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Caregivers of Older Adults: A Focused Look at Those Caring for Someone Age 50+







Conducted by





Acknowledgments

The National Alliance for Caregiving (NAC) and the AARP Public Policy Institute are proud to present *Caregiving in the U.S. 2015 – Focused Look at Caregivers of Adults Age 50+.*

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I. Introduction

This is the second of two companion reports to the full report of the study entitled *Caregiving in the U.S. 2015.* This companion report focuses on 1,087 unpaid family caregivers who provide care to an adult age 50 and older. The other companion report - *Caregivers of Younger Adults: A Focused Look at Those Caring for Someone Age 18 to 49* - provides detail on caregivers of younger adults. All caregivers were interviewed using GfK's web-enabled KnowledgePanel®, a probability-based panel designed to be representative of the U.S. population, between September 11 and November 5, 2014. To see the complete study results, or for more information about the questionnaires or the methodology, please reference the full report and Appendices A and B.

Reading this Report

All figures have been weighted and rounded. In addition, "don't know" or "refused" responses are not always presented in charts and tables. For these reasons, some charts and tables will not add to 100%. The results for multiple-response questions may also add to greater than 100%.

The n sizes shown in each table or graphic represent the unweighted number of respondents who answered each question. All demographic information about the caregivers is in reference to their current situation if currently caregiving, or their situation at the time they last provided care if not a current caregiver. When there are more than two columns or groups being compared, a superscript letter next to a numerical result indicates that it is significantly higher than the numerical result in the column designated by that letter.

Throughout the report, "caregiver of someone 50+" or "50+ caregivers" both refer to the focal group of this report: caregivers who provide care to an adult age 50+.

II. Key Findings

Basics of the Caregiving Situation and Care Recipient Living Situation

An estimated 34.2 million American adults have served as an unpaid caregiver to someone age 50 or older in the prior 12 months.

Caregivers of someone 50+ are 50.3 years old, on average, and most are female (60%). The majority (86%) of 50+ caregivers provide care for a relative, 47% care for a parent or parent-in-law. One in 10 cares for a spouse. One in four caregivers of someone 50+ is providing care to the oldest-old, those who are ages 85 or older. On average, 50+ caregivers' recipients are 74.7 years old.

Most 50+ caregivers say their loved one has a long-term physical condition (63%), while 29% have a memory problem. When 50+ caregivers are asked what they perceive to be the main reason their recipient needs care, the top three problems are "old age" issues (16%), Alzheimer's or dementia (9%), or mobility (7%). Among caregivers of the oldest-old – that is, those ages 85 or older – one in three cites "old age" issues as their recipient's main problem.

Nearly half of 50+ caregivers say they did not have a choice in taking on their caregiving role (49%). They have been in their role for an average of 3.7 years, with a quarter providing care for five years or more. Those caring for the oldest-old have been in their role for 4.6 years – longer than those caring for someone age 50 to 74.

Half of 50+ caregivers report their loved one lives in his or her own home, suggesting that some recipients are aging in place. Those who provide care to the oldest-old are more likely (23%) to report he or she lives in a retirement community, assisted-living facility, or a skilled nursing facility.

Caregiving Activities and Burden of Care

On average, caregivers of someone 50+ spend 24.1 hours a week providing care, with 22% providing 41 or more hours of care each week. Three in five are primary caregivers, meaning they are their recipient's sole or primary unpaid caregiver, and only 34% use paid help from aides, housekeepers, or others.

Six in 10 caregivers of someone 50+ help their loved one with at least one Activity of Daily Living (ADL), most commonly with getting in and out of beds and chairs (45%). One in five who performs ADLs found it difficult. Caregivers who do more ADLs are more likely to report having difficulty providing them.

Caregivers of someone 50+ help, on average, with 4.2 out of seven Instrumental Activities of Daily Living (IADLs), including transportation (78%), grocery or other shopping (76%), or housework (72%). Nearly half (46%) of caregivers providing care to the oldest-old arrange services. All of these activities add up to a high burden of care for 40% of caregivers of someone 50+.²

Caregivers' responsibilities often extend beyond the traditional ADLs and IADLs, to interacting with various providers, agencies, and professionals on their care recipient's behalf. Two out of three monitor their care recipient's condition to adjust care or communicate with health care professionals, and 51% advocate for their recipient.

Six in 10 assist with medical/nursing tasks, of those 43% did so *without any* prior preparation, while 14% report they had some prior preparation. Fourteen percent of 50+ caregivers who provide medical/nursing tasks find it difficult.

² The "burden" of care is a simplified version of the Level of Care index, the construction of which is detailed in Appendix B, Detailed Methodology.

Stress and Strain of Caregiving

Half of 50+ caregivers feel their health is *excellent* or *very good*, while 17% say it is *fair* or *poor*. One in five reports his or her health has gotten worse as a result of caring for a loved one.

Two out five caregivers of someone 50+ report high levels of emotional stress (38%), while 19% report a high level of physical strain and 17% have experienced a high level of financial strain, as a result of their caregiving role.

Impact of Caregiving on Work

Six in 10 of those caring for someone 50+ were employed at some point in the past year while caregiving, working 34.8 hours a week, on average. Nearly one in five is self-employed or owns a business (17%).

Among those employed by an employer,³ most (56%) report that their supervisor is aware of their caregiving responsibility. Half say their employer offers flexible work hours (53%), but few are offered employee assistance programs (24%) or telecommuting (24%).

Among working caregivers of someone 50+, six in 10 report their work has been affected by caregiving. Most commonly, 50+ caregivers have gone in late, left early, or taken time off because of caregiving (49%), while 14% have taken a leave of absence, 6% have given up working entirely, and 4% retired early.

Information Needs and Caregiving Support

A third of caregivers say a health care provider, such as a doctor, nurse, or social worker has asked them what was needed to care for their recipient, but only 16% report similar conversations about self-care. A greater percentage of 50+ caregivers find these conversations helpful than the percentage who report having had them—revealing a 6% "need gap" for conversations about recipient care needs, and an 11% "need gap" for conversations about self-care needs.

More than eight in 10 caregivers of someone 50+ say they could use more information or help on caregiving topics. Caregivers most commonly want information about keeping their loved one safe at home (43%) and about managing their own stress (42%). One in four reports it is difficult to get affordable care services in his or her loved one's community.

Caregivers of the oldest-old – those age 85 or older – are more likely to have already made modifications to their loved one's home, and they also show a greater need for information about incontinence and making end-of-life decisions.

³ Not self-employed.

When asked to gauge how helpful several policies might be to their caregiving experience, the most popular proposals relate to hospitals' or facilities' interactions with themselves, the caregivers. Half would like their own name on their recipient's medical chart, 45% would like to require hospitals to demonstrate medical/nursing tasks, and 43% want to be informed about major decisions. Of three policies focused on providing financial support to caregivers, about a third most prefer being paid for some of their care hours, while three in 10 most prefer an income tax credit.

Long-Range Planning

Half of 50+ caregivers expect they will be a caregiver for some adult (either their current loved one or someone else) during the next five years. Six out of 10 of those providing care to the oldest-old expect their caregiving role to continue.

Only half of caregivers report their recipient has made plans for his or her future care, and just 43% have plans for their own future care.

Demographics

While most (62%) caregivers of someone 50+ are white, 16% are Hispanic. More than a third have a high school education or less, just lower than the percentage who have a college degree (36%). Caregivers' median household income of \$55,000 compares to the \$53,046 for the United States overall.⁴ Most are married or living with a partner, and 28% have a child or grandchild under the age of 18 living in their household. Six in 10 are employed (59%). Most live in an urban or suburban setting. One in 10 has served in the armed forces, and 15% of care recipients have.

Caregivers of oldest-old are themselves, on average, 18 years older than those caring for a recipient age 50 to 64. They are overwhelming white (77%) and have a higher median household income (\$66,500).

III. Detailed Findings

A. Basics of the Caregiving Situation

There are 34.2 million adults (estimated 14.3% of all U.S. adults) in the United States who have been a caregiver to an adult age 50+ within the prior 12 months.

Roughly six in 10 caregivers are currently caring for a loved one age 50+ (57%), while four in 10 provided care in the last 12 months but are no longer doing so.

Two out of three care recipients ages 50+ are female; one in three is male. Six in 10 caregivers are female (40% are male).

⁴ U.S. Census Bureau, American Community Survey, 2013.

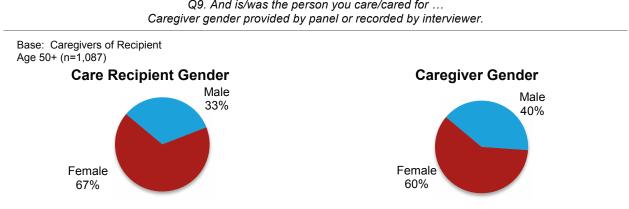


Figure 1: Gender of Care Recipient and Caregiver

Q9. And is/was the person you care/cared for ...

Age of Caregiver and Care Recipient

On average, caregivers of someone 50+ are themselves 50.3 years old.

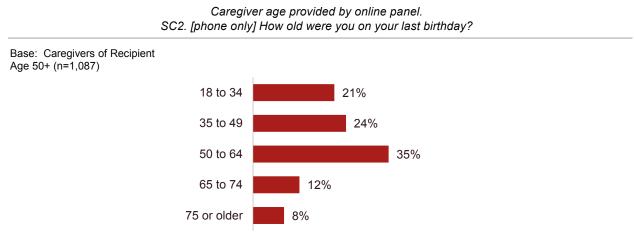


Figure 2: Age of Caregiver

On average, the care recipient is 74.7 years old. More than half (55%) of caregivers of someone 50+ are caring for someone age 75 or older.

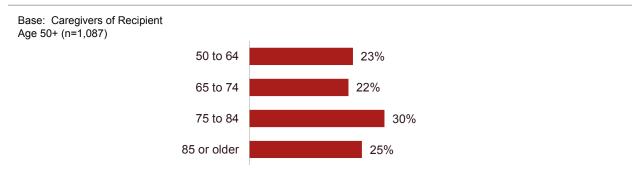


Figure 3: Age of Care Recipient

Q5. How old is that adult/was that adult at the time you provided care?

2015 Caregiver Subgroups

White caregivers are older than African American, Hispanic, and Asian American⁵ caregivers. White and Asian American caregivers are caring for someone older, on average, than African American and Hispanic caregivers.

	Caregiver Race/Ethnicity				
	White (n=613) A	African American (n=178) B	Hispanic (n=175) C	Asian American (n=186) D	
Average caregiver age	53.4 ^{BCD}	45.2	44.2	47.0	
Average recipient age	76.5 ^{BC}	70.7	71.4	75.6 ^{BC}	

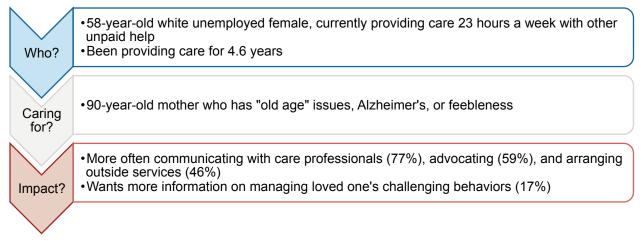
Figure 4: Age of Caregiver and Recipient by Caregiver Race/Ethnicity

- The caregiver's age rises with the care recipient's age. Caregivers ages 18 to 49 care for someone 69.3 years old, on average, 10 years younger than caregivers who are 65 or older, who provide care to a loved one 80.2 years old.
- Higher-hour caregivers (those providing 21 or more hours of care a week) of someone 50+ are 53.1 years old on average, four years older than lower-hour caregivers (49.1).

