

The complexity of caregiving: rewards and challenges

Guest Column / Marian L. Knapp

Tue Oct 09, 2007, 02:37 PM EDT

NEWTON - Taking care of someone you care about is a hard, complicated job, fraught with stress, difficult decisions and sometimes guilt. That is only one side of the experience. It can be full of rewards — satisfaction and profound learning. I know this because I have been on numerous caregiving journeys. Within a few years, I was a caregiver for my mother, several aunts, and a mentally and physically handicapped cousin. They are gone now, and I am left with the time to reflect on these experiences.

My first insight is that caregiving is about choice, and the biggest choice is whether to be a caregiver at all. Of course, I would take care of my loved ones. That's what a good person does. No choice, right? In reality, I did have a choice. I could not take care of them at all or provide complete care. These are two extremes, and I chose a middle ground. None of them lived with me. Being independent individuals, they did not want that, and neither did I. So, I chose to support them wherever they lived. That meant constant contact to assure they got up in the morning, got to doctors' appointments, and ate properly.

Related to choice is decision-making. Gradually, as they became less able to function, I found it was necessary to take over some decision-making, primarily around housing, medical care and end of life. In the beginning, housing was easy. Each lived proudly in her or his place. It worked well until they fell down at home with no one to pick them up, or wandered in the streets, or the sheltered home couldn't manage needs. The challenge became knowing when to take over and make decisions for previously self-sufficient people. There was no good way to know when to step in. It was a back and forth, until it became obvious in terms of practicality and stress that something had to change, and I needed to be the change agent. I had to decide where they should live or what medications they should take. But the most difficult decision of all was when to end a life by rejecting medical care. As a health-care proxy, I made this decision for three people. I tried to decide based on their expressed wishes, in consultation with family. It wasn't simple. Reality conspired against expressed desire. Ultimately, I was left with hard decisions about when to stop life extending treatments.

Finally, there was no clear, right answer. Choices and decisions were based on knowing who my "charges" were, and knowledge about myself. I acted on good intentions, hoping that my actions were worthy of our shared love and respect. But there was no clear path to a decision.

Yet, as hard as caregiving was, it came with tremendous rewards. It was a source of great knowledge gained from years of physical work and emotional struggle. I learned about ailing and aging, and the slow, inevitable processes that impact abilities and routines. Surprisingly, it did not make me fearful of old age and dying. On the contrary, it gave me strength. It allowed me to

face it and say, “Oh, that’s what it is!” I was able to put aside dread, and reflect positively about what I wanted for myself. I am better prepared to discuss my wishes with my children.

From a practical perspective, I learned how systems do or do not work. I saw how individuals try hard to help and how systems set up barriers. Knowing this, perhaps I can influence how systems function, or at least inform my future caregivers about negotiating them.

I learned a lot about my loved ones. I was impressed, actually amazed, at their common sense, joy of life, and resilience. Each was special and competent in dealing with multiple challenges. They were strong even at the very ends of their lives.

I learned a lot about what it takes to be a caregiver — persistence, flexibility, and problem solving. By simply being involved with frail loved ones, I could show them love and respect.

Finally, I learned a great deal about myself. I know now that I can get through difficult times, sort through dilemmas, make decisions, and handle emotion. I know that I have the capacity for inner reflection and to plan my future. Caregiving has helped me expand my knowledge and understanding, and I am profoundly grateful.

Marian Knapp is a longtime Newton resident and doctoral candidate at Antioch New England University. She chairs the upcoming Discovering What’s Next Forum on the topic of Caregiving: Rewards and Challenges held at the Newton Free Library on Oct. 16 from 7-9 p.m. For more information, www.discoveringwhatsnext.com.

<http://www.wickedlocal.com/newton/news/lifestyle/columnists/x1998364940>