

Family Caregiving: Easy? Think Again

Written by Edna Kane-Williams,
Thursday, 13 September 2012 10:21



Edna Kane-Williams, VP, AARP Multicultural Markets

My 90 year-old mother moved in with me after suffering a massive heart attack. Doctors weren't hopeful. They recommended hospice. After two weeks, I knew she'd do better in my home. Eighteen months later, she's done tremendously well, but our lives have changed completely.

I wasn't prepared. I'd been an indirect caregiver, helping my mother move to assisted living near her home in Philadelphia; then later to a senior building near my home in Maryland. After her near death health crisis, it made sense she'd live with me.

Not even working for AARP prepared me to care for my mom 24/7. I was clueless. The first six months were hardest:

- Who do I call?
- What's the cost?
- Why aren't services covered?
- No, I don't need help. Really.

Help!

For me, being a caregiver means my mom doesn't lie awake worrying. She knows I'll take care of her. That's the most important thing.

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Each day brings us joy, anxiety, frustration, guilt, smiles and tears. I work full-time, so someone always has to be with Mom. Business travel means making arrangements well in advance. Mom needs help standing, walking and managing personal needs. And almost monthly, her health prompts a hospital trip.

My fiercely independent mother now relies on someone for all her needs. That's hard for her. And I've gone from an empty nest to looking after someone again and learning important lessons, like checking on Mom at night.

Once, she slipped off the bed. I found her sleeping on the floor the next morning. She didn't have the strength to get back in bed. Finding her like that broke my heart. Acknowledging her physical limitations broke hers.

As a family caregiver, I join about one in four adults caring for adult relatives or friends – typically 50+ with chronic conditions or disabilities.

Sixty-five percent of caregivers are women. The 'average caregiver' is 49, female, employed and caring for her mother nearly 20 hours weekly without compensation. About 53 percent of African Americans are family caregivers or have been.

Growing up, no one called themselves caregivers or thought about their personal sacrifices. If a family member needed help, you helped. When I was little, my grandmother always lived with one of my aunts. And my uncle, disabled after a stroke, eventually lived with his sisters.

Today, more people recognize the importance of family caregivers, their need for relief, and how much their care is worth. In 2009, family caregivers provided \$450 billion in care – just \$59 billion less than Medicare spending that year.

Family caregiving is intense. At work, Mom's on my mind, then I'm rushing home to relieve the caretaker. I'm constantly in prayer, because faith keeps me strengthened and focused.

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Family caregiving also equals spending. That's just the reality. I'm grateful Mom gets Social Security and a pension from years of factory work, but those checks don't cover everything. I balance Mom's care, my son's college tuition, living expenses and everything else. Sometimes, something falls through the cracks. It's challenging, but now I can't imagine things any other way.

Caregivers also need lots of love, support and help. Initially, I turned down help. I thought, "My brother's across the country, so it's all my responsibility."

Wrong! You can't do a good job caring for someone else if you don't take care of yourself. When trusted family and friends offer help, take it! Let people "spell" you, prepare meals or take you out. Rest and relaxation are critical for caregivers.

I'm grateful when my brother visits from Minnesota, my children show up, relatives come by or friends stage an intervention and send me out for the day. It's great for me and for Mom.

Don't go it alone. Here's what I've learned:

- Plan ahead before launching into caregiving;
- Research information and resources;
- Communicate your needs;
- Establish a team of helpers;
- Don't get mad – everyone doesn't have the temperament to help out;
- Don't beat yourself up; there's enough stress.

Visit www.aarp.org/blackcommunity. Learn about AARP's caregiving campaign, resources, online caregiver groups and more. Caregivers and loved ones deserve all the help they can get!{jcomments on}