⁵ 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, or Pacific Islands.

Spotlight: Those providing care to the oldest-old may find themselves navigating a care situation that presents different challenges than that of caregivers of someone younger. Figure 5 shines a spotlight on these caregivers of the oldest-old, by highlighting what is unique about them.⁶

Figure 5: Spotlight on Caregivers of the Oldest-Old



Those providing care to the oldest-old – that is, those who are 85 and older – are themselves older. They are less likely to be working and have been providing care longer. While they are more likely to have others helping them provide unpaid care, they are often taking on the role of advocate and communicator on behalf of their loved one.

⁶ These profiles of caregivers provide a snapshot glance at significant findings that make this subgroup unique, relative to the comparison group—in this case, the comparison group is those caring for someone age 50–84.

Care Recipient Relation to Caregiver

The majority (86%) of 50+ caregivers care for a relative; just 14% care for a friend, neighbor, or other nonrelative. Almost half (47%) care for a parent, more than any other relation (34% mother, 13% father), with 8% reporting they care for a parent-in-law (see Figure 6).

Figure 6: Car	e Recipient	Relation t	to Caregiver
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Q7. Who are you caring/did you care for?

	Recipient Age 50+ (n=1,087)
Relative	86%
Parent	47
Spouse or partner	11
Parent-in-law	8
Grandparent or grandparent-in-law	8
Uncle or aunt	4
Sibling	3
Other relatives	2
Sibling-in-law	2
Child	1
Nonrelative	14
Friend	9
Neighbor	3
Other nonrelative	2

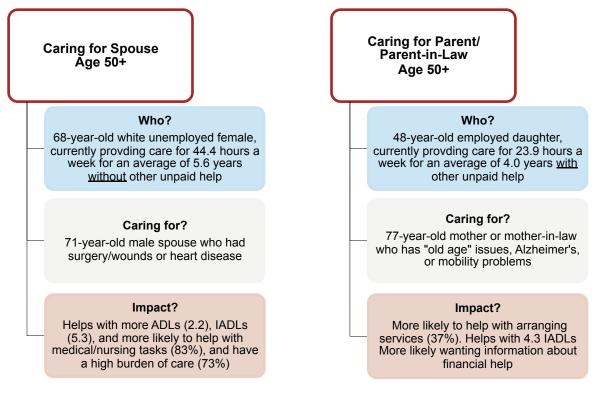
- Higher-hour caregivers that is, those providing 21 or more hours of care each week are more likely to care for a relative (94%) and four times as likely to be caring for a spouse or partner (24%), than lower-hour caregivers (those providing 20 or fewer hours of care weekly).
- African American caregivers are nearly twice as likely to care for a nonrelative (23% vs. 12% for all other race/ethnic groups).
- As caregiver age rises, it becomes more likely they care for their spouse, and less likely they care for a parent or parent-in-law (see Figure 7, next page).

	Caregiver Age					
	18–49 (n=415) A	50–64 (n=422) B	65–74 (n=196) C	75 or older (n=246) D		
Spouse/partner	2%	9% ^A	26% ^{AB}	50% ^{ABC}		
Parent/parent-in-law	60 ^{CD}	68 ACD	37 ^D	9		
Average recipient age	69.3	78.8 ^A	80.2 ^A	80.2 ^A		
Average caregiver age	35.4	56.4 ^A	68.8 ^{AB}	79.0 ^{ABC}		
Age gap ⁷	33.9	22.4	11.4	1.2		

Figure 7: Care Recipient Relationship and Age by Caregiver Age

There are some key differences between caregivers providing care to a spouse and those who care for a parent, besides just age. Both groups of caregivers say they had no choice in taking on their role and feel physically, financially, and emotionally stressed by caregiving. However, they perform slightly different tasks with varying amounts of unpaid help and need different kinds of support services.





⁷ Age Gap is calculated by taking the average care recipient's age and subtracting the average caregiver's age. Positive values indicate the caregiver is providing care to someone older, while negative values indicate the caregiver is providing care to someone younger.

While the face of caregiving tends to be the adult daughter, taking care of her aging mother, there is a sizable proportion of caregivers of someone age 50+ who find themselves providing care well into their later years, usually for a spouse. They provide a high number of hours of care and do so without other unpaid help, resulting in a high burden of care and setting them up for emotional stress, and physical and financial strain. Caregivers of parents are also facing these challenges at a high level, as they face joint demands of working and raising their own families, while providing care for an aging parent.

Duration of Care for Recipient

The average duration of caregiving is 3.7 years, when caring for someone age 50+. About three in 10 50+ caregivers have provided care for one to four years (29%) and nearly a quarter have provided care for five years or more (24%).

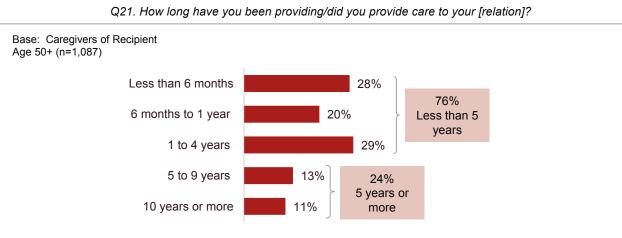


Figure 9: Duration of Care for Recipient

- Those caring for someone 85+ have been in their role an average of 4.6 years, almost two years longer than someone caring for a loved one who is between 50 and 64 (3.0 years) or between 65 and 74 (3.3 years).
- Higher-hour caregivers have been in their role for 5.1 years, longer than lower-hour caregivers (3.0 years).
- Co-resident caregivers that is, those who live with their care recipient have been in their role longer (4.7 years vs. 3.1 years).
- Primary caregivers those who provide all or the majority of the unpaid care for their recipient have been in their role longer than nonprimary caregivers (4.3 years vs. 2.7 years, on average).

Choice in Taking on Caregiver Role

When asked if they had a choice in taking on the responsibility to provide care for their loved one, half of caregivers (49%) say they had no choice in taking on this role.

The feeling of choice seems to be a matter of *who* the recipient is, <u>and</u> whether anyone else is available to provide care. Caregivers caring for someone close to them, such as a spouse or parent, are more likely to report feeling they had no choice, regardless of whether others chipped in with unpaid help. However, caregivers caring for other relatives or nonrelatives are more likely to feel obligated to help when there are no other unpaid caregivers pitching in.

	Spouse/ Partner		•		Other Relative		Nonrelative	
	Had help (n=29) A	No help (n=105) B	Had help (n=375) C	No help (n=224) D	Had help (n=113) E	No help (n=74) F	Had help (n=90) G	No help (n=70) H
Had no choice	52% ^{EGH}	62% ^{EGH}	57% ^{EGH}	61% ^{EGH}	30% ^G	54% ^{EGH}	10%	24% ^G
Had a choice	48	38	43	39	68 ^{BCDF}	45	90 ^{ABCDEFH}	76 ^{ABCDF}

Figure 10: Choice of Providing Care by Care Recipient Relationship and Presence of Other Unpaid Help

This feeling of obligation or lack of choice emerges as an important distinction, one that providers could use to provide support services to caregivers and their care recipients, caregivers who more often are facing some negative impacts arising from the care situation. Those who feel this obligation to provide care more often are primary caregivers and have been in their role for 4.4 years, on average. They provide 27.7 hours of care each week, are doing more IADLs, and performing medical/nursing tasks without preparation. They are more likely to find it difficult to coordinate care and find affordable services for their loved one. They are under physical, emotional, and financial stress from their caregiving responsibilities and feel their role as a caregiver has made their health worse. Caregivers who feel this sense of obligation are also more likely to see their caregiving role continuing over the next five years.

B. Care Recipient Living Situation

Care Recipient Living Alone

One in three care recipients ages 50+, who are not in an assisted-living or skilled nursing facility, live alone (33%); the remaining 66% live with someone.

2015 Caregiver Subgroups

• Older care recipients are more likely to live alone (39% of care recipients age 85 or older compared with 29% of recipients age 50 to 74).

• Higher-hour caregivers are less likely to say their loved one lives alone (17% vs. 41% of lower-hour caregivers).

Where Care Recipient Lives

Half of caregivers caring for someone 50+ report that their loved one lives in his or her own home. Close to one-third (32%) live in their caregiver's household.

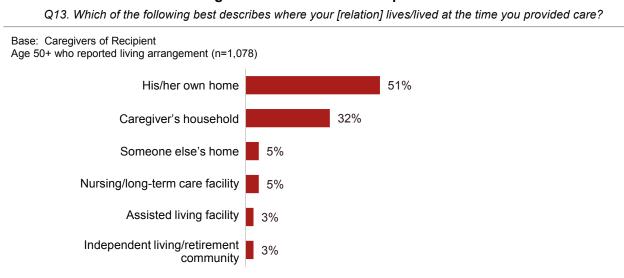


Figure 11: Where Care Recipient Lives

2015 Caregiver Subgroups

- Those providing care to someone 85+ are significantly more likely to report their loved one lives in an older adult community such as a retirement community (6%), assisted-living facility (8%), or skilled nursing facility (9%).
- Caregivers in more complex care situations are more likely to report co-residence with their recipient, including higher-hour caregivers (61% vs. 19% of lower-hour caregivers), primary caregivers (46% vs. 11% nonprimary), those doing medical/nursing tasks (43% vs. 17% not doing such tasks), those who have provided care for 5 years or more (40% vs. 30% caring less than a year), and those with a higher burden of care.

	Low burden (n=436) A	Medium burden (n=188) B	High burden (n=449) C
With caregiver	17%	24%	53% ^{AB}
In his/her own home	63 ^C	54 ^C	36
Community/care facility	16 ^C	15 ^C	6

Figure 12: Where Care Recipient Lives by Burden of Care

- Other caregivers likely to report co-residence include Hispanic (41%) or Asian • American (45%) caregivers (vs. 31% white and 27% African American), and lowerincome caregivers (38% under \$50,000 vs. 27% of \$50,000 or more).
- Care recipients with Alzheimer's or dementia are more likely to live in a community • or care facility (21% retirement community, assisted-living or skilled-nursing facility).

Distance from Care Recipient and Visit Frequency

Most (74%) caregivers of someone 50+ live within 20 minutes of their loved one (74%). 13% live within 20-60 minutes, and 12% live more than an hour's drive away.

Three-quarters (74%) of those who do not live with their 50+ care recipient say they visit him or her at least once a week, including more than five in 10 who say they visit multiple times a week (55%).

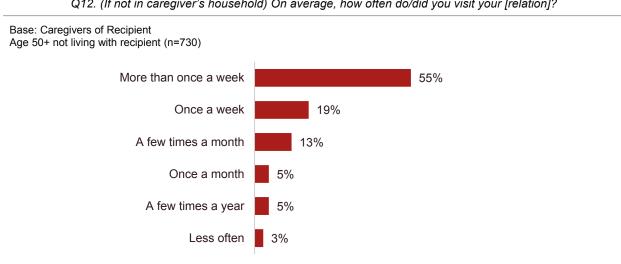


Figure 13: Frequency of Visits

Q12. (If not in caregiver's household) On average, how often do/did you visit your [relation]?

