

I CAN: Investigating Caregivers' Attitudes and Needs

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Conducted on Behalf of:

The Alzheimer's Foundation of America (AFA)
and sponsored by Forest Pharmaceuticals, Inc.

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MARKET RESEARCH

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Introduction

I CAN: Investigating Caregivers' Attitudes and Needs was conducted by Harris Interactive on behalf of the Alzheimer's Foundation of America (AFA) and sponsored by Forest Pharmaceuticals, Inc. The purpose of this study was to learn about caregivers' attitudes and feelings towards all aspects of caregiving including day-to-day care, long-term care decisions, treatment decisions, and the impact of caregiving on their own families and lives.

This report highlights findings among a nationally representative sample of caregivers who are involved in care and treatment decisions on behalf of a relative or friend with Alzheimer's disease. Primary topics covered in this survey include:

- Obstacles that may have delayed getting a diagnosis of Alzheimer's disease
- Impact of caregiving responsibilities on the caregiver's own family and life
- What could help to ease the burden of the responsibilities associated with caregiving
- Impact of the patient's long-term care planning, or lack thereof, on the burden associated with caregiving
- The responsibilities associated with caregiving, and how, if at all, these vary according to caregiver gender and/or birth order

Survey Method and Sample

Harris Interactive surveyed a cross section of 539 U.S. caregivers who are involved in care and treatment decisions on behalf of a relative or friend with Alzheimer's disease during January and February 2006. Respondents were recruited from the Harris Interactive Online Panel (HPOL) as well as sample purchased from an outside vendor. Potential respondents were invited to participate via email and screened online. All interviews were conducted using an Internet methodology. Online interviews averaged 29 minutes in length. A detailed survey methodology appears in Appendix A and the survey questionnaire in Appendix B of this report.

Findings

I. OBSTACLES TO DIAGNOSIS

1. In most cases, the length of time between first symptoms and a diagnosis can be measured in terms of years, not months. Much of the time, caregivers put a good deal of responsibility on themselves (as opposed to the patient or healthcare professionals) when asked to explain the main reasons for the delay.

- A typical patient experiences symptoms for just over 2 years (26.1 months) and visits several doctors (2.3 on average) before receiving a diagnosis of Alzheimer's disease.
- Over half (61%) of caregivers indicated that they are at least partly responsible for the delay between the onset of symptoms and the actual diagnosis. There is not a statistically significant difference between the likelihood of males (66%) and females (61%) to accept part of the responsibility.

2. The most-commonly cited reasons for a delay are cited by both genders and typically cause a delay of 2 ½ years or more.

- Not knowing enough about the disease was a reason for delay for a substantial minority of caregivers (40%). Caregivers who cited this reason indicated a delay of 2 ½ years (29.6 months) on average. Males (41%) and females (40%) are equally likely to cite this reason.
- Their loved one's resistance to visiting the doctor was a reason for another substantial group (38%). Caregivers who cited this as a reason reported a delay of 2 ¾ years (32.7 months) on average. This reason is cited significantly more often by caregivers for a parent (48%) than caregivers for a spouse (23%). There is not a statistically significant difference in the likelihood of males (35%) and females (40%) to cite this reason.

3. Several other secondary reasons may be cited more often by one gender and typically cause a delay ranging from 1 ½ years to 6 years. The longest delay of all (roughly 6 years) is associated with the caregiver's own concern about the stigma of an Alzheimer's disease diagnosis. Among the relative few who mention this barrier, it appears to have a powerful effect on how long the patient waits to receive a diagnosis.

- A subset of caregivers (19%) did not want to face the possibility that something could be wrong. This reason is cited significantly more often by caregivers for a spouse (33%) than caregivers for a parent (12%). Female caregivers (23%) are significantly more likely than males (11%) to say that this was a barrier. On average, caregivers who mentioned this barrier reported a delay of 1 ½ years (18.2 months).
- A small minority of caregivers (11%) say that the patient was concerned about the stigma of an Alzheimer's diagnosis. Male caregivers (17%) are significantly more likely than females (8%) to say that the patient's own concern about a stigma was an obstacle to diagnosis. On average, respondents who mentioned this barrier reported a delay of approximately 3 ½ years (40.1 months).
- For a few caregivers (9%), concern about healthcare costs delayed the diagnosis. Male caregivers (18%) are significantly more likely than females (4%) to express this concern. This is associated with a delay of about 1 ½ years on average (19.4 months).

