

Caregiving in the U.S. 2009

National Alliance for Caregiving
in collaboration with
AARP

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Table of Contents

I.	Introduction.....	1
II.	Overview of Methodology	2
III.	Key Findings	4
IV.	Detailed Findings.....	12
	A. Prevalence of Caregiving.....	12
	B. Basics of the Caregiving Situation	13
	C. Caregiving Activities and Burden of Care	21
	D. Presence of Other Caregivers	30
	E. Care Recipient Living Situation.....	35
	F. Care Recipient's Condition	39
	G. Strain and Stress of Caregiving	47
	H. Impact of Caregiving on Work	52
	I. Information Sources and Needs	56
	J. Support for Caregivers.....	62
	K. Respondent Profile	67

Table of Figures

Figure 1: Estimates of Household Caregiving Prevalence by Age of Recipient.....	12
Figure 2: Estimates of Household Caregiving Prevalence by Household Race/Ethnicity. 12	
Figure 3: Estimates of Individual Caregiving Prevalence by Age of Recipient.....	12
Figure 4: Estimates of Individual Caregiving Prevalence by Age of Predominant Recipient	13
Figure 5: Current vs. Past Care	13
Figure 6: Number of Care Recipients	14
Figure 7: Gender of Care Recipient and Caregiver	14
Figure 8: Age of Predominant Care Recipient.....	15
Figure 9: Age of Predominant Care Recipient by Age of Caregiver	16
Figure 10: Age of Caregiver	17
Figure 11: Age of Caregiver by Caregiver Race/Ethnicity	17
Figure 12: Care Recipient Relation to Caregiver	18
Figure 13: Marital Status of Care Recipient.....	19
Figure 14: Duration of Care for Recipient.....	20
Figure 15: Choice in Taking on Caregiver Role.....	20
Figure 16: Hours of Care Provided.....	21
Figure 17: Help with Activities of Daily Living (ADLs)	22
Figure 18: Help with Instrumental Activities of Daily Living (IADLs)— for Adult Recipients.....	24
Figure 19: Help with Other Supportive Activities—for Adult Recipients	26
Figure 20: Help with Caregiving Support Activities (CSAs)—for Child Recipients.....	27
Figure 21: Level of Care Index	28
Figure 22: Components of Level of Care by Burden Category	28
Figure 23: Burden Category by Caregiver Age.....	29
Figure 24: Presence of Other Unpaid Caregivers.....	30
Figure 25: Primary Caregiver Status	31
Figure 26: Use of Paid Services	32
Figure 27: Predominant Caregiver Among Unpaid and Paid Helpers	33
Figure 28: Where Care Recipient Lives.....	35
Figure 29: Who Care Recipient Lives With.....	36
Figure 30: Caregiver Distance from Care Recipient.....	37
Figure 31: Frequency of Visits.....	38
Figure 32: Types of Care Recipient Conditions	39
Figure 33: Types of Care Recipient Conditions by Age of Recipient	40
Figure 34: Main Problem or Illness Identified by Caregiver	41
Figure 35: Main Problem or Illness by Age of Recipient.....	42

Figure 36: Main Problem or Illness by Burden Category	42
Figure 37: Presence of Alzheimer's or Mental Confusion.....	43
Figure 38: Limitations of Child Recipients	44
Figure 39: Use of Prescription Medicine.....	44
Figure 40: Medication Management.....	45
Figure 41: Ease of Coordinating Care	46
Figure 42: Caregiver Health	47
Figure 43: Impact of Caregiving on Caregiver's Health	48
Figure 44: Physical Strain of Caregiving	49
Figure 45: Emotional Stress of Caregiving	50
Figure 46: Time for Family and Friends.....	51
Figure 47: Financial Hardship of Caregiving.....	51
Figure 48: Concurrence of Employment and Caregiving.....	52
Figure 49: Current Employment Status of Caregiver.....	53
Figure 50: Work Accommodations Due to Caregiving.....	54
Figure 51: Sources Used for Caregiving Information.....	56
Figure 52: Internet Usage for Caregiving Information.....	57
Figure 53: Caregiving Information Sought Online.....	58
Figure 54: Caregiving Training	59
Figure 55: Caregiving Information Needs	60
Figure 56: Use of Services	62
Figure 57: Home Modifications.....	63
Figure 58: Use of Technology in Caregiving.....	64
Figure 59: Reaction to Caregiving-Related Policies	65
Figure 60: Profile of Respondents	67
Figure 61: Profile of Respondents – Trend in Caregivers of Recipient Age 18+	69
Figure 62: Profile of Respondents by Care Recipient Age	72

Introduction

The purpose of this study is to present a portrait of family caregivers today, and to compare it to a portrait of caregivers in the past. A national profile of caregivers first emerged from the 1997 Caregiving in the U.S. study. A related study was conducted in 2004, and now, in 2009, we are presenting the results of the third wave of this important study. Each of the three studies has inquired about certain core elements of caregiving situations, while also exploring new areas.

The core areas that we examined include:

- The prevalence of caregivers in the U.S.
- Demographic characteristics of caregivers and care recipients
- The caregiving situation in terms of the nature of caregiving activities, the intensity and duration of care, the health conditions and living situation of the person to whom care is provided, and other unpaid and paid help provided
- How caregivers are affected by their role, at work, at home, and in their health situation
- Information needs and information sources

This year's unique areas of exploration were:

- Use of the Internet for information
- What public policies would support caregivers
- Use of technology

For the first time, this year's study also includes caregivers of children with special needs, in addition to the caregivers of adults age 50 or older included in the 1997 study and age 18 or older in 2004. The caregiving of children was distinguished from typical parenting by ensuring that it resulted from a medical, behavioral, or other condition or disability. Because caregivers' situations can vary markedly depending on the age of their care recipient, this report includes three companion reports that separately explore the experiences of caregivers whose loved one is (1) under the age of 18, (2) age 18 to 49, or (3) age 50 or older.

In addition, this is the first Caregiving in the U.S. report to present data trends.

Overview of Methodology

This report is based primarily on quantitative telephone interviews with 1,480 family caregivers age 18 or older. Caregivers are defined as those who provide unpaid care to an adult or to a child with special needs, as described in the following two questions.

In the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.

In the last 12 months, has anyone in your household given unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability? This could include care for ongoing medical conditions or serious short-term ones, emotional or behavioral problems, or developmental problems, including mental retardation.

The interviews include a random sample of 1,000 family caregivers and, to supplement the ethnic minority interviews achieved in that sample, 480 additional interviews with minorities. The interviews break out by race as follows: 858 White, non-Hispanic caregivers, 200 African-American caregivers, 201 Hispanic caregivers, 200 Asian-American caregivers, and 21 caregivers of another race. These results came from screening 6,806 adults. In addition to the 1,480 completed caregiver interviews, there were 83 additional validated caregivers who did not complete the interview. The remaining 5,243 screened interviews include 4,795 with no caregiver present and 448 with a non-validated caregiver.

The random sample interviews were reached using random digit dialing. Geographic density samples were used to target the oversample of African-Americans. For Hispanics and Asian-Americans, a combination of surname and density sampling was used. In addition, Knowledge Networks screened their Asian panel members to pre-identify Asian-American caregivers.

All of the data gathered while screening potential respondents for caregivers were saved in order to estimate the proportion of households that include one or more caregivers. The screening data and survey results are weighted by household, based on the race/ethnicity and age of the householder, and type of household (family or non-family) reported by the initial respondent in each household. Weighting targets were derived from the Current Population Survey, 2008 Annual Social and Economic Supplement, conducted by the U.S. Census Bureau.

In addition to the 1,480 caregiver interviews in the base study, an additional 288 interviews were conducted with caregivers of individuals age 50 or older, bringing the total among this caregiving subset to 1,397 caregivers, including just over 800 Whites, 200 African-Americans, and 200 Hispanics, as well as 170 Asian-Americans and a small number of other minorities from the base study. The Whites and some of the minorities were reached through random digit dialing. The remaining minorities were reached through targeted samples like those described above. These interviews were weighted according to the

weighted distribution of caregivers of individuals age 50+ in the base sample by race/ethnicity, age of householder, and type of household (family or non-family).

The questionnaire was designed to replicate many of the questions posed in 1997 and 2004 National Alliance for Caregiving/AARP national caregiving studies as well as to explore new areas. It was designed by a team from the National Alliance for Caregiving, AARP, and Mathew Greenwald & Associates, and was also shaped by input from a team of advisors listed in the acknowledgements. The full questionnaire is presented in Appendix A to this report.

Respondents were given the option of conducting the interview in Spanish or English, and 31% of Hispanic respondents chose to conduct part or all of the interview in Spanish. The average length of the interview was 22.3 minutes. The survey was conducted between March 5 and June 17, 2009.

Results from 1,247 respondents to a similar 2004 survey of caregivers caring for individuals 18 or older are also presented in this report.

The margin of error for the overall 2009 results is plus or minus approximately 3.1 percentage points at the 95% confidence level. This means that 95 times out of 100, a difference of greater than three percentage points would not have occurred by chance. For subgroups of caregivers, the margin of error is larger.

All details of the methodology are included in Appendix B to this report.

Reading this Report

The main graphics and tables in this report present results for *all* 1,480 caregivers in the 2009 study. For any questions that were also asked in 2004, the trend among caregivers of adults age 18 or older is shown in mini-tables to the right of each graphic.

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%.

For statistical purposes, the base number of respondents shown in each table or graphic is unweighted.

To signal *key* differences between 2004 and 2009 findings, the report uses an asterisk to highlight any percentage that is significantly higher than the comparison figure. When there are multiple columns of figures being compared, a superscript letter next to a figure indicates that it is significantly higher than the figure in the column designated by that letter.

When presenting differences between different racial/ethnic groups, any mention of Whites or African-Americans refer solely to non-Hispanic individuals.

Key Findings

Prevalence of Caregiving

In the past 12 months, an estimated 65.7 million people in the U.S. have served as unpaid family caregivers to an adult or a child. About 28.5% of the respondents surveyed reported being caregivers. The percentage of people who are caregivers does not appear to have changed significantly since 2004.¹

More than three in ten U.S. households (31.2%) report that at least one person has served as an unpaid family caregiver within the last twelve months, leading to an estimate of 36.5 million households with a caregiver present.

Basics of the Caregiving Situation

Caregivers are predominantly female (66%). They are 48 years of age, on average. One-third take care of two or more people (34%). A large majority of caregivers provide care for a relative (86%), with over one-third taking care of a parent (36%). One in seven care for their own child (14%). Caregivers have been in their role for an average of 4.6 years, with three in ten having given care to their loved one for five years or more (31%).

The typical recipient of care is also female (62%) and averages 61 years of age. Seven in ten caregivers take care of someone 50 years of age or older, 14% take care of an adult age 18 to 49, while 14% take care of a child under the age of 18.

2004-2009 Trend for Caregivers of Recipient Age 18+

Both caregivers of adults and their care recipients are now older than their counterparts were five years ago. Among caregivers of adults (ages 18 or older), the average age of the caregiver rose from 46.4 to 49.2 years of age. This change is due to a decline among younger caregivers, those under the age of 50, and a shift upward among caregivers age 50 to 64.

The average care recipient's age increased from 66.5 to 69.3—among caregivers of adults—mainly because of an increase in the percentage age 75 or older (from 43% to 51%).

Care Recipient Condition

When caregivers are asked what they perceive to be the main reason their recipient needs care, the top two problems they report are old age (12%) and Alzheimer's or dementia (10%). Other frequent mentions are mental/emotional illness (7%), cancer (7%), heart disease (5%), and stroke (5%).

¹ The 2009 study used a new method for measuring prevalence of caregiving. However, the methodology used in 2004 was applied to the 2009 findings to estimate if a change in prevalence has occurred. See the detailed findings and the detailed methodology appendix for more information.

Given that care recipients are older in 2009 than were 2004 recipients, it is not surprising that a larger share of 2009 caregivers say Alzheimer's or dementia is the *main* problem for which their loved one needs care (6% 2004 vs. 12% 2009). Any caregivers who did not report Alzheimer's, dementia, or confusion as the main problem were asked whether their care recipient had this type of condition. Analysis shows that the overall prevalence of Alzheimer's or mental confusion has not changed significantly (23% 2004 vs. 26% 2009 among caregivers of adult recipients).

Long-term physical conditions are present in seven out of ten caregiving situations (69%) and 35% of caregivers say the person they care for has a short-term physical condition. There is some overlap between these two types of conditions; 17% say their recipient has both. Three in ten say their care recipient has an emotional or mental health problem (32%), although a physical condition is also present in most of these cases (78%). Nine in ten caregivers say their recipient takes prescription medications.

2004-2009 Trend for Caregivers of Recipient Age 18+

Caregivers of adults show an increase in the use of such medications, from 85% in 2004 to 93% in 2009. This change may also be related to the increase in the age of care recipients.

Caregiving Activities and Burden of Care

On average, caregivers spend 20.4 hours per week providing care. Caregiving is particularly time-intensive for those who live with their care recipient (39.3 hours/week), and those caring for a child under the age of 18 (29.7 hours/week). Female caregivers spend more time providing care than men do, on average (21.9 vs. 17.4 hours/week).

2004-2009 Trend for Caregivers of Recipient Age 18+

Since 2004, there have been changes in the amount of time caregivers of adult recipients spend taking care of their loved one, and in the way they use their caregiving time. The number of hours spent giving care declined by 2.6 hours, so now caregivers of adults spend an average of 18.9 hours per week in their helping role.

How is caregivers' time spent? A majority of caregivers help their loved one with at least one Activity of Daily Living (ADL) (56%).² The most common of these is helping the care recipient get in and out of beds and chairs (40%). Personal care tasks are also fairly common—32% help their care recipient get dressed, 26% assist with bathing or showering, 24% help with getting to and from the toilet, and 18% help deal with incontinence. One in five help feed their loved one (19%).

² To distinguish caregiving of children with special needs from typical parenting or child care, caregivers of children were asked to report help with an ADL only if it was because the child was less able to do that task than other children of the same age without his/her condition. Further, ADLs performed for very young children were not counted, since it would be expected that they would need assistance. (See Figure 17.)

Caregivers who were not employed while caregiving are more likely to help with each of the ADLs than employed caregivers are, except getting in and out of beds and chairs. Female caregivers are more likely than men to help with grooming—getting dressed (36% vs. 24%) and bathing (31% vs. 17%).

Caregivers of adults help on average with 4.4 out of seven Instrumental Activities of Daily Living (IADLs), including transportation (83%), housework (75%), grocery shopping (75%), meal preparation (65%), managing finances (64%), and arranging or supervising outside services (34%).

Other types of supportive activities carried out by caregivers of adults include advocating for their care recipient with care providers, government agencies, or schools (52%) and performing medical therapies or treatments (22%).

It is more common for co-resident caregivers and primary³ caregivers to help with these IADLs and the two supportive activities, compared to their counterparts.

2004-2009 Trend for Caregivers of Recipient Age 18+

Even though there was a decline in the average hours that caregivers of adults spent providing care, there was an increase in the proportion of caregivers who help with at least one Activity of Daily Living, from half in 2004 (50%) to 58% in 2009. In particular, the share who help their loved one get in and out of beds and chairs rose from 36% to 43%. This increase is apparent only among caregivers who do not have paid help. It is also fueled by a sharper increase among non-co-resident caregivers.

Caregivers in 2009 are also more likely to help their loved one with several Instrumental Activities of Daily Living, including housework (from 69% to 75%), preparing meals (59% vs. 65%), and arranging or supervising outside services (30% vs. 34%). All of these increases occur regardless of the age of the care recipient, so they do not appear to be due to the higher average age of 2009 care recipients. With the decline in hours of care counterbalanced by increases in selected ADLs and IADLs, the overall burden of care as measured by the Level of Care Index has not changed.

Caregivers of children with special needs help their care recipient with 5.6 out of nine Caregiving Support Activities (CSAs), on average. These include monitoring the child's condition (85%), ensuring that others know how to deal with him/her (84%), advocating on his/her behalf (72%), performing emotional or behavior treatments or therapies (65%), giving medicines or injections (64%), dealing with financial issues (63%), giving physical or medical therapies (44%), preparing a special diet (40%), or arranging/supervising outside services (39%). Male caregivers of children with special needs are more likely than female caregivers to help with financial issues (76% vs. 57%) and to advocate on behalf of the child (85% vs. 67%).

³ A primary caregiver is a person who provides all or the majority of the unpaid care for their care recipient.

All of these activities add up to a burden of care that is high for 32% of caregivers, moderate for 19%, and relatively low for 46%.⁴

Most caregivers (66%) find it *very or somewhat* easy to coordinate care given by the various health professionals and service providers that help their loved one, but 25% indicate some difficulty with it. Caregivers of children with special needs are especially likely to find this coordination at least somewhat difficult (40%), as are those who help arrange or supervise paid services for their care recipient and those who care for recipients with many conditions.

Presence of Other Caregivers

Most caregivers—among those whose recipient is not in a nursing home—say at least one other unpaid caregiver helps their care recipient (66%), while only 35% use paid help from aides, housekeepers, or other people paid to help their recipient.

Older caregivers, those age 65 or older, are most likely to be sole unpaid caregivers, without the support of other unpaid caregivers (47% vs. 30% of younger caregivers). Co-resident caregivers are also twice as likely to be sole caregivers (49% vs. 25% living separately).

The use of paid care is, of course, related to the caregiver's household income, such that 30% of those in households with less than \$50,000 in income use paid help, compared to 48% among those with \$100,000 or more of income.

2004-2009 Trend for Caregivers of Recipient Age 18+

There has been an increase in the share of caregivers of adults who say that their care recipient receives help from other unpaid caregivers, but a decrease in the share who receive paid help. Among caregivers of an adult recipient who is not in a nursing home, two-thirds now say there is at least one other unpaid caregiver helping their loved one (68%), up considerably from the 59% who reported this type of help in 2004. On the other hand, use of paid aides, housekeepers, or other staff declined from 41% in 2004 to 35% in 2009. These shifts could be due to tight budgets resulting from the 2008 recession and the financial crisis late that year.

Of the caregivers of adults whose recipients do use paid help, there has been a sharp increase in the share of caregivers who say this paid help provides more care than they or other unpaid caregivers do, from 19% in 2004 to 37% in 2009. There has not been an increase in the burden of care experienced by those who use paid help, nor an increase in employment while caregiving, either of which might motivate caregivers to shift more responsibilities to paid caregivers. Nor is the change a result of care recipients being older in 2009; the increase is evident in all care recipient age groups.

⁴ 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.

It is possible that the rise in reliance on paid care is driven by additional disposable income among those using paid services. Six in ten (63%) 2009 users of paid services have \$50,000 or more in household income, compared to only 47% in 2004.

In spite of these changes in the use of paid and unpaid help, the proportion of caregivers who consider themselves the primary caregiver has remained unchanged. Just over half of all caregivers say they provide all or most of the unpaid care (56%).

Nearly three in ten caregivers have used an outside transportation service for their loved one (29%), while 12% have used a respite service.

2004-2009 Trend for Caregivers of Recipient Age 18+

Caregivers of adults in 2009 are more likely than 2004 caregivers to avail themselves of two types of supportive services—transportation services (from 18% in 2004 to 29% in 2009) and respite services (5% vs. 11%).

Care Recipient Living Situation

Half of caregivers say their loved one lives in his or her own home (51%), while 29% live together with their care recipient. Only 4% of caregivers say that their care recipient lives in a nursing home, and the same percentage say their recipient's home is an assisted living facility. Co-residence is found more frequently when the caregiver's household income is less than \$50,000 (38% vs. 23% of those in higher income households), suggesting that co-residence arises from necessity. The likelihood of sharing a home with the care recipient declines as the recipient's age rises, from 65% of those caring for a child recipient to 20% of those caring for someone age 50 or older.

Three-quarters of caregivers live either together or within twenty minutes of their care recipient (74%). Of the caregivers who do not live with their care recipient, three-quarters visit him/her at least once a week (76%).

2004-2009 Trend for Caregivers of Recipient Age 18+

Caregivers of adults now live slightly closer to their care recipients than they did in 2004. The proportion living either together or within 20 minutes of their care recipient rose from 66% to 72%, with a complementary decline in the proportion living 20 minutes to one hour away (from 19% to 13%).

Strain and Stress of Caregiving

Most caregivers feel their health is *excellent* or *very good* (57%), while 17% say it is *fair* or *poor*. The longer a caregiver has been providing care, the more likely she or he is to report *fair* or *poor* health. By comparison, 13% of the U.S. adult population describe their health as *fair* or *poor*.⁵

⁵ Source: Provisional Summary Health Statistics for U.S. Adults, National Health Interview Survey, 2008, dated August 2009.

In fact, 17% of caregivers feel their health has gotten worse as a result of caregiving. Those who have been providing care for five years or more are nearly twice as likely as shorter-term caregivers to report this decline (24% vs. 14%). Other caregivers who are more likely to report worsening health include high burden caregivers (28% vs. 12% for medium to low burden caregivers), co-resident caregivers (28% vs. 13%), women (20% vs. 12% men), and those providing 21 or more hours of care per week (29% vs. 13% caring 0 to 20 hours).