- Higher-hour caregivers tend to live closer to their care recipient: 84% live within 20 minutes of their care recipient, compared with just 70% of lower-hour caregivers.
- Among those not living together, higher-hour caregivers visit their loved one more often (82% once a week or more often vs. 72% lower-hour).
- Caregivers who perform medical/nursing tasks also visit more frequently (81% visit once a week or more vs. 68% of those not performing medical/nursing tasks).
- Visit frequency also increases with burden of care (86% high vs. 79% medium vs. ٠ 66% low burden who visit once a week or more), perhaps out of necessity to perform the greater hours and tasks that create their higher burden.

C. Care Recipient's Condition

Types of Care Recipient Conditions

Among caregivers of someone age 50+, six in 10say their loved one has a long-term physical condition (63%), while 34% say their care recipient has a short-term physical condition. Three in 10 report their loved one suffers from a memory problem, and one in five (19%) indicates his or her care recipient has an emotional or mental health problem.

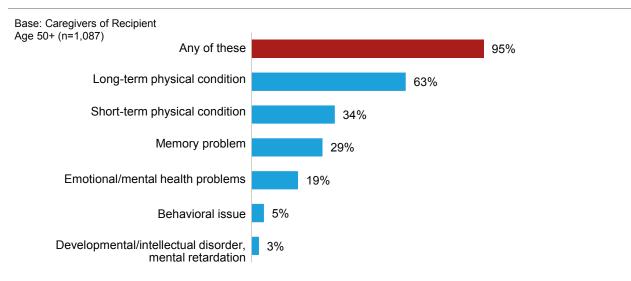


Figure 14: Types of Care Recipient Conditions

Q17. Does/did your [relation] need care because of a ...?

The type of condition varies by the care recipient age.

Figure 15: Types of Care Recipient Conditions by Age of Recipient

	Recipient Age 50–64 (n=234) A	Recipient Age 65–74 (n=239) B	Recipient Age 75–84 (n=316) C	Recipient Age 85 or older (n=298) D
Long-term physical condition	57%	59%	63%	74% ^{ABC}
Short-term physical condition	38% ^D	37% ^D	36% ^D	25%
Memory problems	16%	24% ^A	33% ^{AB}	40% ^{AB}
Emotional/mental health problem	26% ^{CD}	23% ^D	16%	14%
Behavioral issue	3%	4%	8% ^A	5%
Developmental/intellectual disorder or mental retardation	6% ^{CD}	3%	2%	1%

2015 Caregiver Subgroups

• Half of those who have been providing care for less than a year say their loved one has a short-term physical condition (51%), compared with just 19% of those who have provided care longer.

Care Recipient's Main Problem or Illness

Caregivers of those 50+ were asked to identify their loved one's <u>main</u> problem or illness for which they require care. The three most common problems or illnesses for care recipients ages 50+, cited by caregivers include: "old age" (16%), Alzheimer's or dementia (9%), or mobility issues (8%).⁸

Higher-hour caregivers report their care recipients' top problems or illnesses to be: "old age" (12%), Alzheimer's (11%), and cancer (9%).

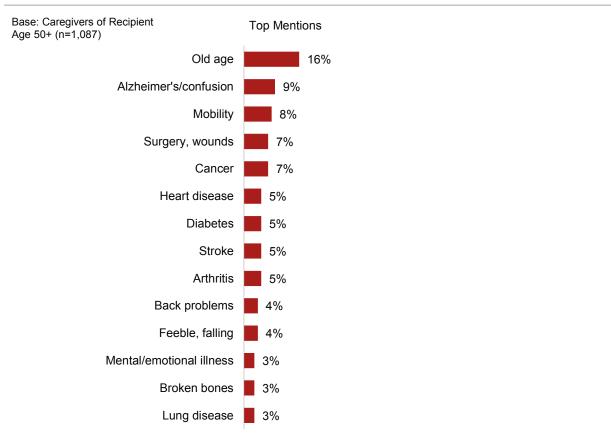


Figure 16: Main Problem or Illness Identified by Caregiver

Q18. What is/was the main problem or illness your [relation] has/had for which he/she needs/needed your care?

⁸ These are self-reports by caregivers, about what the caregiver perceives the recipient's main problem to be for which he or she needs unpaid care, and therefore may not mirror independent health statistics.

2015 Caregiver Subgroups

- Caregivers performing medical/nursing tasks are roughly twice as likely to care for someone with cancer, diabetes, lung disease, or surgery/wounds, and less likely to care for someone with a mental illness or "old age."
- The main problem for which the recipient needs care varies greatly depending on the age of the recipient.

	Recipient Age 50–64 (n=234) A	Recipient Age 65–74 (n=239) B	Recipient Age 75–84 (n=316) C	Recipient Age 85+ (n=298) D
Alzheimer's, dementia, forgetfulness	2%	5%	12% ^{AB}	18% ^{AB}
Arthritis	6 ^D	6 ^D	4	2
Back problems	8 ^{CD}	4	3	2
Cancer	8 ^D	10 ^D	6	3
Diabetes	7 ^D	7 ^D	4 ^D	2
Feeble, unsteady, falling	2	2	3	9 ^{ABC}
Heart disease	3	8 ^{AD}	6 ^A	3
Mobility	9	7	7	8
"Old Age"/aging	3	7	17 ^{AB}	35 ^{ABC}
Stroke	3	8 ^{AD}	5	3
Surgery, wounds	11 ^{CD}	11 ^{CD}	6	3

Figure 17: Selected Main Problem or Illness by Age of Recipient

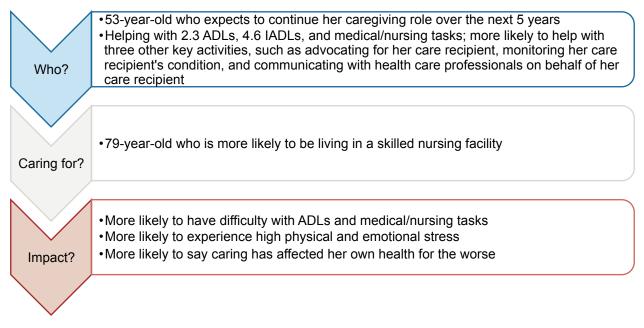
Presence of Alzheimer's or Mental Confusion

Although Alzheimer's or dementia is mentioned by fewer than one in 10 caregivers of someone 50+ as the <u>main</u> condition for which their loved one needs help, one in four says his or her care recipient does suffer from this type of condition (24%).

2015 Caregiver Subgroups

 As one would expect, the prevalence of Alzheimer's or some other mental confusion increases with care recipient age, from 13% among those caring for someone age 50–64, to 16% among recipients ages 65–74, to 28% of recipients ages 75–84, and 36% ages 85+. *Spotlight:* The nearly one in four caregivers providing care to someone age 50+ with Alzheimer's, dementia, or other mental confusion experience a complex care situation, often different from those caring for someone without these kinds of issues. Figure 18 shines a spotlight on these caregivers by highlighting what is unique about them.⁹

Figure 18: Spotlight on Caregivers of Someone 50+ with Alzheimer's, Dementia, or Other Mental Confusion



Those who provide care to someone 50+ with Alzheimer's, dementia, or other mental confusion are often doing a wide variety of tasks for their care recipient, resulting in some difficulty with these tasks, physical and emotional stress, and worsening health.

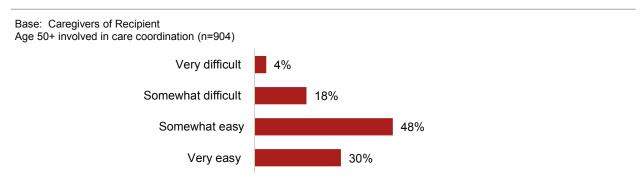
⁹ Spotlights on caregivers provide a snapshot glance at significant findings that make this subgroup unique relative to comparison groups—in this case, the comparison group is caregivers of someone age 50+ who has issues with Alzheimer's, dementia, or other mental confusion.

Ease of Coordinating Care

One in five caregivers of someone 50+ has at least some difficulty in coordinating care among his or her care recipient's providers, (22%) and close to half claim care coordination was only *somewhat easy*.

Figure 19: Ease of Coordinating Care

Q38. (If responsible for coordinating) Please think about all of the health care professionals or service providers who give/gave care or treatment to your [relation]. How easy or difficult is/was it for you to coordinate care between these providers?



- Care coordination is more difficult when the caregiver lives farther from his or her recipient. One in three caregivers who lives an hour or more away from his or her recipient report difficulty with care coordination (34% vs. 22% of those living closer but not together and 19% of co-resident caregivers).
- Care coordination is also more difficult when the recipient has multiple conditions requiring care. Very few (8%) of those caring for someone with no reported conditions¹⁰ have trouble coordinating care, but this figure climbs to 31% when the recipient has three or more conditions.

¹⁰ Count of conditions is based on Q17, list of six conditions (short-term physical condition, long-term physical condition, emotional/mental health issue, behavioral issue, developmental or intellectual delay, or memory problem). As noted earlier, typically when no conditions are selected, the recipient's main problem reported in Q18 is "old age" or aging.

D. Caregiving Activities and Burden of Care

Hours of Care Provided

Caregivers of recipients ages 50+ spend 24.1 hours per week, on average, providing care.¹¹ More than one in five provide care for 41 hours or more (22%), and three in 10 provide between nine and 40 hours of care each week (31%).

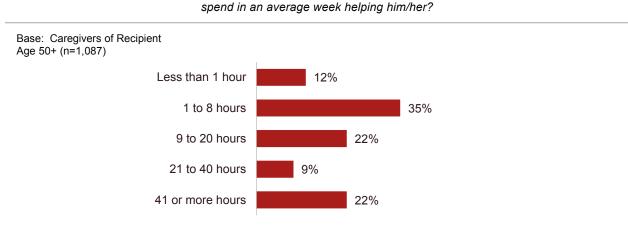


Figure 20: Hours of Care Provided

Q25. Thinking now of all the kinds of help you provide/provided for your [relation], about how many hours do/did you

Caregiver Subgroups Caregivers who provide the equivalent

- Caregivers who provide the equivalent of a fulltime job caring each week, on average, include those caring for a spouse or partner (44.4 hours a week) and those living with their care recipient (41.0 hours a week).
- Caregivers in more intensive care situations provide a greater number of hours of care, including those who perform medical/nursing tasks (33.3 hours vs. 10.9 hours of those not performing these tasks) and primary caregivers (28.7 hours vs. 17.0 hours nonprimary).
- Hispanic caregivers spend more time each week caring for a loved one than white caregivers (32.1 hours vs. 21.1 hours).

Roughly three in 10 Hispanic (32%) and African American (27%) caregivers provide care at a fulltime equivalency (41 hours or more each week), higher than either white (18%) or Asian American (22%) caregivers.

¹¹ Any caregiver-entered hours of care in excess of 98 hours per week are capped at this level, 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 the imputation model, see Appendix B: Detailed Methodology.

Help with Activities of Daily Living (ADLs)

Six in 10 caregivers help their 50+ care recipient with at least one Activity of Daily Living (ADL). Most commonly, caregivers assist their recipient with getting in and out of beds and chairs (45%). On average, caregivers help with 1.7 of the six ADLs.

