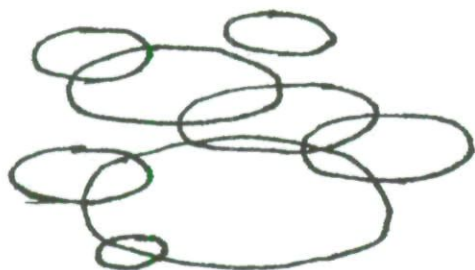


# SOCIAL WORKER, GRANDDAUGHTER, OR CAREGIVER? HOW WHAT WE KNOW AS PROFESSIONALS CAN HELP OR HINDER OUR PERSONAL CAREGIVING ROLE

Stacey Peyer, MSW, California State University, Long Beach

*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 transference 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.

### References

- Kubler-Ross, E. (1978). *To Live Until We Say Goodbye*. New York: Prentice Hall Press.
- McLeod, B.W. (1999). *Caregiving: The Spiritual Journey of Love, Loss and Renewal*. New York: John Wiley and Sons.
- Pipher, M. (1999). *Another Country*. New York: Riverhead Books.

Stacey Peyer, MSW, is a Licensed Clinical Social Worker working as a CalSWEC Child Welfare Field Consultant and a Lecturer at the California State University, Long Beach Department of Social Work. Comments regarding this article can be sent to: [speyer@csulb.edu](mailto:speyer@csulb.edu)



Copyright of Reflections: Narratives of Professional Helping is the property of Cleveland State University and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.