- Those relative few who indicated that their own concern about a stigma was a reason for the delay (5%) reported a delay of roughly 6 years (71.4 months) on average. Males (9%) were significantly more likely than females (3%) to indicate that their own concern about a stigma was the primary reason for the delay.
- 4. Overall, slightly more than half of caregivers mention fear of stigma and/or denial as reasons for a delayed diagnosis, including their own fear of stigma, the patient’s fear of stigma, the patient not wanting to see the doctor, and/or the caregiver not wanting to think something could be wrong with their loved one. Caregivers in the stigma/denial group tend to share certain demographic characteristics, although they are no more likely to care for a parent than a spouse (or vice versa). Remarkably, they appear to have largely overcome the fear of stigma/denial, and at present may be more knowledgeable than other caregivers.**
- Just over half of all caregivers (57%) mentioned that fear of stigma and/or denial (including their own fear of stigma, the patient’s fear of stigma, the patient not wanting to see the doctor, and/or the caregiver not wanting to think something could be wrong with their loved one) contributed to a delayed diagnosis. On average, these caregivers’ loved ones waited 28.7 months to receive a diagnosis of Alzheimer’s disease. Those mentioning their own and/or their loved one’s fear of stigma (14% of total) report that their loved one waited 39.5 months on average to receive a diagnosis.
 - Caregivers who mention stigma/denial are significantly more likely to be female than male (60% vs. 51%), and are younger on average (54.4 vs. 58.6). Caregivers for a parent versus caregivers for a spouse are about equally likely to mention fear of stigma/denial.
 - Today, caregivers for whom stigma/denial delayed the initial diagnosis appear to have made a dramatic turn-around in their approach to caregiving. They are facing the disease head-on and are informing themselves about treatment options for their loved one. These caregivers are significantly more likely than others (72% vs. 59%) to say that today, they are extremely/very knowledgeable about Alzheimer’s disease. On average, they have heard of a significantly greater number of medications by name (3.1 vs. 2.6). They are significantly more likely to provide “quality of life” care for their loved one (66% vs. 51%).
- 5. Lack of long-term care planning on the part of the patient has an impact on the delay between symptoms and diagnosis. On average, those without LTC planning wait significantly longer.**
- On average, those without LTC planning wait over a year longer for a diagnosis than those who made plans (31.5 vs. 20.1 months).
 - Those who didn’t plan for long-term care may be generally less inclined to face issues head-on and plan for the future proactively. Those without plans are significantly more likely to indicate that the patient did not want to visit the doctor (46% vs. 31%). Caregivers for a spouse who made no plans are significantly more likely than others to say they did not want to face the possibility something could be wrong (44% vs. 21%).
 - Those whose loved one made plans may generally be more conscious of the financial impact of long-term care. Not surprisingly, they are significantly more likely than those without plans to say that concerns about the cost of healthcare were a reason for the delay (12% vs. 6%).

II. CAREGIVER NEEDS & CAREGIVING IMPACT

1. **The emotional impact of caring for a loved one with Alzheimer's disease is the hardest part for many caregivers, especially those who experienced fear of stigma and/or denial before the diagnosis. This outweighs more practical hardships like not having enough time for self-care or bearing the financial cost of treatment. Interestingly, many caregivers (especially those in the stigma/denial category) report emotional growth and personal development after the experience of caregiving.**

