yet with reference to any need to impress or deny. He was whole in every sense; his existence was sufficient with no need to embellish or defend.

Now, many years later, I am attempting to acquire a similar presence, a comparable unity of diverse, contradictory elements within my being without a need to withhold or explain, hopefully giving a measure of integrity that will invite the same from my students and clients. To the extent this is achieved in my classroom

or office it is correlated with a sacred, spiritual, and numinous atmosphere beyond physical accruements such as furniture, white boards, walls, and windows.

Second Requirement

The second requirement, however, is to love others out of this process of defeat, making us partners in God's creation—however each of us defines a higher power—consistent with the words of Rilke quoted in Yalom (1980):

> *What will you do, God, if I die?*
> *I am your jug, what if I shatter?*
> *I am your drink, what if I spoil?*
> *I am your robe and your profession*
> *Losing me, you lose your meaning*
> (p. 425).

Rilke brings our relationship with a higher power full circle. We are given to and we give back. For me, this is the point: I can grieve even as I experience relief. By doing both, I can enter into dialectics—with particular reference to intimacy and separation and perfection and imperfection—with more courage to suffer the loss of my mother, to even hit bottom: a violent experience as a forerunner to becoming new, transformed, ready to love others by way of humility, yet strength. This is the astonishing legacy that my mother has given me.

And, surely she would not be surprised to realize that the journey to and through her death would call upon me to consider my intimacy and separation dialectic in the context of my marriage where each of us, to various degrees, is always in the context of some level of mystery. Although some level of mystery should and will always remain, it is equally important to move in the direction of wholeness, including the sharing of as many sides of our nature as we dare, giving foundation and reason for unconditional love, rendering the probability for great joy and suffering.

Palmer (2004) writes:

> *As I stand in the tragic gap between reality and possibility, this small, tight fist of a thing called my heart can break open into greater capacity to hold more of my own and the world's suffering and joy, despair and hope.* (p. 178)

The reality is that the loss of the boundaries of myself, allowing for deeper union with my wife, fosters a lush reprieve from the loneliness of responsible living, giving me a desire to remain in this place of sweetness forever, even as it must inevitably give way to a separation that preserves my sense of a separate self. For me, if not for others, a sense of the sacred, a power beyond the known, gives balm to my wounds in this process, even as I, hopefully, can pass the same to others, including my students and clients, beyond lectures, grading, and therapeutic techniques, which, in and of themselves, lack power and possibility.

Conclusion

I wish to take the journey, but I am not sure I am up to it, for as Thompson (1991) writes, it "entails messing things up" (p. 43). Not to do so, however, is to settle for simply a cognitive awareness of the suffering of others—such as those affirmed in institutional settings, including assisted care, hospitals, and nursing homes—but it shortcuts a deep, meaningful, wrestling encounter with my internal dialectics, the essence of my wholeness. This encounter is a prerequisite, in my opinion, for developing the capacity for genuine empathy and presence, whether personal or professional, with others.

I love my mother for leaving me this legacy, but sometimes I wish she hadn't.

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"You Know What To Do...You're A Social Worker!" A Daughter's Perspective of End-of-Life Caregiving

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This narrative is an account of what happens when a daughter who is a social worker is faced with her most difficult challenge: preparing for and witnessing her father's death. The author describes the challenges of acting as both daughter and social worker and how using social work skills and family experiences assisted her with caring for her father. Despite her knowledge and skills, the author believes she learned more about life and death from her father during his last days.

Introduction

Whenever my family experienced difficulties, my mother's favorite response to me would be, "You know what to do. You're a social worker." Those words carried with them the assumption that, as a social worker, I had the training, knowledge, and skills to handle any crisis, even those within my own family. However, not until I faced a family crisis—the critical illness and subsequent death of my father—did I really know what to do and how to handle the situation. While nothing can ever fully prepare anyone for the loss of a loved one, this narrative describes the social work skills I used to assist my mother in caring for my father during his illness and subsequent and untimely death. Yes, I used my social work skills, but other factors— including my role as a daughter, my spirituality, and my African American cultural tradition—also helped me to handle my father's death. This narrative is an account of my father's final days and what happens when a daughter who is a social worker is faced with her most difficult challenge, preparing for and witnessing her father's death.

Prologue: Family and Cultural Tradition of Caregiving

For women, caring is seen as almost a genetic trait or family inheritance that passes from one generation to the next. As my parents' only daughter, I assumed that it would become my responsibility to care for them. According to Stoller and Cutler (1992), "...daughters are more likely to assume the caregiver role because of cultural norms that support gender role socialization" (as cited by Rozario, Chadiha, Proctor, & Morrow-Howell, 2008, p. 320). I think I was better prepared and understood what I would have to do as a caregiver for my father because I had witnessed other family members provide care to older, ill relatives. As an adolescent, I saw my maternal grandmother care for her ailing and dying mother. Although I was a preteen, my grandmother's devotion to caring for her mother set an empathetic and strong example to me of my role as a daughter and a potential caregiver.

Later in college, I had another opportunity to watch caregiving first hand. My aunt cared for my paternal grandmother with humor, compassion, and enduring devotion. When my grandmother suffered several strokes that required her to be hospitalized, my aunt was there daily, and she was there when my grandmother passed away. I was very concerned about my aunt as she had been my grandmother's primary caregiver for so many years; I knew the constant caring must have taken a toll on her emotionally and physically, and I shared my concerns with my mother. At the time my mother informed me that caring does take a toll, but, "We're family...we care for each other no matter the circumstances..."

My mother's words remained with me as I grew older and I understood that I would some day inherit the caregiving role for my parents. My family shared very traditional African-American values, including a strong family orientation and belief in caring for our

elders. In African-American families it is a common practice for children to provide care for their elders (Dilworth-Anderson & Anderson, 1994; McAdoo, 1993). Further, "Researchers note that African-American families have strong filial bonds" (Rozario et al, 2008, p.321) White, Townsend and Stephens (2000) suggest that "African-American families generally accept that family members should care for an aging relative..." (p.725). As an adult, I chose to live near my parents because I knew that I would be available to care for them if needed.

My maternal grandmother and paternal aunt were incredibly strong African-American women who provided me with living examples of how to care selflessly and with devotion until death ended their roles as caregivers. Their experiences and my mother's words, "You know what to do," were constant reminders of my responsibility to care for my parents.

Daughter as Caregiver

In December 2006, my opportunity to act as a caregiver came sooner than expected. I am always overwhelmed in December, and December 2006 was no exception. My children had their school assignments; my daughter had volleyball practice, and my son had basketball games. To add to my family commitments, I had to prepare for work. I looked forward to working on my computer all day Saturday when the phone rang before 8:00 a.m. It was my mother, informing me that she needed me to come over to her house and take my father to the hospital. I knew my father was sick, in fact my mother had taken him to his primary physician a few days earlier, and he had been prescribed medication. I questioned my mother, "What's going on? I thought Dad was feeling better." My mother told me that it appeared that his condition was not improving and what initially seemed like a minor cold and cough had become a non-stop cough that interfered with my father's ability to sleep and eat.

When I arrived at my parents' house, my father did not appear to be his usual happy self. In fact, he looked very ill. I had to close the front door to his house because he was unable to do so due to his pain. He had a hard time getting into my car and I had to gently place the seat belt on him. I immediately assumed the role of a "double-duty caregiver," professionals that work in the social service or medical profession who also serve as caregivers to their family members (Ward-Griffin, Belle Brown, Vandervoort, McNair, & Dashnay, 2005). My professional and non-professional roles began to blur as I did an initial assessment of his condition. "Daddy, how long have you been feeling like this? Where is the pain? What did your doctor say the other day? Have you been taking your medicine?" Seeing my father, who had always been a very active person who played sports throughout his life, grimace in pain was especially hard for me to accept. I remember as a child going to his basketball games and watching him coach my brother's little league team. As he grew older he maintained his physical health, even walking daily and shooting baskets with his grandchildren. After being diagnosed with a severe form of rheumatoid arthritis, his activity level had been reduced, but not to the level I was now witnessing in my car.

At the emergency room, the receptionist asked my father his symptoms and the list was detailed and exhaustive. I could hear the pain in his voice. As we waited in the emergency room, he admitted to me and another patient in the waiting room that "I just don't feel like myself anymore." Hearing my father describe himself in that manner made me feel helpless. I wished I could have waved the magic wand that would restore my father's health and sense of vitality. Requesting a wheelchair from the triage nurse during her examination, I reemphasized for the nurse my father's medical conditions and his need to be seen as soon as possible due to the intensity of his chronic pain. When I attempted to hold his hand, he recoiled because my touch was painful to him. Despite my request for my father to be seen immediately, we had a long wait in the emergency room. Each minute added to my sense of anxiety and concern for my father.

Finally, after being admitted to a hospital room in the emergency department, I sat with my father, and he showed glimpses of his usual self by joking with the nurses and talking with me. As he downplayed his pain and his

symptoms, I started feeling a little better about my father's condition. Perhaps he was just experiencing another severe rheumatoid arthritis flare-up that would be solved with a pain killer. Then he began coughing and I realized that in my rush to see him admitted to alleviate his pain I had forgotten to report his cough. I immediately found his nurse and told her about the cough. She reassured me that it probably wasn't anything major but she would notify the attending physician. When the physician appeared I notified him of my father's cough and he assured me that the cough was a secondary problem, but he would take chest x-rays to be on the safe side.

I felt a little better after my father's rheumatologist consulted with the emergency room physician and it appeared my father's pain could be alleviated. But there it was again: the unrelenting cough. I immediately went to the nurse's station and reminded the head nurse that my father never was taken to the X-ray department to have his chest X-ray taken. Within a matter of minutes a technician came and wheeled my father away for the exam. Trying to keep a positive outlook on my father's condition, I believed that the X-ray results would be routine and after receiving a few more shots of pain medication he would be released from the hospital and back to his normal self.

The physician assisting my father in the emergency room that day appeared younger than I and not as experienced as some of the other physicians. The physician's youthfulness concerned me because I wanted my father to receive the best medical care possible, especially since he was experiencing so much pain. I knew and trusted my father's primary-care physician, but I had never met the emergency room physician and he would be responsible for diagnosing and deciding my father's treatment plan. About 30 minutes after the X-rays had been completed, the emergency room physician had an opportunity to review them. I sat anxiously, watching the physician look at my father's X-rays, and I noticed a puzzled look on his face. He immediately grabbed one of his colleagues to come over and look at the X-rays. Now I was alarmed and tried not to show my concern to my father who was lying there watching me. I could tell by the expressions on the physicians' faces and their conspiratorial whispering that my father's X-rays were not "normal" and that this routine trip to the hospital was more serious than I had anticipated.

The physician came over to us and explained that it appeared that there was fluid in my father's lungs—a mild case of pneumonia probably, nothing too serious—but my father would have to be hospitalized for further observation. My father, who was usually compliant with his physicians' wishes, began to put up an earnest protest: "I don't want to stay this time...just let me go home!" I was patient and tried to reason with him: "Dad, I know that you want to go home, but if you go home now and get sicker, Mom can't help you and you'll just end up back in the hospital again. Please listen to the doctor; he's trying to do the best thing for you." My father remained steadfast in his desire to leave the hospital: "I still want to go home; I don't want to stay here!" I attempted to compromise with my father by suggesting that I speak with my mother about his desire to go home against physician's advice, and I told my dad that if my mother was willing to let him return home, I'd take him. Of course, when I reached my mother by telephone, she refused to let my father leave the hospital, and I returned to notify my father and the emergency room physician, who appeared relieved that my father would be admitted. I sat there with my dad and reiterated that everyone wanted him well and the best place for him to get the proper treatment and become well was at the hospital.

After my mother arrived at the hospital, I gave my father a kiss and said, "I love you Daddy. Get better!" I did not know it at that time, but that would be the last conversation that I would have with my father...

Worrying about my father's condition and my mother's health, in addition to caring for my own family and working, compromised my own health. As a result, I caught the flu and was unable to visit my father in the hospital over the next few days, but I received daily updates on his condition from my mother, my aunt, and the nursing staff at the hospital. My father was on a ventilator and was in and out

of consciousness. Despite his condition, I firmly believed that he would return home by Christmas to be with our family. My mother and I even started to discuss the type of care he might need when he returned home and how we would ensure that he received the proper care and rehabilitation.

One Sunday, three weeks after my father was hospitalized, my mother was told by my father's pulmonary specialist that his lungs were in the process of failing. She contacted my husband to inform us of the dire nature of my father's prognosis and to tell us to come to the hospital immediately. After he hung up the telephone, he told me to sit down before relaying to me the gravity of my father's condition. I cried, then immediately called my mother and told her that I would meet her at the hospital.

Once at the hospital we met with the pulmonary specialist who informed us of my father's treatment options and his grave prognosis. My mother was strong and steadfast in her decision to allow nature to take its course. Her only request was that my father "...not suffer anymore, or be in pain." I agreed with and supported my mother's decision because I understood that my father's quality of life would never be the same and that for several years prior to this hospitalization, he had been ill and experiencing intense pain. It still was not an easy decision to make, and I was overwhelmed by feelings of sadness and helplessness. I did not want my father to continue to suffer, but I was not ready to let him go. I felt like the English poet, Dylan Thomas, in his poem *Do Not Go Gentle Into That Good Night.* I wanted to tell my father:

Grave men, near death, who see with blinding sight
Blind eyes could blaze like meteors and be gay,
Rage, rage against the dying of the light.

And you, my father, there on the sad height,
Curse, bless, me now with fierce tears, I pray.
Do not go gentle into that good night.
Rage, rage against the dying of the light
(Thomas, 1952).

For me, the whole experience was surreal. I could not believe what was happening, how a routine visit to the emergency room could end like this for my father. I also remembered how he had resisted staying in the hospital; perhaps he knew that he was not going to return home.

Even hearing the physician's diagnosis and seeing my father on the ventilator, unconscious, could not prepare me for the reality that my father was dying and that our family would never be the same. As our family members that were there with us at the hospital broke down into tears, I knew that I would need to be strong to help my mother through this very painful time. I had always been the one in the family who disliked going to hospitals, funerals, and cemeteries, and now I would experience my father's passing. And even though I felt I understood death and dying from an academic standpoint, as I stood in the hospital with my mother, I felt unprepared to experience death in such a personal manner. I could not believe it! I visited my father in the ICU room, protected by gloves, a gown, and a mask, and held his hand. The only thing I could say was, "Thank you, Daddy. I love you!" I still could not believe that my father would not be making a miraculous recovery and walk out of the hospital doors.

Daughter as Social Worker

My mother's refrain, "You're a social worker.....you know what to do," was fresh in my mind as I immediately started to help her. Although I am one of three social workers in my family, I was the only one at the hospital to assist my mother. My father's younger sister, my aunt and a social worker, lived 3,000 miles away. My younger cousin, also a social worker, visited my father on the Sunday we learned my father was critically ill, but was too emotional to return. So, I knew that I would be the one my mother would rely on. However,

being daughter and social worker was emotionally draining. I felt conflicted—I wanted to cry and deal with my own emotions, but I also knew that my mother would expect me to serve as liaison between her and the medical staff. I was used to my role as family social worker because my mother always requested that I assist her when my father had medical crises. As a result, I was familiar with his medical history and felt confident interacting if needed with his physicians. Perhaps if I hadn't been a social worker, my mother would choose to talk to the hospital social worker. But my mother trusted me, and I was willing use my social work knowledge in my caregiving role.

My social work skills were immediately put to use. I used my counseling skills, as I listened to my mother talk about the stress of my father's terminal condition and her sadness that he would not recover. I assessed what needed to be done and immediately began to make a mental list of all the family members that needed to be contacted, beginning with my brother. I suggested that the family priest be contacted to see my father. I asked my mother if there were any additional questions she had for my father's physician. I contacted all of my father's siblings to inform them of the gravity of his condition.

As soon as I contacted them, family members and friends began their pilgrimage to the hospital. During that time, I became a facilitator and counselor, communicating my father's medical condition with the many family members present at the hospital and ensuring that their emotional needs were being met. As each new family member entered the ICU, my mother requested that I accompany them to my father's room and be present with them to explain my father's condition and be there to offer emotional support. After each visit to my father's room, I felt saddened and emotionally drained because I could see my father's health declining rapidly, and I was worried that some of our family members would not have an opportunity to be present with my father in the hospital.

