

Full Circle: A Daughter's Perspective

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Abstract: This narrative is a story about the author's experience with maternal caregiving and discusses situations involving aging and chronic illness. The author describes how culture impacts caregiving, and how the author learned to be respectful of her mother's culture while managing the symptoms of chronic illness. This is also a story of sisterhood, of relationships lost and then rebuilt through the practice of relative caregiving. Finally, this is a story of hope amid unhappy circumstances of a cancer diagnosis, and how caregiving of a parent leads an adult child full circle; from being cared for, to caring for, and then to be cared for again by family.

Keywords: maternal caregiving, sisterhood, cancer, relationships, aging

As the youngest of four girls, the prospect of becoming a caregiver to my parents never crossed my mind. My family is multiracial. My mother was born and reared in Japan, married my father at 17 years old, and moved to the U.S. during the Korean War. My father hailed from Chicago, Illinois, and while his ethnic background was diverse, it was the Irish and German bloodlines that were mostly promoted in his identity. While I attended local public schools or Department of Defense schools when we lived in Germany, I absorbed traditional "American" values and beliefs. However, the influence of my mother's culture was much more subtle. My mother quietly ingrained some Japanese values and beliefs in the way she kept house, served meals, and communicated with us. Therefore, I "knew" I would never be called on to provide caregiving for my parents. First, my brother was responsible for my parents. Although he was a year younger than me, he was the oldest (and only) male child in the family. It was his shoulders that were responsible for the financial and physical well-being of my parents. If he was not physically present to take care of my parents, then my oldest sister would. The caregiving responsibilities would fall to each successive sister, and I was the youngest. There were astronomical odds of all of my siblings being unable to care for my parents. Despite the odds against me, I became a caretaker of my mother in her later years.

My father passed away when my mother was 48 years old. My three older sisters had emancipated from home by that time and were raising families of their own. I left home a few years later, got married, and began raising my own family halfway across the country. The marriage was rocky from the start, and after four years, I returned to Colorado and divorced. My mother welcomed me and my two children with open arms, providing much needed housing,

financial and emotional support. I was able to return to school and earn my Bachelor's degree. By then, my mother was almost 60 years old, and it was apparent that my children needed more consistent child care arrangements. We agreed that she would retire and be a full-time caretaker for my children.

I did not mean to stay with her for more than a few years after I returned to Colorado, but we discovered that living together was mutually beneficial. It certainly was not easy, especially in the beginning. We had to realign our relationship. She had to learn to view me as an adult, and to respect my parental authority with my children. I had to learn to not regress into a child and expect my mother to do everything for me. By the time I finished my Bachelor's degree, we had ironed out most of the wrinkles in our relationship. After a few years, I returned to school to earn my Master's in Social Work, while working full-time at a youth and family agency. My mother stepped into the role of primary caretaker for all of us. I doubt that I would have been able to finish my degree in a timely manner while working full-time and rearing two children as a single parent if she had not been there to help me.

We ended up living together for almost 20 years. Slowly, during that time, my mother became unable to do her usual tasks. Walking up and down the stairs became more difficult for her, and she began to develop gout and high blood pressure. Her eyesight began to fail. Driving with her was slightly terrifying. By then, my children were in high school and between the three of us we were able to drive her to wherever she needed to go. When she tried to renew her driver's license, she failed the eye test. I think all of us were relieved to know that she would not be driving anymore, including my mom. As a social worker, I was concerned that she might feel trapped without transportation, and so my children and I tried to ensure

that we were available whenever she wanted to go somewhere. However, she was concerned about being a “burden” on us, and would often use public transportation instead of having us drive her somewhere. No matter how often we told her that we enjoyed driving her around, or that it was not a bother at all, she still insisted on using public transportation for most errands.

Her oppositional strain ran through most of my attempts to help her. I attended doctor appointments with her and learned what she needed to do to control her high blood pressure and gout. I bought her a food scale to measure her protein intake, and a walker to help her remain mobile during the worst of her gout attacks. She steadfastly refused to change her diet, stating, “That’s what I have pills for.” During the gout attacks, when I was applying compresses, she would swear she was changing her diet, but once the attack was over, she would continue to eat as she wished. No amount of bribing, cajoling, and reminding could get her to change her diet at all. My frustration with her oppositional behavior led me to reflect on her reasons for insisting on doing everything her own way. While I had never been to Japan, nor studied the culture, I had absorbed enough from my mother to realize that her cultural beliefs led her to be reluctant to inconvenience anyone. This, combined with her strong sense of independence led to her refusal to change her lifestyle and accept help from us. I finally realized that I did not need to manage my mother, I needed to support her through the gout attacks and any other illnesses. I also learned to rejoice at small victories, such as when I convinced her to use low sodium soy sauce instead of the regular stuff.

