Alzheimer’s Disease Caregivers

Alzheimer’s disease has a devastating impact not just on those with the disease. It’s also an extreme burden on their caregivers — a job that usually falls on family and friends.

- In 2019, more than 16 million family members and friends provided 18.6 billion hours of unpaid care to people with Alzheimer’s and other dementias, at an economic value of $244 billion.

- Of the unpaid Alzheimer’s and dementia caregivers, 86% have provided care for at least the past year, and half have been providing care for four or more years.

- Nearly one-fourth of Alzheimer’s and dementia caregivers are “sandwich generation” caregivers — caring for both someone with the disease and a child or grandchild.

Caring for people with Alzheimer’s and other dementias is often very intimate and very intrusive.

- Nearly 80% of older adults with dementia receive help with a daily personal care activity such as bathing, dressing, grooming, or eating. In contrast, only 20% of older adults without dementia need help with these activities.

- One in 3 Alzheimer’s caregivers provide help bathing or showering, feeding, or getting to and from the toilet — a higher percentage than caregivers for other older adults.

- About one-third of Alzheimer’s and dementia caregivers deal with incontinence or diapers. For caregivers of older adults without dementia, just 12% help with this personal care task.

Burden of Alzheimer's Caregivers vs. Other Caregivers

- Getting in and out of bed: 45% (Alzheimer's) vs. 43% (Other)
- Getting dressed: 38% (Alzheimer's) vs. 30% (Other)
- Bathing or showering: 34% (Alzheimer's) vs. 23% (Other)
- Feeding: 33% (Alzheimer's) vs. 20% (Other)
- Getting to and from the toilet: 32% (Alzheimer's) vs. 25% (Other)
- Dealing with incontinence or diapers: 32% (Alzheimer's) vs. 12% (Other)
Caring for an individual with Alzheimer’s disease creates or aggravates the health problems of a caregiver.

- Nearly 75% of Alzheimer’s and dementia caregivers are somewhat or very concerned about maintaining their own health since becoming a caregiver.
- Over 1 in 3 dementia caregivers say their health has gotten worse due to their care responsibilities. More than a quarter of dementia caregivers delay or do not do things they should to maintain their health.
- Nearly 60% of Alzheimer’s and dementia caregivers rate the emotional stress of caregiving as high or very high. As many as 40% of family caregivers of people with Alzheimer’s and other dementias suffer from depression.
- One study looked at spousal caregivers of people who were hospitalized. If the care recipient who was hospitalized had dementia, the spousal caregiver was more likely to die within a year than if the care recipient did not have dementia, even after accounting for the age of the caregiver.

Caring for an individual with Alzheimer’s has a negative effect on employment, income, and financial security.

- Among Alzheimer’s and dementia caregivers who are employed full or part time, 57% said they had to go in late, leave early, or take time off because of their caregiving responsibilities.
- In addition, 18% had to go from working full time to part time; 16% had to take a leave of absence; and 8% turned down a promotion due to the burden of caregiving.
- More than 1 in 6 Alzheimer’s and dementia caregivers had to quit work entirely either to become a caregiver in the first place or because their caregiving duties became too burdensome.
- Among female caregivers, 17% believe they have been penalized at work because of the need to care for someone with Alzheimer’s.