

## The Experiences of Alzheimer's Caregivers

*Multiple factors delay diagnosis by more than two years on average*

A recent survey of caregivers of people with Alzheimer's disease sheds new light on their experiences before and after the disease is diagnosed. The survey explores the impact of caregiving on their lives and investigates how they cope with the challenges of caring for a loved one with Alzheimer's. It also provides new insight on some reasons why Alzheimer's disease is often not diagnosed until years after the first symptoms appear.

### About the survey

The *I CAN: Investigating Caregivers' Attitudes and Needs* survey examined the attitudes and perceptions of caregivers of people with Alzheimer's disease. The survey is based on interviews with a nationwide cross section of 539 U.S. adults (aged 18+) who serve as caregivers, currently caring for a loved one with Alzheimer's disease, conducted online within the United States by Harris Interactive between January 30 to February 8, 2006 for the Alzheimer's Foundation of America (AFA) and sponsored by Forest Pharmaceuticals, Inc.

### The caregiver experience: who they are and what they do

Two-thirds of caregivers of Alzheimer's patients in the survey are women. Most of the Alzheimer's patients for whom they care are their parents (47%) or their spouses (31%). Relatively few caregivers look after their grandparents (7%), other relatives (9% including siblings) or friends (5%). The average age of caregivers is 56 years.

**TABLE 1**  
**Characteristics of Patients and Caregivers**

Base: All Caregivers

Relationship of Patient to Caregiver	%
Parent	47
Spouse	31
Grandparent	7
Siblings	1
Other Relative	8
Friend	5
Other	1
<b>Gender of Caregiver</b>	
Male	34
Female	66
<b>Mean Age of Caregiver</b>	<b>56 Years</b>

Caregivers perform many different functions with and for their loved ones with Alzheimer's disease. More than 70 percent attend appointments with them (79%), assist in planning and organizing their lives (76%), assist or take full responsibility for paying bills (76%), and assist in day-to-day activities (73%).

Caregivers also make important decisions affecting the lives of the patients (67%) and provide other care to improve the quality of life of patients (60%). Two in five caregivers (39%) provide full-time care such as helping patients to eat or use the bathroom.

**TABLE 2**  
**Caregiving Activities**

“Which activities do you perform in helping your loved one with his/her Alzheimer’s disease? Please select all that apply.”

Base: All Caregivers

Activity	%
Attend appointments with them (such as doctor, dentist, etc.)	79
Assist in planning and organizing life events (such as helping schedule doctor’s appointments, assist in purchasing food and supplies, help keep track of finances, etc.)	76
Assist or take full responsibility for paying bills associated with care and treatment	76
Assist in day-to-day activities (such as picking out clothes, preparing meals, etc.)	73
Help make important life decisions (such as where he/she will live in the future, what treatments he/she will take, etc.)	67
Provide “quality of life” care, such as involving my loved one in stimulating mental and/or physical activities (i.e., word games, physical exercise, reminiscing, music)	60
Full-time care (such as helping them use the bathroom, helping him/her eat meals, etc.)	39

### The impact of being a caregiver

Virtually all caregivers report that Alzheimer’s disease is a life-changing event for the family of the patient (97%) and wish there were more available treatment options (94%). Very large majorities also worry about how the disease will progress (86%) and their ability to continue to provide care as the disease progresses (83%). Three-quarters of caregivers feel overwhelmed when caring for patients with Alzheimer’s disease (77%).

Most caregivers feel that they have learned that they are stronger than they thought (76%), but wish that they could get more help from their families and friends (69%). They also believe that, as a result of their caregiving, they have become more compassionate (64%) and feel closer to the patient since they began caring for them (59%).

Most caregivers understand that it is difficult to diagnose Alzheimer’s disease (65%). Slightly less than half (45%) of caregivers are satisfied with the support services available for them.

