

CAREGIVER

a love story



**CARING FOR THOSE
WHO GIVE CARE**
BACKGROUND READING



- 3** SCOPE OF CAREGIVING IN THE U.S.
- 4** TERMS TO LEARN AND EXPLORE
- 5** MORE READING ON THE CAREGIVING CRISIS

SCOPE OF CAREGIVING IN THE US

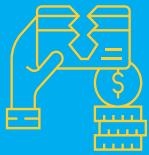
YOU ARE NOT ALONE



More than **1 in 5** Americans are caring for an adult in need in their homes



Caregivers provide care for an average of an average of **4.5 years**



\$470B

The value of caregiver's unpaid labor is estimated at **\$306 billion**¹

CAREGIVERS HAVE NEEDS



Caregivers provide care for an average of **24 hours** per week²



Between 40-70% of caregivers have **symptoms of depression**

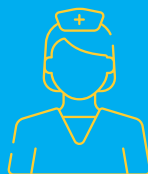


1 in 4 caregivers report a decline in their own physical health²

CAREGIVER NEEDS CAN BE MET



This screening event is designed to **support caregivers** to identify their needs and get the help they need



Education and support programs designed for caregivers **can help**



Understanding caregivers' needs leads to **better care plans** for everyone

¹ https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html?cmp=RDRCT-VALUN_JUN23_015

² <https://www.apa.org/pi/about/publications/caregivers/faq/cdc-factsheet.pdf>

³ <https://www.caregiver.org/caregiver-health>

TERMS TO LEARN AND EXPLORE³

Becoming comfortable with these terms will help you as a familiar. These definitions may also be helpful to share and/or discuss with your group.

CAREGIVER/CAREGIVING

'Caregiver' or 'family caregiver' is a term used to describe family, friends, and other non-professionals who provide care to a family member or someone close to them who is in need. These are important terms to share, as many people who care for a loved one do not know there is a word for what they are doing, and do not know they are part of a group. Knowing this term will help people both to seek resources designed for them, and to find comfort in belonging to a community with a shared experience. Medical professionals may also describe themselves as 'caregivers' or 'formal caregivers', and so it is important to differentiate between the two groups.

CAREGIVER BURDEN

The stress carried by a person, often a family member, who cares for a chronically ill, disabled, or elderly family member at home or at other care facilities. The burden can be financial, emotional, physical, or spiritual.

PALLIATIVE CARE

Palliative care refers broadly to care that focuses on pain relief, symptom management, and spiritual and social support for people with serious illness or symptom burden. It can be provided in hospitals, outpatient clinics, or at home and can be provided alongside treatments designed to cure or alleviate disease. Palliative care is often confused with hospice care but it is broader - hospice care is for people with terminal illness, while palliative care can be appropriate for those at any stage of illness.

HOSPICE

Hospice care comprises a subset of Palliative Care. Like Palliative Care, it aims to alleviate suffering and enhance quality of life, and is administered by a diverse team of professionals who focus on medical, spiritual, and social services. However, unlike Palliative Care, it is only available to people who have chosen to discontinue disease-focused treatments and whose doctors have documented them as having less than six months to live. Hospice services are covered by Medicare and may be provided in a variety of locations, including home or nursing facilities. The home hospice services seen in the film are typical - including a few hours of professional assistance a week, focused mostly on adjusting medicines for comfort and evaluating machinery and tubing. They do not provide significant support for toileting, turning, or nutrition--the bulk of those responsibilities fall to the family. Some, but not all, hospices provide a few volunteer hours per week for housekeeping tasks like shopping, laundry, or tidying. But again, these tasks usually fall to the family. Medicare requires that five percent of hospice patient hours are offered by volunteers who might offer housekeeping help or shopping. But sadly, it is usually not enough.

CARE RECIPIENT

This is a term to refer to chronically ill, disabled, elderly, or terminally ill people who are in need of formal and/or informal care.

³ Terms and definitions adapted from https://www.nextstepincare.org/Terms_and_Definitions/

MORE READING ON THE CAREGIVING CRISIS



“The caregiver saves the system a ton of money.”

