



What Made You
Think Mom Had
Alzheimer's?

2011

National Alliance
for Caregiving

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About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. The Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients. For more information, visit www.caregiving.org

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Introduction

This report describes the results of a study conducted to examine the impact of caring for a family member with Alzheimer's or dementia on unpaid caregivers' daily lives and psychological outlook. In particular, a goal of the study was to determine whether there are any positive outcomes from providing care to someone with this type of condition.

The survey asked family caregivers about the initial signs of the disease, the extent of care they provide, their caregiving tasks, details about their care recipient's symptoms, and specific psychological changes and attitudinal outcomes they experienced.

Methodology

This report is based on a quantitative online survey of 1,000 family caregivers, age 18 or older, who provide unpaid care to an individual with Alzheimer's, dementia, or age-related mental confusion or forgetfulness. Respondents were screened to ensure their care recipient is at least 40 years of age.

The questionnaire was designed by Mathew Greenwald & Associates in collaboration with the National Alliance for Caregiving. The full questionnaire is presented in Appendix A to this report.

The online questionnaire was fielded from September 14 to September 27, 2010 using Research Now's online panel. They targeted individuals who had previously identified themselves as a caregiver for someone with Alzheimer's. Most respondents completed the questionnaire in 14 minutes or less.

The demographics of the respondents closely match those of caregivers of individuals with Alzheimer's or dementia who were surveyed in the 2009 national study entitled *Caregiving in the U.S.* In particular, there do not appear to be significant differences in the age of the caregiver or the care recipient, the gender of the caregiver, the relationship between caregiver and recipient, the percentage living with their recipient, or the perception of choice in taking on the caregiving role. However, this online study's respondents are more likely to be college graduates and less likely to be the primary caregiver. They are more likely to report helping with caregiving activities. Significant differences from the national study are noted in the body of the report.

All figures have been rounded. In addition, "don't know" responses are not always presented in charts and tables. For these reasons, some charts and tables will not add to 100%. The results of questions which allowed respondents to provide multiple responses may also add to greater than 100%.

Balance of Positive and Negative Outcomes

Alzheimer's is a disease with no cure, and individuals with the disease experience a progressive deterioration of their abilities and faculties; the outlook is hardly bright. However, caregivers generally find a balance of the positive and negative aspects of their situations. Half (51%) say their caregiving experience has been equally positive and negative, and 33% say it is more positive than negative. Half as many (17%) rate their experience as negative, on balance.

What kind of positives emerge from their caregiving experience? Among the most prevalent:

- Two out of three feel it gives them the opportunity to “give back” to their loved one (65%).
- Nearly half feel they now have a closer personal relationship with the person to whom they provide care (46%).
- More than four in ten feel they now live more “in the moment” than they did before (44%).

In addition, caregivers say they have been changed by their caregiving experience. According to their reports:

- 67% are more grateful
- 60% are more accepting
- 56% are more patient
- 51% are more assertive

Caregivers' views of the positive/negative balance of their situations are related to two key factors:

- The stage of their loved one's illness. Those who say their recipient has *mild* symptoms are more likely than those reporting *moderate* or *severe* symptoms to rate their situation as positive, on balance (39% vs. 31%).
- Whether or not the caregiver feels she or he had a choice in becoming a caregiver. Caregivers who feel they had a choice in becoming a caregiver are twice as likely as those who did not have a choice to say their experience has been positive, on balance (45% vs. 22%).

Of note, positive caregivers are demographically similar to negative caregivers with the exception that they are more likely to be employed (72% vs. 61%). They also do not appear to differ on the number of hours spent providing care, the number or types of caregiving tasks with which they help their loved one, or their overall burden of care. However, positive caregivers are far more likely than negative caregivers to be in very good or excellent health (66% vs. 40%), and are far less likely to neglect their own medical care as a result of caregiving (15% vs. 42%).

One of the most prevalent negative feelings associated with caregiving is emotional stress—61% report feeling highly stressed. In addition, some caregivers indicate feelings of guilt that they are not doing more to help their loved one (40%) or anger with themselves for becoming frustrated with him/her (39%).

Initial Signs of the Disease

The path to diagnosing Alzheimer's or dementia begins most often with caregivers seeing signs and symptoms of the disease. Nine in ten caregivers say events or situations they observed that led them to believe their loved one probably had Alzheimer's or dementia. Among them, only three in ten say a doctor's examination or questioning was one of the events that initially contributed to their thought that Alzheimer's or dementia was present (31%).

The remaining seven in ten caregivers saw signs and symptoms on their own. The situation they most commonly report as leading them to think that Alzheimer's or dementia was probably present is their care recipient having problems remembering conversations or words (46%). Additional signs that alerted caregivers to this possible diagnosis include changes in mood or personality (30%), misplacing things (29%), difficulty completing familiar tasks (27%), and forgetting who people are (26%).

Timing of Diagnosis by a Doctor

There is often a long lag between the time that the caregiver first observes symptoms and the time that the caregiver feels fairly certain that Alzheimer's or dementia is present. In fact, 44% of those who were involved at the onset of signs and symptoms indicate that at least two years passed from the time that the symptoms were first seen to the time that the caregiver concluded that his/her loved one probably had such a condition. Overall, however, nine in ten caregivers of individuals with Alzheimer's or dementia report that the diagnosis has been confirmed by a doctor (91%). Most often it is a primary care physician or a neurologist who confirms the diagnosis (55% and 26%, respectively, of those with a confirmed diagnosis).

Actions Taken as a Result of Care Recipient's Condition

Nine in ten caregivers say that they or others have tried to find out as much as they could about their loved one's condition (90%). A doctor is the most common source of information that they turn to (70%), although half turn to the Internet (48%). One in four have contacted an Alzheimer's organization for information about the condition (27%).

Beyond gathering information, a large majority say legal and financial steps were taken, with 86% getting involved in their care recipient's finances and 70% obtaining power of attorney. Many also restrict their care recipient's activities—in particular, driving (84%) or other activities (75%).

Severity of Condition

The caregivers responding to this survey span a continuum, from those whose care recipient is in a *mild* stage of Alzheimer's or dementia (22%), to a moderate stage marked by obvious trouble with memory and normal activities or personality changes (50%), to a severe stage (28%) characterized by a need for help with all daily needs, inability to recognize family, or trouble walking, talking or swallowing.

Three-quarters of these caregivers believe that their care recipient is suffering physically, emotionally, or spiritually as a result of their Alzheimer's or dementia (78%).

A. Care Recipient's Condition

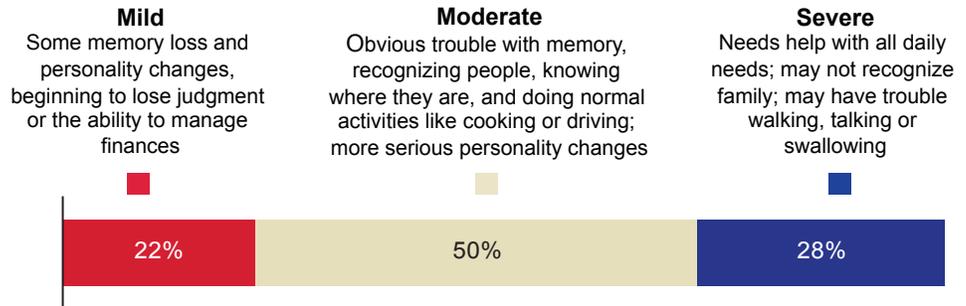
Stage of Alzheimer's or Dementia

One-fifth of family caregivers of individuals with Alzheimer's, dementia or age-related mental confusion or forgetfulness describe their care recipient's Alzheimer's or dementia as *mild*, characterized by some memory loss or personality changes and the early stages of losing judgment (22%). Half say their care recipient is in a *moderate* stage of Alzheimer's or dementia, marked by obvious trouble with memory and normal activities as well as more serious personality changes (50%). The remaining 28% say their care recipient's condition is *severe*, meaning s/he needs help for all daily needs, is unable to recognize family, or has trouble walking, talking or swallowing.

Figure 1: Extent of Alzheimer's/Dementia

Q25. In your opinion, what stage of Alzheimer's or dementia is your [relation] in?

All
(n=1,000)



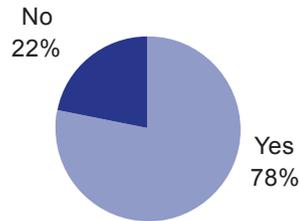
Suffering from Alzheimer's or Dementia

Three-quarters of the caregivers responding to this survey believe that their care recipient is suffering physically, emotionally, or spiritually as a result of Alzheimer's or dementia (78%).

Figure 2: Perceived Suffering of Care Recipient

Q26. If you had to make a judgment, do you think your [relation] is suffering physically, emotionally, or spiritually as a result of Alzheimer's or dementia?

All
(n=1,000)



SUBGROUP DIFFERENCES

- The likelihood of caregivers believing their care recipient is suffering increases with the severity of the Alzheimer's or dementia symptoms, from 72% of those caring for someone with *mild* symptoms to 84% of those with *severe* symptoms.
- Caregivers with younger care recipients are more likely to see them as suffering from their Alzheimer's or dementia (83% vs. 70% of those with recipients age 85 or older).

B. Diagnosis of the Illness

Signs of Alzheimer's or Dementia

Nine out of ten Alzheimer's caregivers say one or more events or situations led them to believe their care recipient had one of these conditions (90%), though for nearly all of these caregivers, it was multiple events or situations (86% overall) rather than a single event (4%) that made them suspect Alzheimer's or dementia. Only 4% of caregivers say a suggestion from someone else led them to believe their care recipient had Alzheimer's or dementia.

