Alzheimer's Disease Facts and Figures 2008:

A Report from the Alzheimer's Association

PART 3

Alzheimer's Disease Facts and Figures 2008 is a comprehensive statistical abstract of US data on Alzheimer's disease (AD), the most common type of dementia. In the third of a series on AD, *Assisted Living Consult* reprints the third part of the Alzheimer's Association report. This section discusses family caregiving. Future sections will focus on use and costs of care and mortality. The first article in the series was on page 24 of the March/April issue of *ALC* (www.assistedlivingconsult.com/issues/04-02/alc34-Alzheimers-331.pdf). The second article was on page 32 of the May/June issue (www.assistedlivingconsult.com/issues/04-03/alc56-Alzheimers%20part%202-527.pdf).

Caring for a person with AD or another dementia is often very difficult, and many family and other unpaid caregivers experience high levels of emotional stress and depression as a result. Caregiving also has a negative impact on the health, employment, income, and financial security of many caregivers.

Number of Caregivers

In 2007, 9.8 million family members, friends, and neighbors provided unpaid care for a person with AD or another dementia. Table 1 shows the number of family and other unpaid caregivers for the United States and selected states. The number of caregivers by state ranges from about 14,000 in Alaska to 1.1 million in California.

Table 1.
Number of AD and Dementia Caregivers, Hours of Unpaid Care and Economic Value of the Care by Selected State, 2007

State	No. Caregivers	Hours Unpaid Care/Year	Economic Value of Unpaid Care
Alaska	14,391	12,422,462	$131,429,647
California	1,103,073	952,172,799	$10,073,988,212
Florida	568,591	490,808,160	$5,192,750,333
Michigan	364,855	314,942,511	$3,332,091,763
New York	643,151	555,168,160	$5,873,679,133
Pennsylvania	430,794	371,861,053	$3,934,289,940
Rhode Island	35,397	30,554,564	$323,267,288
Texas	746,713	644,562,329	$6,819,469,443
Wisconsin	178,748	154,295,166	$1,632,442,856
United States	**9,753,995**	**8,419,648,576**	**$89,079,881,929**

Some people with AD and other dementias have more than 1 unpaid caregiver, for example, people who live with their primary caregiver and receive help from another relative, friend, or neighbor.[1]

Many people with AD or another dementia also have other serious medical conditions, such as diabetes and congestive heart failure.[2] Their family and other unpaid caregivers often help to manage these conditions in addition to the person's AD or other dementia. In all, 29% of all unpaid caregivers of older people in the United States are caring for a person with AD or another dementia.

Hours of Unpaid Care

In 2007, the 9.8 million US family and other unpaid caregivers of people with AD and other dementias provided 8.4 billion hours of care. This number represents an average of 16.6 hours of care per caregiver per week, or 863 hours of care per caregiver per year. As shown in

Table 1, even in a small state, such as Rhode Island, caregivers of people with AD and other dementias provided 31 million hours of unpaid care in 2007.

Caregivers of people with AD and other dementias provide more hours of help, on average, than caregivers of other older people. The number of hours varies in findings from different studies. One study found that 23% of caregivers of people with AD and other dementias provided more than 40 hours a week, compared with 16% of caregivers of other older people.[1] Another study found that 40% of caregivers of people with AD and other dementias provided more than 40 hours a week of help, compared with 28% of caregivers of other older people.[3]

The average number of hours of unpaid care provided for people with AD and other dementias increases as the person's disease worsens.[4] The number of hours of unpaid care is also greater, on average, for people with coexisting medical conditions in addition to AD or another dementia.[4]

Some family and other unpaid caregivers who live with a person who has AD or another dementia provide supervision and help 24 hours a day, 7 days a week, getting up with the person at night and assisting with all daily activities.[5,6] Such around-the-clock care is needed when the person cannot be left alone because of the risk of wandering, getting lost, and other unsafe activities.

Economic Value of Caregiving

In 2007, the economic value of the care provided by family and other unpaid caregivers of people with AD and other dementias was $89 billion. This number represents 8.4 billion hours of care valued at $10.58 per hour, which is the average of the minimum wage ($5.85 per hour) and the average wage of a home health care aide in July 2007 ($15.32 per hour).