My brother was living almost 900 miles away, as he was active duty military. Two of my sisters were estranged from the family and not living in the same town. My other sister lived just a few miles away, and would provide transportation to my mother if needed. However, this sister was not in good health herself, so we rarely asked her for help. Sadly, this sister died a few years later, and my mother decided that she wanted to move into senior housing. I was working in a neighboring town by then, and commuting on a daily basis. My children were emancipating, and my mother felt this was a good time for both of us to move. So we went our

separate ways, with almost 40 miles separating us. She was happy in her new place, and enjoyed going to a neighboring park, or taking all day to do shopping. I visited her weekly, and ran errands with her if she wanted. Things appeared to be going well for her, except for a cough that she just could not seem to shake. She stated she must be allergic to something, and I kept asking her to talk to her doctor. As usual, my mother insisted this was much ado about nothing, but promised to ask about it at her next regularly scheduled doctor’s visit.

At her next doctor’s visit, they took an x-ray of her chest. The diagnosis was small cell carcinoma, lung cancer. Her case was so advanced, they immediately scheduled her for treatment. The next few days were a blur. As strange as it may seem, I never imagined my life without my mother. My vision of the future included us taking trips together, enjoying some quiet time without the hustle and bustle of young children or the hectic schedule of a social work career.

I felt completely alone, without a confidante, as my two remaining sisters were estranged and my brother was more concerned with the specifics of my mother’s treatment than processing our feelings about the event. I had a lovely support system of friends and co-workers, but I dearly missed my sisters. As children, we had all been very close. There were only 7 years separating the oldest and youngest child, so we played together and confided in each other. While growing up, I shared a room with my sister who was closest to me in age. She was only two years older than me, and we stayed up many nights, talking about our hopes and dreams for the future and gossiping about the other students in our school. By this time, we were living in the same town, only a few miles from each other, but I was afraid to make contact as our last interaction was not pleasant. This is what led to her estrangement from the family.

My mother had contacted my sister shortly after she moved into senior housing, and the two of them had begun to rebuild their relationship. It was a few days after the cancer diagnosis, that my sister asked my mother to have me meet her at my mother’s place. When I arrived, she immediately came forward and hugged me. I was overwhelmed with emotion. I finally had my sister back. We cried together and tried to catch up on the years that we missed, then we began to discuss my mother’s diagnosis and how we could

partner to help her. As usual, my mother was adamant that we were not to inconvenience ourselves on her behalf. But this time, I had an ally, and my sister and I were able to convince her to allow us to help.

Because of our work schedules, my sister took the bulk of appointments for chemotherapy and radiation. She organized all of the medical information into a binder that we were able to take with us to each appointment. Although she was not a social worker, my sister even created record of contact notes for us. When she was unable to make an appointment or pick up medication, she called me and I was able to do the task. We both spent many hours with my mother in her home, visiting with her and doing what we could to help her feel comfortable. We were able to laugh together, cry, and reminisce about our childhood. We were pleased to notice how alike we were in thought and deed, even though we had spent many years apart. Even though my mother's medical situation was serious, I felt a sense of comfort in having my "big sister" by my side.

Our story is not over yet. My mother successfully completed her treatment and the cancer was in

remission. Unfortunately, it returned a few months later, and she is now enrolled in hospice services. My mother's tenacity has made all the difference, however. It has been over a year since her recurrence. Although she was expected to live just months, she is still in very good physical condition. She walks daily, still does her own grocery shopping most weeks, and enjoys the frequent visits by family. I have been fortunate to begin spending holidays with my sister and her family and to reconnect with them. While most people would view a cancer diagnosis as a catastrophic life event leading to death, it has actually provided an avenue for reconnection, growth and resolution for my family. I am grateful for every day that I have with my mother, allowing me to verbalize and to show her how much I care. And I am grateful for the connection I have built with my sister and her family. I have come full circle, from being taken care of by my mother, to being one of her caretakers, but I do not have to face this task alone.

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