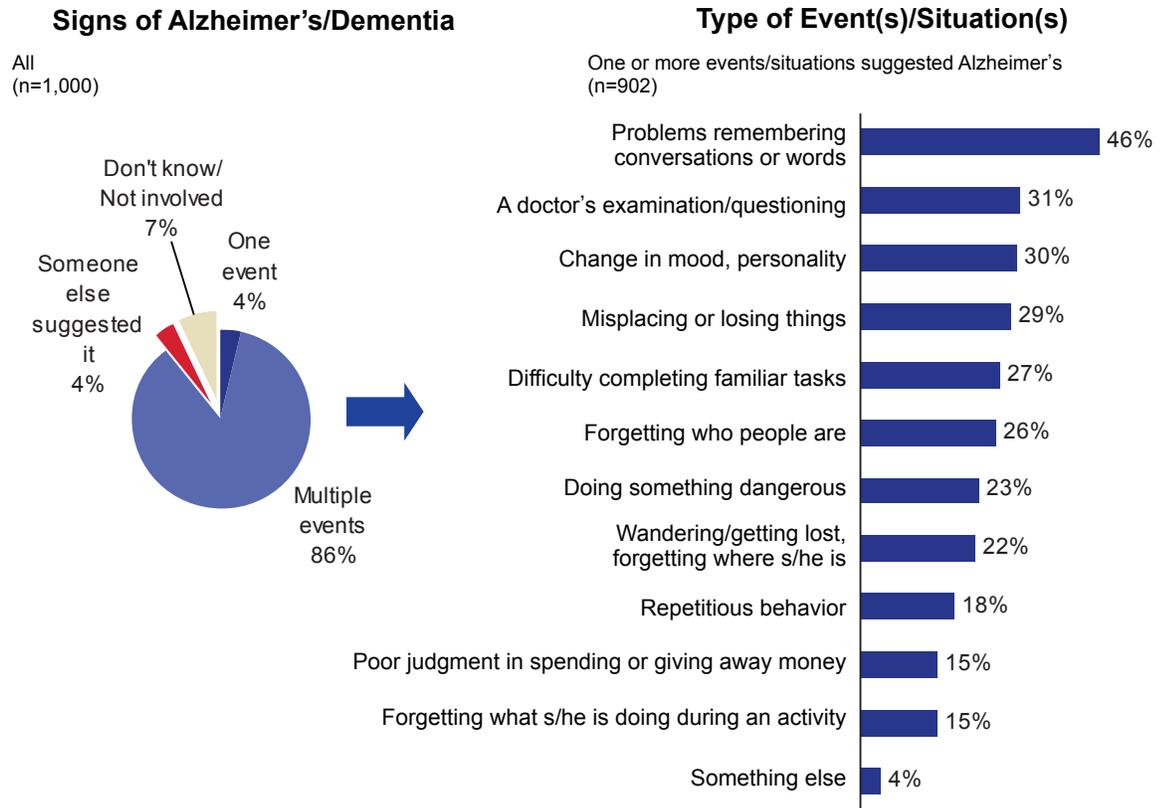
Only three in ten caregivers who noticed a sign or symptom of Alzheimer's or dementia (31%) point to a doctor's exam or questioning as one of the events that made them think their loved one probably had Alzheimer's or dementia. For the remaining seven in ten, it was their own observations of changes in their loved one's behavior that spurred them to this conclusion.

The most common indication of Alzheimer's or dementia is difficulty remembering words; this is noted by 46% of caregivers who say one or more events or situations made them suspect their care recipient had such a disorder. Other common signs, each noted by about three in ten of these caregivers, include changes in mood or personality (30%), or misplacing things (29%). Slightly fewer—roughly one in four caregivers who noticed signs of Alzheimer's or dementia on their own—say their care recipient was having difficulty completing familiar tasks (27%), forgetting people (26%), doing something dangerous (23%), or wandering or getting lost (22%).

Figure 3: First Signs of Alzheimer's/Dementia

Q18. How did you come to think that your [relation] probably had Alzheimer's or dementia?

Q19. What type of event(s)/situation(s) made you think your [relation] probably had Alzheimer's or dementia?



SUBGROUP DIFFERENCES

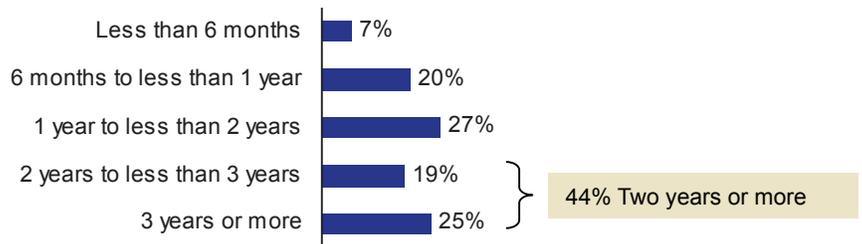
- Women are more likely than men to remark on changes in mood and personality (33% vs. 25%) and poor financial judgment (17% vs. 11%).

There is often a lag between the time that the caregiver first observes symptoms and the time he or she feels fairly certain that Alzheimer's or dementia is present. Of the caregivers who were involved with the individual with Alzheimer's or dementia when the condition was first seen, four in ten say their care recipient was showing signs of the illness for at least two years before they were fairly certain of the condition (44%).

Figure 4: Duration of Symptoms Prior to Concluding Alzheimer's/Dementia

Q20. Looking back, for how long was your [relation] showing symptoms of Alzheimer's/dementia before you were fairly certain that's what it was?

Caregivers involved with care recipient when condition was first seen (n=957)



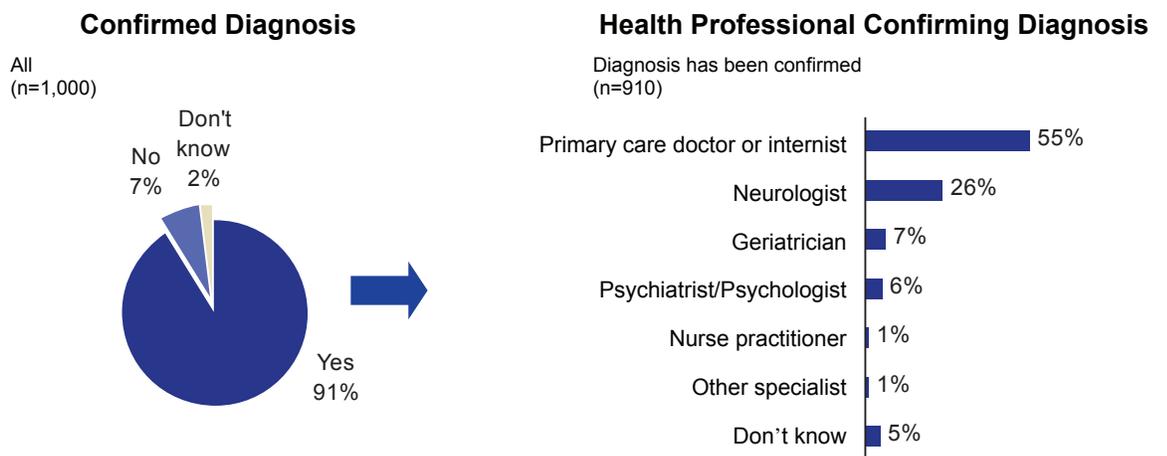
Confirmation of Alzheimer's or Dementia Diagnosis

Nine out of ten caregivers say their care recipient has been to a doctor to confirm the diagnosis of Alzheimer's or dementia (91%). This confirmation is most often provided by a primary care physician (55%), though a notable share of caregivers report that a neurologist confirmed the diagnosis (26%).

Figure 5: Confirmation of Alzheimer's/Dementia

Q23. Has your [relation] ever been to a doctor to confirm a diagnosis of Alzheimer's or dementia?

Q24. What kind of health professional first diagnosed your [relation] with Alzheimer's or dementia?



SUBGROUP DIFFERENCES

- Nearly all of those caring for someone in the *moderate* or *severe* stages of illness say their care recipient has been to a doctor to confirm the diagnosis (96%), but only 74% of those caring for someone with *mild* symptoms say their care recipient has.

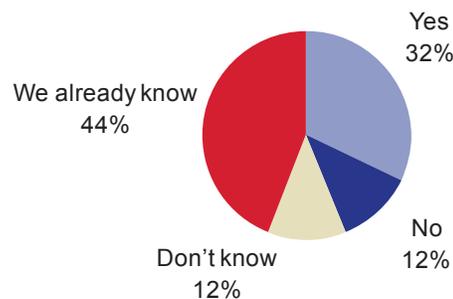
Definitive Test for Alzheimer's Disease

When asked if they would like their care recipient to have a definitive test to determine whether s/he has Alzheimer's disease, nearly half believe they already know for sure whether their care recipient has the condition (44%). Three in ten indicate they would like such a test (32%), well over twice the proportion that say they would not want such a test (12%).

Figure 6: Definitive Test for Alzheimer's Disease

Q26a. Would you want your [relation] to have an accurate test to determine definitively whether or not s/he has Alzheimer's disease? Currently there is no cure for Alzheimer's disease.

All
(n=875)
Question was added
after fielding had begun



SUBGROUP DIFFERENCES

- The likelihood of a caregiver wanting their loved one to have a definitive test for Alzheimer's disease increases with the burden of care; only 24% of those with a low burden would want such a test, compared to 31% of those with a moderate burden and 36% of those with a high burden. [See Figure 25 and the accompanying text for details on burden of care.]
- Caregivers who provide care to someone younger than 85 years old are more likely than those with an older care recipient to want a definitive Alzheimer's test (36% vs. 26%).

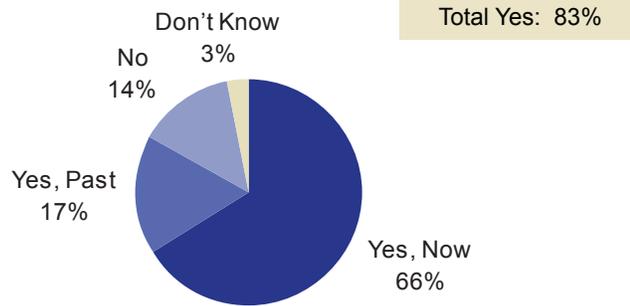
Medication for Alzheimer's or Dementia

More than eight out ten caregivers of individuals with Alzheimer's or dementia report their loved one has taken prescription medication for the condition (83%), with the large majority of these currently taking such medication (66% overall). Only 14% have never taken prescription medication for their Alzheimer's or dementia.

Figure 7: Medication

Q16. Has your [relation] ever taken prescription medication for Alzheimer's or dementia?

All
(n=1,000)



SUBGROUP DIFFERENCES

- As would be expected, the likelihood of taking prescription medication for Alzheimer's or dementia increases with severity of the symptoms, from 62% when the symptoms are still *mild* to 92% when they are *severe*.

C. Actions Taken and Information Sources Used

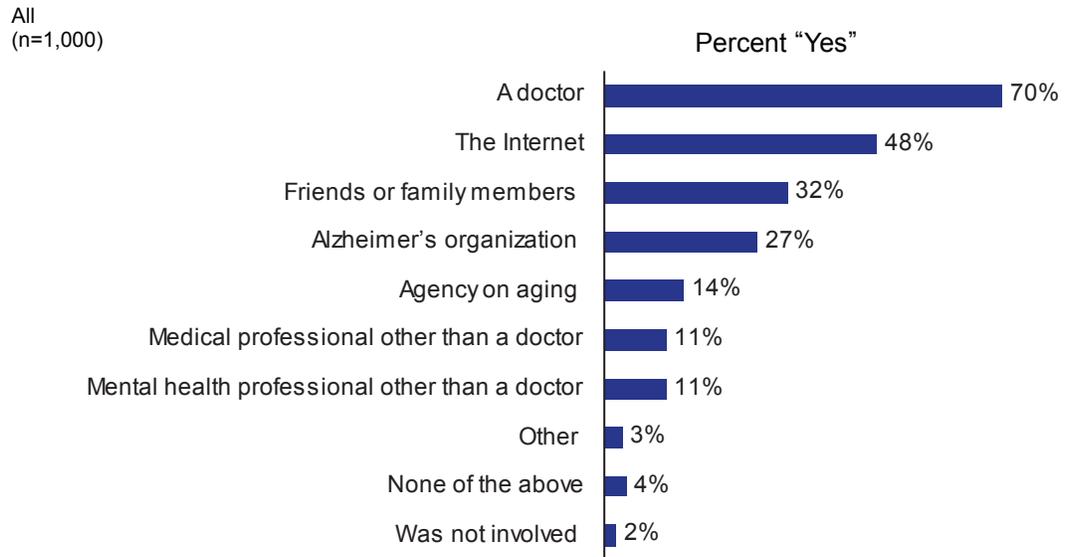
Information Sources

Physicians are by far the source of information to which caregivers most commonly turn when they first suspect a loved one has Alzheimer's or dementia (70%).