Informal Support

As we kept our daily vigil at the hospital, we were fortunate to have family and friends come by and sit with us and help us with errands. It seemed as though the world stopped when my father became critically ill, but it did not. Our family members and friends were my anchors to remind me to eat and to help me complete those daily tasks that I had neglected in order to stay with my mother and father at the hospital. Often they would share some of their positive memories and stories about my father which would help to remind us that my father touched many people throughout his lifetime.

A family friend, Carol, who was a doctor at the hospital where my father was hospitalized, met with us. She was able to alleviate our fears regarding the decision to remove my father from life support and she also explained the process of death to us and answered our questions. Her support and professional expertise was invaluable. I trusted Carol and felt comfortable sharing my fears regarding my father's impending death. Hearing Carol inform us that she knew and trusted my father's physician and the medical staff helped me trust that they would provide my father with competent care as he prepared for death.

Advocacy during a Difficult Time

Due to the long hours at the hospital and because of lack of sleep, by Tuesday, December 12, I felt mentally and physically exhausted. Each minute at the hospital became agonizing. It hurt to see my father languishing away, and it also hurt to realize that his death was imminent as he could not support his vitals without life support. I believe in the sanctity of life and I especially felt that the life of my father—the man who gave me life—was precious and should be given every opportunity to continue. However, looking at my father in his hospital room, unable to think, move, or breathe unassisted, tested my definition of life, especially since my father was a vibrant, energetic, and engaging person. To me life means vitality, the ability to think and to breathe unassisted. In my naïve definition of life, there was no need for medical intervention or

artificial means of support. In some instances, there is a fine line between life and death, and the literature indicates it is not easy defining death (Dickinson, 2005). I could see that extending my father's life by using life support would not restore him to his former health. By December 12, I felt as though the life-support measures were preventing my father from experiencing a gentle death and the afterlife. I also knew that my father had very specific, advanced directives and a Do Not Resuscitate (DNR) order, so I felt that my father had defined the terms of his death. As difficult as it would be to witness his death, I knew that I would obey my father's wishes.

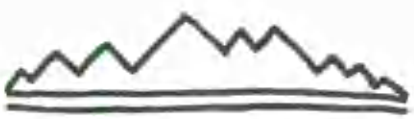
My mother and I also met with and continued to discuss my father's medical condition with his physician. According to Barrett (2006), "African-Americans as a cultural group have been documented to reflect a preference for open communication and discussion with their physicians as means to making decisions about end-of-life care" (p.256). My father's physician performed all the necessary medical examinations, including a lung scan, to ensure that there was no possible medical recovery for my father and that any additional medical efforts would be futile. My mother and I believed the physician when he said that nothing more could be done for my father medically. He was a very gentle, knowledgeable, honest, and compassionate physician. He had even taken the time to consult my cousin Debra, a surgeon in Chicago, regarding my father's medical status. After that meeting, my mother decided the time had come to withdraw my father's life-support system since it was no longer extending his life, merely prolonging his death. My mother showed her enormous strength and courage at that moment. There was no long discussion between her, the doctor, and me. She simply stated, "I know your father told me that he wouldn't want to remain on life support. He's in God's hands now." I felt overwhelming sorrow for my mother at that time because I knew she would be losing the love of her life, her best friend and her support.

My role as a daughter was to notify all our family members and ensure that they would come to the hospital immediately and to notify our family priest that my father's condition had worsened. Additionally, my mother requested that I go to the ICU during the process to check on my father. On one hand, I was the scared little girl, terrified about witnessing my father's death. On the other hand, I was still trying to be the brave social worker who knew what to do during a very emotional time. It was difficult but, at my mother's request, I again became a "double-duty" caregiver: a daughter and social worker, using my advocacy skills. According to Ward-Griffin and colleagues (2005), double-duty caregivers often "advocate on behalf of their relatives, especially if they were not in the position to speak for themselves" (p.386). My father was unable to tell the doctor of his need for a peaceful and dignified death, but I wanted to ensure that would happen for him. According to Dickinson (2005), the physician's role at the end of life is critical, and physicians have a responsibility to the dying patient to "mitigate their suffering while allowing them to die" (p.3). I met with my father's physician, asking questions regarding the process of removing his life-support system, advocating for my father's right to die with dignity and in peace.

I wanted to ensure that my father experienced no pain as he transitioned from this world to the afterlife. As a social worker, I was familiar with the term "palliative care," but I had never worked with dying individuals nor had I experienced the process of death first hand. My father's nurse was empathetic and patient with me as I observed him prepare my father for his end-of-life experience. Feeling very anxious and uncomfortable, I was direct and purposeful in my interactions with the nurse. "How are you going to make sure that my father won't experience any pain? Will my family members be able to be with him in his final moments?" The nurse assured me that Father would have a peaceful death surrounded by our family. I was too sad and scared to remain with the nurse or to witness the removal of my father's life-support system. I asked my oldest friend, Kate, to remain with the respiratory therapist as he removed the tubes from my father and to let the family know when to return to my father's bedside.

In the hospital waiting room, the family members present were joined by one of the hospital's chaplains who prayed with us and offered us words of support. I was nervous and anxious as we waited. I wondered if the nurse was ensuring that my father would not feel any pain. I worried about my mother and brother and how they would handle my father's death. I was scared that my father's death would be long and painful. It seemed as though the process was taking forever, but about thirty minutes later, Kate told my family it was time to join my father in his hospital room.

My anxiety and apprehension about witnessing the process of death subsided as I stood with my family members. As I stood near my father, I could only thank him for being the wonderful and loving father that he had been to me. I wondered if he could hear and understand my words. I wanted to make sure that he knew that I loved him and was there at that moment. I felt that it was important that he knew he was not alone as he transitioned from this world to the afterlife. I was prepared to accept God's plan for my father and during that moment, my prayer was that my father would experience no pain. My father passed away peacefully and with dignity and grace in the presence of his loved ones. I could not believe that he passed away so quickly and peacefully. All of my fears of a prolonged and painful death for him were never realized. Immediately following my father's passing, our family members joined hands around his hospital bed and prayed for him and for ourselves. Leaving his hospital room, I felt a calmness and relief that my father did not suffer in death.



Epilogue

My mother's words, "You know what to do. You're a social worker," were my mantra during my father's last days in the hospital. I used my advocacy, counseling, facilitating, and assessment skills during those days. However, I also feel other factors helped me during the process including family cohesion and spirituality.

Family Cohesion

Having a cohesive and supportive family was also beneficial to me during my father's illness and subsequent death. In my family's African-American cultural tradition, we believe in caring for and supporting each other. A strong family orientation and a family-centered approach to end-of–life care are documented as common values for African-American families (Barrett, 2006). Four years prior to my father's death, my parents and I had discussed how the end of their lives should be handled. At the time of our discussion, I was in denial. My parents had chronic medical conditions but were healthy, happy, and active individuals. Also, our family was known for the longevity of its elders; my paternal grandmother lived to 90 and my maternal grandfather is 92 years old. After the discussion, I felt my parents' deaths would be many, many years into the future.

Knowing and understanding my father's end-of-life desires made it somewhat easier for my mother and me to accept the decisions that were made pertaining to his treatment. I experienced some level of comfort knowing that we were following my father's request not to have his life prolonged. Even though the decision to remove him from life support was my mother's to make, she used a family-centered approach by discussing it with my brother and me and talking to us about our feelings regarding her decision. I appreciated the fact that my mother talked to us about her decision. I was not surprised or angered by the decision because I knew my father's wishes. My brother and I were saddened by the decision, but we also knew that it was what our father requested. We communicated with each other during each step of the process and supported our mother during her difficult decision. I felt as though we were walking through this difficult time together, relying on each other for support and guidance. Our family's cohesiveness and support of each other strengthened me. I believe that I could not have witnessed my father's death without

my family being present with me because we were able to comfort each other.

Spirituality

Lastly, spirituality and a belief in God helped me during the days of my father's illness and death. For many African-American families, faith and spiritual practices are a fundamental part of life and family values (Turner, Wallace, Anderson, & Bird, 2004). My family is very religious and those spiritual values are part of my identity. As soon as my father was hospitalized, I asked family members and friends to pray for his well-being. At the hospital my family welcomed the prayers and spiritual words of encouragement offered by our family priest and the hospital chaplain. The importance of spirituality for caregivers is acknowledged by White, Townsend, and Stephens (2000) who state, "For African-American caregivers, prayer and faith may raise their threshold for the stresses of caregiving, may act as a buffer when caregiving stresses arise, and may be associated with perceptions of caregiving rewards, such as being blessed by God for their caregiving efforts." Each day prior to going to the hospital, I would go to my church and pray for my father and our family. It was my coping strategy. I am not a physician, so I could not give my father any medical intervention that could save his life, but I could offer my prayers as spiritual intervention. The research of Branch, Torke, and Brown-Haithco (2006) identified one of the essential spiritual values of African Americans as a belief in God's providence especially during crisis situations and an acknowledgment that, "Whatever happens is part of God's plan" (p.1203). Praying allowed me to turn over the stress of caring for my father and family to a "Higher Power" whom I trusted would hear my concerns and guide me during my difficulties. Also, being with the members of my church community helped me to realize that I was not alone, and that gave me a sense of strength. Finally, going to my church gave me a sense of peace, as it reinforced my beliefs that my father who was a very spiritual person, would transition into an afterlife with God.

In addition to my spirituality, I also believed that it was important to have my father's spiritual needs met as he was preparing for his end-of- life experience. The International Work Group on Death, Dying and Bereavement (2006) agree that in addition to providing medical care for a loved one preparing to die, other factors including spirituality must be addressed. They state, "Providing optimal caregiving to a dying...individual...as a family member...involves a complex of cognitive, psychological, social and spiritual factors..." (p. 661). Additionally, the research of Branch and colleagues (2006) acknowledges the salient role of spirituality for African-Americans end-of-life experiences. My father was a deeply religious man who was a dedicated and involved member of his church. Throughout my life he shared with me the importance of spirituality, especially in difficult times. So, as soon as I discovered that my father was gravely ill, one of my first inclinations was to contact a priest who was a friend of our family and knew my father. Despite his obligations to his church, he came to the hospital and prayed with my family. He was also kind enough to sit with me and pray with me in my father's room and offer support to me as I cried. It was comforting to hear the priest talk to me about how my father served his church community and family. Even though my father was gravely ill and comatose, I believe he was comforted during the time our priest prayed for him.

Conclusion

When my father died I lost a friend, a hero, a supporter, and a wise sage. Throughout my life he taught me many invaluable lessons that I will always cherish. During his final days, I believe my mother looked at me to offer assistance because she believed as a social worker I'd know what to do. It was hard to be both daughter and social worker. Truthfully, it was a difficult transition for me to use my social work skills during such a personal time and to balance the emotions I experienced as a daughter. However, I believe those social work skills (assessment, counseling, facilitating, and advocating), coupled with my family and

cultural experiences (tradition of caregiving, family cohesiveness, informal support, and spirituality) provided a foundation for me to assist my father and my family. And yes, even with those skills and family experiences, being present for my father's final days was still a difficult and life-changing event for me.

True, I am a social worker and I should have known what to do, but my father taught me so much more in his final days. I have gained new insights as a result of my experience caring for my father in his last days and being present during his death. Prior to my father's death, I viewed it as a painful and prolonged process and I anticipated it with fear. However, through my father, I learned that death was part of the process of life and that it could be dignified and peaceful. Being able to share such an intimate and emotional experience with my father and my family members has helped my understanding of death. It was a very touching gift that my father gave me in his final days...for I now have a greater appreciation for life and a better understanding of death.

Acknowledgement

The author is grateful to the reviewers for their valuable comments on earlier drafts of the manuscript.

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Mama's Map for Living—and Dying

Erlene Grise-Owens, Ed.D., Spalding University

The following narrative describes how the simple life lessons (or "Mama-isms") taught by the author's mother provided the framework for her personal and professional life. These lessons came into sharp focus when seeking out and providing end-of-life care for her mother.

My one-of-a-kind, spunky, 86-year-old mother, Beulah Erma Jenkins Grise, died July 23, 2006. She lived her entire life within an approximately 20-mile geographic parameter. Her experience of the broader world was limited, but her experience of living was deep and complex. Along with my father, my mother raised twelve children on a family farm in rural Kentucky. Previously a force akin to the "Energizer Bunny"—which her children affectionately called our petite, lively, life-force—my mother's health declined dramatically in her later years. Because of progressive Alzheimer's and other ailments, my mother lived the last few months of her life at a nursing home in a small town near her home place. During her nursing home stay, she had several medical crises that required hospitalization.

My partner, Larry, and I were ending a two-week trip to England when we learned that Mom had been hospitalized Friday, July 21. Initially, my siblings who were with Mom thought that, like so many previous times, our resilient Energizer Bunny would bounce back from this medical incident. However, her condition deteriorated precipitously on Saturday, and we learned on Sunday morning, July 23, that Mom's death was imminent. It was an excruciating, heart-wrenching experience to be across an ocean as my mother breathed her last. However, it was also a humbling and holy experience to recognize both the limitations of physical humanness and the unbounded grace of spiritual connectedness. This experience was somewhat metaphorical of my story of unanticipated and painful distance, and yet deep connection, with my mother during her last years.

My story is told from the viewpoint of a support role. Like any family story, it has layers of stories within the story, some of which I will articulate and others which will remain untold. I want my story to provide a perspective and serve as a resource for those family members/loved ones who may not play a starring role—i.e., primary caregivers—but, nonetheless, have a story. As my mother's health declined, some of my siblings became more distant, emotionally and/or geographically, for myriad reasons of family and individual dynamics that would constitute a novel, which I won't write! Ultimately, my three siblings who lived near Mom and an older sister who lived out of town became her primary caregivers. As well, we were most fortunate to have a long-time neighbor become a spiritually adopted daughter/caregiver during Mom's final years. In particular, one of my older brothers, who was Mom's power-of-attorney, took on the mantle of primary decision maker. For instance, he and a younger sister—who is a nurse—carried out the difficult decision of moving Mom to the nursing home.

Our father had died twenty years before our mother; she lived alone after his death.

I lived over two hours away and had a full-time faculty position in an MSW program with classes every other week-end. Typically, I visited Mom monthly. I learned early in the process, as Mom's health declined, the importance of supporting my siblings who bore primary caregiving roles. It was unrealistic for me to try to be a primary caregiver. I could flagellate and frustrate myself with guilt and regret for not doing that, or I could accept and honor my supporting role. Often, like many family members in similar circumstances, my supporting role involved listening, providing perspective, and being present, even at a distance.

However, I did not anticipate a literal ocean's distance in my mother's last hours. When we learned Mom probably would not live through the night, my dear partner began frantically—albeit, totally unrealistically—trying to get us a flight home before Mom died. That Sunday night, after hours of unsuccessful berating, bargaining, and begging the airlines, we walked wearily along the moonlit Brighton Beach. I kept saying to Larry, "I can't believe I can't be there for my mother." I could not accept that this mere ocean could keep me from this most important person and moment.

But, returning to the small room of our inn, I asked Larry to give me some time alone. As I lay on the bed, exhausted and anguished, I accepted the limitations of my position. I came to a calm centeredness. I cannot describe the spiritual serenity that entered my hollow spirit, but I released my mother and my sense of guilt and regret for not being there. In that release, I said to my mother that I did not want her to continue to be in pain, and, selfishly, to want her to wait until I could be there to say, "Good-bye." I recalled another time years earlier when Larry and I were traveling (as we do frequently) and I was unable to be with Mom on some special occasion. When I expressed my regret to Mom, she simply said, "Your place is with Larry. You come see me when you can." I realized that those were the words that my Mom would have spoken (was speaking?) to me: "You are where you are meant to be."

When Larry returned to the room, I shared this abiding acceptance. I slept deeply. Early Monday morning (British time) I learned that it had been around the same time of my release on Sunday night when my mother died. She was not alone. Several of her children were at her side. And, I believe, I was with her in my supporting role—even across an ocean with my partner.