- Nearly half (45%) say that the hardest part is the emotional toll of seeing someone they love lose their ability to function effectively. This is mentioned significantly more often than any other burden associated with caregiving.
- However, since caring for someone with Alzheimer's disease, most respondents (76%) say they have learned that they are stronger than they thought. This is especially true of those who experienced fear of stigma and/or denial (82% vs. 70%). Roughly two-thirds (64%) say that they have become a more compassionate person.
- Another emotional impact of caregiving is that some respondents (59%) have become concerned that they could someday develop Alzheimer's disease. This is especially prevalent among caregivers for a parent (74%), who are significantly more likely to be concerned than caregivers for a spouse (31%).
- Given this powerful emotional impact, it is not surprising that the vast majority of caregivers indicate that Alzheimer's disease is life changing for the family of someone who is diagnosed (97%) and that having a loved one with Alzheimer's disease can be quite stressful (94%).
- More practical, day-to-day concerns, such as not having enough help (10%), not being able to take care of their own physical/emotional needs (7%), of the financial strain of providing care (4%) are mentioned much less frequently than the emotional impact (in terms of the hardest part of caregiving). However, the day-to-day aspects of caregiving are a significant source of stress for most caregivers. A strong majority (76%) say that they worry about the cost of caring for their loved one with Alzheimer's disease, and the same number (76%) agree that they are stressed out by the activities required for day-to-day care. Over half (62%) say that they don't have as much time for themselves and a large minority (45%) say that they don't see their friends as often as before.
- Caregiving may be more disruptive to the caregiver's own life when a child cares for a parent, as opposed to a spouse caring for his/her mate. Caregivers for a parent experience significantly more life changes on average (whether positive or negative in nature) than caregivers for a spouse (5.7 vs. 4.7 changes). On the downside, caregivers for a parent are significantly more likely to say they now have less time for themselves (74% vs. 56%), have felt abandoned by family (34% vs. 14%), have less time for their own families (31% vs. 10%), and have had to quit their job (25% vs. 4%). On the upside, caregivers for a parent are significantly more likely to report developing closer relationships with family (27% vs. 16%). Caregivers for a spouse are significantly more likely than caregivers for a parent to say their lives have not changed (8% vs. 2%).

2. While caring for a loved one with this condition is emotionally taxing, caregivers indicate that extra help in certain areas could ease the burden. Asked to indicate the one type of help that would go the farthest to make caregiving easier, respondents mention a diverse range of types of assistance.

- In terms of the one type of help that would go the farthest to make caregiving easier, respondents mention a diverse range of types of assistance. Mentioned most often are more help with day-to-day caregiving activities (20%), more financial support (16%), more emotional support (15%) and more time for themselves (13%).
- Most caregivers (69%) indicate they wish they got more help from family and friends. Those caring for a parent (77%) are significantly more likely than those caring for a spouse (52%) to say they would like more help. Birth order and gender do not have a significant impact on the desire for more help.

3. Respondents get information about Alzheimer's disease and caregiving from a variety of sources. Many of those who have access to support groups and/or advocacy organizations make use of these services. Caregivers who make use of advocacy organizations are significantly more likely than others to express satisfaction with the resources available to them.

- Overall, the three most important sources of information include their loved one's doctor (52%), advocacy organizations (such as the Alzheimer's Foundation of America, Alzheimer's Association) (37%), and articles on Web sites (such as WebMD.com). Caregivers for a parent are significantly more likely than caregivers for spouses to refer to articles on Web sites (49% vs. 25%), probably because they tend to be significantly younger in age. On the other hand, caregivers for a spouse are significantly more likely to rely on their own doctor (28% vs. 14%) and/or local support groups (21% vs. 9%) for information.
- Many caregivers report having access to local support groups (46%) or advocacy organizations (37%), or both. Caregivers for a spouse are significantly more likely to indicate having access to local support groups than caregivers for a parent (54% vs. 39%). Caregivers whose loved one had made plans for long-term care are significantly more likely than others to indicate that they have access to support groups (54% vs. 38%) and/or advocacy organizations (44% vs. 30%).
- However, nearly half of all caregivers (46%) say they don't have access to either of these support systems, or aren't sure. Caregivers for a parent are significantly more likely than caregivers for a spouse to be unsure whether they have access to local support groups/advocacy organizations (27% vs. 15%). Caregivers whose loved one made no plans for long-term care are significantly more likely than others to be unsure (25% vs. 16%).
- A majority (65%) of those with access to advocacy organizations say that they use them. Fewer (50%) of those with access to local support groups say they actually use these groups. There is no apparent gender or relationship to the patient effect in terms of likelihood to use if these services are available to a caregiver. Those whose loved one had made long-term care plans are significantly more likely (64%) than those whose loved one did not (32%) to use support groups. However, this association does not hold true for advocacy organizations. Those who have access but don't use support groups (50%) say that they have no time to participate (55%), feel knowledgeable enough already (27%), or have no desire to participate (19%).

