

Lessons Learned: Experiences of a Caregiver

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Abstract: In the following narrative, the author shares experiences from the time when she was the full time caregiver for her mother who suffered from dementia. She reflects on the lasting impact this experience had on her life and her identity as a social work practitioner and educator.

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Introduction

When I read the call for papers for reflections on caregiving, I felt that I had a story to share. The time I spent being the primary caregiver for my mother was one that I have never regretted, but it was also a humbling time filled with mixed emotions, doubts, and frustration. I experienced moments of contentment as well as exasperation. There were many lessons that I learned: 1) one can never be objective about or prepared for the experience; 2) caring for a loved one with dementia means navigating a “maze” of policies and services that is illogical and confusing at best; and, 3) solace can come from the most unexpected places.

My mother was the most independent woman I have ever known and in my eyes, she was infallible. She had endured many experiences and environments that would have broken the spirit of most people: an abusive marriage; a nomadic existence in a military culture which isolated her from extended family; serving as a safety zone for her children from the nightmare behaviors of a substance abusing parent; and then, the sudden, violent loss of a spouse who though abusive was still the only long term relationship she had known. During her later adulthood, she suffered from chronic health issues that included hyperparathyroidism (collateral damage from the removal of her diseased thyroid); chronic kidney disease; Non-Hodgkin’s Lymphoma, and a bowel obstruction that necessitated the performance of a colostomy with no option for reversal. Throughout these years, I was able to care for my mother and our bond grew stronger as is often the case with mothers and daughters.

The adage “hindsight is always 20-20” comes to mind when I think back to the process of recognizing and acknowledging my mother’s dementia. I can now see the progression of behaviors that were clear “markers” of the disease’s early progression. It is embarrassing to admit, but as

many people do, I dismissed most of them for years. It was not until the time of her recovery from her colostomy that I was willing to approach the possibility that my mother had dementia. This alone was a huge learning experience because there are numerous variations of the disease and the diagnosis is maddening unless it falls under the umbrella of a type that can be “visibly observed”. Shortly after my mother’s ostomy, she began to share with me the content of her “visions”, how she was joyful that her mother (long deceased) was with her and that she would find herself in a garden with her mother and sisters (also deceased). She also experienced frightening hallucinations so devastating that she would need to be held and comforted for hours until the feelings of despair and hopelessness subsided. After numerous doctor appointments with her primary care providers and specialists, a MRI was taken, past scans and MRI’s were collected, and a diagnosis rendered: multi-infarct vascular dementia. Her disease would continue to progress and her abilities to manage her life independently would disappear. This was all uncharted territory for me and that surprised me. I thought that as a professional social worker I would be able to handle this in a professional and objective manner. I couldn’t have been more wrong. When you are caring for a parent suffering from the devastating disease of dementia, when you are watching that person lose herself to the disease, you become immersed in an emotional vortex. My mother had dementia, and my life changed forever.

The Transition to Full Time Caregiving

In what I now call a futile effort to prepare myself, I first contacted my cousins and asked them to recount their experiences and describe their strategies of coping while caring for sick family members. I read everything I thought would provide me with a “plan of action” for becoming the caregiver for a parent with dementia. This included popular books such as *The 36 Hour Day* by Mace & Robbins (2009) and web sites such as Seniorcare.com. I conducted literature

searches using social work and gerontology data bases. I would like to inject my biased opinion here, one that surprises me to say: speaking with relatives and friends who have been caregivers is far more informative than any of the material I read that was authored from either a clinician's or an academic researcher's perspective. I was scared when I realized that my armor as a professional social worker would not immunize me from the sadness, anger, guilt, and isolation that were coming my way. My fears during the transition from an academic and clinician to a caregiver lessened when I started "letting go" of my "professional self" and started connecting directly with persons I knew had been down this path before me. This is one of the most surprising lessons I learned and I am glad to pass it on.

The best perspective I can offer about transitioning to caregiver is that no two transitions are alike; the experience is singular, and there are absolutely NO rules. Step away from what you feel you should know and embrace what makes sense for your reality. My initial months at my mother's home were filled with a whirlwind of emotions that had to take a back seat to my mother's needs. My first priority had to be to learn how to care for my mother. I remember coming across a number of discussion forums on various web sites (i.e. AARP, Caregivers.com, etc.) and one discussion in particular caught my attention. It was titled, "What do you wish you knew when you first started caregiving that you know now"? I found kinship in reading the pages of individual contributions and narratives that were posted. It was something I could go to anytime of the day or night and yes, I could share my thoughts and feelings. It is often said that knowing you are not alone is comforting and I found that homespun wisdom to be true. The simple sharing of emotions and experiences even though it was anonymous and with strangers nevertheless gave me more comfort and reassurance than any other source both during my initial transition as well as throughout the time I shared with Mom.

