

# Theirs Is a Labor of Love . . . BUT WHO CARES FOR THE CAREGIVERS?



## WANTED:

Sensitive, capable, reliable professional to act as a caregiver. Must be available to work 10 to 40 hours per week, in addition to holding another full-time job.

Responsibilities may include, but are not limited to: bathing, dressing, feeding, cooking, cleaning, shopping, administering medicines, scheduling and transporting patient to all doctor's appointments.

Must also provide physical therapy, psychological counseling, bill paying, home maintenance, entertainment and recreational activities. Volunteers only need apply, as monetary compensation WILL NOT be provided.

*We Offer a Care Package of Advice and Encouragement from Some Who Have Been There and Done That*

**W**ould you apply for that job? I certainly wouldn't, but like many other women, I ended up doing it anyway. Overachiever that I am, I did it twice. Right now, more than 44 million people, 60 percent of whom are women, are following in my footsteps. As we baby boomers age, even more of us will take a spin on the caregiving carousel.

It's been about eight years since I was a full-time caregiver. When I was in the thick of it, I didn't have time to contemplate the toll it took on me, financially or emotionally. I was too busy doing all those things in that job description. Now that I have more time, I've done a little digging to see what the current state of affairs is for caregivers. What I discovered knocked me for a loop.

Met Life's Mature Market Institute did a study, appropriately titled "Juggling Act," to follow up on work done by the National Alliance for Caregiving (NAC). They were able to quantify the significant loss of wealth experienced by caregivers as a result of their responsibilities. Totaling up wages, Social Security and pension benefits, each caregiver lost an average of \$659,139 over her lifetime. Whew, that's a boatload of dough! Now I know why there's only a tiny egg in my retirement nest. The others flew the coop, along with a few promotions, a cool job in Phoenix, and an exchange program in London.

Lost wages and retirement benefits are not new problems for women. The same thing happens when we take time off to care for young children, to the tune of nearly a million dollars (for the college-educated professional). Nowadays, many women whose careers were interrupted once for the kids are being pulled away a second time, just as their careers are getting back on course, to care for their aging parents.

### A Big Bite in the Pocketbook

Something else in the NAC study struck me. In addition to all of the time spent pro-

viding unpaid care—and the cost in lost wages and benefits—caregivers shell out more than \$200 each month for their recipients' care. That's a mighty big "out-of-pocketbook" expense. That information was no surprise to my friend Louise. For the last four years, she has provided care for her 83-year-old mother who lives about 30 miles away. Between the trips back and forth, often twice a day, Louise has spent her fair share on cars, gas and tolls, not to mention food shopping and pharmacy expenses. (Her mother had just enough annual income to keep her from qualifying for prescription-drug assistance.)

**"**I estimate that I spent between \$30,000 and \$40,000 a year on stuff just for Mom to live, not to mention having to take care of everything myself, including managing Mom's finances and paying her bills," Louise recounts. Her brother in California is "no help, financially or emotionally." He tells Louise he wants to "remember Mom the way she used to be." Last year, her mom's dementia worsened so much that she had to move her to an assisted living facility. Louise, like many caregivers, was so overwrought, she didn't think to consult an elder law attorney. Had she done so, she might have been able to protect some of her mother's assets and someday would have inherited something to pay herself back for all of her caregiving expenses.

"When you're in a crisis like I was, there's no thinking straight," Louise says. "I found an assisted living place that would cost roughly what I was spending each month on Mom and figured it would keep her safe and give me some peace of mind. I'd tried hiring home health aides, but that didn't work out. I agonized about placing Mom, because she always made me promise never to put her in a nursing home."

Assisted living was a compromise. For \$3,600 a month, Louise's mom gets food, shelter and supervision, so that she doesn't



## TAKING CARE OF YOUR FINANCES . . .

**Don't Pass Up This Tax Deduction:** If you are providing financial support to your parents or another elderly relative, you may be able to claim that person as a personal exemption on your tax return. You must be able to document that you provide more than half of the person's support for the tax year. Support includes clothing, shelter, medical expenses and transportation. The potential dependent's gross income cannot be higher than the personal exemption for that tax year, which currently is \$3,050. But Social Security and tax-free income are not included in that figure. Isabel shared the expenses with her brother. "We each filed a multiple-support agreement, which allowed me to take the deduction one year and Bob to take it the next year," she says. Isabel is referring to Federal Tax Form 2120. Often, the sibling who would receive the highest dollar benefit from the claim, which is usually the one in the highest tax bracket, takes the deduction.

**Or This Tax Credit:** You may be eligible for the Child and Dependent Care Credit, to cover day-care expenses for your elderly relative, if both you and your spouse work (unless the dependent is your spouse) and the dependent lives with you. The credit is a percentage, based on your adjusted gross income, of the care expenses you paid to a care provider, up to a maximum of \$3,000 for one individual (or \$6,000 for two or more). This is the same credit you may have taken for day-care expenses for your children.

