



## Hidden Costs of Caring: Where to Turn for Help When You Are the Helper

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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 advisors and clients with an overview of caregiving—what it is, who is 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.



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*Dr. Joe Coughlin, PhD  
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## 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.

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.

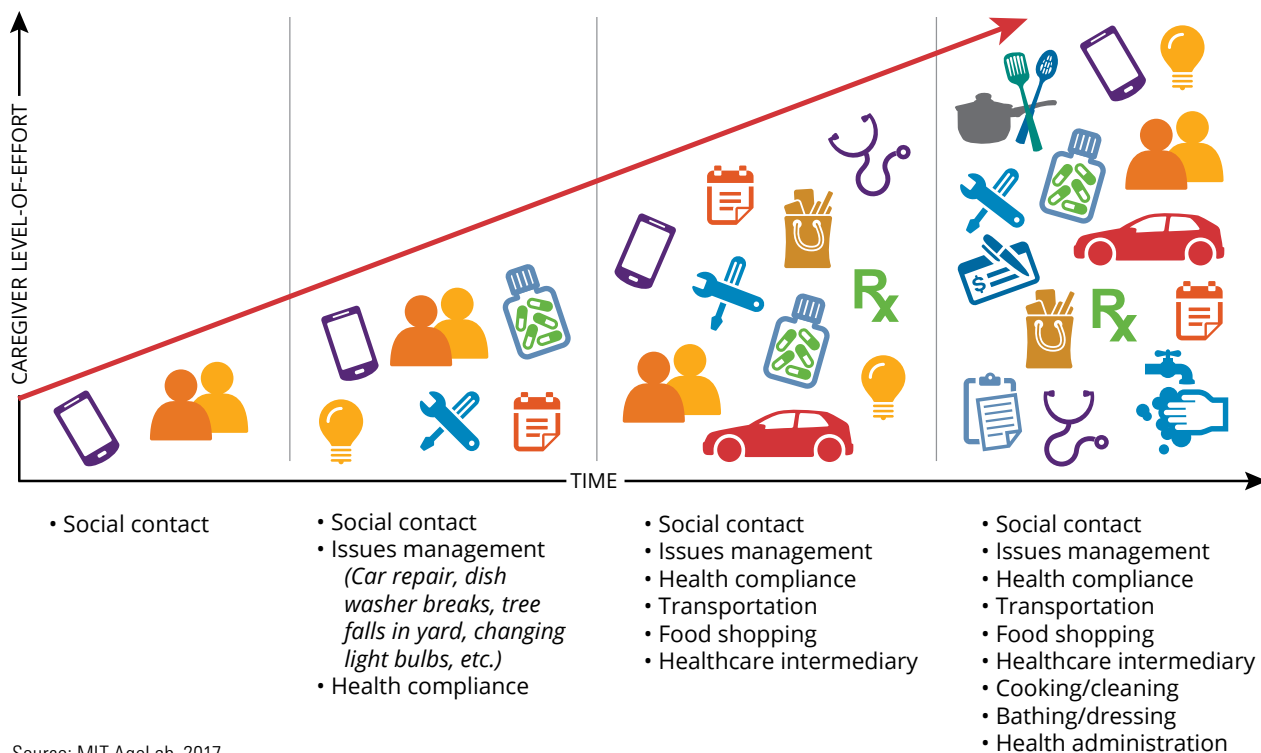
Caregivers may also provide assistance with financial responsibilities such as paying bills or balancing the household checkbook, especially in situations with cognitive decline. Increasing physical frailty or limitations may require the caregiver to help with daily activities, such as washing, dressing,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

## Who Is the Caregiver?

Today, 34.2 million Americans (14.3% of the population) provide care for someone age 50 or older. The number of caregivers will continue to increase as our population ages. More than half of these caregivers are assisting a parent or parent-in-law. Quite often, the face of the caregiver is a middle-aged adult daughter or daughter-in-law, as 60% of caregivers are female<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 are juggling.

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



Source: MIT AgeLab, 2017

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

Those caring for someone 50+

- One in 10 care for a spouse or partner (11%)
- More than half care for a parent or parent-in-law (55%)
- One in four care for someone age 85 or older
- 14% care for a nonrelative
- Average age of a 50+ caregiver is 74.7 years old
- 60% of caregivers are female
- Six in 10 caregivers are between the ages of 35 and 64 (59%)

## 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.

According to the National Alliance for Caregiving and AARP, the average time dedicated to caregiving for someone age 50 or older is 24.1 hours per week.<sup>1</sup> However, the amount of time dedicated to caregiving varies among individuals' situations and is dependent on multiple factors. For example, 22% of caregivers caring for someone age 50+ spend 41 hours or more per week providing care.<sup>1</sup> One in five caregivers report high physical strain and four in 10 caregivers report high emotional stress, yet the physical and emotional well-being of the caregiver is often not acknowledged.<sup>1</sup> Further, one in five caregivers report financial strain from caregiving<sup>1</sup>. Caregivers spend on average \$5,531 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 over time or sometimes instantly, as the result of a health event or accident. 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. Below are selected organizations and service providers that may help caregivers with a range of 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), homecare (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](#)
- [alzhaimers.gov](#)
- [Alzheimer's & Dementia Caregiver Center](#)
- [ARCH National Respite Network](#)
- [Eldercare locator](#)
- [Family Caregiver Alliance](#)
- [National Alliance for Caregiving](#)
- [National Association of Area Agencies on Aging](#)
- [Caregiver Action Network](#)
- [WISER's Financial Steps for Caregivers](#)
- [Lotsa Helping Hands](#)
- [CareZone](#)

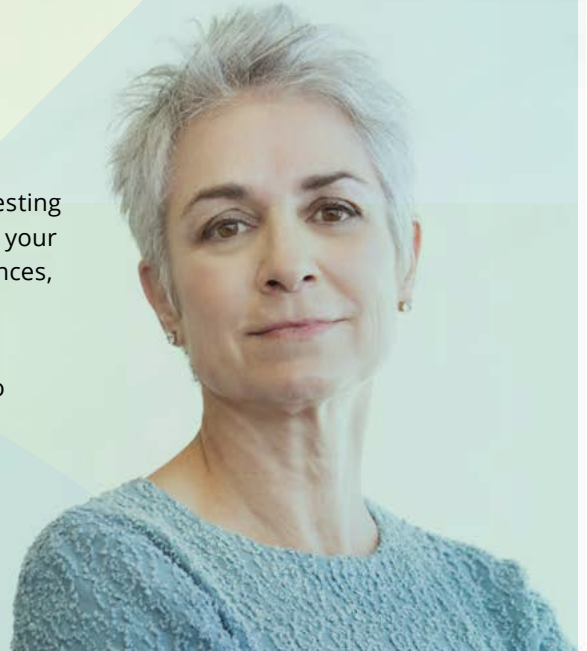
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**Joseph F. Coughlin, Ph.D.** is Director of the Massachusetts Institute of Technology AgeLab. His research examines how the disruptive demographics of an aging society, social trends, and technology will shape future innovations in business and government. Coughlin teaches in MIT's Department of Urban Studies and Planning as well as Sloan School of Management Advanced Management Program. Coughlin is frequently interviewed by The Economist, The Financial Times, The New York Times, The Wall Street Journal, Straights Times, and other business and technology publications.

Sources:

<sup>1</sup> *Caregivers of older adults: A focused look at those caring for someone age 50+*, AARP & National Alliance for Caregiving, 2015. Most recent data available.

<sup>2</sup> *Evercare study of family caregivers – what they spend, what they sacrifice*, Evercare & National Alliance for Caregivers, 2007. Most recent data available.

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