Three in ten caregivers consider their caregiving situation to be emotionally stressful (31% rating their stress as 4 to 5 on a 5-point scale), and co-residence and burden of care are again factors related to stress. Women are also more likely than men to feel high stress (35% vs. 25%).

Half of caregivers (53%) say that their caregiving takes time away from friends and other family members. Those who have sacrificed this time with family and friends are far more likely to feel high emotional stress (47%) than are those who have been able to maintain the time they spend with family and friends (14%).

Even after the economy tumbled in late 2008 and during the ongoing recession, only 15% of caregivers report feeling a strong financial hardship—defined as a rating of 4 to 5 on a 5-point scale—as a result of caring for their loved one. However, this hardship is far more prevalent among those caring for their own child (37% vs. 11% of those caring for some other family member or friend), and those in households with less than \$50,000 in income (21% vs. 10% in higher income households). High burden situations are also correlated with financial challenge. In high burden situations, 23% report a strong financial hardship compared to 10% of low burden caregivers who do.

Impact of Caregiving on Work

Over seven in ten caregivers were employed at some time when they were caregiving (73%). Among them, two-thirds have gone in late, left early, or taken time off during the day to deal with caregiving issues (66%). One in five took a leave of absence at some point while they were caregiving (20%).

2004-2009 Trend for Caregivers of Recipient Age 18+

Caregivers in 2009 more commonly report that they shift their arrival or departure times or take time off to provide care than did 2004 caregivers (57% 2004 vs. 65% 2009). This increase is apparent only among caregivers providing less than 40 hours of care a week, and is especially prominent among those providing 0 to 8 hours or 9 to 20 hours per week. Coming during a recession when feelings of job security would be expected to be low, these findings are somewhat surprising. They could be a result of broadened employer tolerance of informal flextime behavior on the part of their employees.

Information Sources and Needs

One in five caregivers say they have obtained formal caregiver training (19%), but caregivers are hungry for more help or information. In fact, three-quarters (78%) feel they need more help or information about at least one of 14 specific topics related to caregiving. Caregivers in high burden situations are particularly likely to want help or information (83% vs. 73% of low burden caregivers).

The most popular aspects of caregiving for which caregivers would like help or information are keeping their loved one safe at home (37%), managing their own stress (34%), easy activities to do with their care recipient (34%), and finding time for themselves (32%).

2004-2009 Trend for Caregivers of Recipient Age 18+

In general, the demand for caregiving information seems to have increased over the past five years. A greater proportion of caregivers desire information on at least one topic (77% vs. 67% in 2004), with 2009 caregivers showing increased interest in care recipient safety at home (36% vs. 30% in 2004), easy activities (32% vs. 27%), and choosing either a home care agency (24% vs. 13%), an assisted living facility (19% vs. 13%), or a nursing home (17% vs. 8%).

2009 caregivers express less desire for information about finding time for themselves (30% vs. 35% in 2004).

It is important that any groups who wish to support caregivers know where they turn for information related to caregiving. If caregivers were to look for information to help them take care of their loved one, their top source of information would be a health or caregiving provider (36%)—including a doctor (22%), nurse or other health professional (11%), or a hospital, caregiving provider, social worker, etc.

The Internet is also a popular resource, named top of mind as a potential resource by 25% of caregivers. However, half of all caregivers say they have used the Internet in the past year to find caregiving information (53%). Use of this resource rises in relation with household income, from 36% of caregivers with less than \$30,000 in income to 66% of those with \$100,000 or more. As one might expect, older caregivers are far less likely than younger ones to use the Internet for a caregiving-related purpose. Specifically, only 30% of those who are 65 or older used it, compared to 56% of younger caregivers. There are racial/ethnic differences in Internet usage as well. Two-thirds of Asian-American caregivers have gone online for caregiving information (66%), more so than Whites, African-Americans, or Hispanics (54%, 44%, and 50%, respectively).

Among those who used the Internet for a caregiving-related purpose, three in four looked for information about their loved one's condition or treatment (78%), while a smaller majority (58%) sought information about services for their recipient. Other goals of their online research include finding doctors or other health professionals (36%), finding information about care facilities (34%), or learning about how to do caregiving tasks (26%). Relatively few (13%) looked for support for themselves as caregivers.

Other sources of information that caregivers would consult include family, friends, and other caregivers (20%), aging or disease-specific organizations (12%), and government programs (7%).

Support for Caregivers

Technology offers great promise for facilitating some of the responsibilities that caregivers' shoulder and more generally to improve the care of their recipients. Nearly half of caregivers say some sort of technology has been used in the care of their recipient. The most prevalent technology used is an electronic organizer or calendar (24%). Half as many say their care recipient has used an emergency response system like Lifeline (12%) or that the care recipient uses a device that sends information electronically to a doctor or a care manager (11%). Nearly one in ten report use of a sensor that detects problems in the home, like when someone falls, wanders away, or leaves the stove on (9%), and 7% report use of a website or computer software to keep track of personal health records.

Of six potential national policies or programs that could be offered to help caregivers, by far the most popular is a caregiver tax credit of \$3,000. Half of caregivers rate it as the first or second most preferred policy. About three in ten prefer a voucher program where their care recipient could pay them minimum wage for at least some of their caregiving hours (29% first or second choice), and a similar proportion prefer respite services (26%). Preference for the tax credit *rises* in relation to household income, while the voucher program is much more popular among the low income caregivers.

Demographics

Seven in ten caregivers are White (72%), 13% are African-American, and 2% each are Hispanic or Asian-American. Six in ten caregivers are married (58%). More than one-third (37%) have children or grandchildren under the age of 18 in the household.

Four in ten have completed college (43%), although three in ten have had a high school education or less (29%). Four in ten have less than \$50,000 in household income (42%).

2004-2009 Trend for Caregivers of Recipient Age 18+

Caregivers of adults in 2009 have higher educational levels than seen in 2004. Specifically, 45% now have completed college, up from 36% in 2004.

Detailed Findings

A. Prevalence of Caregiving

Of the 6,806 households that were screened for this survey, 31.2% reported at least one person in the household had served as an unpaid family caregiver in the past 12 months. Given a 2008 estimate of 116,783,000 households in the U.S., the study leads to an estimate of 36.5 million households with one or more caregivers in them.

Figure 1: Estimates of Household Caregiving Prevalence by Age of Recipient

Type of Recipient	Prevalence	Estimated Number of Household with Caregivers
Overall	31.2%	36.5 million
Only child recipients	1.8%	2.2 million
Only adult recipients	24.0%	28.0 million
Both adult and child recipients	5.4%	6.3 million

The household prevalence of caregiving varies by racial/ethnic group. It is highest among Hispanics (36.1%), while Asian-Americans report the lowest rates of caregiving.

Figure 2: Estimates of Household Caregiving Prevalence by Household Race/Ethnicity

Race/Ethnicity	Prevalence	Estimated Number of Household with Caregivers
White	30.5%	25.2 million
African-American	33.6%	4.7 million
Asian-American	20.0%	.9 million
Hispanic	36.1%	4.8 million

These prevalence levels are not significantly different from those seen in 2004.⁶

The proportion of initial respondents who had served as unpaid caregivers was 28.5%. Using a 2008 estimate of 230,087,000 Americans age 18 or older, that percentage leads to an estimate of 65.7 million adults who have been caregivers within the past 12 months.

Figure 3: Estimates of Individual Caregiving Prevalence by Age of Recipient

Type of Recipient	Prevalence	Estimated Number of Caregivers
Overall	28.5%	65.7 million
Only child recipients	1.7%	3.9 million
Only adult recipients	21.2%	48.9 million
Both adult and child recipients	5.6%	12.9 million

⁶ The method of calculating prevalence has been enhanced since the 2004 study was conducted. The rate of prevalence at that time was reported as 21%. The 2009 comparable figure is 22%; it results from replicating the prior study's calculation method and assuming that we had the exact same rate of converting reported caregivers into completed interviews.

Two-thirds of caregivers provide care to only one person. However, the one-third who care for two or more people were asked to respond to survey questions with respect to the one person to whom they provide the most assistance, regardless of his/her age. This care recipient who is the subject of the survey will be called the *predominant* care recipient.

The proportion of initial respondents who served as unpaid caregivers to a predominant recipient age 50+ is 18.9%. This translates to 43.5 million Americans caring for someone of this age. This figure would be even larger if we were able to count those who care for a person 50 or older, but whose predominant recipient is younger. We also estimate there are at least 54.1 million (23.5%) of caregivers whose predominant recipient is an adult family member or friend who is age 18 or older.

Figure 4: Estimates of Individual Caregiving Prevalence by Age of Predominant Recipient⁷

Type of Predominant Recipient	Prevalence	Estimated Number of Caregivers
Predominant recipient age 50+	18.9%	43.5 million
Predominant recipient age 18+	23.5%	54.1 million

B. Basics of the Caregiving Situation

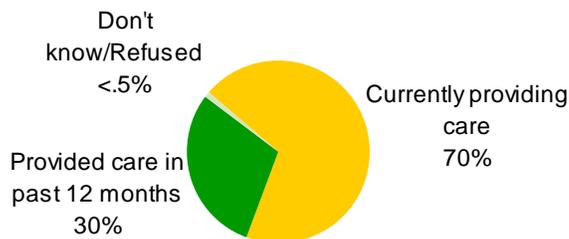
Current vs. Past Care

Seven in ten caregivers (70%) are currently caring for a loved one, while three in ten (30%) provided care in the last 12 months but are no longer doing so.

Figure 5: Current vs. Past Care

Q1. Are you currently providing unpaid help to a relative, friend, or child, or was this something you did in the past 12 months but are no longer doing?

Base: 2009 All caregivers (n=1,480)



% Currently Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
66%	68%

⁷ In order to estimate the prevalence of caregiving for a person age 50 or older, one must look at that *predominant* care recipient, since the questionnaire did not ask generally whether the caregiver provided care of *any* person age 50+. The magnitude of difference between prevalence of giving care to a predominant recipient vs. any recipient can be illustrated by looking at caregiving of adult's ages 18+. The prevalence of providing care to a predominant recipient of this age is 23.5%, somewhat lower than the 26.8% known to be caring for any recipient age 18+.

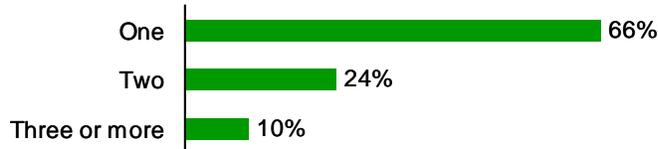
Number of Care Recipients

Two-thirds of caregivers (66%) take care of one care recipient, 24% take care of two people, and 10% take care of three or more.

Figure 6: Number of Care Recipients

Q2. *How many people, including adults and children, do/did you provide this care for [in the past 12 months]?*

Base: 2009 All caregivers
(n=1,480)



Caregivers of Recipient Age 18+	
2004† (n=1,247)	2009 (n=1,307)
69%	68%
22	22
8	10

†Note: In 2004, caregivers reported on the number of adult recipients only, so 2004 and 2009 data are not comparable.

2009 Caregiver Subgroups

- Primary caregivers—those who provide all or the majority of the unpaid care for their recipient—are more likely than non-primary caregivers to report caring for only one person (70% vs. 61%).
- The likelihood of caring for just one care recipient rises in relation to the age of the caregiver, with 62% of 18- to 49-year-old caregivers providing care to one person while 78% of caregivers age 65+ care for one care recipient.
- A similar pattern emerges with care recipient age. Specifically, 51% of those caring for a child report caring for one person, compared to 63% of those caring for an 18- to 49-year-old and 70% of those caring for someone age 50 or older.

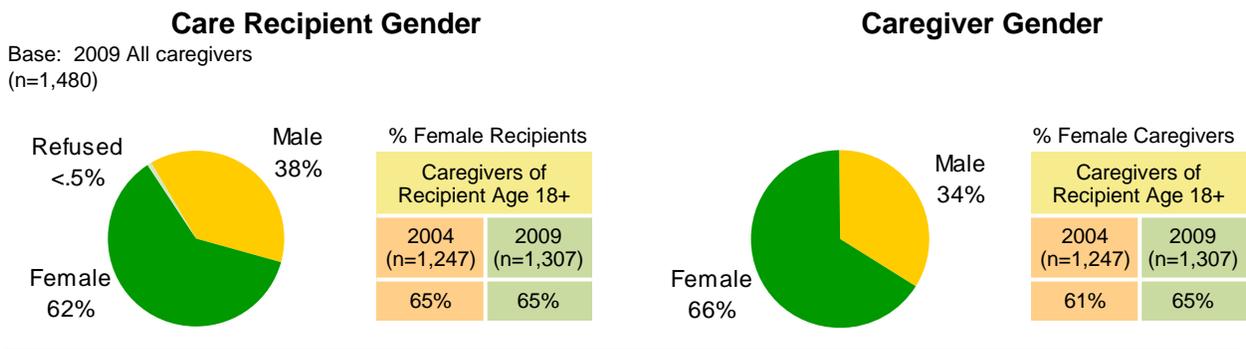
Gender of Caregiver and Care Recipient

Two-thirds of caregivers are female (66%) and one-third are male (34%). A majority of caregivers' recipients are female (62%).

Figure 7: Gender of Care Recipient and Caregiver

Q9. *[IF NEEDED] Would you mind telling me if your [relation] is/was male or female?*

Caregiver gender recorded by interviewer



2009 Caregiver Subgroups

- Half of Asian-American caregivers are male (50%), whereas the proportion of caregivers who are male is smaller among Hispanics (34%), African-Americans (30%), and Whites (34%).
- The proportion of male caregivers is also higher among those who have a college degree (38% vs. 31% of those with less education).
- Primary caregivers are more apt to be female (70%) than non-primary caregivers (61%).
- The younger the care recipient, the more likely he or she is to be male. Among child recipients, most are male (59%). The gender balance shifts to close to 50/50 among the 18- to 49-year-old recipients (47% are male), and among the 50+ recipients, the balance tips toward females (32% male, 68% female).

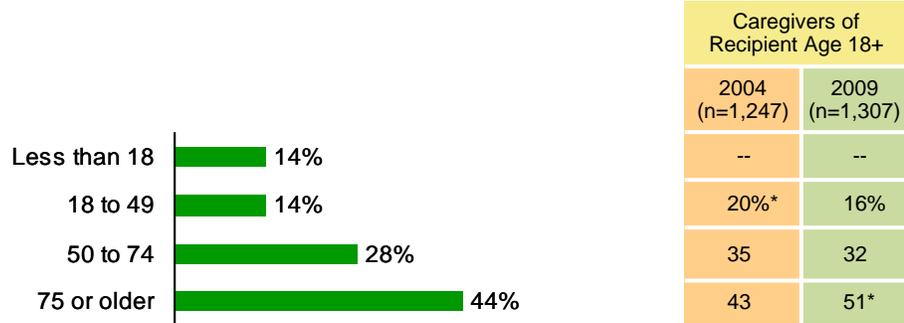
Age of Care Recipient

The average age of care recipients is 60.9 years. A plurality of caregivers (44%) take care of a person who is 75 years of age or older, and an additional 28% care for a person age 50 to 74. One in seven caregivers (14%) take care of an 18- to 49-year-old, and an equal proportion care for a child under the age of 18 (14%).

Figure 8: Age of Predominant Care Recipient

Q5. [IF 1 RECIPIENT] Now, I'd like to ask you some questions about the person for whom you provide/provided care. [IF 2+ RECIPIENTS] Let's focus on the person for whom you provide/provided the most assistance. How old is/was that person?

Base: 2009 All caregivers (n=1,480)



2004-2009 Trend for Caregivers of Recipient Age 18+

- Among those taking care of an adult, the average age of the care recipient rose from 66.5 years in 2004 to 69.3 in 2009. In particular, the proportion of care recipients ages 75 or older jumped from 43% in 2004 to 51% in 2009, while the share of recipients ages 18 to 49 declined from 20% to 16%.

2009 Caregiver Subgroups

- As one might expect, care recipient age differs in relation to the age of the caregiver. Caregivers ages 18 to 49 are three times as likely as older caregivers to take care of a child under the age of 18, and they are roughly half as likely to be caring for someone age 75 or older.

Figure 9: Age of Predominant Care Recipient by Age of Caregiver

	Caregiver Age		
	18 to 49 (n=560)	50 to 64 (n=616)	65 or older (n=285)
<i>Average Recipient Age</i>	52.8	69.4	69.5
Recipient 0 to 17 years	21%	7%	6%
Recipient 18 to 49 years	15	12	13
Recipient 50 to 74 years	35	17	29
Recipient 75+	29	63	53

- Asian-Americans tend to take care of the oldest recipients, 68.0 years old, on average, followed by Whites (63.8). African-Americans and Hispanics report younger recipients (53.1 and 49.3, respectively). Hispanic caregivers stand out as the most likely of the ethnic groups to be caregivers of children with special needs (22%), especially relative to Whites (12%).
- Primary caregivers are twice as likely as non-primary caregivers to have a child recipient (18% vs. 9%).
- College graduate caregivers' care recipients are older (65.9 years of age, on average) than the recipients of those with less education (57.1).
- Similarly, as the caregiver's household income rises, so does the likelihood that he/she takes care of an older recipient. Among caregivers with less than \$30,000 in household income, the average care recipient age is 53.3 years, and this rises to 65.7 years for caregivers in households with at least \$100,000 in income.
- Caregivers who live with their recipient take care of someone younger, on average, than do those who live separately (45.8 years of age vs. 67.1). This large difference seems to be driven by the large proportion of child recipients who live with their caregiver (65%).

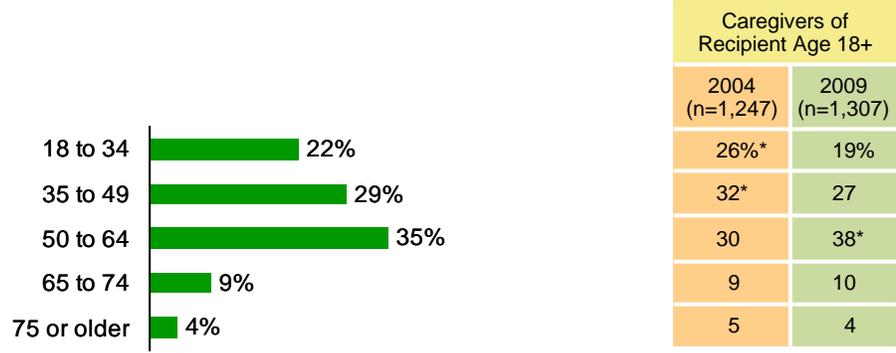
Age of Caregiver

The average age of caregivers is 48.0. About half of all caregivers are between the ages of 18 and 49 (51%).

Figure 10: Age of Caregiver

S2, S15. *How old were you on your last birthday?*

Base: 2009 All caregivers
(n=1,480)



2004-2009 Trend for Caregivers of Recipient Age 18+

- Just as the age of adult care recipients has risen since 2004, so has the average age of caregivers who care for adults, from an average of 46.4 to 49.2 years of age. The rise appears to be due mainly to an increase in the proportion of caregivers who are ages 50 to 64, from 30% 2004 to 38% now, with a complementary decline in the proportion of caregivers under the age of 50.

2009 Caregiver Subgroups

- White caregivers tend to be older than African-American and Hispanic caregivers.

Figure 11: Age of Caregiver by Caregiver Race/Ethnicity

	Caregiver Race/Ethnicity			
	White (n=858)	African-American (n=200)	Hispanic (n=201)	Asian-American (n=200)
<i>Average Caregiver Age</i>	49.9	44.5	41.6	44.3
Caregiver 18 to 34 years	16%	34%	35%	31%
Caregiver 35 to 49 years	30	23	33	26
Caregiver 50+ years	52	41	31	42

- Female caregivers are older than males, on average (48.8 years vs. 46.6 years).
- Those who were employed while they were caregivers are younger (45.9 years of age on average) than those who were not employed (54.0 years), not surprising since a notable share of the latter (40%) are retirees whom one would expect to be older.

Care Recipient Relation to Caregiver

The large majority of caregivers take care of a relative (86%), and 14% care for a friend, neighbor, or other non-relative. More care for a parent (36%) than any other relation. Specifically, 26% of caregivers care for their mother and 10% care for their father. One in seven care for their child (14%). One in twelve caregivers provide care to a parent-in-law (8%) or a grandparent or grandparent-in-law (8%).

Figure 12: Care Recipient Relation to Caregiver

Q7. What is/was this person's relationship to you?

	2009 Caregivers (n=1,480)
Relative	86%
Parent	36
Child	14
Parent-in-law	8
Grandparent or grandparent-in-law	8
Spouse or partner	5
Sibling	5
Grandchild	3
Uncle, aunt	3
Sibling-in-law	1
Other relatives	4
Non-relative	14
Friend	11
Neighbor	1
Foster child	<.5

2004-2009 Trend for Caregivers of Recipient Age 18+

- The proportion of caregivers of adults who take care of their father rose from 8% in 2004 to 12% in 2009, and there was a small decline in the share who take care of their grandmother (from 9% to 6%).