About half first turned to the Internet to get more information about Alzheimer's or dementia (48%), while 32% turned to friends or family and 27% first went to an Alzheimer's organization as a resource. Fourteen percent turned to an agency on aging for information when they first suspected their care recipient had Alzheimer's, and 11% each turned to a non-physician medical professional or mental health professional.

Figure 8: Sources of Information

Q22. When you thought your [relation] may have Alzheimer's or dementia, where did you first turn in order to get more information about the condition? (Check all that apply)



SUBGROUP DIFFERENCES

- The likelihood of a caregiver turning to an Alzheimer's organization rises in relation to the severity of the care recipient's symptoms, from 16% of those caring for someone with *mild* symptoms to 33% of those caring for someone with *severe* symptoms.
- Caregivers who are caring for a parent or parent-in-law with Alzheimer's or dementia are more likely than those who are providing care for someone else to have first turned to a doctor (73% vs. 64%), the Internet (51% vs. 43%), or an agency on aging (17% vs. 9%).

Actions Taken as a Result of Alzheimer's or Dementia

What action do caregivers take to address their care recipient's Alzheimer's disease or dementia? The vast majority report that they or someone else have arranged for their care recipient to see a doctor (94%), made an effort to spend more time with him or her (91%), or tried to find out as much as possible about their care recipient's condition (90%). Legal and financial steps are also common, with 86% getting involved in their care recipient's finances and 70% obtaining a power of attorney.

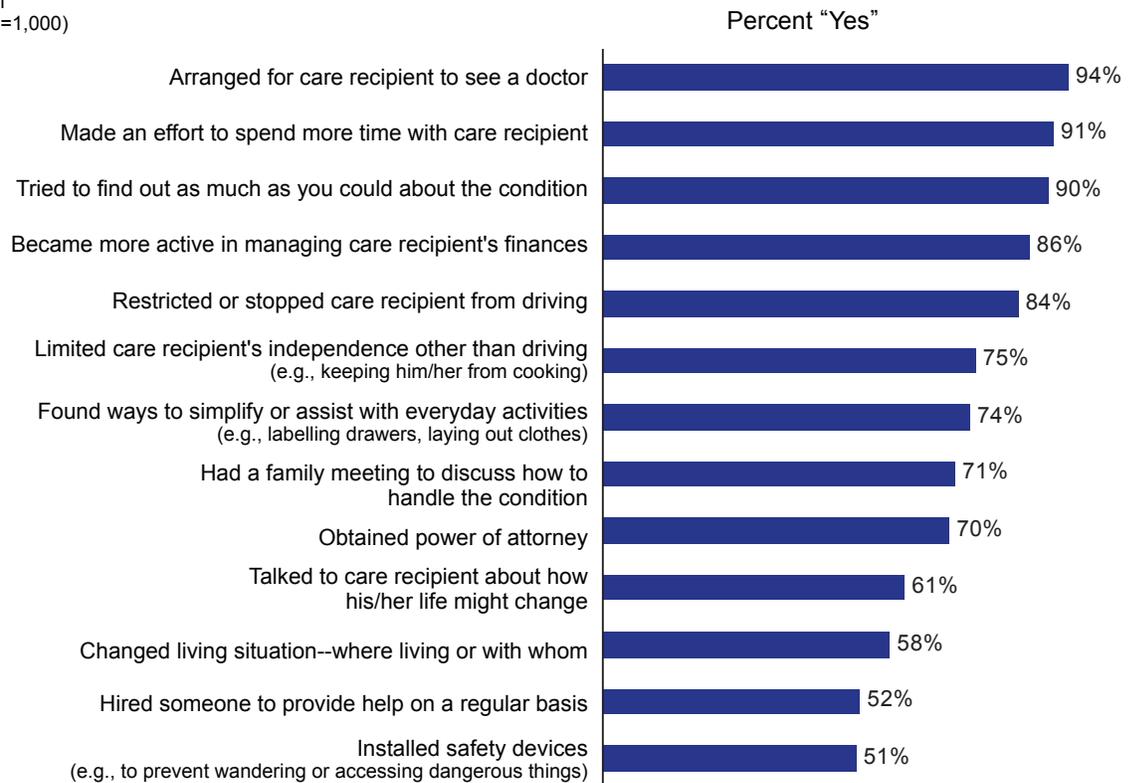
Restrictions of the care recipient's activities are common as well, with 84% restricting driving and 75% limiting the care recipient's independence in other ways. While limiting activities on one hand, on the other, caregivers report finding ways to assist the person to whom they give care with everyday activities (74%).

Majorities of caregivers have held family discussions on how to handle the condition (71%) or held conversations with the care recipient about how his/her life might change (61%). Other actions, also taken by majorities, include making changes to the care recipient's living situation (58%), hiring a paid caregiver (52%), and installing safety devices (51%).

Figure 9: Actions as a Result of Condition

Q21. Which of the following, if any, have you or others done as a result of your [relation]'s condition?

All
(n=1,000)



SUBGROUP DIFFERENCES

- Not surprisingly, the likelihood of taking many of these actions increases with the length of time that they have been caregivers and with their care recipient's symptom severity and age.
- Many of these actions are also more likely to be taken by those who are caring for a parent with Alzheimer's or dementia than by those who are caring for another relative or friend, even when controlling for the stage of the illness. The most distinct differences are seen in the proportions arranging for the care recipient to see a doctor, an increasing role in finances, obtaining power of attorney, and installing safety devices.

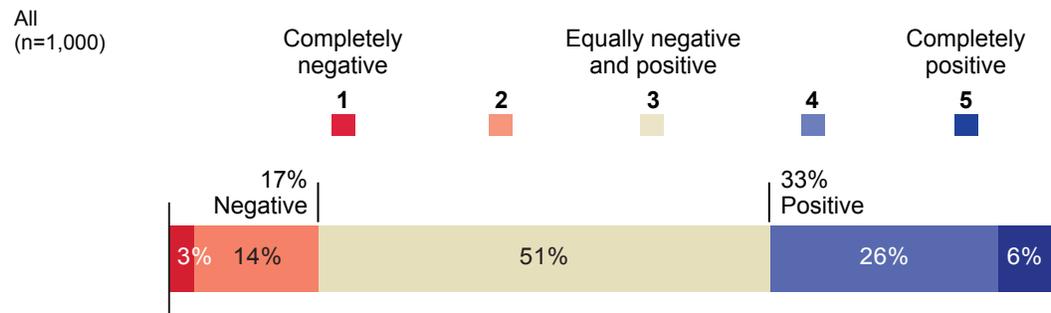
D. Impact of the Caregiving Situation

Balance of Positive and Negative in Caregiving Experience

One in three respondents report their experience as a caregiver to someone with Alzheimer’s or dementia has been at least more positive than negative (with 33% rating a 4 or 5 on a 5-point scale). That is twice the percentage who rate their experience, on balance, as negative (17%). The largest share, 51%, say their experience has been equally positive and negative.

Figure 10: Positive vs. Negative Caregiving Experience Overall

Q27. Please indicate overall how positive or negative your experience as a caregiver is.



SUBGROUP DIFFERENCES

- Caregivers who feel they had a choice in taking on the responsibility of caregiving are twice as likely as those who did not have a choice to say their experience has been more positive than negative (45% vs. 22%).
- In addition, caregivers who rate their care recipient’s Alzheimer’s or dementia symptoms as *mild* are more likely than those who rate these symptoms as *moderate* or *severe* to say their experience as a caregiver has been positive, on balance (39% vs. 31%).
- Caregivers who are racial or ethnic minorities are more likely than non-minority white caregivers to rate their experience on the positive side of the scale (40% vs. 31%).
- In addition, caregivers who feel their care recipient is not suffering are more likely than those who believe their care recipient is suffering to rate their experience as mostly positive (42% vs. 30%).

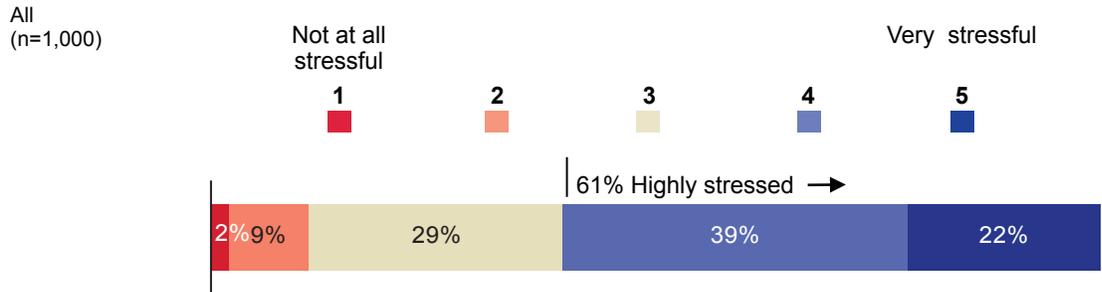
Negative Aspects of Caregiving

In order to understand the overall positive/negative balance that Alzheimer’s caregivers report, the survey posed questions about specific negative outcomes as well as particular positive impacts that caregivers may experience—whether changes in attitude, opinion, or behavior.

One negative impact of caregiving is a feeling of emotional stress. Six in ten (61%) caregivers of individuals with Alzheimer’s or dementia rate their level of emotional stress highly, giving it a 4 or 5 on a 5-point scale.

