

# Hidden Costs of Caring

Where to turn for help when you're the helper



By Dr. Joseph F. Coughlin, Director of the MIT AgeLab

Aging is not just about the old. Families are typically the primary source of care and support as we age. While doctors, nurses, social workers, and other professionals may call it caregiving, most people simply consider providing help to an older loved one being a loving spouse or a good adult child.

Caregiving is a catchall phrase that encompasses an important and extensive set of activities that evolve (sometimes slowly, other times rapidly) with the needs of the care recipient. This paper provides financial professionals and investors with an overview of caregiving—what it is, who's most likely to provide it, what the associated costs are, and where those who are providing care to an older adult can turn for help.

## What Is Caregiving?

Caregiving, or informal care, is when a family member or friend provides unpaid help with a wide range of tasks to assist an older adult in his or her daily life. These activities can be as simple as giving a ride to the grocery store and cleaning out the refrigerator, or as complex as managing multiple medications and administering care to a wound.



There is no training or manual for providing care. Consequently, caregivers often feel alone and left to navigate an unknown set of problems and a maze of possible services.

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The nature of caregiving and associated tasks change as the care recipient's condition evolves. The figure below provides an overview of the 'caregiver career.' Over time, the demands of providing care are likely to increase in their diversity and intensity, placing a commensurate increase of physical and emotional burden on the caregiver.

However, there is no set schedule for any one set of tasks. Rather, change can happen gradually or dramatically with a health event such as a stroke or an accident in the home.

At first, caregiving may look like periodic, simple phone calls or check-ins to maintain social contact. While still independent, an older loved one may need to be reminded to refill prescriptions, or take medications on time, in the correct dose, with the appropriate meal.

Over time, other tasks may emerge, such as providing transportation to the doctor's office or routine home maintenance, such as changing a light bulb. In many instances, a caregiver may serve as a healthcare advocate or intermediary, speaking with physicians, pharmacists, and others.

Caregivers may also provide assistance with financial responsibilities such as paying bills or balancing the household checkbook, especially in situations with cognitive decline. Increasing physical frailty or limitations may require the caregiver to help with daily activities, such as washing, dressing, and toileting, adding significant physical and emotional demand to the caregiver.

## Who Is the Caregiver?

A 2020 study found that 41.8 million Americans (14.3% of the population) provide care for someone age 50 or older.<sup>1</sup> The number of caregivers continues to increase as our population ages. Most caregivers are caring for a parent (42%) or parent-in-law (8%), or for a spouse or partner (12%).<sup>1</sup> Two out of 3 care recipients are women and about 4 in 10 are men.<sup>1</sup>

Often referred to as the "sandwich generation," younger baby boomers in their 50s and Gen X-ers in their late 40s, are described as "sandwiched," or caught in the middle, caring for both their children and aging parents. Many of these caregivers are also employed, adding their career to the list of "jobs" they're juggling.

### Caregiving Gets More Complex Over Time: Four Levels of Caregiving



- Social contact

- Social contact
- Issues management  
(Car repair, dish washer breaks, tree falls in yard, changing light bulbs, etc.)
- Health compliance

- Social contact
- Issues management
- Health compliance
- Transportation
- Food shopping
- Healthcare intermediary

- Social contact
- Issues management
- Health compliance
- Transportation
- Food shopping
- Healthcare intermediary
- Cooking/cleaning
- Bathing/dressing
- Health administration

Source: MIT AgeLab

## Costs of Caring

While providing care to an elderly family member or friend is most often done out of love and loyalty, there is a cost to caring. Caregiving affects time, physical and emotional well-being, and finances.

On average, caregivers spend 23.7 hours per week providing care.<sup>1</sup> However, the amount of time dedicated to caregiving varies among individuals' situations and is dependent on multiple factors. For example, 21% of caregivers caring for someone age 50+ spend 41 hours or more per week providing care.<sup>1</sup>

Thirty six percent of caregivers consider their caregiving situation to be highly stressful.<sup>1</sup> Further, 18% of caregivers report experiencing high financial strain as a result of providing care.<sup>1</sup> Caregivers spend on average \$7,200 out-of-pocket annually on caregiving-related expenses, such as household goods, food and meals, travel and transportation costs, and medical expenses.<sup>2</sup>

## Where to Find Help

Becoming a caregiver can happen gradually or suddenly due to a health event or accident. There's no training manual for this role, so caregivers often feel isolated and overwhelmed by the challenges and the maze of available services.

### Percentage of Caregivers of Adults Who Are in Each Generation, 2020<sup>1</sup>

Generation Z (born 1997 or after)	6%
Millennial (born 1981 to 1996)	23%
Generation X (born 1965 to 1980)	29%
Baby Boomers (born 1946 to 1964)	34%
Silent/Greatest (born 1945 or prior)	7%

Source: *Caregiving in the US*, AARP and National Alliance for Caregiving, 2020. Most recent data available.

### Faces of Caregivers<sup>1</sup>

Those caring for someone 50+

- 12% care for a spouse or partner
- 50% care for a parent or parent-in-law
- 46% of caregivers care for someone age 75 or older
- 10% care for a non-relative
- Average age of caregivers is 49.4
- 61% of caregivers are female
- 76% of caregivers care for one person, 24% care for more than one person

Here are some organizations and service providers that can assist with various caregiving tasks.

**Area Agencies on Aging:** Area Agencies on Aging (AAAs) are experts on all aspects of aging. Created by a Federal law, AAAs help older Americans and their caregivers live quality lives with independence and dignity. There are over 600 AAAs in the United States providing a wide range of services including meals-on-wheels, transportation, home care, and general support.

**Alzheimer's Association Chapters:** The Alzheimer's Association provides supportive programs, services, and information throughout the United States. Local chapters help people with Alzheimer's and their caregivers deal with the disease and its impact on their lives.

**Sharing Economy Services:** On-demand service providers that can be organized and requested by smartphone or online are widely available in major metropolitan areas. Examples include Lyft and Uber for transportation as well as wide variety of other firms that can assist with home maintenance (TaskRabbit), home care (Honor), home grocery delivery (Peapod), and other services.

**Home Health Aides and Home Care Providers:** Home health aides typically provide assistance with a range of activities, such as bathing, ambulation, transferring, cooking, eating, housekeeping, and basic health services. Home care assistants help with household chores and personal care. There are both for-profit and non-profit service providers.

### **Additional Resources for Caregivers:**

- AARP Home & Family Caregiving
- ARCH National Respite Network
- National Alliance for Caregiving
- WISER's Financial Steps for Caregivers
- alzheimers.gov
- Eldercare locator
- National Association of Area Agencies on Aging
- Lotsa Helping Hands
- Alzheimer's & Dementia Caregiver Center
- Family Caregiver Alliance
- Caregiver Action Network
- CareZone

## **Next Step**

1. Realize that caregiving gets more complicated over time
2. Don't do caregiving by yourself. Explore caregiving support resources on pages 3-4 of this whitepaper.



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### Sources:

<sup>1</sup> 2020 Report: *Caregiving in the US*, AARP & National Alliance for Caregiving, 2020. Most recent data available.

<sup>2</sup> *Planning for Retirement? Don't Forget Caregiving Costs*, AARP, 1/24/22

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