Monday, Larry and I rambled around Brighton, England. Acute grief sensitized us to spiritual gifts encountered that day, including several small kindnesses (although is any kindness small?) from strangers. An elderly, dapper gentleman stopped to ask us, "Are you lost?" We found peculiar comfort in the studio of a lovely, whimsical artist, Sam Toft. The print we purchased, "Long Way Home," captured some of our mood and commemorates that surreal, serene, sad day. Monday night we moved closer to the London airport to an inn owned by attentive hosts, Mary and Joseph (really!). Thankfully, we had already been scheduled to fly home on Tuesday morning and we kept our original itinerary.

On the transatlantic flight, I knew that my siblings were taking primary roles of arranging the funeral. But, the forced circumstances of sitting for hours in airports and planes opened up the space for me to reflect and write. Once again, my purpose was in a supporting role. I wrote a tribute to my mother in which I delineated twenty simple lessons that my mother taught. These lessons were not necessarily written or spoken by our mother. Rather, they were modeled in her living—and dying. The minister who officiated at Mom's funeral shared my tribute, "Some Things Mama Taught." In our family, "Mom" was our usual reference to our mother. "Mama" is reserved as a special term of endearment and respect.

In the following pages, I share some of Mama's lessons and tell stories that illuminate and illustrate their meaning. I have decades of professional social work experience; I read materials to help deal with the illnesses assailing Mom; and I benefited from professional advice and friends' good counsel. I found workshop materials and professional

writings (e.g., Doka, 2004; Powell & Courtice, 2002) as well as websites (e.g., caregiving.org) to be helpful in my journey through this phase of my mother's life and my subsequent grief of her death.

However, in her living, Mama had provided a map for her children to use as we traveled this new territory of losing her: first, to the disease of Alzheimer's and then, to death. As anyone who has traveled a similar path knows, the journey was difficult, complex, and oftentimes we, indeed, felt map-less. However, these lessons from Mama's life-map provided sight for the path, even when we could only dimly see the present footprints and no further; solace for the journey, even when we were lost; and sustenance for our daily walk, especially when we hungered for direction in the void.

I begin with three lessons Mama taught that reflect some of her unique character as a woman, farmer, homemaker. First lesson: *A woman who can wring a chicken's neck, cut down trees, and pick up hot coals with her bare hands is to be respected.* These visuals are some of my first, and enduring, memories of my mother. Indeed, I learned to respect her tenacity and talents in providing for and protecting her family, which led to another lesson she lived: *Work hard; live with integrity; give gratefully.* In coming to know many families in both my professional practice and personal experience, I also recognized the lesson that *Motherhood is common; only a special few are called to be "mamas."* Although my mother became childlike in many ways and our relationship changed accordingly, I tried to honor her core Mama-character by following the lessons she taught.

A central Mama lesson: *Pain is just part of a full life.* At another time, when Mama was hospitalized, I asked her, "Mama, are you in pain?"—knowing that she was, but wanting to invite her to complain about it. In her inimitably pragmatic and philosophical way, Mama replied, "Oh, Erlene, pain is just a part of life." This incident summed up Mama's perspective: She accepted pain. This acceptance seemed to enable her to more fully experience deep joys and plain pleasures.

This perspective relates to another lesson: *Choose an attitude of gratitude in all circumstances.* Here's another story from this same hospital incident. Mama traveled by ambulance approximately an hour away to receive needed medical treatment. Upon Mama's arrival at the hospital in the ambulance, an attendant asked Mama how she was doing. Mama replied that she was fine. She elaborated, "What do I have to complain about? I just laid back and watched the pretty countryside on this beautiful sunny day." My adolescent niece declared, "Only Ma could turn an ambulance ride into a road trip!"
These lessons helped me remember and hold onto who Mama was and how she would want us to handle the vicissitudes of her waning years: with acceptance of the pain so that we could be open to gratitude for unexpected gifts along the road. In relating these lesson-stories, I do not mean to gloss over the painful times of seeing my mother agitated, hurting, hurtful, angry, sad, lost, unfamiliar, fading. But, I tried to learn to accept those painful times—as just what they were, part of life—and, then, be open to other lessons.

The above lessons intertwine with the following Mama lessons: *Savor the simple pleasures; Enjoy the flowers while they bloom; Practice "porch therapy"—sit on the porch often; Enjoy the rain that cools the day and waters the parched soil.* Even in her "Energizer" days of raising twelve children and managing a farm, Mom knew how to savor the simple pleasure of sitting on her front porch, enjoying flowers, bird song, cooling rain. Early in our marriage, Larry began calling these times "porch therapy." So, during my visits with her in the nursing home, I tried to practice porch therapy with Mama.

Those familiar with Alzheimer's know its effects, including diminishing cognitive capacities, and loved ones must adapt accordingly (Strauss, 2002). Because Mama often did not know where she was, I found it important to practice Zen mindfulness—a particularly meaningful activity for a lifelong Baptist—i.e., to be present in that moment of being. In these Zen times, I savored sitting with Mama. Unlike my siblings who lived locally, I did not have encroaching demands,

nor did I experience the weight of responsibility for Mama's day-to-day care. When I was there, I tried to really be present.

When we moved Mama to the nursing home, I was disturbed and saddened by the limited, stark space allotted Mama. On a grading scale, I would give this nursing home a "C." While many staff members were caring and committed, our family experienced first-hand the many problems documented nationally in nursing home care, such as inadequate staffing levels and staff training (e.g., General Accounting Office, 2003). The nursing home frequently had offensive odors, including second-hand cigarette smoke. Second only to the unstinting dedication of our family caregiver who stayed with Mama five days a week, my favorite resource was the nursing home's tree-lined courtyard. We used the courtyard frequently, taking Mama outside for fresh air whenever possible. Early on, I explained to a staff member that Mama was an "outdoor gal" who loved nature. However, unless family caregivers took them, residents rarely ventured outside. In myriad ways, I observed the sad neglect of residents with little support.

This nursing home was chosen primarily because of its proximity to where my siblings lived, which enabled them to provide more consistent care. On my own, I would have chosen a different place, but I certainly supported the decision. I committed to making this arrangement work, which included assiduously refraining from adding to my siblings' burdens by questioning or criticizing this choice. They dealt with this decision on a daily basis. So, I tried to never speak negatively about this facility unless my siblings who were primary caregivers initiated the criticism, which they did. At times I acted in concert with them to address problems. For example, with my siblings' agreement, I wrote a letter to nursing home administrators asking them to enforce a policy of protecting residents from second-hand smoke.

Before my personal experience with this end-of-life caregiving in a nursing home setting, I knew about the barriers to ensuring quality care, including staff stress. But, my knowledge was largely academic and affected others. Through my personal experience, I learned at deeper levels about the importance of political intervention for nursing home quality of care; valuing nursing home staff; and appreciating the complexities of navigating this life phase and care system.

In coming to terms with this nursing home situation, I found two Mama lessons helpful: *Make do with what you have; and, no matter how little or much you have, share with others. Appreciate material possessions; but, do not let them possess you.* I tried not to operate out of materialistic values. I knew that my mother valued people above things; she could find profound pleasure and peace even in the simplest surroundings and starkest circumstances. I tried to do the same.

As Mama's physical and cognitive world grew ever smaller, the sensory world became even more crucial. I evoke two of Mama's lessons: *Eat your oats! Always, always have desserts!* (Note: Emphasis on the plural!) In her salt-of-the-earth way, Mama was a proponent of healthy living. She could have done a testimonial on the lived benefits of daily consumption of oatmeal; we shared many mornings communing over oats! In this sensate, smaller world, familiar foods with familiar folks—even if she did not recognize who we were in the moment—seemed to provide comfort for Mama. Part of healthy, happy life for Mama was desserts. (Did I mention *emphasis on the plural?*) So, as I had been doing for over a decade, when I visited I brought her special treats. In particular, I brought her favorite fresh candies and cookies, medjool dates, and candied apricots purchased from my local fruit market. I knew that, although these specialty items were not essential, they brought her familiar pleasure and in a small way conveyed that she was special.

Primary caregivers are the main course on the menu of caregiving: essential elements. A support role, however, like desserts, is somewhat non-essential. But, as support caregivers, we can make life a bit sweeter for our loved ones. By the way, Mama's last meal consisted of cake and ice cream. I hope to continue the family tradition.

Another inside family joke Mama-lesson that I shared in my Tribute was: *You can never have too much shampoo.* My mother collected shampoo—seriously. Having been poor, Mama experienced times when shampoo was a luxury item. So, a pleasure of her comparatively comfortable lifestyle in later years was to purchase shampoo—every time she shopped! Also, Mama's cheap therapy was combing her hair. Growing up, we twelve children often observed Mama's stress-reduction strategy of rhythmically combing her thick, red hair. So, whenever I visited, I would simply sit with Mama and comb her hair. A sacred time was sitting in the sunshine combing Mama's hair, savoring the silence. Words did not have to be spoken; nature and this lifelong tactile habit communicated comfort and serenity.

Similarly, especially when my partner or another family member was present, we would wheel Mama into a commons area that held a piano. (My parents had sacrificed to afford my piano lessons.) I would play piano and sing old hymns, at times joined by other family members or visitors. Mama would contentedly listen to the music. On my last visit with Mama—a couple of days before leaving for England—Larry, some of my siblings, and I shared a wonderful afternoon with Mama, singing hymns. She even hummed along with some of them. I shall forever be grateful for that time. I believe these familiar expressions of her faith soothed her soul.

Lessons from Mama's simple, unadorned, abundant faith include: *Jesus loves me. Living one's faith is more important—and more difficult—than participating in religion.* To unpack this faith perspective could require a theological treatise; but, basically, Mama's life of simple faith meant that gifts of grace would be there for her even in the darkest times. When Mama needed her most, her long-time neighbor became an incredible adopted spiritual-daughter. We refer to this woman—quite seriously—as an angel. In her later years, Mama was not connected to a particular church. But, Mama's last roommate at the nursing home (a middle-aged woman with a neurological disease) was the spouse of a minister. This minister came to know Mama through his encounters with her and our stories about her; he gave a loving eulogy that captured Mama's character and honored her life. Mama trusted that "It's all in God's hands." I honor that.

Another lesson from Mama was: *Laughter is good medicine—tears can be too.* As a coping strategy during this time, our family collected both "Mama" stories and "Alzheimer's" stories. Here's a favorite, which we call "Dr. Freud Meets Mama." A few months into her nursing home stay, the staff called in a psychiatric consult, whom we later dubbed Dr. "Freud." When Dr. Freud came to talk with Mama, our adopted sister, Jo Freida, was with Mama and reported the following (mis)communication. Dr. Freud greeted Mama and asked her name. She replied, "Beulah Jenkins." (Jenkins is her birth name, which she had not used in over 60 years.) Next, he asked, "Do you know where you are?" Mama, with an incredulous and somewhat haughty tone, said, "Why! Yes! I'm right here! Do you know where you are?" Next, Dr. Freud asked, "Can you tell me how old you are?" Mama looked at him with astonished disgust and declared, "Well, that's a nosey question!" To his credit, Dr. Freud recovered nicely, and said, "Oh, that's right you never ask a lady her age!" After that interchange, Dr. Freud seemed to try a different tack. He pointed to Jo Freida and said, "Who is this?" Mama confidently said, "That's my cousin." The doctor followed up with, "Oh, what's her name?" Leaning toward Jo Freida, Mama whispered, loudly and conspiratorially, "What's your name?!" Jo Freida told her and Mama promptly repeated this information to the doctor. Then, Dr. Freud said, "Now, Mrs. Grise, I understand that you have been crying a lot..." Mama looked at him with much wonderment, and said, "Well, yes, anybody with a lick of sense knows you have to have a good cry every now and then." Nonplussed, Dr. Freud hastily made social niceties, left the room, and increased Mama's medications. The doctor did not speak to any family member about his rationale for this increase; we conjectured that he thought Mama's audacious answers warranted sedation. My sister, who is a nurse, worked

with Mama's family doctor, who had a long-term relationship with Mama, to recalibrate the medications; Dr. Freud did not return.

We tell this family story to remember Mama's strong character, including her pragmatic disdain for silly questions. We enjoy the humor. Also, we tell this story because it underlines another Mama lesson: *Education is a priority, wisdom even more so.* My parents did not go to high school. But, they ensured that all twelve children graduated from high school and could go to college, and many completed graduate degrees. Mom proudly declared, "None of my kids stayed home from school to work on the farm." This accomplishment was significant in a farming community where the pressures of ensuring the family livelihood often depended on children missing school to tend crops.

The "Dr. Freud" story reminds us that Mama—even with dementia—had wisdom beyond full cognitive capacities and multiple educational degrees. This incident, and many others in this phase of Mama's life, taught me the importance of balancing professional knowledge with human connection and honor of personhood: education and wisdom. As both a personal caregiver and professional social worker, I am always reminded to ask: Whose reality? Do we really know where we are? Do we respect our loved one's/clients' privacy, self-determination, identity, and humanity—even though it may not fit with our "reality"? Do we honor and access their "anybody-with-a-lick-of-sense" wisdom? Do we engage the joy, humor, and surprise of interchanges like these to both enlighten and lighten our understandings of humanity and outlooks on life?

Mama's final lesson: *A good night's rest is a blessing,* brings us back to the beginning of this story. Especially before her failing health, a typical bedtime benediction from Mama was: "Love you. Have a good sleep." Mama would frequently count the fact that she slept well as one of her many, simple blessings. She would comment about how so many people had restless nights and say with heartfelt gratitude that she "always slept." Whenever I helped Mama to bed in the nursing home, I repeated this familiar benediction. My funeral benediction for my mother was from her lesson: "Love you. Have a good sleep." Just as, I believe, that night in Brighton, Mama's benediction across the ocean and all time was "Love you. Have a good sleep." I rested in another lesson I learned from Mama: *Love—while in human form imperfect—is constant, deep, immeasurable.* I had a good night's rest, with Mama's blessing. And, I believe that—although I do not comprehend the spiritual mysteries—Mama truly is at rest.

My friend, Kim Crum (2006), in reflecting on her parents' deaths and her long-distance caregiving role in their last years, cites Kierkegaard as saying, "Life can only be understood backwards" (p. 25). She offers this further advice: "Trust the process and accept its endpoint" (Crum, p. 25). Jacobs (2007), in writing about the intersection of personal grief and therapy with dying persons and their families, relates that "...grief unfolds in a variety of guises, and the lingering sense of loss never entirely disappears, but continues to shift and change gradually as time goes on" (p. 39). Through writings and conversations, others remind me that there comes a time when we must release those we love, with benediction. Yet, this release opens up new experiences and connections.

In my career, I have taught in my social work classes and practice about such professional concepts as the importance of relationships, honoring our clients, complexities of caring, and the dynamics of death and grief. I deeply value the importance of professional knowledge to inform competent practice. But, now, I understand at new levels that some of the best wisdom comes from life—and death. I know the importance of honoring personhood,

even when that personhood becomes both stunted and unfathomable at times. I know the power of presence, albeit not always in a physical sense. I know the essence of love as both tangible and inexpressible; in the moment and unending. I know that grief is not a static event or a single emotion. Rather, grief is a complex process of celebrating the lessons of living and honoring the lessons of dying.

Mama often philosophized: *Life is short—even if you live to be old.* (One of many Mama-isms I treasure.) So, I try to live this short life learning the lessons Mama taught in both her living and dying. These lessons inimitably inform and shape my teaching, learning, life. I offer these lessons for those of us who share a love connection of both grief and gratitude. May we be present and live forward, even as we learn backwards.

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Time Taken as a Caring Family

Susan Steiger-Tebb, Ph.D., and F. Robert Steiger, Ed.D.

Viewing caregiving from both a personal and professional angle has given the family in the following narrative a more holistic and realistic view of the role of family caregiver. "Dad," who lived caregiving on a daily basis, offers wisdom from experience for those facing the prospect of giving full-time (or part-time) care to loved ones. Their personal caregiving experience has helped the author as a social worker see that all kinds of interventions and choices need to be available to those who are caring for a loved one.

Take Time

Take time to Hold Their Hand.
for their hands are what made
the things that give us comfort.

Take Time to Look in Their Eyes
for their eyes have seen our
world through the changing times.

Take Time to Help Them Walk
for their feet have traveled
a thousand miles.

Take Time to Listen to Them Speak
for we can learn from
their endless wisdom.

Take Time To Care
for someday we will all need
someone to take time with us.

By Vicki Walleck (One of the students wrote this poem after working in the Caregiver Unit at the Topeka VA Hospital.)