—RICK

In 2017, about 41 million family caregivers in the United States provided an estimated 34 billion hours of care to adults with limitations in daily activities. The estimated economic value of their unpaid contributions was approximately \$470 billion.⁴

- **65 percent** of adults in the United States with long-term care needs rely on a family caregiver
- More than **75 percent** of family caregivers are women⁵
- **One in four** family caregivers are Millennials, born between 1981-1996⁶
- **One in five** Americans between the ages of 55 and 64 are caring for an elder family member, and **20 percent** of those caregivers also have children at home.⁷

⁴ AARP “Valuing the Invaluable”

⁵ <https://www.ioaging.org/aging-in-america>

⁶ <https://www.aarp.org/content/dam/aarp/ppi/2018/05/millennial-family-caregivers.pdf>

⁷ <https://www.nytimes.com/2019/08/29/business/economy/labor-family-care.html?action=click&module=RelatedLinks&pgtype=Article>

⁸ AARP “Valuing the Invaluable”

THE POPULATION IS CHANGING

The Census Bureau projects that by 2035 the population will include more adults over the age of 65 than children under the age of 18. Americans are living longer, having fewer children, and adult children are more likely to live far away from aging parents. Simply stated, the number of available family caregivers is decreasing just as the number of people needing care is increasing.⁸

ANTICIPATING MENTAL AND PHYSICAL EFFECTS OF GIVING CARE

Caring for a family member at home can both provide emotional benefits and put caregivers at risk for emotional, physical, social, and financial distress—risks that are often referred to as “caregiver burden.”

Most family caregivers (**63%**) experience positive effects, such as feelings of closeness to their family member, pride in their ability to overcome challenges, and satisfaction that their loved one is well-cared for.⁹

At the same time, caregivers are at risk for adverse mental and physical health effects:

- **1 in 10** caregivers report a decline in their physical health
- **10 percent** of caregivers report physical strain like back pain
- Caregivers are at **higher risk** than non-caregivers for heart disease or high blood pressure
- Caregivers are **less likely** to seek out preventive care
- Caregivers aged 66-96 who experience stress taking care of their spouses have a **63 percent** higher mortality rate than non-caregivers of the same age¹⁰

Caregivers with higher risk of negative impact on their physical and mental health are those who:

- feel they **do not** have a choice in offering care
- are otherwise employed for more than **20 hours** a week.¹¹
- perform a **high number** of tasks like personal care, household chores, medical interventions, and paying bills
- are **older**
- are **low income**
- must coordinate care with **multiple** care providers.¹²

People caring for a family member with Alzheimer’s Disease or other forms of dementia are at particularly high risk for negative mental and physical effects, both because of the potential for behavioral disturbances like aggressive behavior, and because of decreasing or unpredictable reciprocity between the patient and the caregiver. In a 2018 study, 72 percent of informal caregivers for people with Alzheimer’s reported their overall health had decreased, and 59 percent experienced anxiety or depression.¹³

⁹ <https://aspe.hhs.gov/report/informal-caregiving-older-americans-analysis-2011-national-study-caregiving/balance-positive-and-negative-aspects-caregiving>

¹⁰ <https://www.caregiver.org/caregiver-health>

¹¹ Ibid.

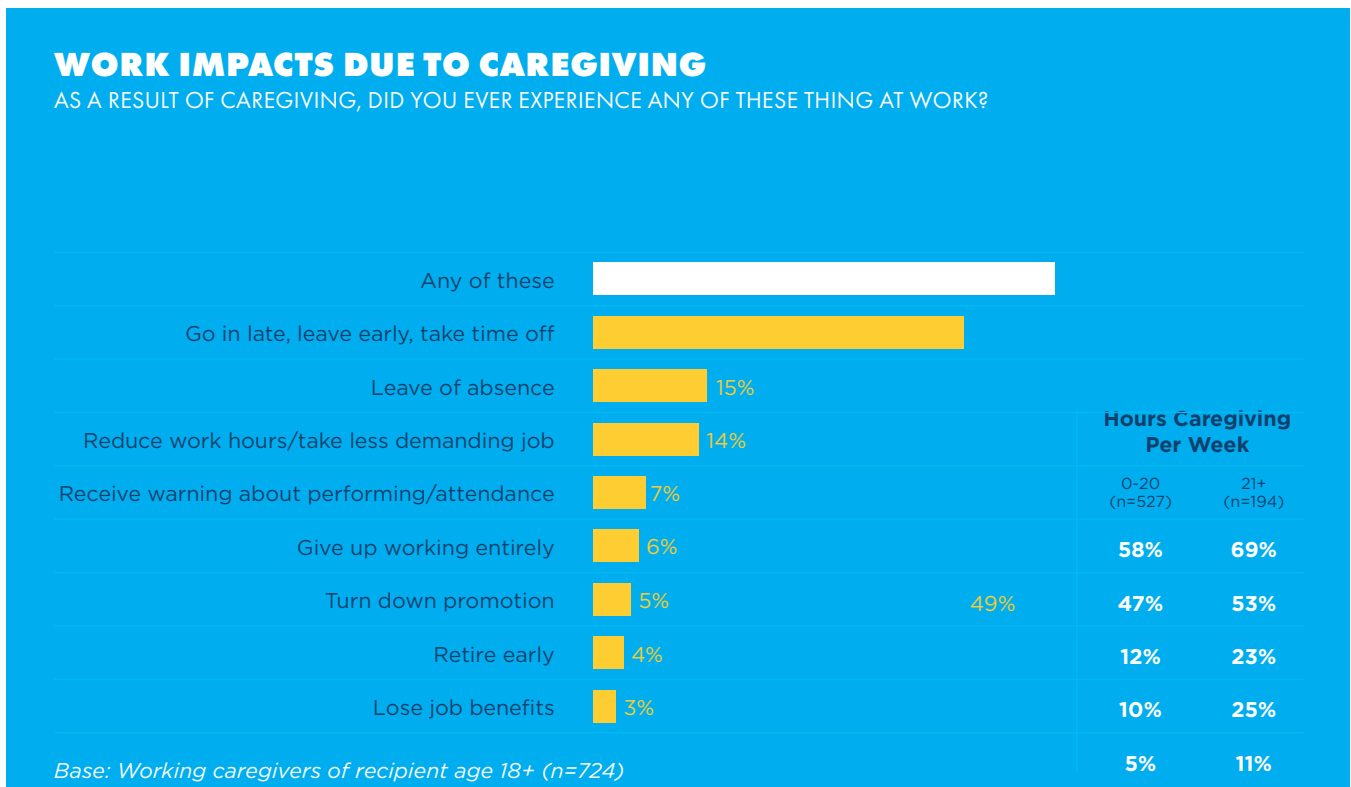
¹² <https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf>