2009 Caregiver Subgroups

- The care recipient's relationship to the caregiver varies greatly depending on the caregiver's age. Caregivers who are 65 or older are more likely than younger caregivers to care for a spouse (19% vs. 3%), a sibling (12% vs. 4%), or a non-relative (19% vs. 13%).
- By contrast, the 18- to 64-year-old caregivers are more likely than older caregivers to care for relatives of an older generation, such as their parent or parent-in-law (48% vs. 23%) or a grandparent or grandparent-in-law (9% vs. 0%).

- Asian-American caregivers are more likely than caregivers overall to care for a relative (92% vs. 86%). In fact, they are twice as likely to care for a grandparent or grandparent-in-law (18% vs. 8%).

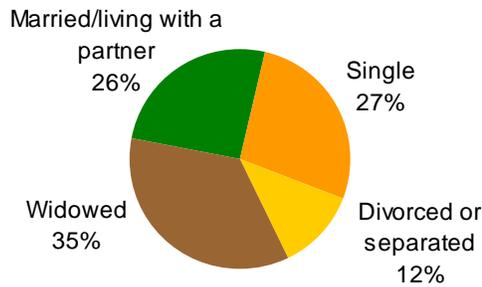
Marital Status of Care Recipient

One in three caregivers report that their care recipient is widowed (35%), one-quarter say their recipient is single, never married (27%), another one in four report their loved one is married or living with a partner (26%), and 12% report a divorced or separated marital status.

Figure 13: Marital Status of Care Recipient

Q10. Is your [relation] currently/Was your [relation] widowed, married, living with a partner, separated, divorced, or single—that is, never been married?

Base: 2009 All caregivers
(n=1,480)



% Married/Living with Partner

Caregivers of Recipient Age 18+

Year	Sample Size (n)	% Married/Living with Partner
2004	1,247	29%
2009	1,307	30%

2009 Caregiver Subgroups

- White and Asian-American caregivers are more likely to report caring for a married person (27% and 36%, respectively) than are African-American and Hispanic caregivers (13% and 19%). African-Americans and Hispanics are more apt to say their care recipient is single (40% and 38%, respectively) than are Whites (23%) or Asian-Americans (19%).

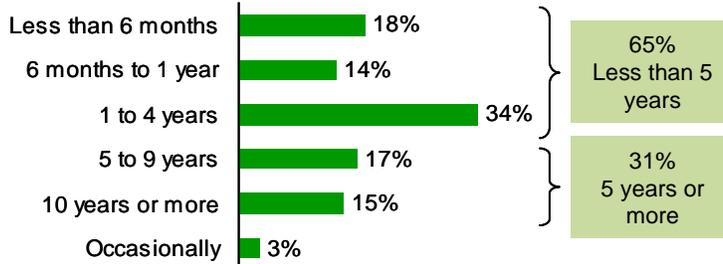
Duration of Care for Recipient

The average duration of caregiving is 4.6 years. Three in ten caregivers have provided care for less than one year (31%) and a similar proportion have cared for their loved one for one to four years (34%). Another three in ten have given care for five years or more (31%).

Figure 14: Duration of Care for Recipient

Q21. For how long have you been providing/did you provide care to your [relation]
 [FOR CHILD RECIPIENT: for his/her condition?]

Base: 2009 Caregivers
 (n=1,480)



Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
16%	18%
18*	13
33	34
13	16*
14	15
5	3

2009 Caregiver Subgroups

- Older caregivers tend to have provided care for a longer period. Caregivers age 65 or older have been in this role for an average of 7.2 years, compared to 4.9 years for 50- to 64-year-old caregivers and 3.7 years for younger caregivers.
- Primary caregivers have been in their role longer than non-primary caregivers (5.3 years vs. 3.7 years, on average). A similar difference is evident between those who feel they did not have a choice in becoming a caregiver and those who feel they did (5.5 vs. 3.9 years).
- Those who live with their care recipient have also been in their role longer, on average (6.5 vs. 3.8 years for those who live separately).
- Caregivers who are parents to their recipient have been caregivers longer, on average, than those with other relationships to their recipient (9.5 vs. 3.8 years).

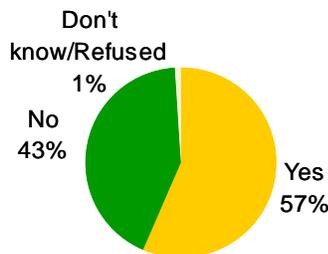
Choice in Taking on Caregiver Role

Four in ten caregivers do not feel they had a choice in taking on their caregiving responsibility (43%).

Figure 15: Choice in Taking on Caregiver Role

Q39. We have been talking about the help you provide/provided for your [relation].
 Do you feel you had a choice in taking on this responsibility for caring for your [relation]?

Base: 2009 All caregivers
 (n=1,480)



% Yes	
Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
59%	57%

2009 Caregiver Subgroups

- A larger share of White and Asian-American caregivers feel they did not have a choice (44% and 51%, respectively) than Hispanics (34%).
- Other groups who are more likely to feel they did not have a choice include:
 - Women (45% vs. 38% of male caregivers)
 - Those with more than \$50,000 in household income (46% vs. 39% of lower income caregivers)
 - Caregivers who live in the same household as their recipient (51% vs. 39% of those who live separately)
 - Primary caregivers (49% vs. 36% of non-primary)

C. Caregiving Activities and Burden of Care

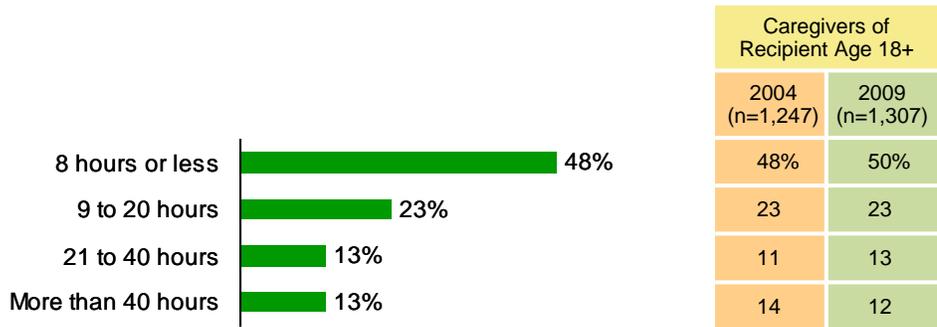
Hours of Care Provided

On average, caregivers spend 20.4 hours per week providing care.⁸ Nearly half of caregivers are in situations where their time commitment is modest, no more than eight hours each week (48%). At the other end of the scale, 13% of caregivers provide more than 40 hours of care per week, including some who indicate they provide care around the clock.

Figure 16: 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 spend in an average week doing these things?

Base: 2009 All caregivers (n=1,480)



2004-2009 Trend for Caregivers of Recipient Age 18+

- The number of hours spent providing care declined from 21.5 hours per week in 2004 to 18.9 hours in 2009, among those caring for an adult.

2009 Caregiver Subgroups

- Caregivers who live with their care recipient provide three times as many hours of care per week (39.3 vs. 12.9 hours). Primary caregivers also spend considerably

⁸ Any reports of constant care or caregiving in excess of 98 hours per week are capped at this level, equivalent to 14 hours per day.

more hours giving care (26.9 per week, on average) than non-primary caregivers (12.4 hours).

- Care for children is more time intensive than care given to adults (29.7 hours per week vs. 19.9 for recipients age 18 to 49 and 18.8 for recipients age 50 or older).
- Female caregivers spend more time providing care, on average, than male caregivers (21.9 vs. 17.4 hours).
- Hispanic and African-American caregivers spend more time on average (27.1 hours and 25.1 hours per week, respectively) than do White caregivers (18.4 hours). Only 5% of Asian-American caregivers spend more than 40 hours per week giving care, less than all other ethnic groups (White 11%, African-American 18%, Hispanic 20%).
- Caregivers age 65 or older provide care for notably more hours per week, on average, than do younger caregivers (30.6 vs. 18.8 hours).
- As one might expect, caregivers who are not employed tend to spend more time in their caregiving role (27.8 vs. 17.7 hours per week for employed caregivers).
- Caregivers in lower income households provide more hours of care on average (24.5 vs. 17.3 hours for those in households with \$50,000 or more in income).

Help with Activities of Daily Living (ADLs)

A majority of caregivers help their care recipient with at least one Activity of Daily Living (ADL) (56%). The most common ADL is helping their loved one get in and out of beds and chairs; 40% of caregivers help with this. Three in ten help their care recipient get dressed (32%), one in four help with bathing or showering (26%) or getting to and from the toilet (24%). Roughly one in five help their loved one by feeding him/her (19%) or dealing with incontinence or diapers (18%). On average, caregivers provide help with 1.6 of the six ADLs.

Figure 17: Help with Activities of Daily Living (ADLs)

Q22. I'm going to read a list of kinds of help which might be provided to a person if the person cannot do this by him or herself. Do/Did you help your [relation] with [ADL] [IF CHILD RECIPIENT: because he/she is/was less able to do this task than children of the same age without his/her condition]?

Base: 2009 All caregivers (n=1,480 for any ADL; otherwise, n varies by item)

	Percentage Helping with Task	Caregivers of Recipient Age 18+	
		2004 (n=1,247)	2009 (n=1,307)
Any ADL	56%	50%	58%
Getting in and out of beds and chairs	40%	36%	43%
Getting dressed	32%	29%	32%
Bathing or showering	26%	26%	26%
Getting to and from the toilet	24%	23%	25%
Feeding	19%	18%	19%
Dealing with incontinence or diapers	18%	16%	19%

Of note, to distinguish caregiving of children with special needs from typical parenting or child care, caregivers of children were asked to report help with an ADL only if it was because the child was less able to do that task than other children of the same age without his/her condition. Further, ADLs performed for very young children—below the age thresholds shown in the chart above—were not counted, since it would be expected that they would need assistance.

2004-2009 Trend for Caregivers of Recipient Age 18+

- The proportion of caregivers of adults who provide help with at least one ADL increased from 50% in 2004 to 58% in 2009.
- There was an increase in the share who help their loved one get in and out of beds and chairs (from 36% to 43%). This increase is apparent only among caregivers who do not have paid help. It is also fueled by a sharper increase among non-co-resident caregivers.

2009 Caregiver Subgroups

- The average number of ADLs rises in relation to the hours spent caregiving. Caregivers who spend eight hours or less per week providing care help with 1.0 ADLs on average, compared to 1.5 ADLs for those spending 9 to 20 hours per week, and 2.7 for those giving at least 21 hours of care per week.
- Among caregivers who spend more than 20 hours per week giving care, those who live *apart* from their care recipient are more likely than co-resident caregivers to help with most ADLs, including transferring from beds and chairs (63% vs. 51%), getting dressed (65% vs. 54%), getting to and from the toilet (55% vs. 39%), and feeding (40% vs. 28%).
- Caregivers who were not employed while a caregiver more commonly help with each of the ADLs, except getting in and out of beds and chairs.
- Female caregivers report helping their loved one with two specific tasks more commonly than male caregivers: getting dressed (36% vs. 24%) and bathing (31% vs. 17%).
- Caregivers with \$30,000 to \$49,999 in household income are more apt than both lower and higher income households to help with incontinence (25% vs. 16% lower income and 17% higher income) and feeding (26% vs. 18% and 18%).
- Caregivers whose recipient is age 50 or older are more likely than those with younger recipients to report helping with getting in and out of beds and chairs (46% vs. 23%), getting to and from the toilet (28% vs. 14%), and dealing with incontinence (20% vs. 12%).
- Hispanic caregivers are more apt to feed their care recipient (33%), than are Whites (16%), African-Americans (21%), and Asian-Americans (19%).
- Asian-Americans stand out as less likely to help their care recipient get dressed (23% vs. African-Americans 38% and Hispanics 42%), get to and from the toilet

(16% vs. Whites 25% and Hispanics 28%), or bathe/shower (15% vs. at least 25% for each of the other racial/ethnic groups).

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

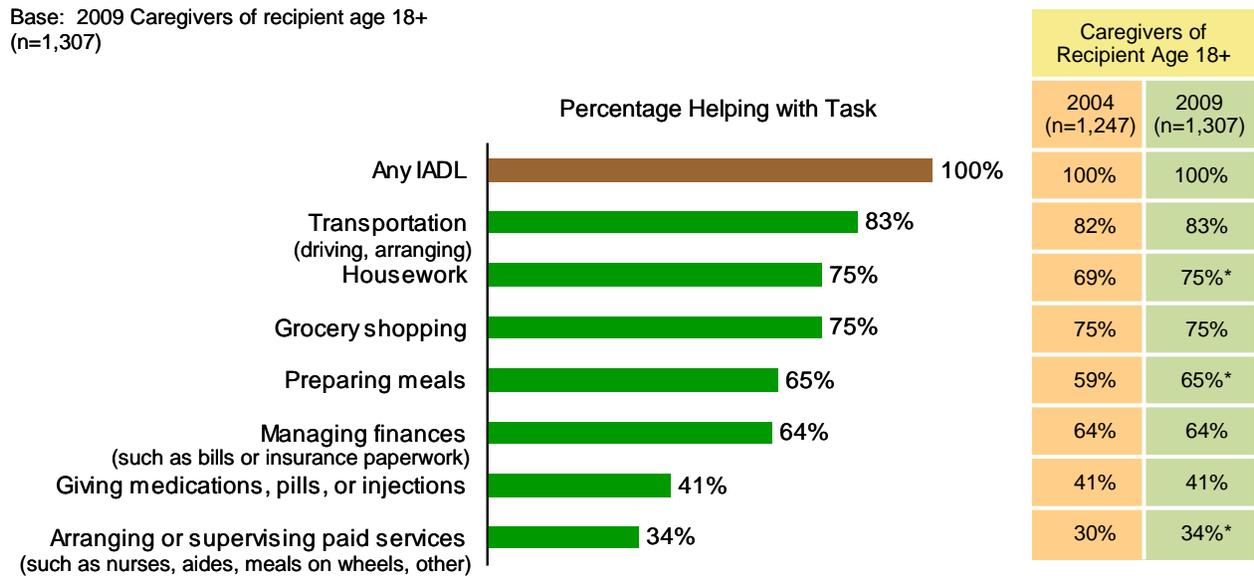
There is an established list of Instrumental Activities of Daily Living (IADLs) that pertain to adult caregiving. However, caregivers of children with special needs were asked about several new IADL-like tasks, since it would be routine for parents, babysitters, and caregivers alike to help children with the standard IADLs. Thus, analysis of IADLs is done separately for children and adults.

On average, caregivers of adults help their loved one with 4.4 out of seven Instrumental Activities of Daily Living (IADLs). For each of the IADLs, except two, at least six in ten caregivers say they help their care recipient with it: transportation (83%), housework (75%), grocery shopping (75%), meal preparation (65%), and managing finances (64%). The exceptions are giving medications (41%) and arranging or supervising outside services (34%).

IADLs for Adult Recipients

Figure 18: Help with Instrumental Activities of Daily Living (IADLs)—for Adult Recipients
Q23. Do/Did you provide help to your [relation]...?

Base: 2009 Caregivers of recipient age 18+ (n=1,307)



2004-2009 Trend for Caregivers of Recipient Age 18+

- 2009 saw an increase in the proportion of caregivers of adults who help their loved one with housework (75%, up from 69% in 2004), preparing meals (65%, up from 59%), and arranging or supervising outside services (34%, up from 30%).
- Accordingly, the average number of IADLs performed by caregivers is slightly higher in 2009 (4.4, up from 4.2).

2009 Caregiver Subgroups

- Not surprisingly, co-resident caregivers help with more IADLs, on average (5.5 vs. 4.0 for those who live separately). They are much more likely than caregivers who live apart from their care recipient to help with each IADL.
- Primary caregivers also help with more IADLs on average (4.7 vs. 4.0), and they are specifically more likely to help with transportation (87% vs. 81% for non-primary caregivers), grocery shopping (80% vs. 68%), managing finances (76% vs. 51%), preparing meals (71% vs. 58%), and giving medicines or injections (46% vs. 36%).
- African-American and Hispanic caregivers help with more IADLs than White caregivers do, on average (4.7 and 4.8, respectively vs. 4.2). In particular, both groups are more likely to assist with grocery shopping and meal preparation. African-American caregivers are also more likely to help manage their loved one's finances or to do housework for them.
- Help in arranging or supervising outside services is more common among caregivers whose care recipient is age 50 or older (37%) than it is when the care recipient is 18 to 49 (23%). By contrast, help with finances is more prevalent with the younger adult recipients (72%) than with those age 50 or older (62%).
- More so than women, male caregivers tend to help arrange or oversee outside services (39% vs. 32%).
- Caregivers who are at least 50 years of age show a greater tendency than younger caregivers to help with overseeing outside services (40% vs. 27%) and managing finances (69% vs. 58%). Younger caregivers, by contrast, are more prone to help with housework (80% vs. 71%).
- Lower education levels also bring an increased likelihood of helping with housework (79% of those with less than a college education vs. 71% of college educated caregivers) and meal preparation (69% vs. 60%). Those with less than \$50,000 in household income are more likely to help with each of these tasks (housework 80% vs. 72% of higher income households; meal preparation 71% vs. 60%), as well as with grocery shopping (80% vs. 71%).

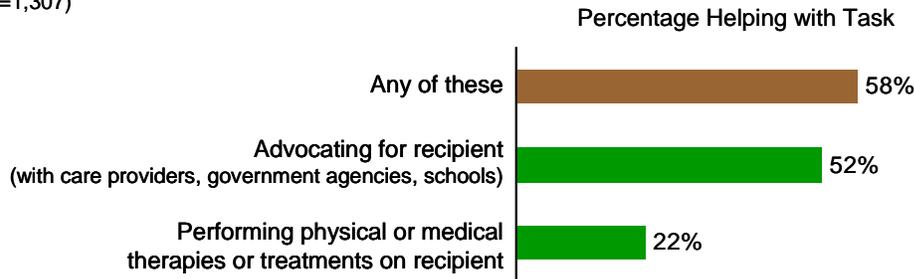
Other Supportive Activities for Adult Recipients

Half of adults advocate for their care recipient with care providers, government agencies, or schools (52%), and one in five do physical or medical therapies or treatments on their loved one (22%).

Figure 19: Help with Other Supportive Activities—for Adult Recipients

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

Base: 2009 Caregivers of recipient age 18+
(n=1,307)



2009 Caregiver Subgroups

- These two supportive activities are more commonly reported by primary caregivers, those who spend more time providing care, those who felt they had no choice in becoming a caregiver, and co-resident caregivers.
- Caregivers with a higher education level are more likely to say they advocate for their loved one with care providers, government agencies, or schools. In particular, 58% of college graduates say they advocate for their loved one, whereas only 46% of those with less education do.
- Caregivers are more likely to say they advocate on behalf of their loved one when their care recipient is age 50 or older (54% vs. 44% of those caring for younger adult recipients).

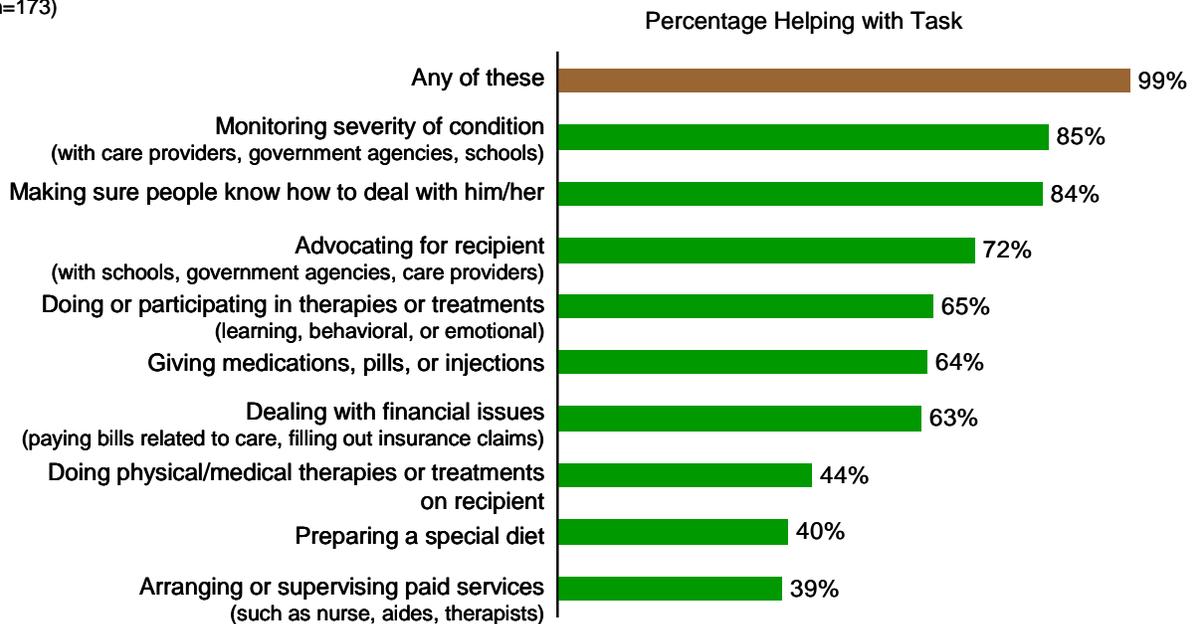
Supportive Activities for Child Recipients

Caregivers of children with special needs help their care recipient with 5.6 out of nine Caregiving Support Activities (CSAs), on average. A large majority of caregivers of children help by monitoring the child's condition (85%), by ensuring that others know how to deal with him/her (84%), and by advocating on his/her behalf (72%). Six in ten do emotional or behavior treatments or therapies (65%), give medicines or injections (64%), and deal with financial issues (63%). Four in ten are involved in giving physical or medical therapies (44%), preparing a special diet (40%), or arranging/supervising outside services (39%).

Figure 20: Help with Caregiving Support Activities (CSAs)—for Child Recipients

Q24. As a result of your [relation's] condition, do/did you provide help by...?

Base: 2009 Caregivers of recipient age 0 to 17 (n=173)



2009 Caregiver Subgroups

- Nearly all of these support activities are more frequently reported by caregivers who spend more time providing care.
 - Those who serve as caregivers more than eight hours a week are more apt to help with medicines (73% vs. 44% of those providing up to 8 hours per week of care), financial issues (71% vs. 45%), preparing a special diet (49% vs. 23%) and making sure those who interact with the child know how to deal with him/her (91% vs. 70%).
 - Caregivers of children with special needs who spent more than 20 hours per week providing care are more likely than others to arrange/supervise outside services (52% vs. 29%), do physical/medical treatments (54% vs. 37%), and manage or administer medications (75% vs. 55%).

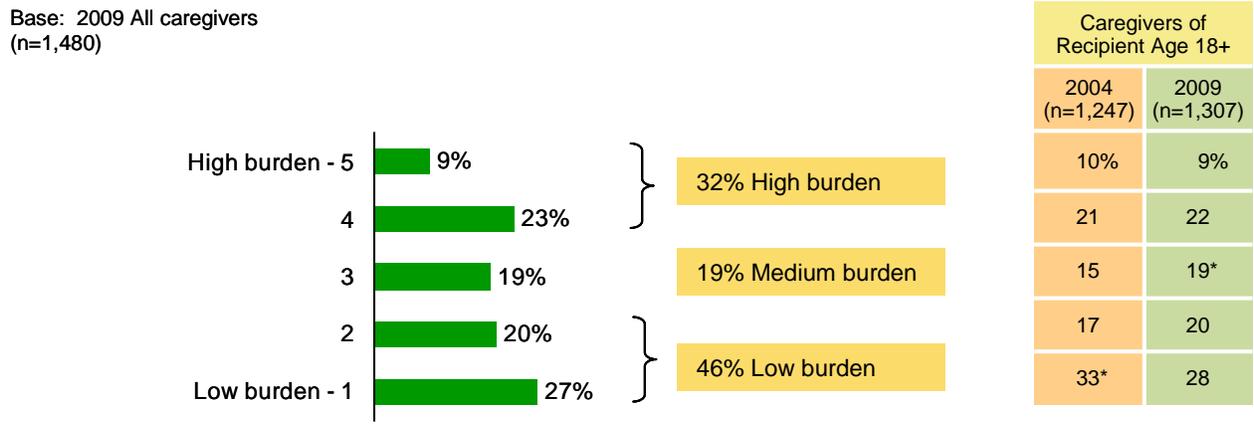
- Male caregivers of children with special needs are more apt than female caregivers to help with financial issues (76% vs. 57%) and to advocate on behalf of the child recipient (85% vs. 67%).
- As education rises, so does the likelihood that a child's caregiver monitors the severity of his/her condition to be able to adjust care. Of those with no more than a high school education, 73% do this monitoring, compared to 93% of college graduates. A similar pattern emerges for advocacy on the child's behalf (59% high school vs. 81% college graduates).

Burden of Care

A Level of Care Index, first developed in the 1997 study *Family Caregiving in the U.S.* and used in the 2004 study as well, 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. For caregivers of children with special needs, Caregiving Support Activities (CSAs) are substituted for IADLs in the calculations. The details of the index's construction are shown in Appendix B.

Three in ten caregivers are in high burden situations (32%), 19% have a medium burden, and 46% have a low burden.

Figure 21: Level of Care Index



For each level of care, the average number of hours of care provided, ADLs performed, and IADLs performed are as follows:

Figure 22: Components of Level of Care by Burden Category

Level of Care	Low Burden (n=674)	Medium Burden (n=274)	High Burden (n=487)
Hours of Care per Week	5.9	11.3	46.9
Number of ADLs – out of 6 total	0.2	2.2	3.2
Number of IADLs (adults) – out of 7 total	3.6	4.4	5.5
Number of CSAs (children) – out of 9 total	4.9	5.4	6.4

2009 Caregiver Subgroups

- The older the caregiver is, the more likely she or he is to be in a high burden situation, as shown in the following table:

Figure 23: Burden Category by Caregiver Age

	Caregiver Age		
	18 to 49 (n=560)	50 to 64 (n=616)	65 or older (n=285)
Low burden	49%	45%	39%
Medium burden	20	20	14
High burden	30	32	41

- High burden situations are more prevalent among caregivers who live with their care recipient than they are among those who live separately (54% vs. 23%), although for caregivers who spend more than 20 hours per week providing care, co-residence does not have an added effect on burden of care.
- A high burden is also more commonly reported by the following subgroups of caregivers:
 - Primary caregivers (40% vs. 22% of non-primary caregivers)
 - Those who did not have a choice whether or not to take on their caregiving responsibility (38% vs. 28%)
 - Caregivers with less than a college education (37% vs. 26% of college grads)
 - Whites (31%), African-Americans (35%), and Hispanics (39%) relative to Asian-Americans (20%).
 - Caregivers who were not employed while caregiving (40% vs. 29% of employed caregivers)
- Male caregivers are more likely than females to be in low burden situations (51% vs. 44%).

D. Presence of Other Caregivers

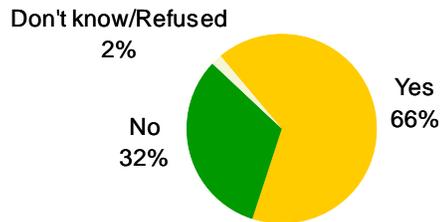
Presence of Other Unpaid Caregivers

Two-thirds of caregivers (66%) report that someone else has also provided unpaid care to their relation within the past 12 months.

Figure 24: Presence of Other Unpaid Caregivers

Q28. Has anyone else provided unpaid help to your [relation] during the last 12 months?

Base: 2009 All caregivers
(n=1,480)



% Yes	
Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
59%	68%*

2004-2009 Trend for Caregivers of Recipient Age 18+

- There has been an increase in the proportion of caregivers of adults who say there is at least one other unpaid caregiver helping their loved one, from 59% in 2004 to 68% in 2009.
- The increase in unpaid help is driven by increases in those caring for someone age 18 to 49 (38% in 2004 to 58% in 2009) and someone 65 to 74 (58% in 2004 to 74% in 2009). The change in unpaid help among 18- to 49-year olds may be because the 2009 caregivers of younger adults are in more intensive caregiving situations than in 2004 (with longer caregiving duration and greater needs for help selecting a nursing home or a home care agency).
- Furthermore, increases in unpaid help occurred among all racial/ethnic groups of caregivers, with the exception of African-American caregivers.

2009 Caregiver Subgroups

- Male caregivers are more likely to report that other caregivers carry part of the responsibility (73%) than are females (62%).
- White and Asian-American caregivers are more likely than African-American caregivers to report the presence of other unpaid caregivers (White 68% and Asian-American 72% vs. African-American 53%).
- Caregivers whose care recipient is at least 50 years of age are more likely to share caregiving with other unpaid caregivers (70% vs. 58% of those with 18- to 49-year-old recipients and 54% of those with child recipients).
- By contrast, older caregivers—those age 65 or older—are *less* likely to have this kind of support (50% vs. 68% of younger caregivers).

- As one might expect, caregivers who do not live with their recipient are also more apt to say someone else also provides unpaid care (72% vs. 50% for co-resident caregivers).
- Further, among those who live apart from their recipient, those who spend 20 hours or less providing care are more likely than those spending more time caregiving to say there are other unpaid caregivers (74% vs. 63%).
- A larger share of employed caregivers report there were other unpaid caregivers (69% vs. 57% of caregivers who were not employed while providing care).

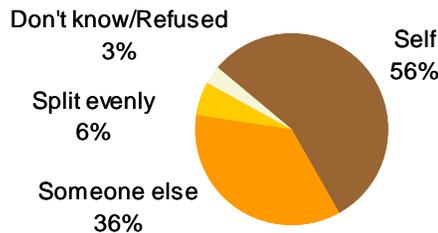
Primary Caregiver Status

Over half of caregivers perceive themselves to be the primary unpaid caregiver (56%), meaning either that they are sole caregivers (32%) or that there are other unpaid caregivers but they themselves provide the majority of unpaid care (24%). The 42% who are non-primary caregivers include 6% who share caregiving equally with someone else and 36% who say another caregiver provides most of the unpaid care.

Figure 25: Primary Caregiver Status

Q28. Has anyone else provided unpaid help to your [relation] during the last 12 months?
 Q29. Who would you consider to be the person who provides/provided most of the unpaid care for your [relation]—you yourself, or someone else?

Base: 2009 All caregivers (n=1,480)



% Primary Caregiver	
Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
57%	53%

2009 Caregiver Subgroups

- Caregivers of recipients under the age of 50 are much more likely to be primary caregivers than are caregivers of older recipients (70% vs. 51%).
- Likewise, 70% of caregivers who are 65 or older are primary caregivers compared to far fewer younger caregivers (54%).
- African-Americans and Hispanics are more likely to be primary caregivers (65% and 63% respectively) than are Whites (53%) or Asian-Americans (48%).
- The prevalence of primary caregiver status rises in relation to the hours spent caregiving, from 42% of those who provide up to 8 hours of care per week to 75% of those who provide more than 20 hours of care.
- Those who live with their care recipient are far more likely than those who live separately to provide most or all of the unpaid care (83% vs. 44%). Of those who live more than one hour away, only 35% consider themselves the primary caregiver.

- Other groups among which primary caregiver status is more common include:
 - Women (59% vs. 49% of men)
 - Those who are not employed (65% vs. 52% of employed caregivers)
 - Caregivers who feel they did not have a choice in becoming a caregiver (64% vs. 49% of those who feel they had a choice)
 - Those in households with less than \$50,000 in income (61% vs. 52% of higher income caregivers)
- Interestingly, caregivers with a mid-level burden of care are the least likely to be primary caregivers (42%). High burden caregivers are most likely (69%) and low burden caregivers follow (52%).

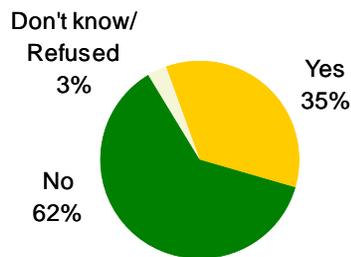
Use of Paid Services

Among caregivers whose recipient was not in a nursing home, most say their care recipient did not receive any paid help from aides, housekeepers or others during the last 12 months (62%).

Figure 26: Use of Paid Services

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?

Base: 2009 Caregivers of recipient not in nursing home (n=1,416)



% Yes	
Caregivers of Recipient Age 18+	
2004 (n=1,191)	2009 (n=1,243)
41%*	35%

2004-2009 Trend for Caregivers of Recipient Age 18+

- Among caregivers of adults who were not in a nursing home, a smaller share in 2009 indicate that their care recipient had paid help from aides, housekeepers or others (35% vs. 41% in 2004). This trend complements the rise in the percentage of caregivers who say other *unpaid* caregivers also help their care recipient; these changes may have resulted from the recession and severe economic downturn in late 2008.
- Analyses show that the use of paid help went down among non-primary caregivers (47% in 2004 to 41% in 2009), as well as among primary caregivers who live with their care recipient (35% to 27%).
- Declines in paid help occurred among those caring for someone age 18 to 64 (27% in 2004 to 18% in 2009), but not among those caring for someone age 65 and older.

- Finally, declines in the use of paid help occurred among those caring for someone *without* Alzheimer’s or dementia (37% to 33%), while those caring for someone with Alzheimer’s or dementia showed no decline.

2009 Caregiver Subgroups

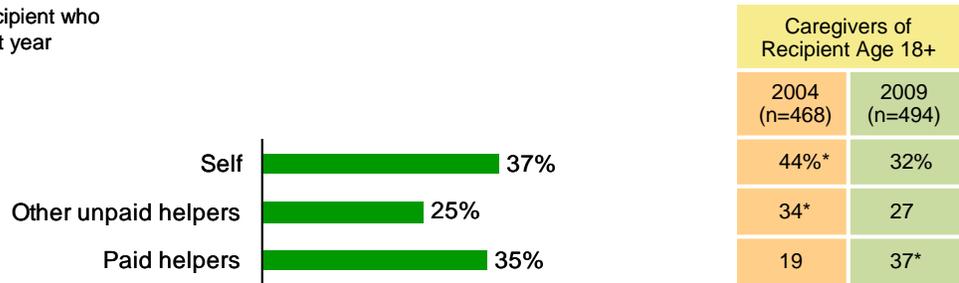
- As one might expect, the use of paid care increases as the caregiver's household income rises. Among caregivers in households with less than \$50,000 in income, 30% say their recipient had paid help compared to 36% of those with \$50,000 to \$99,999 in income and nearly half (48%) of those with an income of \$100,000 or more.
- Other subgroups who are more likely to report paid help are:
 - Caregivers age 50 or older (39% vs. 32% of younger caregivers)
 - Non-primary caregivers (39% vs. 33% of primary)
 - High burden caregivers (42% vs. 31% of low burden caregivers)
 - Those who care for child recipients (35%) and those who care for adults age 50+ (41%), compared to half as many (18%) among caregivers of recipients ages 18 to 49.
 - White caregivers (39%) relative to African-Americans (25%) and Hispanics (28%). This difference appears to be independent of income differences between these groups.

One-third of those whose care recipients receive paid help say the paid helpers provide most of the care for their loved one (35%), although a similar proportion of caregivers say that they themselves provide more of the care (37%). The remaining one in four report that other unpaid helpers provide more of the care (25%).

Figure 27: Predominant Caregiver Among Unpaid and Paid Helpers

Q31. *Who would you say provides/provided more of your [relation's] care—you, other unpaid helpers, or paid helpers?*

Base: 2009 Caregivers of recipient who has received paid help in past year (n=548)



2004-2009 Trend for Caregivers of Recipient Age 18+

- Although the proportion using paid help has declined, those caregivers who do hire these staff rely on them more. Specifically, among the caregivers who use paid helpers, there has been an increase in the proportion who say this paid help provides more of the care, from 19% in 2004 to 37% in 2009. This may be because those who use paid services can now afford to use them more. In 2009, 63% of users of paid services have at least \$50,000 in income, compared to only 47% in 2004.
- There was a complementary drop in the share of caregivers who say they are the ones who provide more of their recipient's care, from 44% in 2004 to 32% now.
- Further, a smaller share now say that other unpaid caregivers provide more of the care (2004 34% vs. 2009 27%).
- There is no discernable increase in the burden of care experienced by those who use paid help or any apparent increase in employment while caregiving, either of which might motivate caregivers to shift more responsibilities to paid caregivers.
- However, household income has increased among those who use paid services, so it could be that additional dependence on paid care relates to an increase in disposable income among those who use this type of help.

2009 Caregiver Subgroups

- Among caregivers whose recipient had paid help, affordability of the paid care appears to be an issue. Medium to high income caregivers—those with at least \$30,000 in household income—are twice as likely as lower income caregivers to report that paid helpers provide the most care (39% vs. 19%).
- Perhaps related, employed caregivers are also more apt than those who are not employed to indicate that paid helpers shoulder more of the care (38% vs. 27%).
- Reliance on paid caregivers is also more prevalent among the following subgroups of caregivers whose recipients use paid services:
 - Those who provide no more than 20 hours of care per week (43% vs. 17% of caregivers providing more hours of care)
 - Those who live separately from their care recipients (44% vs. 9% of co-resident caregivers)
- Among caregivers whose recipient had paid help, those who care for a child are twice as likely as those caring for older respondents to say they provide more of the help (67% vs. 31%).

E. Care Recipient Living Situation

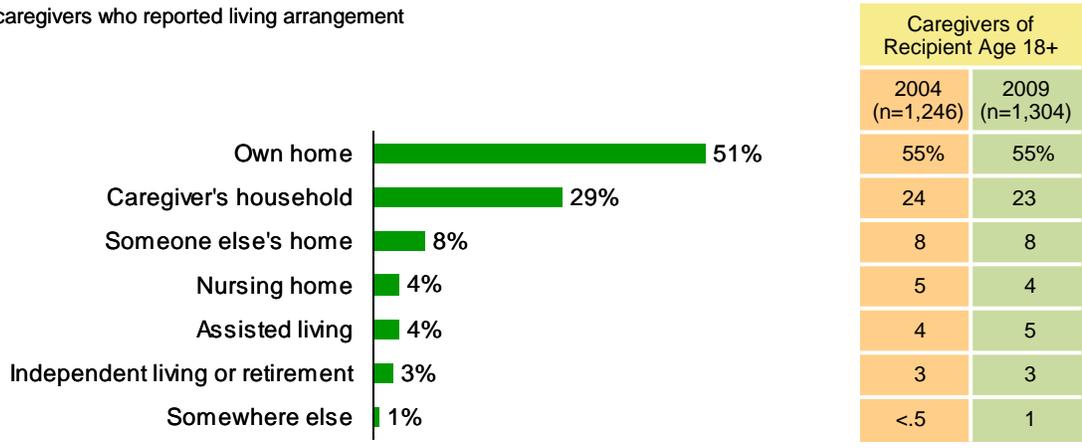
Where Care Recipient Lives

Half of caregivers say their loved one lives in his or her own home (51%). Three in ten say they live together with their care recipient in the caregiver's household (29%).

Figure 28: Where Care Recipient Lives

Q13. [IF NOT IN CAREGIVER'S HOUSEHOLD] Does/Did your [relation] live in his or her own home, someone else's home, an independent living or retirement community, an assisted living facility where some care may be provided, a nursing home or long-term care facility [IF CHILD RECIPIENT: a group home, foster care], or somewhere else? (Analyzed with Q11: Does/Did your [relation] live in your household, within twenty minutes of your home, etc?)

Base: 2009 All caregivers who reported living arrangement (n=1,477)



2009 Caregiver Subgroups

- Caregivers' income appears to be a driving force in determining whether they and the care recipient live in the same household. A larger share of caregivers in households with less than \$50,000 in income live with their recipients (38% vs. 23% of those in higher income households). Because spousal caregivers are so likely to live with their recipient (in 2009, 100% do) and they are so often retired (39%), we examined whether the income pattern holds true for non-spousal caregivers. It does—33% of non-spousal caregivers in lower income households live with their care recipient vs. 21% in higher income households.
- Prevalence of living in an assisted living facility rises with income, from 2% of those with less than \$50,000 in household income to 5% of those with \$50,000 to \$99,999, and reaching 9% of caregivers in households with at least \$100,000 in income.
- In cases where the care recipient has a short-term physical condition, but not a long-term one, the caregiver is more likely to report that their loved one lives in his/her own home (63%) than when a long-term physical condition is affecting the recipient (51%) or when there is no physical condition involved (39%).
- The proportion of caregivers who say their recipient lives in his/her own home is highest among those who have been providing care for less than one year (62%)

and it declines to 40% for caregivers who have been providing care for five years or more.

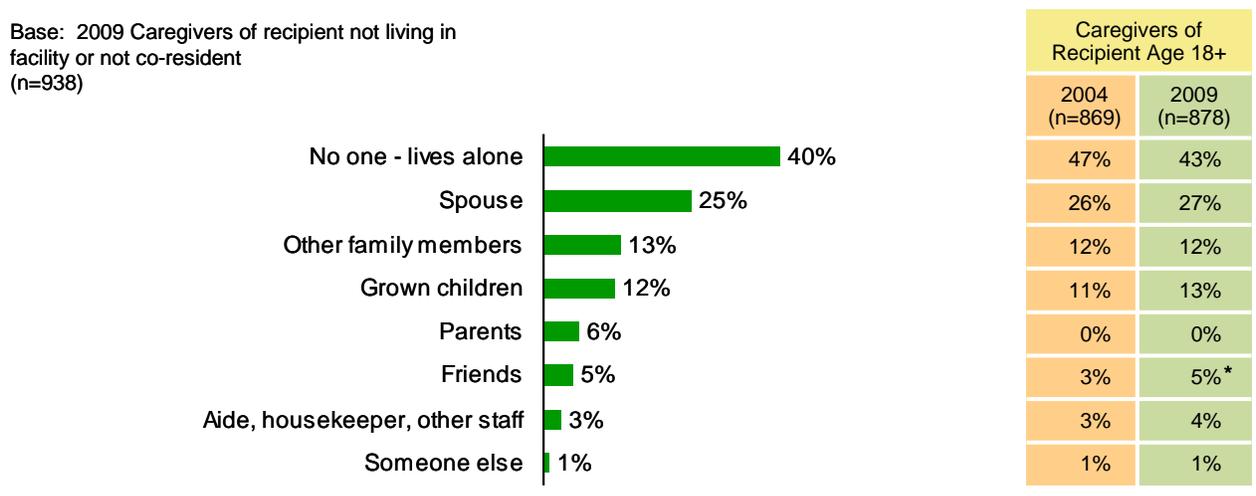
- The likelihood of the caregiver sharing a home with the recipient of care declines as the recipient's age rises, from 65% of those with child recipients to 40% of those caring for 18- to 49-year-olds and 20% of those with recipients age 50 or older. Note that nearly all caregivers who are parents caring for their own child age 0 to 17 live with their child (96%).
- There is a similar pattern with caregiver age. Four in ten (40%) caregivers age 65 or older share a home with their loved one compared to 28% of younger caregivers. Among the older caregivers, 39% have a care recipient who lives separately in his/her own home whereas only 53% of younger caregivers do.
- Co-residency is more than three times as likely among primary caregivers (43%) as it is among non-primary caregivers (12%). Similarly, it is also seen more frequently among caregivers who provide more than 20 hours of care per week (58% vs. 17% of those giving fewer hours of care).
- Hispanic caregivers are more likely than Whites to live with their care recipient (39% vs. 27%). It is more common for Whites, by contrast, to report their recipient lives in his/her own home (54%) than it is for African-American caregivers (42%) or Hispanics (45%).

Who Care Recipient Lives With

Of the care recipients who do not live with their caregiver or in a facility, group setting, or foster care, four in ten live alone (40%). One in four live with his/her spouse (25%), and about one in eight live with grown children (12%) or other family members (13%).

Figure 29: Who Care Recipient Lives With

Q14. Does/Did your [relation] live: [IF ADULT RECIPIENT: alone, with his/her spouse, with his/her grown children] [IF CHILD RECIPIENT: with his/her parents], with other family members, with friends, with an aide, housekeeper or other staff, or with someone else? [MULTIPLE RESPONSE ALLOWED]



2009 Caregiver Subgroups

- Among non-co-resident caregivers whose recipient is not in a facility or group setting, larger shares of Whites and Asian-Americans say their care recipient lives with his/her spouse (28% and 37%, respectively) than African-Americans (14%) or Hispanics (15%).
- On the other hand, extended family plays more of a role with African-American and Hispanic caregivers. Specifically, reports of the care recipient living with family members other than a spouse or grown children are more common among these two groups (31% and 25%, respectively) than among Whites (8%) or Asian-Americans (9%).
- Nearly half of those with recipients age 50 or older who are not living with their caregiver or in a facility say their care recipient lives alone (47%). Far fewer, 19%, report that a recipient age 18 to 49 lives alone. The most prevalent arrangement reported by caregivers of these younger recipients is living with other family members (38%); a notable proportion of their recipients also live with friends (14%).
- Most caregivers of child recipients who do not live with their caregiver or in a facility or group setting say their care recipient lives with his/her parents (84%).

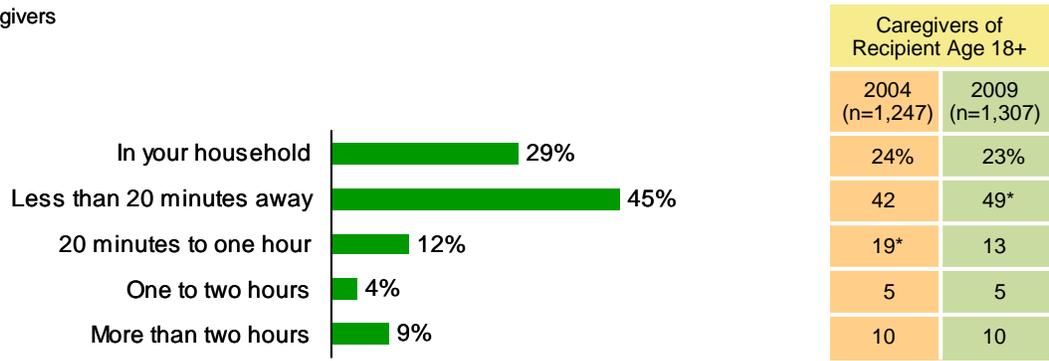
Caregiver Distance from Care Recipient

Three-quarters of caregivers live within twenty minutes of their care recipient (74%).

Figure 30: Caregiver Distance from Care Recipient

Q11. Does/Did your [relation] live in your household, within twenty minutes of your home, between twenty minutes and an hour from your home, a one to two hour drive from your home, or more than two hours away?

Base: 2009 All caregivers (n=1,480)



2004-2009 Trend for Caregivers of Recipient Age 18+

- Travel distances between caregivers of adults and the recipients of their care shrank a little in the past five years. The proportion living either together or within 20 minutes of their recipient rose from 66% to 72%. There was a concomitant decline in the share who report living between twenty minutes and an hour from their care recipient (from 19% to 13%). Long distance caregiving—living one hour or more from the care recipient—has remained steady.

2009 Caregiver Subgroups

- As income rises, so does the likelihood of living more than two hours away from the care recipient; 4% of caregivers with less than \$50,000 in household income live this far away, compared to 10% of those with \$50,000 to \$99,999 and 18% of those with \$100,000 or more in household income.
- Three-quarters of parents who are caregivers for their own children live with their child (77%). Among those who are caregivers for someone other than their own child, only one-fifth live with the recipient (21%).

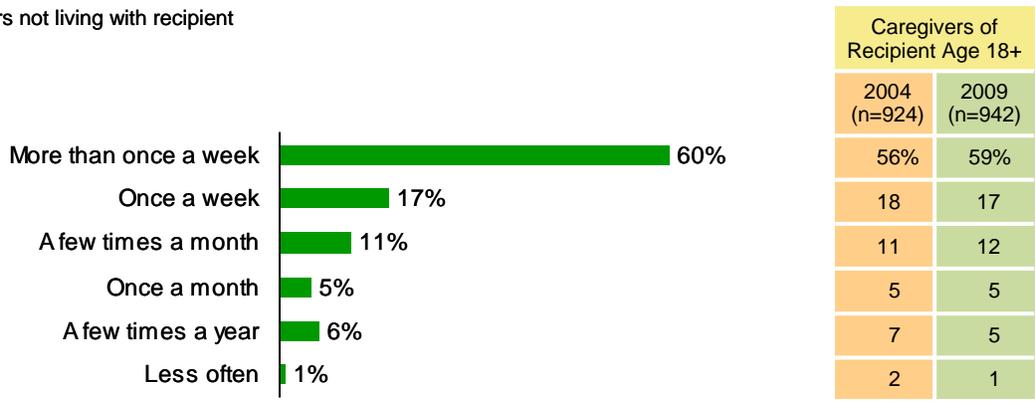
Frequency of Visits

Of the caregivers who do not live with their care recipient, three-quarters say they visit him/her at least once a week (76%), including six in ten who say they visit more than once a week (60%).

Figure 31: Frequency of Visits

Q12. On average, how often do/did you visit your [relation]?

Base: 2009 Caregivers not living with recipient (n=1,003)



2009 Caregiver Subgroups

- Among the caregivers who do not live with their care recipient, seven in ten African-Americans (73%) and Hispanics (71%) visit more than once a week, a significantly larger proportion than the half of Whites (56%) and Asian-Americans (49%) who do.
- Still among non-co-resident caregivers, those with less than \$50,000 in household income are more likely than higher income caregivers to say they visit more than once a week (69% vs. 53%). This difference may be driven by the fact that lower income caregivers who live more than an hour from their recipient are more than three times as likely as higher income caregivers to visit weekly (31% vs. 8%).
- Other subgroups of non-co-resident caregivers who are more likely to say they visit more than once a week include:
 - Primary caregivers (66% vs. 54% of non-primary)
 - High burden caregivers (81% vs. 53% of caregivers with no more than a medium burden)

F. Care Recipient's Condition

Types of Care Recipient Conditions

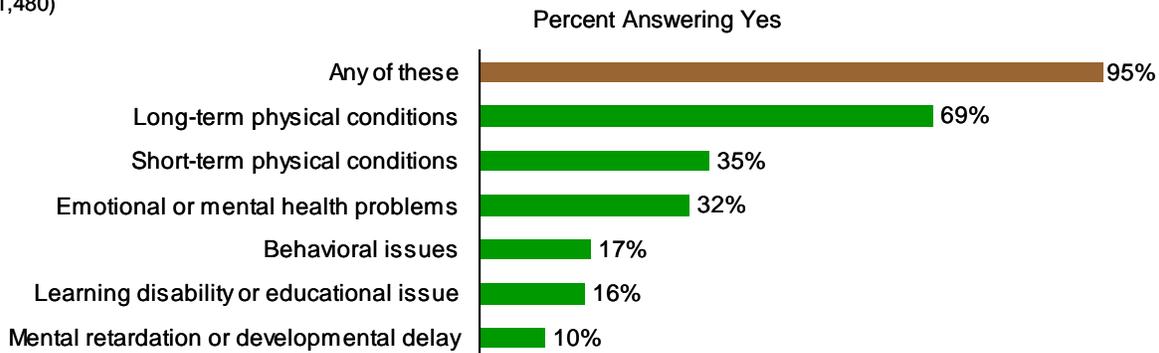
About seven in ten caregivers have a care recipient with a long-term physical condition (69%), and 35% say their loved one has a short-term physical condition. There is some overlap between these two; only 17% of caregivers have a care recipient with short-term physical condition but *no* long-term physical issues. Twelve percent of caregivers note there is no physical condition at all.

Emotional or mental health problems are reported by three in ten caregivers (32%). Three-quarters of these caregivers also report their loved one has some kind of physical condition (78%). Smaller proportions indicate their care recipient has behavioral issues (17%), a learning disability or educational issue (16%), or developmental delay or mental retardation (10%). The small percentage of caregivers who do not report any of these six conditions are typically caring for a recipient whose main problem is old age.

Figure 32: Types of Care Recipient Conditions

Q17. *Would you say that your [relation] needs/needed care because of any...?*
 [MULTIPLE RESPONSES ALLOWED]

Base: 2009 All caregivers
 (n=1,480)



2009 Caregiver Subgroups

- Caregivers in a high burden situation are more likely than low burden caregivers to state that their loved one has a long-term physical condition (73% vs. 63%), developmental delay (14% vs. 7%), or a learning issue (20% vs. 13%). By contrast, burden appears to be unrelated to the likelihood of short-term physical conditions or emotional/mental health problems.
- Co-resident caregivers are far more likely than those living separately to say their recipient has emotional or mental health problems (42% vs. 28%), developmental delay or mental retardation (18% vs. 7%), a learning/education issue (29% vs. 10%), or a behavioral issue (26% vs. 13%).

- Long-term conditions are more common among older recipients, whereas several other conditions—emotional or mental health problems, developmental delay, learning issues, and behavioral issues—are more common among younger recipients.

Figure 33: Types of Care Recipient Conditions by Age of Recipient

Q17. *Would you say that your [relation] needs/needed care because of any...?*
 [MULTIPLE RESPONSES ALLOWED]

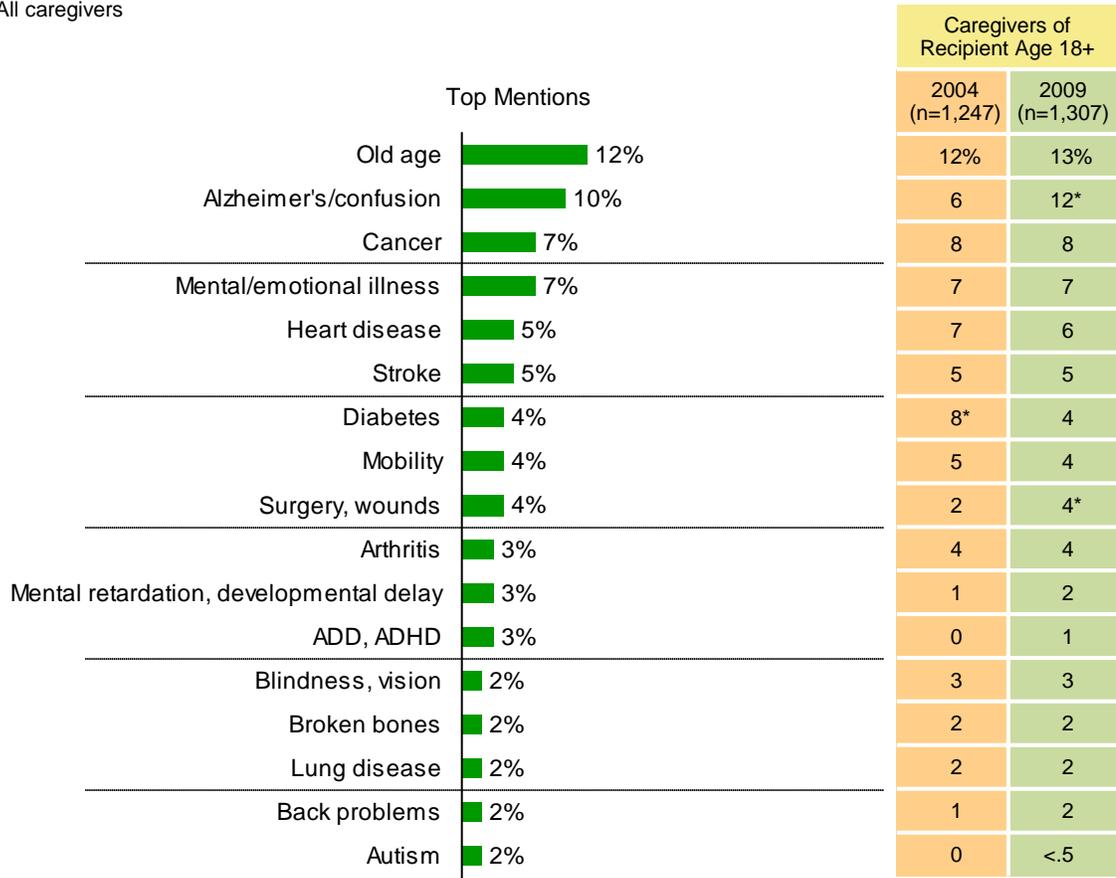
	Recipient Age 0 to 17 (n=173)	Recipient Age 18 to 49 (n=187)	Recipient Age 50 or older (n=1,397)
Short-term physical condition	30%	35%	36%
Long-term physical condition	52%	54%	76%
Emotional or mental health problem	57%	46%	25%
Developmental delay or mental retardation	41%	18%	3%
Learning disability or educational issue	61%	28%	4%
Behavioral issue	45%	31%	10%

Care Recipient's Main Problem or Illness

Old age (12%) and Alzheimer's or dementia (10%) emerge as the top two problems or illnesses for which the care recipient needs care, according to caregivers' top of mind mentions. Other top illness or conditions for which the recipient needs care include mental/emotional illness (7%), cancer (7%), heart disease (5%), and stroke (5%). Note that these perceptions may not mirror independent health statistics.

Figure 34: Main Problem or Illness Identified by Caregiver
 Q18. What would you say is/was the main problem or illness your [relation] has/had for which he/she needs/needed your care?

Base: 2009 All caregivers (n=1,480)



2004-2009 Trend for Caregivers of Recipient Age 18+

- Since 2004, the proportion of caregivers of adults who mention Alzheimer's or dementia as the main problem has risen (from 6% to 12%), perhaps since the study shows an increase in the share of care recipients age 75 or older.⁹
- The share citing diabetes decreased from 8% to 4%.

⁹ A total of 22% of 2009 caregivers indicate their recipient does suffer from Alzheimer's or mental confusion, including those who respond affirmatively to a close-ended question about this condition. There is no significant change in this percentage since 2004.

2009 Caregiver Subgroups

- The main problem for which the recipient needs care varies greatly depending on the age of the recipient. Caregivers of children with special needs cite attention deficit disorder more than any other issue (18%), followed by asthma (11%), autism (11%), mental or emotional issues (10%), and developmental delay (9%).

Figure 35: Main Problem or Illness by Age of Recipient

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

	Recipient Age 0 to 17 (n=173)	Recipient Age 18 to 49 (n=187)	Recipient Age 50 or older (n=1,397)
Attention deficit disorder or ADHD	18%	4%	<.5%
Alzheimer's, dementia, forgetfulness	0	0	15
Asthma, breathing	4	0	1
Autism	11	2	0
Cancer	1	3	8
Heart disease	0	1	8
Developmental delay or mental retardation	9	9	<.5
Mental/emotional illness, depression	10	23	4
Mobility	1	3	5
Old age	0	0	15
Stroke	1	<.5	6

- With 26% of Asian-American caregivers noting that old age is the main problem for which their recipient needs care, they are more than twice as likely as Whites (12%), African-Americans (8%), and Hispanics (9%) to say this is the case.
- Certain conditions are associated with a higher burden to the caregiver—Alzheimer's, broken bones, and cancer. Other conditions—including arthritis, mental or emotional illness, and old age—are more commonly associated with a low burden.

Figure 36: Main Problem or Illness by Burden Category

	Low Burden (n=674)	Medium Burden (n=274)	High Burden (n=487)
Greater Prevalence in Higher Burden Situations			
Alzheimer's, dementia, forgetfulness	8%	12%	13%
Broken bones	1	3	4
Cancer	5	6	10
Greater Prevalence in Lower Burden Situations			
Arthritis	5	2	2
Mental/emotional illness, depression	9	6	5
Old age	16	10	6

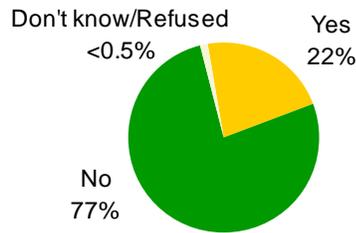
Presence of Alzheimer's or Mental Confusion

Although Alzheimer's or mental confusion is cited by only 10% of caregivers as the main condition for which the care recipient needs help, a total of 22% of caregivers say their loved one does suffer from this type of condition. While 83% of caregivers of those with Alzheimer's or dementia say their recipient has a long-term physical condition, 48% say he or she has emotional or mental health problems.

Figure 37: Presence of Alzheimer's or Mental Confusion

Q20/Q18. Does/Did your [relation] suffer from Alzheimer's or other mental confusion?

Base: 2009 All caregivers
(n=1,480)



% Yes	
Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
23%	26%

2009 Caregiver Subgroups

- The presence of Alzheimer's or mental confusion is associated with a higher burden of care. Among caregivers whose recipient has Alzheimer's or mental confusion, far fewer are classified as having the lowest level of burden (17% Level 1 vs. 31% of caregivers whose care recipients do not have Alzheimer's) and a larger share have the highest burden of care (14% Level 5 vs. 8%). In particular, these caregivers are much more likely to help with at least one ADL (70% vs. 52%).
- It is not surprising then that these Alzheimer's caregivers report a greater physical strain than do others (with an average rating of 2.3 on a 5-point scale vs. 2.0). They also perceive their caregiving situation to be more emotionally stressful (3.1 vs. 2.7).
- This condition is more frequently reported by non-primary caregivers (29%) than by primary caregivers (18%).
- As one would expect, the prevalence of Alzheimer's or some other mental confusion is higher among caregivers of individuals age 50+ than it is among those with care recipients ages 18 to 49 (30% vs. 11%). The average age of the recipient with Alzheimer's or dementia is 77.6, compared to 56.0 for those without this condition.
- White and Asian-American caregivers are more likely to report their care recipient has Alzheimer's or mental confusion (25% and 29%, respectively) than are African-American (14%) and Hispanic (16%) caregivers. This is consistent with findings that show the recipients of White and Asian-American caregivers are older, on average.

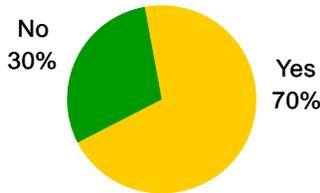
Limitations of Child Recipients

Seven in ten (70%) caregivers who provide care to a child with special needs indicate the child is limited in his/her ability to do things that most children of the same age do.

Figure 38: Limitations of Child Recipients

Q19. As a result of your [relation's] condition, is/was your [relation] limited in any way in his/her ability to do the things that most children of the same age do?

Base: 2009 Caregivers of recipient age 0 to 17 (n=173)



2009 Caregiver Subgroups

- Caregivers of children who live in higher income households are more likely than those with less income to report these limitations (\$50,000+ 85% vs. <\$50,000 60%).
- These limitations are also more commonly reported when the care recipient has a long-term physical condition (77%) than when s/he has no physical conditions (57%). Similarly, when the care recipient has a mental or emotional condition, 78% of caregivers report these limitations, compared to 61% of those whose recipient has no emotional or mental condition.
- High burden caregivers are more apt than low burden caregivers to acknowledge these limitations (81% vs. 55%).

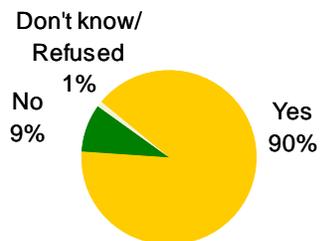
Medication Management

Nine in ten caregivers say their care recipient takes prescription medications (90%). Half of caregivers whose loved one takes medicine (excluding those caring for a child under the age of eight) say the care recipient needs help to take the medicine properly (48%).

Figure 39: Use of Prescription Medicine

Q26. Does/Did your [relation] take any prescription medicine?

Base: 2009 All caregivers (n=1,480)

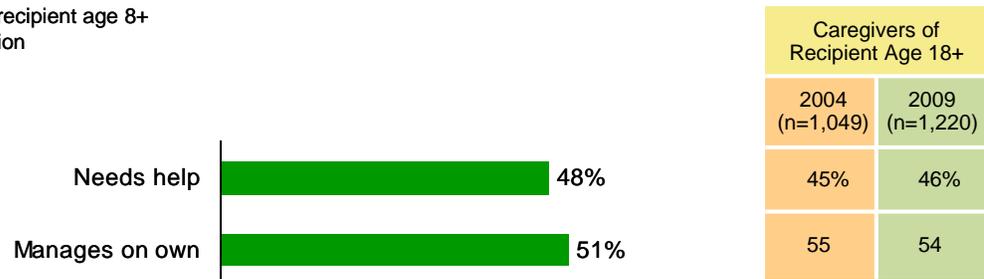


% Yes	
Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
85%	93%*

Figure 40: Medication Management

Q27. *Would you say your [relation] needs/needed someone to oversee giving him/her medicine in the right amount and on time or that he/she manages/managed this well on his/her own?*

Base: 2009 Caregivers of recipient age 8+ taking prescription medication (n=1,294)



2004-2009 Trend for Caregivers of Recipient Age 18+

- The proportion of caregivers of adults who say their loved one takes prescription medication rose from 85% in 2004 to 93% in 2009. This may be because the 2009 care recipients are older than the 2004 recipients.

2009 Caregiver Subgroups

- Usage of prescription medicine is reported by nearly all caregivers whose care recipients are age 50 or older (96%), with about half needing some assistance (48%).
- Prescription usage is noted much less frequently by those with child recipients (70%), but caregivers of children are far more likely to say their loved one needs help taking the medicines properly (84%, excluding recipients under the age of eight). Caregivers of recipients ages 18 to 49 are least likely to say their loved one needs help with medicines (33% vs. 48% of recipients 50+ and 84% of child recipients age 8 or older).
- Medium to high burden caregivers are more apt to note use of prescription medications (94% vs. 85% of low burden caregivers). The need for oversight in taking medicines properly is also more common among high burden caregivers than low burden caregivers (66% vs. 33%).
- Whites are more likely than African-American or Hispanic caregivers to say their recipient takes prescription medicines (Whites 92% vs. African-Americans 83% and Hispanics 82%).
- Caregiver household income is related to reports of care recipient prescription use (\$50,000+ 92% vs. <\$50,000 87%).

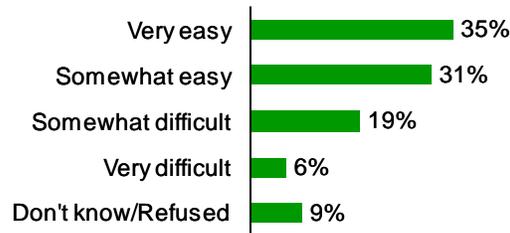
Ease of Coordinating Care

Most caregivers claim it is *very* or *somewhat* easy to coordinate the various health care professionals and service providers for their care recipient (66%), although one in four have some difficulty with this (25%).

Figure 41: Ease of Coordinating Care

Q38. 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?

Base: 2009 All caregivers
(n=1,480)



2009 Caregiver Subgroups

- Caregivers of children with special needs find this coordination more challenging. Four in ten (40%) report some difficulty, compared to 25% of caregivers whose recipient is an adult.
- Those who help arrange or supervise paid services for their care recipient are more likely to find care coordination difficult (36% very or somewhat difficult vs. 20% not performing this ADL).
- As the number of conditions that the care recipient has increases (e.g., short-term physical, long-term physical, mental health, developmental delay, learning/education, behavioral), so does the caregiver's difficulty with care coordination. For example, when the care recipient has no more than one of the six asked about conditions, just 20% of caregivers find it very or somewhat difficult to coordinate care providers, compared to 28% of those caring for someone with two to three types of conditions and 43% of those caring for someone with four or more.
- In addition, caregivers who note the presence of a long-term physical condition are more likely to say care coordination is difficult (28% vs. 16% of those dealing with a short-term physical condition). Similarly, caregivers whose recipient has an emotional or mental health problem are also more likely to consider coordinating care difficult (34% vs. 22% of those without this type of condition)
- Caregivers who want non-English language educational materials are more likely to find care coordination difficult (35% vs. 25%), indicating that perhaps some difficulty in care coordination is due to language barriers.

- Other subgroups of caregivers who are more likely to report some difficulty in coordinating care include:
 - High burden caregivers (35% vs. 24% of medium and 20% of low burden caregivers)
 - Co-resident caregivers (34% vs. 22% of those who live apart from their loved one)

G. Strain and Stress of Caregiving

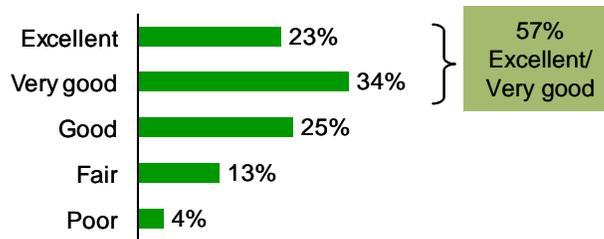
Caregiver Health

Over half of caregivers consider their health to be *excellent* or *very good* (57%), 25% evaluate their health as *good*, and 17% say it is *fair* or *poor*.¹⁰ By comparison, 13% of the general adult population describe their health as *fair* or *poor*.¹⁰

Figure 42: Caregiver Health

D1. How would you describe your own health?

Base: 2009 All caregivers (n=1,480)



% Excellent/Very Good	
Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
55%	59%

2009 Caregiver Subgroups

- The toll on the caregiver's health appears to increase over time. Of those providing care for five years or more, 23% report their health is *fair* or *poor*, compared to 15% of those who have been giving care for a shorter period.
- Primary caregivers are more likely to say their health is *fair* or *poor* (20% vs. 14% of non-primary caregivers), as are co-residing caregivers (25% vs. 14% of those living separately).
- The caregiver's health is strongly correlated to his/her household income. Of caregivers with less than \$30,000 in household income, 34% report *fair* or *poor* health, and this percentage declines sharply to 3% of caregivers with household incomes of \$100,000 or more. There is a similar pattern with caregiver education levels.
- One-quarter of Hispanic caregivers indicate their health is *fair* or *poor* (27%) compared to smaller proportions of Whites (15%) and Asian-Americans (15%).

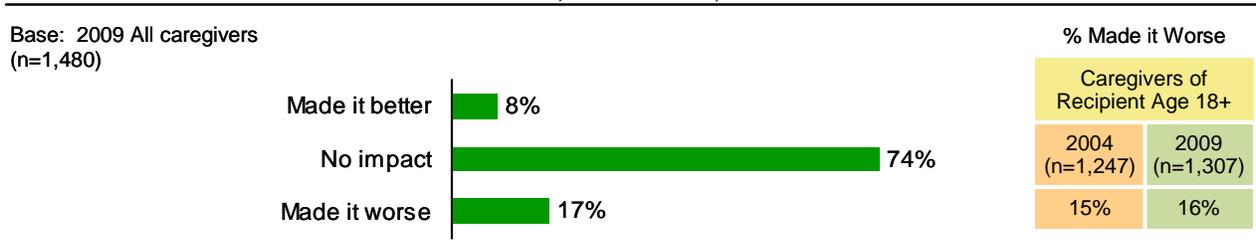
¹⁰ Source: Provisional Summary Health Statistics for U.S. Adults, National Health Interview Survey, 2008, dated August 2009.

- Other groups who are more apt to say their health is *fair* or *poor* include:
 - Those who feel they did not have a choice in taking on their role (20% vs. 15% of those who feel they did have a choice)
 - Caregivers age 65 or older (27% vs. 16% of younger caregivers)
 - Those caring for a child (26% vs. 16% with a recipient age 50+).

Three quarters of caregivers believe their health has not been affected by caregiving (74%), while 17% think caregiving has worsened their health. One in twelve caregivers (8%) feel that taking care of their loved one has made their health better.

Figure 43: Impact of Caregiving on Caregiver's Health

D2. How would you say taking care of your [relation] has affected your health?
Has it made it better, not affected it, or made it worse?



2009 Caregiver Subgroups

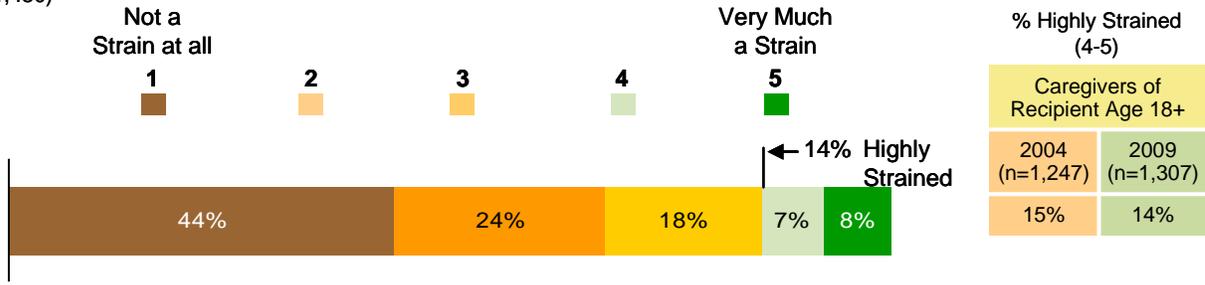
- Longer-term caregivers, those who have provided care for five or more years, are more likely to acknowledge that caregiving has had a negative impact on their own health (24% vs. 14% of those giving care for up to four years).
- When a caregiver lives with his/her recipient, the likelihood of worsened health is much greater (28% vs. 13% when the caregiver lives apart from the recipient). Those in high burden situations—common when the caregiver lives with the care recipient—are also twice as likely as medium or low burden caregivers to say their health took a turn for the worse (28% vs. 12%). Similarly, those providing 21 or more hours of care per week are more likely to say their health has suffered as a result of caregiving (29% vs. 13% caring 0 to 20 hours).
- A larger share of female than male caregivers report declining health as a result of their caregiving (20% vs. 12%).
- Parents taking care of their own children are particularly vulnerable to worsening health as a result of caregiving (30% vs. 15% of those caring for someone else).
- Caregivers whose recipient has emotional or mental health problems are more likely than others to report a decline in their own health as a result of caregiving (28% vs. 12%).

Two-thirds of caregivers report that they experience no more than a low level of physical strain in caring for their loved one (68% rating it 1 to 2 on a 5-point scale), 18% experience a moderate strain (a rating of 3), and 14% face a high level of strain (with a rating of 4 to 5).

Figure 44: Physical Strain of Caregiving

Q35. Think of a scale from 1 to 5, where 1 is not a strain at all and 5 is very much a strain.
How much of a physical strain would you say that caring for your [relation] is/was for you?

Base: 2009 All caregivers
(n=1,480)



2009 Caregiver Subgroups

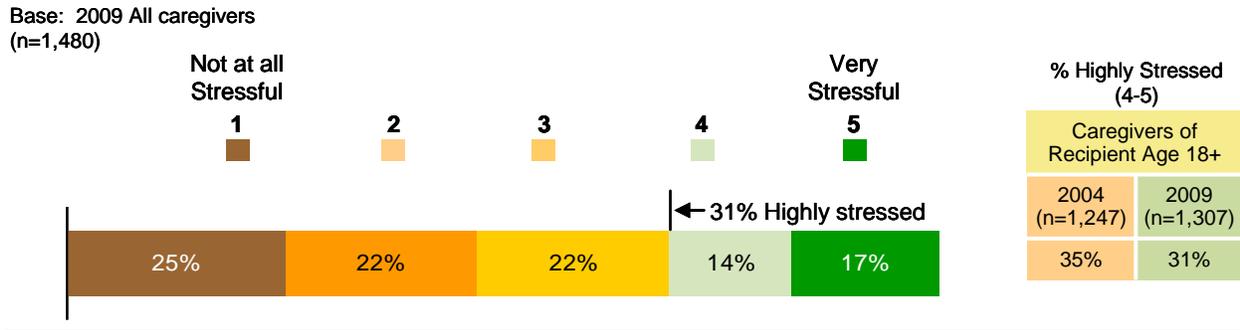
- Subgroups who are more likely to report a high degree of physical strain (4 to 5 on a 5-point scale) include:
 - Primary caregivers (20% vs. 7% of non-primary)
 - Those who did not have a choice in taking on their caregiving role (19% vs. 11% of those who did)
 - Those spending more than 20 hours a week providing care (30% vs. 8%), and likewise, high burden caregivers (28% vs. 5% of low burden caregivers)
 - Co-resident caregivers (24% vs. 10% of those who live separately)
 - Women (16% vs. 11% of men)
 - Hispanics (23%) relative to White caregivers (12%)
 - Older caregivers (21% of those age 65 or older, compared to 13% of those who are younger)

Emotional Stress of Caregiving

Three in ten caregivers consider their caregiving situation to be highly stressful (31% rating stress 4 to 5 on a 5-point scale). An additional 22% report moderate stress (with a rating of 3); nearly half indicate little to no stress (46% giving a rating of 1 to 2).

Figure 45: Emotional Stress of Caregiving

Q36. Using the same scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful, how emotionally stressful would you say that caring for your [relation] is/was for you?



2009 Caregiver Subgroups

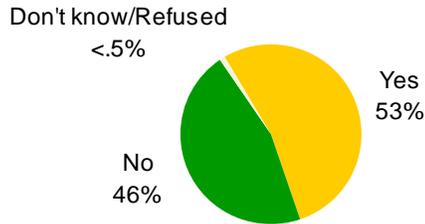
- The proportion reporting a high emotional stress level (with a 4 to 5 rating) rises in relation to:
 - Caregiving hours (51% of those who provide care for 21+ hours rate their stress as high vs. 24% of those providing no more than 20 hours of care)
 - Perceived lack of choice in taking on their caregiving role (44% of those who feel they did not have a choice vs. 22% of those who feel they did)
 - Primary caregiver status (36% vs. 27% of non-primary caregivers)
- Although co-residence does not appear related to feelings of stress among caregivers who provide more than 20 hours of care per week, it does seem to increase stress among those who provide fewer hours of care. Among the latter, 31% of those living with their recipient feel a high level of stress compared to 22% of those living separately.
- White and Hispanic caregivers are more likely than African-Americans to rate their experience as highly stressful (32% and 35%, respectively vs. 21%).
- Those who care for their own child are also more likely to experience high stress (43% vs. 29% of those who have some other relationship with their care recipient).
- Female caregivers also report high stress more often than male caregivers do (35% vs. 25%).

Half of caregivers (53%) say that their caregiving takes away from time with friends and other family members.

Figure 46: Time for Family and Friends

Q40. As a caregiver, do/did you have less time for friends or other family members than before?

Base: 2009 All caregivers (n=1,480)



% Yes	
Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
51%	52%

2009 Caregiver Subgroups

- Feelings of emotional stress are more prevalent among those who have sacrificed time with friends and family as a result of caregiving. Nearly half of them feel high emotional stress (47%), whereas only 14% of those who have been able to keep up with family and friends feel this level of stress.
- Accordingly, the same subgroups of caregivers who are more likely to feel highly stressed are also more apt to say they see friends and family less: high burden caregivers, primary caregivers, those who did not have a choice in taking on their responsibility, those providing more than 20 hours of care per week, co-resident caregivers, and those caring for their own child.
- Six in ten Hispanic and Asian-American caregivers have sacrificed time with friends and family as a result of caregiving (59% each), but a smaller share of African-American caregivers have (46%).

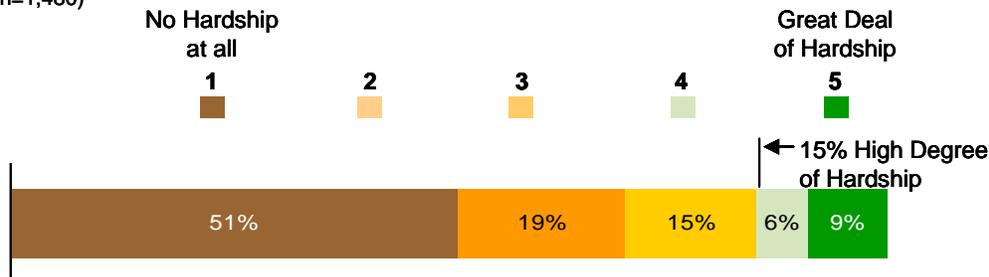
Financial Hardship from Caregiving

Most caregivers feel little or no financial hardship as a result of caring for their loved one (70%). However, 15% report a high degree of financial hardship (4 to 5 on a 5-point scale).

Figure 47: Financial Hardship of Caregiving

Q37. Using the same scale from 1 to 5, where 1 is no hardship at all and 5 is a great deal of hardship, how much of a financial hardship would you say that caring for your [relation] is/was for you?

Base: 2009 All caregivers (n=1,480)



% High Degree of Hardship (4-5)	
Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
12%	13%

2009 Caregiver Subgroups

- As one might expect, caregivers in households with less than \$50,000 in income are twice as likely as those in higher income households to report a high degree of financial hardship as a result of caring for their loved one (21% giving a rating of 4 to 5 on a 5-point scale vs. 10% of those in higher income households).
- Serious hardship is twice as prevalent for caregivers whose recipient is less than 50 years old than for those with an older recipient (26% vs. 10%).
- Hispanic caregivers are more likely than White caregivers to rate their financial hardship highly (22% vs. 12%).
- Caregivers who are providing care to their own child are three times as likely as those taking care of some other relation or friend to report serious financial hardship as a result of the care (37% vs. 11%).
- High burden situations are also correlated with financial challenge. In high burden situations, 23% report a strong financial hardship compared to 10% of low burden caregivers who do.
- In line with this high burden finding, other groups more likely than their counterparts to report a strong financial hardship include primary caregivers, those who did not have a choice in taking on their caregiving responsibility, those who provide care for more than 20 hours per week, and co-resident caregivers.

H. Impact of Caregiving on Work

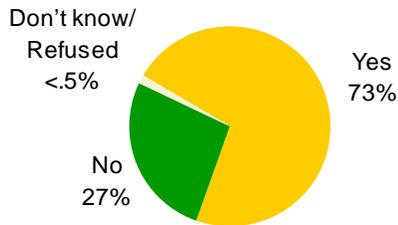
Concurrence of Employment and Caregiving

Seven in ten caregivers indicate they were employed at some time while they were caregiving (73%).

Figure 48: Concurrence of Employment and Caregiving

Q33. *Have you been/Were you employed at any time since you began helping your [relation]?*
 Analyzed with Q32 current employment status and Q1 whether current or past caregiver

Base: 2009 All caregivers
 (n=1,480)



% Ever Employed
 While Caregiving

Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
74%	74%

2009 Caregiver Subgroups

- The rate of employment is quite different for caregivers who are 65 years of age or older—only 35% have ever been employed while caregiving, compared to 79% of younger caregivers.
- Employment while caregiving is more prevalent among the following subgroups of caregivers:
 - Caregivers with a low burden or medium burden (77% were employed while caregiving vs. 66% of those with a high burden)
 - Those spending no more than 20 hours per week providing care (77% vs. 64% of those spending more time)
 - Non-primary caregivers (80% vs. 69% of primary caregivers who were).
 - Males (82% vs. 69% for female caregivers)
 - College graduate caregivers (81% vs. 67% of those with less education)
 - Those who have provided care for one year or more (77% vs. 65% of those who have spent less than a year caregiving)

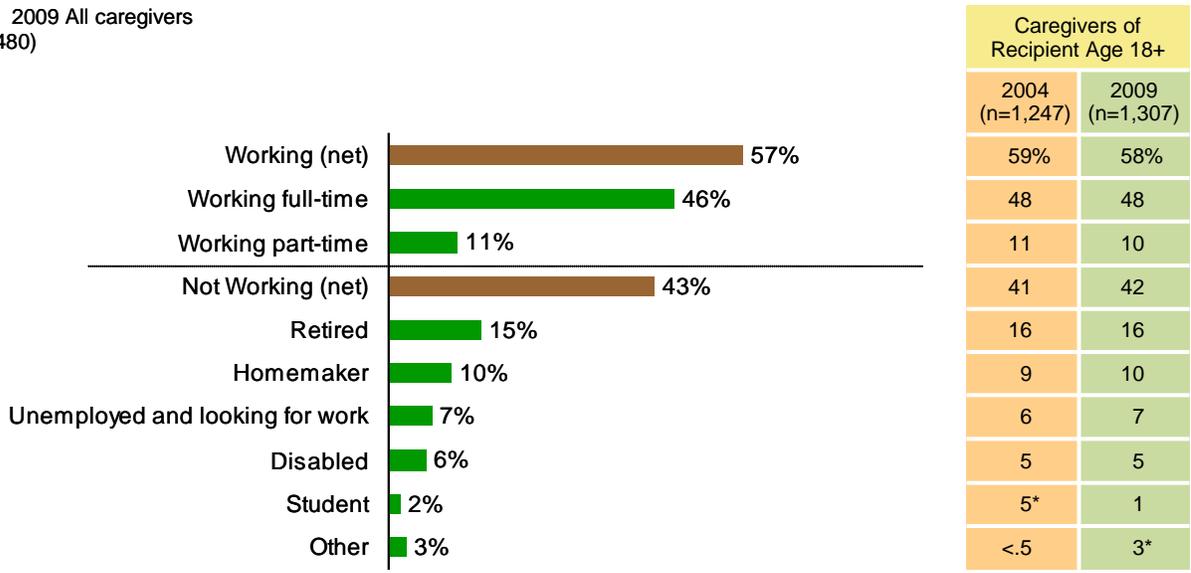
Current Employment Status of Caregiver

Nearly six in ten of those who were caregivers in the past 12 months are currently employed (57%), with 46% working full time and 11% working part time. Fifteen percent of are retired and 10% are homemakers.

Figure 49: Current Employment Status of Caregiver

Q32. Are you currently working full time, working part time, a student, disabled, retired, a homemaker, unemployed and looking for work, or something else?

Base: 2009 All caregivers (n=1,480)



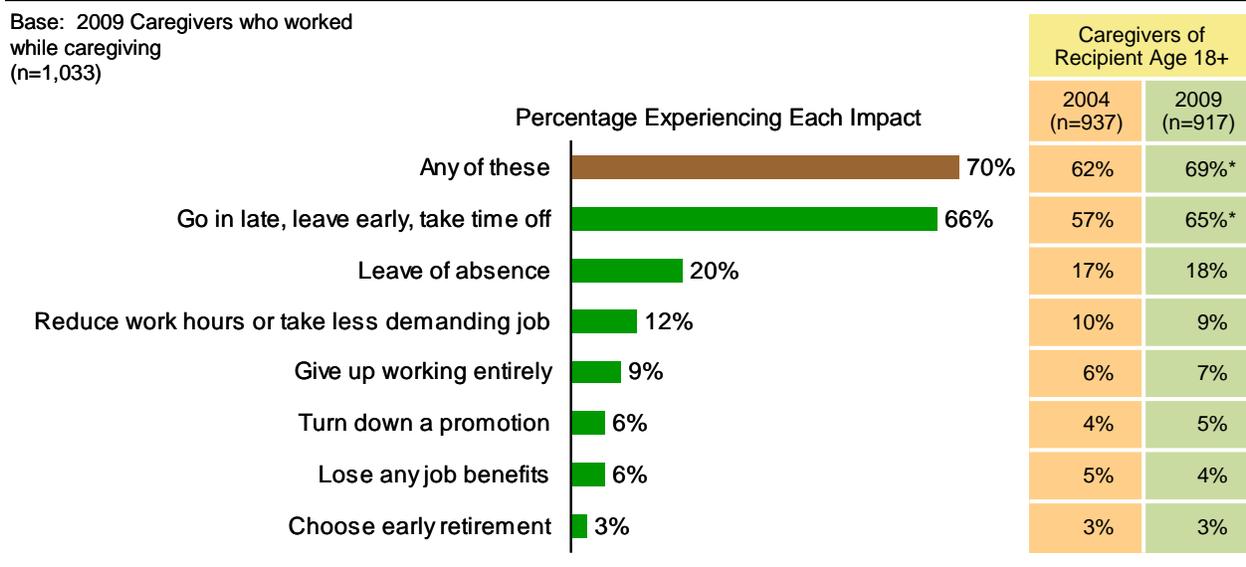
2009 Caregiver Subgroups

- Not surprisingly, the pattern of employment is quite different for caregivers who are 65 years of age or older—72% are retired and only 17% are employed.
- Other subgroup differences are similar to those found in the previous analysis of the concurrence of employment and caregiving. Of note also:
 - Non-primary caregivers are more likely than primary caregivers to be currently employed (66% vs. 50%) and less likely to be retired (11% vs. 18%).
 - 15% of female caregivers say they are currently homemakers, compared to only 1% of males.

Work Accommodations Due to Caregiving

When it becomes difficult to balance caregiving with work, or if the demands of work come into conflict with one's caregiving responsibilities, sometimes caregivers choose to make changes to their work situation. Seven in ten caregivers report making changes such as cutting back on their working hours, changing jobs, stopping work entirely, taking a leave of absence, or other such changes as a result of their caregiving role (70%).

Figure 50: Work Accommodations Due to Caregiving
 Q34. In your experience as both a worker and a caregiver, did you ever...?



2004-2009 Trend for Caregivers of Recipient Age 18+

- The proportion of caregivers of adults who experienced at least one job impact as a result of their caregiving rose from 62% of those who worked while caregiving in 2004 to 69% in 2009. This appears to be caused by the significant increase in caregivers who had to go in late, leave early, or take time off during the day to provide care (from 57% in 2004 to 65% in 2009).

- This increase in the share who shift their arrival or departure time, or take time off during the day, is apparent only among caregivers providing less than 40 hours of care a week, but is especially prominent among those providing 0 to 8 hours or 9 to 20 hours per week. Coming during a recession when feelings of job security would be expected to be low, these findings are somewhat surprising. They could be due to greater employer tolerance of informal flextime behavior on the part of their employees.

2009 Caregiver Subgroups

- Caregivers in the more intensive care situations—those who provide 21+ hours of care each week, have a high burden of care, are the primary caregiver, or share a household with their care recipient—report having to make these work accommodations more so than their counterparts. For example, those with a high burden of care are more likely than those in low burden situations to have made one or more of these changes (83% vs. 64%).
- Caregivers who felt they did not have a choice in taking on their caregiving role are more apt to have made changes in their work situation than are those who felt they had a choice (83% vs. 61%).
- Female caregivers are more likely than males to have made certain work arrangements: reducing hours or taking a less demanding job (16% vs. 6%), giving up work entirely (12% vs. 3%), and losing job benefits (7% vs. 3%).
- Caregivers whose care recipient has emotional or mental health issues are more likely to have made work accommodations (77% vs. 67% of those caring for someone with no emotional or mental health issues).
- Three-quarters (78%) of those caring for a child under age 18 have experienced at least one of these job impacts, significantly more than those caring for an adult age 50 or older (68%).

I. Information Sources and Needs

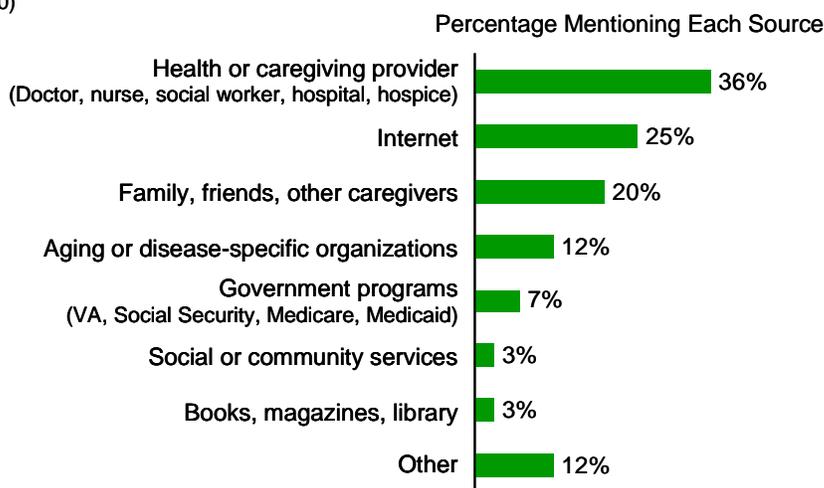
Sources of Information

When asked where they would turn for information related to caregiving, one in three caregivers would seek out a health or caregiving provider (36%). These include doctors (22%), nurses (11%), as well as hospitals, residential facilities, social workers, and others. Another one in four would refer to the Internet (25%), while two in ten would turn to family, friends, or other caregivers (20%).

Figure 51: Sources Used for Caregiving Information

Q41. If you were looking for information about some aspect of helping take care of your [relation], where would you turn?

Base: 2009 All caregivers
(n=1,480)



2009 Caregiver Subgroups

- Caregivers in high burden caregiving situations would turn to health care and caregiving providers (40%) more than those in low burden situations (30%). Conversely, low burden providers would rely more on the Internet (27% vs. 18% high burden).
- Caregivers who feel they had a choice in taking on the responsibility of caring for their loved one turn to friends and family for advice more often than those who feel they had no choice (25% vs. 13%).
- The use of the Internet as a caregiving information resource is higher among:
 - Asian-American caregivers (38% vs. 25% Whites, 26% Hispanics, and 22% African-Americans)
 - Males (32% vs. 22% females)
 - College graduate caregivers (34% vs. 18% of those with less education)
 - Younger caregivers (29% age 18 to 49 and 25% age 50 to 64 vs. 10% age 65+)

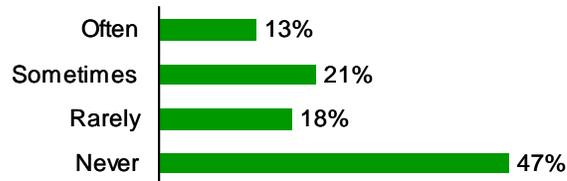
Internet Usage

Half of caregivers report going to the Internet in the past year to find caregiving information (53%), including 34% who did so *sometimes* or *often*, and 18% who did so *rarely*.

Figure 52: Internet Usage for Caregiving Information

Q42. How often, if at all, have you gone to Internet websites in the past year to find information in any way related to being a caregiver for your [relation]?

Base: 2009 All caregivers
(n=1,480)



2009 Caregiver Subgroups

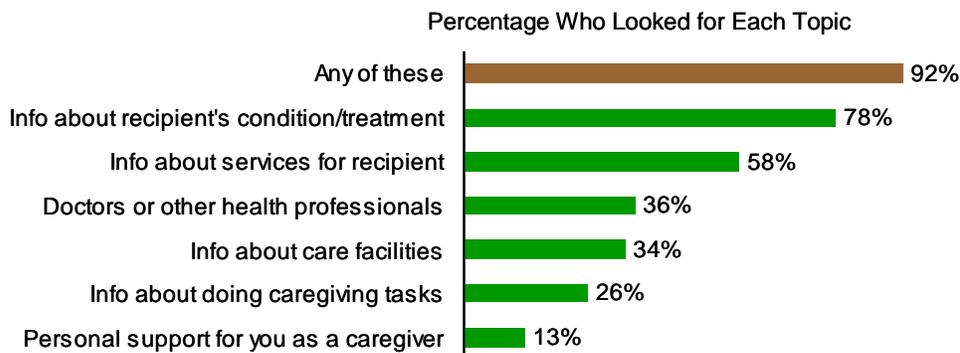
- Usage of the Internet for caregiving information is higher among caregivers with more education and income. For example, 36% of caregivers with household incomes of less than \$30,000 went online for caregiving information—a figure that increases steadily with income, reaching 66% of caregivers with \$100,000 or more in income.
- Two-thirds of Asian-American caregivers have gone online for caregiving information (66%), more so than Whites, African-Americans, or Hispanics (54%, 44%, and 50%, respectively).
- As one might expect, older caregivers are far less likely than younger ones to use the Internet. Specifically, only 30% of those who are 65 or older used it for a caregiving-related purpose, compared to 56% of younger caregivers.
- Frequent use of the Internet (*sometimes/often*) is more common among the following groups:
 - Those caring for a child (50% *sometimes/often* vs. 33% caring for an adult)
 - Caregivers caring for a recipient with an emotional or mental health problem (45% vs. 30% without this type of problem)

Among those who used the Internet for a caregiving-related purpose, three-quarters of caregivers report they have looked online for information about their loved one's condition or treatment (78%), while 58% have sought out information about services for their recipient. Relatively few (13%) have tried to find information online about support for themselves as a caregiver.

Figure 53: Caregiving Information Sought Online

Q43. Did you look online for...?

Base: 2009 Caregivers who used the internet for a caregiving-related purpose (n=771)



2009 Caregiver Subgroups

- Among those who used the Internet for a caregiving-related purpose, the information sought differs depending on the age of the recipient. Caregivers of a child under the age of 18 are the most likely to have sought support for themselves as a caregiver (27%) or information about how to do caregiving tasks (44%). Caregivers of individuals age 50+ are far less likely to have used the Internet in these ways (9% and 22%, respectively); however, they stand out as more interested in information about care facilities (40% vs. 26% of caregivers with younger recipients).
- Others more apt to seek out support for themselves personally include African-American (22%) and Asian-American caregivers (27%) relative to Whites (11%), primary caregivers (18% vs. 8% of non-primary caregivers), co-resident caregivers (24% vs. 9% of non-co-resident caregivers), and those providing more than 20 hours of care per week (22% vs. 10% of those providing 0 to 20 hours).
- Minority caregivers who used the Internet are more likely than White caregivers to use it to look for doctors or other health professionals (47% vs. 32%).

Caregiver Training and Information Needs

One in five caregivers report having had some sort of formal caregiver training to make it easier to care for their loved one (19%).

Figure 54: Caregiving Training

Q46. Have you done or obtained any of these types of things to make it easier to care for your [relation]?

Base: 2009 All caregivers
(n=1,480)



Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
18%	16%

2009 Caregiver Subgroups

- Formal caregiver training is more common among those with more intensive caregiving situations, including higher burden caregivers (31% high vs. 19% medium vs. 11% low), primary caregivers (22% vs. 15% non-primary), those caring for 21+ hours a week (32% vs. 14% 0 to 20 hours), and co-resident caregivers (29% vs. 15% not co-resident).
- Other groups who are more likely to have attended caregiver training include:
 - Those caring for a child under 18 (36% vs. 16% adult recipient)
 - Females (21% vs. 15% male)
 - Parents caring for their own child (34% vs. 16% non-parent)
 - Long-term caregivers (24% cared for five years or more vs. 17% less than five years)

Whether or not they have had any formal training, a large majority of caregivers feel they need more help or information about at least one of fourteen topics related to caregiving (78%). About one in three want more information on keeping their loved one safe at home (37%), managing their own stress (34%), easy activities to do with their care recipient (34%), or finding time for themselves (32%).

Figure 55: Caregiving Information Needs

Q48. As a caregiver, on which of the following do you feel you need/needed more help or information?

Base: 2009 All caregivers
(n=1,480)

Percentage Needing More Help or Information in Each Area	Caregivers of Recipient Age 18+	
	2004 (n=1,247)	2009 (n=1,307)
Any of these	67%	77%*
Keeping recipient safe at home	30%	36%*
Managing your emotional/physical stress	29%	32%
Easy activities to do with recipient	27%	32%*
Finding time for yourself	35%*	30%
Balancing work/family responsibilities	29%	25%
Talking to doctors/other professionals	22%	23%
Choosing home care agency	13%	24%*
Making end of life decisions	20%	21%
Choosing assisted living facility	13%	19%*
Managing challenging behaviors	14%	14%
Choosing nursing home	8%	17%*
Moving, lifting recipient	16%	17%
Managing incontinence	11%	10%
Finding non-English language materials	5%	6%

2004-2009 Trend for Caregivers of Recipient Age 18+

- In general, the demand for caregiving information seems to have increased over the past five years. A greater proportion desire information on at least one topic (77% vs. 67% in 2004), with 2009 caregivers showing increased interest in care recipient safety at home (36% vs. 30% in 2004), easy activities (32% vs. 27%), and choosing either a home care agency (24% vs. 13%), an assisted living facility (19% vs. 13%), or a nursing home (17% vs. 8%).
- The desire for information or help on finding easy activities becomes more marked as the age of the care recipient rises, and is most prominent among caregivers whose recipient is 65 or older. This may relate to increasing media coverage on keeping active in one's older years.
- The increases in demand for help keeping their loved one safe and active are both driven by change among caregivers with less than \$50,000 in household income. No change is apparent among higher income caregivers.
- There are no apparent patterns explaining the increase in a desire for help in finding assisted living, a home care agency, or a nursing home. However, the increased demand for information on choosing an assisted living facility is found only among those who live separately from their care recipient.

- 2009 caregivers express less desire for information about finding time for themselves (30% vs. 35% in 2004). The decrease is mainly among caregivers with less than \$50,000 in household income and in caregivers of individuals without Alzheimer's or mental confusion. Of note, this decline is not apparent among co-resident caregivers.

2009 Caregiver Subgroups

- Caregivers in more intensive caregiving situations are most likely to want more information. Over eight in ten caregivers with a medium to high burden of care desire more information on at least one topic (83%), compared to just 73% of low burden caregivers.
- Caregivers co-residing with the person for whom they provide care are more likely to need more information (84% vs. 75% not co-resident), as are those providing care for 9 or more hours each week (84% vs. 73% of those giving care 0 to 8 hours a week).
- The need for more help or information also varies by the care recipient's age. Caregivers caring for children are more likely to want more help or information on at least one topic mentioned (85% vs. 77% of caregivers caring for an adult).
- Minority caregivers are also more likely to want information than White caregivers (84% African-American, 88% Hispanic, 88% Asian-American vs. 75% White).
- Caregivers whose recipient has an emotional or mental health problem are more likely to want more help or information with at least one topic mentioned (88% vs. 73% of caregivers caring for someone *without* an emotional/mental health issue).
- Desired information for certain topics varies by education. Caregivers who graduated college are more likely to want assistance with choosing outside caregiving services or specialized residences, including assisted living (21% vs. 13% HS grad or less), a nursing home (19% vs. 13% HS grad or less), or a home care agency (27% vs. 19% less than a college degree).
- However, caregivers who have a high school degree or less are more likely to want help regarding speaking with doctors (29%), compared to those with more education (22%).
- Female caregivers are more likely than men to want help with moving or lifting the recipient (18% vs. 13%) and with managing emotional and physical stress (38% vs. 25%). Men are more likely than women to want help choosing an assisted living facility (21% vs. 16%) or nursing home (20% vs. 14%).

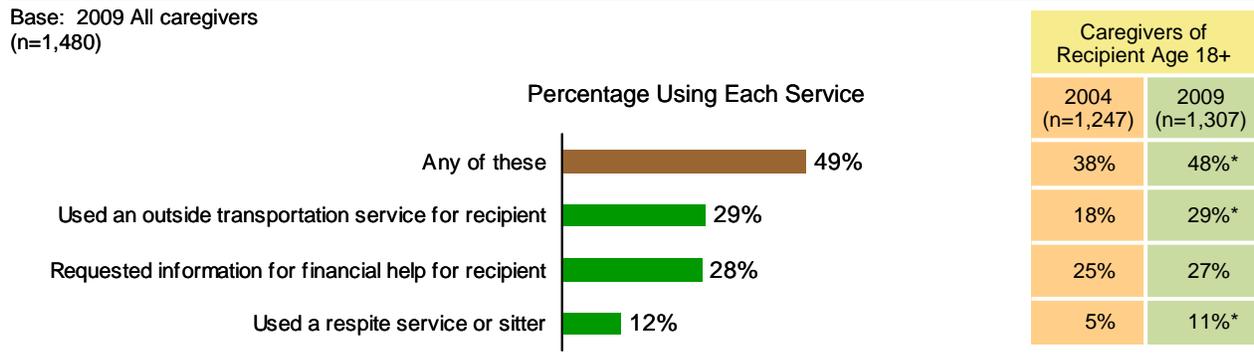
J. Support for Caregivers

Supportive Services and Practices

About half of all caregivers (49%) have sought at least one of three specific types of help on behalf of their care recipient. Most common is using an outside transportation service (29%), followed closely by requesting financial assistance (28%) for their loved one. Few have used a respite service or a sitter (12%).

Figure 56: Use of Services

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



2004-2009 Trend for Caregivers of Recipient Age 18+

- The proportion of caregivers of adults who have used at least one of these outside services has increased over the past five years (48% vs. 38% in 2004). This is due to significant increases in the use of transportation (29% vs. 18% in 2004) and respite services (11% vs. 5%).

2009 Caregiver Subgroups

- The likelihood of having used any of these outside resources increases with the length of time care has been provided. Four in ten (39%) caregivers who have provided care for less than a year have used one or more of these three services, compared to 49% of those who have been caregiving for one to four years, and 60% of those caring for a longer period.
- Use of these services varies by the care recipient's age, as well. Caregivers caring for a child are more likely to report use of respite or sitter services (19% vs. 11% with recipients 50+). Caregivers of adults ages 18 to 49 are more likely to have sought out financial help (44%) than those caring for older (25%) or younger (32%) recipients.
- Use of respite and sitter services is higher among caregivers in more intensive caregiving situations. Those with a high burden of care (20%) are more likely than less burdened caregivers to have used respite services (8%). As hours of care per week increase, so too does the likelihood of having used a respite or sitter service. And finally, those co-residing with their care recipient are more likely to have used respite or sitter services (20% vs. 9% not co-resident).

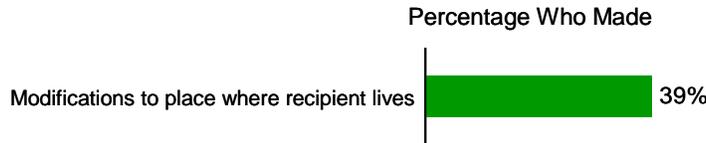
- Caregivers whose care recipient has a long-term physical condition are more likely to have used each of the three services than are those caring for someone with only a short-term physical condition.

Four in ten caregivers report having made home modifications to make things easier for their care recipient (39%).

Figure 57: Home Modifications

Q46. Have you done or obtained any of these types of things to make it easier to care for your [relation]?

Base: 2009 All caregivers
(n=1,480)



Caregivers of Recipient Age 18+	
2004 (n=1,247)	2009 (n=1,307)
39%	41%

2009 Caregiver Subgroups

- Caregivers who are more likely to have made home modifications include:
 - Those caring for an adult age 50 years or older (45% vs. 24% age 0 to 49)
 - High burden caregivers (53% vs. 32% low and medium burden)
 - Those caregiving 21 or more hours per week (49% vs. 35% fewer hours)
 - Those whose care recipient has a long-term physical condition (45% vs. 24% of those without any long-term physical conditions)
 - Longer-term caregivers (43% cared at least one year vs. 30% cared less than one year)

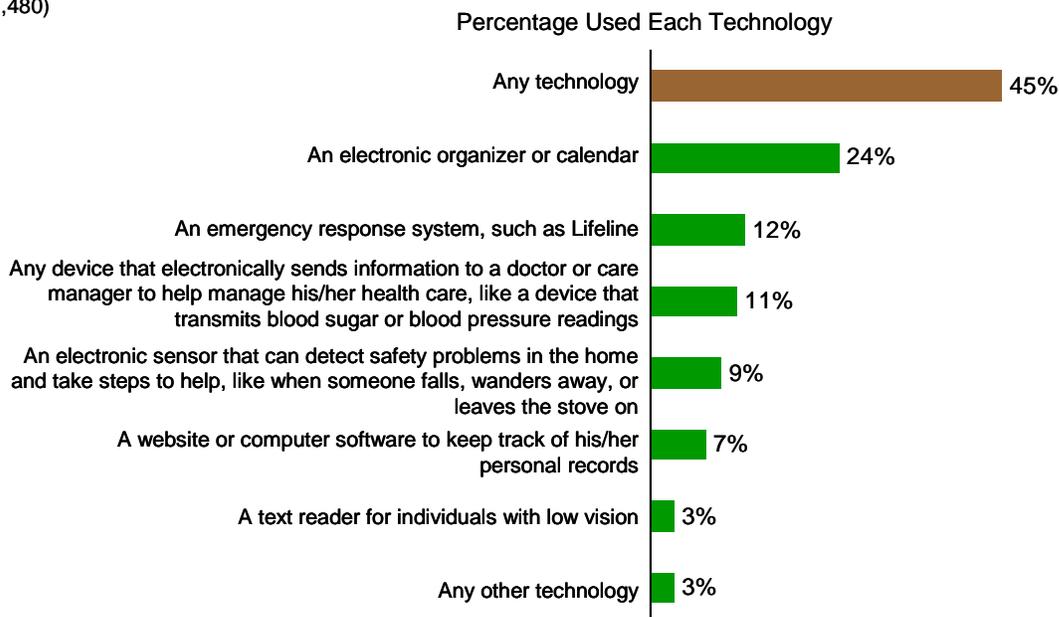
Use of Technology

When asked about their use of technology while caregiving, 45% of caregivers have used at least one specified technology. One-quarter have used an electronic organizer or calendar (24%), while about one in ten each have used an emergency response system such as Lifeline (12%), a device that electronically sends information to a doctor or care manager to help manage the recipient’s care (11%), or an electronic sensor that can detect safety problems in the home and take steps to help (9%). Use of a website or software for personal health records is reported by 7%.¹¹

Figure 58: Use of Technology in Caregiving

Q44. *In caring for your [relation], was the following ever used?*

Base: 2009 All caregivers
(n=1,480)



2009 Caregiver Subgroups

- Use of these technologies is more common among caregivers who are caring for a loved one age 50 or older (49% vs. 38% of younger recipients).
- Half of caregivers in medium or high burden situations have used at least one of these technologies (50%), more than those in low burden situations (40%).
- Those who have cared for their loved one for at least five years are also more likely to have used at least one of these technologies (50% vs. 39% cared less than one year).
- Caregivers who do *not* live with their care recipient are more likely to use emergency response systems (15% vs. 6% co-resident) and electronic transmission devices (12% vs. 8% co-resident).

¹¹ An additional 8% of caregivers volunteer that they use some other sort of technology, but actually report standard communication, security, treatment, or monitoring devices (e.g., cell phone, smoke detector, glucose or blood pressure monitor, oxygen machine, pacemaker, muscle stimulator). These are not counted as technologies in the graphic or analysis.

Reaction to Caregiving-Related Policies

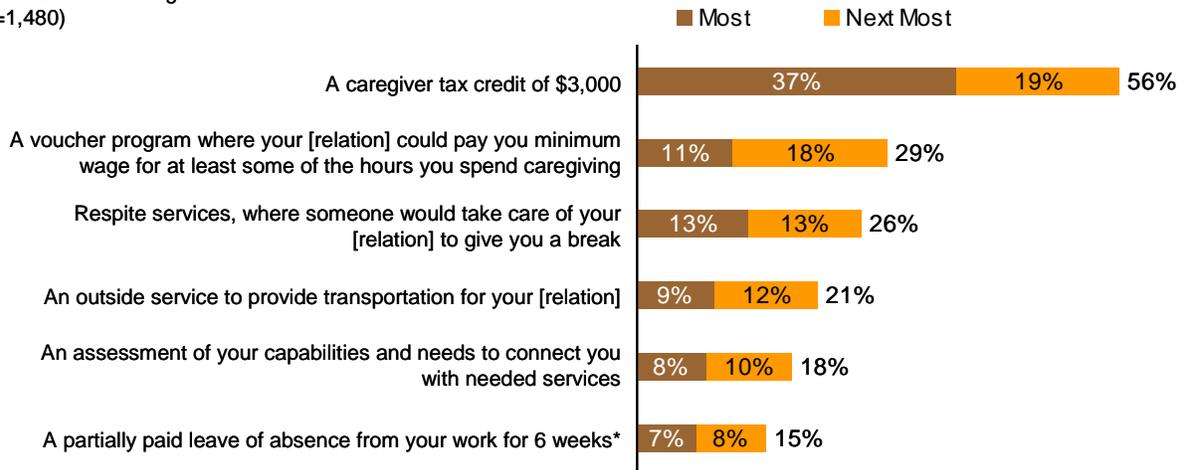
Of six national policies or programs presented to caregivers as potential ways to help them, the most popular by far is a caregiver tax credit of \$3,000 (56% rate it as their first or second most preferred policy). About three in ten prefer a voucher program where they could be paid minimum wage for at least some of their caregiving hours (29% first or second choice), while 26% prefer respite services.

Among just the caregivers who were employed while caregiving, 20% place the leave of absence among their top two choices.

Figure 59: Reaction to Caregiving-Related Policies

Q47. I am going to read you a list of things that policymakers are proposing to help caregivers like yourself. Please tell me which one you would find/have found most/second most helpful, regardless of whether or not you have used it already?

Base: 2009 All caregivers
(n=1,480)



*Asked only of caregivers who were employed while caregiving, but percentages shown are based on all caregivers to be comparable with other policy items.

2009 Caregiver Subgroups

- Younger caregivers are more interested in financial interventions. As age of caregiver decreases, interest increases in the tax credit, the voucher program that could give them a minimum wage, and the partially paid leave of absence.
- Interestingly, preference for the tax credit *rises* in relation to household income. Among caregivers with less than \$30,000 in household income, 52% choose the tax credit as their first or second choice, compared to 62% of those with \$100,000 or more in income.
- However, the voucher program where the care recipient can pay the caregiver minimum wage for at least a portion of their caregiving hours is much more popular among the low income caregivers. Four in ten (42%) of those with less than \$30,000 in household income prefer the voucher program, and this percentage declines to 17% of the highest income caregivers—those with \$100,000 or more in household income.

- Co-resident caregivers also show significantly higher interest in financial-related policies, in comparison to caregivers who do *not* live with their care recipient. Six in ten (62%) would find a tax credit helpful (vs. 54% not co-resident), while 36% feel a voucher program would be helpful (vs. 26% not co-resident).
- Caregiver expectations about the helpfulness of various policies vary by the hours of care provided per week. Those caring for 20 hours or less each week show more interest in a needs assessment (19% vs. 14% 21+ hours spent caregiving) and outside transportation (24% vs. 16%). However, these lower-hour caregivers are *less* interested in the voucher program (27% vs. 34% 21+ hours) and respite services (23% vs. 37%).
- Caregivers with more than a high school education are more interested in the tax credit (60%) than those with less education (48%).
- Those who have cared for their loved one for less than one year are more interested in a partially paid leave of absence (20% vs. 13% cared for one year or more).

K. Respondent Profile

Two-thirds of caregivers are female, and the caregivers' average age is 48.0. Seven in ten caregivers are White, 13% are African-American, and small percentages are Hispanic or Asian-American. Six in ten caregivers are married, and just over one in three have children or grandchildren under the age of 18 in their household.

Figure 60: Profile of Respondents

	Total (n=1,480) A	White (n=858) B	African- American (n=200) C	Hispanic (n=201) D	Asian- American (n=200) E
Gender					
Male	34%	34%	30%	34%	50% ^{BCD}
Female	66	66 ^E	70 ^E	66 ^E	50
Age of Caregiver					
18 to 34	22%	16%	34% ^B	35% ^B	31% ^B
35 to 49	29	30	23	33	26
50 to 64	35	38 ^D	31	25	33
65 to 74	9	10 ^D	7	5	7
75 or older	4	4 ^D	4	1	2
<i>Mean age</i>	<i>48.0</i>	<i>49.9^{CD}</i>	<i>44.5</i>	<i>41.6</i>	<i>44.3</i>
Race/Ethnicity of Caregiver					
White	72%	100%	0%	0%	0%
African-American	13	0	100	0	0
Hispanic	12	0	0	100	0
Asian-American	2	0	0	0	100
Other	2	0	0	0	0
Marital Status					
Married	58%	63% ^{CD}	39%	52% ^C	63% ^C
Living with a partner	5	5 ^{CE}	2	9 ^{CE}	1
Single, never married	16	12	38 ^{BDE}	18	25 ^B
Separated, divorced	14	14	15	15	9
Widowed	6	7 ^E	6	5	2
Children/Grandchildren <Age 18 in Household					
Yes	37%	34%	37%	53% ^{BC}	44% ^B
No	63	66 ^{DE}	63 ^D	46	55

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

Three in ten caregivers have no more than a high school education, while more than four in ten caregivers have completed college. About half have at least \$50,000 in household income. Nearly six in ten are currently employed, and 15% are retired.

Profile of Respondents (continued)

	Total (n=1,480) A	White (n=858) B	African- American (n=200) C	Hispanic (n=201) D	Asian- American (n=200) E
Education					
Less than high school	6%	3%	11% ^B	17% ^{BE}	5%
High school graduate	23	23 ^E	23 ^E	25 ^E	5
Some college	25	24 ^E	31 ^E	25 ^E	14
Technical school	2	2	3	4	1
College graduate	25	27 ^D	20	17	37 ^{BCD}
Graduate school	18	20 ^{CD}	12	10	37 ^{BCD}
Household Income					
Less than \$50,000 (net)	42%	35%	61% ^{BE}	61% ^{BE}	28%
Less than \$15,000	8	6	14 ^B	16 ^{BE}	8
\$15,000 to \$29,999	14	11	19 ^{BE}	23 ^{BE}	8
\$30,000 to \$49,999	18	17	28 ^{BE}	20	12
Less than \$50,000, not fully specified	1	1	<.5	1	0
\$50,000 or more (net)	53	60 ^{CD}	32	34	68 ^{CD}
\$50,000 to \$74,999	19	21 ^C	12	17	16
\$75,000 to \$99,999	13	14 ^{CD}	7	8	14
\$100,000 or more	19	22 ^{CD}	12	8	35 ^{BCD}
\$50,000+, not fully specified	2	2	1	1	3
Current Employment Status					
Working full time	46%	48% ^D	45%	37%	51% ^D
Working part time	11	11 ^C	6	14 ^C	17 ^C
Retired	15	17 ^D	14	8	13
Homemaker	10	10 ^C	3	16 ^{CE}	8
Unemployed and looking for work	7	5	18 ^{BE}	11 ^B	7
Disabled	6	5 ^E	7 ^E	6 ^E	1
Student	2	1	3	5 ^B	3
Other	3	3	4	4	2

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

A plurality of caregivers live in a suburban setting, but three in ten each live in urban or rural areas. A similar distribution is seen for care recipients. Eleven percent of caregivers have served in the armed forces, and 17% of their adult care recipients have.

Profile of Respondents (continued)

	Total (n=1,480) A	White (n=858) B	African- American (n=200) C	Hispanic (n=201) D	Asian- American (n=200) E
Caregiver Living Location					
Urban	29%	22%	42% ^B	49% ^B	40% ^B
Suburban	39	42 ^D	37 ^D	24	45 ^D
Rural	31	35 ^{CDE}	19	22	15
Care Recipient Living Location					
Urban	33%	27%	45% ^B	53% ^B	43% ^B
Suburban	37	40 ^D	35 ^D	21	44 ^D
Rural	28	32 ^{CDE}	18	22	13
Caregiver Service in Armed Forces					
Served on active duty	11%	11%	8%	10%	8%
Did not ever serve	89	89	91	90	91
Care Recipient Service in Armed Forces (among those with adult recipients)	(n=1,307)	(n=773)	(n=169)	(n=163)	(n=183)
Served on active duty	17%	19% ^{CD}	9%	8%	14%
Did not ever serve	82	80	89 ^B	92 ^B	85

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

2004-2009 Trend for Caregivers of Recipient Age 18+

- Caregivers of adults are now older, on average, than were their counterparts in 2004. Their average age is now 49.2 years, compared to 46.4 in 2004.

Figure 61: Profile of Respondents – Trend in Caregivers of Recipient Age 18+

	Caregivers of Recipient Age 18+	
	2004 (n=1,247)	2009 (n=1,307)
Gender		
Male	39%	35%
Female	61	65
Age of Caregiver		
18 to 34	26%*	19%
35 to 49	32*	27
50 to 64	30	38*
65 to 74	9	10
75 or older	5	4
<i>Mean age</i>	46.4	49.2*

Caregivers of adults in 2009 have higher educational levels than seen in 2004. Specifically, 45% now have completed college, up from 36% in 2004. They are also more likely to have incomes of \$50,000 or more (56% vs. 41% in 2004). The 2004 median income of \$46,700 for caregivers 18 or older is equivalent to about \$54,650 in 2009.

Profile of Respondents – Trend in Caregivers of Recipient Age 18+ (continued)

	Caregivers of Recipient Age 18+	
	2004 (n=1,247)	2009 (n=1,307)
Race/Ethnicity of Caregiver		
White	73%	73%
African-American	12	12
Hispanic	10	11
Asian-American	4*	2
Other	<.5	2*
Marital Status		
Married	56%	59%
Living with a partner	6	5
Single, never married	18	15
Separated, divorced	14	14
Widowed	6	6
Children/Grandchildren <Age 18 in Household		
Yes	37%*	30%
No	62	70*
Education		
Less than high school	5%	5%
High school graduate	29*	23
Some college	27	25
Technical school	3	2
College graduate	22	26
Graduate school	13	19*
Household Income		
Less than \$50,000 (net)	50%*	39%
Less than \$15,000	8	7
\$15,000 to \$29,999	17*	13
\$30,000 to \$49,999	26*	18
Less than \$50,000, not fully specified	0	1
\$50,000 or more (net)	41	56*
\$50,000 to \$74,999	18	21
\$75,000 to \$99,999	9	13*
\$100,000 or more	15	20*
\$50,000+, not fully specified	0	2
<i>Median Household Income</i>	<i>\$46,700</i>	<i>\$57,200</i>

Profile of Respondents – Trend in Caregivers of Recipient Age 18+ (continued)

	Caregivers of Recipient Age 18+	
	2004 (n=1,247)	2009 (n=1,307)
Current Employment Status		
Working full time	48%	48%
Working part time	11	10
Retired	16	16
Homemaker	9	10
Unemployed and looking for work	6	7
Student	5*	1
Disabled	5	5
Other	<.5	3*
Caregiver Living Location		
Urban	29%	28%
Suburban	39	39
Rural	29	32
Care Recipient Living Location		
Urban	33%	33%
Suburban	37	37
Rural	28	29
Caregiver Service in Armed Forces		
Served on active duty	14%	11%
Did not ever serve	86	89
Care Recipient Service in Armed Forces		
Served on active duty	17%	17%
Did not ever serve	82	82

The profile of respondents, broken out by the age of the care recipient, is as follows.

Figure 62: Profile of Respondents by Care Recipient Age

	Total (n=1,480)	Caregivers of Children 0 to 17 (n=173) A	Caregivers of Younger Adults 18 to 49 (n=187) B	Caregivers of Older Adults 50+ (n=1,397) C
Gender				
Male	34%	28%	40% ^A	33%
Female	66	72 ^B	59	67
Age of Caregiver				
18 to 34	22%	35% ^C	30% ^C	18%
35 to 49	29	41 ^{BC}	26	27
50 to 64	35	17	31 ^A	40 ^{AB}
65 to 74	9	5	10	9 ^A
75 or older	4	1	2	5 ^{AB}
<i>Mean age</i>	<i>48.0</i>	<i>40.6</i>	<i>45.8^A</i>	<i>49.9^{AB}</i>
Race/Ethnicity of Caregiver				
White	72%	60%	61%	76% ^{AB}
African-American	13	17	17	11
Hispanic	12	19 ^C	20 ^C	10
Asian-American	2	2	1	2
Other	2	1	1	2
Marital Status				
Married	58%	53%	56%	59%
Living with a partner	5	6	4	5
Single, never married	16	21	19	15
Separated, divorced	14	16	15	14
Widowed	6	4	6	7
Children/Grandchildren <Age 18 in Household				
Yes	37%	79% ^{BC}	30%	32%
No	63	21	70 ^A	68 ^A

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

Caregivers' median household income of \$57,200 compares to the \$52,029 for the U.S. overall.¹²

Profile of Respondents by Care Recipient Age (continued)

	Total (n=1,480)	Caregivers of Children 0 to 17 (n=173) A	Caregivers of Younger Adults 18 to 49 (n=187) B	Caregivers of Older Adults 50+ (n=1,397) C
Education				
Less than high school	6%	13% ^C	8%	4%
High school graduate	23	21	29	23
Some college	25	28	28	24
Technical school	2	4	2	2
College graduate	25	17	18	26 ^{AB}
Graduate school	18	15	15	20
Household Income				
Less than \$50,000 (net)	42%	59% ^{BC}	44%	39%
Less than \$15,000	8	15 ^{BC}	6	7
\$15,000 to \$29,999	14	18	21 ^C	12
\$30,000 to \$49,999	18	24	16	19
Less than \$50,000, not fully specified	1	1	1	1
\$50,000 or more (net)	53	37	49 ^A	55 ^A
\$50,000 to \$74,999	19	11	22 ^A	20 ^A
\$75,000 to \$99,999	13	10	13	13
\$100,000 or more	19	15	13	20 ^B
\$50,000+, not fully specified	2	1	1	3 ^A
<i>Median Household Income</i>	<i>\$57,200</i>	<i>\$41,700</i>	<i>\$53,100</i>	<i>\$60,300</i>
Current Employment Status				
Working full time	46%	35%	44%	50% ^A
Working part time	11	18 ^{BC}	5	11 ^B
Retired	15	7	14	17 ^A
Homemaker	10	14 ^C	15 ^C	8
Unemployed and looking for work	7	12 ^C	10	5
Disabled	6	8	7	5
Student	2	4 ^B	<.5	2 ^B
Other	3	2	5	3

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

¹² Source: U.S. Census Bureau, American Community Survey, 2008.

Profile of Respondents by Care Recipient Age (continued)

	Total (n=1,480)	Caregivers of Children 0 to 17 (n=173) A	Caregivers of Younger Adults 18 to 49 (n=187) B	Caregivers of Older Adults 50+ (n=1,397) C
Caregiver Living Location				
Urban	29%	30%	27%	29%
Suburban	39	40	35	39
Rural	31	26	36	31
Care Recipient Living Location				
Urban	33%	31%	34%	32%
Suburban	37	39	32	38
Rural	28	26	31	28
Caregiver Service in Armed Forces				
Served on active duty	11%	7%	14%	11%
Did not ever serve	89	92	86	89
Care Recipient Service in Armed Forces (among those with adult recipients)	(n=1,307)		(n=187)	(n=1,397)
Served on active duty	17%	--	5%	20% ^B
Did not ever serve	82	--	95 ^C	79

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