Figure 11: Emotional Stress of Caregiving

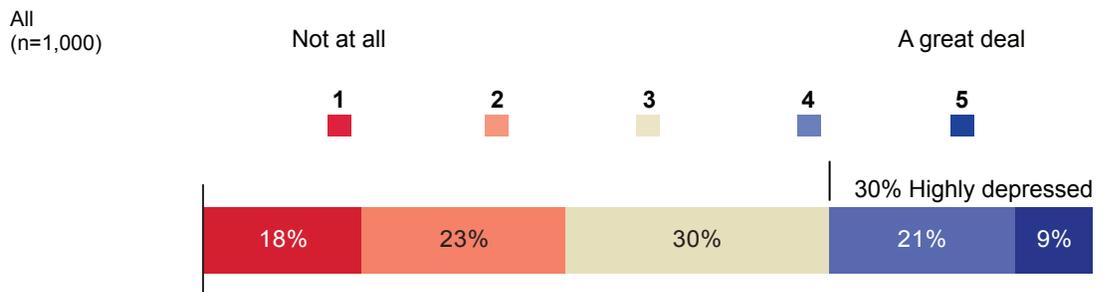
Q30. How emotionally stressful would you say that caring for your [relation] is for you?



Only half as many, 30%, say they have been highly depressed as a result of caring for their loved one with Alzheimer’s or dementia (rating a 4 or 5 on a 5-point scale).

Figure 12: Depression from Caregiving

Q31. To what degree, if at all, have you been depressed as a result of caring for your [relation]?



SUBGROUP DIFFERENCES

- Caregivers who believe their care recipient is suffering are much more likely to feel a high level of emotional stress from caregiving (64% vs. 49% of those who do not perceive suffering) and depression (33% vs. 20%).
- Those who believe they did not have a choice in assuming their caregiver role are also more likely to report stress (70% vs. 48% of those with a choice) and depression (36% vs. 23%).
- Reports of high emotional stress and depression also increase in relation to:
 - The severity of Alzheimer’s symptoms
 - Duration of caregiving
 - Burden of care
 - Co-residence

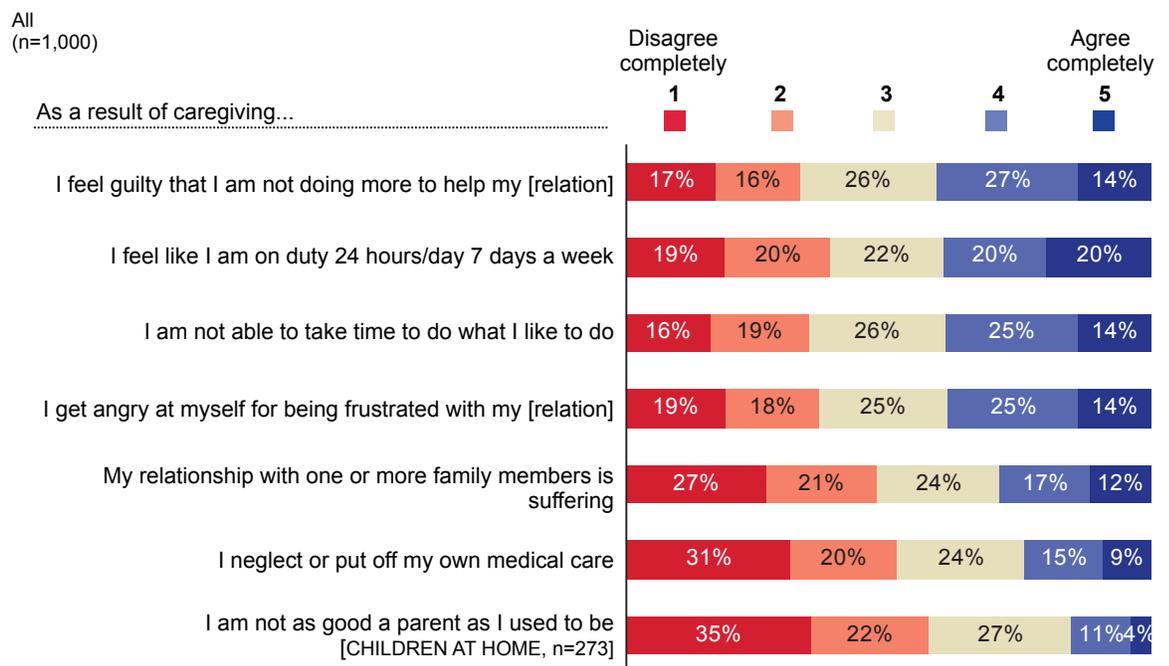
Four additional negative outcomes of caregiving for a person with Alzheimer’s or dementia are each reported by two out of five caregivers: guilt that they are not doing more to help their care recipient (40% rate their agreement a 4 or 5 on a 5-point agreement scale),

a feeling that their responsibilities are present around the clock (40%), an inability to take the time to do what they want to do (39%), and anger at themselves for being frustrated with their care recipient (39%). Of note, however, almost as many caregivers say they disagree with each of these perceptions (34%, 39%, 35%, and 36%, respectively).

For each of the three remaining negative outcomes examined, a larger share of caregivers disagree than agree.

Figure 13: Negative Life Changes as a Result of Caregiving

Q28. Please indicate how much you agree or disagree with the statement below:



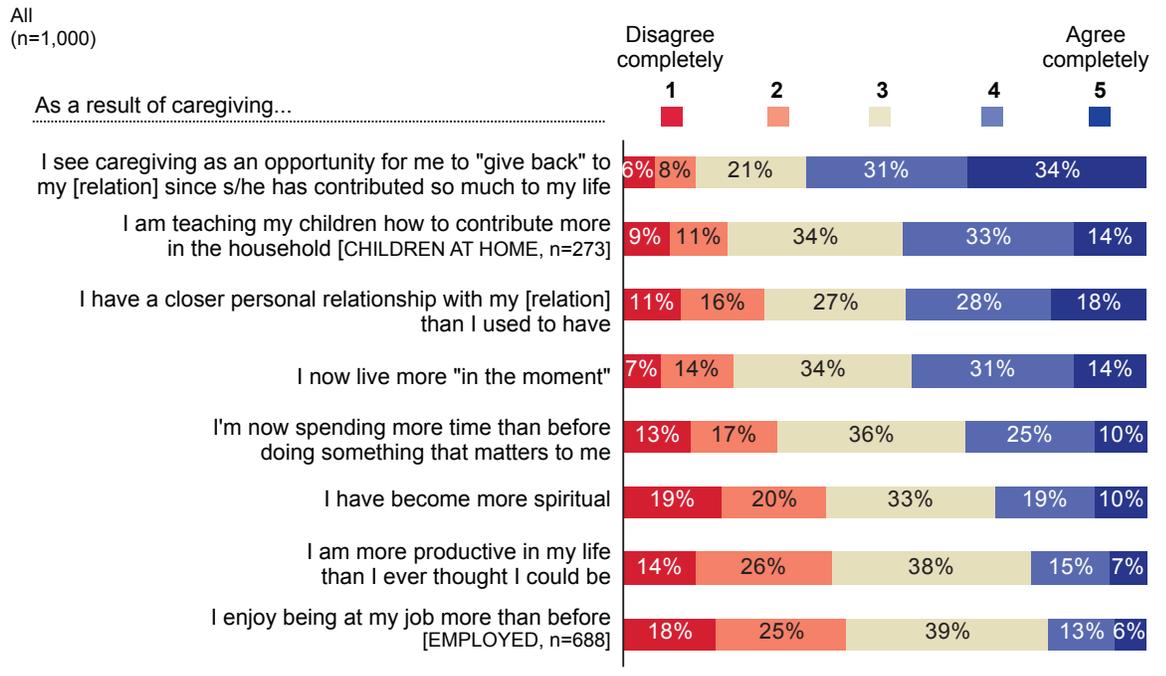
Positive Aspects of Caregiving

An array of positive outcomes of caregiving help counter-balance the negative aspects of the experience. One positive outcome that stands out is the feeling reported by two out of three Alzheimer’s caregivers that caregiving “is an opportunity to give back” to their care recipient (65% agree with this statement, rating it a 4 or 5 on a 5-point scale). Almost half of those with children in the household agree that caregiving has led them to teach their children how to contribute more to the household (47%). Similar proportions agree that caregiving has brought them into a closer relationship with their care recipient (46%), or that they live more “in the moment” as a result of caregiving (44%).

One in three feel they are now able to spend more time doing something that matters to them as a result of caregiving (35%), but almost as many disagree (29%). Increasing spirituality resulted from caregiving for 28%, but 39% indicate this is not true for them. The perception that caregiving has increased their productivity in life is reported by 22%, but a larger share disagree with that view (40%). Only 18% of employed caregivers enjoy being at their job more than before, compared to 43% who disagree.

Figure 14: Positive Life Changes as a Result of Caregiving

Q28. Please indicate how much you agree or disagree with the statement below:



SUBGROUP DIFFERENCES

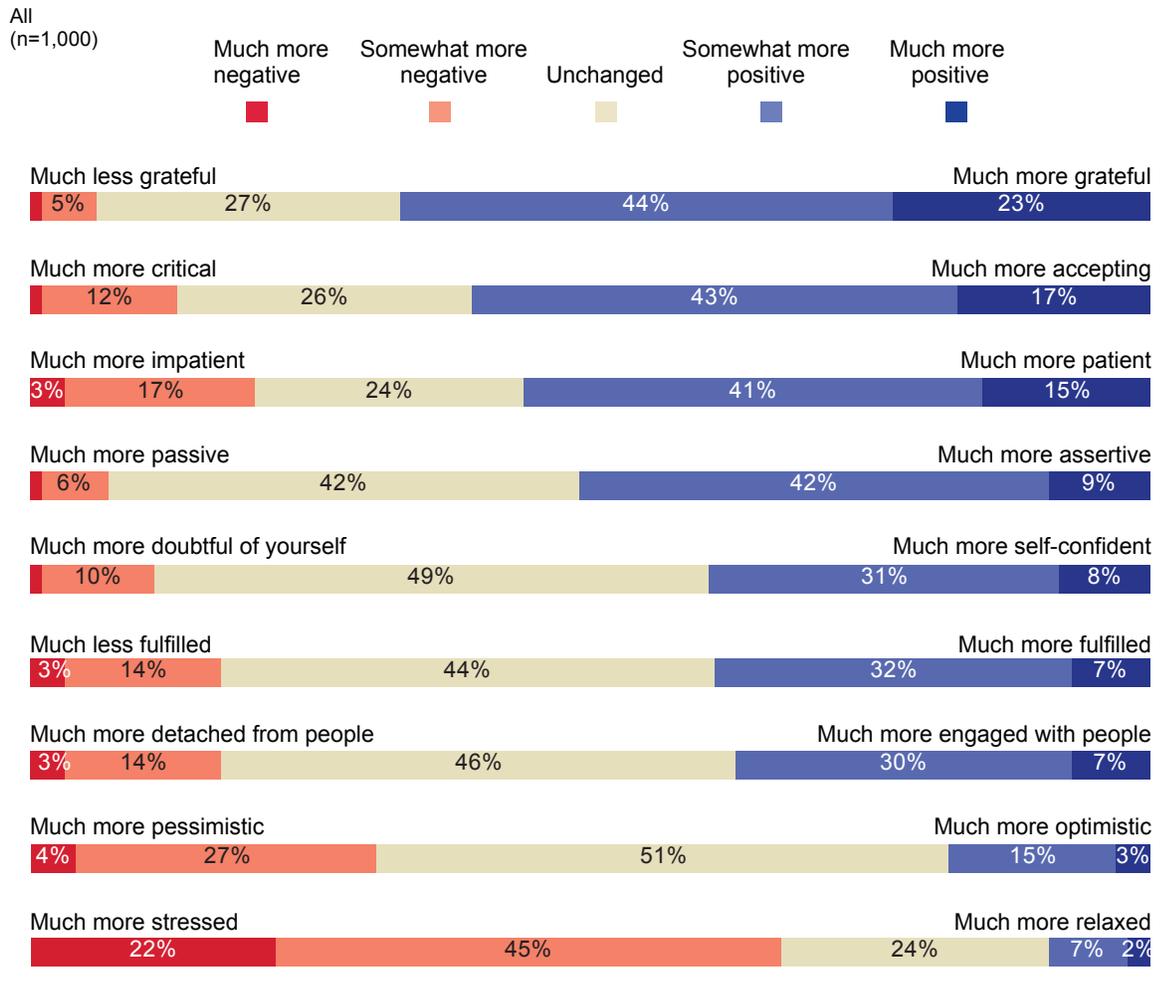
- In almost all cases, caregivers who feel they had a choice in becoming a caregiver for someone with Alzheimer’s or dementia are more likely than those who did not feel they had this choice to agree with these positive statements about caregiving.
- Caregivers who live with their care recipient are more likely than those who live separately to agree that they now live more “in the moment” (53% vs. 42%).
- The feeling that the caregiver has a closer relationship with the care recipient is more common among those who report their loved one is in the *mild* stage of Alzheimer’s (53%) than among those who report a *moderate* (45%) or *severe* stage (41%). None of the other positive feelings, however, appear to be correlated with the stage of the care recipient’s illness.

