



Caring for the Caregiver

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- Caregiving is hard work and a **swirl of emotions**.
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- **Here's help** for your grief, guilt and exhaustion.

Caring for the Caregiver



By Sally
Abrahms

Ever since I've been a caregiver, I've been waiting for The Call. If you're caring for a loved one, you know what I mean—the telephone rings and you learn that your parent has taken a turn for the worse and you must rush to his side. In the past 12 years, I've taken care of my father, then my mother, and now my 93-year-old mother-in-law. The Call keeps coming, and I've been on edge the whole time, waiting.

Last August my husband and I were reluctant to take our annual family vacation. Would something happen? But we went, knowing that time with our adult children, who live all around the country, was also important.

We had just entered the rental house when the phone rang. My mother-in-law had been admitted to a hospital many hours away. My brother-in-law gave us bedside reports, and she was released the next day.

On the last day of vacation, the phone rang again. My mother had had a massive stroke. I traveled for six hours to her and stayed in the hospital with her for six days until she died.

Caregiving brings about a swirl of feelings: sadness, frustration, anger, anxiety, guilt, re-



sentment, confusion, isolation, loss, fear, grief, impatience and stress. I have been overwhelmed, drained by sibling tension and torn between my own family, work, personal time and parental needs.

I've also experienced devotion, tenderness, intimacy, gratitude, patience and purpose in my role. In fact, a recent study from the Sloan Center on Aging & Work at Boston College found that older Americans who feel they are making a difference in caregiving and are highly engaged in what they're doing feel happier and more content. I understand that as well.

But from my on-the-job training, professional reporting and research, including writing a weekly blog for AARP on the topic, I believe most caregivers confront three distinct and difficult experiences. With help from experts, I've also learned ways to manage them.

Grief

Caregivers frequently grieve the loss of the person they once knew, even though their loved one is still alive. Until her first stroke in 2008, my mother, a former university English teacher, read a book a day, without glasses, and was in three book clubs. Post-stroke, she could no longer see well enough to read and couldn't process books on tape. Instead of dashing to a play, a lecture or a party, she stayed home, unable to walk unaided or get up from a chair by herself. She was a different person.

Your World ■

“When someone dies, it is an overwhelming and horrible experience, but it is the end of something,” says Suzanne Mintz, cofounder of the National Family Caregivers Association and author of *A Family Caregiver Speaks Up: It Doesn’t Have to Be This Hard*. “But with a caregiver, the grief is perpetual; it goes on and on and on.” Mintz has watched her husband, diagnosed with multiple sclerosis in 1974, lose his independence. “You grieve because you’ve lost the life you had, and you know it won’t be coming back. Both of you have the diagnosis, the person with the condition and the family caregiver,” says Mintz.

One way to combat grief is to forge a way to relate to the “new” person. Chuck Niggley’s wife was diagnosed with Parkinson’s disease 27 years ago. “Do I ever think about what if my wife weren’t ill? Sure,” says the Beaverton, Ore., 73-year-old. “But I don’t spend time dwelling on it. I’ve given up going to a three-hour movie or a baseball game with her, but we’ve substituted things we can do together, like attending our grandchildren’s events and going to music programs.”

The arts, in fact, give caregivers and their charges a powerful way to connect. Interactive creative programs—such as songwrit-



My mother, father
and mother-in-law
with my daughter

Christmas, 2011
 My mother-in-law (age 92) with
 my children and daughter-in-law visiting her
 in assisted living.



ing, storytelling, dancing, playing instruments and painting—provide ways for caregivers and care recipients to relinquish their usual roles and enjoy a fun and stimulating sensory experience together.

New York's Museum of Modern Art opens its doors to those with dementia and their caregivers each month. An art educator leads a discussion about master artists—van Gogh, Picasso, Degas—while the group views their works. This exercise taps into little-used senses and memories and ignites lively conversation, often making it impossible to tell who's taking care of whom.

My mother had always loved poetry, so I would bring Robert Louis Stevenson's *A Child's Garden of Verses*, a collection of the same poems she had once read to me and I had read to my children, when I visited. She'd smile as we finished the lines together and I felt close to the mother I remembered while relating to the person she had become.

Guilt

During caregiving, guilt is constant. Guilt for not spending enough time with your loved one. Guilt for not tending to your own family. Guilt for having negative feelings. And guilt for resenting your new role. On my hundreds of trips back and forth

to visit my mother, I remember thinking that—shame on me—I wish this would be over so I could get my life back.

What caregivers must remember is that this is a situation over which you have limited control and shouldn't feel guilty about, says Alexis Abramson, a gerontologist and author of *The Caregiver's Survival Handbook*. "However, you are in control of how you react to it," she says. And that is empowering.

Abramson advises reaching out to caregiving organizations that offer education and support, investigating elder care benefits at work and resources in the community (respite programs, adult day care centers, transportation services), and scheduling time for yourself.

Without a network of support, caregivers often become isolated, which can lead to depression and their own serious health issues, and further exacerbate problems—one being guilt.

One way for caregivers to handle guilt is "to accept that having negative feelings about caregiving is normal," says Barry J. Jacobs, a psychologist and author of *The Emotional Survival Guide for Caregivers*. "You love the person you're caring for, but you hate the caregiving. That's normal."

Exhaustion

Caregiving often leaves the caregiver feeling depleted, both physically and mentally. For years, every other Saturday or Sunday my husband and I would pull a "doubleheader," driving two hours to see my mother, then driving another hour to be with his mother, finally getting back home by 8 that night when I would fall into bed and not move. It was physically draining, sure, but the mental toll also wiped me out for the next day and left me dreading the time we'd have to return.

"That's when the caregiving plan needs to be changed," says Jacobs. "Caregivers need to be smart and strategic about setting limits on the tasks they take on, and recruit others to pitch in."

Yes, taking the pressure off yourself is key. Hire outside help. Involve other family members and friends. A sibling or in-law who lives far away may be able to pay Mom's bills online, deal with insurance companies or take time off to stay with her so you can take a breather. "When family members do pitch in, then everyone feels like a team in caring for a loved one," says Jacobs. "Caregivers feel better supported and more resilient; family relationships become stronger and more enduring even after their loved one has died."

Talking out emotions with a friend, an elder mediator, a therapist or a peer group can also lighten the mental load. "Many of the caregivers I see who do well go to support groups," says Lisa Campbell, a clinical psychologist who specializes in 50-plus issues at the Willow Wellness Center in Park Ridge, Ill. "It's normal to feel overwhelmed," she says. "Families are complicated."

This is why, in part, there is no pat formula for navigating your own maze when you become a caregiver. Each experience is unpredictable, ever changing and unique. Your plan will require constant revision. You'll need to reach out to others for ideas, advice and help, and that includes finding ways to take care of the caregiver—you. □

Sally Abrahms blogs about caregiving at blog.aarp.org/author/aarpally.



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