**Do You Know About the Family Medical Leave Act?** This Federal law requires an employer with at least 50 employees to offer unpaid leave for 12 weeks during any 12-month period to care for an immediate family member with a serious health condition. The leave can be continuous, taken intermittently, or on a reduced-schedule basis.

wander off. Louise gets to cut her daily trips to three or four, instead of seven. Mom's assets have dwindled enough so that she now qualifies for some prescription assistance. Even so, Louise still digs deep into her pocketbook to pay for Depends, facial tissues and baby wipes for her mother. Those "incidentals" aren't included in Mom's monthly rent. They run Louise between \$200 and \$250 a month.

Louise and her mom are in the unenviable position of being middle class. They have too much income to qualify for public-assistance programs and too little income to provide for the kind of round-the-clock care that her memory-impaired mother needs. When she goes to visit, Louise must still spend hours doing laundry, coaxing her mother to eat, changing soiled clothing or taking her mother to the doctors. Before you say that Louise should move her mom to a better facility, hold your tongue. The

one her mom lives in is rated as one of the best in a 50-mile radius. In eldercare, \$3,600 doesn't buy what you think it might.

In a way, Louise is lucky that she lives fairly close. Many caregivers have the added stress of being thousands of miles away. My friend Rae lives in New Jersey, and her father lives in Florida. "I spent a long time feeling guilty every day for not moving down there. But our jobs are here, and our kids love their school. Uprooting my family wasn't an option," she says.

For now, Rae's father is okay. His complex provides transportation, and he has a lot of friends to keep him busy. Rae visits whenever she gets vacation time. "It was fine for the first few years. Now the kids are getting older, and they want to do something other than get dropped off at Disney World for the day." She figures she spends \$3,000 to \$5,000 a year in airfare for scheduled trips and maybe another \$3,000 when

she's had to fly down in an emergency—theme-park admissions not included.

### Time Is Money, Too

Is there any help to defray the costs of caregiving? The answer is, it depends. In my mom's case, she received a great deal of assistance with medical costs, because she had no assets and essentially no income. We decided not to have her declared as my dependent, because when we looked at the aid she received versus the tax breaks I would receive for taking care of her, it didn't make sense. Louise's situation is trickier, because her mother had an income and assets that disqualified her from certain assistance programs. Both of us would have benefited from meeting with an elder-law attorney to help us understand our options.

My biggest cost savings came from friends who volunteered their services. For a few years, a Girl Scout troop even "adopted" my mother, providing her with companionship twice a month on days when I couldn't be there. The biggest mistake caregivers make is not asking for help, either from family members or government programs. Time is money when it comes to caregiving, too. If your siblings can't or won't chip in cash, maybe they can take over for a day, so that you can apply for aid.

### Hitting 'The Caregiving' Canopy'

Both Louise and Rae felt their careers suffered because of their caregiving responsibilities. I'll second that. We all commiserate that most of the time we were either feeling guilty about taking time off from work, or feeling guilty about being at work when we should have been caregiving. "I always feel like I'm not where I should be," says Louise. "I work for someone who doesn't understand. I know from the way she treats me in meetings and because she never puts me on any high-profile projects."

I was fortunate that I worked for people who were pretty understanding. Even so, my

career suffered. Like these friends, I found myself banging my head on the caregiving canopy, the one that hangs just below the glass ceiling.

### Lessons in Grit & Grace

We all agree that caregiving is easier when you know what your loved one expects. My mom could articulate what she wanted and didn't want, sometimes a little too loudly. But at least we could negotiate, and she could participate in decisions about her care. Louise doesn't have that luxury. Her mom is too far gone to help with any decisions. They never planned for this, and now they are paying the price. Rae has learned from each of us that having some well-timed conversations with her father will make things so much easier for everyone concerned. My advice to future caregivers:

**Even with all the years of lost time and lost wages, I'd be her caregiver again without hesitation. I would give anything to spend another hour pushing my mother's wheelchair or five minutes more brushing her hair.**

have a heartfelt discussion with your ailing family member. Ask questions like: How did your family handle caring for loved ones? How do you expect to be cared for? What happens if you can't stay at home?

I admire my godmother. When she lost her third husband, she got busy preparing for her own future. At 84, she figured that a fourth husband was a long shot (although the rumor around the assisted-living coffee pot says she has a boyfriend). I helped her "shop" for an assisted-living community, where she would feel comfortable aging in place. She wants to be as independent as possible for as long as possible, and she picked her new home accordingly. Her family is so lucky. I'll remind them of that if ever I →

## TAKING CARE OF YOURSELF . . .



**L**ike most family caregivers, I received my “training” the hard way. My indoctrination was a crash course in dealing with acute rheumatoid arthritis. In a matter of weeks, my mother was completely crippled, and I went from being a bratty 16-year-old to being a full-fledged nurse. For the remaining 18 years, I just muddled through, making it up as I went along. I wish I’d had the wisdom of family therapist and author Allison Acken, Ph.D. (“It’s Only Money: A Primer for Women”; [www.womentalkmoney.com](http://www.womentalkmoney.com)), whom I spoke with recently about the challenges caregivers face. Below, she passes along three on-target tips to help you get through your caregiving years.

