

Care for the Caregiver – A Personal Journey

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Family members who have become caregivers have their own stories to tell, their own unique circumstances. This is my story.

It was in the fall of 1986 when my mother came to live in my house. I have no siblings and my father had died 12 years previously. At the time my eldest daughter had just left for her first year at the University of Arizona. Her brother was a sophomore in high school. Their little sisters were two and five years old, and I was forty three. My husband and I had a child in every level of school, including pre-school. We were a busy family!

My mother, Sybil, age 76, moved in with us after several episodes of falling. Things went very well for her for six months, but then she fell and suffered a severe hip fracture. We hoped for a return to mobility for mom, but other problems arose. Soon we learned the devastating news: She would never walk again unassisted, and then only for a few difficult steps. She never again would be able to care for herself. As help was needed twice a night with a bedpan, my sleep was fragmented.

To aid my mother at home we secured an electric bed, a commode and a wheelchair. From her bed or wheelchair, mom could look out the window and see our girls playing in the yard or in the pool. When I went outside with my young daughters I took a phone so that she could page me when she needed some assistance. Time outside was necessarily brief.

My mother was dealing with the sadness and depression brought on by a life-changing, permanent event. Even in the midst of her distress, she was attentive to my situation. She encouraged me to continue activities outside of the house. I recruited two women from my church and one friend from my neighborhood to be caregivers in my absence. They ranged in age from late teens to around 60, and did a great job. My mother enjoyed visiting with them. They were paid from my mother's funds.

If we were to be gone for a weekend, such as when we visited our older daughter at college on Parent's Weekend, we paid an agency to provide the 24 hour care of nursing aides. Most of the time my mother and I were satisfied with these persons, but not always.

We continued with our situation in this manner for six months. Being a caregiver was much more lonesome for me when I was in my forties than it would be now more than two decades later. No one then could relate to my situation. Now many of my friends talk about elderly family members and the care they are giving to them.

In the fall of 1987 my mother made a surprise announcement. She was going to move to a nursing home. The idea was painful to contemplate, but I understood her thinking. My active family continued to get busier all the time. My mother's two older sisters, who lived two blocks from us in their own home, had begun to have significant problems, and I wanted to help them remain in their home. Cleo was 79 and Bernice was 87.

My mother had made a choice for my family's well-being. It was a huge sacrifice, made in love, which brings me to tears even today as I write about it. My mother was a wonderful, courageous

and amazing woman. I learned much about sacrificial love from her, and I hope my children did also. She spent seven years until her death at age 84, in a skilled nursing care facility. I became her advocate in dealing with problems inherent in such an environment. During her time there she transitioned from a paying patient to one covered by county assistance.

While my mother was in the nursing home, I became quite active in caring for her sisters. For about nine years I went to their house three times daily to prepare meals, to do laundry, housework and pay the bills. I drove them to their appointments. My husband did all the yard work. As our children were able, they helped out. Again, I asked for backup help from the friends who had been so good to my mother. They responded and brought needed respite to me. Bernice died in 1992, my mother in 1994 and Cleo in 1998. Two years before Cleo's death, I returned to work. In 1996 Cleo began to need twenty-four hour a day nursing care, necessitating a move to the same facility where my mother had been. I continued to visit her several times a week as I had visited my mother when she was there. Since 1998 however, I have not wanted to visit anyone there or even drive down the street where the nursing home is located.

Throughout this decade of caregiving, I struggled with great amounts of sadness. I countered this situation by working to create a healthy environment for myself. I celebrated every joy in my life, including the knowledge that I surely was in the place God had prepared for me. I was where I was needed, and I had said "Yes" when I was called to serve. I attempted to be cheerful and positive around Sybil, Cleo and Bernice. Trying to get to sleep was usually the most difficult time for me, because sad thoughts would keep me awake.

I was able to share my feeling with my husband, who was very supportive. There often were situations that couldn't be changed. My husband loved me, and that was what I needed.

Caregivers will be diminished in their effectiveness and compassion when they are mentally and physically overburdened and exhausted. Some find themselves without anyone to help out. They may endure loneliness, depression and fatigue, with no end in sight.

My elderly family members did not suffer from any form of dementia. But if dementia-related violence against the caregiver occurs, seek advice from health care professionals. Dementia-caused violence is not a choice; your response to it is. When the person being cared for becomes a danger to him/herself or to others, this often is the appropriate time for care to be provided in a secure setting.

I can only speak for myself and my own situation. You must find your own best way as you deal with your situation. Find trustworthy, kind people who will step in for you. If you don't know anyone personally, there often are resources within your state and community. To care for yourself, see a counselor, therapist, your pastor or perhaps a good friend. Look for a support group – there may be one out there for you, or start one yourself. Revel in the company of friends and family. Never deny yourself an opportunity to take some time away from your duties. You will be a better caregiver for it. Constantly putting aside your own needs and desires is not healthy or productive. Take time to pray and meditate. Give yourself every opportunity to refresh your body, mind and spirit. Our God works at all times and in all circumstances to love, support and heal us. Hopefully, at the end of the day, each of us can feel that we have been the Word incarnate to those for whom we provide care. Blessings to you on your journey.