I realized I needed to write this with my father when I saw the Reflections call for the special issue entitled "No Map for the Journey: Professionals Reflect on their Experience with End-of-Life Caregiving." Several months after seeing the call I received a letter from my dad talking about the future not in years but "as the seasons come and go" and I realized that if I were ever to write with my father about our experience as family caregivers, it was now.

Twenty years ago, we became a "family with Parkinson's Disease," as my father puts it. My mother, diagnosed at the early age of 58 with Parkinson's, was now ten years into her diagnosis and no longer able to function on her own. At the same time, I made a career change and after 15 years of practicing social work, mostly with children and families but also with people with renal failure, I moved from California with my two grade-school-aged children to Kansas where I entered the Ph.D. program at the University of Kansas. At the time of my acceptance interview, they asked if I would like to start up a Caregiver Support Unit in the Topeka VA Hospital. Not knowing what the term "caregiver" meant, but being the true social worker that I am, I said "sure" and thus helped to develop the first caregiver unit in any of the VA hospitals across the country. In so doing, I learned what the term "caregiver" involved and have since devoted my academic scholarship to helping better the plight of caregiving for family members. My parents remained in California and the following letters were sent to me by my dad as I embarked on writing a national manual of caregiving for the VA. Our family, especially my father, became more enmeshed in the daily caregiving of a loved one, my mother.

Now almost twenty years later and ten years after my mom's death in 1997, Dad agreed to write this article with me, or alongside me as it appears to be falling into place. The

following are excerpts from letters written to me by my dad in November 1988 and April 2007. To differentiate between our two voices within the dated entries, my thoughts are written in italics.

November 10, 1988

Dear Sue,

Surprise! Your Dad will write a letter, once-in-a-while, when given a chance.

I always loved getting letters from my dad because it was not a frequent occurrence; Mom was the one who usually wrote, and as is usual with the diagnosis of Parkinson's, writing became progressively harder for Mom. Dad occasionally would write to catch me up on the daily happenings in their lives. I savored these infrequent letters from Dad.

I'm at the public library, enjoying a day of respite. We have a lady staying with your Mom from 8 A.M to 5 P.M today, and I'm on my own. I played 14 holes of golf this morning (decided that was enough for a first time out.) Then I went to Nancy's and finished a wiring job I've been working at off and on for several weeks. I've put in a shop light over the workbench and put in outlets for my bench saw and other power tools. I had lunch at a fancy Mexican restaurant and am now at the library.

As a family we *talked about ways that Dad could have some time by himself and he had hired someone to come each week to allow him a "day off."*

I just finished re-reading your paper which I received a couple of weeks ago: *Exchanging Caregiver Well-Being: A New Role for Social Work.* I've also studied through an *Aid to Empowering: A Caregiver Well-Being Scale.* I find both very interesting, although some of the latter escapes me, largely due to the research methodology vocabulary and the statistical terminology.

My dad is a retired academic and so as I began to learn more about caregiving I shared my writing with him both for editing comments, which I valued, but also so he might glean some of the information that I was learning from other family caregivers and researchers. The first of his comments focuses on the fact that most caregivers that I dealt with were female, as is the case today. Dad's comments made me realize how he personalized what I was writing, wanting me to be sure to look at the male side of providing care. My hopes were raised in reading his letter because I realized he might be obtaining some suggestions to better care for himself in the materials that I was sending him.

The following are some comments that occur to me:

1. If a choice must be made as to use of "she" or "he" in referring to the caregiver then yours is an appropriate choice as it focuses attention on the major segment of the caregiving population. (I'm not sure such a choice must be made however. Also, selecting terms to use generically on the basis of majority application can add a negative burden to the minority—whatever that minority may be.)

2. Such focusing of the social workers' and researchers' attention on one segment of the caregiving population can turn that attention away from some possibly different questions related to the male minority of caregivers.

Words of wisdom from a male caregiver's point of view who wanted to make sure he was heard. At the time few male caregivers were being heard from and the same is true twenty years later; it is recommended that caregivers be studied by gender (Pinquart & Sorensen, 2003). Researchers have noted, as Dad tried to point out to me, that over-sampling of one particular type of caregiver may influence the development of interventions and thus we are not able to best serve many of those providing care (Berg-Weger & Tebb, 2003-2004).

3. Your paper refers to "loss of control" by the caregiver, as regards his/her environment, as a major source of frustration. I can attest that this is of tremendous significance. How to increase the measure of control, or to expand it to new, meaningful areas, is something greatly sought by all of us.

4. When approached from the patient side, this loss of control has long been recognized. Now what of the areas of conflict that arise over need for control by both patient and caregiver in their interrelationship? How may these by resolved, or risen above? Ideally, the caregiver gains greater control of the sort needed in the very act or process of enhancing the patient's control. Some of this should be possible; but the stuff of conflict on control questions is daily there.

Numbers 3 and 4 are areas we often would talk about when together or on the phone, especially when there were conflicts between his loss and Mom's, such as in the area of Dad's need to have friends, continue active traveling, and be involved in his community. Mom was unable to comprehend how she affected his ability to do the things he enjoyed. I believe these discussions helped me to better understand the caregiver's and the care receiver's points of view as I worked with and supervised students who provided support to caregiving families. It greatly influenced my ability to offer respite opportunities and to help others develop interventions with respite provided. My research influenced by these comments looked at and continues to look at how caregivers manage both the loss of and gain of control as their caring continues over time. For me it is the sense of or lack of well-being that is key to how well a caregiving family manages (Berg-Weger, Rubio, & Tebb, 2000; Tebb, S. 1995).

Well that's enough of that, possibly more than I'm in position to knowledgeably give. But I want you to know that I think your approach is excellent. I haven't seen anyone undertaking it from this approach, and it is greatly needed. (It's also one more way to get social work moving toward constructive models.)

In his career as an academic administrator he had helped start an MSW program at a college and was very much in favor of social work programs building their theoretical base in what he calls the "constructive model" which is what I term the strengths model. His use of "constructive" meant helping people see that they had the ability to make positive changes within themselves. (This is one of the first times I have realized that my strengths-based social work model was grounded in my upbringing.)

My effort in all this is simply a way of trying to share with you my deep respect for what you are doing. If anything I've written sounds critical, believe me, it is not! Suggestions and questions are my way of expressing support.

That last sentence has other applications. I've never been able to get your mom to understand that about me. Now, when I voice a question it is often interpreted as criticizing her or arguing with her. I guess that underneath it has always been that way. Present circumstances seem to exacerbate it, however. Thus, I must choose my words with greater care, lest I upset her. And emotional upsets now have severe physical consequences—consequences that then affect my ability to work with her and to "run smoothly." It is potentially a neat control tool also, which she is adept at using, all the while being totally unaware of that fact. That's probably one of the toughest things I have to deal with.

As I reflect on this now, this is an important insight into my parents' marriage and also into how I relate to my husband. Active discord has always been the way dad has interacted with all his children and grandchildren. It is not a conversational mode easy for many who have not grown up in it, as my mother and my husband.

We are doing reasonably "OK." Mom has fairly extreme "on-off" periods related to her medication. During the "on" she can do most things for herself, and even forgets to expect the "off" times. During the "off" she is greatly handicapped, forgets what her next medication can do for her, and is convinced this is the worst she has ever felt and she will never feel better than this again.

I often wonder what it must have been like for my mom to go through these on-off times each and every day and not to remember that she would soon have a better time as soon as the medication kicked in. Looking at care receivers and learning from them is one of the influences my mother has had on my scholarship path. Often people working with the sick person have no idea what she was like when healthy, and I have encouraged, both in my teaching and in my writing, those involved with caregiving families to get to know the care receivers as they are today and also as they were before they needed care. These perspectives help in selecting interventions that might help (Berg-Weger & Tebb, 1998).

I don't want to burden you with any of this. It's just that I've never written some of it before, and it keeps coming out, once I have started to write.

She is on a three-day no protein diet just now. The effort is to see to what degree, if any, protein interferes with her absorption of her Parkinson's medication. She completes that program tomorrow morning. "No protein" is leaving her with increased weakness and shakiness. I'll be glad when we're through it. If it shows us anything, then the trick will be to withhold protein through the day and give her the minimum required at the end of the day. (Another problem for the chief cook, me).

Daddy hated to cook and Mom was a great cook. He could put together a breakfast if he had to and open a can of soup when needed, but beyond that he depended on Mom. Now he is the one who has to plan her meals and fix most of their meals. He did work with a dietician and my sister and I gave him meals ideas, but this has never been an interest of his. But he did it and now is not a bad cook, but still does not enjoy cooking for himself.

We appreciated the copy of the booklet on Parkinson's that you made and sent us. I'm writing for more of them to share with other Parkinsonians here at Rosewood.

Rosewood is a retirement community my parents bought into in 1987 with the thought that my mother would need nursing home care and she could receive it there and Dad could live in an apartment on the grounds. Mom ended up living in the nursing care unit for eight-and-a-half years. (My dad remarried after Mom died and moved to another community in California that had a sister facility. He was able to transfer to the sister facility and his new wife bought in at a lower rate since he was already a member. He continues to live in an apartment at this facility.) This housing plan worked well for Mom and Dad.

Thanks for your regular letters. They are a really bright spot in the week for both of us. I know how hard it is to write and how overburdened you are—thus the letters are appreciated many times over.

My first year in college, the President's wife told me I should pick a day each week and write my family because I owed that to them for all that they had given me. To this day Sunday is the day I make contact with family, less now in writing but if I do write it is on Sunday. At the time my father wrote me I was still writing each week on Sunday to my parents; it had been twenty-five years since I was a freshman in college.

Well, I must wrap this up and head for home. My break day is about to come to an end. I'm delighted it gave me a chance to write at length. Love to all, and I love you.

Dad

November 17, 1988

Dear Sue,

Came across this item in an American Baptist newsletter for pastors. Course materials look expensive, but I think might be useful for learning what other caregivers are doing. I feel sure this would not be a bible-thumper's conservative approach, but a constructive one.

Dad had found material on caregiving and was sending it to me but also wanted to make sure that it would be helpful or if I thought it was helpful and grounded in what I was seeing in other caregivers. I realized upon reading this that dad was looking for help in whatever medium he could find it to help him deal with the daily life of giving care.

Mom has been doing about the same. Sure wish we could get some sort of "normal" schedule established—then we'd know how to plan our day and I'd be able to get at least something done.

Oh, well—so it goes.

"Normal" soon began to mean not knowing and not able to have a regular schedule. He had to learn that his day could not be planned and often he felt as if he had accomplished nothing during the day. This was very hard for my father because he usually had control of what happened each day before Mom became ill. It reminds me of mothers of young children who try to say what they did during the day but can think of nothing but that they cared for the child, which is a huge accomplishment but one that is not recognized or appreciated; nor is caring for an older adult. I think now as Dad reflects back on the time he cared for Mom he finds that he eventually became more comfortable with not living a regular schedule and now is probably better able to deal with the irregularities of his daily schedule today due to being over 90 years of age.

Love, Dad

November 30, 1988

Dear Sue,

Here is the copy of the manual you sent me. It is an excellent piece of work, professional and humanly sensitive. I congratulate you on it!

As supervisor of the Caregiver Support Unit at the Topeka VA Hospital, one of my tasks was to write a manual for family caregivers to be distributed to all VA hospitals. As I researched to prepare myself to write the manual I began to have a better sense of what my parents were experiencing and would send material to my dad to read. When I had a draft of the manual I sent it to him and this letter is what I received following his read of the manual.

I've taken the liberty to proofread it and to make editing suggestions. Since you said this is a first draft I hope some of this might be helpful. If I haven't caught what you want (in some of the changes I suggest) or if some of what I have done is too trivial, then just "consider the source" and ignore it.

My relationship with my father has always been one of "interested discussion." He and Mother provided us as we grew up with opportunities to question, discuss, and debate within the family. As I read this now I realize that Dad's approach to me has always been one of good positive criticism and he has asked the same of me. As an academic I have sought always to be open to constructive input from those with whom I work and live and I now better understand where that constructive criticism is grounded.

For a part of this, you had some difficulty with gender references. I tried to phrase around some of those. Others need to stand as "her/his" or "his/her" as you have them (where primary reference is to the general caregiving situation. Where attention turns more specifically to the caregivers with whom you work, you have gone entirely to the feminine gender, which is fully appropriate.

This is in view of the fact that the highly preponderant numbers of veterans (thus of care-receivers) are male and thus caregivers are female. Perhaps a note to that effect at an appropriate place (such as bottom of page 32) would be helpful.

Dad's attention to gender has encouraged me to look at the male view *in caregiving. Much of the research is with females, but Dad's experience and his urging made me more aware of the plights of both male and female caregivers.*

We're about as usual. Your mom is having a bit more difficulty week by week. I find it almost impossible to know when to respond to her requests for help and when to insist that she try to do it for herself. I think I encourage more dependency by giving help, and I don't want to do that. Her insistence often wins over however. We had a confrontation on that the other night, and she informed me I just didn't know what it is like to have Parkinson's. I told her she has never experienced what it was like to care for a Parkinsonian either so I guessed she would just have to deal with the way I do it – I think it was a "thought stopper" for her for a little while at least.

I remember reading this nineteen years ago and thinking—yea for both of them to have a "normal" argument, how healthy. My parents, before Mom was sick, had good healthy disagreements and could talk it out and compromise, but I had not seen that in their relationship for some time; and here it was, a brief glimpse of what they had had.

Getting her to bed now is almost like getting a four year old to bed. The lights have to be just so, her hips and shoulders must be aligned in the right position (varying from time to time), she needs a drink, a Kleenex, her bed socks, etc. Then every 30 minutes she must have help getting to the bathroom. It is getting a bit thick. I'm coping *OK* for now. Prayer helps a lot; having a sitter once a week makes a difference (I very soon shoot for twice a week); etc. There is friendly support here (though few direct and immediate help) and we're making it. For how long I don't know, but I feel it can be dealt with as each new level of need occurs. Out of paper; hope you can read my scrawl.

Love ya!
Dad

This last paragraph helped me with the caregivers we were working with at the VA hospital. It provides coping ideas and that is what most of our work with the caregivers was, helping them find good coping mechanisms for themselves.

I asked Dad to reflect on these letters he wrote almost twenty years ago and to think about what he learned that might help caregiving families today. The following is the letter I recently received.

May, 2007

Dear Sue,

Ever since you sent copies of those three letters of mine you had hung onto from November, 1988, and asked me to write my perspective looking back on the caregiving situation I was in at the time, I have been at a loss to know what to say. I have a severe case of writer's block (and not only associated with this "assignment"). The days are passing swiftly and the month of May (when I planned to do the writing) is already more than half over. So here I am at the keyboard looking for a way to make a start. I have decided simply to begin writing (in the form of this "letter" to you) with the hope that the effort will begin to uncover some of what I have filed away in my consciousness as being "in the past," and have given little or no attention for several years.

The 1988 letters do trigger a line of thought, so I'll try to develop that for a bit. I remember well the circumstances of discovering that your mom had Parkinson's. In the late spring of 1976, I noticed a change in her walking. She was developing a shuffle and also a tendency to take small, mincing

steps while on her tippy-toes. When she gave thought to her walking she strode along in her normal way, but when her attention was elsewhere she lapsed more and more into this new and strange way of movement. We went shortly thereafter to Canada for the summer and stopped by Miniwanca on the way. Dr. Robert Shank of Washington University Medical School was serving as Camp Miniwanca physician at the time, so I took this opportunity to discuss with him my puzzlement and concern regarding your mother's walking. He suggested we would do well to have her seen by a neurologist after our return from Canada in the fall. He did us the favor of arranging an appointment with a leading neurologist in the Chicago area.

A battery of tests and two thorough consultations with the neurologist produced a tentative diagnosis of Parkinson's disease. We, as a family, were set upon a journey we had not contemplated and of which we had little knowledge. Through succeeding years we came to realize that your mom's disease was not hers alone—it was ours as a family as well. Year by year there were adjustments necessary to enable her to keep functioning and to keep strong family bonds supporting her.

The need for physical support was obvious for the most part, and family rallied around and increasingly provided that support. Changes were made in the home; changes of major proportions were also made at the summer home in Canada; and ongoing changes were made in transportation, shopping, meal planning and preparation, and countless other areas of family life.