**Take Care of Yourself.** “When you’re on a plane, the flight attendant tells you to secure your own oxygen mask for a reason,” says Dr. Acken. “If you pass out from a lack of oxygen, you cannot help your loved one. Caregivers have a demanding job that requires rest and nourishment for body and mind, or they won’t survive.” I did a lousy job of taking care of myself. I felt compelled to do everything myself, instead of asking for help.

I was taking care of both my mother and her sister, who had the same disease. Three households, three grocery lists, three sets of laundry . . . you get the picture. I was overweight, overworked, and way past overtired. I ended up with an ulcer. If I had arranged for someone to relieve me on a regular basis, I would definitely have been better off. Thankfully, many of my friends intervened, when they saw me falling apart.

**Give up on Perfection.** “Caregiving is not a job that can be done even close to perfectly,” says Dr. Acken. “Let the concept of ‘good enough’ be your mantra.” This was another trouble spot for an overachiever like me. I was great at caregiving. In addition to the day-to-day stuff, I knew everything there was to know about therapies, medicines, and health aids. I spoke out for handicapped rights. Caregiving literally defined who I was. When my aunt, and then my mother, died, I was out of a job. I remember exactly when the panic set in. I was planning Mom’s funeral. I asked the pastor if the church had an elevator for wheelchairs. He said, “No, but we have some ramps and a few strong guys who will be able to get your guests into the sanctuary.” That’s when it hit me. I had been sitting there, figuring out in my head how I was going to get my mother into the church. I started to cry. My tears were as much for her death as they were for my lost purpose in life. Never again would I have to measure doorways, count steps or call ahead to have a ramp lowered. I realized in that moment that it was time to get on with my life, and I really wasn’t sure how to do that.

**Accept the thanks and the compliments that you receive for a job well done.** “Caregiving is a very difficult job, but in the end, a very satisfying one,” says Dr. Acken. I will gladly accept her compliment. Caregiving was the most difficult thing I have ever done. It also was the most rewarding thing I have ever done. It taught me about myself, about love, about strength, and about courage. I know that if the job of caregiver comes my way again, I won’t be afraid. I’ll just do it differently, using all that I’ve learned.

**My tears were as much for her death, as they were for my lost purpose in life. Never again would I have to measure doorways, count steps, or call ahead to have a ramp lowered.**

—E.K.

hear them grumble about how much money it costs for her to live there. She has given them an enormous gift: she’s spared them from making the tough decisions that my friends and I have made. I’m following my godmother’s lead. I signed up for long-term care insurance.

There’s a book I read once called “The Grit and Grace of Being a Caregiver.” I think those traits apply to care-receivers, as well. Nobody had more grit or grace than my mother. She was 52 when she became disabled. There were times when she would rail with anger, because she needed me to walk her to the bathroom or put on her shoes. There were times when she would swallow her excruciating pain to cheer for me in the audience of one of my plays. And then there were times when our life was almost ordinary, like when I was fixing her hair or fastening the back of her blouse. If I hadn’t been her caregiver, I wouldn’t have been able to see the beauty in those simple

acts. Even with all the years of lost time and lost wages, I’d be her caregiver again without hesitation. I would give anything to spend another hour pushing my mother’s wheelchair or five minutes more brushing her hair.

While preparing for this story, I visited the Web site for the Rosalyn Carter Institute for Caregiving ([www.rci.gsw.edu](http://www.rci.gsw.edu)). A quote appears when you access the site. It scrolls slowly across your screen one line at a time, saying, “There are only four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”

If it were up to me, that quote would have one more line: “Take heart—because we’re all in this together.”

*Elizabeth Kaminsky is a contributing editor to MAKING BREAD. She teaches continuing-education courses at an East Coast university and frequently writes about financial matters as they relate to women.*

## WHERE TO GO FOR HELP . . .

**F**irst stop, if you need financial aid, should be your county or state Department of Health and Human Services. The National Association of Area Agencies on Aging will refer you to the area agency on aging nearest to your care-receiver. Call (800) 677-1116 or go to [www.aoa.gov](http://www.aoa.gov) or [www.eldercare.gov](http://www.eldercare.gov). Many area agencies on aging offer money-management programs.

If you live far away or feel you can’t take care of daily money management for your parent(s), consider using a daily money manager, who can help with these tasks for a small fee. The American Association of Daily Money Managers ([www.aadmm.com](http://www.aadmm.com)) can provide names of daily money managers in your parent’s community or nearby. Some organizations provide volunteers who perform the same function.

An organization called Comfort Keepers ([www.comfortkeepers.com](http://www.comfortkeepers.com)) provides assistance with the daily tasks of living.

For legal questions, an excellent starting point is [www.elderlawanswers.com](http://www.elderlawanswers.com).

### Other useful resources include:

**The Medicine Program**  
[www.themedicineprogram.com](http://www.themedicineprogram.com)

**National Association of Professional Geriatric Care Managers**  
[www.caremanager.org](http://www.caremanager.org)

**National Council on the Aging, Inc.**  
[www.ncoa.org](http://www.ncoa.org)

**Well Spouse Foundation**  
[www.wellspouse.org](http://www.wellspouse.org)