

# Who Cares?



FAMILIES CARING  
FOR PERSONS WITH  
ALZHEIMER'S DISEASE



A Report of the Alzheimer's Association and the National Alliance for Caregiving



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# SUMMARY OF FINDINGS AND RECOMMENDATIONS

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## FINDINGS

This report is a portrait of the overwhelming task of caring for a loved one who has Alzheimer's disease — a task that at least 5 million American families carry out every day.

Every caregiving situation presents its own special challenge — whether care is provided for a spouse, a parent, a child, a sibling or a friend, and whatever the disease or disability that gives rise to the need for care. This study shows that Alzheimer caregiving is particularly hard work and carries with it heavy costs—for families and for society. It underscores the fact that these caregivers need help — physical and emotional support, education and training, financial assistance, and time away from constant caregiving demands. It demands a response — from the health care system, from the community, and from policy makers.

The survey on which this report is based identified caregivers in the broadest sense of the word — from those who offer occasional assistance for a relative or friend living elsewhere to those who live with a family member who requires constant attention and help with every aspect of daily life. Among all of the caregivers interviewed, 22% were caring for a person who had Alzheimer's disease or "mental confusion." This report looks at this subset of caregivers to find out who they are, what they do, and how they compare with caregivers in general.

These findings are not surprising to anyone who has been through the experience of Alzheimer's disease.

### **ALZHEIMER CAREGIVING IS INTENSE, HARD WORK.**

Alzheimer caregivers spend more time in the day to day tasks of caring and they provide the most difficult type of care. They are twice as likely as other caregivers to be providing the highest levels of care. And they are more likely to be living with the person for whom they are providing care.

- They are twice as likely to be providing more than 40 hours of care each week.
- Nearly three-fourths have been providing care for at least a year, and 38% have been providing care for more than 5 years.
- It is not just the amount of time they spend but the type of care they provide that makes Alzheimer caregiving so intense. They provide help with more activities of daily living. They are twice as likely to be dealing with incontinence (one of the biggest challenges of caregiving) and feeding. They are more likely to be caring for someone who is using a wheelchair or walker and much more likely to be caring for someone who needs help with medications.
- In this study, caregivers reported that 53% of care recipients who had Alzheimer's disease were living with a caregiver — either the caregiver who answered the survey (25%) or another family member or friend (28%).

Older Alzheimer caregivers have the biggest job of all. They are more likely to be living with the person needing care, to be providing more than 40 hours of direct care each week, to be providing care for more than 5 years, and to be providing the most intense care. 73% of caregivers age 65 and over are providing the highest levels of care.

**THE COSTS OF CAREGIVING —  
PHYSICAL, EMOTIONAL, AND  
FINANCIAL — ARE PARTICULARLY  
HIGH FOR ALZHEIMER CAREGIVERS.**

- They are twice as likely to report **physical strain** and high levels of **emotional stress** as a direct result of their caregiving responsibilities.
- Caring places huge **pressures on other family responsibilities**. Three-fourths of Alzheimer caregivers are women, and one in three have children or grandchildren under the age of 18 living at home. Alzheimer caregivers are much more likely to report family conflict and less time to spend with other family members. They are much more likely to give up vacations, hobbies and their own activities.
- Alzheimer caregivers also report higher levels of **financial strain**. These are not wealthy people — almost one in five have household incomes below \$15,000 and only 11% have incomes of \$75,000 or more.
- Nonspouse caregivers who are living with and providing financial support for the person who has Alzheimer's report spending an average of \$261 a month of their own money for prescription drugs, clothing and other out-of-pocket expenses. This does not include what is being spent from the patient's own resources. Nor does it take into consideration the huge costs the family will incur when the person needs full-time paid care at home or in a nursing home or other residential care facility.
- Caregiving seriously interferes with a **caregiver's employment** outside the home. Over 7 in 10 Alzheimer caregivers in this study were employed for at least some of the time they are caregivers. A majority of those employed caregivers report missing time from work, cutting back from full time to parttime work, taking a less demanding job, choosing early retirement, turning down a promotion, or giving up work altogether.

**ALZHEIMER CAREGIVERS NEED HELP  
THAT THEY ARE NOT RECEIVING.**

- 40% of Alzheimer caregivers, and two-thirds of those who live with the person needing care, provide most or all of the care themselves.
- Alzheimer caregivers are more likely than others to be using supportive services, but for many those services do not fully meet their needs.
- Caregivers “learn by doing.” The majority have never received any advice or training in how to help their loved one with their activities of daily living, training that is particularly important for dealing with a person who is cognitively impaired.
- When asked what they need most, they are most likely to say “extra money to help pay for things” and “free time or a break” for themselves.

## CONCLUSIONS AND RECOMMENDATIONS

This report confirms the reality of caregiving in the United States — that families are the backbone of the long term care system. They take personal responsibility for the challenges imposed by a long term illness like Alzheimer's disease. They do it willingly, but at enormous personal cost — to their physical and mental health, to their other family and job responsibilities, and to their own financial security. They need support. And they need help.

The Alzheimer's Association exists to provide that support through its chapter network and the patient and family services it provides. The National Alliance for Caregiving conducts research, develops programs and works to increase public awareness of the issues of family caregiving. But the challenge is too great for the voluntary sector to meet on its own. That is why the Alzheimer's Association and the National Alliance for Caregiving are issuing this report — as a wake up call to the nation — to our health care system, to communities, and to policy makers.

1. The **health care system** must recognize and support caregivers as essential members of the health care team and as individuals at risk of serious health problems of their own. This includes educating caregivers in the care tasks they are assuming, consulting with caregivers as essential members of the care team, and providing preventive health care to caregivers — including counseling and respite — to reduce the physical and mental health risks of caregiving. Insurers, particularly Medicare, must provide adequate reimbursement for caregiver training, consultation, and support.
2. **Community organizations**, including voluntary agencies, religious communities, and the aging network, must adapt their services to meet the special needs of caregivers. This includes developing outreach programs and coordinated information and referral systems to assure that caregivers know what services are available in the community and to make it easy for them to access and use them.

3. The **federal government and the states** must develop family caregiver support programs that include direct services — especially respite, adult day care, and caregiver information and education, as well as direct financial assistance through targeted subsidies and tax credits.
4. Finally, policy makers must recognize that, critical as the family caregiving system is, families alone cannot meet the challenge of Alzheimer's disease. For many people stricken by the disease, the time will come when care at home will not be an option — because there is no caregiver available, because they need more care than their family can provide or because the caregiver becomes too frail or ill to continue. The larger challenge of providing affordable high quality long term care must be addressed.

– *Alzheimer's Association*

– *National Alliance for Caregiving*



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# Background

This report presents the results of analysis of data on caregivers conducted by Mathew Greenwald & Associates, Inc. on behalf of the Alzheimer's Association and the National Alliance for Caregiving. The purpose of this study was to develop a profile of those who care for people with Alzheimer's or mental confusion, and to compare them to those who care for people with other conditions.

Information for this study was gathered in a telephone survey conducted by the National Alliance for Caregiving and AARP in the fall of 1996, and published in a report entitled *Family Caregiving in the U.S.: Findings from a National Survey*. There were 1,509 respondents to that survey, of which 320 cared for individuals with Alzheimer's or mental confusion.

Caregiving was defined as "providing unpaid care to a relative or friend who is aged 50 or older to help them take care of themselves." Further, respondents were told, "Caregiving may include help with personal needs or household chores. It might be taking care of a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you." To be included in the study, the respondent had to be 18 years or older, and had to either be serving currently as a caregiver or have provided caregiving at some point during the past 12 months.

The original telephone survey oversampled Black, Hispanic, and Asian caregivers to ensure adequate numbers of each of these groups for analytical purposes. The survey results were then weighted to reflect the actual proportion of these groups in the U.S. population. This analysis uses the weights from the original study, so that results from both studies are fully comparable.

This analysis also uses an index developed in the original study to represent the intensity of care given by the caregiver. The Level of Care Index classifies caregivers according to the number of hours they spend giving care, and the numbers and types of activities of daily living and instrumental activities of daily living they perform. A Level 1 reflects the lowest intensity and a Level 5 the highest.

The sampling error for this study, at the 95% confidence level, is plus or minus approximately 5.5 percentage points for Alzheimer's caregivers and 2.8 percentage points for non-Alzheimer's caregivers. Statistically significant differences between these two caregiver subgroups are presented in the report text, and are indicated in graphics with an asterisk (\*).



# Overview of Survey Results

- Over one in five caregivers say they take care of someone with Alzheimer's disease, mental confusion, dementia or forgetfulness as the primary or secondary illness or condition. Among these caregivers, four in ten name Alzheimer's or mental confusion as the main illness or problem.
- Almost nine in ten Alzheimer's caregivers are giving care to a relative—most commonly a parent, but often a grandparent, aunt or uncle, a parent in-law or a spouse.
- Three-quarters of Alzheimer's caregivers live close to their care recipient—either in the same household or within twenty minutes. Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to live in the same household as their care recipient.
- Alzheimer's caregivers report spending an average of 17.6 hours per week giving care—significantly higher than the amount of time non-Alzheimer's caregivers report spending (11.8 hours).
- Four in ten Alzheimer's caregivers say they provide most of the care for their care recipient, and nearly as many say someone else provides most of the care.
- Nearly seven out of ten Alzheimer's caregivers help their care recipient with at least one Activity of Daily Living (ADL). Most commonly, they help with dressing the care recipient or helping him/her get in and out of beds and chairs.
- A majority of Alzheimer's caregivers perform each of the Instrumental Activities of Daily Living (IADLs) asked about in the survey. At least two-thirds help with transportation, housework, grocery shopping, preparing meals, arranging outside services, and managing finances, while just over half help with medicines. Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to help with meals, outside services, finances and medicines.
- Alzheimer's caregivers are twice as likely as non-Alzheimer's caregivers to have a highly intense care experience based on the tasks they perform and the time they spend giving care.
- Older Alzheimer's caregivers—those at least 65 years of age—tend to spend more time giving care, and have a more intense caregiving experience. They are more than twice as likely to live with the care recipient, and over five times as likely to be taking care of a spouse.

- Half of Alzheimer's caregivers report that their care recipient has trouble taking medications as directed—a problem reported by only 15% of non-Alzheimer's caregivers.
- Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to say their caregiving negatively affects the time they have for family members, the amount of time they devote to vacations and their own activities, and the physical or mental health problems they suffer.
- Alzheimer's caregivers are also much more likely to report high levels of emotional stress and physical stress due to their caregiving. Those who live with the care recipient are more likely to report feeling stress.
- The coping strategies used most commonly by Alzheimer's caregivers are prayer and talking with friends or relatives.
- The two most often mentioned difficulties of caregiving reported by Alzheimer's caregivers are seeing the progressive deterioration of the care recipient, and having high demands on their time.
- The biggest rewards they cite are the personal satisfaction they receive and the care recipient's appreciation or happiness.
- Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to use nearly every one of the supportive services examined in the survey. Over half each use walkers or wheelchairs and/or a service for personal care or nursing care, and four in ten have made modifications to the home.
- Seven in ten Alzheimer's caregivers have been employed at some time since they began their role as caregivers. More than half of these caregivers report having had to go in late, leave early or take time off during the day to provide care at least once.
- Two-thirds of Alzheimer's caregivers who have worked at some point since they began giving care believe their employer was “very understanding” of the demands of their caregiving.

# Demographic Profile of Survey Respondents

Three-quarters of the Alzheimer's caregivers who responded to the original 1996 survey were currently providing care (75%), and one-quarter had given care within the past twelve months (25%).

The average age of Alzheimer's caregivers is 49 years—slightly older than the average of 45 years for non-Alzheimer's caregivers. In fact, nearly half of the Alzheimer's caregivers are 50 years or older (46%) compared to 36% for non-Alzheimer's caregivers.

The majority of Alzheimer's caregivers are White, non-Hispanic (81%). Thirteen percent are Black, non-Hispanic, 4% are either Black or White Hispanics (4%), and 1% are Asian, non-Hispanic.

Three-fourths of Alzheimer's caregivers are female (76%). Two-thirds of Alzheimer's caregivers are married or living with a partner (66%), 16% are divorced or separated and 10% are single. Three percent are widowed.

Because Alzheimer's caregivers tend to be older, it is not surprising that they are more likely to be retired than non-Alzheimer's caregivers (21% vs. 14%, correspondingly). Close to half of Alzheimer's caregivers work full-time (46%), 14% work part-time, and 19% are not employed.

About one in three Alzheimer's caregivers have children or grandchildren under the age of 18 living in their home (36%), slightly less than among non-Alzheimer's caregivers (43%).

Over half of Alzheimer's caregivers have attended some college or completed college (55%), including 25% who have some college but who have not graduated, 18% who are college graduates, and 12% with some graduate school. About one in four is a high school graduate (28%), 10% have less than a high school education, and 5% have some technical schooling.

Alzheimer's caregivers' annual household income is evenly distributed across income levels—36% have household incomes under \$25,000, 35% have incomes of \$25,000 to \$49,999, and 29% receive \$50,000 or more in household income.

Twelve percent of Alzheimer's caregivers have served on active duty in the U.S. Armed Forces.

Eight in ten Alzheimer's caregivers own their homes (80%), while two in ten rent (18%).

With the exception of age and employment status, the demographic characteristics of Alzheimer's caregivers do not differ significantly from those of non-Alzheimer's caregivers.

In general, as the age of Alzheimer's caregivers increases, so does the likelihood that their caregiving situation is marked by several characteristics. Specifically, Alzheimer's caregivers age 65 and older are more likely than younger Alzheimer's caregivers to be taking care of a spouse, to live with the care recipient, to spend forty hours or more giving care per week, and to have a more intense caregiving experience in terms of the tasks performed and hours spent giving care.

**TABLE ONE**  
**CHARACTERISTICS OF ALZHEIMER'S AND**  
**NON-ALZHEIMER'S CAREGIVERS**

		<b>Alzheimer's Caregivers</b>	<b>Non Alzheimer's Caregivers</b>
<b>Caregiving Status</b>	Currently giving care	75%	77%
	Gave care within past 12 months	25	23
<b>Age</b>	18 to 34 years	18%	24%
	35 to 49 years	36	40
	50 to 64 years	30	25
	65 and older	16	11
<b>Race/Ethnicity</b>	White, Non-Hispanic	81%	83%
	Black, Non-Hispanic	13	10
	Asian, Non-Hispanic	1	2
	Hispanic, Black or White	4	5
<b>Gender</b>	Female	76%	71%
	Male	24	29
<b>Marital Status</b>	Married	64%	62%
	Divorced	13	11
	Separated	3	1
	Widowed	7	8
	Single, living with a partner	2	4
	Single, never married	10	13
<b>Employment Status</b>	Working Full-time	46%	53%
	Working Part-time	14	12
	Retired	21	14
	Not Employed	19	20
<b>Children/Grandchildren Under 18 Living at Home</b>	Yes	36%	43%
	No	63	56

**TABLE ONE (CONTINUED)**

		<b><u>Alzheimer's Caregivers</u></b>	<b><u>Non Alzheimer's Caregivers</u></b>
<b>Educational Status</b>	Less than high school graduate	10%	9%
	High school graduate	28	37
	Some college	25	22
	Graduated college	18	21
	Graduate school or more	12	8
	Technical school/other	5	3
<b>Household Income</b>	Less than \$10,000	11%	8%
	\$10,000 to \$14,999	8	7
	\$15,000 to \$19,999	9	10
	\$20,000 to \$24,999	8	9
	\$25,000 to \$29,999	7	11
	\$30,000 to \$39,999	19	15
	\$40,000 to \$49,999	9	12
	\$50,000 to \$74,999	18	15
\$75,000 and over	11	13	
<b>Armed Forces</b>	Served on active duty	12%	11%
	Did not serve active duty	87	88
<b>Home Ownership</b>	Own	80%	79%
	Rent	18	20

# Detailed Report of Findings

## CHARACTERISTICS OF THE CAREGIVING SITUATION

Most of the Alzheimer's caregivers care for just one older person (69%), but one in four cares for two people (25%), and a few care for more than two (5%).

On average, Alzheimer's caregivers have been providing help to their care recipients for four years, about the same as non-Alzheimer's caregivers. Twenty-four percent have been providing care for one year or less, 35% for one to four years, and 38% for five or more years. A small percentage gives care episodically (2%). [See Figure 1.]

## RECIPIENTS OF CARE

### **Relationship between Caregiver and Care Recipient**

Nearly nine in ten Alzheimer's caregivers are giving care to a relative (89%), while one in ten (11%) cares for a non-relative or friend. The most common relationship between the care recipient and the caregiver is that of parent and child. Specifically, 31% of Alzheimer's caregivers take care of their mother and 11% take care of their father. It is also common for them to take care of other relatives such as a grandparent (11%), a parent-in-law (10%), an aunt or uncle (9%), or a spouse (9%). [See Figure 2.]

Alzheimer's caregivers are slightly more likely to be taking care of a relative than non-Alzheimer's caregivers (89% vs. 84%, respectively), and in particular, are more likely to be caring for a spouse (9% vs. 4%). Among just the Alzheimer's caregivers, those in intense caregiving situations—with a Level of Care Index of 4 or 5—are more likely to be caring for a spouse than those with less intense caregiving situations (19% vs. 2%).

### **Age of Care Recipient**

Care recipients with Alzheimer's tend to be older than other care recipients (average age 79.2 years vs. 76.6 years). One-fourth of the care-recipients with Alzheimer's are 50 to 74 years old (25%) and three-fourths are 75 years or older (74%). By contrast, among those who do not have Alzheimer's, only 61% are 75 years or older. [See Figure 3.]

Older Alzheimer's caregivers tend to take care of older care recipients. Specifically, caregivers over the age of 50 take care of someone who is, on average, 82 years of age, compared to 76 years of age for younger caregivers.

## LIVING ARRANGEMENTS

Most of the Alzheimer's caregivers live close to their care recipient—25% live in the same household and an additional 54% live within 20 minutes of their care recipient. Only one in ten lives more than one hour from their care recipient (10%). [See Figure 4.]

A sizable proportion of the care recipients with Alzheimer's live with a family member or friend other than the caregiver (28%). Seventeen percent live alone in their own home, and 16% live in an apartment or retirement community. Nine percent live in a nursing home, 4% live in an assisted living facility, and 1% live in a boarding home or group home. [See Figure 5.]

Caregivers of those with Alzheimer's or mental confusion are more likely to live in the same household as their care recipient than those who care for people with other conditions (25% vs. 19%, respectively). In most of these cases, this living arrangement is established because of the needs of the care recipient (64%). The care recipients with Alzheimer's are also more likely to live in a nursing home (9% vs. 3%), and much less likely to live alone in their own home (17% vs. 33%).

## HEALTH CONDITION OF CARE RECIPIENTS

Four in ten Alzheimer's caregivers name Alzheimer's or mental confusion as the main illness or problem their care recipient has (43%). Eleven percent name stroke as the main problem, 7% say the main problem is aging, and 6% each name mental/emotional illness or immobility. Five percent each name cancer or heart disease. No other illness is named as the main one by more than 3% of the Alzheimer's caregivers.

One in four Alzheimer's care recipients who do not live alone or with their caregiver live in a special facility where they receive care for Alzheimer's or mental confusion (28%).

As expected, nearly all caregivers of those with Alzheimer's or mental confusion say the care recipient's condition is long-term in nature (91%). Small percentages say it is short-term (4%) or they do not know (4%).

## INTENSITY OF CAREGIVING

### **Hours of Care Provided**

Alzheimer's caregivers report spending more time providing care each week than do non-Alzheimer's caregivers (an average of 17.6 hours vs. 11.8 hours, respectively). Many Alzheimer's caregivers report providing more than 40 hours of care each week (27% compared to 14% of non-Alzheimer's caregivers). On the other hand, most non-Alzheimer's caregivers provide care for 8 hours or less per week (51% vs. 35%). [See Figure 6.]

Younger Alzheimer's caregivers tend to spend less time giving care than older Alzheimer's caregivers. Specifically, 44% of caregivers ages 18 to 49 spend eight hours or less giving care each week, compared to 29% of those ages 50 to 64 and 18% of those 65 years or older. Over half of the caregivers ages 65 or older give 41 or more hours of care per week (61%).

### **Activities of Daily Living**

Nearly seven out of ten Alzheimer's caregivers help their care recipient with at least one Activity of Daily Living, or ADL (69%). The activities considered ADLs are getting in and out of beds and chairs, dressing, getting to and from the toilet, bathing, dealing with continence or diapers, and feeding. Specifically, one-fourth helps with one or two ADLs (28%), one-fifth helps with three or four ADLs (20%), and another fifth helps with five or six (21%).

The ADLs with which Alzheimer's caregivers most often help their care recipient are dressing and helping him/her get in and out of beds and chairs (45% each). Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to perform each of the ADLs asked about. In fact, they are more than twice as likely to feed their care recipient (33% vs. 15%, respectively) or deal with continence or diapers (25% vs. 10%). [See Figure 7.]

### **Instrumental Activities of Daily Living**

Nearly all Alzheimer's caregivers perform at least one Instrumental Activity of Daily Living, or IADL, for their care recipient (98%). In this, they are not different from other caregivers, nearly all of whom also perform IADLs. However, Alzheimer's caregivers are more likely to perform a greater number of IADLs—75% perform at least four IADLs compared to 65% of non-Alzheimer's caregivers.

All of the IADLs asked about are performed by a majority of Alzheimer's caregivers: helping with transportation (81%), housework (76%), grocery shopping (73%), preparing meals (70%), arranging outside services (68%), managing finances (67%), and giving medicines (52%). Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to help with meals, outside services, finances and medicines. [See Figure 8.]

The Alzheimer's caregivers who say they provide most of the care themselves, and those who live with the care recipient are more likely to perform nearly every one of the IADLs; on average, they perform six of them while their counterparts perform four.



## **Instruction on Performing Caregiving Activities**

Alzheimer's caregivers are equally as likely as non-Alzheimer's caregivers to have been taught to perform any of the ADLs or to give medication. About four in ten of each group report having been taught how to do one or more of these tasks (38% and 42%, respectively).

## **Level of Care Index**

Taking into account both the number of hours that the respondents spend giving care and the types of caregiving activities they perform, it is clear that Alzheimer's caregivers have caregiving experiences that are more involved or more intense. They are twice as likely as non-Alzheimer's caregivers to have a Level 5 care experience (23% vs. 10%), and half as likely to have a Level 1 experience (19% vs. 38%). [See Figure 9.]

As the age of Alzheimer's caregivers increases, so does the intensity of the caregiving situation as measured by the Level of Care Index. Along these lines, 73% of caregivers ages 65 or older are Levels 4 and 5, compared to roughly half as many young caregivers ages 18 to 49 (38%).

## **MEDICATION MANAGEMENT**

While only 15% of non-Alzheimer's caregivers report that their care recipient has trouble taking medications as directed, half of Alzheimer's caregivers report that theirs has some trouble (51%). [See Figure 10.]

Of those Alzheimer's caregivers who give medicines, pills or injections, all report knowing how to administer the medicines as prescribed, that is, on time and in the right amount (100%). Nearly all know what each medicine is for (94%), and most claim to know the possible side effects of each medicine (81%) and how the medicines may react with one another (74%). They are slightly more knowledgeable than non-Alzheimer's caregivers in giving the medicines as prescribed, and knowing the interactions of the medications.

Among those who give medicines to their care recipients, Alzheimer's caregivers are slightly more likely than non-Alzheimer's caregivers to have problems, at times, giving the medicines (34% vs. 25%). Alzheimer's caregivers are also more likely to consult someone—typically a doctor or a pharmacist—about a medicine that was prescribed (85% vs. 73%).

Among the Alzheimer's caregivers who help with medicines, three subgroups are more likely to know possible side effects of medicines and how they may interact with one another: those in Level 4 and 5 situations, those who provide most of the care, and females. White Alzheimer's caregivers are more likely than minority Alzheimer's caregivers to have consulted someone, typically a doctor or pharmacist, about a medicine that was prescribed for their care recipient (90% vs. 69%).

## CAREGIVER SUPPORT: WHO ALSO HELPS PROVIDE CARE

Four in ten Alzheimer's caregivers consider themselves to be the person who provides most or all of the care for their care recipient (43%). An almost equal number say someone else provides most of the care (38%), and the remaining two in ten say the care is split about 50-50 with someone else (19%). [See Figure 11.]

Level 4 and 5 Alzheimer's caregivers are more than three times as likely as caregivers in less intense situations to report being the one who provides most of the care. Those who have household incomes of less than \$30,000, female caregivers, caregivers who are retired or not employed, and those who live with the care recipient are also much more likely to say they provide most of the care.

Alzheimer's caregivers are a little more likely than non-Alzheimer's caregivers to say that no one else provides unpaid help to their care recipient (22% vs. 17%). Nevertheless, nearly three-quarters report that one of the care recipient's relatives is also providing unpaid help (74%). One-third specifically mentions a daughter (35%), one-fifth mentions a son (21%), and 12% each mention a spouse or a granddaughter. Nine percent say someone who is not a relative also provides unpaid care. [See Figure 12.]

Of those who report that other relatives help with caregiving, only 60% of Alzheimer's caregivers believe that the other relatives are doing their fair share of the caregiving. By contrast, non-Alzheimer's caregivers who share responsibilities with other relatives are more likely to feel the situation is fair (73%). Alzheimer's caregivers are also more likely to report some level of family conflict over the caregiving (37% vs. 24%). [See Figure 13.]

The Alzheimer's caregivers who work full-time and those who are young (ages 18 to 49) are more likely to feel that other relatives are not doing their fair share of the caregiving. They are also more likely to report some level of family conflict over caregiving.

## PHYSICAL, EMOTIONAL AND FINANCIAL STRAIN AND STRESS OF CAREGIVING

Caring for someone with Alzheimer's seems to have a greater negative impact on one's personal life than caring for someone with other conditions. Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to report that they have less time for their family members than they did before (56% vs. 40%). They are also more likely to have given up vacations, hobbies or their own activities (53% vs. 40%). Alzheimer's caregivers are almost twice as likely to report suffering physical or mental health problems themselves as a result of their caregiving (23% vs. 12%). [See Figure 14.]

As one might expect, Alzheimer's caregivers in intense caregiving situations are more likely to report each of these three signs of impact on their personal life than those with less intense caregiving situations. So are the caregivers who report giving most of the care themselves, those who live with the care recipient, and female caregivers.

One in five Alzheimer's caregivers reports a high degree of physical strain from their caregiving, with 21% rating their strain as a 4 or 5 on a 5-point scale—more than twice as many as non-Alzheimer's caregivers (8%). [See Figure 15.]

Alzheimer's caregivers are also twice as likely to report a high level of emotional stress due to their caregiving (43%) than non-Alzheimer's caregivers (20%). [See Figure 16.]

Several subgroups of Alzheimer's caregivers are more likely to report a high physical strain and a high level of stress: Level 4 and 5 caregivers, those who are retired or not-employed, women, those who provide most of the care, and those who live with the care recipient.

Alzheimer's caregivers tend to report a higher level of financial strain—12% describe that strain as high, compared to 5% of non-Alzheimer's caregivers. Interestingly, this is the case even though—excluding those who care for a spouse—the amount they actually spend is not significantly different from the amount non-Alzheimer's caregivers spend. Excluding the four in ten who say they do not spend any of their own money on the care recipient, Alzheimer's caregivers report spending \$152 per month compared to \$177 per month for non-Alzheimer's caregivers.

Those with more intense caregiving experiences are more likely to report spending some of their own money on the care recipient than those with less intense experiences (56% for Level 4 to 5 vs. 41% for Level 1 to 3). Those who spend also tend to spend a greater amount (\$197 per month vs. \$106 per month). Similarly, those who live with their care recipient (excluding spouses) are more likely to report spending their own money compared to those who live apart (54% vs. 42%), and if they do spend, to report spending more (\$261 per month versus \$192 per month). Minority Alzheimer's caregivers are more likely to spend some of their own money on the care recipient than white caregivers (55% vs. 43%). All the subgroups which spend more on their care recipients are also more likely to report feeling a high level of financial hardship as a result of their caregiving.

### **DEALING WITH STRESS: COPING BEHAVIOR**

Alzheimer's caregivers use a variety of coping strategies. By far the most common strategies are prayer and talking with friends or relatives, each used by eight in ten Alzheimer's caregivers (81% and 79% respectively). Just under half cope sometimes by doing hobbies (46%). Alzheimer's caregivers are more likely than non-Alzheimer's to use each of these strategies. They are also more likely to get help from a counselor or other professional (22% vs. 14%). [See Figure 17.]

Alzheimer's caregivers are about as likely as non-Alzheimer's caregivers to use several other coping strategies. About four in ten use exercise to cope (39%), 9% percent report using medications, and 5% say they use alcohol.

Among the Alzheimer's caregivers, those with more intense caregiving experiences and those who report providing most of the care are more likely to report trying several of the coping behaviors, including talking to friends or relatives, getting help from a professional, using medication, praying, exercise and hobbies.

### **BIGGEST DIFFICULTY AND GREATEST REWARD OF CAREGIVING**

Two difficulties of providing care top the list of those named by Alzheimer's caregivers: seeing the progressive deterioration of the care recipient (22%), and the demands on their time or not being able to do what they want to (20%). Twelve percent say the care recipient's attitude or uncooperative manner is the biggest difficulty. Eight percent say the responsibility of making sure s/he is being cared for is most difficult. [See Figure 18.]

As might be expected, Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to mention the difficulty of witnessing the deterioration (22% vs. 12%). Among Alzheimer's caregivers, those in Level 4 and 5 situations are more likely to mention this than those in less intense situations (26% vs. 18%). Those who are employed full-time are more likely to mention demands on their time than those who are not employed (28% vs. 16%).

The biggest reward felt by Alzheimer's caregivers is personal satisfaction or the sense of doing a good deed (16%). Many cite the care recipient's appreciation or happiness (15%) or knowing that the care recipient is well cared for (13%). Ten percent each mention rewards such as watching the care recipient's health improve, giving back or family loyalty, or feelings of love or friendship with the care recipient.

## **WORDS CAREGIVERS USE TO DESCRIBE THE CAREGIVING EXPERIENCE**

A majority of Alzheimer's caregivers (53%) describe the caregiving experience in positive terms, such as rewarding (17%), good (10%), thankful (5%) and loving (4%). Thirty percent use a negative term such as obligation (9%), tiring (5%), burdened (4%) or frustrated (4%) to describe the experience. A larger proportion of non-Alzheimer's caregivers—nearly two-thirds—use a positive adjective to describe the experience (65%).

## **USE OF SUPPORTIVE SERVICES**

Alzheimer's caregivers avail themselves of an average of three of the ten types of supportive services examined in this survey. They are more likely than non-Alzheimer's caregivers to use at least one of the services (83% vs. 71%) and more likely to use five or more (19% vs. 9%). In fact, the only specific services that non-Alzheimer's caregivers mention as often as Alzheimer's caregivers are transportation and housework.

Over half of Alzheimer's caregivers have obtained assistive devices such as wheelchairs or walkers for their care recipient (57%). A similar number have used a personal care or nursing service (53%), however the Alzheimer's caregivers who have used such a service are less likely than non-Alzheimer's caregivers to say it fully meets their needs (61% vs. 73%). [See Figure 19.]

Four in ten Alzheimer's caregivers have had modifications made to the home (40%). They are most likely to report having these done by a private agency for which they paid, rather than by family, friends, or volunteers who most commonly do the home modifications for non-Alzheimer's caregivers.

Other services are each used by fewer than one-fourth of Alzheimer's caregivers. Twenty-three percent have used respite services, 22% have used outside meal delivery services, 20% have requested information about how to get financial help for their care recipient.

Slightly fewer have enrolled their care recipient in a senior center or adult day care program (18%), used transportation services (17%), used housework services (14%), or taken part in a support group for caregivers (12%).

The large majority of Alzheimer's caregivers who do not use a particular supportive service say it is because they have no need for it. Nevertheless, for six of the ten services asked about, they are less likely than non-Alzheimer's caregivers to explain their lack of usage in this way. The reasons Alzheimer's caregivers do offer in explanation of their lack of usage of these six services do not follow any pattern. For personal nursing care and transportation services, they are more likely to say they were not aware of the service; for support groups, they are more likely to say they were too busy; for adult daycare, they are more likely to say the service is not available; for housework, they are more apt to say they do not want strangers coming in; and for respite care, no reasons stood out as different from those of non-Alzheimer's caregivers. For two of the other services, the Alzheimer's caregivers who do not use them are also more likely to say the non-use is due to lack of awareness of the services, although, typically, very few give that reason.

Level 4 and 5 Alzheimer's caregivers are more likely than those in less intense situations to use many of the supportive services, including asking for financial help, support groups, respite services, home modifications, personal or nursing care services, and assistive devices.

### **UNMET NEEDS FOR HELP, INFORMATION, OR SUPPORT IN CAREGIVER ROLE**

When Alzheimer's caregivers are asked what kinds of help, information or support they would use in their situation, more than one in ten each mention extra money to help pay for things, and free time or a break for themselves (12% and 11%, respectively). They are twice as likely as non-Alzheimer's caregivers to mention these. [See Figure 20.]

They mention having someone to talk to or counseling next most often (8%), followed by help with housekeeping (7%), help with bathing, dressing or grooming (5%), and someone to check on things (4%).

### **IMPACT OF CAREGIVING ON WORK**

The majority of Alzheimer's caregivers have been employed at some time since they began their role as caregiver (72%), but employment is still slightly more common among non-Alzheimer's caregivers (78%). Among Alzheimer's caregivers who have worked, 57% say they have had to go in late, leave early or take time off during the day to provide care at least once. By comparison, only 47% of non-Alzheimer's caregivers have had to do so. Alzheimer's caregivers are also more likely than non-Alzheimer's caregivers to have reduced from full-time to part-time work, or to have taken a less demanding job (13% vs. 6%). A greater proportion of Alzheimer's caregivers also report choosing early retirement (7% vs. 3%) or having to turn down a promotion (6% vs. 2%). Similar proportions of Alzheimer's caregivers and non-Alzheimer's caregivers have had to take a leave of absence (10% vs. 11%), have lost some of their job benefits (6% vs. 4%), or have had to give up work entirely (10% vs. 6%). [See Figure 21.]

Among Alzheimer's caregivers, those in intense caregiving situations are more likely than those in less intense situations to report each of these effects at the workplace.

Two-thirds of Alzheimer's caregivers rate their employer as "very understanding" toward the demands of their caregiving (68%). An additional 15% say their employer is "somewhat understanding," 7% say the employer is "not very understanding," and 4% say the employer is not aware of the situation. [See Figure 22.]



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