The Maze

As a social worker, I am not surprised by the complications surrounding our health care system, social security system, and the various governmental branches that must be navigated while seeking

services for a child, an adult or an elder. I knew about guardianships and conservatorships and I successfully navigated the state court to obtain them for my mother. I was glad that I had worked in a social work position that interfaced with the criminal justice courts because going to court on behalf of my mother did not intimidate me although I realize it may be intimidating to others who have never had contact with our legal system. Believe it or not, the court system was the simplest and clearest to navigate, especially compared with what came next: dealing with my mother's residency status. My mother was not a naturalized U.S. citizen; she was a legal alien resident who had always had a green card since her marriage to my father in 1950. She maintained her Canadian citizenship. As I was going through her mail, a letter arrived from the United States Citizenship and Immigration Services notifying my mother of a hearing to determine whether or not she could maintain her status as a legal alien. Mom had not renewed her green card the year before I moved in with her. After searching through the house, I found the renewal notice in the dining room china cabinet. I was on the phone, confident that I could resolve the issue quickly. I believe I spent at least ten hours on hold and 45 minutes actually speaking with someone. Despite my efforts, I had to travel over 100 miles for a hearing with my mother. After presenting court orders related to my status, her medical documentation, and an explanation of why the card was not renewed, we left with a temporary card and went through a series of home visits that I can only assume were aimed at verifying that my mother had dementia and that I did indeed reside full time as her caregiver.

I had now earned a new badge of distinction: I was a maze runner. I have advantages that others thrown into care giving probably don't have. My education and profession enabled me to navigate both the court system in Virginia and deal with the U.S. Department of Citizenship and Immigration. My father's military career afforded my mother excellent medical coverage and pension benefits. As an online teacher, I was comfortable using the Internet and visiting discussion boards. By comparing my experience to that of others, I found out just how fortunate I was: I had a working knowledge of government agencies; I did not have the pressure of huge medical bills; and I had a job teaching online courses that enabled me to be in Virginia caring for my mother while I was teaching "at" a North Carolina university.

Solace

As my mother's disease progressed, so did my feelings of isolation, anger, and guilt. I found myself logging onto my computer frequently to check on the latest postings on the caregiver discussion boards I was following. The majority of my virtual community members often posted about how isolated they felt from friends, work colleagues, and social networks and I echoed those sentiments. I am not married nor do I have children, but I was filled with compassion and empathy for the persons who posted about wishing their family was more supportive or would offer them a respite to recharge. I was fortunate that my brother and his wife who lived nearby were able to provide me with times of respite. My extended family frequently called, and while they are scattered all across New England and Canada and could not be there in person to help, they were willing to listen to me vent and process my own feelings, they sent me notes of encouragement, and praised me for my efforts. However, I felt too guilty to share this with my virtual community. I had this irrational fear that if I spoke of my support system and my advantages in work and education that I would no longer be accepted by the online community. Reflecting back to these feelings, I now can recognize clearly that these were generated by my growing depression from caregiving. While many of us posted about the importance of keeping in contact with friends and taking time for ourselves, few actually posted about times when they were able to do this. It seemed that we knew what to do but were frozen in immobility and unable to achieve it. I especially remember one post where the author described how her mother's depression had become her depression and how she felt like a prisoner in her own home. This resonated with me because I was now into two years of not

living in my own home other than for a quick trip home to pick up mail or take care of work related business that could not be done via internet. A night or weekend in my own home was a vacation, but the elation quickly dissolved when I returned to my mother's home. While I recognize now that I had lows and highs, it is hard to keep that perspective when you are immersed in the experience.

Hard Won Lessons

As a social worker and educator, I now feel more at ease with permitting the client or student to arrive at an "answer" on their own. I feel less pushed as an educator to dissect practice into steps or place behaviors/experiences into categories. I have sometimes frustrated my students in field by not providing definitive answers. I feel this experience of care giving has enabled me to feel comfortable serving as a resource for both my clients and my students by urging and guiding them to explore avenues in order to discover their own style. To this day my personal experience has been translated to one of my favorite policy lectures on being a policy practitioner and the importance of knowing the "system" inside and out that your clients are involved with. In addition, I now make it a point to seek out opportunities to network with other caregivers in order to offer any assistance I can with questions concerning navigation through social policies and services. I wrote this paper to reach others who may be looking for solace to ensure them that they will survive the experience and that this life experience will help them make strides in their own life's journey. The only experience truly wasted is one from which we learn nothing.

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