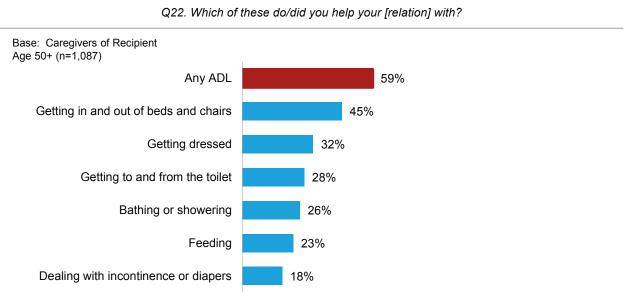


Figure 21: Help with Activities of Daily Living (ADLs)

- Caregivers who help with medical/nursing tasks are three times as likely to help with ADLs (2.4 vs. 0.7 among caregivers not doing medical/nursing tasks).
- Three-fourths of higher-hour caregivers assist with at least one ADL (76% vs. 52% for lower-hour caregivers). On average, higher-hour caregivers help with 2.7 ADLs, and are more likely than lower-hour caregivers to help with each of the six ADLs.
- Other groups more likely to be helping with at least one ADL include spousal caregivers (73% vs. 58% for all other relationships) and those caring for someone with a physical condition (63% vs. 33% when recipient has no physical condition).

What is the impact on caregivers who perform these kinds of tasks for their loved one? As the number of ADLs performed goes up, caregivers become more likely to say that caregiving has made their health worse.

	No ADLs (n=426) A	1 or 2 ADLs (n=303) B	3 to 5 ADLs (n=298) C	6 ADLs (n=60) D
Made health worse	15%	20%	28% ^{AB}	43% ^{ABC}

Figure 22: Impact on Caregiver Health by ADLs Performed

Difficulty with Activities of Daily Living (ADLs)

One in five caregivers finds it difficult to help his or her 50+ care recipient with ADLs (22% rating 4 to 5 on a 5-point scale).

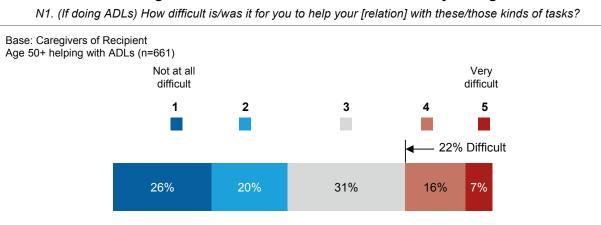


Figure 23: Difficulties with Activities of Daily Living

Caregivers who do more ADLs are more likely to report having difficulty doing them. Just 9% of those performing only one ADL have difficulty doing so, while 45% of those who perform all six ADLs find it difficult. The most difficult individual ADLs involve personal care activities, like dealing with incontinence or diapers (39% difficult), helping the recipient to and from the toilet (32%), and bathing/showering assistance (31%).

2015 Caregiver Subgroups

 Caregivers who are most likely to have difficulty with ADLs are those caring for someone with Alzheimer's or dementia (33%), higher-hour caregivers (32%), those who have been providing care for at least a year (30%), and high burden caregivers (28%).

Help with Instrumental Activities of Daily Living (IADLs) and Other Supportive Activities

There is an established list of seven Instrumental Activities of Daily Living (IADLs) that pertain to adult caregiving. On average, caregivers of those 50+ help their loved one with 4.2 IADLs. Most commonly, caregivers are helping with transportation (78%), grocery or other shopping (76%), and housework (72%).

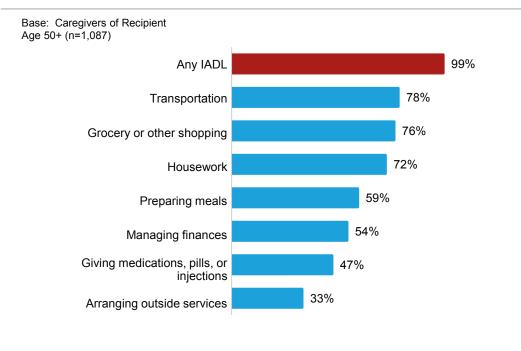


Figure 24: Help with Instrumental Activities of Daily Living (IADLs)

Q23. Do/Did you provide help to your [relation] with...?

- As with ADLs, caregivers in more complex care situations tend to help with more IADLs including: higher-hour caregivers (5.4 on average), co-resident caregivers (5.2), primary caregivers (4.5), and those caring for someone with a long-term physical condition (4.4).
- Caregivers of someone with Alzheimer's or dementia assist with 4.6 IADLs on average. They are more likely to provide transportation (83% vs. 76%), manage finances (65% vs. 50%), give medicines or injections (59% vs. 43%), and arrange services (47% vs. 29%).
- Those who provide care to someone 75+ are more likely to say they have helped arrange transportation (82%) than those caring for someone younger (70% of 50– 64-year-old recipients). Nearly half of those providing care to an 85+ recipient have helped arrange outside services (46%).

• Nearly nine in 10 Asian American caregivers provide transportation to their care recipient (86%), more than either white (78%) or African American (73%) caregivers. Asian American (4.6) caregivers also assist with more IADLs on average than white (4.2) or African American (4.2) caregivers.

Help With Other Key Activities

Caregivers of those who are 50+ have responsibilities that often extend beyond traditional caregiving tasks. Caregivers are often interacting on behalf of their loved one with providers, agencies, and professionals. Two-thirds monitor their care recipient's condition so they can adjust care accordingly (68%) and communicate with health care professionals about their recipient's' care (66%). Half advocate for their care recipient with care providers, community services, or government agencies.

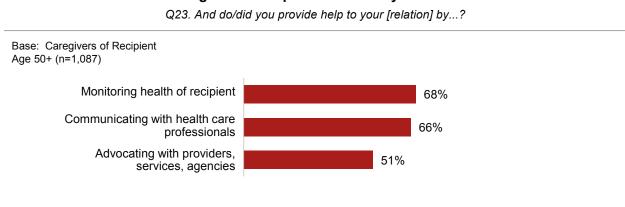


Figure 25: Help with Other Key Activities

2015 Caregiver Subgroups

• As with ADLs and IADLs, caregivers in complex care situations are more likely to perform these key activities. This includes:

Higher-hour caregivers (80% monitor, 81% communicate, 61% advocate);

High burden caregivers (82% monitor, 80% communicate, 61% advocate);

Those caring for someone with Alzheimer's or dementia (78% monitor, 80% communicate, 63% advocate); and

Those performing medical/nursing tasks (80% monitor, 78% communicate, 60% advocate).

• As care recipient age increases, so too does the likelihood that the caregiver is helping with the three key activities:

	Recipient Age 50–64 (n=234) A	Recipient Age 65–74 (n=239) B	Recipient Age 75–84 (n=316) C	Recipient Age 85+ (n=298) D
Monitoring health of recipient	62%	65%	70%	72% ^A
Communicating with health care professionals	50%	63% ^A	69% ^A	77% ^{ABC}
Advocating with providers, services, agencies	45%	48%	51%	59% ^{AB}

Figure 26: Help with Other Supportive Activities by Care Recipient Age

- Asian American caregivers are more likely (77%) than all other caregivers of other race/ethnicities to communicate with health care professionals on behalf of their care recipient.
- Those caring for a close relative (parent or spouse) are most likely to do these key activities, while those caring for some other relative are more often doing these activities than those caring for a nonrelative.

Figure 27: Help with Other Supportive Activities by Care Recipient Relationship

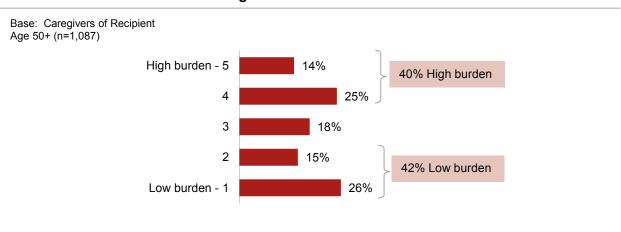
	Spouse/ Partner (n=134) A	Parent (n=602) B	Other relative (n=191) C	Nonrelative (n=160) D
Monitoring health of recipient	75% ^{CD}	75% ^{CD}	62% ^D	43%
Communicating with health care professionals	77% ^{CD}	71% ^{CD}	60% ^D	42%
Advocating with providers, services, agencies	56% ^D	57% ^{CD}	47% ^D	27%

Burden of Care

A Level of Care Index is replicated in this study to convey in a simple measure the level of "burden" experienced by the caregiver. The index is based on the number of hours of care given, as well as the number of ADLs and IADLs performed.¹²

¹² See Appendix B of Main Study in *Caregiving in the U.S. 2015* for full details of index construction.

Four in 10 caregivers caring for someone 50+ are in high burden situations (40%), 18% have a medium burden, and 42% have a low burden.





For each level of care, the average hours of care provided, ADLs performed, and IADLs performed are as listed in figure 29:

Level of Care	Low Burden (n=438)	Medium Burden (n=190)	High Burden (n=454)
Hours of care per week	4.9	9.5 ^A	50.9 ^{AB}
Number of ADLs – out of 6 total	0.2	2.2 ^A	3.1 ^{AB}
Number of IADLs – out of 7 total	3.2	4.0 ^A	5.2 ^{AB}

Figure 29: Components of Level of Care by Burden Category

- High burden situations are more common among Hispanic (50%), Asian American (49%), and African American (46%) caregivers, than among white (36%) caregivers.
- Two out of three co-resident caregivers have a high burden of care (64%), significantly more than those whose care recipient does not live with them (28%).
- A high burden is also more commonly reported by those providing care to a spouse (73%), those who perform medical/nursing tasks (58%), and those who were not employed while caregiving (50%).

Medical/Nursing Tasks Ε.

Assistance with Medical/Nursing Tasks

Recent research¹³ revealed that in addition to ADLs and IADLs, family caregivers are increasingly performing tasks that nurses typically perform. Known now as "medical/nursing tasks," these skilled activities include injections, tube feedings, catheter and colostomy care, and many other complex care responsibilities. Six in 10 caregivers of someone 50+ assist with medical/nursing tasks (58%).

Difficulties with Medical/Nursing Tasks

Of those caring for someone 50+ who perform medical/nursing tasks, 14% find it difficult (rating 4 or 5 on a 5-point scale).

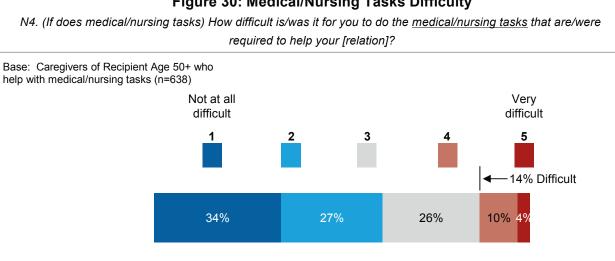


Figure 30: Medical/Nursing Tasks Difficulty

- Caregivers of someone 50+ whose care recipient has Alzheimer's or dementia are • twice as likely to have difficulty performing medical/nursing tasks (22% vs. 11% for those whose recipient does not have Alzheimer's or dementia).
- Higher-hour caregivers are more likely to feel that performing medical/nursing tasks • is difficult (20% vs. 9% of lower-hour caregivers).
- Those who have been providing care for five years or longer are more likely to say • medical/nursing tasks are difficult to provide (22% vs. 10% of those who have been caregiving for a year or less).

¹³ Reinhard, S. C., Levine, C., & Samis, S. (2012) "Home Alone: Family Caregivers Providing Complex Chronic Care," AARP Public Policy Institute & United Hospital Fund.

• High burden caregivers are most likely to say these tasks are difficult to provide (19% vs. 11% medium burden and 4% low burden).

Preparation for Medical/Nursing Tasks

Most commonly, caregivers of those 50+ are performing medical/nursing tasks *without any* preparation (43%). Only 14% of caregivers are performing medical/nursing tasks after some preparation or training. As noted above, four in 10 are not performing medical/nursing tasks.



Figure 31: Medical/Nursing Task Preparation

2015 Caregiver Subgroups

Caregivers in the most complex care situations are most likely performing medical/nursing tasks without prior preparation, including spousal caregivers (63%), those caring for someone with Alzheimer's or dementia (51%), and those who feel they had no choice (51%).

• As burden of care rises, so too does the likelihood of performing medical/nursing tasks, and doing so without preparation.

Figure 32: Medical/Nursing Task Preparation by Burden of Care Index

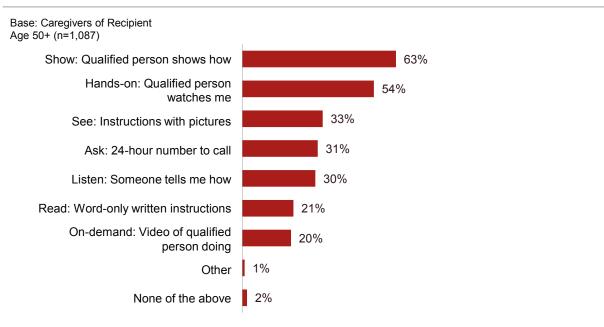
	Low Burden (n=438) A	Medium Burden (n=190) B	High Burden (n=454) C
Does tasks, not prepared	24%	43% ^A	62% ^{AB}
Does not do tasks	67 ^{BC}	36 ^C	14
Does tasks and prepared	7	18 ^A	21 ^A

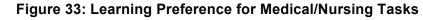
• Nearly two out of three higher-hour caregivers perform medical/nursing tasks without prior preparation (64% vs. 33% of lower-hour caregivers).

Of the limited proportion of caregivers caring for someone 50+ who received training, most (59%) say they were taught by health care staff, while more than one in four (28%) learned from a family member or friend.

Medical/Nursing Task Training

When all caregivers of those caring for someone 50+ were asked how they would like to learn a medical/nursing task, the involvement of a qualified person seems to be key, with 63% wanting such a person to *show* them how to do it and 54% wanting a *hands-on* training with a qualified person. The fewest said they would *read* word-only written instructions (21%) or watch an *on-demand* video (20%).





N8. If you had to learn how to do a medical/nursing task, how would you prefer to learn?

2015 Caregiver Subgroups

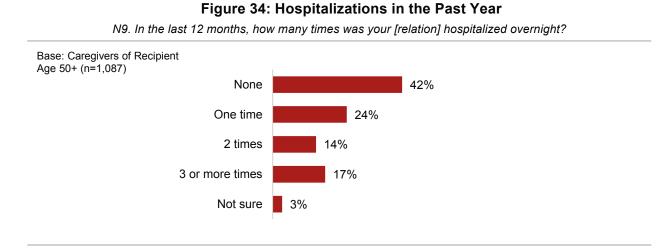
• Caregivers ages 75 or older are more interested in *listening* to someone explain how to perform the task (38% vs. 27% of caregivers age 18 to 49 years).

Of the few caregivers who received some sort of preparation to provide medical/nursing tasks, three out of four (74%) feel they were prepared very well (74%). Caregivers' evaluations of their medical/nursing training do not vary by the number of hours they provide care.

F. Care Recipient Hospitalization

Frequency of Care Recipient in the Hospital

Over half (55%) of caregivers of someone 50+ indicate their loved one has been hospitalized in the past year.



2015 Caregiver Subgroups

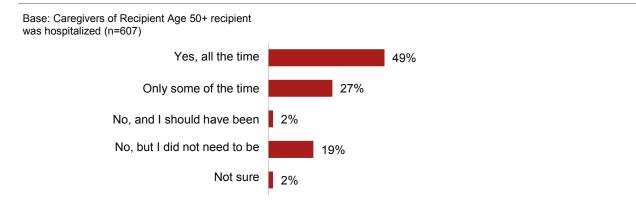
- Caregivers performing medical/nursing tasks are among the most likely to say their loved one was hospitalized in the past year (62% vs. 46% of caregivers not doing medical/nursing tasks).
- Higher-hour caregivers are more likely to report that their loved one was hospitalized three or more times in the past year (22% vs. 14% lower-hour caregivers).
- High and medium burden caregivers (63% and 60%, respectively) are more likely to report their loved one was hospitalized than low burden caregivers (45%).

Included in Health Care Discussions at the Hospital

Among caregivers of those 50+ whose recipient has been hospitalized in the past year, more than a quarter say they were included in discussions about their loved one's care only some of the time. About half say they were included all the time.

Figure 35: Care Discussion Inclusion

N10. (If care recipient was in hospital) When your [relation] was in the hospital, were you included by health care workers, like nurses, doctors, or social workers, in discussions about your [relation's] care?



2015 Caregiver Subgroups

- Higher-hour caregivers are more likely to say they were included in care discussions all of the time (58% vs. 45% of lower-hour caregivers). However, lowerhour caregivers were more likely to feel they did not need to be included in these discussions (24% vs. 11% higher-hour).
- Those caring for a spouse are more likely than someone caring for another family member (including parents) or friend to feel they were included in discussions about care only some of the time or not included at all and should have been (42% vs. 29% and 17%, respectively).

Medical/Nursing Task Preparation for Hospitalized Care Recipients

Thirteen percent of caregivers performing medical/nursing tasks for a loved one 50+ who was hospitalized say no one gave them instructions about how to perform these tasks prior to their loved one being discharged.

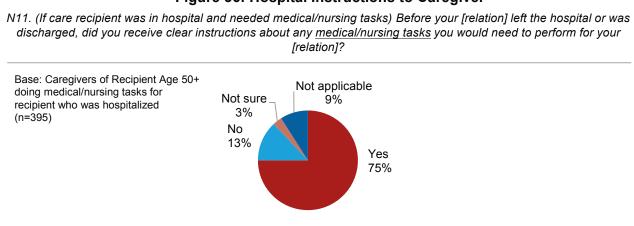


Figure 36: Hospital Instructions to Caregiver

2015 Caregiver Subgroups

- Those more likely to say they did <u>not</u> receive instructions include caregivers of adults ages 50 to 64 (20% vs. 11% caring for someone 65+).
- Higher-hour caregivers are more likely to report they *did* receive medical/nursing task instructions (87% vs. 65% of lower-hour caregivers).

G. Presence of Other Caregivers

Presence of Other Unpaid Caregivers

More than half (55%) of caregivers who care for someone 50+ report someone else has provided unpaid care to their care recipient over the past year.

2015 Caregiver Subgroups

- Certain groups of those providing care to someone 50+ are more likely to report having no other unpaid help, meaning they are their care recipient's only caregiver. This includes: those providing care to a spouse (79% with no help), high burden caregivers (52% with no help), and lower-income caregivers (51% vs. 39% with household incomes \$50,000 or greater).
- Caregivers of care recipients with Alzheimer's or dementia are more likely to <u>have</u> other help (63% with other unpaid help vs. 53% of those caring for someone without these issues).
- Two in three caregivers providing care to someone 85+ report they have additional unpaid help, while only 45% of those caring for someone age 50 to 64 report additional assistance.
- Higher-hour caregivers are less likely to have additional unpaid help (43%) than lower-hour caregivers (61%).

Primary Caregiver Status

Six in 10 caregivers of someone 50+ are primary unpaid caregivers (61%), meaning that they are sole caregivers (44%) or there are other unpaid caregivers but they themselves provide the majority of unpaid care (16%). The 39% who are nonprimary caregivers includes 12% who share caregiving responsibilities equally with someone else and 27% who say another caregiver provides most of the unpaid care.

2015 Caregiver Subgroups

- Three out of four (76%) higher-hour caregivers of someone 50+ are their care recipient's primary caregiver, more so than lower-hour caregivers (54%).
- As caregiver age rises, so too does the likelihood of being the primary caregiver for a loved one.

	Caregiver Age					
	18–49 50–64 65–74 75 or olde					
	(n=415) A	(n=422) B	(n=196) C	(n=246) D		
Percent Primary Caregiver	59%	55%	68% ^{AB}	83% ^{ABC}		

Figure 37: Primary Caregiver Status by Caregiver Age

Use of Paid Services

Among those providing care to someone age 50+ not living in a nursing home, 34% report their care recipient received paid help in the past year.

2015 Caregiver Subgroups

• As care recipient age increases, so too does the likelihood that the caregiver has paid assistance:

			Recipient Age 75–84	•
	(n=224)	(n=227)	(n=292)	(n=248)
	А	В	С	D
Has paid assistance	22%	26%	42% ^{AB}	44% ^{AB}

Figure 38: Paid Assistance by Care Recipient Age

- Use of paid services is often related to the care recipient's illness or condition and, therefore, a presumed need for additional assistance with more arduous tasks. Caregiver groups that are most likely to report the presence of other paid help include those caring for someone with Alzheimer's or dementia (47% vs. 30% without), and caregivers caring for someone with a long-term physical condition (40% vs. 27% of those with a short-term condition).
- Caregivers not living with their recipient are more likely to report use of paid services (38% vs. 27% co-resident caregivers). However, among co-resident caregivers, higher-hour caregivers are twice as likely to have utilized paid services (33%) than lower-hour caregivers (17%).
- As the caregiver's socioeconomic status rises, so too does the chance that his or her care recipient utilized paid help. This includes:

College-educated caregivers (43% vs. 30% with less education), and

Caregivers with \$50,000 or more in household income (37% vs. 30% with lower income).

Η. Strain and Stress of Caregiving

Caregiver Health

Half (48%) of caregivers caring for someone 50+ say their health is excellent or very good. 36% rate their health as good, and 17% state it is fair or poor. By comparison, 10% of the general adult population describes their health as *fair* or *poor*.¹⁴



Figure 39: Caregiver Health

2015 Caregiver Subgroups

- As burden rises, so too does the percentage of caregivers in fair or poor health (21% high burden vs. 12% low burden).
- A caregiver's health is strongly correlated to his or her household income. Of caregivers with less than \$30,000 in household income, 30% describe their health as fair or poor. This percentage declines sharply to 7% of caregivers with household incomes of \$100,000 or more. There is a similar pattern with caregiver education levels.
- Other groups apt to say their health is *fair* or *poor* include those caring for a spouse (24% vs. 15% for all other relationships), higher-hour caregivers (22% vs. 14% lower-hour), and those performing medical/nursing tasks (20% vs. 12% not doing this).

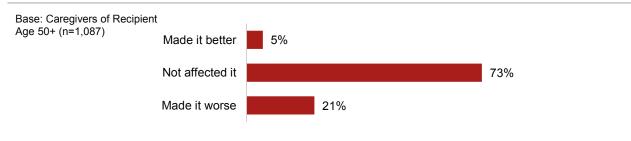
¹⁴ CDC/NCHS, National Health Interview Survey, January–June 2014, Family Core component.

Caregiver Health Changes

Seven in 10 caregivers of someone 50+ feel providing care has not affected their own health (73%), and one in five feels caregiving has made his or her health worse.

Figure 40: Impact of Caregiving on Caregiver's Health

D2. How would you say taking care of your [relation] has affected your health?



2015 Caregiver Subgroups

• Those caring for a close relative, such as a spouse or parent, are at a much greater risk of declining health as a result of caregiving.

	Spouse (n=134) A	Parent (n=602) B	Other relative (n=191) C	Nonrelative (n=160) D
Made it worse	34% ^{CD}	25% ^{CD}	14% ^D	5%
Not affected it	63	70	79 ^{AB}	86 ^{AB}
Made it better	4	4	7	9 ^B

Figure 41: Impact on Caregiver Health by Care Recipient Relationship

• As with health status, caregivers in more complex care situations are more likely to report their health has suffered as a result of providing care. This includes:

Those who felt they had no choice in taking on their role (32% vs. 11% with a choice),

Those caring for someone with Alzheimer's or dementia (32% vs. 18%),

Higher-hour caregivers (29% vs. 18% lower-hour),

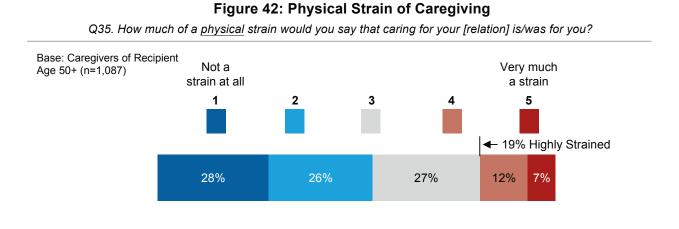
High burden caregivers (28% vs. 14% of low burden caregivers), and

Caregivers in their role for a year or more (28% vs. 14% caring for less than a year).

• White and Asian American (25% and 24%, respectively) caregivers are more likely to say caregiving made their health worse (vs. 14% of African Americans and 16% of Hispanics).

Physical Strain of Caregiving

One in five caregivers of someone 50+ faces a high level of physical strain as a result of his or her caregiving duties (19% rating a 4 or 5 on a 5-point scale). One in four experiences a moderate strain (27% rating a 3).



2015 Caregiver Subgroups

 Again, caregivers in complex care situations, are more likely to experience negative impacts as a result of caregiving – in this case, physical strain. This includes higherhour caregivers (33% high physical strain), high burden caregivers (32%), Alzheimer's or dementia caregivers (29%), those performing medical/nursing tasks (27%), and co-resident caregivers (26%).

Emotional Stress of Caregiving

Four in 10 caregivers who provide care to someone 50+ say their caregiving situation is highly stressful (38% rating stress 4 or 5 on a 5-point scale). An additional 26% report moderate stress (rating of 3).

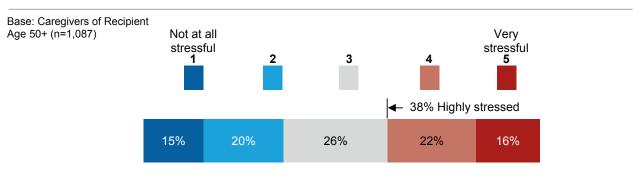


Figure 43: Emotional Stress of Caregiving

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

2015 Caregiver Subgroups

• Caring for a close relative, like a spouse or parent, who is 50+, is more emotionally stressful for caregivers than caring for another relative or nonrelative.

Figure 44: Emotional Stress by Care Recipient Relationship

	Spouse (n=134) A	Parent (n=602) B	Other relative (n=191) C	Nonrelative (n=160) D
Highly stressed (4–5)	42% ^D	44% ^{CD}	32% ^D	17%

- Chronic or long-term conditions among 50+ care recipients seem to be particularly likely to cause emotional stress for caregivers. About half of those caring for someone who has Alzheimer's or dementia (50%) or a long-term physical condition (44%) report feeling emotional stress.
- Emotional stress is especially high among those who feel they had a lack of choice (53%) and co-resident higher-hour caregivers (50%).
- In addition, emotional stress increases as caregiving continues beyond a year's time (44% vs. 31% less than a year) or as the burden of care increases (46% high vs. 37% medium and 30% low).
- White caregivers (41%) are more likely than African Americans (32%) or Hispanics (31%) to feel emotionally stressed by their role as a caregiver.

Financial Strain from Caregiving

Nearly one in five caregivers of someone 50+ indicate financial strain as a result of providing care (17% rating 4 or 5 on a 5-point scale); an additional 19% report moderate financial strain.

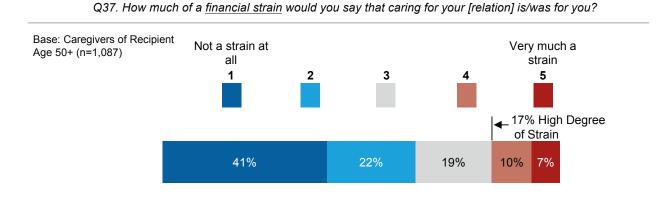


Figure 45: Financial Strain of Caregiving

2015 Caregiver Subgroups

- Living with a care recipient and providing 21+ hours of care a week can increase financial strain (30% vs. 14% all non-co-residents). However, distance does not always buffer caregivers from feeling a financial pinch. One in five (21%) caregivers who live one or more hours away experiences a financial strain, perhaps due to travel costs.
- High burden caregivers (25%) more often face financial strain than lower burden caregivers (12% low or medium).
- One in five (21%) caregivers who have been providing care for a year or longer feel financial strain, compared with just 14% of caregivers who have been in their role for less than a year.

I. Impact of Caregiving on Work

Concurrence of Employment and Caregiving

Six in 10 caregivers of someone 50+ (59%) were employed at some point in the past year while also providing care.

2015 Caregiver Subgroups

• Employment while caregiving for someone 50+ is more prevalent among the following subgroups of caregivers:

Lower-hour caregivers (66% vs. 45% of higher-hour caregivers);

Nonprimary caregivers (63% vs. 57% primary caregivers);

Low and medium burden caregivers (62% and 68%, respectively, vs. only 48% of high burden caregivers);

Males (66% vs. 54% among female caregivers); and

Higher education (65% of those with some college or more vs. 49% with less).

Hours Worked

Six in 10 employed¹⁵ caregivers providing care to someone 50+ work full time (57%), and another 15% work between 30 and 39 hours. On average, employed caregivers work 34.8 hours a week.

¹⁵ Employed caregiver refers to caregivers who were both working and providing care at the same time in the past 12 months.

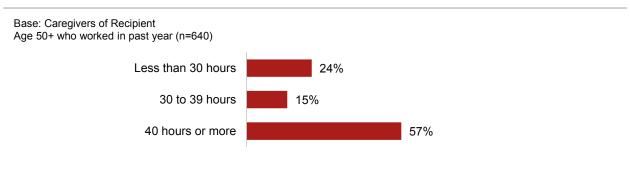


Figure 46: Number of Hours Worked per Week by Caregiver

N13. About how many hours a week, on average, do/did you work?

2015 Caregiver Subgroups

• Not surprisingly, the pattern of employment is notably different for caregivers who are 65 years of age or older—78% do not work and of those who do work, only 34% work full time. Younger caregivers are more likely to work full time (58% of those age 18 to 49 and 60% of those age 50 to 64).

Nearly one in five (17%) caregivers of someone 50+ is self-employed or own their own business. By comparison, 9.4% of all U.S. workers are self-employed.¹⁶ Self-employed caregivers work fewer hours (29.2 hours per week) than those who work for an employer (36.0).

Supervisory Knowledge of Caregiver's Role

Among caregivers working for an employer, over half report that their supervisor at work is aware of their caregiving responsibility (55%), 35% say their supervisor did not know, and one in 10 (11%) says he or she was not sure if his or her supervisor knew.

2015 Caregiver Subgroups

- As burden of care increases, so too does the chance that a caregiver's supervisor is knowledgeable of his or her caregiving role (78% high burden vs. 53% medium burden vs. 40% low burden).
- Again, working caregivers whose recipient has complex care needs are more likely to say their supervisor is aware of their caregiving responsibilities. This includes higher-hour caregivers (77% vs. 48% of lower-hour caregivers), those caring for someone with Alzheimer's or dementia (70% vs. 50% without), and those performing medical/nursing tasks (67% vs. 40% not).

¹⁶ Current Population Survey, Annual Social and Economic Supplement, 2012 data, presented in Bureau of Labor Statistics Monthly Labor Review article "Female self-employment in the United States: An update to 2012" (October 2014).

If a working caregiver is providing care for a close relative, such as a spouse (71%) or parent (61%), it becomes increasingly common for the caregiver's supervisor to be aware of his or her care role.

Workplace Benefits for Caregivers

Among working caregivers of someone 50+, half report their employer offers paid sick days (53%) or flexible work hours (53%). Fewer than a quarter of employers offer employee assistance programs (24%) or telecommuting (24%).¹⁷

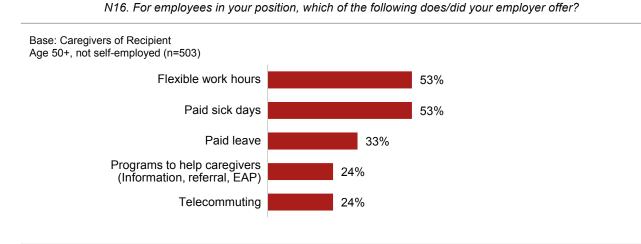


Figure 47: Workplace Benefits for Caregivers

2015 Caregiver Subgroups

• Nearly all workplace benefits, with the exception of flexible work hours, are more commonly reported by caregivers working fulltime.

	Hours worked per week Among those not self-employed				
	Less than 30 30 to 39 40 or mo (n=115) (n=61) (n=327 A B C				
Flexible work hours	59%	48%	52%		
Paid sick days	22%	45% ^A	66% ^{AB}		
Telecommuting or working from home	21%	13%	27% ^B		
Programs to help caregivers	14%	13%	30% ^{AB}		

Figure 48: Workplace Benefits by Hours Worked per Week

¹⁷ These numbers may be higher than actual occurrence because prior research has shown that 40% of employees do not fully understand their benefits package. Society for Human Resource Management (SHRM) (December 2011) "40% Don't Understand Their Benefit Options; Web-Based Tools Can Help," SHRM Online.

Work Impacts as a Result of Caregiving

Often, it is difficult for caregivers to balance work and caregiving. Caregivers sometimes make choices that change their work situations when caregiving demands become too much. Six in 10 caregivers say they have experienced at least one impact or change to their employment situation as a result of caregiving, such as cutting back on their working hours, taking a leave of absence, receiving a warning about performance or attendance, or other such impacts.

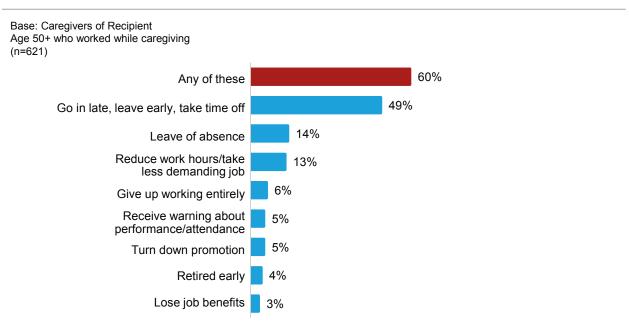


Figure 49: Work Impacts Due to Caregiving

Q34. As a result of caregiving, did you ever experience any of these things at work?

2015 Caregiver Subgroups

• Those caregivers in complex care situations are more likely to report work impacts, again presenting yet another way caregiving can negatively affect particular groups of caregivers. Groups include the following:

High burden caregivers are among the most likely subgroup of caregivers of those 50+ to report having experienced <u>any</u> work impacts as a result of caregiving (73% vs. 65% moderate burden and 49% low burden). They are more likely to report they experienced seven of the eight work impacts (exception is being warned about performance or attendance).

Primary caregivers are more likely to report impacts on their work (67% vs. 52% of nonprimary caregivers), as are those who feel they had no choice in taking on their caregiving role (70% vs. 50% with a choice).

Caregivers who perform medical/nursing tasks are more likely to have experienced all of the eight work impacts (70% report experiencing at least one vs. 49% of those not doing medical/nursing tasks).

Working caregivers of those 50+ who retired or quit working did so to have more time to care for their loved one (38%) or because their work did not allow flexible hours (29%). Very few (2%) caregivers of those 50+ say they have been fired from a job as a result of being a caregiver.

J. Information Needs and Caregiver Support

Caregiver Training and Information Needs

More than eight out of 10caregivers providing care to someone 50+ say they could use more information or help on caregiving topics (84%). Caregivers most often want information about keeping their loved one safe at home (43%) and about managing their own stress (42%). One in four caregivers providing care to someone 50+ would like more information about making end-of-life decisions (24%).

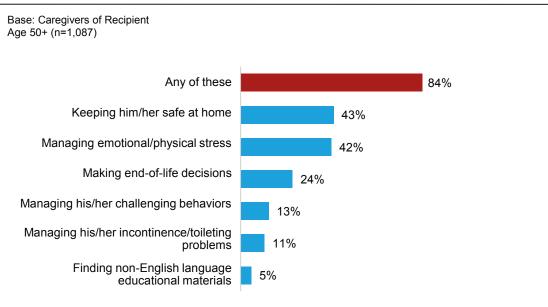


Figure 50: Caregiving Information Needs

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

2015 Caregiver Subgroups

• As noted earlier, those who perform medical/nursing tasks feel higher levels of physical and emotional stress, and are more likely to help their care recipient with getting to and from the toilet and with incontinence. Therefore, it is not surprising that caregivers who perform medical/nursing tasks are more likely to want information on managing emotional or physical stress (49%), making end-of-life

decisions (27%), managing their recipient's challenging behaviors (17%), and incontinence (15%).

- Those caring for someone with Alzheimer's or dementia are more likely to experience emotional stress and therefore more likely to want information on how to manage stress (49%). These caregivers are also more likely to want information about managing challenging behaviors (31%).
- Caregivers who feel higher levels of emotional stress are the same caregivers likely to want more information about managing stress, including: co-resident caregivers (53%), those who feel they had no choice in taking on their role (52%), and high burden caregivers (52%).
- Caregivers providing care to someone 85+ are more likely to want information about end-of-life decisions (28%) and incontinence than caregivers of younger care recipients (15%).
- Hispanic (25%) and Asian American (20%) caregivers are more likely to want non-English language materials (vs. 1% each whites and African Americans).

The youngest caregivers (age 18 to 49) are more likely to want non-English materials (6% vs. 3% of caregivers age 50+), echoing demographic shifts that have made the youngest caregivers more diverse than the older caregivers.

Conversations with Health Care Providers

One in three caregivers of someone 50+ says a health care provider, such as a doctor, nurse, or social worker, has asked about what was needed to care for their recipient. Only 16% say a health care provider has asked what they need to care for themselves.

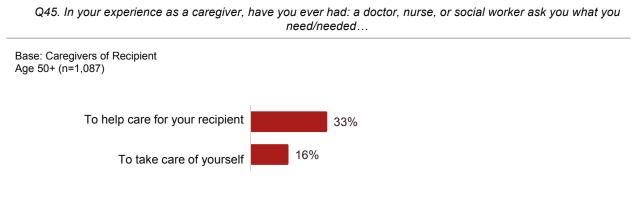


Figure 51: Conversations with Health Care Providers

2015 Caregiver Subgroups

 Caregivers in more complex care situations are more likely to report having these kinds of conversations, both about their needs for recipient care and needs for selfcare, including:

High burden caregivers (46% vs. 21% of low burden caregivers; 23% self-care vs. 10%);

Alzheimer's caregivers (46% recipient care vs. 30% recipient without Alzheimer's or dementia; 24% self-care vs. 14%); and

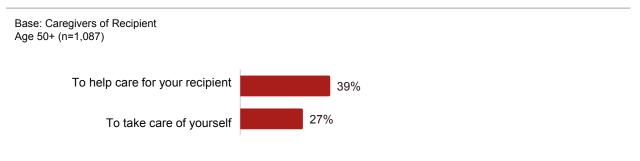
Those performing medical/nursing tasks (43% recipient care vs. 20% who do not; 21% self-care vs. 9%).

Unfortunately, these conversations are <u>not</u> occurring for a majority of caregivers, even among those groups likely to discuss these issues with health care providers.

When asked if these kinds of conversations would have been helpful, four in 10 say they would like to be asked about their needs for recipient care, (39%) and 27% show interest in conversations about self-care.

Figure 52: Helpfulness of Conversations with Providers

N20. Which of the following do you think would be/have been helpful to you: require a doctor, nurse, or social worker to ask you about what you need/needed...



2015 Caregiver Subgroups

 Caregivers of someone 50+ who are more likely to see value in these discussions include:

High burden caregivers (49% recipient care vs. 32% low burden; 37% self care vs. 17%);

Caregivers of someone with Alzheimer's or dementia (47% recipient care vs. 37% without this issue; 34% self-care vs. 25%);

Those performing medical/nursing tasks (46% recipient care vs. 30% not doing medical/nursing tasks; 32% self-care vs. 19%); and

Co-resident caregivers (45% recipient care vs. 36% those not living together with recipient; 35% self-care vs. 23%).

• African American and Asian American caregivers providing care to someone 50+ are especially likely to feel these conversations would be helpful.

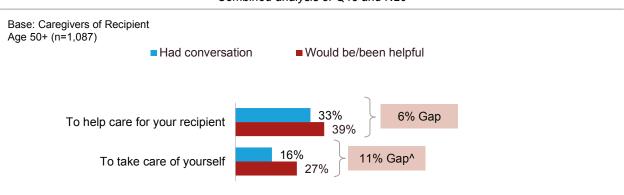
Figure 53: Helpfulness of Conversations with Providers by Caregiver, Race/Ethnicity

	Caregiver Race/Ethnicity				
How helpful would it have been to require a doctor, nurse, or social worker ask you about what you need to…	White (n=613) A	African American (n=178) B	Hispanic (n=175) C	Asian American (n=186) D	
Help care for your recipient	38%	50% ^{AC}	37%	54% ^{AC}	
Take care of yourself	23%	40% ^{AC}	29%	41% ^{AC}	

Need Gap in Conversations

There is a greater demand for these types of conversations among caregivers of someone 50+ than there are conversations happening; this creates a need gap. The need gap is greater in terms of discussions about caregiver's own needs for self-care (11% gap) than it is for discussions about recipient care (6% gap).

Figure 54: Need Gap in Conversations with Providers



Combined analysis of Q45 and N20

^ Gap is significantly higher for self-care conversations than for recipient care conversations

Use of Caregiver Support Services

Three out of five caregivers providing care to someone 50+ have received or experienced at least one supportive service. Most common is having modifications made to their loved ones' home (36%), followed by requesting financial assistance for their loved one (27%). Fewer have used transportation or respite services.

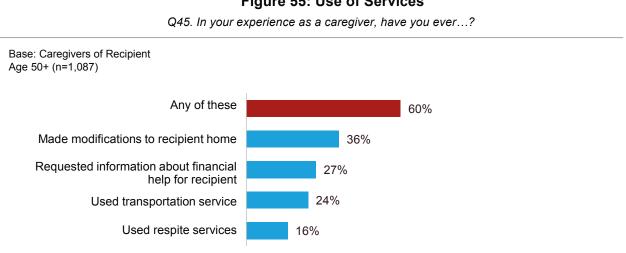


Figure 55: Use of Services

2015 Caregiver Subgroups

The likelihood of using these supports or services goes up markedly—for all but • respite—once caregivers have been providing care for a year or longer.

	Less than a year (n=503) A	1 year or longer (n=583) B
Had modifications made to recipient's home	29%	43% ^A
Requested information about financial help	20%	34% ^A
Used transportation service	21%	27% ^A
Used respite services	15%	16%

Figure 56: Use of Services by Duration of Care

- Caregivers of a close relative, like a parent or spouse, are more likely (41%) to report having made home modifications than those caring for other relatives (31%) or nonrelatives (19%).
- More than four in 10 caregivers providing care to someone 85+ report their care recipient has had modifications made to his or her home (44% vs. 31% of those 50-64 and 31% of those 65–74).

- Caregivers who do not live with their loved one are more likely to report the use of transportation services (26% vs. 20% co-resident).
- The use of respite services is more common among Asian American (21%), Hispanic (20%), and African American (22%) caregivers than it is among white (13%) caregivers.

Affordability of Services

One in four (25%) caregivers of someone 50+ says it is difficult to get affordable services in his or her loved one's community that would help with his or her care.

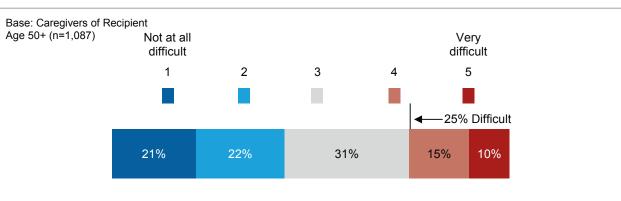


Figure 57: Affordable Assistance in Care Recipient's Area

N19. How difficult is/was it to get affordable services in your [relation's] local area or community that could help/would

have helped you care for your [relation], like delivered meals, transportation, or in-home health services?

2015 Caregiver Subgroups

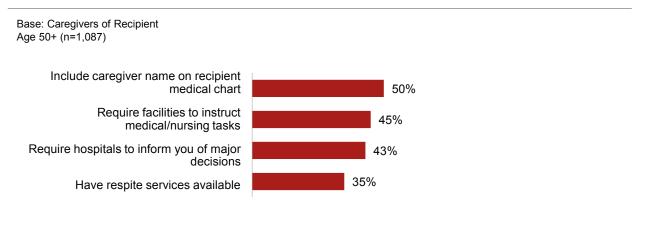
Caregivers in complex care situations often have difficulty finding affordable support services. This includes high burden caregivers (32% vs. 19% low burden), higher-hour caregivers (30% vs. 22%), those performing medical/nursing tasks (29% vs. 18% not performing these), and those caring for someone with a long-term physical condition (28% vs. 19% without).

Policy Proposals for Caregiver Support

When asked to gauge their perception of how helpful several policy proposals might be in improving their caregiving experience, 50% of caregivers of someone 50+ feel a policy to have their own name on the recipient's medical chart would be helpful, while 45% feel it would be helpful to require hospitals to demonstrate medical/nursing tasks, or inform them about major decisions (43%).

Figure 58: Helpfulness of Caregiving Support Policies

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?



2015 Caregiver Subgroups

- Caregivers caring for loved ones 85 and older are more likely to find each of the facility/hospital-related policies helpful.
- As education level increases, so too does the perceived helpfulness of the three facility/hospital-related policies (include caregiver name on recipient medical chart, instruction of medical/nursing tasks, and inform caregiver of major decisions about recipient care).
- Those caring for someone with a long-term physical condition are more likely to find helpfulness in all four proposed policies.
- As caregiving duration rises, so too does the perceived helpfulness of having the caregiver's name on their loved one's medical chart (43% helpful among those caring less than a year vs. 53% caring 1–4 years vs. 61% caring 5 years or longer).
- The idea of "getting a break" by having respite services available is especially appealing to higher-hour co-resident caregivers (45%), high burden caregivers (45% vs. 24% low burden), and those caring for someone with Alzheimer's or dementia (47%).

Of three financial policies or programs presented to caregivers of those 50+ as potential ways to help them, equal proportions felt that being paid for some of their care hours (32%) and an income tax credit (29%) would be most helpful.¹⁸

¹⁸ Caregivers were asked to pick the one financial policy they find/would have found most helpful, which is unlike the caregiver support policies where caregivers were able to indicate helpfulness of multiple policies.

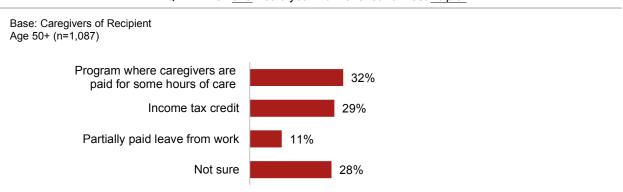


Figure 59: Most Preferred Financial Support Policy

Q47. Which one would you find/ have found most helpful?

2015 Caregiver Subgroups

 Lower-income caregivers are more interested in being paid to provide care, while higher-income caregivers show greater interest in a tax credit.¹⁹

Figure 60: Most Preferred Financial Support Policy by Caregiver Household Income

	Less than \$30,000 (n=303) A	\$30,000 to \$49,999 (n=199) B	\$50,000 to \$99,999 (n=335) C	\$100,000 or more (n=250) D
Income tax credit	17%	28% ^A	32% ^A	41% ^{ABC}
Paid for some hours of care provided	46% ^{BCD}	34% ^D	27% ^D	18%
Partially paid leave of absence from work	11%	10%	10%	14%

- Caregivers who are not working prefer to be paid for the hours of care they provide (38% vs. 27% employed), while those working prefer the tax credit (36% vs. 20% not working), or the leave of absence (13% vs. 8% not working).
- The idea of being paid for at least some hours of care is more popular among coresident higher-hour caregivers (44% vs. 32% co-resident lower-hour and 26% nonco-resident lower-hours caregivers).

Caregivers of those 50+ generally support an additional policy proposal of banning workplace discrimination against workers with caregiving responsibilities, with two out of three in support of this proposal (67%).

¹⁹ While there are some differences in financial policy preference by race/ethnicity and caregiver age, these are due to income differentials in these key demographic groups.

K. Long-Range Planning

Expectations of Future Caregiving Role(s)

More than half (54%) of 50+ caregivers expect they will be a caregiver for some adult (either their current recipient or someone else) during the next five years. Nearly one in four are not sure if they will be a caregiver during the next five years (23%), and almost as many say they do not expect their caregiving role to continue (22%).

2015 Caregiver Subgroups

- Three in five caregivers providing care to someone 85+ expect to have a caregiving role in the next five years (61%), compared with only 47% of those caring for someone 50 to 64 or 49% of those caring for someone 65 to 74.
- Those caring for immediate family members who are 50+, particularly a spouse or parent, are especially likely to believe their caregiving role will continue.

Figure 61: Expectation of Future Caregiving by Care Recipient Relationship

	Spouse	Parent	Other relative	Nonrelative
	(n=134)	(n=602)	(n=191)	(n=160)
	A	B	C	D
Expects to be caregiver	56% ^{CD}	63% ^{CD}	43%	33%

- As length of time providing care goes up, so too does the expectation to continue caregiving in the next five years (41% of those caring less than 1 year vs. 61% 1–4 years vs. 73% 5+ years).
- Asian American caregivers are more likely to believe their caregiving role will continue during the next five years (65% vs. 55% for all other racial/ethnic groups).
- The expectation for continued caregiving also rises with income (60% with \$50,000 or more vs. 49% lower income).

Long-Term Planning

Only half of caregivers say their 50+ care recipient has/had plans in place for future care. Three in 10 are able to confirm there are no such plans in place (29%); two in 10 are not sure (21%).

2015 Caregiver Subgroups

• Some caregivers of someone 50+ are more likely to report their loved one *has* made future care plans, including those:

Caring for someone 75+ (59% vs. 39% of those caring for someone 50–74),

Caring for someone with Alzheimer's or dementia (57% vs. 47%), and

Higher-income caregivers (54% vs. 44% of those with \$50,000 or less).

• Those caring for a spouse are especially likely to indicate a lack of planning, while those caring for a nonrelative are unsure about their recipient's plans.

	Spouse (n=134) A	Parent (n=602) B	Other relative (n=191) C	Nonrelative (n=160) D
Has made plans for future care	51%	51%	47%	46%
Has no plans for future care	40 ^{CD}	31 ^D	27 ^D	16
Unsure if recipient has made plans	8	18 ^A	25 ^A	37 ^{ABC}

Figure 62: Care Recipient's Future Care Planning by Care Recipient Relationship

When asked about their own plans for future care, just 43% of caregivers indicate they have plans in place.

2015 Caregiver Subgroups

• Older caregivers are more likely to have plans in place for their own care.

Figure 63: Caregiver Future Care Planning by Caregiver Age

	18–49	50–64	65–74	75 or older
	(n=415)	(n=422)	(n=196)	(n=246)
	A	B	C	D
Has made plans for future care	33%	42% ^A	56% ^{AB}	78% ^{ABC}

- Those who are caring for a spouse (56%) are more likely than those caring for a parent or other relative (39%) to say they have plans in place for the future.
- As income rises, so too does future planning for care (36% earning less than \$50,000, vs. 45% earning \$50,000 to \$99,999, vs. 53% earning \$100,000 or more).

L. Respondent Profile

Six in 10 caregivers of someone 50+ are female, and the caregivers' average age is 50.3. More than 60 percent are white, and 16 percent are Hispanic. One-third (35%) have a high school education or less, about the same as those who have a college degree (36%).

	Recipient Age 50+ (n=1,087)	Recipient Age 50–64 (n=234) A	Recipient Age 65–74 (n=239) B	Recipient Age 75–84 (n=316) C	Recipient Age 85+ (n=298) D
Caregiver Gender					
Male	40%	43%	44%	37%	39%
Female	60	57	56	63	61
Age of Caregiver					
18 to 34	21%	44% ^{BCD}	23% ^{CD}	14% ^D	7%
35 to 49	24	28 ^D	32 ^D	25 ^D	11
50 to 64	35	19	25	40 ^{AB}	52 ^{ABC}
65 to 74	12	5	15 ^{AC}	8	22 ^{AC}
75 or older	8	3	5	13 ^{ABD}	8 ^A
Mean age	50.3	40.6	48.3 ^A	52.6 ^{AB}	58.2 ^{ABC}
Race/Ethnicity of Caregiver					
White	62%	50%	56%	64% ^A	77% ^{ABC}
African American	13	16 ^D	19 ^{CD}	11	7
Hispanic	16	22 ^D	17 ^D	16 ^D	9
Asian American	7	8	6	7	6
Other	2	4	2	2	1
Caregiver Education					
Less than high school	7%	8%	8%	8%	5%
High school graduate	28	33	27	26	28
Some college	21	26 ^C	20	19	21
Technical school	7	7	10	7	6
College graduate	20	16	19	23	23
Graduate school	16	10	17 ^A	18 ^A	18 ^A

Figure 64: Demographic Summary by Care Recipient Age

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

Caregivers caring for someone 50+ have an average household income of \$55,000, comparable to the United States overall,²⁰ six in 10 are employed.

	Recipient Age 50+ (n=1,087)	Recipient Age 50–64 (n=234) A	Recipient Age 65–74 (n=239) B	Recipient Age 75–84 (n=316) C	Recipient Age 85+ (n=298) D
Caregiver Marital Status					
Married	57%	50%	55%	62% ^A	57%
Living with a partner	7	11 ^C	8	5	6
Widowed	5	4	5	3	9 ^{ABC}
Separated	2	1	3	1	2
Divorced	8	4	10 ^A	9 ^A	10 ^A
Single, never married	20	27 ^{BCD}	19	18	14
Children/Grandchildren in Caregiver's Household					
Yes	28%	35% ^{CD}	35% ^{CD}	25% ^D	18%
No	71	62	63	75 ^{AB}	81 ^{ABC}
Caregiver Household Income					
Less than \$50,000 (net)	46%	58% ^{CD}	49% ^D	44%	38%
Less than \$15,000	12	20 ^{BCD}	12	8	10
\$15,000 to \$29,999	16	16	18	16	13
\$30,000 to \$49,999	19	22 ^D	19	20	15
\$50,000 or more (net)	54	42	51	56 ^A	62 ^{AB}
\$50,000 to \$74,999	18	14	19	19	19
\$75,000 to \$99,999	13	12	10	13	16 ^B
\$100,000 or more	23	17	22	24 ^A	28 ^A
Median household income	\$55,000	\$43,100	\$51,700	\$58,400	\$66,500
Caregiver Employment Status					
Employed in past year while caregiving	59%	64% ^D	56%	61%	55%
Not employed	41	36	44	39	45 ^A

Demographic Summary by Care Recipient Age (continued)

²⁰ The median U.S. household income is \$53,046. U.S. Census Bureau, American Community Survey, 2013.

Most live in an urban or suburban setting. One in 10 served in the armed forces, and a similar proportion of care recipients have. Nine percent of caregivers of someone 50+ self-identify as lesbian, gay, bisexual, or transgender (LGBT).²¹

	Recipient Age 50+ (n=1,087)	Recipient Age 50–64 (n=234) A	Recipient Age 65–74 (n=239) B	Recipient Age 75–84 (n=316) C	Recipient Age 85+ (n=298) D
Care Recipient Living Location					
Urban/Suburban	71%	73%	72%	68%	73%
Rural	28	26	27	32	26
Caregiver Living Location					
Urban/Suburban	85%	85%	87%	84%	84%
Rural	15	15	13	16	16
Caregiver Armed Forces Service					
Served on active duty	10%	9%	13%	9%	11%
Did not ever serve	89	89	86	92	88
Recipient Armed Forces Service					
Served on active duty	15%	6%	15% ^A	20% ^A	19% ^A
Did not ever serve	83	92 ^{BCD}	84	78	80
Caregiver LGBT status					
Yes	9%	13% ^{CD}	8%	7%	7%
No	91	86	91	92 ^A	93 ^A

Demographic Summary by Care Recipient Age (continued)

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

²¹ Of all screened respondents in *Caregiving in the U.S. 2015*, 6.9% self-identify as LGBT. In addition, we find that caregiving for an adult is more common among those who identify as LGBT (20.4% vs. 16.5% not identifying as LGBT). Nationally, Gallup estimates 5.6% of Americans are LGBT. Gates, G.J. (October 2014) "LGBT Demographics: Comparisons among population-based surveys," The Williams Institute.

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 wellbeing of those they care for, the Alliance supports a network of 80+ state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations. Learn more at www.caregiving.org.

About AARP

AARP is a nonprofit, nonpartisan organization, with a membership of nearly 38 million, that helps people turn their goals and dreams into real possibilities, strengthens communities and fights for the issues that matter most to families such as healthcare, employment and income security, retirement planning, affordable utilities and protection from financial abuse. We advocate for individuals in the marketplace by selecting products and services of high quality and value to carry the AARP name as well as help our members obtain discounts on a wide range of products, travel, and services. A trusted source for lifestyle tips, news and educational information, AARP produces AARP The Magazine, the world's largest circulation magazine; AARP Bulletin; www.aarp.org; AARP TV & Radio; AARP Books; and AARP en Español, a Spanish-language website addressing the interests and needs of Hispanics. AARP does not endorse candidates for public office or make contributions to political campaigns or candidates. The AARP Foundation is an affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. AARP has staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. Learn more at www.aarp.org.

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