**TABLE 3**

**Caregiver Attitudes and Perceptions**

“Please indicate how much you agree or disagree with the following statements.”  
*Percent saying they somewhat or strongly agree*

Base: All Caregivers

Statements	%
Alzheimer’s disease is life changing for the family of someone who is diagnosed	97
I wish there were more treatments available for people with Alzheimer’s disease	94
I am concerned about what to expect from this disease as it progresses	86
I am concerned about my ability to continue to provide care as the disease progresses	83
I feel overwhelmed when caring for my loved one with Alzheimer’s disease	77
I am concerned about the cost of caring for my loved one’s Alzheimer’s disease	76
Since becoming a caregiver of someone with Alzheimer’s disease, I learned that I am stronger than I thought	76
I wish my family and friends would assist more with care giving	69
Alzheimer’s disease is difficult for doctors to diagnose	65
Since becoming a caregiver of someone with Alzheimer’s disease, I’ve become a more compassionate person	64
I feel closer to my loved one since I assumed care giving responsibilities	59
I prefer a combination of prescription medications as well as alternative therapies to treat my loved one’s Alzheimer’s disease	50
I am satisfied with the support services available to me as a caregiver	45
I prefer that my loved one with Alzheimer’s disease is treated using only pre- scription medications	37

**Stigma and denial delay diagnosis**

Caregivers report that, on average, more than two years (26 months) pass between the time symptoms of Alzheimer’s disease are first observed and the date when the disease is diagnosed. Fear of stigma appears to delay diagnosis substantially. When people with Alzheimer’s disease are concerned about stigma, a diagnosis of Alzheimer’s disease occurred on average 3.5 years (40 months) after symptoms appear. When caregivers are concerned about stigma, delay of diagnosis is even more severe, averaging 6 years (71 months).

The delay in diagnosing Alzheimer’s disease is potentially serious. “Any delay in diagnosis is a setback for people with Alzheimer’s disease and their caregivers, and a delay of two years or more is a serious and unnecessary setback,” said Eric J. Hall, Chief Executive Officer of the Alzheimer’s Foundation of America. “While facing Alzheimer’s disease is never easy, getting a diagnosis is an essential step to managing and treating the disease. Living with this in silence can isolate people with Alzheimer’s disease and their caregivers, leaving them without critical support, resources, and proper treatment.”

More than half of caregivers surveyed report that caregivers or other acquaintances first raised the possibility that the patient might have Alzheimer's disease (52%). In about a third of the cases (34%), a physician was the first to raise the topic.

However, the majority of caregivers surveyed (74%) believe that patients had Alzheimer's before the disease was diagnosed by a physician.

**TABLE 4**  
**Length of Time Between Patient Experiencing Symptoms and Diagnosis**

Mean: 26 Months

Base: All Caregivers

Who first raised topic of Alzheimer's disease?	%
Patient	5
Doctor	34
Caregiver or someone else	52
Not sure	9
Caregiver believed patient had Alzheimer's disease before doctor diagnosed it	%
Yes	74
No/Not sure	26

The delay in diagnosis is mainly attributed to lack of knowledge or denial. Caregivers report that the greatest obstacles to getting earlier diagnosis are not knowing enough about Alzheimer's disease and its symptoms (40%), the reluctance of the patients to visit their doctors (38%) and the caregivers not wanting to face the possibility that something could be wrong with the patients (19%).

**TABLE 5**  
**Delayed Diagnosis**

“Which of the following, if any, were the greatest obstacle(s) that may have delayed getting a diagnosis of Alzheimer’s disease? Please select up to three answers.”

Base: All Caregivers

	%
I do not know enough about Alzheimer’s disease/did not know how to recognize or make sense of the symptoms	40
The person I care for did not want to visit the doctor	38
I did not want to face the possibility that something could be wrong with the person I care for	19
The person I care for was concerned about the potential stigma of a diagnosis of Alzheimer’s disease	11
I was concerned about healthcare costs	9
I was concerned that a diagnosis would mean disqualification for long-term care insurance for the person with the disease	5
I and/or other caregivers were concerned about the potential stigma of a diagnosis of Alzheimer’s disease	5
I was fearful of the responsibility that would be placed on me as the caregiver	4
I have little access to healthcare professional/memory screening	3
I did not have time to take the person I care for to the doctor	2
My cultural background	2

Note: Total exceeds 100% because some people gave two or more answers. “None” and other reasons excluded.