Need for support in the realms of mind and spirit provided the greatest challenge, for these are subtle in their origins, difficult to sense and to define, but tragically devastating if not well and adequately served. As with most long journeys, we began in full strength, and found the going relatively easy. In its early years, little seemed altered, little special effort was required. As the years proceeded, bit by bit your mom experienced losses in body and spirit resulting in behavioral changes, and increasingly defining differing roles—that of the one requiring care and of those giving care. The letters you have unearthed reflect a time (roughly mid-way in the twenty year Parkinson's journey) when those roles were clearly in play, but had not yet been fully accepted by your mom. This was the time of multiple falls, broken shoulder, broken femur and continuing denial. For the caregiver(s) the time brought frustration and fatigue.

Also we as a family were gaining a better understanding of what relationship changes were occurring with Mom and those of us giving the care, especially Dad, and how Mom had become so dependent on others for care and this was not in her nature.

A few years earlier your sisters had invited me to their apartment (in Downer's Grove) for dinner, discussed their observations of what was taking place with their mom, and then focused their concern on me. The issue was the condition of my health of body, mind and spirit as I continued as primary caregiver in this ever-changing scene. Their concern was, "We don't want you to die of her disease." That brought me to what, on reflection, I see as a significant turning point in the way I would fulfill my role. No longer could I permit my activities and interests to be controlled and determined solely by the progress of your mom's disease.

Nor could we as a family. That summer, for the first time since my parents bought the land in Canada, Mom did not go to Canada. Dad used the care facility to care for her that summer and hired people to look in on her when he was in Canada. The summer before, her final summer in Canada, was not a rest for anyone. Dad was exhausted so he did nothing while there but read and relax, and my sister and I who were there with our three active grade school and middle school children did nothing but cook, clean, and do laundry, which was no small chore because mother was soiling herself most days and the

laundromat was half an hour drive away. The children could not understand why their mothers were so tired and not willing to play. My sister and I told Dad something had to change because the summer was not good for any of us. That next year things did change; Mom fell and broke her hip. She only saw her beloved Canadian cabin in photos after that.

Three main concerns became intertwined in my caregiving efforts. Ideally, none of the three should be in competition with the other two—each should be pursued with full regard to the others, in ways supportive each to all. And those three concerns?

1. Attend directly and fully to those things which must be done and which only you can do. If time and energy permit do whatever else can be comfortably done, otherwise seek additional help.

2. Share together with her, at whatever level she can function, the ongoing relationship of two people on a life path together. Memories, family stories, family activities, celebratory moments, special events, sometimes even frank discussion of the disease process and what together we are able to do about it—these and other ways of sharing create the context within which meaning for everyday living can be preserved and extended.

3. For yourself, look through, beside and beyond the confines of her illness. Define and seek activities and relationships that are nurturing to your own sense of self. The "Servant Self" must also be the "Growing Self," else burnout will cancel all hopes, all joys and all meaning for both parties to the journey.

In retrospect, your mom's time of multiple falls and fractures and the caregivers' time of frustration and fatigue mentioned above provided the threat and the challenge which confirmed the necessity for me to actually weave those three strands into the fabric of my living. However vaguely they were recognized in my mind before, now they became a lifeline for me.

Two months or so after you received those letters from me your mom sustained another fall, resulting in a broken hip. During her hospital stay she began having strange hallucinations. That, of course, is not unusual for many folk confined in a strange bed following an accident, and here it seemed to pass very soon. It proved, however, to be the beginning of observable dementia, for it recurred, at first occasionally, then with increasing frequency in the months that followed.

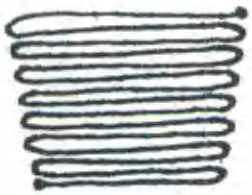
Reflecting now on the course of my mother's illness I realize that as a family the discussion of death is one that we do not shy away from. We did not with Mother's; we discussed what she wanted in regard to end-of-life care and we have not with Dad's. Each of us has talked about what we want at our own funeral and what if any life-support measures we might want. This has been especially poignant because my daughter was diagnosed with ovarian cancer at 25 years of age and we again had this conversation, painful for me, but necessary, thanks to what my mother helped us realize is an important part of living.

Her fall and hip fracture marked a significant turn in the journey both for your mom and for the rest of us as her caregivers. She was released from the hospital to the health center at the retirement facility where we lived. For a number of months there was a question as to how soon she would recuperate sufficiently to return to our apartment. Her physician, the Director of Nursing and family members monitored this issue carefully, and finally came to consensus that the answer to the time question was "Never." That, of course, changed the caregiver role to one of "attending to," and no longer "caring for." That is another chapter in the story, another passage in the journey, which would merit its own account.

But as many of us know, the" attending to" is also very stressful and many caregivers of people in nursing homes fall ill themselves. Maybe it is because they are

finally able to "let down," and in *doing this their immune system is affected and they fall victim to many illnesses. Dad was diagnosed with colon cancer about a year and a half after Mom began her residency in the nursing care unit. Studies demonstrate that caregivers have a lower immune response and thus they are at risk for cancer (Kiecolt-Glaser, Dura, & Speicher, 1991. Vitaliano, Zhang, & Scanian, 2003).*

I conclude these musings with statements of some learnings that came to me in or from efforts to perform the caring role. I think all are important, even though some came to me too late to really help to any great extent. But here they are as they occur to me now:



1. Although it is the patient who bears the chronic problem, the entire family suffers the problem and is inescapably its victim also.
2. The caregiver could truly "die of the patient's disease," if he/she permits burnout to occur.
3. Don't take negatives personally when expressed by the patient.
4. Your loved one is a fractured person. You may not be hearing from the person with whom you once shared life and love.
5. Live your life anyway, even when you must serve her in crucial ways. Take regular and special breaks.
6. Find and/or create events/settings where she is included in group experience. Help her continue to belong.
7. Do not lay expectations on her that she cannot fulfill, even if she has carried that item all her life before she became very ill.
8. Teach yourself the art of silent grief – dispose of grief, day by day as losses occur.
9. Project your own life not only "with," but also "aside from" and "beyond" the stresses of everyday caring.
10. Seek all the help you can get as caregiver. Call on every resource you can unearth. Even then it will never seem enough. Few primary caregivers are as fortunate as I in having in the family both a social worker and a nurse as helpers, consultants, and supporters. (Still, there were times when even more insight and assistance could have been helpful.)

Of course every list should contain ten items. OK, there are probably several more learnings that hit me at the time or on the spot, but these are what come to me now. Thanks for pressing me to do this, even against my apparent reluctance. It has been a good exercise for me. It has helped me remember and understand why I am touched by the pains and problems of many of my peers, especially here at San Joaquin Gardens.

Love,
Dad

Dad has continued to stay in a retirement community and, as he notes, because of what we shared as a caregiving family, we are able to help many approach and confront family issues around death and dying. I know that my siblings, our children, and I have grown from this caregiving experience. We have had numerous and long talks about how this experience has touched our family and four of the gifts we received as a caregiving family are:

1. The experience has helped our family understand and be touched by the pains and problems of other caregivers and hopefully will prepare us for when it is our time to care or receive it.

2. Because of what we learned as a caregiving family, Dad especially is able to help many of the residents in his community to live "with," "aside from," and "beyond" the everyday care they are giving their loved ones. We, as Mom and Dad's children and grandchildren, are all able to work with and be around older people. All three of the grandchildren have a strong compassion and respect for older people.

3. My siblings, our children, and I have grown from the caregiving experience. We are more aware of the possible changes that occur in families and how families need to continue to work, grow, and support each

other through the difficult times of needing care.

4. We also are very aware that we will more than likely be caregivers in our lifetime and hope we can be as gracious at it as our Dad/Grandpa was. (Dad became more sensitive and appreciative of the everyday little things that my mother did for him each and every day that he did not notice while she was well. He began to think about how people in similar situations might be helped and what was helpful and what hindered caregiver's well-being.)

In writing this article with my father I realized that I also have grown into the caregiving role over the past twenty years. As I noted earlier I had not heard the term "caregiver" until I started at the VA hospital in Topeka. While there I set up a caregiver unit in the hospital and wrote the VA's first national caregiver manual. Upon leaving the VA, I continued to direct my scholarship in the area of caregiver well-being and with colleagues have written over 30 articles and two books on the subject. My teaching is enhanced by our family's experience because I can speak about caregiving both from the heart and as an academic and, I hope, am better able to encourage new social workers to develop caregiving interventions that will help caregivers gain control and better well-being. I think more than anything this experience has helped me to see that caregivers and their families need options, all kinds of options for end-of-life care and that they need to be allowed to make the decisions that best suit their situation no matter whether it is understood by others or not.

I find that the following quote by Olympia Dukakis (May 2007) describes what we as a family came to learn, believe, and support in our twenty years of caregiving:

"Whether the illness is cancer or Alzheimer's, there can be no hard-and-fast rules about life after diagnosis—except that you need to be honest and flexible. It's an inherently personal process, and I doubt that care giving decisions are ever easy. But made conscientiously...those decisions should be respected." (p.35)

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SAVING SANDY:
A STRUGGLE WITH A RARE BRAIN CANCER

James H. Williams, Ph.D., Savannah State University

A spouse develops a rare terminal cancer. She and her social worker husband struggle to find treatments and, eventually to face death. A social worker revises his practice perspective.

In the summer of 1995, my wife Sondra "Sandy" Patrinos began to experience strange symptoms. She would become disoriented and had difficulty seeing and keeping her balance. A visit to her primary care physician began a series of encounters with a complex medical system. She was referred to a neurologist, who began a battery of tests. A CAT scan revealed a lesion in her brain. More tests were ordered, each seeming progressively more intrusive. Our fear and frustration grew accordingly with each inconclusive test. We were in the clutches of managed care, which meant that each test had to be scheduled individually at different locations. This took time and we were running out of patience.

A brief biography: Sandy and I were from working class families. After a lifetime of political and union activism, we had gone back to school. Sandy was a fighter. One of two daughters born to a Jewish Communist family, she grew up in a tough neighborhood in Philadelphia. Her first political memory was helping her mother distribute literature for Henry Wallace's Progressive Party in 1948. At the age of 15 she joined the Communist Party- later becoming head of the CP in Eastern Pennsylvania. As the nation emerged from the McCarthy period, Sandy became the public face of the party in Philadelphia. Later, in Chicago, she was director of Women for Racial and Economic Equality (WREE). She was known for her tenacity and determination never flinching from a fight simply because the odds were stacked against her. (She finally left the Communist Party in 1990.)

This cancer was to get the same treatment from her. In 1993, we both graduated with professional degrees: I had gotten a Masters in Social Work (MSW) and Sandy a Masters in Public Administration (MPA). Sandy got a job at Cook County Hospital in Chicago, to develop and run a mobile mammography unit. I started working with mentally ill and substance-abusing persons in the criminal justice system. By 1995 we felt as though we had finally settled and we were both doing work that we found interesting, and we were making, for the first time in our lives, decent salaries. We even bought a nice co-op apartment.

As the tests dragged on, Sandy's symptoms began to impair her functioning more severely. The tests revealed what we had feared: Sandy had a brain tumor. To find out what kind of brain tumor, a stereo-tactic biopsy had to be performed. We had to wait a month for our managed-care approved provider to schedule the test at the University of Illinois hospital. As news of Sandy's predicament spread through Cook County Hospital (CCH), a top specialist at the hospital offered to do it there. We knew he was good since he had trained other doctors at the University of Illinois facility.

The day of the biopsy, Sandy was all prepped and ready to go. She had spent the night in a ward at Cook County Hospital, a hospital which was in dilapidated condition, but whose staff struggled valiantly to provide excellent care. As she was wheeled to the operating room, I walked alongside clutching her hand, trying not to show my nervousness.

Trying to be strong. We passed a priest in the hall. He made the sign of the cross over Sandy (a Jewish atheist) and blessed her. She smiled and thanked him.

When we parted at the operating room doors, I was left standing in the hall. Many of Sandy's friends from the hospital were able to get into the operating theater. That's when I felt really alone. The biopsy revealed brain cancer - primary central nervous system leukemia, (PCNSL) which is a very rare form of cancer. It is terminal and few patients had lived more that a couple of years.

Sandy had a wonderful, caring oncologist who impressed us on many counts, but we most appreciated her readiness to include both of us in decision-making and to enable a participatory process in treatment. She confessed that she had never encountered this extremely rare cancer before. She supported my frantic search for information and treatments: many doctors would have considered this unwarranted interference. I searched the internet (still somewhat in its infancy in those days). I began to call around to various hospitals and labs that specialized in cancer. People at the M.D.Anderson Cancer Center in Houston were helpful in assisting me to learn about the cancer, and they also recommended Memorial Sloan-Kettering Hospital (MSK) in New York, where Dr. Lisa DeAngelis (1999) had successfully treated patients with this disease. Dr. DeAngelis is a renowned expert in this cancer and she had developed a treatment protocol that showed promise. Dr. DeAngelis' treatment was a tough regime of full-head radiation and some possibly dangerous chemotherapy (Correa, et al., 2004). From what I learned, the treatments could result in some permanent cognitive damage. But without treatment, Sandy didn't have long to live. We hadn't expected a trade-off like this. What would it mean for Sandy? Reluctantly, we concluded that this was the only choice open to us.

Our oncologist continued to be open to working collaboratively with me. I was surprised at her willingness to put up with such a frantic, intrusive husband. We all three sat down and had a long discussion, weighing the pros and cons of treatment. Sandy agreed that she would try the protocols developed at Memorial Sloan Kettering Hospital.

We began a long period of alternating treatments: first a series of whole-head radiation, then a series of chemotherapy. The chemo took place over a 24-hour period in the hospital and was injected directly into Sandy's brain. When the treatment was over, the doctor gave us a prescription for an antidote to the treatment's toxicity. Unfortunately, when I tried to fill the prescription, the drug was not in stock. I really panicked then. I was faced with a toxic chemo that could hurt Sandy, and I could not find the antidote! However, our oncologist came to our rescue and arranged a shipment of the medication to the hospital pharmacy.

After some weeks, it looked like Sandy had achieved remission. The tumor had receded. Her hair grew back; she fleshed out again and got her color back. Sandy decided to go back to work at the hospital. She could no longer drive, but it was easy for me to drop her off and pick her up. The mobile mammography project at Cook Count Hospital, which she had founded, was designed to give poor women in distant areas in the county access to mammograms. The program was under funded and understaffed, and Sandy pushed herself to make sure that the project continually made the rounds of some of the poorest areas.

This remission was an important milestone for us. We were able to travel again and could visit her relatives. We went on a vacation to Spain. I had long promised a vacation to take her to Europe, and we went and spent a pleasant week in Madrid going to museums and visiting with striking Spanish workers, who had conveniently set up a tent city across from the Prado museum.

While most of our family and friends knew about Sandy's situation, Sandy had not told her 85-year-old father how sick she was. She was afraid that he would be adversely affected by the news. When we visited him in Philadelphia, she appeared normal and healthy. Her father never knew that she was sick. He died two years later.

After a year of remission, the cancer returned. We knew this would happen eventually, but we didn't know when. The oncologist had explained that this particular cancer would return again and that it would steadily gain ground because the cancer would gradually become treatment-resistant. Sandy was to experience three recurrences of the cancer in all. Even the best estimates of the Memorial Sloan Kettering protocol at the time showed patients not making it past three years. Sandy was determined to beat the odds.

She began yet another round of chemo, and then she was able to return to work. When the cancer appeared the third time, the doctor felt that the cancer had become too resistant to the previous treatments. We had to find something new. I once more began frantically scouring clinical trials around the county, looking for new treatments. Sandy's cousin Hal, a research chemist, helped me scour the lists. A couple of things seemed promising and I grabbed at them as a drowning man grabs at passing branches. Although laboratory rats developed full remission by using these treatments, Sandy did not.

Another round of the old chemotherapy produced a brief respite, but the cancer soon returned for yet a fourth time. As Sandy's oncologist gave us the news, I broke down in sobs. There was nothing more that modern medicine could do for her. I was finally forced to face the fact that Sandy was going to die.

Sandy's oncologist suggested it was time to consider home hospice care. She suggested Hospice. By this time, I had taken full leave from work (Gods Bless the Family Leave Act). But since Sandy needed care 24 hours a day, Sandy's sister, Marian, took leave from her job as a speech therapist in Los Angeles and came to help me during the final weeks. We took turns taking care of Sandy in shifts. Additionally, friends and neighbors pitched in to help as well. Neighbors in the building where we lived cooked wonderful meals for us. They were compassionate and helpful in many ways.

