



## Family Care for America's Sick and Frail Elders

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Most Americans are familiar with the image of a frail older person receiving care at home from a spouse or adult offspring – most often, a daughter. This depiction informs stories in the newspaper, television dramas, movies – and public advocacy. For example, the Family Caregiver Alliance, an advocacy group, includes on its website the following Caregiving Fact: “The typical informal caregiver is a married woman in her mid-forties to mid-fifties. She is employed full time and also spends an average of twenty hours per week on caregiving duties.”

Is this correct? Are most of those who help the elderly at home actually fully employed middle-aged women struggling to do at least a job and a half of weekly work? Unfortunately, there is no standard definition of “family caregiver” and existing research on who does what to care for incapacitated older men and women is scattered, incomplete, and often out of date. What we do know is that the world of family care is varied. Clarity about what is known – and what remains to be learned – is important, because community groups and policymakers need to understand the diverse situations and needs of people who provide important care for disabled, sick, or frail elderly relatives.

### Not All Care is the Same

“Caregiving” encompasses a broad range of tasks, from driving someone to medical appointments and performing routine household tasks, to daily assistance with personal-care activities such as bathing, dressing, and eating. The most demanding assistance may be the full-time supervision or monitoring of someone with advanced dementia. Various kinds of caregiving obviously demand very different time commitments, and work on different schedules. Supportive efforts such as doing housework or shopping are much easier to fit in an employment schedule than are the more burdensome tasks associated with tending to a very frail elderly person or an Alzheimer’s patient.

Not surprisingly, given the diverse kinds of tasks involved, caregivers report spending highly varied amounts of time. In one 2009 survey of caregivers for people 50 or more years old, more than half said they spent eight hours or less “in an average week.” Only about one in ten spent more than forty hours. In another survey, 15 percent of all people listed as “helpers” of a disabled elder reportedly spent zero hours in the “last week” just prior to the survey. Their efforts may be sporadic – such as taking a relative to an occasional medical appointment.

### The Old Often Care for the Very Old

A striking fact is that many of those who provide care to very elderly people are themselves age 65 or older. Self-described caregivers are people who say they provide “regular assistance to individuals with a disability or long-term health problem of all ages.” Fully a fifth of them are 65 or older. And among those more precisely identified as primary caregivers of chronically disabled people 65 and older, more than two-fifths (nearly 43 percent) are themselves aged 65 and older. Many of these older caregivers are married to the person being helped. Elderly men and women caring for a spouse may well face difficult problems, but most are out of the paid workforce and face minimal conflict, if any, between paid work and caregiving activities.

### Juggling Jobs and Caregiving

Yet many caregivers are in fact employed adults. According to available estimates, about 32 percent of the primary caregivers of people 65 and older hold paid jobs, as do more than 60 percent of the caregivers of people aged 50 and above. Many of these caregivers are likely to experience conflicts between obligations at work and the requisites of caring for older dependents.

The conflicts employed caregivers may experience vary in severity, and they can be alleviated by a variety of

steps – ranging from formal retirement or leaving a job, to cutting back on hours or making use of sick or vacation days, to taking advantage of rights to take unpaid time off under the U.S. Family and Medical Leave Act. The states of California and New Jersey offer paid family leaves to employees who must take time to care for a seriously ill or disabled family member. And not all conflicts are resolved in the direction of finding time for caregiving, of course. Some potential long-term caregivers may have opted out of providing care precisely to avoid ongoing conflicts between the demands of a job and the needs of a frail or ill older person.

A number of research studies have compared employment status or hours of work between caregivers and noncaregivers. The findings are mixed. One review of the research literature concluded that overall, caregivers are no less likely to be employed than non-caregiving adults, and also found that caregivers exhibit only moderate reductions in hours of work. Studies have also shown that being employed does not seem to deter women from becoming caregivers. However, becoming a caregiver does increase the chances that women will later reduce work hours or end their employment. Workplace supports such as paid or unpaid leave, flexible work schedules, and paid sick or vacation days have been found to increase the chances that employed caregivers will remain employed.

## What Does the Future Hold?

We cannot presume that conflicts between family caregiving and employment are intractable or will only become worse. In fact, while some trends may exacerbate this challenge, others may alleviate it. Trends that may tighten the squeeze between caregiving and employment – especially for women – include higher levels of educational attainment and stronger attachments to the labor force, coupled with later childbearing and the fact that older parents live longer. With smaller families, there may also be fewer adult siblings to pitch in. But there are countervailing trends as well: Better health and less disability in old age may cause needs for extra care to come later in life, when the spouses and children of those needing help will themselves be older and less likely to be employed. Overall, much more remains to be learned about who gives care, when, and in the face of what kinds of conflicts and pressures. Some, but not all, of the pressures come from the complexities of balancing paid work and family caregiving.

Data for this brief come from many reports and studies. Key sources include Jennifer Wolff and Judith Kasper, “Caregivers of Frail Elders: Updating a National Profile.” *The Gerontologist* 46, no. 3 (2006): 344-356, and the National Alliance for Caregiving/AARP report *Caregiving in the U.S. 2009*. For additional information, contact the author of this brief.

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