### Coping with caregiving stresses

As noted in Table 3, caregiving for Alzheimer’s patients is a life-changing and often overwhelming experience. Caregivers need all the help, support and resources possible as they care for loved ones.

Information about Alzheimer’s disease comes from many different sources. The most important sources for the largest numbers of caregivers are the patients’ physicians (52%), advocacy organizations (37%), websites (35%), the caregivers’ doctors (21%), articles in medical journals (19%), magazines (18%), other health-care professionals such as nurses (16%), family members (15%), local support groups (13%), friends (12%), Internet message boards or chat rooms (11%).

**TABLE 6**

**Important Sources for Information About Alzheimer's**

"Please rank the top three sources of information that have been most important to you in learning about Alzheimer's disease."

*Percent giving ranking of 1, 2 or 3*

Base: All Caregivers

Information Source	%
My loved one's doctor	52
Advocacy organizations (e.g., Alzheimer's Foundation of America, Alzheimer's Association)	37
Articles on websites (such as WebMD.com)	35
My personal doctor	21
Medical journal articles	19
Magazine articles	18
My loved one's healthcare professional (e.g., nurse)	16
Family members	15
Local support groups	13
Friends	12
Internet message boards/support groups/chat rooms	11
Newspaper articles	9
My personal healthcare professional (e.g., nurse)	9
Television shows	6
Houses of worship (e.g., temple/church)	5
Health fairs	3
Telephone hotline	2
Radio shows	1

The caregiving experience changes the lives of caregivers in many different ways. Most caregivers believe that they have learned that they are stronger than they thought (64%), that they have less time for themselves (62%), and that they are not able to go out as often as before (53%).

Many also believe that caregiving has made them more compassionate (48%), more anxious, stressed, or burnt-out (46%), and that they don't see their friends as often as before (45%). Other experiences include: feeling abandoned by family (25%), having less time for their families (24%) and developing closer relationships with family members (22%).

One in three (35%) caregivers report that they are more open to asking for assistance. One in seven (15%) have quit a job.

**TABLE 7**

**How Caregivers' Lives Have Changed**

"How has your life changed since caring for someone with Alzheimer's disease? Please select all that apply."

Base: All Caregivers

	%
I learned that I am stronger than I thought	64
I have less time for myself	62
I'm not able to go out as often as before	53
I became a more compassionate person	48
I have become more anxious, stressed, or burnt-out	46
I don't see my friends as often as before	45
I am more open to asking for assistance	35
I have felt abandoned by family	25
I have less time for my family	24
I have developed closer relationships with my family	22
I have become an advocate for the cause	16
I've had to quit my job	15
I have become more religious	14
I have felt abandoned by friends	11
I've had to take on less responsibility at work	9
I have developed closer ties to my community	4

**Methodology**

Harris Interactive conducted the *I CAN: Investigating Caregivers' Attitudes and Needs* survey online within the United States on behalf of the Alzheimer's Foundation of America between January 30 and February 8, 2006 among a nationwide cross section of 539 adults (aged 18 and over) who are caregivers – currently caring for a loved one with Alzheimer's disease. Figures for age, sex, education, region and household income were weighted where necessary to bring them into line with their actual proportions in the population. Propensity score weighting was also used to adjust for respondents' propensity to be online. The weighting parameters were derived through previous research conducted by Harris Interactive as well as from statistics generated by the Current Population Survey.

All surveys are subject to several sources of error. These include: sampling error (because only a sample of a population is interviewed); measurement error due to question wording and/or question order, deliberately or unintentionally inaccurate responses, nonresponse (including refusals), interviewer effects (when live interviewers are used) and weighting.

With one exception (sampling error) the magnitude of the errors that result cannot be estimated. There is, therefore, no way to calculate a finite "margin of error" for any survey and the use of these words should be avoided.

With pure probability samples, with 100 percent response rates, it is possible to calculate the probability that the sampling error (but not other sources of error) is not greater than some number. With a pure probability sample of 539 caregivers one could say with a 95 percent probability that the overall results have a sampling error of +/- 4 percentage points. However that does not take other sources of error into account. This online survey is not based on a probability sample and therefore no theoretical sampling error can be calculated.

*These statements conform to the principles of disclosure of the National Council on Public Polls.*

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