Marian and I were both sleep-deprived. It now took two of us to move Sandy for even the smallest things. Sandy seldom slept; she was taking a lot of steroids, which kept her brain swelling down, but which also kept her awake. Night and day seemed to merge together in my consciousness; I felt like a zombie. My own major depression, which had plagued me for years, returned. It became increasingly hard for me cope with my depression and to do what I had to do for Sandy. With additional medication, I was able to keep plugging away.

Sandy's body had failed her, but now her mind began to be affected. A kind of dementia set in, and her short-term memory was damaged. She could watch *Wheel of Fortune* and *Jeopardy* and easily guess the answers - but she could no longer follow the story line in her favorite dramas. Sandy could not write or handle a pencil now, so Marian and I would read the New York Times crossword puzzles to her, and she would dictate the answers. She now had trouble recognizing the friends who came to see her. I began to try to discourage Sandy's friends from coming to see her – I didn't want them to see her like that. She had always been a super-competent person who everyone looked to for leadership, and I couldn't bear for people to see her. In retrospect, I know that I was wrong. This was my problem - not Sandy's. She was happy to see whoever came, even if she couldn't remember their names or how she knew them. I worried about inconsequential things; probably hurting many feelings in the process.

Finally, it became clear that Sandy was in her last days. She could no longer eat or move. Marian and I had to shift her around in bed to protect against bedsores. Her breathing became labored. Marian and I now both sat up nights at her bedside, keeping vigil. We sat there in the silence listening to her increasingly labored breathing. Finally her breathing

stopped. I sat with her for about an hour, tears streaming down my face. However, we still had work to do: the hospice people had to be contacted, relatives had to be called. Marian and I threw ourselves into our tasks. Sandy didn't want a funeral, but she had made arrangements to donate her body to medicine. I buried a lock of her hair at labor leader Elizabeth Gurley Flynn's gravesite at Waldheim Cemetery in Chicago. Sandy had known Elizabeth and considered her a mentor.

Sandy's relatives and friends in Philadelphia began to organize a memorial there, and I began to organize one in Chicago. Hundreds came to the memorial in Philadelphia. More than a hundred came to the meeting in Chicago. Newspapers in both cities ran lengthy obituaries.

Three days after the Chicago memorial, the Human Resources Department called and told me I had to come back to work. I dragged myself back in. Copies of Sandy's obituaries were posted all over the office and people were extraordinarily kind. (Well, not everyone was kind, however. Some evangelical Christians dropped by to warn me that, while Sandy was no doubt roasting in hell, I still had a chance to redeem myself).

During the previous years I had been totally task-focused, drawing reserves of energy from God knows where. This finally took its toll on me. I worked for about two weeks and then collapsed from exhaustion. The depression that I had kept at bay finally overwhelmed me. Mentally, I was reliving Sandy's last days over and over. My psychiatrist diagnosed Post Traumatic Stress Syndrome. It was another two weeks before I could face work again.

CODA

In the fall of 1993, right after I finished my MSW, I entered the Ph.D. program at Jane Addams College of Social Work. By the end of 1996 I had finished my PhD and received my LCSW. As an MSW student I had taken the usual courses, including death and dying. I understood the various stages of dying indicated by Dr. Kubler-Ross (1969, 1974), but nothing had prepared me for a struggle like this. I was on a constant emotional roller coaster, going from heights to depths in rapid succession as we went through the stages of remission and recurrence. Oh yes, I knew intellectually - but nothing had prepared me for the frantic, emotional ups and downs, then having to come to grips with Sandy's death. Fortunately for me, I had a lot of help. I am particularly grateful for the aid of Dr. Nicholas Christakis (1999), a noted specialist in palliative care, who was Sandy's physician. His compassion and advice was a blessing to me.

What I have learned is that Social Workers need to learn to ask for help and to accept help. That was hard for me because I thought I should have all the answers. After all, I was a Licensed Clinical Social Worker.

The most important factor in this story is Sandy's incredible resilience. I think the fact that she lived five years with this disease, when the odds said she couldn't do better than three years, is testimony to this. Furthermore, until her last year, she was able to function at her demanding job, play a role in community affairs, and enjoy life.

Sandy's experience caused me to reexamine some of my own assumptions about my practice. I began to realize the role of resilience, and our own hidden abilities to withstand trauma and loss. I learned, from a client's perspective, how important it is to be involved in the process and not merely a recipient of services. The ability of a client to participate and exercise self-determination was no longer something I read about in social work text books. I learned how enormously empowering and healing it is to be involved even if the outcome is not so good.

This experience was the beginning of my break with the "medical model" which I had embraced so thoroughly in my early practice. My work was with persons diagnosed with Schizophrenia and other serious disorders. I found myself locked into practicing a deficit model, where I was focused on the client's disorder and not the client as a whole person. I focused on clients as chronically hopeless, with little or no chance of recovery.

Sandy blew these assumptions out of the water. Certainly Sandy was more than her disease. And if Sandy was more than the sum of her problems, then what about my clients?

Sandy certainly had enormous inner strength and resilience, but she also had other resources outside herself that she could draw upon: family, friends, wonderful medical care and a comfortable middle-class life. I began to ask myself what untapped inner resources I was missing with my clients. Obviously they were surviving on the street and that required a lot of skills, strengths and initiatives that I wasn't paying enough attention to. How could I find those strengths (De Jong & Miller, 1995)? How could I help to combine those strengths with other resources available in the community?

Sandy and I were atheists, but I saw in her struggle a kind of spirituality. (She would not approve of my characterization.) I began to ask myself about the role of spirituality in recovery and its place in client resilience. I began to ask myself how I had mobilized resilience in myself, what internal forces I was able to draw upon. I don't credit myself, but I do credit those friends and family who helped: those who cooked us dinners, who ran errands, who made generous donations while I was on leave from work, so that I could take care of Sandy and still pay the bills. Sandy's sister Marian was a tower of strength for me. I hope that I was for her.

Today I have opened myself up to new theories and new approaches that are based on strengths and resilience. I look at clients (and now my students) in new ways, looking for strengths to build upon.

I hope that my clients and my students benefit as well.

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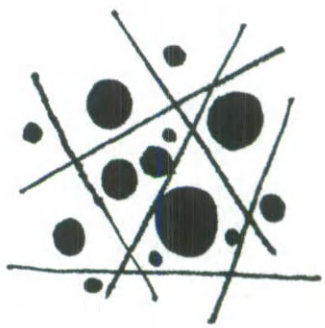

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The Path of Caregiving: From Family Caregiving to Supporting and Giving Voice to Those Who Provide Care to Loved Ones

Kristina Hash, Ph.D., West Virginia University.

This narrative focuses on the author's path of caregiving, including her early family experiences as a caregiver for an elderly grandparent with dementia. This personal experience fueled her desire to work with caregivers as a medical social worker in a home health setting. This path of caregiving was continued when she conducted her dissertation research on caregiving among older, same-sex couples. Through these personal and professional experiences, the author developed astute insight into the challenges and rewards of caregiving, and also provided essential education about the supports that are needed (at the personal and policy levels) to sustain the caregivers.

The Personal Path: A Life before Dementia

This is a story of three generations of women and one life-altering experience that they shared. To understand this experience, it is imperative to provide a brief account of my grandmother's life before the onset of dementia. Anne Barry was born on October 19, 1900, as the only child of Daniel and Anna (of Irish and German descent) and was raised to be a proper, middle-class, Philadelphia lady. She completed twelve years of formal education and was voted "best looking" by her graduating class. After high school she held various secretarial and training positions. She married Joseph Smith, an engineer, in 1937, and his job relocated the couple to Ohio. In 1938 they welcomed their first and only child, Anne. Anne (my mother) was always closer to her father and was his constant companion at football games and in fixing things around the house. This closeness to her father seemed to only distance my mother from my grandmother and created somewhat of a competition between the two ladies.

Like many women of her cohort, Anne never learned to drive. She appreciated a good Latin Mass and the Ave Maria and despite her general conservatism, she loved the television show "Three's Company." Black coffee and jelly donuts were her food and drink of choice and she made no excuses about her use of cake mixes and other conveniences over cooking from scratch. Her avid reading, passion for crossword puzzles, and constant correcting of the grammar of others led some to believe she was a retired English teacher.

During the 1960s, Anne and Joe Smith became grandparents to David, Daniel, Amy, and Kristina. At that point her AKA (also known as) became "Granny." In 1971, she lost Joe as a result of a stroke. She never remarried but did not live alone after my grandfather died. My mother, siblings, and I moved into my grandparents' house one year later when I was four. Nothing in Granny's life had prepared her for living with the "shenanigans" of my three teenage siblings. In particular, she was subjected to Dann's pranks, which included his calling her, pretending to be department store security staff who had detained her grandson for charging several thousand dollars to her account. Distraught by the unsightly appearance of Amy's bedroom, she swore on several occasions that when she died, she wanted a special "peep-hole" in the clouds to look down on Amy and her family to see if her adult home was kept any better.

As my teenage siblings were challenging her values and keeping her young, Granny was very much my caregiver in childhood. She walked me to school on my first day of kindergarten and sat nervously on a bench during my first swimming lesson. In the morning she brushed and braided my tangled hair and chased me into the bathtub at night. She sent me to the corner store for candy and gave me change for the ice cream truck. She rubbed my back every night to put me to sleep. Despite her dismay with my tomboyish behavior, she repeatedly told me I was the

"best little girl in the world." Little did I know that I would have the opportunity to return the care she gave to me.

The Path Begins

When my parents relocated to Iowa in the early 80s, Granny lived with us briefly, but then rented an apartment near my high school. A few years later we began to suspect that Granny was having problems with her memory. She began to burn coffee pots, bathed less frequently, and forgot to take her medicines. After being hospitalized for water retention, it was decided that she should recover at our house since my mother was a nurse and my father was a physician. As her care needs increased, she eventually gave up her apartment and became a full-time occupant at our house. I was in high school and the only child still in the house.

At first, I did not know what to make of Granny's illness or the situation. Looking back, I cannot recall anyone else that I knew whose family was caring for an older relative at home. She become increasingly confused and disoriented to time and place and would frequently ask, "Where am I?" I sometimes found her behavior to be embarrassing, especially when my friends were around. She also began to seclude herself in her room when we would have company; I think she, too, was embarrassed by her condition. It became necessary to safety-proof the house; we removed the knobs from the stove to keep Granny from turning it on and removed the coffee pot from the kitchen. She began to sleep most of the day and sundown (wander) at night. Through this, our dog, Tess, was her constant companion, keeping her feet warm during the day and walking beside her at night. Although I am now aware of the therapeutic benefits of pets for persons with dementia (Churchill, Safaoui, McCabe, & Baun, 1999), I'm ashamed that during that time Tess was more understanding of her situation and more responsive to her needs than I. It wasn't until I was called upon to help with feeding and bathing that I really understood her condition and appreciated the opportunity to return the care Granny had given to me.

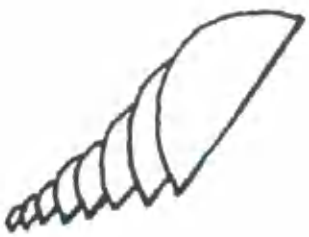
In contrast, the progression of Granny's illness only further strained the relationship between her and my mother. Once Granny's inhibitions subsided, she could be combative, and she often uttered hurtful words to my mother. While I was able to convince her to get into the bathtub, she would sometimes take swings at my mother when she attempted the same task. Being an only child, working full time, attending graduate school, and raising a teenager, on top of serving as a caregiver, my mother was the picture of the "woman in the middle," trying to balance these responsibilities.

Despite the challenging aspects of the experience, it is the humorous events that I choose to revisit most often this decade later. Granny's sundowning involved pacing but also snacking throughout the night. My two most vivid recollections are the night she ate the entire top row of a box of Whitman Sampler candy (her favorite) and the night she ate an entire pie. When asked, she would always suggest that the food consumption was the work of someone else. Tess was blamed for polishing off the pie and my brother Dann, who would have been a likely suspect had he not been away at college, for devouring the candy. During this time my mom and I couldn't help but think, "Wouldn't it be great to be able to eat an entire pie, not feel guilty because you don't remember eating it, and not gain a pound because you have walked it off?"

Following Granny's hospitalization in 1990 for water retention and congestive heart failure, my parents decided that it was no longer safe for Granny to reside in our home and that she needed skilled nursing care. As many know, caregiving does not end when a loved one enters a facility. I became a familiar face around the facility and tried to arrive during mealtimes to be sure she was actually eating from the tray they left in front of her. She was not a big fan of yogurt, but I discovered that she would eat it if it was lemon flavored and I told her it was lemon meringue pie. Deceitful? Maybe, but necessary given her rapid drop in weight and questionable nutrition. I would also make sure she was wearing clean (and her own) clothes and that her glasses, as well as a box of chocolates, were within her reach. Her weight was not my only care concern. Due to

what I know now are the realities of nursing care facilities, I was amazed by her loss of individuality and the assembly line way in which she was treated. I arrived one day to find her hair in pigtails and ribbons, by which she would have been utterly horrified. Her television would always be blaring something other than her beloved soap operas and coffee was only offered once in the morning.

On May 27, 1991, the nursing home called my mother to tell her that my grandmother was dying of congestive heart failure. During the past few weeks she had eaten less and less. Standing by her bedside, my mom and I sobbed as we realized that this was it. Because she did not have the energy to sip, I placed drops of water on her tongue. My mom changed her undergarment and cleaned her. For the first time I knew that this is what dying looked like and what losing someone you loved felt like. Just then my mom took her mother's hand, leaned over, and said, "It's OK, go and be with Dad." Later that night, when I was sleeping, I faintly heard the phone ring. More than half asleep, I could feel something lightly touching my back. In the morning my mom told me what I somehow already knew: Granny had passed.



The Path Continues

The experience of caregiving touched my life in infinite ways, one of which is professional. I knew toward the end of my caregiving experience that I wanted to learn more about aging and families' coping with the needs of older loved ones. During my undergraduate years I sought out aging-focused or related courses in college and specialized in gerontology, and I worked as a graduate assistant in the Center on Aging during my MSW program, writing papers about dementia and/or family caregiving when given the chance during both of these educational experiences.

My post-MSW practice experience involved a position as a medical social worker for a home health-care agency. The service area included a mixture of urban and rural areas. The majority of my clients were older adults; many suffered from one or more chronic illnesses and required assistance with activities of daily living (ADLs), such as assistance with feeding, toileting, and bathing. Many received full- or part-time ADL assistance from family members.

In this position, I was able to see and intervene in the day-to-day problems of the chronically ill and their care-providers. These problems often involved a lack of resources, both human and financial. The need for hands-on care and transportation often surpassed the friends, relatives, and community social services available to meet these needs. The household bills, compounded by the rising costs of needed medications, left many older adults with only pocket change at the end of the month. Acquiring supports that would allow individuals to stay in their homes was never an easy task, and case management often felt like putting a band-aid on a situation that required a cast.

Older clients in rural areas appeared to have an advantage over their urban counterparts, as many lived close to family members. It was not uncommon for three generations to live within a mile of each other. This worked amazingly well when it came to caregiving. Often, the client would remain independent in his/her own home, while children and grandchildren took turns cooking meals and providing transportation. With the growing mobility of today's population, living near and receiving care from family members becomes less feasible for many older adults. For this reason, coordination with families across the miles became increasingly more common in this position. This across-the-miles or "long-distance" caregiving was also gaining national attention and was experienced by some seven million Americans (National Council on Aging, 1997).

Resource gathering and coordination was a daily activity in this position. The most difficult responsibility, though, was introducing the topic of institutionalization. Because of my previous caregiving experience, I was sensitive to the physical and emotional strain of providing care and always discussed this option with caregivers. Unfortunately, families often avoid the topic of long-term planning and possible placement, as no one wants to see his/her loved one in a nursing home. Likewise, promises

were often made to never send the loved one to a nursing home. As a result, placements were often made at the absolute breaking point and usually after a hospital stay. In this case, families had less than adequate time to find the optimal setting for their loved one. At this point, families often felt that they were committing the ultimate betrayal and were left feeling extremely guilty.

