## Are You a Caregiver or Just a Good Child?

The way you view your role makes a big difference

By Nancy Mattia for Next Avenue



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For some of us, middle age brings new opportunities — career reinvention, an empty nest, and time to pursue new interests. For millions of others, it brings the daunting and awkward responsibility of caring for an ailing parent. Nearly 10 million adults over age 50 give full- or part-time care to their parents in the United States, and their numbers are growing.

As a recent paper in the academic journal The Geronotlogist put it, "the longevity of the relationships that baby boomers have with their parents and siblings is unprecedented," and the generation "will witness unprecedented numbers of people who both provide care to the generation that preceded them and require care from the generation that will follow." The role of caregiver is as old as human history. But today, as several experts in family caregiving have discovered, how you identify yourself — as a "caregiver" or a "good child" who is "helping Mom out" — can make a crucial difference in how the role affects you.

## Why Your Identification Matters

"Caregiving means caring for both your loved one and yourself, so the health and well-being of two people are at stake when caregivers do not self-identify," says Next Avenue columnist Sherri Snelling, chief executive of the Caregiving Club. When you don't think of yourself as a caregiver, you may fail to take advantage of a range of support services available to help you manage the role. "Employers, community agencies, national organizations, and local and federal government offer services to help caregivers, but first you have to know you are one. By speaking up and saying 'I'm a caregiver' you will find resources that can help you care for your loved one," Snelling says. "You will also learn about the pitfalls of caregiving, such as burnout, and what steps you can take to bring balance and self-care into your life."

Full- or part-time, on-site or long-distance, caregiving is both physically and emotionally draining. As a parent's health or cognition declines, an adult child needs to take on more responsibility and become more active in decision-making. "Caregiving changes the relationship you have with the person," says Gail Hunt, president and chief executive of the National Alliance for Caregiving. "You may be having a role reversal with your mother, and you have to acknowledge you're caring for her in a way you never expected to."

That role reversal often exacts a psychological toll. "When a parent isn't able to provide the security and support he or she used to," says Leah Eskenazi, director of operations at the Family Caregiving Alliance, "the caregiver may feel more vulnerable." Resisting the label "caregiver," in a way, denies both that role reversal and the scope of the task an adult child faces. When you say you're just helping Mom out, Eskenazi argues, "What you're really saying is, 'I'm not ready to take on that level of responsibility or change roles with her.'"

## Is Caregiving Natural or Optional?

Given the number of boomers becoming caregivers, and the apparent risks to those who do not self-identify in the role, a Canadian study published in The Gerontologist raises concerns. The study tracked and interviewed 39 baby boomers caring for a family member and found a persistent refusal among these adults to identify themselves primarily as caregivers. "In contrast to our perceptions of previous generations, the majority of interviewees refuse to be confined to the sole identity of caregiver, as they work to juggle caregiving, work, family and social commitments," the co-authors wrote.

For the subjects of the study, "the documented, negative consequences of caregiving such as poor mental and physical health, sacrificed personal and family life, or impacts on employment, are no longer considered legitimate," the study's lead author, University of Quebec social work professor Nancy Guberman wrote in a blog post that accompanied its release.

The Quebec study found that these boomer caregivers relied upon, and had high expectations for, aid from outside groups to help them manage their caregiving roles. "From their point of view, family members should be responsible for offering emotional and moral support, and accompanying the disabled or ill family member to appointments. In contrast, they believe that hands-on physical and nursing tasks (bathing, feeding, giving injections, etc.) should be assumed by home care services or assisted living residences," Guberman wrote.

This apparent "new approach to caregiving" led the authors to conclude that a "denaturalization" of care had occurred among many boomers, for whom the role was no longer seen as a "natural" destiny or a "normal" family responsibility. These caregivers' parents, especially their non-working mothers, may have devoted themselves to caring for ailing loved ones full-time. It's not a place they want to find themselves.

The problem for modern caregivers who expect outside services to support them is that the infrastructure may not exist to meet that goal. Their "new conception of caregiving as work that can and should be shared with services," the researchers wrote, "is in direct opposition to public policy that is based on the assumption of family care as the cornerstone of long-term care." They asked, "Can the health care system adapt to the new expectations of the baby boom generation or will these caregivers be forced to take on elements of caregiving they no longer consider legitimate?"

Caregivers who expect help may end up disappointed. But caregivers who put all the responsibility on themselves may be at even greater risk. A third Gerontologist-published study, led by UCLA researchers, supports a growing body of research that middle-aged people who assume full caregiving responsibility are likely to see the job negatively impact their own health.

The team tracked about 6,000 caregivers and about twice as many non-caregivers, and found that the caregivers were more likely to take part in "negative health behavior" — defined by the study as smoking, consuming fast food and regular sodas, and being sedentary. Interestingly, the amount of time caregivers spent in the role did not make a significant difference in the study's results, an indication that the stress of caregiving has an impact on those who live with their parents as much as those who stop by once a week.

Carol Evans, 64, a former research librarian who lives with her 92-year-old mother in Walnut Creek, Calif., is perhaps typical of caregivers who put their parents before themselves. Evans suffers chronic pain from arthritis and tendonitis, but gets little relief. A community volunteer comes over once a week, but even during that break, "I never fully relax," Evans says. Even if she could afford to hire additional home care, she's not sure she would, as she worries that such companions wouldn't "stimulate" her mother. So she takes her mother shopping, out to eat, and to the theater herself.

While Evans describes her mother as "loving and appreciative," caring for her can be allconsuming. "I don't sleep much," she says. "At night, I can hear her breathing — she has sleep apnea — and I worry about her."

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