Caregiver's Corner Column (August 2015)

I Love Her So Much, So Why do I Feel so Bad? (A Daughter's Perspective on Caregiving) By Kendra S. Schumaker SarahCare Adult Day Care Centers

My caregiving story is much like that of other people, in that I was not destined to become a caregiver. I certainly was not expecting to live both my childhood, and my adult lives with my mother. In fact, growing up, we had periods like many parents and teens do where we didn't necessarily get along. There are times we still don't get along. How then, has it been almost seventeen years since she has lived with myself, my husband, and our kids? Who planned this? Was this really the way it was meant to be?

That is a question I ask myself frequently. I certainly would not have chosen this path for myself. I did not ask for these cards. This is the hand I was dealt. The next questions I then ask myself is: WHY is this part of my life, what is it meant to teach me. How can I protect myself so I don't become one of the many caregivers who succumb to significant medical problems, depression/anxiety, or even die before the ones they are caring for? These are important questions for caregivers, but especially those who are caught between two generations.

I have five children at home. They were 5, 3, and 1 when Grandma moved in (two were not born yet). Her moving in was thought to be on a very temporary basis. We had a clear end in sight when she moved in. Just until she was able to retire and move to her home Up North. She then experienced several serious falls occurred, some with injuries. She had some surgeries, illnesses, and she was not able to live independently. She was also widowed at a very young age, and her financial means were limited. My children do not remember a time when Grandma did not live with us. In fact, when one of my son's was in fourth grade he came home from school with shocking news that he was, "the only kid in my class whose Grandma lives with them. 'Can you even believe that?" If I love her so much WHY is this so hard?

Between the Fourth of July 2014 and early November this year, my mother had nine falls. Four of them occurred outside, one where she fell backwards onto a cement sidewalk with me standing right beside her. It happened so fast, and I felt so bad. I couldn't do anything to stop it. I was right there. Why did it happen? There were three emergency room visits, none of which resulted in any particular type of care. The paranoid side of me believes my mother is "black-listed" from hospital admissions. They say there is nothing new to treat. "We are treating chronic conditions and therefore they cannot admit her." I asked what I should do for her. The answer was, "take her home." So we went home. She cannot private pay for a nursing home, nor will her insurance pay. It is time like this that my spirit weakens and I ask, "If I love her so much, why is this so hard?"

Flash forward to the present day. We have been living this life almost seventeen years. When my mother's health issues are particularly bad on me emotionally after an extended period of time, sometimes I just want to run away. Her frequent falls lead to emergency room visits, missed time at work, additional doctor visits, referrals to specialists, lonely times at the hospital, and added stress on the entire family. We are a relatively "normal" and resourceful family, but still it feels overwhelming at times. We have eight people in our house, and still find it difficult to make sure that Grandma is not home alone for long periods of time. Most families who care

for a loved one often have to do what we did, hire someone from the community to help when we cannot be there. You look for assistance as a caregiver, someone you can trust, and someone your loved one enjoys spending time with. Look at home and community based care options, and take a break when you need one. If I love her so much, why does it hurt so bad? That is an unfortunate side effect of being a family caregiver. My hope is that I will feel peace and joy after she is gone, and that will lead to an understanding of why this journey was destined to be part of my life.

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