



National Alliance for Caregiving

A National Resource for Caregivers

Testimony for

**THE UNITED STATES SENATE
FINANCE COMMITTEE**

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By

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Mr. Chairman and members of the committee:

Thank you for the opportunity to speak to you today. My name is Gail Gibson Hunt, the Executive Director of the National Alliance for Caregiving, a nonprofit coalition of 25 national organizations that have come together around the issues of family caregiving. The Alliance conducts research, develops national programs to support family caregivers and the professionals who work with them, and works to increase public awareness of caregiver needs and concerns.

THE DEMOGRAPHICS OF FAMILY CAREGIVING

Dimensions of the Issue

According to the 1997 national caregiver survey by the National Alliance for Caregiving and AARP, 22.4 million US households--nearly one-quarter--contain someone 18 or older who is caring for a family member, friend or neighbor who is 50 or older (the definition we used for caregiver).

What is the national profile of the family caregiver of an older person: a 46-year-old baby boomer woman who works full-time and cares for her 77-year-old mother who has a chronic illness and lives nearby. The caregiver spends an average of 18 hours per week caring for her mother and, on average, will spend four-and-a-half years doing so. The MetLife Juggling Act study showed that people's expectations of how long they would be responsible for someone significantly underestimated how long they actually spent. For example, those who thought that they might only have to be caregivers for six months or so, say after a relative's hospitalization and convalescence, found themselves caregiving for a year or more. Those who expected to do these tasks for a year or two ended up doing them for four or more years. Also keep in mind that nearly one-third of caregivers take care of two or more people over a "caregiving career".

The average annual income of the caregiver is roughly equal to Americans as a whole: \$35,000. Forty-one percent also have children under 18 living at home.

What formal, paid services do caregivers use most for their relative or friend:

Personal and nursing care	38%	
Home modifications	28	
Meals-on-wheels		16
Assistance with housework	16	

When asked what services they would like to have had available to help with caregiving, caregivers in the national survey responded 1) they "don't know" what would have helped (38%) or "nothing" (18.5%); and 2) they would like "free time/time for oneself" (17%). These responses indicate a lack of knowledge of what existing and available services can do for them (that is, they recognize services by name but do not know how the services can help), together with the clear need for some time off.

In addition, when asked in another survey what information they want most, caregivers ask for information on how to deal with stress, how to find and evaluate good quality home care, and how to balance the demands of work and caregiving. Caregivers also cited the need for practical, hands-on training in their everyday tasks--bathing, transferring from bed to chair, nutrition, etc.

Caregiving and Money

In 1998, the United Hospital Fund conducted an analysis that estimated the value of caregiving to society at \$196 billion per year--which is more than the value of in-home care and nursing home care combined. Without family caregivers, the long-term care system would bankrupt the country--especially as the Baby Boomers age.

As for caregivers themselves, they spend on average \$171 per month out-of-pocket for groceries, medications, home modifications, etc. The major expenses: food, transportation, medications, utilities, medical care and in-home care for the care recipient. This conservative amount is roughly equivalent to an IRA that the caregiver might otherwise be able to save for his or her retirement. The Juggling Act study of working caregivers calculated that, over a "lifetime" of intense caregiving, this out-of-pocket amount could average nearly \$20,000. Yet it is important to keep in mind that only a small percentage of caregivers (between 7-20%, depending upon the study) complain that caregiving represents a financial hardship.

Interestingly, in another study, half of caregivers report feeling financially unprepared for their own long term care.

Caregivers more than most people are aware of the tremendous financial drain that long-term care can have on a family.

Caregiving and Work

Three-quarters of caregivers work full or part-time, and 54% of those who work are making work-related adjustments--an important factor because of the implications for productivity. Those workplace accommodations break out as follows:

Go in late, leave early, time off during work	49%	
Leave of absence		11
Dropped back to part-time, less demanding job	7	
Lost job benefits		4
Turned down promotion		3
Chose early retirement		4
Give up work entirely		6

In the MetLife Study of the cost of caregiving to US employers, the estimate of annual cost in terms of lost productivity is between \$11.4 to \$29 billion per year. The lower figure counts caregivers who work full-time, live nearby their relative and perform personal care tasks (e.g., bathing , dressing, feeding, etc.) The \$29 billion per year includes caregivers who work part-time, do long-distance caregiving, and who also perform less intensive Instrumental Activities of Daily Living (e.g., managing finances, providing transportation to doctor's appointments, shopping for groceries).

The chances of a caregiver's having to make the types of workplace accommodations listed above increase if the following risk factors are in place: the caregiver helps with two or more personal care activities, resides together with the care recipient, is the primary caregiver, or if the care recipient has Alzheimer's.

Beyond the cost to employers, the total cost to working caregivers over their caregiving and work career was documented in the Juggling Act study at nearly \$660,000. This figure is comprised of:

Negative impact on Social Security	\$25,494
Pension lost	67,202
Wages lost	566,443
TOTAL WEALTH LOST	\$659,139

Caregiving and Health

There are many well-documented studies of the impact of caregiving on the caregiver's health, especially where the caregiver is older and frailer to begin with or where the care recipient has Alzheimer's. In broad-based surveys of caregiving, such as the national caregiver survey, only about 15% of caregivers say they've actually experienced physical or mental health problems as a result of caregiving. About one-quarter of caregivers say that they find caregiving as emotionally stressful, although that percentage goes up considerably as factors such as co-residence, amount of time spent caregiving, and Alzheimer's caregiving increase.

Almost three-quarters of working caregivers doing the more intense, personal care say that it has somewhat or a lot of negative impact on their health. Of these caregivers, half cited making additional visits to their physician as a result, which can translate into higher health care costs for themselves and their employer. In addition, 40% of working caregivers doing the more intense personal care tasks believe that their ability to work productively and to continue to work was affected by their caregiving-related health problems.