¹³ <https://www.healthline.com/health/state-of-alzheimers#key-findings>

ANTICIPATING FINANCIAL EFFECTS FOR CAREGIVERS

- Family caregivers are also likely to experience both short and long-term financial strains-36 percent of those caring for an adult over the age of 50 reported high levels of financial strain.¹⁴ In 2016, family caregivers had, on average, out of pocket expenses of \$7,000. Those that live an hour or more away from their family member spent \$11,000
- Family caregivers are spending 20 percent of their annual income on caregiving.¹⁵

Caregiving has severe implications on caregivers' current and future employment:



https://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf

¹⁴ Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine; Schulz R, Eden J, editors. Families Caring for an Aging America. Washington (DC): National Academies Press (US); 2016 Nov 8. 4, Economic Impact of Family Caregiving. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK396402/>

¹⁵ <https://www.aarp.org/research/topics/care/info-2016/family-caregivers-cost-survey.html?CMP=RDRCT-PPI-CAREGIVING-102416>

“Hospice did its job in this film. But that is just the tip of the iceberg of what caregivers need.”

—DR. JESSICA ZITTER¹⁶

SUPPORTS FOR CAREGIVERS

Family and informal caregivers are critically important to the safety and well-being of the millions of aging, disabled, chronically or terminally ill adults in the United States. And yet, all too often, the caregivers are invisible to the medical and social systems who rely on them so heavily.

In order to care for family members, caregivers need:

- Education and training about what caregiving entails
- A fuller understanding of resources and services available
- Social support and resources to sustain their mental and physical health
- Resources to alleviate the financial burdens of caregiving

Offering support services for caregivers has positive outcomes not just for the caregivers themselves, but for patients as well. One study showed that a comprehensive program for dementia patients that included caregiver support services resulted in significantly reduced patient admissions to long-term care facilities.¹⁷ Another metastudy demonstrated that integrating caregivers into hospital discharge plans for elderly patients in need of long-term care significantly reduced the likelihood of hospital readmission.¹⁸

In 2018, Congress passed the RAISE Act, or Recognize, Assist, Include, Support, and Engage Family Caregivers, that established a national advisory committee to create a national plan to address the needs of family caregivers.¹⁹

In 2018, the [Geriatrics Workforce Improvement Act](#) was introduced in the U.S. Senate to offer tax breaks and other features that would incentivize people to age at home, which is far cheaper than institutionalized care. As of February, 2020, the act is under review by the Committee on Health, Education, Labor and Pensions.²⁰

Building support for caregivers includes considering the cultural, racial, age, gender, and socio-economic diversity of family caregivers. Family caregivers are as diverse as the nation’s population, and different groups experience caregiving and the expectations for caregiving differently. For example, people from different cultures may have differing perceptions of the expectations for family caretaking that influence their level of stress when the need arises. Furthermore, already existing socio-economic inequalities are amplified by the time and economic pressures of family caregiving. People who start caregiving with fewer resources experience greater challenges; housing and job security often become critical issues, and often people with fewer resources are required to provide more caregiving needs, from nursing care to taking care of the home.²¹

¹⁶ In conversation w Blueshift 12/17

¹⁷ <https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2719196>

¹⁸ <https://www.upmc.com/media/news/jamesrodakowski-caregiverintegration>

¹⁹ <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>

²⁰ <https://www.congress.gov/bill/115th-congress/senate-bill/2888/text>

²¹ <https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf>