

# DEMENTIA CAREGIVING IN THE U.S.



## **ACKNOWLEDGEMENTS**

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# **Dementia Caregiving in the U.S.**

National Alliance for Caregiving,  
in partnership with the Alzheimer's Association

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# Executive Summary

## Key Findings

This report analyzes the experiences of providing unpaid care in the United States to a relative or friend diagnosed with Alzheimer's disease, dementia, or other mental confusion, with the goals of both understanding the experiences of people caring for someone with dementia and identifying approaches to enhance and support this unique caregiving experience.

We draw our analyses from the nationally representative study *Caregiving in the U.S. 2015* and examine caregivers who indicate that their care recipient had Alzheimer's disease, dementia, or some other type of mental confusion as either a primary or a secondary reason for providing care. This paper describes the experiences of these caregivers (n=372, referred to hereafter as *dementia caregivers*) and compares their experiences with those of caregivers who provided care to someone without dementia (n=963, referred to hereafter as *non-dementia caregivers*). In addition, we analyze subgroups of caregivers within dementia caregivers to better understand variations in experiences of dementia caregiving.

These dementia caregivers have diverse backgrounds. A majority of dementia caregivers are women (58 percent). On average, they are 54 years old—about six years older than non-dementia caregivers. Their care recipient—that is, the person with Alzheimer's disease or dementia—is most often a relative, and 77.2 years old, on average, which is significantly older than other care recipients who are managing other conditions or diseases. These care recipients are less likely to live in their own home (40 percent) and more likely to live in some sort of facility (16 percent live in nursing/long-term care or assisted living).

Dementia caregivers shoulder more caregiving responsibilities than do other caregivers: they help with a wider variety of activities and spend more hours per week providing care. On average, dementia caregivers provide care for 28 hours per week. They assist in significantly more tasks than do other caregivers, including more Activities of Daily Living (ADLs) and more Instrumental Activities of Daily Living (IADLs). In addition, most dementia caregivers play an important role in guiding their loved one through the healthcare system and ensuring that they receive needed treatments. Moreover, two out of three dementia caregivers (67 percent) say they themselves perform medical/nursing tasks<sup>1</sup> for their care recipient, and more than half of all dementia caregivers do these medical/nursing tasks with no prior training or preparation.

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<sup>1</sup> Medical/nursing tasks include skilled activities such as administering injections, tube feedings, catheter and colostomy care, and many other complex medical responsibilities. For additional work on these tasks, see: S.C. Reinhard, C. Levine, and S. Samis, "Home Alone: Family Caregivers Providing Complex Chronic Care," AARP Public Policy Institute & United Hospital Fund, 2012.

Considering all of the responsibilities that dementia caregivers often shoulder, it is of no surprise that the Burden of Care Index<sup>2</sup> shows them as one of the more burdened groups of caregivers. Nearly half of dementia caregivers are in a high-burden situation. Dementia caregivers are not *the* most-burdened group—for example, cancer caregivers are more likely to be in high-burden care relationships (62 percent).<sup>3</sup> However, whereas cancer caregiver relationships are short and episodic, dementia caregiver relationships tend to be longer: nearly seven in ten (69 percent) dementia caregivers have provided care for more than a year, and three in ten have provided care for more than five years.

This high burden of care over a longer period can take a significant mental and physical toll on dementia caregivers. Nearly half of dementia caregivers say providing care is emotionally stressful, and three in ten say that providing care often involves physical strain. Ultimately, this physical and emotional stress appears to have a negative impact on the health of many dementia caregivers. About four in ten (42 percent) say their health is “excellent” or “very good”—statistically significantly lower than the share among non-dementia caregivers (50 percent). Alarming, dementia caregivers are nearly twice as likely to say that their health has gotten worse as a result of their caregiving responsibilities. More than one in three dementia caregivers says their health has declined (35 percent), versus just one in five non-dementia caregivers.

Many dementia caregivers report that they receive help. Dementia caregivers, more than non-dementia caregivers, are often one part of a larger care team, and they receive more paid and unpaid assistance than non-dementia caregivers. Four in ten dementia caregivers are the sole unpaid caregiver for their loved one. Nearly half of dementia caregivers say their loved one has received help from aides, housekeepers, or other paid help (45 percent), including 43 percent of sole unpaid dementia caregivers. More than one in four has used a respite service (27 percent). However, not all dementia caregivers can find resources when they need them: 28 percent say they find it difficult to get affordable services in their loved one’s community.

Six in ten dementia caregivers were employed in the last year while they provided care to their loved one. Employed dementia caregivers work an average of 34.9 hours per week while caregiving, and more than half (57 percent) work full time. Seven in ten employed dementia caregivers (70 percent) say their supervisor was aware of their caregiving situation. Nonetheless, many employed caregivers struggle to balance their job and their caregiving responsibilities. Two in three employed dementia caregivers report that their caregiving responsibilities affected their work in some way (statistically significantly higher than the 59 percent of non-dementia caregivers).

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<sup>2</sup> “Burden of Care” is an index that is based on the number of hours of care provided by the caregiver, the number of ADLs performed, and the number of IADLs performed. Points are assigned for each of them; ultimately, these points are consolidated into three burden categories: low (values 1–2), medium (3), and high (values 4–5). See *Caregiving in the U.S. 2015* Appendix B, Detailed Methodology for the details of creating the index ([www.caregiving.org/caregiving2015](http://www.caregiving.org/caregiving2015)).

<sup>3</sup> G.G. Hunt, C.G. Whiting, M.L. Longacre, L. Weber-Raley, and L. Popham, “Cancer Caregiving in the U.S.—An Intense, Episodic, and Challenging Care Experience,” National Alliance for Caregiving, National Cancer Institute, and Cancer Support Community, 2016.



Dementia caregivers want greater support from healthcare professionals. Many dementia caregivers want more support from healthcare providers in caring for their loved one as well as themselves. Less than half of dementia caregivers (44 percent) report having a doctor, nurse, or social worker *ever* ask them what they need to care for their loved one. Moreover, roughly a quarter (24 percent) of dementia caregivers have *ever* been asked about their own self-care needs by a doctor, nurse, or social worker. About the same number (26 percent) report wanting these kinds of self-care conversations, but say they have never had them. This suggests that the need or desire for self-care conversations between healthcare professionals and dementia caregivers is greater than the *actual occurrence* of these conversations.

Many want more information on specific aspects of providing care. More than half (52 percent) of dementia caregivers say they need more help and information about managing their own emotional and physical stress. In addition to managing stress, 39 percent say they need help and information about keeping their loved one safe at home. Dementia caregivers are *more than four times more* likely to say they need help managing their loved one's challenging behavior and are nearly *three times more* likely to want help managing incontinence.

Many dementia caregivers want to be kept more involved in their loved one's medical care. More than half would find it helpful to require health providers to include their name on their care recipient's chart (56 percent). One out of four (27 percent) has never made use of respite care but wants to do so. This indicates that there is a need among some dementia caregivers for easily accessible respite services.

In summary, dementia caregivers are in intensive, demanding care situations. While they do have more support from other unpaid caregivers, paid help, and the healthcare system than do non-dementia caregivers, many remain in need of greater support and resources.

## Policy Implications

With unique challenges facing dementia caregivers, we recommend the following:

### **Establish a National Strategy that Recognizes and Supports Family Caregivers**

Family caregivers are the backbone of the long-term care system, especially for those with dementia. They take on challenges that affect their health, emotional wellbeing, and financial security. All too often, family caregivers are not recognized and included in appropriate health and social service programs, and ultimately not receiving the care and support they need. Dementia caregivers shoulder more caregiving responsibility than other caregivers do: they help with a wider variety of activities and spend more hours per week providing care.

The recently released *Families Caring for an Aging America*, conducted by the National Academies of Sciences, Engineering and Medicine, includes a recommendation that the new Administration develop and execute a National Family Caregiver Strategy.

Although the National Academies' recommendation was focused only on caregivers of older adults, we believe that the National Family Caregiver Strategy should address the needs of all caregivers across the lifespan.

### **Provide Dementia Caregivers with a Comprehensive Needs Assessment**

Less than half of dementia caregivers (44 percent) report having a doctor, nurse, or social worker *ever* ask them what they need to care for their loved one. Moreover, only one-quarter (24%) of dementia caregivers have *ever* been asked what assistance they need for self-care. Similar to a patient, dementia caregivers require a comprehensive assessment prior to the development of the care plans. A caregiver assessment will serve as an entry point to understanding what a care plan will need to include to ensure patient and family centered goals are met.

### **Protect the Financial Security of Dementia Caregivers**

The inordinate amount of time they spend providing care—28 hours per week on average—leaves dementia caregivers at a disadvantage as they attempt to maintain employment. To most effectively balance their job and caregiving responsibilities, caregivers need employers to provide paid and flexible family and medical leave options. This must include at least partial income during the time they spend away from work due to caregiving obligations. Previously, legislation was introduced in Congress that would provide workers with up to 12 weeks of partial income when they take time away from work to care for themselves or a loved one. It is essential to protect the financial security of dementia caregivers by providing them with options for paid-leave.

Over half (57 percent) of dementia caregivers work part-time. On average, they work only 34.9 hours per week. Not only does this loss of income have a negative impact on their take-home pay, it also hinders their ability to adequately save for retirement. Dementia caregivers need a refundable tax-credit to help reduce the financial burden of providing care. Additionally, these caregivers need social security earnings credits to ensure that their retirement security is not jeopardized due to their caregiving role.

### **Expand Dementia Caregiver Access to Long-Term Supports and Services**

Dementia caregivers are often managing multiple health and behavioral conditions. In addition, most dementia caregivers play an important role in guiding their loved one through the healthcare system and ensuring that they receive the treatments they need. Health care providers need to be incentivized to offer advance care planning assistance for those diagnosed with dementia and their caregiver(s). Advance care planning benefits help caregivers make informed decisions while managing the complexity of care and may help to prevent care recipients from prematurely entering into long-term care programs.

Over half (52 percent) of dementia caregivers say they need more help and information about managing their own emotional and physical stress. The Centers for Medicare and Medicaid Services should test support models for caregivers, recognizing that support

for caregivers will help care recipients remain in the home longer, ultimately reducing Medicare and Medicaid program costs. Support models should include options for individual and family counseling, caregiver support groups, and a call-in phone line offering immediate assistance for dementia caregivers.

One out of four (27 percent) dementia caregivers has never made use of respite care, but wants to do so. This indicates that there is a need among dementia caregivers for easily accessible support services. Strengthening federal programs that help sustain family caregivers can bolster our Long-Term Supports and Services system. The federal government provides high-impact support for family caregivers through the National Family Caregiver Support Program, the Department of Veterans Affairs' VA Caregiver Support Program, and the Lifespan Respite Program. These programs include relief, education, training, and financial support to family caregivers. It is vital that efforts are made to expand these programs.

### **Include Dementia Caregivers as Vital Members of the Health Care Team**

Dementia caregivers want to be involved in their loved one's medical care. Health care policy should explicitly and clearly include family caregivers in all aspects of care planning for those with dementia. Family caregivers are an essential component of the patient and family-centered care model. Meanwhile, over half of all dementia caregivers perform medical/nursing tasks with no prior training or preparation. Family caregivers must be recognized and included as legitimate members of health care intervention teams. The Alliance applauds state efforts through the CARE Act to achieve these goals.

# Full Report

## Introduction

This report reviews the experiences of providing unpaid care<sup>4</sup> in the United States to a relative or friend diagnosed with Alzheimer's disease or dementia. Our analyses come from the study *Caregiving in the U.S. 2015* and examine caregivers who indicated that one of the reasons why this family member or friend needed care was due to Alzheimer's disease, dementia, or other mental confusion.<sup>5</sup> These caregivers are hereafter referred to as *dementia caregivers*. This paper describes the experiences of these dementia caregivers and compares them with those of caregivers who provide care to an adult family member or friend who does not have dementia (hereafter referred to as *non-dementia caregivers*). In select places, this paper also summarizes differences *within* the experiences of dementia caregivers by key subgroups.

## Methodology

*Caregiving in the U.S. 2015* is a nationally representative study of adults, ages 18 and older, conducted in late 2014 using GfK's probability-based online KnowledgePanel®. *Caregiving in the U.S. 2015* aimed to achieve two goals for the National Alliance for Caregiving and AARP Public Policy Institute. First: estimate the prevalence of caregiving for someone of any age as a share of both the U.S. population and U.S. households. Second: describe the characteristics, roles, and needs among caregivers who provide care to an adult age 18 or older.<sup>6</sup>

In order to qualify for the study, respondents must have self-identified as an unpaid caregiver of an adult either currently or at some point in the 12 months prior to the survey. Self-identified caregivers also had to report providing help with at least one Activity of Daily Living (ADL), Instrumental Activity of Daily Living (IADL), or medical/nursing task. Surveys were conducted between September 18 and November 5, 2014, and averaged 24 minutes to complete (23.8 minutes online; 24.7 minutes on the phone).

*Caregiving in the U.S. 2015* finds that, among a nationally representative sample of caregivers of adults, 22% provide care to someone with Alzheimer's or dementia. This paper examines the responses of 372 dementia caregivers and 963 non-dementia

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<sup>4</sup> In order to qualify for this study, caregivers had to self-identify as providing unpaid care to a family member or friend in the 12 months leading up to the time of survey; those who were paid in some way to provide care were ineligible to complete this study.

<sup>5</sup> Dementia caregivers include two groups: (1) those who indicated their care recipient's *main* problem for which he or she needed care was Alzheimer's disease or dementia; and (2) those who indicated their care recipient had Alzheimer's disease, dementia, or other mental confusion but it was not the main caregiving issue.

<sup>6</sup> To see complete study results, questionnaires, or detailed study methodology, please see *Caregiving in the U.S. 2015* full report and Appendices A and B.

caregivers.<sup>7,8</sup> For more information about the prevalence of dementia caregiving, the samples used for this paper, and weighting strategies, please see Detailed Methodology (page 38).

## Reading This Report

All demographic information about caregivers refers to their current situations if currently caregiving, or to when they last provided care if not currently serving as a caregiver (but served in the past 12 months).

All figures have been weighted and rounded. In addition, "don't know" or "refused to answer" responses are not always presented in charts and tables; therefore, some charts and tables will not total 100 percent. The results for multiple-response questions may total more than 100 percent.

The sample sizes (n) noted in each table or graphic represent the unweighted number of respondents who answered each question. All results were tested for statistical significance at the 95 percent confidence level using the appropriate test, depending on the result presented.<sup>9</sup> All differences between dementia caregivers and non-dementia caregivers discussed in the text are statistically significant. In all tables and graphs, a notation of \* shown on a result indicates that the value is statistically significantly higher than that of the comparison group.

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<sup>7</sup> Four in ten dementia caregivers (38 percent) say that this Alzheimer's disease, dementia, or mental confusion is the main reason their loved one needed their care. The remaining 62 percent said that there was another primary issue in addition to the Alzheimer's disease, dementia, or mental confusion, including "old age" (15 percent), mental or emotional illness (6 percent), and mobility issues (5 percent). For brevity, this paper uses the term *dementia caregivers* to refer anyone caring for someone with Alzheimer's disease, dementia, or mental confusion regardless of whether the condition is the main reason for which the recipient is receiving care.

<sup>8</sup> The most common main reasons for care among non-dementia caregivers include old age or frailty (13 percent), surgery or wounds (10 percent), mobility issues (8 percent), cancer (7 percent), and diabetes (5 percent).

<sup>9</sup> Statistical testing applied to comparison of dementia caregivers and non-dementia caregivers were: Independent T-Test for Means with assumption of equal variances and Independent Z-Test for Percentages with assumption of unpooled proportions.

## Detailed Findings

### Who Are Dementia Caregivers?

A majority of dementia caregivers are women (58 percent). They are 54 years old, on average—about six years older than non-dementia caregivers. Two in three are 50 or older (66 percent), and one in four is 65 or older (25 percent); both figures are significantly higher than those for non-dementia caregivers (49 percent and 18 percent, respectively).

**Figure 1: Age of Caregiver**

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
18 to 34	16%	26%*
35 to 49	17%	25%*
50 to 64	41%*	31%
65 to 74	16%*	11%
75 or older	10%	7%
Mean age	53.9*	48.1
Median age	55.0	49.0

Among all dementia caregivers, about two in three are non-Hispanic whites, six in ten have less than a college degree (61 percent), and the median household income for a dementia caregiver is about \$58,200 per year, which is close to the median household income in the United States.<sup>10</sup>

### Who Are Millennial (Ages 18–34) Dementia Caregivers?

- ❖ Care for a grandparent (44 percent) or parent (26 percent) who typically lives in his or her own home (57 percent)
- ❖ Care recipient is 71 years old, on average, (significantly younger than dementia caregivers from older generations)
- ❖ Provide 18.5 hours of care weekly (significantly less than dementia caregivers from older generations)
- ❖ Perform 1.9 ADLs and 4.3 IADLs, on average
- ❖ 57 percent do medical/nursing tasks
- ❖ 38 percent are the sole unpaid caregiver for loved one

<sup>10</sup> For a full demographic profile of dementia caregivers included in this analysis, including a comparison to non-dementia caregivers, see Figure 30 (Demographic Summary by Caregiver Type) at the end of the report.



Most are providing care to a family member; more than half provide care to a parent or parent-in-law (53 percent). More than one in ten provides care for a spouse. One in ten provides care for a grandparent or grandparent-in-law, a figure significantly higher than the share among non-dementia caregivers. While most care for a family member or relative, one in nine cares for a non-relative—most commonly a friend or neighbor.

**Figure 2: Care Recipient Relation**  
Q7: Who are you caring/did you care for?

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
<b>Relative</b>	<b>88%</b>	<b>84%</b>
Parent	42%	42%
Spouse/partner	12%	13%
Parent-in-law	11%*	6%
Grandparent/in-law	10%*	6%
Child	4%	5%
Aunt/Uncle	4%	4%
Sibling	3%	4%
Other relative	3%	5%
<b>Nonrelative</b>	<b>12%</b>	<b>16%</b>
Friend	7%	10%
Neighbor	3%	3%
Other nonrelative	2%	3%

While most dementia caregivers provide unpaid care to only their loved one with dementia (82 percent), one in six (18 percent) is providing unpaid care to at least one other adult as well. Moreover, one in four dementia caregivers (26 percent) has a child or grandchild under the age of 18 living in their home, suggesting an additional level of care responsibility.

### Who Are Grandchildren Caring for a Grandparent with Dementia?

- ❖ Grandparent is 82.1 years old, on average, and typically lives in his or her own home (62 percent)
- ❖ Provide 14.3 hours of care weekly (significantly less than dementia caregivers generally)
- ❖ 42 percent have been caring for less than a year
- ❖ 47 percent have low burden of care
- ❖ 31 percent are the sole unpaid caregiver for loved one
- ❖ 32.6 years old, on average
- ❖ 67 percent are

## Who Are Dementia Care Recipients?

Like their caregivers, dementia care recipients are typically women (67 percent) and tend to be significantly older than other care recipients. Dementia care recipients are five years older, on average, than non-dementia care recipients.

**Figure 3: Age of Care Recipient**  
*Q5: How old is/was this adult at the time you provided care?*

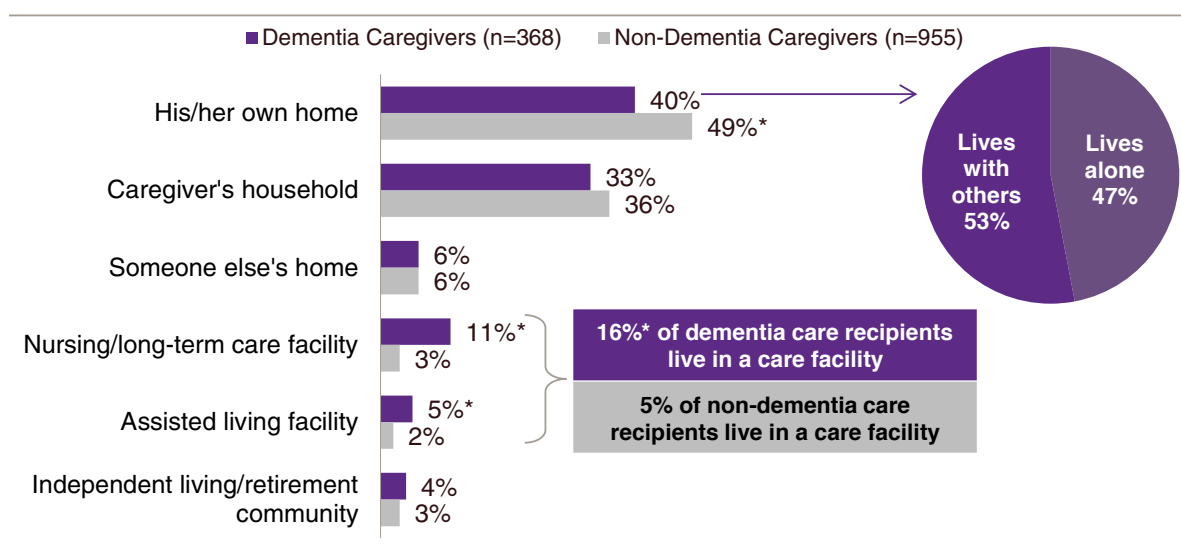
	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
18 to 64	16%	38%*
65 to 74	14%	20%*
75 to 84	33%*	23%
85 to 89	20%*	10%
90 or older	17%*	8%
Average age	77.2*	67.3

More than a third of dementia care recipients are 85 or older (37 percent), double the share of non-dementia care recipients (18 percent). Dementia caregivers caring for the “oldest old” (age 85+) are more likely to have paid assistance from aides or housekeepers (57 percent) than do other dementia caregivers (39 percent). However, there are few other significant differences between the two groups; notably, ADLs/IADLs, emotional stress, physical strain, health, and recipient living situation are similar no matter the age of the dementia care recipient. This suggests that the increased dementia caregiver burden relates more to the demands of caring for someone with Alzheimer’s or dementia than to the advanced age of the care recipient.

Four in ten dementia caregivers say their loved one lives in his or her own home, with nearly half (47 percent; see Figure 4) of that number living alone. One in three dementia caregivers says their care recipient lives with them in the caregiver’s household. Meanwhile, one in seven cares for a loved one who lives in a long-term care or assisted living facility— nearly three times the rate among non-dementia caregivers.

### Figure 4: Where the Care Recipient Lives

Q11. Where does/did your [relation] live at the time you provided care?  
Q13. Which of the following best describes where your [relation] lives/lived at the time you provided care?



Dementia caregivers tend to live within 20 minutes of their loved one (72 percent, including those that co-reside). About one in seven (15 percent) lives between 20 minutes and an hour away, and 12 percent live more than an hour away.

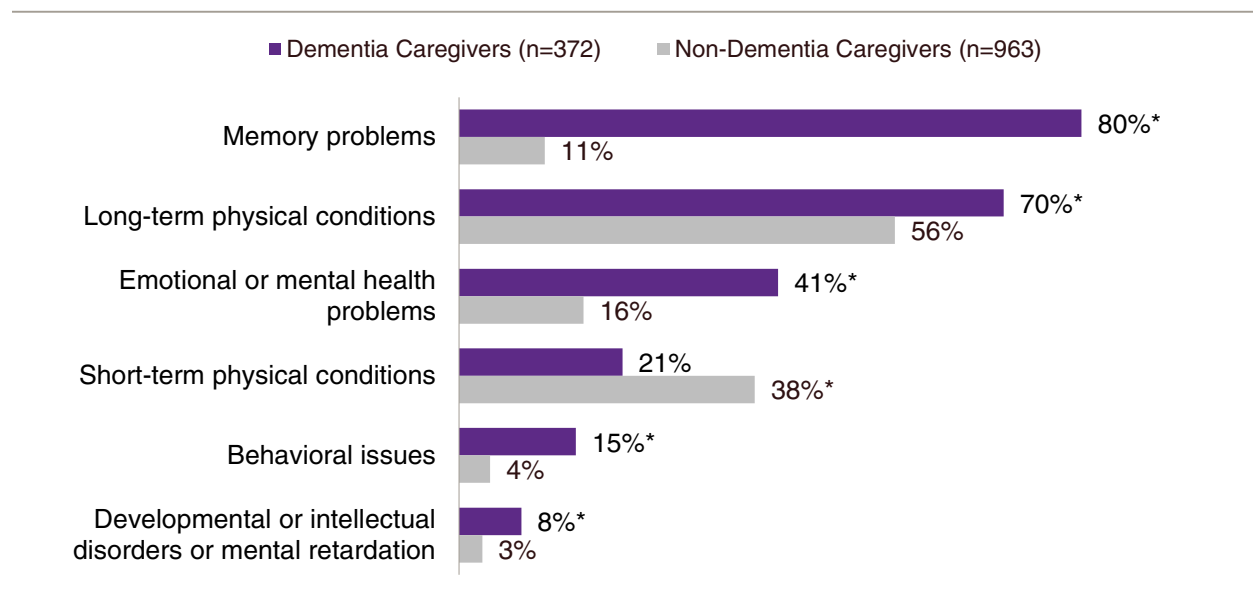
### Who Are Long-Distance (Greater Than One Hour Away) Dementia Caregivers?

- ❖ Caring for parent (68 percent) who is 80 years old, on average
- ❖ Recipient typically lives in his or her own home (53 percent) or some care facility or community (31 percent)
- ❖ Provide 17.7 hours of care weekly (significantly less than dementia caregivers who live closer)
- ❖ 59 percent report high levels of emotional stress
- ❖ 51 years old, on average
- ❖ Employed while caregiving (64 percent)
- ❖ Significantly higher education and income than dementia caregivers who live closer: 67 percent have

## Dementia Caregivers Report Caring for More Conditions

Dementia caregivers tend to classify their loved one's problems as multifaceted and often as being physical, emotional, or behavioral in nature. Dementia caregivers are significantly more likely than non-dementia caregivers to report their loved one requires care not only for memory problems but also for long-term physical conditions, emotional or mental health problems, behavioral issues, or developmental or intellectual disorders (see Figure 5).

**Figure 5: Care Recipient Condition Categories**  
*Q17: Does/did your [relation] ever need care because of a...?*



Three in four dementia caregivers (76 percent) say that their recipient has multiple categories of conditions requiring care, compared with 26 percent of non-dementia caregivers.

## High Demand Caregiving: Hours and Care Tasks

This range of conditions may translate into more difficult care settings for dementia caregivers. In fact, dementia caregivers shoulder more caregiving responsibilities than do non-dementia caregivers: they help with a wider variety of activities and spend more hours per week providing care. The average dementia caregiver provides care for 28 hours per week, about four hours more than a non-dementia caregiver (see Figure 6).

**Figure 6: Hours of Care per Week**

*Q25: About how many hours do/did you spend in an average week helping him/her?*

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
Fewer than 9 hours	39%	48%*
9 to 20 hours	24%	21%
21 to 40 hours	9%	10%
41 or more hours	26%	22%
<i>Average hours of care provided per week</i>	<i>27.8*</i>	<i>23.7</i>

<sup>a</sup> Any caregiver who indicated providing care in excess of 98 hours per week is capped at this level, which is equivalent to 14 hours per day. Caregivers who selected constant care were capped at 77 hours per week, the mean hours of care derived from an imputation model predicting hours of care provided. For more details on mean imputation, see Caregiving in the U.S. 2015 Appendix B, Detailed Methodology.

Dementia caregivers assume a wide range of responsibilities and assist in significantly more tasks than do non-dementia caregivers. Responsibilities of dementia caregivers include helping with Activities of Daily Living (ADLs) such as feeding and dressing, helping with Instrumental Activities of Daily Living (IADLs) such as managing their loved one's finances and household, and advocating for them within the healthcare system. Caregivers also may assist with medical/nursing tasks, such as administering medications or injections, often without prior training.

Dementia caregivers help with more ADLs, on average (2.1 out of 6), than non-dementia caregivers do (1.5, see Figure 7). In particular, dementia caregivers are significantly more likely to help their loved one with more intimate ADLs, including incontinence issues, bathing, and feeding. More than one in ten dementia caregivers (12 percent) report helping with *all six* ADLs—four times the rate among non-dementia caregivers.

**Figure 7: Help with Activities of Daily Living (ADLs)**  
*Q22: Which of these do/did you help your [relation] with?*

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
Get in and out of beds and chairs	45%	43%
Get dressed	38%*	30%
Bathe or shower	34%*	23%
By feeding him or her	33%*	20%
Get to and from the toilet	32%*	25%
By dealing with incontinence/diapers	32%*	12%
<i>Helps with three or more ADLs</i>	<i>38%*</i>	<i>28%</i>
<i>Helps with all six ADLs</i>	<i>12%*</i>	<i>3%</i>
<i>Average number of ADLs</i>	<i>2.1*</i>	<i>1.5</i>

Dementia caregivers are also more likely to say performing ADLs for their loved one is difficult (31 percent versus 20 percent of non-dementia caregivers).<sup>11</sup>

Dementia caregivers also help with significantly more IADLs (see Figure 8, next page). The average dementia caregiver helps with 4.7 of 7 IADLs, compared with 4.1 by the average non-dementia caregiver. Dementia caregivers are significantly more likely to provide transportation, coordinate outside services (such as home-care nurses or Meals on Wheels), and administer medicines or injections. Nearly one in four dementia caregivers (24 percent) helps with all 7 IADLs, more than double the rate of non-dementia caregivers (10 percent). This indicates that a sizable portion of dementia caregivers completely manage their loved one's household in addition to their other care responsibilities.

<sup>11</sup> Difficulty is rating a 4 or 5 on a scale where 1 is "not at all difficult" and 5 is "very difficult" for the question "How difficult is it for you to help your loved one with [ADLs]?"



**Figure 8: Help with Instrumental Activities of Daily Living (IADLs)**  
*Q23: Do/did you provide help to your [relation] with...*

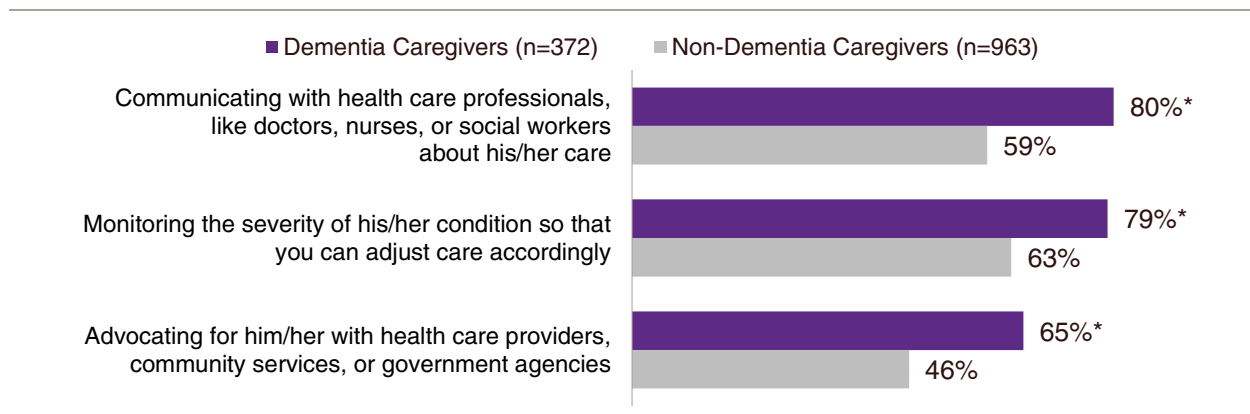
	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
Transportation	83%*	76%
Grocery or other shopping	80%	75%
Housework	70%	73%
Managing finances	68%*	50%
Preparing meals	64%	60%
Giving medicines, pills, or injections	61%*	43%
Arranging outside services	46%*	27%
<i>Helps with four or more IADLs</i>	<i>71%*</i>	<i>61%</i>
<i>Helps with all seven IADLs</i>	<i>24%*</i>	<i>10%</i>
<i>Average number of IADLs</i>	<i>4.7*</i>	<i>4.1</i>

In addition, dementia caregivers are significantly more likely to help manage their loved one's finances. One in five such caregivers (22 percent) reports experiencing problems when dealing with a bank or credit union in the course of helping with their loved one's finances. This is more than twice the rate among non-dementia caregivers who help manage finances (9 percent), highlighting the importance of creating thorough financial plans for future scenarios before someone with Alzheimer's disease or dementia is unable to manage their own finances.

### Navigating in and Through the Healthcare System

Most dementia caregivers play an important role in guiding their loved one through the healthcare system and ensuring that they receive needed treatments. A large majority of dementia caregivers say they help their loved one by communicating with healthcare professionals, monitoring the severity of their recipient's condition, and advocating for their loved one's care within the medical system, all at rates significantly higher than those among non-dementia caregivers (see Figure 9).

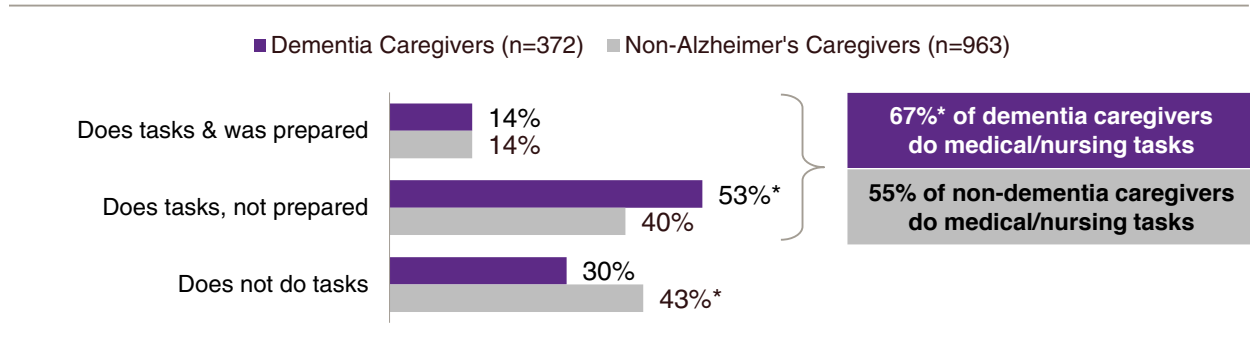
**Figure 9: Help with Key Activities**  
*Q23: And do/did you provide help to your [relation] by...*



Moreover, two in three dementia caregivers (67 percent) say they themselves perform medical/nursing tasks, which include skilled activities such as administering injections and tube feedings, and catheter and colostomy care.<sup>12</sup> More than half of all dementia caregivers do these medical/nursing tasks with no prior training or preparation, which is significantly higher than the rate among non-dementia caregivers.

**Figure 10: Preparation with Medical/Nursing Tasks**

*N3: Do/did you help your [relation] with any medical/nursing tasks? This might include giving medicines like pills, eyedrops, or injections; preparing food for special diets; tube feedings; or wound care. You could be monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.*

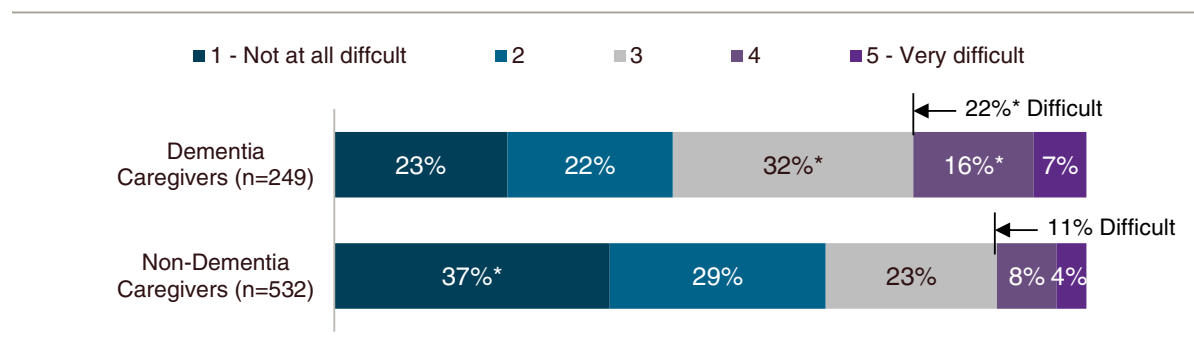


<sup>12</sup> For additional work on these tasks, see: Reinhard, S.C., Levine, C., & Samis, S. (2012) "Home Alone: Family Caregivers Providing Complex Chronic Care" AARP Public Policy Institute & United Hospital Fund.

Dementia caregivers are *twice as likely* to say that doing medical/nursing tasks is difficult (22 percent versus 11 percent of non-dementia caregivers; see Figure 11).

**Figure 11: Difficulty of Performing Medical/Nursing Tasks**

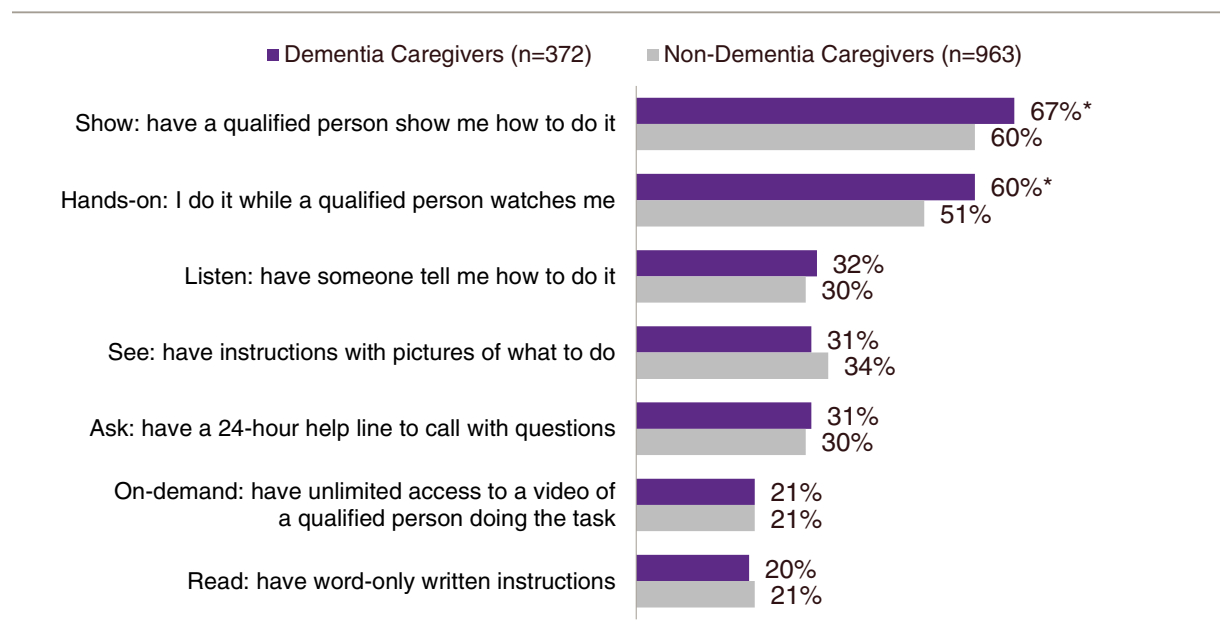
*N4: How difficult is/was it for you to do the medical/nursing tasks that are/were required to help your [relation]?*



Dementia caregivers' lack of prior preparation and difficulty doing these complex medical/nursing tasks suggest a need for additional training and support. Some ways that dementia caregivers would prefer to learn medical/nursing tasks are to work in person with a qualified teacher or other professional. Most say they would like to have a qualified person show them how to do medical/nursing tasks (67 percent) or do it themselves while a qualified person watches (60 percent). Fewer say they would want videos on demand or written instructions.

**Figure 12: Preferred Way of Learning Medical/Nursing Tasks**

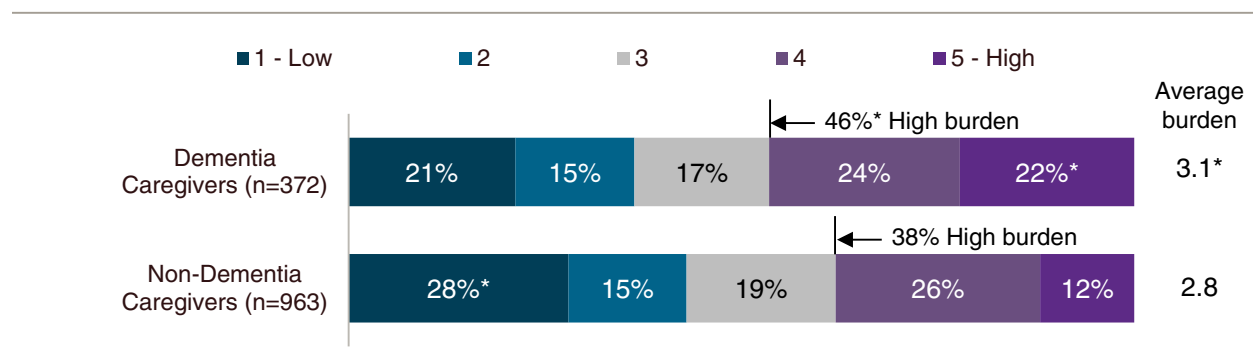
*N8: If you had to learn how to do a medical/nursing tasks, how would you prefer to learn?*



## High Care Burden over Longer Period Endangers Caregiver Health

Considering all of the responsibilities dementia caregivers shoulder, it should come as no surprise that the Burden of Care Index<sup>13</sup> scores them as one of the more burdened groups of caregivers. Nearly half of dementia caregivers are in a high-burden situation, and dementia caregivers have a significantly higher average burden than do non-dementia caregivers.

**Figure 13: Burden of Care Index**



Dementia caregivers are not the most-burdened group—for example, cancer caregivers are more likely to be in high-burden care relationships (62 percent).<sup>14</sup> However, where cancer caregiver relationships are short and episodic, dementia care relationships tend to be longer in duration.

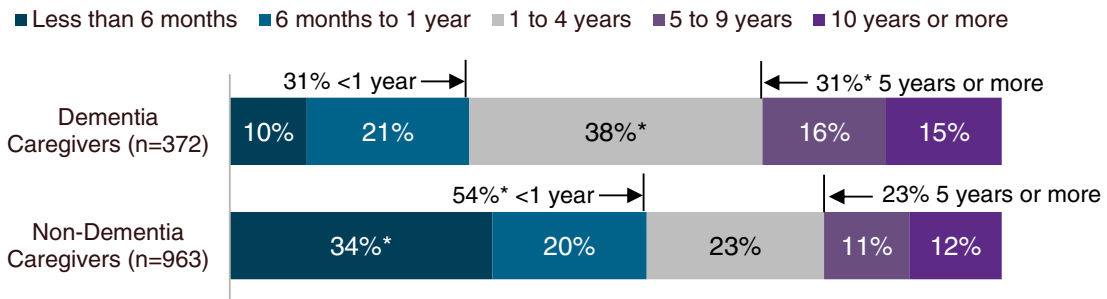
Nearly seven in ten (69 percent) dementia caregivers have provided care for more than a year, and three in ten have provided care for more than five years; both rates are significantly higher than those among non-dementia caregivers. More than one in seven dementia caregivers has provided care for over a decade (see Figure 14, next page).

<sup>13</sup> “Burden of Care” is an index based on the number of hours of care provided by the caregiver, the number of Activities of Daily Living performed, and the number of Instrumental Activities of Daily Living. Points are assigned for each of these, and ultimately, these points are consolidated into three burden categories: low (values 1 and 2), medium (3), and high (values 4 and 5). See *Caregiving in the U.S. 2015* Appendix B, Detailed Methodology for the details of creating the index.

<sup>14</sup> Hunt, G. G., Whiting, C. G., Longacre, M. L., Weber-Raley, L., Popham, L. (2016). “Cancer Caregiving in the U.S. – An Intense, Episodic, and Challenging Care Experience” National Alliance for Caregiving, National Cancer Institute, and Cancer Support Community.

**Figure 14: Duration of Care**

*Q21: How long have you been providing/did you provide care to your [relation]?*

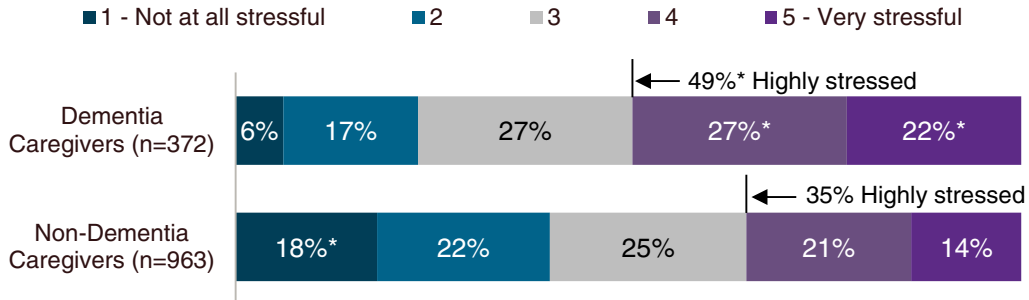


In addition, more than six in ten (63 percent) dementia caregivers expect to continue to have caregiving responsibilities for some adult over the next five years (versus 49 percent among non-dementia caregivers).

This high burden of care over a longer period can take a significant mental and physical toll. Nearly half of dementia caregivers say providing care is emotionally stressful (49 percent rating 4 or 5 on a 5-point scale), a figure that is significantly higher than that of non-dementia caregivers.

**Figure 15: Emotional Stress of Caregiving**

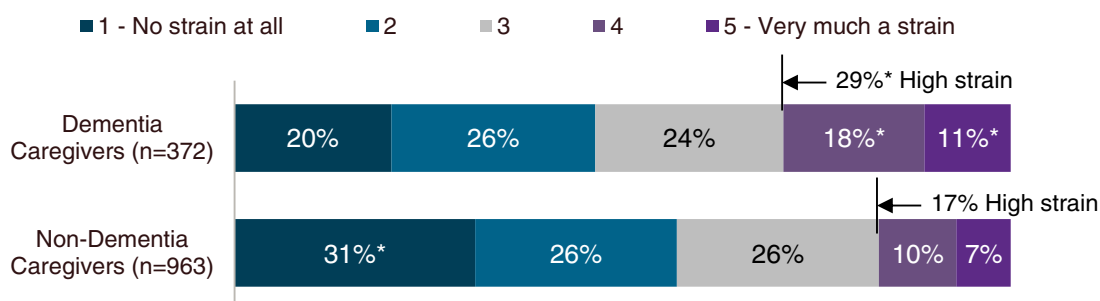
*Q36: How emotionally stressful would you say that caring for your [relation] is/was for you?*



In addition, many dementia caregivers find providing care for their loved one is physically demanding. Three in ten say that providing care creates physical strain (29 percent say 4 or 5 on a 5-point scale), which, again, is significantly higher than the rate among non-dementia caregivers (17 percent; see Figure 16).

**Figure 16: Physical Strain of Caregiving**

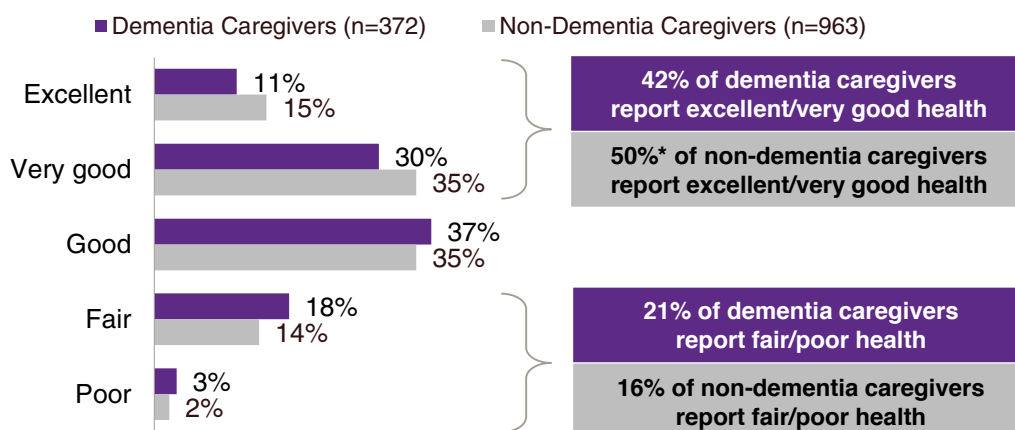
Q35: How much of a physical strain would you say that caring for your [relation] is/was for you?



Ultimately, this physical and emotional stress appears to have a negative impact on the health of many dementia caregivers. About four in ten (42 percent) say their health is “excellent” or “very good,” significantly lower than the share among non-dementia caregivers (50 percent). About one in five (21 percent) says their health is “fair” or “poor.” By comparison, 10 percent of the general adult population describes their health as “fair” or “poor.”<sup>15</sup>

**Figure 17: Caregiver Health**

D1: How would you describe your health/when you were last caregiving, how was your health?

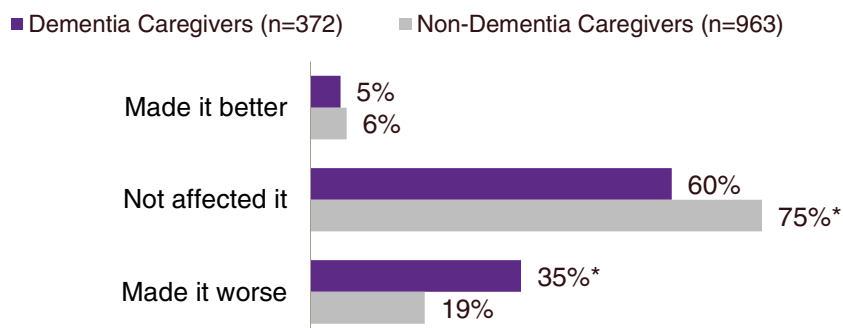


Dementia caregivers are nearly twice as likely to say that their health has gotten worse due to their caregiving responsibilities. More than one in three dementia caregivers reports that their health has declined (35 percent, see Figure 18 next page), versus 19 percent among non-dementia caregivers.

<sup>15</sup> CDC/NCHS, National Health Interview Survey, January–June 2014, Family Core component. <https://www.cdc.gov/nchs/data/nhis/earlyrelease/earlyrelease201412.pdf>

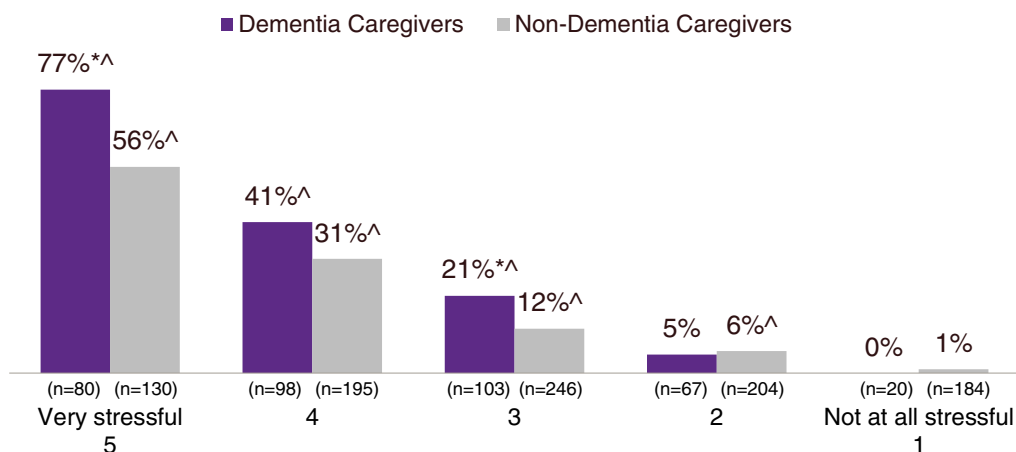


**Figure 18: Impact of Caregiving on Caregiver Health**  
D2: How would you say taking care of your [relation] has affected your health?



The negative health impacts from dementia caregiving do not seem to be a result of caregiver age.<sup>16</sup> Rather, whether a caregiver's health declines as a result of caregiving appears to correlate strongly with rates of emotional stress and physical strain (see Figures 19 and 20). As the emotional stress level of dementia caregivers increases, so too do reports of worsening health. In fact, once emotional stress hits a middle level (3 out of 5), dementia caregivers report negative health impacts nearly *twice* as often as non-dementia caregivers do. Among dementia caregivers with the highest emotional stress (5 out of 5), three out of four say caregiving has made their health worse.

**Figure 19: Negative Health Impacts of Caregiving by Emotional Stress**  
Percent reporting worse health as a result of caregiving

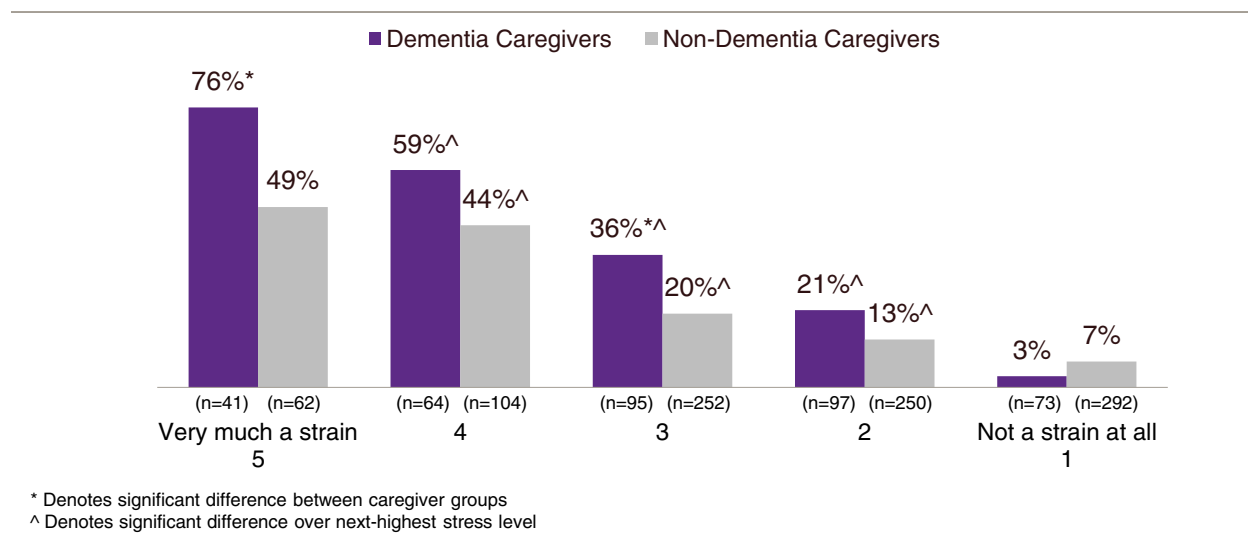


\* Denotes significant difference between caregiver groups  
^ Denotes significant difference over next-highest stress level

<sup>16</sup> The rate of caregivers reporting they have worse health as a result of caregiving is similar among those ages 45–54 (38 percent), 55–64 (43 percent), and 65–74 (38 percent). The youngest and oldest dementia caregivers do report lower rates of caregiving causing worsening health (25 percent ages 18–44; 24 percent ages 75+).

The pattern is similar for physical strain: as dementia caregivers report increasing levels of physical strain, they become more likely to report worsening health—such that among those who report high physical strain (5 out of 5), three out of four report caregiving has worsened their health (76 percent).

**Figure 20: Negative Health Impacts of Caregiving by Physical Strain**  
*Percent reporting worse health as a result of caregiving*



Overall, this suggests that dementia caregivers' greater likelihood to experience worsening health could be at least partially attributed to the more difficult emotional and physical requirements of their caregiving duties. As emotional stress and physical strain levels rise, negative health impacts increase for both dementia caregivers and non-dementia caregivers, though the phenomenon appears to be more severe or extreme for dementia caregivers. Further, dementia caregivers more often experience emotional stress and physical strain than do non-dementia caregivers—a situation that contributes to the disproportionately worsening health among dementia caregivers.

Prior research has documented the ways caregiving can affect caregivers' health and well-being. Caregiving has been associated with higher levels depression and anxiety, compromised immune function, and increased mortality.<sup>17</sup> These negative health impacts mean that caregiving is a crucially important public health issue—caregivers' health suffers under the pressure of caregiving responsibilities, and such decline in health compromises the caregiver's ability to provide care. This problem is particularly pressing for dementia caregivers, as health impacts are worse and loved ones rely on these caregivers for more daily assistance. Therefore, it is critical to improve the resources and help available to dementia caregivers so that they can easily and adequately care for their loved ones and for themselves.

<sup>17</sup> Centers for Disease Control and Prevention and the Kimberly-Clark Corporation, "Assuring Healthy Caregivers, A Public Health Approach to Translating Research into Practice: The RE-AIM Framework," Kimberly-Clark Corporation, Neenah, WI, 2008.

## Dementia Caregiving: A Team Effort

Dementia caregivers appear to have more help than non-dementia caregivers in navigating this complex and stressful care situation. Dementia caregivers are often one part of a larger care team and receive more paid and unpaid assistance than do non-dementia caregivers.

Four in ten dementia caregivers are the sole unpaid caregiver for their loved one, which is significantly lower than the rate among non-dementia caregivers (38 percent, compared with 49 percent). This means that six in ten dementia caregivers share at least some of the caregiving role with at least one other person (62 percent, versus 51 percent of non-dementia caregivers).

**Figure 21: Primary Caregiver Status**

*Q28: Has anyone else provided unpaid help to your [relation] over the last 12 months?*

*Q29: Who would you consider to be the person who provides/provided most of the unpaid care for your [relation]?*

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
Sole unpaid caregiver	38%	49%*
Net: Shares unpaid caregiving	62%*	51%
Provides most unpaid care among the unpaid caregivers	21%*	15%
Caregiving shared equally	11%	12%
Other caregiver provides most of the unpaid care	31%*	23%

In addition, dementia caregivers are more likely to utilize a variety of paid resources to support their loved one and make caregiving easier. Nearly half of dementia caregivers say their loved one has received help from aides, housekeepers, or others (45 percent, compared with 29 percent among non-dementia caregivers; see Figure 22). More than one in four has used a respite service to free up their time, over twice the rate among non-dementia caregivers. They are also more likely to use an outside transportation service and have had modifications made to the home where their care recipient lives.

### Spousal Dementia Caregivers Are Particularly Vulnerable

- ❖ 12 percent care for spouse or partner with dementia
- ❖ Caregiver is female (63 percent) and 71 years old, on average
- ❖ Provide 55.5 hours of care per week, significantly more—twice as much—as dementia caregivers generally
- ❖ Help with significantly more ADLs like bathing (52 percent) and dealing with incontinence (44 percent), than do other dementia caregivers
- ❖ 92 percent do medical/nursing tasks; just 8 percent were shown how to do them
- ❖ 68 percent are the sole unpaid caregiver for their spouse
- ❖ Just 33 percent get help from paid aides, and 19 percent have used respite care
- ❖ 34 percent say they have fair or poor health
- ❖ 44 percent say their health has gotten

**Figure 22: Paid Help/Resources Utilized**

*Q30: During the last 12 months, did your [relation] receive paid help from any aides, housekeepers, or other people who were paid to help him/her?*  
*Q45: In your experience as a caregiver, have you ever...*

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
Care recipient received paid help from any aides, housekeepers, or others	45%*	29%
Caregiver had modifications made in the house or apartment where care recipient lives	45%*	31%
Caregiver had an outside service provide transportation for care recipient instead of providing transportation themselves	32%*	20%
Caregiver used a respite service or a sitter to take care of care recipient to free up their time	27%*	12%

Rather than making greater use of paid services, sole unpaid dementia caregivers typically use these services at a similar rate or less often than do dementia caregivers who have other unpaid help. Four in ten sole unpaid dementia caregivers (43 percent) say their care recipient has received paid help from an aide, housekeeper, or other paid assistant (see Figure 23, next page). Just one in five (19 percent) has used a respite service—a figure that is significantly lower than that among dementia caregivers with other unpaid help. This suggests that sole unpaid dementia caregivers are truly “going it alone”—with fewer sources of paid help or other resources.

**Figure 23: Paid Help/Resources Utilized by Primary Caregiver Status**

*Q30: During the last 12 months, did your [relation] receive paid help from any aides, housekeepers, or other people who were paid to help him/her?*

*Q45: In your experience as a caregiver, have you ever...*

	Sole Unpaid Dementia Caregiver (n=142)	Dementia Caregiver with Other Unpaid Help (n=230)
Care recipient received paid help from any aides, housekeepers, or others	43%	46%
Caregiver had modifications made in the house or apartment where care recipient lives	39%	48%
Caregiver had an outside service provide transportation for care recipient instead of providing transportation themselves	26%	34%
Caregiver used a respite service or a sitter to take care of care recipient to free up their time	19%	32%*

Dementia caregivers, in general, report difficulty finding or getting paid help. More than a quarter (28 percent) say they find it difficult to get affordable services in their loved one's community. More than one in three (37 percent) has requested information about how to get financial help for their loved one, which is a rate significantly higher than that of non-dementia caregivers (25 percent).

### Dementia Caregivers in the Workplace

Despite the paid and unpaid help that many dementia caregivers receive, caregiving responsibilities can significantly disrupt day-to-day life for caregivers, especially those who are employed. Six in ten dementia caregivers were employed in the past year while providing care to their loved one. One in five employed dementia caregivers (20 percent) is self-employed.<sup>18</sup>

Employed dementia caregivers work an average of 34.9 hours per week while caregiving, and more than half (57 percent) work full time. There tends to be greater awareness about dementia caregiving by employers: seven in ten dementia caregivers (70 percent) say their supervisor was aware of their caregiving situation (versus 52 percent of non-dementia caregivers).<sup>19</sup>

<sup>18</sup> In comparison, 9.4 percent of all U.S. workers report being self-employed. Current Population Survey, Annual Social and Economic Supplement, 2012 data, presented in Bureau of Labor Statistics, "Female Self-Employment in the United States: An Update to 2012," *Monthly Labor Review* (October 2014). *Caregiving in the U.S. 2015* found higher rates of self-employment among caregivers of adults generally, so this does not seem to be an employment arrangement unique to dementia caregiving.

<sup>19</sup> Among those not self-employed.

Dementia caregivers report similar levels of assistance and workplace benefits as do non-dementia caregivers—most commonly, flexible work hours. Fewer than one in three caregivers report paid leave, employee assistance programs (EAPs) for information or counseling, or telecommuting.

**Figure 24: Workplace Benefits**

*N16: At the time when you were last working and providing care to your [relation], for employees in your position, which of the following did your employer offer?*

	Employed Dementia Caregiver (n=152)	Employed Non-Dementia Caregiver (n=963)
Flexible work hours	57%	51%
Paid leave (paid time off for several weeks to care for a family member)	27%	32%
Programs like information, referrals, counseling, or EAPs	24%	23%
Telecommuting	21%	22%

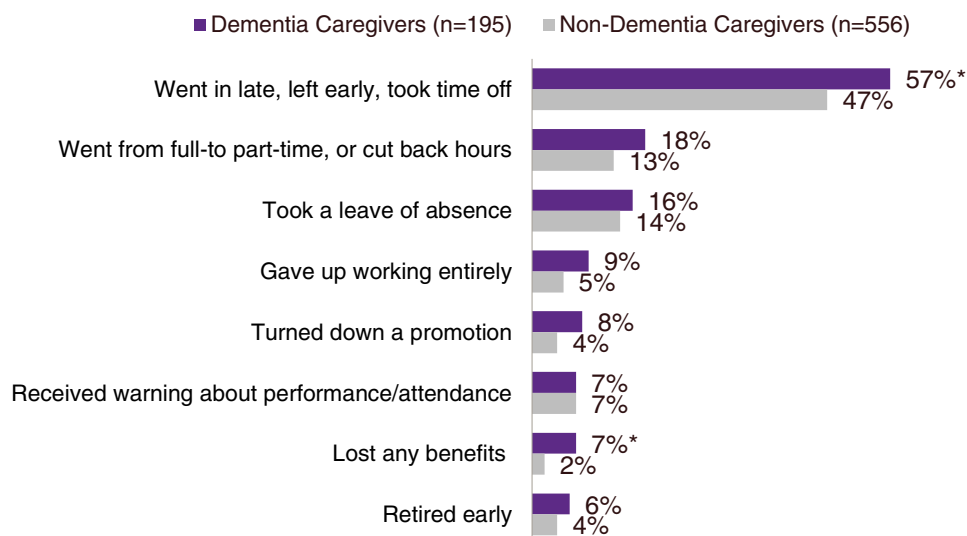
### Special Look: Male Dementia Caregivers

- ❖ 42 percent of dementia caregivers are male
- ❖ 75 percent help manage recipient finances—significantly more than female dementia caregivers (62 percent)
- ❖ 55 percent arrange outside services—significantly more than female dementia caregivers (40 percent)
- ❖ 53 percent report their loved one has paid help—significantly more than female dementia caregivers (39 percent)
- ❖ Employed 39 hours per week while providing care, significantly more than working female

Still, a majority of employed caregivers struggle to balance their job and their caregiving responsibilities. Two in three employed dementia caregivers report that their caregiving responsibilities affected their work in some way (significantly higher than the 59 percent of employed non-dementia caregivers). Most commonly, dementia caregivers come in late, leave early, or take off time to provide care (57 percent); cut back their hours or go from full-time to part-time (18 percent); or take a leave of absence (16 percent; see Figure 25, next page). They are three times as likely as non-dementia caregivers to say they lost job benefits, and one in eleven gave up working entirely.



**Figure 25: Work Impacts Due to Caregiving**  
Q34: As a result of caregiving, did you ever experience any of these things at work?



## Financial Impacts of Caregiving

Nearly one in five dementia caregivers (19 percent) reports high financial strain due to caring for their loved one, similar to the figure for non-dementia caregivers (17 percent). As mentioned previously, 28 percent say it is difficult to find affordable services in their loved one's area. In response to three different proposals intended to provide financial relief for caregivers, dementia caregivers tended to prefer a tax credit (33 percent) or programs that include a stipend for at least some of the hours they provide care (28 percent).

**Figure 26: Proposals to Provide Financial Aid to Caregivers**  
Q47a: Below are some ways that people are proposing to help caregivers financially. Which one would you find/have found most helpful?

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
Income tax credit to caregivers, to help offset the cost of care	33%	29%
Program where caregivers could be paid for at least some of the hours they provide care	28%	31%
Partially paid leave of absence from work, for employed caregivers <sup>a</sup>	12%	11%
Not sure	26%	29%

<sup>a</sup> Support for partially paid work leave was similar among dementia caregivers who were employed (13 percent) and not employed (11 percent).

## Support and Information Needs

Dementia caregivers want support from professionals within the healthcare system: many want to be kept more involved in their loved one's medical care, while some want more information on specific aspects of providing care. However, perhaps most important, many dementia caregivers want more discussions with healthcare providers about caring for their loved one *and* for themselves.

Less than half of dementia caregivers (44 percent) report having a doctor, nurse, or social worker ever ask them what they needed to care for their loved one. While this is significantly higher than the rate for non-dementia caregivers, it still leaves room for improvement—a majority has not had these kinds of conversations (56 percent). One in five (21 percent) has not had these conversations *and* believes it would be helpful to require doctors, nurses, or social workers to initiate these conversations with caregivers (see Figure 27).

**Figure 27: Areas for Improvement: Conversations with Providers**

*Q45: In your experience as a caregiver, have you ever...?*

*N20: Which of the following do you think would be/have been helpful to you?*

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
<b>Caring for Loved One</b>		
Have been asked what they need to care for their loved one by a doctor, nurse, or social worker	44%*	28%
Have not been asked, and say these conversations would have been helpful <sup>a</sup>	21%	21%
<b>Caring for Self</b>		
Have been asked what they need to care for themselves by a doctor, nurse, or social worker	24%*	14%
Have not been asked, and say these conversations would have been helpful <sup>b</sup>	26%*	19%

<sup>a</sup> We asked caregivers two questions: (1) whether they have been asked what they need to care for their loved one by a doctor, nurse, or social worker; and (2) whether it would have been helpful to them to require doctors, nurses, or social workers to ask caregivers what they need to help their loved one. Among dementia caregivers, 56 percent said they have not been asked this by a doctor, nurse, or social worker, and 48 percent say it would have been helpful to require doctors, nurses, or social workers to ask them about this. The overlap between these two groups represents 21 percent of all dementia caregivers.

<sup>b</sup> Similar to the previous note, among dementia caregivers, 76 percent have not been asked what they need to care for themselves by a doctor, nurse, or social worker, and 36 percent say it would have been helpful to them to require doctors, nurses, or social workers to ask this of them. The overlap between these two groups is 26 percent of all dementia caregivers.

Few dementia caregivers have been asked about their own self-care needs: just one in four has been asked what they need to care for themselves by a doctor, nurse, or social worker (24 percent). Another 26 percent have never had such a conversation about self-care but believe it would be helpful to require doctors, nurses, or social workers to initiate such conversations with caregivers.

The vast majority of dementia caregivers report needing more help or information on care topics. Here again, self-care is a pressing need: more than half (52 percent) say they need more help and information about managing their own emotional and physical stress. Considering the degree to which physical strain and emotional stress have an impact on caregiver health, it is crucial that medical professionals find additional opportunities to talk with caregivers about self-care.

**Figure 28: Areas Where Caregivers Need More Information**

*Q48: Which of the following topics do you feel you need/needed more help or information?*

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
Managing your emotional and physical stress	52%*	40%
Keeping your [loved one] safe at home	39%	42%
Making end-of-life decisions	32%*	20%
Managing his/her challenging behavior, such as wandering	31%*	7%
Managing his/her incontinence or toileting problems	22%*	8%
Finding non-English language educational materials	4%	5%
<i>Needs help in at least one area</i>	89%*	82%

In addition to managing stress, 39 percent say they need help and information about keeping their loved one safe at home. Dementia caregivers are *more than four times more* likely to say they need help managing their loved one's challenging behavior and nearly *three times more* likely to need help managing incontinence. In addition, one in three reports they want more information on end-of-life decisions (32 percent), a significantly greater need than among non-dementia caregivers.

Nearly six in ten (56 percent) dementia caregivers report their care recipient has plans in place for handling future financial matters, healthcare decisions, and/or living arrangements. While this is significantly higher than among non-dementia caregivers' reports of their loved one's plans (43 percent), there is still much room for improvement.

Many dementia caregivers also say they want to be more closely included by healthcare professionals in matters involving their loved one's care. Communication between dementia caregivers and medical professionals seems to be stronger during more severe care episodes for their care recipient. Slightly more than half of dementia

caregivers (53 percent) report that their loved one was hospitalized overnight within the last year. Among those, four in five (80 percent) report being involved in healthcare discussions during hospitalization, including 56 percent who said they were included in *all* discussions.

However, there are still important opportunities to help caregivers be more involved in their loved one's care. When asked, roughly half of dementia caregivers favored a number of proposals that would improve their communication with healthcare professionals and integration into the greater healthcare team. More than half would find it helpful to require health providers to include their name on their care recipient's chart (56 percent; see Figure 29). Almost half want hospitals or care facilities to demonstrate medical/nursing tasks and to inform the caregiver about major care decisions. Finally, nearly half of dementia caregivers (44 percent) say it would be helpful to have respite services available for them to use (compared with just 30 percent of non-dementia caregivers). One out of four (27 percent) dementia caregivers has never made use of a respite service but wants to do so. This indicates that there is a need among some dementia caregivers for easily accessible respite services especially because of the higher burden of care.

**Figure 29: Proposals to Improve Healthcare System for Caregivers**

*N20: Various organizations are thinking about ways to help caregivers like you. Which of the following do you think would be/have been helpful to you?*

Which of the following do you think would {be/have been} helpful to you?	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
Requiring healthcare providers to include your name on your [loved one's] chart	56%*	46%
Requiring hospitals or facilities to instruct or demonstrate any medical/nursing tasks	46%	42%
Requiring hospitals to [keep/have kept] you informed about major decisions	46%	40%
Having respite services available	44%*	30%

## Promising Interventions for Dementia Caregivers

Below are two Evidence-based promising practices for caregivers of persons with dementia. Both examples started as community-based programs, then were adapted and made available to Department of Veterans Affairs caregivers.

### Partners in Dementia Care

Over 300,000 veterans living with dementia receive care from the Department of Veterans Affairs (VA).<sup>20</sup> The annual cost of caring for someone with dementia at home in the U.S. is estimated at \$56,000.<sup>21</sup> This represents a burden on the patient and their families, as well as VA resources. Individuals with dementia and their caregivers often seek assistance regarding non-medical but important care issues in order to continue caring at home. Issues include understanding VA benefits, accessing community resources, and assessing and addressing caregiver burden.<sup>22</sup> The Cleveland Alzheimer's Managed Care Demonstration and the Chronic Care Networks for Alzheimer's Disease were two dementia-related intervention studies used to create a new care coordination program supporting veterans with dementia and their family caregivers.

Partners in Dementia Care (PDC) is a telephone-based care coordination and support service intervention program, implemented by the Veterans Health Administration (VHA) and regional Alzheimer's Association chapters. PDC supported 508 veterans with dementia and 486 of their family caregivers in intervention and comparison sites located in Boston, Providence, RI, Oklahoma City, and Beaumont and Houston, TX.<sup>23</sup> Partners in Dementia Care was designed to be a practical intervention which addresses the complex and diverse care issues associated with dementia, as well as other issues reported by patients and their caregivers. It was implemented to resolve or ease the burden of issues such as lack of coordination between medical care and community services, insufficient attention given to the needs of family caregivers from healthcare providers, lack of proper information and educational resources on caregiving, limited attention given to patients' and caregivers' feelings of isolation and strain, and families' challenges accessing quality medical and nonmedical services.<sup>24</sup>

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<sup>20</sup> Bass, D. M., Judge, K. S., Snow, A. L., Wilson, N. L., Morgan, R. O., Maslow, K., & Kunik, M. E. (2014). A controlled trial of Partners in Dementia Care: Veteran outcomes after six and twelve months. *Alzheimer's Research & Therapy*, 6(1), 9. doi:10.1186/alzrt242

<sup>21</sup> Ibid

<sup>22</sup> Piercy, K. W., Judge, K. S., Bass, D. M., Snow, A. L., Wilson, N., Morgan, R. O., Looman, W. J., McCarthy, C., & Kunik, M. E. (2011). Partners in Dementia Care: A Care Coordination Intervention for Individuals with Dementia and Their Family Caregivers. *The Gerontologist*, 51(2), 261-272. doi:10.1093/geront/gnq097

<sup>23</sup> Ibid

<sup>24</sup> Bass, D. M., Judge, K. S., Snow, A. L., Wilson, N. L., Morgan, R., Looman, W. J., & Kunik, M. E. (2013). Caregiver Outcomes of Partners in Dementia Care: Effect of a Care Coordination Program for Veterans with Dementia and Their Family Members and Friends. *Journal of the American Geriatrics Society*, 61(8), 1377-1386.

Since its implementation, PDC has been successful in reducing dementia-related problems and improving the overall well-being of patients and their caregivers. Eligibility for PDC was restricted to veterans 50+ receiving care from the VHA, residing in the community, while eligibility for caregivers included being the primary family caregiver.<sup>25</sup> Patients and their caregivers were provided with two care coordinators a month for up to 12 months.<sup>26</sup> The PDC program begins with a process of initial assessment, then an action plan, followed by ongoing monitoring and reassessment of the patient and caregiver. Care Coordinators assist by providing dementia-related education and resources, offering emotional support and guidance, connecting families to medical and non-medical services, and utilizing the informal care network.<sup>27</sup> PDC is effective because the care-coordination intervention program integrated healthcare and community resources through proper coaching and support for veterans affected by dementia and their family caregivers.

## Reach VA

In 2010, new regulations mandated the VA to provide support for caregivers of veterans.<sup>28</sup> Family caregivers provide the majority of care to these patients, and the VA has created various programs in which their clinicians support family caregivers. REACH VA is one of the caregiver-focused programs implemented during this transition.

The VA believes that caregivers are an integral part of the healthcare team and should have the resources, knowledge, and tools to provide the best-quality care for their loved one. They recognize that many family caregivers lack the skills to manage their veteran's behavioral problems and manage their own stress, both of which are crucial to proper caregiving. Caregivers' lack of skills may result in patient health problems such as depression, anxiety, sleep disturbance, hospitalization, mortality, and increased risk of institutionalization.<sup>29</sup> Interventions can also ease the burden of caregiving on family members and friends.

The National Institute on Aging's randomized controlled trial, Resources for Enhancing Alzheimer's Caregiver Health (REACH II), provided family caregivers assistance through education, support, and skills-building both in-home and via telephone.<sup>30</sup> REACH VA was developed to provide family caregivers with information relating to

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<sup>25</sup> Morgan, R. O., Bass, D. M., Judge, K. S., Liu, C. F., Wilson, N., Snow, A. L., & Kunik, M. E. (2015). A Break-Even Analysis for Dementia Care Collaboration: Partners in Dementia Care. *Journal of General Internal Medicine*, 30(6), 804-809.

<sup>26</sup> Kunik et al.: A Care Coordination Intervention for Individuals with Dementia and Their Family Caregivers

<sup>27</sup> Ibid

<sup>28</sup> Nichols, L. O., Martindale-Adams, J., Burns, R., Graney, M. J., & Zuber, J. (2011). Translation of a Dementia Caregiver Support Program in a Health Care System—REACH VA. *Archives of Internal Medicine*, 171(4).

<sup>29</sup> Nichols et al.: Translation of a Dementia Caregiver Support Program in a Health Care System

<sup>30</sup> Nichols, L. O., Martindale-Adams, J., Burns, R., Zuber, J., & Graney, M. J. (2014). REACH VA: Moving from Translation to System Implementation. *The Gerontologist*, 56(1), 135-144.

disease-specific knowledge and appropriate skills training to increase their effectiveness in caring for their family member. The REACH VA's home and telephone sessions included discussions of resources such as education and skills training to address caregiving risk areas. The REACH intervention program is designed to help family caregivers oversee their patient's emotional well-being as well as their own personal health. The intervention is a process of providing different activities to occur at each session and is personalized using a risk assessment. The goal in implementing REACH in the VA system was for inclusion of the REACH intervention into the skill sets of caregivers and clinicians.<sup>31</sup>

An important piece of the intervention is strategies for caregiving-related issues or patient problems identified by the risk assessment. For REACH VA interventions, a Caregiver Notebook includes strategies for behavioral management, caregiver stress, and coping.<sup>32</sup> The REACH intervention program has proven to be simple to implement and has had promising results. Also, the transition from mainly face-to-face to telephone has not seen any negative results and has enabled the program to reach more people. The REACH program is an efficient way to interact with family caregivers and augments a clinical or social service worker's tools for supporting worried and burdened caregivers.

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<sup>31</sup> Ibid

<sup>32</sup> Nichols et al.: Translation of a Dementia Caregiver Support Program in a Health Care System

## Respondent Profile

Figure 30 (multiple pages) provides the demographic characteristics of dementia and non-dementia caregivers. With the exception of caregiver age, most characteristics are not significantly different between dementia and non-dementia caregivers. Dementia caregivers are 54 years old, on average, and 58 percent are female. About two-thirds of dementia caregivers are non-Hispanic white, 13 percent are Hispanic, and 13 percent are non-Hispanic African American.

**Figure 30: Demographic Summary by Caregiver Type**

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
<b>Caregiver Gender</b>		
Male	42%	40%
Female	58%	60%
<b>Age of Caregiver</b>		
18 to 34	16%	26%*
35 to 49	17%	25%*
50 to 64	41%*	31%
65 to 74	16%*	11%
75 or older	10%	7%
<i>Mean age</i>	<i>53.9*</i>	<i>48.1</i>
<b>Race/Ethnicity of Caregiver</b>		
White non-Hispanic	66%	60%
Hispanic	13%	18%*
African American non-Hispanic	13%	13%
Asian American <sup>a</sup>	6%	6%
Other	2%	3%

<sup>a</sup> Asian American is inclusive of those caregivers who are of Asian origin, background, or descent, including the regions of the Indian subcontinent, Far East, Southeast Asia, and Pacific Islands.



Dementia caregivers have a median household income of \$58,200, compared with to \$53,046 for the U.S. overall.<sup>33</sup> Four in ten dementia caregivers have a college or graduate degree (39 percent). Most are married or living with a partner, and a little more than a quarter have a child or grandchild under the age of 18 living in their household.

**Demographic Summary (continued)**

	<b>Dementia Caregiver (n=372)</b>	<b>Non-Dementia Caregiver (n=963)</b>
<b>Caregiver Marital Status</b>		
Married	61%	56%
Living with a partner	8%	8%
Widowed	5%	5%
Separated	1%	1%
Divorced	8%	8%
Single, never married	14%	21%*
<b>Caregiver Education</b>		
Less than high school	7%	8%
High school graduate	26%	29%
Some college	20%	23%
Technical school	9%	7%
College graduate	22%	19%
Graduate school	18%	14%
<b>Caregiver Household Income</b>		
Less than \$50,000 (net)	42%	48%
Less than \$15,000	9%	13%*
\$15,000 to \$29,999	15%	16%
\$30,000 to \$49,999	18%	18%
\$50,000 or more (net)	57%	52%
\$50,000 to \$74,999	23%*	16%
\$75,000 to \$99,999	12%	13%
\$100,000 or more	22%	23%
<i>Median Household Income</i>	<i>\$58,200</i>	<i>\$53,400</i>
<b>Children/Grandchildren in Caregiver's Household</b>		
Yes	26%	29%
No	73%	69%

Six in ten dementia caregivers (59 percent) worked while providing care, and most live in an urban/suburban setting (83 percent). One in eight (13 percent) has served on

<sup>33</sup> U.S. Census Bureau, American Community Survey, 2013 5-year estimates.  
[https://factfinder.census.gov/faces/nav/jsf/pages/guided\\_search.xhtml](https://factfinder.census.gov/faces/nav/jsf/pages/guided_search.xhtml)

active duty in the armed forces. One in 12 (8 percent) self-identifies as lesbian, gay, bisexual, and/or transgender.

**Demographic Summary *(continued)***

	Dementia Caregiver (n=372)	Non-Dementia Caregiver (n=963)
<b>Caregiver Living Location</b>		
Urban/Suburban	83%	85%
Rural	17%	15%
<b>Care Recipient Living Location</b>		
Urban/Suburban	69%	72%
Rural	29%	27%
<b>Caregiver Employment Status</b>		
Employed in past year while caregiving	59%	59%
Not employed	41%	41%
<b>Caregiver Service in Armed Forces</b>		
Ever served on active duty	13%	10%
Did not ever serve	86%	90%
<b>Care Recipient Service in Armed Forces</b>		
Ever served on active duty	17%	13%
Did not ever serve	81%	85%
<b>Caregiver LGBT status<sup>a</sup></b>		
Yes	8%	9%
No	92%	91%

<sup>a</sup> Indicates whether a caregiver identifies as lesbian, gay, bisexual, and/or transgender.

## Detailed Methodology

*Caregiving in the U.S. 2015* used a complex, six-part sampling design. Online interviews were conducted with a random sample of 1,015 adult caregivers. In addition, 233 additional online interviews were conducted via targeted sampling of racial/ethnic groups to supplement the sample of ethnic adult caregivers. This yielded a total of 1,248 full online interviews with caregivers of adults (by race/ethnicity: 698 white non-Hispanic caregivers, 206 non-Hispanic African American caregivers, 208 Hispanic caregivers, 95 Asian American caregivers, and 41 caregivers of another race). These 1,248 interviews represent the base online study. Among this nationally representative base study, *Caregiving in the U.S. 2015* finds that 22% of adult caregivers provide care to someone with Alzheimer's dementia, or other mental confusion.

In addition to the base study, the study also included an oversample of older caregivers. Specifically, an additional 209 online interviews were conducted with caregivers ages 65 or older, yielding a total of 213 caregivers ages 65 to 74 and 269 caregivers ages 75 or older.<sup>34</sup> Further, 106 Asian American caregivers were interviewed via telephone (65 landline and 41 cell phone) to bring the total among this caregiving subset to 201 caregivers.<sup>35</sup>

There were 285 dementia caregivers present in the base study, and 87 additional dementia caregivers present in the oversamples, combining to 372 total dementia caregivers used for analyses in this paper.

Custom population weights were designed in order to analyze data from these 372 dementia caregivers, pulled from all six samples of the *Caregiving in the U.S. 2015* study. Understanding the demographic characteristics of dementia caregivers in the general population is a challenge, as there are no standard population-based studies to draw upon for benchmarking data. Given this lack of weighting targets, we drew upon the knowledge present in the *Caregiving in the U.S. 2015* study and developed a multistep weighting process.

First, in order to produce targets for weighting—that is, a description of what dementia caregivers look like in the general population—a demographic profile of the 285 dementia caregivers from the base study samples was developed. The age, race/ethnicity, and gender distributions of the sample of 285 dementia caregivers was used to create a profile of a typical caregiver of an adult with Alzheimer's disease, dementia, or other mental confusion. Second, responses from dementia caregivers across all samples (n=372) were examined unweighted for their comparable demographic composition. Third, responses from these 372 dementia caregivers were then weighted in a stepwise fashion (first age, then race/ethnicity, finally gender) to

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<sup>34</sup> All online interviews in this study were conducted using GfK's KnowledgePanel®, the only probability-based online panel. For more information, see *Caregiving in the U.S. 2015*.

<sup>35</sup> Telephone interviews included landline and cell phone interviewing. Landline sample was targeted by surname and geographic density, while cell phone sample was targeted by surname.

match the population-weighted profile of dementia caregivers developed from the *Caregiving in the U.S. 2015* base study results. All results shown for dementia caregivers in this paper are adjusted by these custom weights.

The comparison group of non-dementia caregivers (n=963) is drawn from the remaining base study sample of participants of *Caregiving in the U.S. 2015*, and analyses of this group utilize the population weight provided from the base study results. This includes the 1,248 base study caregivers, minus the 285 dementia caregivers present in the base study, for a total of 963 non-dementia caregivers.

## ABOUT THE NATIONAL ALLIANCE FOR CAREGIVING

*Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at [www.caregiving.org](http://www.caregiving.org).*

## ABOUT THE ALZHEIMER'S ASSOCIATION

*The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Its mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.*

