When You Are Shamed for Moving a Parent into a Care Center

How to cope when other relatives don't understand your decision

By Rachael Wonderlin August 8, 2016 Part of the Transforming Life As We Age Special Report

Beth came up to me, tears in her eyes.

"My cousins came into town," she lamented. Normally this would not seem like a big deal, but Beth's cousins were diametrically opposed to the idea of her moving her mother — their aunt — into a long-term dementia care community.

"They think I shouldn't have moved Mom...they think I should have just kept taking care of her at home," Beth sighed, dabbing at her eyes. "Maybe they're right. Maybe I should just take Mom back home with me."

I would love to tell you that this was the first story of a family member getting shamed for moving their loved one into a care community, but it is not. I am the director of Memory Care at an assisted living community, and I've been working in dementia care for five years. I hear this kind of thing all the time.

Harsh Judgment

We've all heard of "shaming," a phrase that seems to have picked up more popularity recently. We have seen everything from "body shaming" to "middle class shaming" in articles online. I've become very familiar with another type of shaming: shaming people for moving their loved ones into long-term care communities.

No matter what her cousins from out of town had to say, they were not the ones caring for her mother.

Although it would be very nice if everyone could take care of their aging loved ones at home forever, this is just not the case for many families. There are many factors involved: where the family lives, what jobs and responsibilities the family members have, what type of care the aging adult needs, financial concerns, nutrition and health concerns.

Most complicated are mental health concerns for the aging adult. Taking care of anyone at home is challenging. Taking care of an adult with dementia at home is particularly difficult. For example, if you are caring for someone with dementia in your three-story house, you cannot explain to that person that he or she should not attempt to use the stairs if they are home alone. People with dementia have trouble remembering facts, following directions, or understanding risks.

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I cannot tell you how many people have had to move their loved ones with dementia into an assisted living or skilled nursing facility because of a major fall.

A Limited View

I explained all of this to Beth. I also reminded her that, no matter what her cousins from out of town had to say, they were not the ones caring for her mother. They didn't come visit her every single day. They hadn't been taking care of her at home for the past two years, watching her dementia progress and her falls become more frequent.

These cousins hadn't retired early, just so they could help care for this aging woman in her own home. They weren't taking time away from friends, other family, and vacations to bathe, clothe and feed this woman.

Beth's cousins had absolutely no idea what it was like to take care of another human being at home without much in the way of other help.

It's Different With Kids

When you are raising children at home, there's a community that rallies around you. You host big birthday parties, invite other parents and their children over to your house, plan nights out, call up babysitters, and, although you are probably exhausted, you feel joy in watching your children learn and grow.

From what I have seen, caring for an aging parent is the complete opposite. There is no sense of community. There is no joy in watching them grow and learn. There is only guilt, sadness and panic as you watch them descend deeper into physical and mental disability. There aren't birthday parties, family gatherings and babysitters to lend you a hand.

A Common Theme

I offer a phone call service for caregivers who have questions about dementia care. While I always help these caregivers troubleshoot their dementia-related issues and provide advice about care communities or care at home, we always end up talking about guilt. All of these caregivers feel guilty, even the ones who are taking care of their loved ones at home.

They don't give themselves time off, they don't get paid, and they certainly don't let themselves off the hook about mistakes they feel that they have made.

"Mom fell the other day," one told me. "I left the room for 20 minutes to do her laundry, and I should have put the phone next to her — she could have called me for help! This was all my fault."

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'Clean, State-of-the-Art'

Choosing to move a loved one into a care community is a personal decision. Care communities are also not the awful places we read about decades ago. "Putting someone in a home" does not carry the painful weight it used to carry.

Many of the care communities I've visited are clean, state-of-the-art buildings that offer social activities and outings. Sure, care communities are not perfect, but caring for people is an imperfect science. Choosing to move a loved one into assisted living or skilled nursing should not be a worst-case scenario. Sometimes it's the best-case scenario for aging adults and their families.

My hope is that, as our population continues to age, our society will begin to understand the need for all types of care. The U.S. prides itself on being made up of many types of people and families. Yet we lack the progress and understanding that comes with accommodating different types of caregiving. You can care for a loved one from across the country and still be a fantastic caregiver. There is no shame in choosing the best possible care situation for you and your loved ones.

By Rachael Wonderlin

Rachael Wonderlin has a master's in gerontology and works in long-term dementia care communities. Her book, When Someone You Know Is Living in a Dementia Care Community: Words to Say and Things to Do, will be on shelves November 1, 2016 from Johns Hopkins University Press. Rachael writes a blog about dementia care, www.dementia-by-day.com. She is available for caregiver live phone-call assistance.