My personal and work experience related to caregiving fueled a desire to conduct research in this area. Because I wanted to do research and teach, I enrolled in a Ph.D. program in social work. During my first semester I became interested in the experiences of non-traditional caregivers, those whose voices were not often heard in the traditional caregiving studies. Discovering a major gap in the literature and for personal reasons, I narrowed my focus to midlife and older (50+) gay men and lesbians who provide or who had provided care to same-sex partners. This became the topic of my dissertation in which I conducted qualitative interviews to uncover the unique experiences of these often-hidden caregivers (Hash, 2006).

During this research, I was fortunate to encounter 19 wonderful individuals who were willing to share their remarkable stories. They ranged in ages from 50-77. What I discovered through this study was that gay and lesbian caregivers experience many of the same strains as traditional caregivers, including exhaustion, decreased finances, conflicts with employment responsibilities, and emotional strain (Cantor, 1983; Poulshock & Deimling, 1984; Shultz, Visintainer, & Williamson, 1990; Zarit, Reever, & Bach-Peterson, 1980). The unique aspects of their experiences, though, involved their interactions with informal (family, friends, coworkers) and formal (health care and other professionals) support persons and services and their long-term planning and decision-making processes. Persons outside of the partner relationship had the potential to greatly affect the caregiving experiences. Respondents were often faced with informal support persons who were not accepting of their partner relationship. As a result, some of their family and coworkers did not acknowledge the relationship or provide the level of support needed during caregiving or bereavement. Ex-spouses and adult children, in some cases, were particularly hostile toward the couple and the caregiver. Heterosexual couples in this situation do not often face this type of treatment and discrimination by others. Despite family and coworkers, who were unsupportive, some had the advantage of a strong network of friends and family members who were supportive of the partner relationship.

Although homophobic attitudes were not often overtly expressed by professionals, they were many times apparent through slighting remarks or rude or hostile behavior on the part of professionals. A few respondents mentioned staff that gave them "dirty looks," were "uneasy" or "un-engaging" or "acted like they didn't want anything to do with gay patients." A particularly upsetting occurrence involved a nursing assistant asking a patient's elderly mother whether her son was the "husband or the wife" in his relationship with his same-sex partner. Some policies and practices were also insensitive to same-sex partners, often insisting that the "next of kin" was not a partner. Although some poor treatment was attributed to homophobia, much was seen as the result of a health-care system that has become far too impersonal. Respondents described supportive professionals as those who were supportive and respectful of the partner relationship and those who referred the respondents to other supportive professionals and services. At times, these professionals also bent the rules and treated partners as immediate family as far as policies and decision making were concerned. Unfortunately, respondents expected to be faced with insensitive professionals and individuals because of their sexual orientation.

In many ways, the long-term plans and decisions made by the couple and the caregiver appeared to be very different from those of their heterosexual counterparts. Although many couples set up advanced directive documents that stated their medical and financial wishes, the reasons the respondents and their partners drafted these documents are seemingly very different. Many set up advanced directives to ensure that their wishes

would be protected within health care and other settings. This included living wills that stated the measures to be used to keep the individual alive and powers of attorney which designated a partner as the primary financial and medical decision maker should the individual become incapacitated. For some, this was based on fear that their family members would try to interfere with their plans. Additionally, some used advanced directives to clarify the nature of their relationship and their wishes to health- care professionals. The intention was that if a partner's name was listed as a power of attorney and primary decision maker, a professional would understand that this was the most important person in an individual's life. There was also great variety in the arrangements of finances and property ownership among the respondents and their partners. Some owned property and held finances jointly, while others kept finances completely separate. Still others had a mixture of shared and separate property and finances. As far as their own long-term plans, several respondents voiced concern over who would be available should they need care in the future. Very few felt that they could rely upon a circle of friends for assistance and many feared harsh and hateful attitudes and behaviors they would encounter (as a gay man or lesbian) should they need skilled nursing care.

The Path Comes Full Circle

Following the completion of my Ph.D., I started a position as an assistant professor in the department where I received my MSW and had held my first professional social work position. In this position, I continued to focus my research and teaching efforts on caregiving and aging. My training in the Ph.D. program had prepared me to meet the expectations of an academic career. Granny had prepared me for the transition that would come next, that of a parent.

The challenge of raising dogs was significant but that of raising a child would be momentous. Given my poorly behaved dogs, I wondered if I had what it takes to be a good parent. Our daughter is two years old and I now know that "what it takes" to be a parent changes on a daily basis. Her first six months I spent taking care of her during the day and teaching courses at night. In that time I became much more proficient in diaper changing and baby handling. Believe me, I had a long way to go in terms of proficiency. By the end of the spring semester, we were a finely tuned mother and daughter daytime team. While bathing and dressing her, I sometimes think about Granny and how she had done the same for me when I was a child. My thoughts then turn to how I was able to return this very care when Granny needed me the most.

The path has come full circle now, and I am building upon the love and care Granny and I shared as I nurture and care for my daughter. The patience and sense of humor I honed while providing care to Granny have served me well in caring for the next generation. I marvel at my daughter's growth and cherish the opportunity to care for her and contribute to the beautiful little person she is becoming. I am convinced that my daughter is "the best little girl in the world" and I fear that our walk to kindergarten will come much too soon. When that walk comes, I will show her the photograph of Granny and me on the front porch before heading off to my first day of school.

Implications

I still have the *Newsweek* magazine whose cover study focused on women in the middle and family caregiving for older adults (Beck, Kantrowitz, Gordon, Roberts, & Hammill, 1990). That was the first time I had seen the popular media tackle this subject. Twenty years later, the general public is well versed in this phenomenon. Despite the increased visibility, providing care for older loved ones and keeping them in the home remains one of the biggest challenges faced by our nation. Through my personal experience as a caregiver, as well as my educational work and research endeavors, I have developed certain insights into the present and future of caregiving for older adults. These insights can best be explained as implications for research in this area, policies and services, and health and human service professionals.

Research on Caregiving

The family caregiving literature has been rapidly growing since the late 1970s and has contributed greatly to the understanding of the caregiving experience for people with Alzheimer's disease and related dementias. In general, these studies have shown caregiving to be a very challenging role, one that is physically, emotionally, and financially taxing for families (Cantor, 1983; Cuijpers, 2005; Poulshock & Deimling, 1984; Vitaliano, Zhang, & Scanlan, 2003). Despite these adverse effects, research has also shown positive outcomes of caregiving, including a sense of pride in providing care and the ability to keep loved ones in the home environment (Farran, Keane-Hagerty, Sallowat, Kupferer, & Wilken, 1991).

The majority of these studies have focused on the experiences of the "primary" caregiver and the care of older family members. This person is described as the person who assumes most of the caregiving responsibilities (Baum & Page, 1991). The primary caregiver is often a spouse. In the absence of a spouse who can provide care, an adult daughter or daughter-in-law typically assumes the role (Cantor, 1983; Stone, Cafferata, & Sangl, 1987). As primary caregivers, adult daughters and daughters-in-law often become "women in the middle," caring for ailing parents while also caring for and raising children and working outside the home (Brody, 1981).

Very few studies have looked at the experiences of secondary caregivers, or those who do not have primary responsibility but who also provide ongoing assistance (Bedard, Raney, Molloy, Lever, Pedlar, & Dubois, 2001; Tennstedt, McKinlay, & Sullivan, 1989). Compared to primary caregivers, secondary caregivers are younger (often adult children), report less burden, often do not live with the care-recipient, and provide fewer hours of hands-on care (Bedard, Raney, Molloy, Lever, Pedlar, & Dubois, 2001; Tennstedt, McKinlay, & Sullivan, 1989). Tennstedt et al found that secondary caregivers are more involved in supplemental and instrumental tasks, such as shopping and transportation. They also provide a great deal of emotional support to the primary caregiver (Bedard et al, 2001; Tennstedt, McKinlay, & Sullivan, 1989). Because of their instrumental role in the caregiving situation, future studies should further investigate the role of secondary caregivers and the special challenges they face.

Secondary caregivers are not the only persons whose experiences are largely invisible in the caregiving literature. The experiences of minority and non-traditional caregivers deserve much more attention. Fortunately, the unique experiences of ethnic minority caregivers (Chun, Knight, & Youn, 2007; John, Hennessy, Dyeson, & Garrett, 2001; John & McMillian, 1998; Mahoney, Cloutterbuck, Neary, & Lin, 2005) and male caregivers (Kaye & Applegate, 1990) have been given increased consideration in the recent years. The experiences of sexual minorities are still hidden from view. The model of family caregiving should continue to expand by including the voices of ethnic and cultural minority caregivers. Reliance on the traditional model of caregiving can only adversely affect the policies created for and services rendered to caregivers and care-recipients.

Policies and Services

The advantages of home versus institutional care are quite evident. In the interest of containing state and federal healthcare spending, homecare provided by informal support persons is far more cost effective than the average yearly nursing home cost of $60,000 per resident (MetLife, 2004).

Caregivers, then, are clearly the best defense against the rising costs of institutional care and the strain those costs place upon the Medicare and Medicaid systems. Not only is homecare cost effective, but it is also preferred by older adults and their loved ones. In addition, future demographics will likely lead to fewer available caregivers for chronically ill older adults due to the graying of the "baby-boom" generation and the shrinking sizes of American families (International Longevity Center & Schmieding Center for Senior Health and Education, 2006). For fiscal as well as compassionate reasons, when one or more individuals are willing to provide in-home care to an older adult, we need to do everything in our power to sustain them and the situation.

This cannot be accomplished while Medicare and Medicaid continually cut funding for homecare services. To sustain homecare situations, the Medicare and Medicaid programs will need to re-commit funding for local services that provide in-home medical and respite services.

In addition to increased funding for in-home services, supporting and sustaining caregiving situations will require a re-conceptualization of what we now consider "family caregivers." This will need to be accomplished by federal and state policy makers as well as administrators of local health and human service organizations. Recognizing same-sex couples as legal partners would go a long way in supporting gay and lesbian caregivers. The enactment of such a policy at the federal level would logically lead to Social Security benefits, provision of tax benefits for in-home caregiving, paid leaves of absence at places of employment, and equality in health insurance policies. At the local service level, hospitals and other organizations should include same-sex partners as "next of kin" on their forms and procedures. As a term, "next of kin" should be replaced by "primary contact person," which would allow a client or patient to designate the person who provides care and/or who is dearest to them. For many, this may not include blood relatives, but instead, friends and neighbors. Expanding our concept of family at the policy and organizational levels can only increase the support to diverse caregivers.

Health and Human Service Professionals

One of the simplest, as well as most important, ways to support caregivers is to recognize the care they provide and praise them for taking on one of life's most difficult tasks. Health and human service professionals should never forget that caregiving is a life altering experience; thus they should convey empathy for those who take on the caregiver role. In addition, encouraging caregivers to talk about the positive aspects (including humorous events) of their experiences and the meaning the role has brought to their lives is an important but often neglected aspect of communication (Farran et al, 1991; Hash, 2006; Sanders, 2005). Also critical is letting caregivers discuss their feelings of strain and guilt and reminding them to take care of themselves and each other. It is often helpful to promote the view that they need to take care of themselves before they can fully take care of someone else. The analogy of airline emergency procedure announcements can illustrate this point: "If you are traveling with [someone vulnerable], in case of emergency, place your oxygen mask on first before assisting the other person."

In addition to encouraging caregivers to take care of themselves, health and human service professionals should engage caregivers as well as themselves in burnout prevention. This can be accomplished by resource planning and discussing long-term plans with both caregiver and receiver (Whitlatch, Judge, Zarit, & Femia, 2006). Caregivers need to plan for the time when they can no longer provide in-home care and professionals need to provide information on alternatives and be ready to support caregivers through such a process.

Together with recognizing their efforts and encouraging long-term planning among caregivers, professionals should think outside of the box in assessing caregiving situations and informal supports. In assessment it is important not only to look at present family dynamics but also to identify the history between family members. In my caregiving experience, the situation was exacerbated by a mother-daughter relationship that had been strained for many years prior to the onset of care. The role of secondary caregivers should also be considered in assessment, especially since these persons often serve as emotional supports for the primary caregiver. Thus, sustaining secondary caregivers is equally important. Thinking outside of the box also means understanding the unique needs and experiences of diverse caregivers, including friends and neighbors, same-sex partners, men, and ethnic minorities (Dilworth-Anderson, Williams, & Gibson, 2002; Hash, 2006; Himes & Reidy, 2000).

Professionals and educators in health and human services have an additional and ever-increasing challenge in meeting the needs of caregivers and care-recipients. A growing

number of social workers, nurses, and physicians will be needed to meet the needs of a rising population of older adults with chronic illnesses. The critical need for geriatric social workers in particular has been widely noted in the literature (Berkman, Gardner, Zodikoff, & Harootyan, 2006; Scharlach, Damron-Rodriguez, Robinson, & Feldman, 2000). Professions and educational programs will need to increase their efforts and investment in geriatric education and training. Dramatically increasing the number of educational courses related to aging, caregiving, and health care would be a step in the right direction. Professional visibility and organization will also be required to actively recruit individuals to work and study in this area. In addition to these professional and educational efforts, I anticipate that others (like me) will be drawn to work with and on behalf of older adults and caregivers through personal life experiences. Given my experience, I hope that Granny has found that peep-hole in the clouds and can see not only that Amy's home is tidy but also that her involvement in my life and the opportunity to care for her has shaped my life.

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Social Worker, Granddaughter, or Caregiver? How What We Know as Professionals can Help or Hinder Our Personal Caregiving Role

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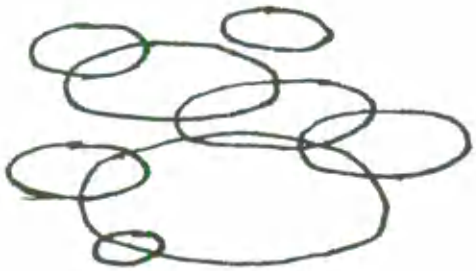
Lay people often assume that professional helpers are able to handle life's ups and downs with greater aplomb than the rest. When a professional helper takes on the role of caregiver for their own elderly relative, the same lay folk may assume that the task is somehow much easier for them. This narrative explores the author's experience as a social worker, a granddaughter, and a caregiver, as she attempts to understand the ways in which each role was impacted by the others.



In November 2003, my family and I gathered for Thanksgiving at my sister's home in the woods on Vashon Island near Seattle. The annual gathering at her home had been our ritual since the loss of my mother in December 1997. It was the second Thanksgiving on the island for my two-year-old daughter, and would be nearly the last for my grandmother "Nana," who was then 93 years old.

Nana had been proud of her lifelong good health, particularly her complete resistance to the colds and flu viruses that frequently struck those around her. She was ornery, opinionated, and proudly both socially and politically liberal. She was a wild and striking woman. She was so strong and vibrant that we all thought she'd live forever and we couldn't imagine life without Nana.

Soon after our arrival on the island that year, however, Nana began to complain about not feeling well. She slept a great deal of the time, but her symptoms were nonspecific. The day after Thanksgiving, after walking across a room, she leaned against a wall and slid down, seemingly in slow motion. My brother-in-law and I rushed to catch her.

The ambulance arrived quickly, finding us at the end of an unpaved dirt road, and took her to a local physician's office because there was no hospital on the island. In the ambulance, Nana developed uncontrollable and explosive diarrhea that continued in the doctor's office. The doctor decided she probably had some sort of virus and then sent us all back home without providing any treatment. Unfortunately, her diarrhea continued all night, weakening the defiant and independent matriarch. The chronic diarrhea forced my sister and me to wash her off in the shower leaving her exhausted and humiliated. Since her condition was no better in the morning, yet another ambulance took her by ferry to a hospital in Seattle. We never learned exactly what was wrong; however, she remained in the hospital for ten days, followed by two weeks at a nursing home, and yet another two-week stay at my sister's home before she was strong enough to be able to return to her own home in Los Angeles.

During that month of overseeing her healthcare, I realized two important things. The first was that as much as I believed I would be emotionally ready when Nana died, I was mistaken. I learned then I could *never* be ready. During those days when I was caring for her, when I saw her collapse and her eyes roll back, I knew it was going to be an emotionally challenging time for me. I was

simply terrified at seeing her so vulnerable. The second realization was that Nana could no longer continue to live independently. That realization was also shared by my sister and both of our partners. Nana agreed with our conclusion, but only half-heartedly, and only on some days. She had talked about assisted living for years, but naturally feared actually making the change. She also felt hindered by the possibility of outliving her meager savings.

