



Family Caregiving in an Aging America

Women Remain the Unsung Heroes

In the United States, March is designated by Presidential proclamation as Women's History Month, and women are recognized internationally on International Women's Day (IWD). The IWD website articulates the 2020 theme by stating, "An equal world is an enabled world."

But when it comes to caring for an aging family member, the world is not yet equal. Women are disproportionately responsible for caring for family members who need support, particularly for the intimate and domestic duties that caregiving demands. Some researchers who study the issue distinguish between primary and secondary caregivers. Primary family caregivers provide most of the care and spend more time doing so compared to secondary caregivers who provide intermittent supplementary or complementary care. Their findings indicate that spouses and daughters are more likely to be primary caregivers, while men and non-family members tend to play a secondary role.

Gayle is just such a daughter, and her story is all too familiar. As a whole in the U.S., families in large part have historically shouldered the responsibility of providing long-term services and support for older people as they age. The unprecedented longevity that more and more people now experience means the critical role that families play in meeting the medical, social, and spiritual needs of loved-ones as they age will only grow.

Gayle's Story

At 68, Gayle is a retired school teacher. She and her husband grew up in the town where their mothers still live, but spent most of their adult lives building careers in another region of the country. Five years ago, they moved back to be closer to their mothers – both now in their 90s. Like many adult children caring for aging parents, their goal is to keep their moms in their homes for as long as possible. They have cobbled together a network of family members who check on their parents regularly. Both moms seem safe for the time being with daily monitoring, but it's anyone's guess how long the situation will remain tenable.

According to Gayle, "My mom basically has three caregivers - me, my husband who also takes care of his mother with his sister, and my older brother who lives further away. My brother gets down around once a week. Between the three of us we pretty much meet everybody's needs. Both my mom and mother-in-law are in pretty good shape for their ages."

"We don't have a diagnosis for my mom's condition, says Gayle. She has some form of dementia, and it presents mostly as short-term memory loss. She's semi-independent, but can't write checks, pay bills, or

shop anymore so I do that for her. She can dress herself and open a can of soup, if needed. Meals-on-Wheels delivers meals, and we bring her food as well, which she can heat up in the microwave. She can live safely in her home at this point as long as we check in regularly.”

How the Savvy Caregiver Program Helped

Gayle knew when she moved back to be near her mom, she’d be taking on this new caregiving role. She also quickly realized that her relationship with her mom had profoundly changed, and she needed to learn new ways to communicate effectively and optimize the years left as her mother’s daughter.

“One of the things I wanted to do was to find a way not to be so impatient with her, says Gayle. I stumbled upon the Savvy Caregiver program. It’s a six-week program. We met once a week, two hours a day. It was the best 12 hours I have ever given to anything, and I’ve taken a lot of courses.”

She goes on to say, “Savvy taught me a lot of things that ramped down the frustration and impatience I was feeling. There’s a lot of emotion involved with caring for someone who used to be one way and now they’ve changed. I feel sad realizing that my mother who I love, and with whom I was good friends, just isn’t there anymore.”

The Savvy Caregiver program taught Gayle about the eight areas of the brain that control communication and rational thought process. Then she learned what happens as these cognitive processes start to deteriorate with time, and how it affects behavior.

“My mom’s short-term memory loss has resulted in repetitive questioning, says Gayle. The Savvy trainers helped me develop strategies to meet my mom’s needs without making me crazy, but also don’t make my mom feel like she’s a burden, or that she’s frustrating me. The two trainers really knew their stuff, and they were all about solutions. They helped me understand my mother, and that her behavior is not meant to annoy me. They helped me cultivate patience.”

Another technique Gayle learned was how to communicate with her mother so that she could get the information needed to understand how her mother was really doing.

“When I used to visit my mother, I always kept busy around the house, says Gayle. I’d wipe the counters, get her something to eat, feed the cat, and I’d talk to her while I was doing these things. I would ask how are you, how did you sleep, have you eaten today? And she would say – ‘what, what did you say, what do you mean?’ I learned that there’s stuff going on in her head. It could be noise, it could just be fogginess, but she’s not processing the way she used to. I learned that if I want to get information in a meaningful way, I would need to sit down at the table across from her and ask the questions clearly and slowly. And then give her time to sift through my questions so that she could answer.”

As a graduate of Savvy Gayle offers some final advice. “Ask for support – especially as women, we think we can do this and there’s no one who can care for your loved-one like you can. Ask your kids to help if possible.

I came away from the Savvy workshop thinking, things can always be worse. With support and helpful information, I came to realize that this is not so bad.”

The Savvy Caregiver Program is an example of the evidence-based programs supported by Elder Services of Merrimack Valley’s Healthy Living Center of Excellence (HLCE), which means their benefit has been

proven or informed by research and evaluation. These programs are designed to promote healthy aging among older people. To find out more about HLCE programs go to healthyliving4me.org or call 978-946-1211.

A grant from Harvard Pilgrim Health Care Foundation supports two evidence-based programs offered by Elder Services of Merrimack Valley's Healthy Living Center of Excellence, including the Savvy Caregiver and Matter of Balance Trainings in Massachusetts, Maine and New Hampshire.