Unpaid caregivers of people with AD and other dementias provided care valued at more than $1 billion in each of 31 states. Unpaid caregivers in California, Florida, New York, and Texas provided care valued at more than $4 billion.

Who Are the Caregivers?

Family and other unpaid caregivers of people with AD and other dementias are more likely to be women than men. About 60% of unpaid caregivers are wives, daughters, daughters-in-law, granddaughters, and other female relatives, friends, and neighbors.[1,3,7] The remaining 40% are husbands, sons, sons-in-law, grandsons, and other male relatives, friends, and neighbors.

Caregivers range in age from very young to very old. As shown in Figure 1, among caregivers ages 18 and older, 19% were under age 35; 29% were ages 35 to 49; 37% were ages 50 to 64; and 14% were age 65 and older.[1] Their average age was 48.

In addition, about 250,000 American children ages 8 to 18 are unpaid caregivers for a person with AD or another dementia.[8] These children represent 18% of the 1.4 million American children ages 8 to 18 who provide unpaid help for any person. About two-thirds of the 1.4 million children caregivers live in the same household as the person they are helping—usually a parent or grandparent—and more than half of children caregivers assist with bathing, dressing, feeding, or helping the person use the toilet.[8]

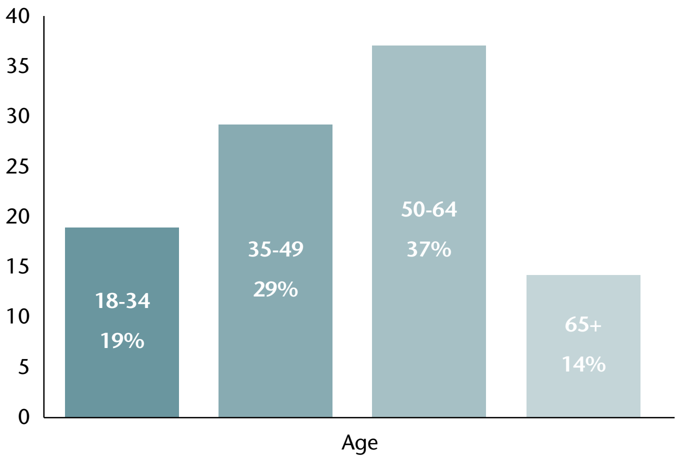
Long-distance Caregivers

Ten percent of the 9.8 million family and other unpaid caregivers of people with AD and other dementias live more than 2 hours from the person for whom they provide care, and another 4% live 1 to 2 hours from the person.[1] Depending on the definition of "long-distance caregiving," these numbers indicate that 980,000 to 1.4 million caregivers of people with AD and other dementias are "long-distance caregivers."

Caregiving Tasks

The kinds of help provided by family and other unpaid caregivers depend on the needs of the person

Figure 1.
Age of AD and Dementia Caregivers, 2003

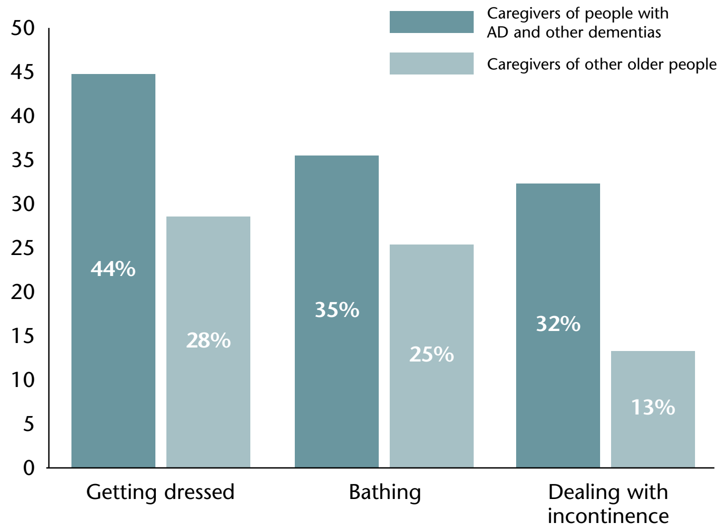


Source: Alzheimer's Association and National Alliance for Caregiving. *Families Care: Alzheimer's Caregiving in the United States, 2004.*

and change as the person's AD or other dementia worsens. Caregiving tasks can include[1,3]:

- Shopping for groceries, preparing meals, and providing transportation
- Helping the person take medications correctly and follow treatment recommendations for his or her dementia and other medical conditions
- Managing finances and legal affairs
- Supervising the person to avoid unsafe activities, such as wandering and getting lost
- Bathing, dressing, feeding, helping the person use the toilet, or providing incontinence care
- Making arrangements for medical care and paid in-home, assisted living (AL), or nursing home care
- Managing behavioral symptoms

Figure 2.
Age of AD and Dementia Caregivers, 2003



Source: Alzheimer's Association and National Alliance for Caregiving. *Families Care: Alzheimer's Caregiving in the United States, 2004.*

As shown in Figure 2, family and other unpaid caregivers of people with AD and other dementias are more likely than caregivers of other older people to assist with all kinds of personal care, for example, bathing the person (35% of AD and dementia caregivers vs 25% of other caregivers) and dealing with bladder and bowel incontinence (32% of AD and dementia caregivers vs 13% of other caregivers).[1] These tasks are often made more difficult by the confusion and disorientation of the person with dementia, who may be unable to cooperate and may even resist care.

When a person with AD or another dementia moves to an AL residence or nursing home, the kinds of help provided by his or her family and other unpaid caregivers usually change, but many caregivers continue to assist with financial and legal affairs and arrangements for medical care and provide emotional support. Some also continue to help with bathing, dressing, and other personal care needs.[9,10]

Duration of Caregiving

Because AD and other dementias usually progress slowly, most caregivers spend many years in the caregiving role. At any one time, 32% of family and other unpaid caregivers of people with AD and other dementias have been providing help for 5 years or longer, and 39% have been providing care for 1 to 4 years.[1] In contrast, 27% of caregivers of other older people have been providing help for 5 years or longer, and 32% have been providing care for 1 to 4 years. Figure 3 shows the percentage of AD and dementia caregivers compared with caregivers of other older people who have provided care for various lengths of time.

Impact of Caregiving on the Caregiver

Caring for a person with AD or another dementia poses special challenges. Although memory loss is the best-known symptom, these diseases also cause loss of judgment, orientation, ability to understand and communicate effectively, and, frequently, changes in personality and behavior.

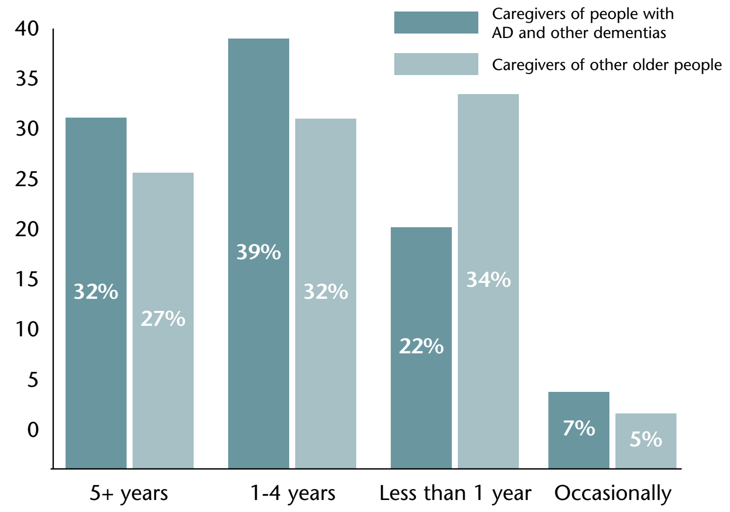
Individuals require increasing levels of supervision and personal care, and many caregivers experience high levels of stress and negative effects on their health, employment, income, and financial security.

Impact on the Caregiver's Emotional Well-being

Most family and other unpaid caregivers are proud of the help they provide, and some manage caregiving tasks with little difficulty.[11,12] Yet many caregivers experience high levels of stress and depression associated with caregiving.