My Introduction to Caregiving

Drawing on my professional skills as a social worker, I began to look at assisted-living facilities for her in early 2004. I gathered information, made lists of pros and cons, visited different facilities, spoke to administrators and social workers, and obtained numerous referrals. Everything responsible social workers should do. Meanwhile, Nana changed her mind: she dug in her heels and declared to all of us that she would stay in her apartment in the senior subsidized building where she had lived for nearly 20 years. The location of her home was a problem since it required me, as the nearest relative, to travel from her home to mine more than 18 miles through the notorious traffic of Los Angeles, particularly the parking-lot traffic jam of the Sepulveda Pass. Obviously, if anything happened, I could not get to her quickly.

In addition to location, communication was a challenge. Because she did not want to burden me with her troubles, Nana rarely let me know when she did not feel well. I repeatedly explained to her that it would be *more* of a burden if I learned she was in a hospital emergency room when I was already at work some 50 miles away. In response, she made solemn promises that next time she would let me know right away if something was amiss regarding her health, but she never did.

Many of Nana's memories of my mother, who died seven years earlier, consisted of complaints that my mother was "selfish" and "never there for me." I knew even as a child that my mother put plenty of time and effort into caring for Nana, yet because of Nana's independent spirit, my grandmother rarely allowed my mother or anyone to actually help her. As her health deteriorated, Nana did not want to burden me, yet I feared she would repeat the pattern by later insisting until her last breath that I was selfish "like your mother."

As a professional, I know this type of dynamic is common in family caregiving. Beth Wilson McLeod (1999) states in her book on the subject: "Dramatically and unexpectedly, caregiving propels unfinished business to the foreground" (p.17). But as a family member I found the dynamic hard to stomach as it forced me to relive the pain of the chasm between two women I loved fiercely.

When Nana did, on occasion, accept services, she made it nearly impossible to provide them because she insisted that others do things the same way she did. For example, when Nana complained about the wrinkles in her handkerchiefs laundered by the assisted-living facility where she eventually moved, my partner offered to iron them for her. But Nana's insistence on compliance with her method—spraying the handkerchiefs with water, wrapping them in aluminum foil, and keeping the flat packets in the refrigerator!—made it impossible to help her. If I were simply Nana's social worker, I might have dismissed her behavior as quirky and amusing. But as a family member, I found her behavior frustrating and irritating, feelings that made caregiving more difficult for me.

Eventually, after Nana had vacillated repeatedly about her desire to stay home and/or receive in-home assistance, it became clear that I would need to act more assertively. As a social worker, I worried about interfering with Nana's right to self-determination. But as a granddaughter, I could see that she clearly, albeit reluctantly, wanted my assistance. I resolved this conflict by rationalizing that I could not assist her properly if she continued living at such a distance. Accordingly, I chose two skilled nursing facilities and arranged for Nana, me, and my sister to visit and have a meal at each place. In June 2004, Nana went for a "trial" stay at a facility about four miles from our home. After two weeks, she agreed to stay. After three weeks, she told me to sell her car. It seemed she was, if not happy, at least content.

When Personal and Professional Worlds Collide—or Accepting My New Role

Soon after Nana moved, I was venting to a friend about Nana's slow adjustment and my difficulty in determining when to intervene on her behalf at the facility. I felt tremendous anxiety and pressure. One day during a typical visit with her at the facility, Nana questioned why I had sold her car and accused me of selling it without her consent. As a granddaughter I wanted to leap to my own defense and correct her faulty memory. However, as a professional social worker, I understood that she had a need to remember the event in her own way in order to deal with her feelings of helplessness and lost independence.

As a granddaughter, I felt blamed and unappreciated; even though I was now taking care of my grandmother, part of me still wanted *her* to take care of *me*. Nana's rocky months at the assisted-living facility were emotionally draining; I did not have the luxury of only being a professional. All my professional experiences in social work practice didn't seem to prepare me, as a granddaughter, for this transition. A supportive friend told me, "Stacey, you need a caregivers' support group." Confused, and maybe even shocked by her suggestion, I snapped, "But I am not a caregiver!" I immediately realized how silly that sounded, and soon began to identify with the term and seek out resources and support for myself in that role.

Mary Pipher (1999) writes in *Another Country* that an elderly person moving to a facility must have "courage, forbearance, stoicism, and the ability to laugh and forget about problems, to assert needs, to communicate openly, and to process pain" (p.127). Nana had many of these qualities, but still she struggled. She could be incredibly charming; the facility staff was amazed at her lucidity, her wit, and even her mobility. She participated in current events discussions in the facility, but rarely wanted to leave the facility. I thought that driving my grandmother around her new neighborhood could help her feel more comfortable but such an outing, Nana said, required "too much effort." She had always been a complainer, but now the habit was even more exaggerated.

At one point, I began to worry about her having delusions and paranoia because she insisted to my partner and me that the administration was out to get her and repeatedly claimed that the facility put narcotics in everyone's food to keep them sleepy and docile. I took her for a psychiatric evaluation, knowing that she was depressed and possibly experiencing some dementia, along with paranoia. She presented to the psychiatrist that she never had any negative thoughts about her current or past life. In truth, Nana had had plenty of losses and tragedies in her life and could actually be very bitter about them, but the doctor accepted Nana's description at face value; after a brief assessment, he sent us on our way. As a professional and as a granddaughter, I was shocked that the psychiatrist did not challenge my grandmother's false claims of joyfulness. Perhaps the rubber-stamp assessment can be blamed on the demands of managed care; the psychiatrist had a waiting room full of patients, each of whom he had to meet and assess in a matter of minutes—digging deeper and confronting denial maybe was not on his checklist. Unfortunately, it had taken me months to convince my grandmother to visit a mental health professional. The psychiatrist let this one opportunity slip through our hands. I knew my grandmother would not be willing to try again.

Letting Go of Nana

At the same time Nana was mentally and physically declining, I also began to experience more and more feelings of loss and separation from her. There were fewer activities we could do together and our conversations were strained. One night at a restaurant in October 2006, I finally understood that Nana's growing aversion to restaurants was not only because of her weak hearing aids—being out at restaurants actually made her uncomfortable—but because she was getting old and tired and she wanted comfort and control of her surroundings.

Interestingly, that restaurant is a pivotal location in my life. It was the same restaurant

at which my partner and I had our first date, a marker of the beginning of our lives together. However, on that night, the restaurant acquired an additional meaning: the moment and location marked an ending of how I could relate to Nana. On that night, in that place, I began to accept that the vibrant, obstinate, courageous, and powerful woman I had known and loved was changing. I could see with new eyes that Nana was frail and tired and her health was fading. From now on, our time together would be limited to her room, my car, my home, and the offices of various physicians who participated in her care.

There were many trips to the Emergency Room over the next few months. Although numerous tests were performed, the final "diagnosis" was the same: she was getting old. I yearned for a more satisfying explanation; one that indicated some course of action. But, her physical and mental health was declining and there was nothing to be done.

I had often wondered how it would end for her. Would she die in her sleep? Would she be in pain? Would I be there? Sometimes I asked her doctors what percentage of people her age and condition die this way or that. What was the doctor's prognosis? I know now that my questions were the only way I could direct my grief and gain an illusion of control; my actions were those of a confused and scared family member, not of a professional whose role would be to confront reality.

And Then She Was Gone

On January 14, 2007, we had had a birthday party for my five-year-old daughter, the apple of Nana's eye. Nana had very much wanted to be there and we arranged for her to be as comfortable as possible. She stayed the whole time, just sitting, watching, and talking about how tired she got watching the kids run around. Many of my close friends were there as well. Nana had developed her own relationships with some of them in the years she had spent living closer to us, and some felt a strong affection for her as a result of hearing my stories through the years. She spent what would turn out to be her last day of life surrounded by laughter and friends

Nana died the very next day while I was out of town. I'm sure she planned it that way. She was the ultimate planner. She had her funeral and burial planned and paid for years in advance. She reviewed all her plans with me, in part because her son is buried on the east coast and she wanted to be with him. In part, such planning was just her way. She planned so well, that when I later went to retrieve her clothing for burial, I found the exact outfit my sister and I had decided upon, fully laid out on her chair...head to toe. Once again, Nana was trying not to be a burden; she had shielded us from needing to sort through her things or make decisions in the midst of our acute grief.

Nana had not felt well all that day. I had talked to her and her physician and caretakers numerous times, trying to determine what could be done. Her symptoms were vague and did not appear acute. I received a call about 5:00 p.m. from a nurse stating that the staff had left her room for a brief period of time (they had been with her almost all day) and returned to find her unconscious on the floor. I was told that the paramedics were "working on her." I was horrified and distraught. I knew she did not want such measures; we had reviewed her advanced directive with the facility just one month before. I asked about her directive and the nurse told me that they could not find it and so had called the paramedics. Quick thinking and fast fingers helped me connect to her physician, who called the Emergency Room and advised them of her wishes. I soon received a call from the doctor at the hospital, who acknowledged to me that she had already intubated Nana. She further said that she was certain that if she turned off the ventilator, Nana would die. I could not believe that with all the perfect planning she'd done, in part to save me from having to be in the position of making such a decision, this had occurred.

A few days later, a mutual friend told me that at the party Nana had said, "I am ready to go, but I don't know how to tell Stacey." In actuality, I had known for some time, and now think that perhaps I should have told her that I knew, and that I would be okay. Once again, she seemed to be trying to protect me. Perhaps if we'd talked about it, she would have gone

with greater peace, perhaps dying in her sleep. As a professional, I knew that dying people sometimes need permission from loved ones to "let go," but as a caregiver and granddaughter, I was too lost in my own grief to realize that she needed that from me.

She might have escaped the horror of the paramedics pounding on her chest and I would not be haunted by that vision and by the sound of my own voice saying to the doctor, "Yes, please turn it off."

Reflecting on the Journey

I have never practiced in geriatrics, but two of my good friends are geriatric social workers; one of them specializes in support for caregivers. Despite my concerns for this friend, it has been a relief for me to see her struggle with her own caregiving role with her own mother. I realize that no helping professional is immune to personal struggles.

Being a social worker gave me an advantage as I negotiated services for Nana. I knew whom to ask for assisted living referrals. I knew where to call to access in-home care services. I understood the importance of my becoming active in her healthcare and developing my own relationships with her doctors. I was able to arrange for a psychotherapist to see her in the assisted living facility as a "Friendly Visitor" because Nana, like many of her generation, didn't see the need to pay a stranger to listen to her talk about personal issues. My familiarity with institutional dynamics helped me to maintain some objectivity when she complained about the nursing facility staff. And my sensitivity to professional boundaries and ethics allowed me to quickly identify it and respond when one administrator acted inappropriately.

Through my profession, I knew of various resources and support groups. McLeod (1999) describes the role of caregiver support groups in "sharing your feelings, venting outrage with others who won't criticize but instead help you to move forward" (p.147). As a professional, I knew how healing this can be. But as a devoted group worker and instructor, I have had great difficulty removing my professional hat so that I can fully participate as a client. Even so, I tried out a caregivers' support group facilitated by paraprofessionals. The facilitators most often responded to complex problems by offering obvious or simple solutions or interventions without considering them in the context of family history and dynamics. Even when the facilitator was doing fine, it was hard for me to simply be a participant rather than a co-leader, teacher, or critic. I cringed at the canned jargon the facilitators used; when one facilitator asked, "So who is taking care of Stacey?" I wanted to scream.

Professionals Are Not Immune

During my caregiving years, family and friends acted as if my education and experience would serve to inoculate me from the difficult feelings that come with the situation in which I found myself. As I experienced feelings of loss, guilt, sadness, regret, and fear, the wealth of knowledge I had acquired in the profession did not prepare me for the personal losses and personal struggles inherent in caregiving.

I knew that resistant patients may minimize their symptoms when they finally see a physician, so it was no surprise that Nana told the psychiatrist that she was fine when I knew she was miserable, but I was still frustrated and disappointed. I knew, too, that moving my grandmother to a more restrictive environment with a higher level of care might be a mixed blessing. In many ways, her new living arrangement had the potential to save her from grave injury but would potentially hasten her demise as it stole her *joie de vivre*.

Knowing did not save me from feeling. I was losing my larger-than-life grandmother: the ornery, opinionated old woman who drove until she was 94 and had every radical, liberal bumper sticker on her car; the tenacious, fiery old lady who held onto her twisted versions of being wronged by family members and friends in spite of mountains of evidence to the contrary. My grandmother was a huge part of my growing-up years and I am very grateful that she remained close to me in my adulthood as well. I know my family—my sister, my partner, and our daughter—gave her much joy in the last years of her life. I am certain she lived longer due to the delight of an unexpected

great-grandchild. But my knowledge of the heavy losses in her life no doubt exacerbated my sadness at her impending death. Through my work, I knew of the many opportunities that Nana could have taken advantage of to help her to reflect on her life and to come to peace with the past. As Elizabeth Kubler-Ross (1978) stated, such therapies help to "do away with the drain of energy required to repress all these negative feelings" (p.150). I wished that Nana had participated in therapy groups or done life review. To deal with my frustration, I attempted to apply the social workers' credo of self determination to my personal experience.

Looking Back

It has been about 18 months since Nana died. I think I can say with relative certainty that my knowledge and experience as a social worker was a benefit in the end, though often during the process it was not enough. I don't think I gave myself enough permission to truly feel what was happening. Although I knew that caregivers' guilt was a normal, if undeserved, response, I could not stop myself from feeling guilty. I reasoned that because I knew (professionally) that Nana would decline after moving, I should not feel sad when it occurred.

Fighting my feelings—not denying them as much as criticizing myself for their strength and power, and especially for any transferential aspects—has been a pattern throughout my life. I have learned that the more I do this, the worse I feel. How can I grieve when I am telling myself that I should not be grieving? Accepting my feelings in all of their intensity is always the path to my healing and highest degree of mental health. I may have been open to psychotherapy and understood or developed insight into my reactions to the loss of my grandmother more quickly as a consequence of being a social worker.

My grieving continues and I doubt it will end. It changes, but the waves still come. While tears used to run, now they drip. If I could use my experience to help myself and other professionals in the future, I would let them know (and remind myself) of all I have written here. We need to commit to "take our own medicine": seek support, accept our feelings, and ask for help when we need it. We need to remember that while love and its subsequent loss is perhaps the greatest source of emotional pain, it is first our greatest source of joy and, I believe, our very reason for being.

Dedicated to the loving memory of Bess Prince: March 27, 1911, to January 15, 2007.

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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 beside 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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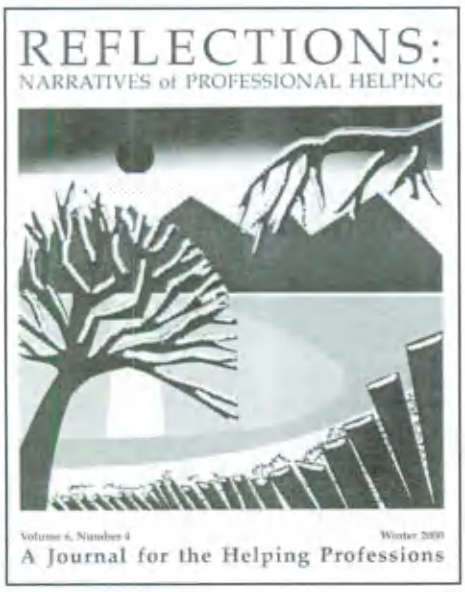

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NARRATIVES OF PROFESSIONAL HELPING

Reflections: Narratives of Professional Helping (ISSN 1080-0220) is published quarterly by the University Press at California State University, Long Beach under the auspices of the Department of Social Work. Annual Subscription Rate: individuals, $40.00; libraries and institutions, $65.00; outside USA, add $15.00. Single copies: $10.00. Payment: check, money order, or credit card (Visa or MasterCard, please include number and expiration date). Please send to **REFLECTIONS: CSULB; 1250 Bellflower Boulevard, Long Beach, CA 90840-0902.** We remind subscribers to please immediately notify Reflections of address changes, providing both new and old addresses. Please allow six weeks for address changes to take effect.

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Periodicals postage paid at Long Beach, CA.

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