The experience of caregiving also changes caregivers’ feelings and outlook in several positive ways. At least six in ten caregivers for someone with Alzheimer’s or dementia say they have become more grateful (67%) or accepting (60%) as a result of caregiving. Majorities also feel they have become more patient (56%) or assertive (51%). Roughly four in ten feel more self confident (40%), fulfilled (39%), or engaged with people (37%) as a result of providing care to someone with Alzheimer’s or dementia.

The small shares that feel more optimistic (18%) or relaxed (9%) as a result of caregiving are far outweighed by those who feel more pessimistic (31%) or stressed (67%).

Figure 15: Changes in Feelings and Outlook as a Result of Caregiving

Q29. How has your experience of providing care to someone with Alzheimer's or dementia changed you on each of the following dimensions? Has caregiving made you...



SUBGROUP DIFFERENCES

- Caregivers who feel they had a choice to take on these responsibilities are more likely than those who did not have a choice to report all of the positive changes of caregiving, except increased assertiveness.
- Those who live separately from their care recipient are more apt than those living with their loved one to report positive outcomes from caregiving, including feeling grateful, accepting, patient, fulfilled, and engaged with people.
- Caregivers newer to their role—those with fewer than two years as caregivers—are more likely than longer-term caregivers to feel more grateful, patient, fulfilled, engaged with people, optimistic, and relaxed.

- However, the actual stage of the care recipient's Alzheimer's or dementia does not appear to be related to changes in caregiver outlook.
- Reports of increased assertiveness, self confidence, fulfillment, optimism, and relaxation are greater among high-burden caregivers than low-burden caregivers.

E. Profile of Positive Caregivers

I feel like I need to make sign for myself and hang it up in the kitchen [that says] I am a strong, good daughter who loves her mom and I am different. I have changed because of her disease [and] I am making a difference in her life.

Caregiving Situation

Predictably, one of the factors related to caregivers' perspectives on their experience as positive overall or negative overall is the severity of their care recipients' symptoms. Those who rate their experience as more positive than negative—"positive caregivers"—are twice as likely as those who rate their experience as negative on balance—"negative caregivers"—to say their care recipient has *mild* symptoms (27% vs. 14%) and less likely to say s/he has *moderate* symptoms (46% vs. 60%). They are equally likely to say their loved one has *severe* symptoms (27% vs. 26%). Perhaps related to these differences in the stage of the illness, positive caregivers are less likely to think their care recipient is suffering as a result of Alzheimer's or dementia (71% vs. 82%).

Caregivers' perspective is also related to the type of symptoms their care recipient has. Those with a positive experience are more likely than negative caregivers to say their care recipient has simple memory problems (forgetting who people are: 31% vs. 21% or forgetting what s/he was doing in an activity: 17% vs. 9%) but are less likely than their counterparts to say they noticed other types of changes, such as in mood or personality (23% vs. 39%) or a tendency toward dangerous activities (16% vs. 30%).

Of note, positive Alzheimer's caregivers do not generally appear to be demographically different from those who rate their experience as negative, with the exception that positive caregivers are more likely to be employed (72% vs. 61%). Positive caregivers also do not appear to be different in the number of hours spent providing care, the number or types of personal care their care recipient needs help with (e.g., feeding, dressing, bathing, toileting, incontinence care, and getting in and out of beds and chairs), or their overall burden of care. However, they are slightly less likely to help with a few other caregiving tasks, namely transportation, managing finances, and grocery shopping.

Although caregivers overall are evenly split in feeling they had a choice to become a caregiver, positive caregivers are dramatically more likely than those with a negative experience to feel they had a choice in assuming their caregiving role (63% vs. 23%). Positive caregivers are less likely to be providing care to a parent (57%) than are negative caregivers (72%).

Perspective and Outcomes

There are some areas where the situation with my mom had made me a more patient person.

I am realizing the good things that come with helping.

Although stress and depression seem to be particular risks for caregivers of individuals with Alzheimer's or dementia, those who rate their experience as positive are much less likely than negative caregivers to report these as outcomes of caregiving (depression: 18% vs. 52%; emotional stress: 43% vs. 83%).

Positive caregivers are characterized by a greater likelihood of:

- Seeing caregiving as a way of “giving back” to their care recipient (79% vs. 42% for negative caregivers)
- Having a closer relationship with their care recipient (62% vs. 21%)
- Living more “in the moment” (51% vs. 35%)
- Spending more time doing something that matters to them (48% vs. 18%)
- Becoming more spiritual (37% vs. 13%)
- Being more productive in their life than they thought they could be (32% vs. 13%)

Caregivers who feel their experience has been more positive than negative are also more likely than their negative counterparts to say that caregiving has made them more:

- Grateful (85% vs. 46%)
- Accepting (75% vs. 39%)
- Patient (72% vs. 41%)
- Self-confident (49% vs. 25%)
- Fulfilled (59% vs. 14%)
- Engaged with people (49% vs. 21%)
- Optimistic (34% vs. 4%)
- Relaxed (17% vs. 1%)

Positive caregivers are less likely than those with negative experiences to feel:

- Guilty that they are not doing more to help their care recipient (35% vs. 48%)
- Like they are on duty 24 hours a day/7 days a week (31% vs. 56%)
- They are not able to take the time to do what they need to do (29% vs. 61%)
- Angry at themselves for being frustrated with their caregiver (29% vs. 57%)
- That their relationship with one or more family members is suffering (18% vs. 48%)
- That they are not as good parents as they used to be (9% vs. 36% of those who have children under the age of 18 in the household).

Finally, positive caregivers are far more likely than negative caregivers to be in very good or excellent health (66% vs. 40%), and are far less likely to neglect their own medical care as a result of caregiving (15% vs. 42%).

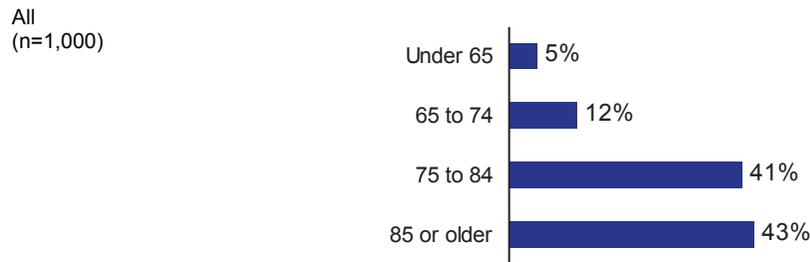
F. Background on the Caregiving Situation

Care Recipient's Age

Eight in ten of these family caregivers of individuals with Alzheimer's, dementia or age-related mental confusion or forgetfulness say their care recipient is age 75 or older (83%).

Figure 16: Age of Care Recipient

Q6. How old is the person to whom you care provide care for Alzheimer's or dementia?

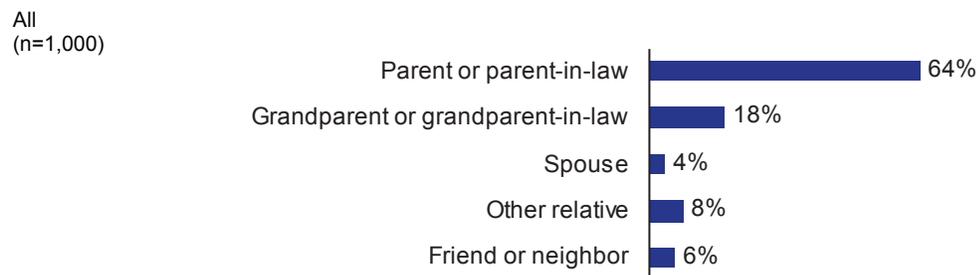


Care Recipient's Relationship

Most Alzheimer's caregivers are providing care to their parents or parents-in-law (64%). Fewer than one in five (18%) are taking care of a grandparent, and only 4% are providing care to a spouse.

Figure 17: Care Recipient's Relationship to Caregiver

Q7. Is the person to whom you provide care for Alzheimer's or dementia your...?



Care Recipient’s Living Situation

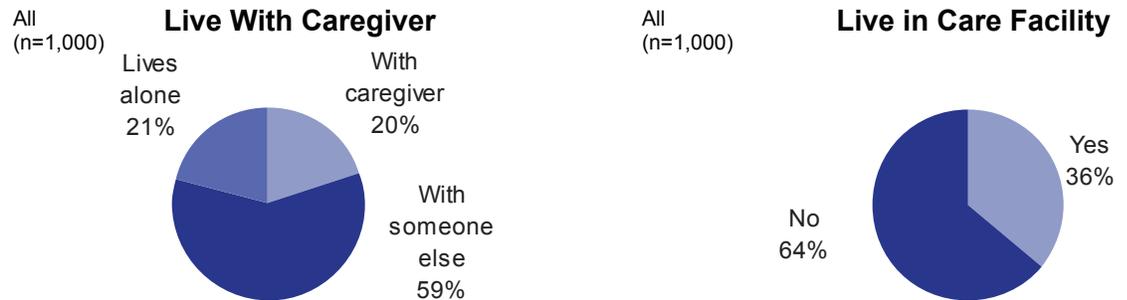
One in five caregivers of individuals with Alzheimer’s or dementia live with their care recipients (20%), but a majority say their care recipient lives with someone else (59%). One in five (21%) say their care recipient lives alone.

One in three say their care recipient lives in a nursing home, assisted living or other facility (36%).

Figure 18: Living Situation

Q11. Who does your [relation] live with?

Q12. Does your [relation] live in a nursing home, assisted living, or any other care facility?



SUBGROUP DIFFERENCES

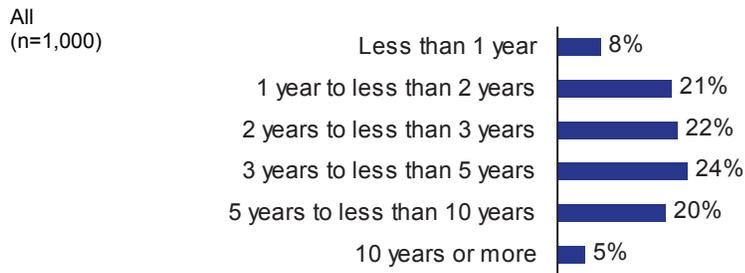
- Predictably, caregivers with older care recipients—those 85 or older—are the most apt to say their care recipient lives in a nursing home or assisted living facility (45% vs. 29% for younger recipients).
- Only half of those who say their recipient has reached the severe stage of Alzheimer’s indicate s/he lives in a care facility (52%), compared to 36% of those in a moderate stage and only 17% of those in a mild stage.
- A larger share of white, non-minority caregivers than racial/ethnic minorities report their loved one lives in a care facility (39% vs. 24%).

Duration of Caregiving

As may be expected, providing care to someone with Alzheimer’s or dementia is often a long-term commitment, with half (50%) of caregivers providing care for three years or more and only 8% doing so for less than a year. Caregivers in this study are less likely than Alzheimer’s caregivers interviewed in the 2009 *Caregiving in the U.S.* study to have been providing care for 10 years or more (5% vs. 12%).

Figure 19: Duration of Caregiving

Q10. For how long have you been a caregiver to your [relation]?



SUBGROUP DIFFERENCES

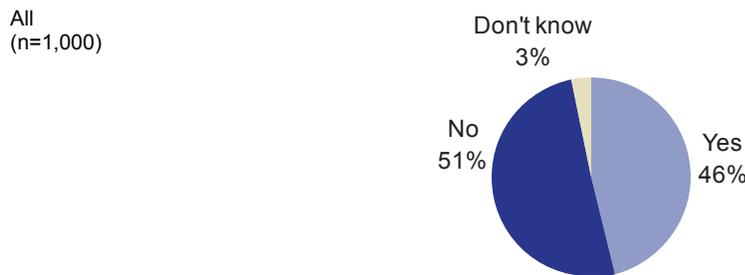
- Those providing care to someone with *severe* symptoms of Alzheimer’s or dementia are more likely than those with *mild* or *moderate* symptoms to have been providing care for three years or more (64% vs. 44%).
- Caregivers for a parent (56%) are more likely than those caring for someone else (39%) to have been providing care for three years or more.

Choice in Becoming a Caregiver

Caregivers of someone with Alzheimer’s or dementia are evenly split in whether they feel they had a choice in taking on their caregiving role.

Figure 20: Choice in Taking on Caregiver Role

Q17. Do you feel you had a choice in taking on this responsibility of caring for your [relation]?



SUBGROUP DIFFERENCES

- Caregivers who are taking care of a parent are much less likely than those taking care of someone else to feel they had a choice in assuming their caregiving role (38% vs. 60%).
- The likelihood of feeling one had a choice to provide care decreases the longer caregivers have been providing care (57% of caregivers who have been providing care for less than two years feel they had a choice, compared to 38% of those who have been providing care for five years or more).

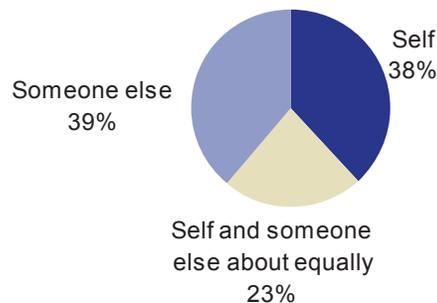
Primary Caregiver Status

Nearly four in ten caregivers consider themselves to be the person who provides most of the unpaid care to their loved one with Alzheimer's or dementia (38%) and an additional 23% report they share caregiving responsibilities with someone else about equally. The remaining four in ten caregivers say someone else provides most of the care for their loved one (39%). In *Caregiving in the U.S.*, a larger share of Alzheimer's caregivers reported they provided most of the care (46% vs. 38%).

Figure 21: Primary Caregiver Status

Q9. Who provides most of the unpaid care for your [relation]?

All
(n=1,000)



SUBGROUP DIFFERENCES

- Those who live with their care recipient (73%) are far more likely than those who live separately (29%) to consider themselves the primary caregiver.
- Other subgroups of caregivers who are more likely to say they provide most of the unpaid care include:
 - Those with a high burden of care (49% vs. 27% of those with a low to moderate burden).
 - Those who have provided care for five years or more (45%) relative to those in their role for two to four years (39%) or less than two years (30%).
 - Those who feel they did not have a choice in taking on their caregiving role (45% vs. 30% of those who had a choice).

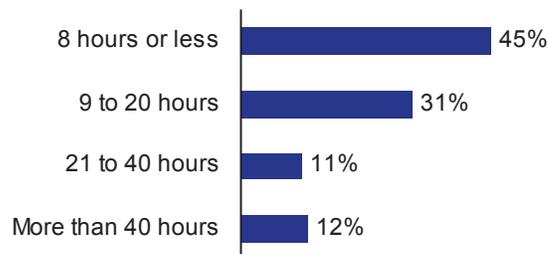
Hours of Care Provided

Nearly half of caregivers of individuals with Alzheimer's or dementia say they spend eight hours or less per week providing care to their care recipient (45%). More than two in ten (23%) spend more than 20 hours per week in their role as caregiver.

Figure 22: Hours of Care Provided

Q8. About how many hours do you spend in an average week providing care to your [relation]?

All
(n=1,000)



SUBGROUP DIFFERENCES

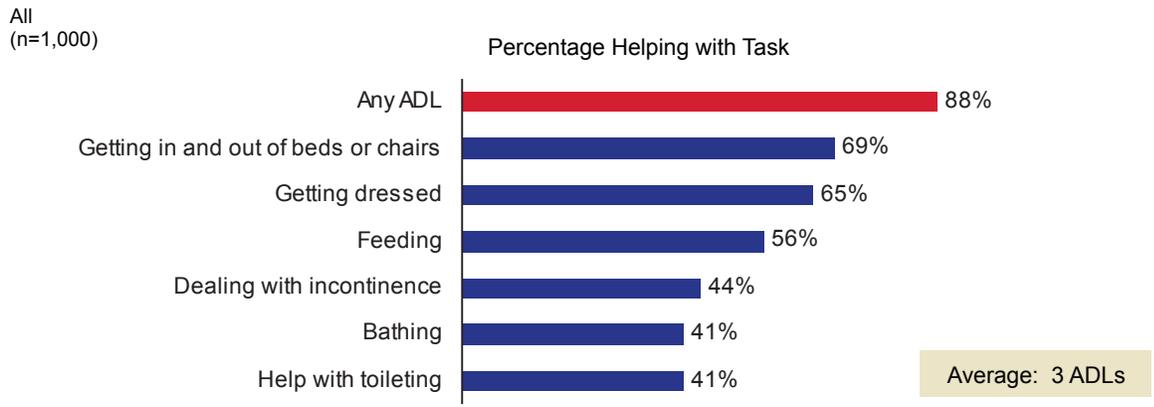
- Primary caregivers for their loved one with Alzheimer's or dementia are many times more likely than others to provide more than 40 hours of care a week (25% vs. 4%).
- Those who live with their care recipient are particularly likely to provide more than 40 hours per week providing care (46%).
- As one might expect, the hours of care provided rise in relation to the severity of the care recipient's symptoms. Among caregivers whose loved one has *mild* symptoms, only 8% provide more than 40 hours of care per week, compared to 13% of those who report their care recipient has *moderate* or *severe* symptoms of Alzheimer's or dementia.

Help with Activities of Daily Living and Instrumental Activities of Daily Living

Nearly nine out of ten caregivers of an individual with Alzheimer's or dementia have helped their care recipient with one or more activities of daily living (ADLs) in the past year (88%). On average, they provide assistance with three of the six listed activities. The ADLs caregivers most commonly assist with are getting in and out of beds and chairs (69%) and getting dressed (65%), followed by feeding (56%). Fewer, but still at least four in ten, help with hygiene activities including dealing with incontinence (44%), bathing (41%), or toileting (41%). These caregivers are more likely than similar Alzheimer's caregivers surveyed in *Caregiving in the U.S.* to report helping with each of the ADLs.

Figure 23: Help with Activities of Daily Living (ADLs)

Q14. Which of the following kinds of help, if any, have you provided to your [relation] within the last 12 months?



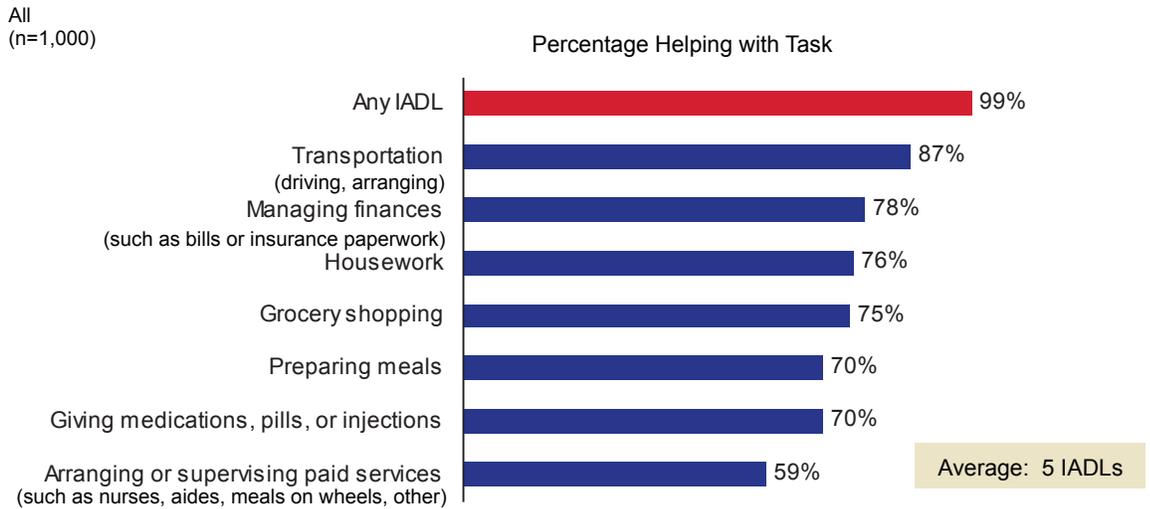
SUBGROUP DIFFERENCES

- Men are more likely than women to report helping their care recipients with getting in and out of chairs or beds (74% vs. 66%) and feeding (67% vs. 51%).
- The likelihood of a caregiver helping with each of the ADLs increases with severity of their care recipient’s Alzheimer’s or dementia symptoms.
- Racial/ethnic minority caregivers are more likely than white caregivers to report helping their care recipient with dressing (74% vs. 62%) and bathing (56% vs. 38%).
- Larger proportions of caregivers who co-reside with their care recipient than those who live separately help with dressing, bathing, dealing with incontinence, and toileting.

Nearly all who provide care to someone with Alzheimer’s or dementia help with at least one Instrumental Activity of Daily Living (IADL); on average, they help with five of the seven listed activities. Most commonly, they help with transportation (87%), followed by the management of finances (78%), housework (76%), or grocery shopping (75%). Fewer, but still seven out of ten caregivers, help prepare meals or give medications (70% each), while six out of ten help their care recipient by arranging or supervising paid services (59%). The proportions reporting they help with these tasks exceed the proportions found among Alzheimer’s caregivers in *Caregiving in the U.S.*, with the exception of managing finances and helping with housework.

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

Q15. Which of the following kinds of help, if any, have you provided to your [relation] within the last 12 months?

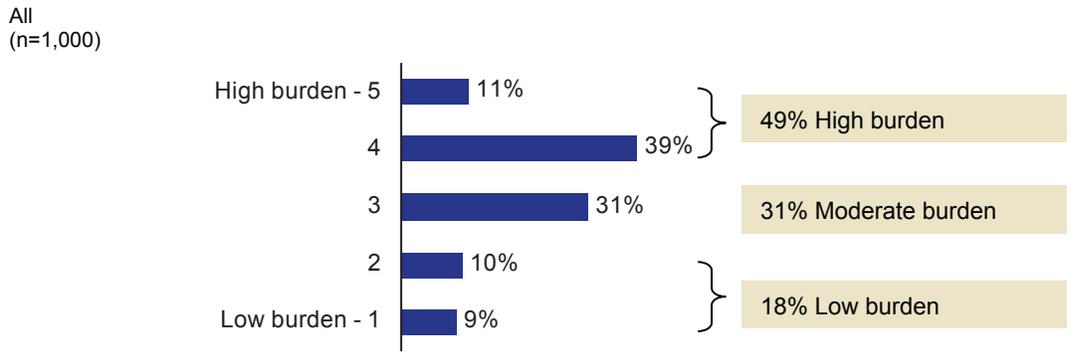


Burden of Care

A Level of Care Index, first developed in the 1997 study *Family Caregiving in the U.S.* and used in the 2004 and 2009 studies 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. The details of the index’s construction are shown in Appendix B.

Caregiving for someone with Alzheimer’s or dementia seems to entail a high burden—fully half of caregivers are in high-burden situations (49%), 31% have a moderate burden, and only 18% have a low burden caring for someone with Alzheimer’s or dementia. The proportion with a high burden is greater than the proportion seen among Alzheimer’s caregivers in *Caregiving in the U.S.* (36%), because in the current study, caregivers are more likely to help with the ADLs and most of the IADLs.

Figure 25: Level of Care Index



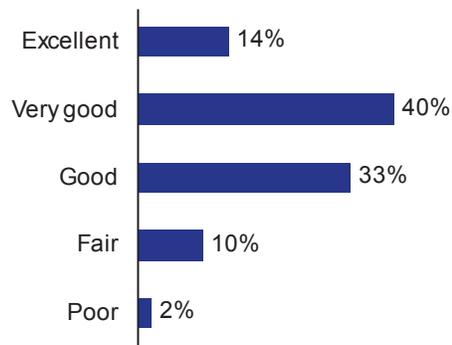
Caregiver Health

Alzheimer's caregivers seem to be in strong health overall, with 54% saying it is *excellent* or *very good*. One in eight (12%) describe their health as *fair* to *poor*, similar to the percentage of adults nationally who do so.¹ In the study *Caregiving in the U.S.*, a slightly larger share of caregivers of individuals with Alzheimer's or dementia report being in *excellent* or *very good* health (60%).

Figure 26: Caregiver Health

Q32. How would you describe your own health?

All
(n=1,000)



SUBGROUP DIFFERENCES

- For caregivers under the age of 65, those who feel they had a choice in providing care to a loved one are more likely than those who did not to be in *excellent* or *very good* health. Their feeling of choice does not appear to be related to the caregiver's health for caregivers age 65 or older.
- Those with a low or moderate burden of care are also more likely than caregivers with a high burden of care to be in *very good* or *excellent* health (62% vs. 47%).
- The likelihood of caregivers reporting that they are in *fair* to *poor* health increases with the length of time they have spent caregiving, from 11% of those who have provided care for less than two years to 18% of those who have been caregivers for five years or more.

¹Source: Provisional Summary Health Statistics for U.S. Adults, National Health Interview Survey, 2008, dated August 2009.

G. Profile of Respondents

Two out of three Alzheimer’s caregivers who responded to this survey are female (67%). Forty percent are younger than 50, and another 45% are 50 to 64 years old. Seven in ten are employed, with 51% working full time and 18% working part time. One in four (27%) have children or grandchildren in the home. More than six in ten have completed college (66%), a higher proportion than found in *Caregiving in the U.S.* (49%).

Figure 27: Profile of Respondents

	Total (n=1,000)
Gender	
Male	33%
Female	67
Age of Caregiver	
18 to 34	18%
35 to 49	22
50 to 64	45
65 to 74	13
75 or older	2
Race/Ethnicity of Caregiver	
White	80%
African-American	8
Hispanic	4
Asian-American	7
Other	2
Employment Status	
Working full time	51%
Working part time	18
Not employed	31
Children/Grandchildren < Age 18 in Household	
Yes	27%
No	73
Education	
Less than high school	< .5%
High school graduate/GED	8ne m
Some college	22
Technical school	4
College graduate	34
Graduate school	32

Caregiving of People with Alzheimer's or Dementia Survey on Diagnosis and Positives

(Among online panelists who have been pre-identified as providing care for someone with Alzheimer's)

1. How old are you?

Younger than 18 [TERMINATE]	1
18 to 34	2 [Recruit 40%]
35 to 49	3
50 to 64	4 [Recruit 45%]
65 to 74	5
75 or older	6

2. Are you... (Check all that apply)

White	1 [Recruit 80%]
African American	2
Hispanic	3
Asian	4
Other	5

3. Are you...

Male	1 [Recruit 33%]
Female	2 [Recruit 66%]

The targets listed above will help ensure that the demographic characteristics of respondents to this study will match those established by the Alzheimer's Caregiving study.

4. Are you currently employed?

Yes, full time	1
Yes, part time	2
No, not employed	3

5. In the last 12 months, have you 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.

Yes	1
No [TERMINATE]	2
Don't know [TERMINATE]	3

Appendix A: Questionnaire

5a. Does the person you provide unpaid care for have...(Check all that apply)
[RANDOMIZE; SHOW 7 LAST.]

Alzheimer's/dementia/age-related mental confusion or forgetfulness	1
Lung disease/asthma/Chronic Obstructive Pulmonary Disease (COPD)	2
Multiple sclerosis	3
Stroke-related disabilities	4
Blindness or age-related macular degeneration	5
Parkinson's disease	6
Some other health condition or disorder	7

*[TERMINATE IF OPTION 1 ABOVE IS NOT SELECTED.
ALSO TERMINATE IF MORE THAN 3 OF CONDITIONS 1 THRU 6 ARE CHECKED.]*

DISPLAY FOLLOWING STATEMENT ON A SEPARATE SCREEN:

For the remaining questions on this survey, please only think about the person for whom you provide unpaid care who has **Alzheimer's, dementia, or age-related mental confusion or forgetfulness**.

If you provide unpaid care to more than one person with that condition, please think about the person you provide **the most** care to.

Click Next to continue.

6. How old is the person to whom you provide care for Alzheimer's or dementia?

Under 40 years old [TERMINATE]	1
40 to 49 years old	2
50 to 64 years old	3
65 to 74 years old	4
75 to 84 years old	5
85 or older	6
Don't know [TERMINATE]	7

7. Is the person to whom you provide care for Alzheimer's or dementia your...

Parent (or parent in law)	1
Grandparent (or grandparent in law)	2
Spouse	3
Other relative	4
Friend or neighbor	5

Use these as inserts for programming:

Parent (in-law)

Grandparent (in-law)

Spouse

Relative

Friend

Appendix A: Questionnaire

8. About how many hours do you spend in an average week providing care to your ____ ?

8 hours or less	1
9 to 20 hours	2
21 to 40 hours	3
More than 40 hours	4
Don't know	5

9. Who provides most of the unpaid care for your ____ ?

You	1
Someone else	2
You and someone else about equally	3

10. For how long have you been a caregiver to your ____ ?

Less than 1 year	1
1 year to less than 2 years	2
2 years to less than 3 years	3
3 years to less than 5 years	4
5 years to less than 10 years	5
10 years or more	6
Don't know	7

11. Who does your ____ live with?

With you	1
With someone else	2
No one, lives alone	3

12. Does your ____ live in a nursing home, assisted living, or any other care facility?

Yes	1
No	2

13. Are there any children or grandchildren currently living in your household under 18 years of age?

Yes	1
No	2

14. Which of the following kinds of help, if any, have you provided to your ____ within the last 12 months? [RANDOMIZE.]

	Yes	No
a. Bathing	1	2
b. Getting dressed	1	2
c. Feeding	1	2
d. Getting in and out of beds or chairs	1	2
e. Help with toileting	1	2
f. Dealing with incontinence or diapers	1	2

Appendix A: Questionnaire

15. Which of the following kinds of help, if any, have you provided to your _____ within the last 12 months? [RANDOMIZE.]