- More than 40% of family and other unpaid caregivers of people with AD and other dementias rate the emotional stress of caregiving as high or very high.[1]
- About one-third of family caregivers of people with AD and other dementias have symptoms of depression.[13]
- One study of family care provided for people with dementia in the year before the person's death found that half the caregivers spent at least 46 hours a week assisting the person; 59% felt that they were "on duty" 24

Figure 3.
Percentage of AD and Dementia Caregivers Compared with Caregivers of Other Older People by Duration of Caregiving, 2003



Source: Alzheimer's Association and National Alliance for Caregiving. *Families Care: Alzheimer's Caregiving in the United States, 2004.*

hours a day; and many felt that caregiving in this end-of-life period was extremely stressful.[6] The stress of caregiving was so great that 72% of the family caregivers said they experienced relief when the person died.

- Caregiver stress, especially stress related to the person's behavioral symptoms, is associated with nursing home placement.[14,15] One study found, however, that family caregiver stress and depression were just as high after the person was placed in a nursing home as before placement.[9]

Impact on the Caregiver's Health

Many caregivers of people with AD and other dementias experience negative health outcomes associated with caregiving.

- Family and other unpaid caregivers of people with AD and other dementias are more likely than noncaregivers to report that their health is fair or poor.[16,17] They are also more likely than unpaid caregivers of other older people to say that caregiving made their health worse.[1,3]
- Family and other unpaid caregivers of people with AD or another dementia are more likely than noncaregivers to have high levels of stress hormones,[17-20] reduced immune function,[17,21] slow wound healing,[22] new hypertension,[23] and new coronary heart disease.[24]
- Family caregivers of people with AD have significantly shorter telomeres on average than other people of the same age and gender.[25] (Telomeres are the genetic material at the end of chromosomes that promotes error-free cell division. Shortened telomeres are an indication of the body's aging processes.)
- One study of spouse caregivers of people hospitalized for various diseases and conditions found that caregivers of people hospitalized for dementia were more likely than caregivers of people hospitalized for other diseases and conditions to die in the following year.[26] (These findings were adjusted for the age of the spouse caregiver.) Among men, 9% died in the year after a wife's hospitalization for dementia, compared with 6% who died in the year after a wife's hospitalization for colon cancer and 7% who died in the year after a wife's hospitalization for stroke. Among women, 5% died in the year after a husband's hospitalization for dementia, compared with 3% who died in the year after a husband's hospitalization for colon cancer and 4% who died in the year after a husband's hospitalization for stroke.

Impact on the Caregiver's Employment

Many caregivers of people with AD and other dementias have to quit work, reduce their work hours, or take time off because of caregiving responsibilities.

- One study of family and other unpaid caregivers of people with AD and other dementias found that 57% were employed full time or part time. Of those who were employed, two-thirds said they had to go in late, leave early, or take time off because of caregiving; 18% had to take a leave of absence; 13% had reduced their hours; and 8% had turned down promotions.[1] Eight percent of caregivers in the study had to quit work entirely because of caregiving.
- Another study of family and other unpaid caregivers of more than 2000 older people found that caregivers of people who had AD or other dementias without behavioral symptoms were 31% more likely than caregivers of other older people to have reduced their hours or quit work.[27] Caregivers of people who had AD or other dementias with behavioral symptoms were 68% more likely than caregivers of

other older people to have reduced their hours or quit work.

Impact on the Caregiver's Income and Financial Security

Family and other unpaid caregivers who turn down promotions, reduce their work hours, and quit work lose job-related income and benefits, including employer contributions to their own retirement savings. In addition, people with AD and other dementias use substantial amounts of paid care. (See "Use and Costs of Long-term Care," in the next issue of *ALC*.) Some of this care is covered for some people by public programs and private insurance, but the person and family must pay out-of-pocket for much of the care.

- One study found that 49% of family and other unpaid caregivers of people with AD and other dementias (not including spouse caregivers) had caregiving-related out-of-pocket expenditures that averaged $219 a month.[1]
- Another study of family caregivers of people ages 50 and over, including people with AD and other dementias, found that long-distance caregivers had higher caregiving-related out-of-pocket expenditures than did other caregivers.[28] ALC

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THOUGHTS ON AGING

> **When you are forty, half of you belongs to the past…And when you are seventy, nearly all of you.**
>
> **– Jean Anouilh**