	Yes	No
a. Giving medicines, pills or injections	1	2
b. Managing finances (such as bills or insurance paperwork)	1	2
c. Grocery shopping	1	2
d. Housework (such as dishes, laundry, or straightening up)	1	2
e. Preparing meals	1	2
f. Transportation (driving, helping arrange for transportation, or accompanying on public transit)	1	2
g. Arranging or supervising paid services (such as nurses, aides, Meals on Wheels, or other services)	1	2

16. Has your _____ ever taken prescription medication for Alzheimer's or dementia?

Yes, s/he takes it now	1
Yes, in the past but not now	2
No	3
Don't know	4

17. Do you feel you had a choice in taking on this responsibility for caring for your _____ ?

Yes	1
No	2
Don't know	3

18. How did you come to think that your _____ probably had Alzheimer's or dementia?

One particular event/situation made you realize it	1
Multiple events over time made you realize it	2
Someone else suggested the idea	3
Don't know	4
Not applicable – You were not involved when the condition was first seen [SKIP TO Q21.]	5

19. [IF PRIOR QUESTION=1 or 2] What type of [IF 1: event/situation / IF 2+: events/situations] made you think that your _____ probably had Alzheimer's or dementia? [IF PRIOR Q=2, ADD INSTRUCTION: "YOU MAY SELECT UP TO THREE RESPONSES." IF PRIORQ=1, ALLOW ONLY ONE RESPONSE.] [RANDOMIZE; SHOW 11-13 LAST AND IN ORDER.]

Forgetting who people are	1
Forgetting what s/he is doing during an activity	2
Wandering, getting lost, forgetting where s/he is	3
Problems with remembering conversation or words	4
Doing something dangerous (like leaving the stove on, having several car accidents, taking medication incorrectly, etc.)	5
Change in mood or personality (like feeling suspicious, depressed, fearful, easily upset, etc.)	6
Misplacing or losing things	7
Poor judgment in spending or giving away money	8
Difficulty completing familiar tasks	9

Appendix A: Questionnaire

A doctor's examination/questioning	10
Repetitious behavior	11
Something else: _____	12
Don't know	13

20. Looking back, for how long was your ____ showing symptoms of Alzheimer's/dementia before you were fairly certain that's what it was?

Less than 6 months	1
6 months to less than 1 year	2
1 year to less than 2 years	3
2 years to less than 3 years	4
3 years or more	5
Don't know	6

21. Which of the following, if any, have you or others done as a result of your ____'s condition? [RANDOMIZE]

	Yes	No	Don't Know
a. Hired someone to provide help on a regular basis	1	2	3
b. Changed living situation—where living or with whom	1	2	3
c. Installed safety devices (e.g., to keep him/her from wandering or accessing dangerous things)	1	2	3
d. Restricted or stopped him/her from driving	1	2	3
e. Found ways to simplify or assist with everyday activities (e.g., labeling drawers, laying out his/her clothes)	1	2	3
f. Had a family meeting to discuss how to handle the condition	1	2	3
g. Become more active in managing their finances	1	2	3
h. Obtained power of attorney	1	2	3
i. Tried to find out as much as you could about the condition	1	2	3
j. Talked to him/her about how his/her life might change	1	2	3
k. Limited their independence other than driving (e.g., keeping them from cooking)	1	2	3
l. Made an effort to spend more time with him/her	1	2	3
m. Arranged for him/her to see a doctor	1	2	3

22. When you thought your ____ may have Alzheimer's or dementia, where did you first turn in order to get more information about the condition? (Select all that apply) [RANDOMIZE; SHOW 8, 9, 10 LAST AND IN ORDER.]

A doctor	1
A medical professional other than a doctor	2
A mental health professional other than a doctor	3
Agency on aging	4
Alzheimer's organization	5
Internet	6
Friends or family members	7
Other (specify)	8
None of the above – did not seek information	9
Not involved / Other family or friends handled this	10

Appendix A: Questionnaire

23. Has your ____ ever been to a doctor to confirm a diagnosis of Alzheimer's or dementia?

- | | |
|------------|---|
| Yes | 1 |
| No | 2 |
| Don't know | 3 |

24. [IF PRIOR Q=1] What kind of health professional first diagnosed your ____ with Alzheimer's or dementia? (Select one)

- | | |
|------------------------------------|---|
| A primary care doctor or internist | 1 |
| A neurologist | 2 |
| A psychiatrist or psychologist | 3 |
| A geriatrician | 4 |
| A nurse practitioner | 5 |
| Some other specialist | 6 |
| Don't know | 7 |

25. In your opinion, what stage of Alzheimer's or dementia is your ____ in?
Rate this on the following scale:

- | 1 | 2 | 3 |
|--|--|--|
| Mild | Moderate | Severe |
| Some memory loss and personality changes, beginning to lose judgment or the ability to manage finances | Obvious trouble with memory, recognizing people, knowing where they are, and doing normal activities like cooking or driving; more serious personality changes | Needs help with all daily needs; may not recognize family; may have trouble walking, talking or swallowing |

26. If you had to make a judgment, do you think your ____ is suffering physically, emotionally, or spiritually as a result of Alzheimer's or dementia?

- | | |
|-----|---|
| Yes | 1 |
| No | 2 |

26a. Would you want your ____ to have an accurate test to determine definitively whether or not s/he has Alzheimer's disease? Currently there is no cure for Alzheimer's disease.

- | | |
|---|---|
| Yes | 1 |
| No | 2 |
| Don't know | 3 |
| Not applicable; we already know whether or not it's Alzheimer's | 4 |

27. Please indicate overall how positive or negative your experience as a caregiver is. (Think only about your experience, and not the experience of the person for whom you are caring.)

- | | | | | |
|---------------------|-------------------------------|---------------------|---|---|
| Completely Negative | Equally Negative and Positive | Completely Positive | | |
| 1 | 2 | 3 | 4 | 5 |

Appendix A: Questionnaire

28. Please indicate how much you agree or disagree with each statement below.
 [RANDOMIZE ON TWO PAGES]

	Disagree Completely				Agree Completely
a. As a result of caregiving... I now live more “in the moment”	1	2	3	4	5
b. As a result of caregiving... I have become more spiritual	1	2	3	4	5
c. As a result of caregiving... I have a closer personal relationship with my ___ than I used to have	1	2	3	4	5
d. As a result of caregiving... I am more productive in my life than I ever thought I could be	1	2	3	4	5
e. [IF KIDS AT HOME] As a result of caregiving... I am teaching my children how to contribute more in the household	1	2	3	4	5
f. As a result of caregiving...I’m now spending more time than before doing something that matters to me	1	2	3	4	5
g. As a result of caregiving...I enjoy being at my job more than before	1	2	3	4	5
h. I see caregiving as an opportunity for me to “give back” to my _____ since s/he has contributed so much to my life	1	2	3	4	5
i. As a result of caregiving...I neglect or put off my own medical care	1	2	3	4	5
j. As a result of caregiving... I feel like I am on duty 24 hours/ day 7 days a week	1	2	3	4	5
k. As a result of caregiving... My relationship with one or more family members is suffering	1	2	3	4	5
l. [IF KIDS AT HOME] As a result of caregiving...I am not as good a parent as I used to be	1	2	3	4	5
m. As a result of caregiving...I feel guilty that I am not doing more to help my ____.	1	2	3	4	5

Appendix A: Questionnaire

	Disagree Completely				Agree Completely
n. As a result of caregiving...I get angry at myself for being frustrated with ____ .	1	2	3	4	5
o. As a result of caregiving...I am not able to take time to do what I like to do	1	2	3	4	5

[RANDOMIZE ORDER OF ITEMS, BREAKING INTO GROUPS OF 3 TO A PAGE. ALSO RANDOMLY REVERSE THE ORDER OF THE SCALES.]

29. How has the experience of providing care to someone with Alzheimer's or dementia changed you on each of the following dimensions?

Has caregiving made you... [DO NOT SHOW RATING NUMBERS]

a.	Much More Pessimistic [1]	Somewhat More Pessimistic	Unchanged	Somewhat More Optimistic	Much More Optimistic [5]
b.	Much More Impatient [1]	Somewhat More Impatient	Unchanged	Somewhat More Patient	Much More Patient [5]
c.	Much More Detached from People [1]	Somewhat More Detached from People	Unchanged	Somewhat More Engaged with People	Much More Engaged with People [5]

How has the experience of providing care to someone with Alzheimer's or dementia changed you on each of the following dimensions?

Has caregiving made you...

d.	Much More Doubtful of Yourself [1]	Somewhat More Doubtful of Yourself	Unchanged	Somewhat More Self-Confident	Much More Self-Confident [5]
e.	Much More Stressed [1]	Somewhat More Stressed	Unchanged	Somewhat More Relaxed	Much More Relaxed [5]
f.	Much More Passive [1]	Somewhat More Passive	Unchanged	Somewhat More Assertive	Much More Assertive [5]

Appendix A: Questionnaire

How has the experience of providing care to someone with Alzheimer's or dementia changed you on each of the following dimensions?

Has caregiving made you feel...

- | | | | | | |
|----|----------------------------------|-------------------------------|-----------|-------------------------------------|----------------------------------|
| g. | Much
More
Critical
[1] | Somewhat
More
Critical | Unchanged | Somewhat
More
Accepting | Much
More
Accepting
[5] |
| h. | Much
Less
Fulfilled
[1] | Somewhat
Less
Fulfilled | Unchanged | Somewhat
More
Fulfilled | Much
More
Fulfilled
[5] |
| i. | Much
Less
Grateful
[1] | Somewhat
Less
Grateful | Unchanged | Somewhat
More
Grateful
[5] | Much
More
Grateful |

30. How emotionally stressful would you say that caring for your _____ is for you?

[SHOW RATING NUMBERS]

Not at all stressful

[1]

[2]

[3]

[4]

Very stressful

[5]

31. To what degree, if at all, have you been depressed as a result of caring for your _____?

[SHOW RATING NUMBERS]

Not at all

[1]

[2]

[3]

[4]

A great deal

[5]

Respondent Demographics

32. How would you describe your own health?

Excellent	5
Very good	4
Good	3
Fair	2
Poor	1

33. What is the last grade of school you completed?

Less than high school	1
High school grad/GED	2
Some college	3
Technical school	4
College grad	5
Graduate school/Grad work	6

34. Did you experience any issues or problems when completing this survey? (If yes, please explain.)

Thank you so much for your time! We hope our learning about the experiences of caregivers like you will ultimately help other caregivers.

Appendix B: Level of Burden

The calculation of the level of burden index begins by assigning points for the number of hours of care, as follows:

Hours of Care

0 to 8 hours	1 point
9 to 20 hours	2 points
21 to 40 hours	3 points
41 or more hours	4 points

In addition, points are assigned for the number of ADLs and IADLs performed, as follows.

Types of Care Provided

0 ADLs, 1 IADL	1 point
0 ADLs, 2+ IADLS	2 points
1 ADL, any number of IADLs	3 points
2+ ADLs, any number of IADLs	4 points

Then, the total number of points is consolidated into five levels of care. In this report, analysis often further collapses the five levels into three categories of burden, with “high burden” equating to Levels 4 to 5, “medium burden” corresponding to Level 3, and “low burden” equating to Levels 1 and 2.

Consolidating Points into Five Levels of Care and Three Burden Categories

2 to 3 points	Level 1	Low burden
4 points	Level 2	Low burden
5 points	Level 3	Medium burden
6 to 7 points	Level 4	High burden
8 points	Level 5	High burden





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