- Slightly fewer than half of all caregivers (45%) are satisfied with the services currently available to them. Caregivers for a spouse are significantly more likely to be satisfied with the services than caregivers for a parent (53% vs. 40%). Additionally, those whose loved one made long-term care plans are significantly more likely than others to be satisfied (53% vs. 38%). Overall, those who use advocacy organizations are significantly more likely to be among those who are satisfied (59% vs. 41%). However, use of support groups does not appear to impact likelihood to be satisfied with resources.
- Roughly half of all respondents say they would be interested in more information from support groups (50%) and/or advocacy organizations (47%).

III. PERSONAL SUPPORT SYSTEM OF CAREGIVERS

1. Overall, caregivers tend to rely on friends and family for support. On an individual level, there is a significant association between the caregiver's gender and their relationship to the patient and the specific people in whom they confide. Caregivers for a parent tend to confide in their friends, spouses, and siblings, while caregivers for a spouse often turn to their children. In general, female caregivers with any relationship to the patient are more likely than males to turn to friends and/or children. Support from physicians/healthcare professionals is also common regardless of caregiver gender or relationship to the patient.

- In general, caregivers are most likely to confide in friends (58%), physicians/healthcare professionals (41%), children (38%), spouses (35%), and siblings (33%).
- Caregivers for a parent are significantly more inclined than caregivers for a spouse to confide in friends (67% vs. 52%) and/or siblings (40% vs. 25%). Compared to caregivers for a spouse (64%), caregivers for a parent (80%) are significantly more likely to feel comfortable talking about the condition with all of the people in their life.
- On average, caregivers for a spouse have significantly fewer sources of support than caregivers for a parent (2.7 vs. 3.3). They are more likely than caregivers for a parent to confide in their children (59% vs. 33%). However, caregivers for a spouse are significantly more likely (18% vs. 6%) to feel uncomfortable talking about the condition with friends.
- The caregiver's gender also plays a role in determining the makeup of his/her support system. Females with any relationship to the patient are more inclined than males to seek the support of friends (67% vs. 42%) and/or children (45% vs. 25%).
- Likelihood to confide in physicians/healthcare professionals does not appear to be influenced by relationship to the patient or caregiver gender.
- Caregivers who were affected by fear of stigma and/or denial at the time of diagnosis may feel less comfortable sharing their feelings today. They are significantly more likely to feel hesitant to discuss the condition with children (10% vs. 4%) and their spouse (6% vs. 1%). They are less likely to say they feel comfortable confiding in all of the people in their life (66% vs. 79%).

2. The vast majority of caregivers feel that their activities as a caregiver are valued by at least one other person.

- 97% indicate that at least one person values their contributions to their loved one's care. Just 3% feel that no one values their activities as a caregiver.
- Over half of all caregivers (57%) feel that their loved one with Alzheimer's disease appreciates the care they provide.
- Half of caregivers feel that their care is valued by their friends (48%), children (48%) and/or doctors (47%).
- A large minority feel that their care is valued by their spouse (42%) and/or siblings (36%).

IV. CAREGIVER RESPONSIBILITIES & IMPACT OF BIRTH ORDER

1. Most respondents who care for a parent say that they are the only one responsible—regardless of birth order or gender.

- The division of responsibility cited most often (60%) is that the respondent is the only one who is responsible for the parent's care.
- Oldest children (53%), middle children (68%), and youngest children (61%) are about equally likely indicate that they are the only one responsible. There is not a statistically significant relationship between birth order and being the only sibling responsible for care.

2. However, a subset of respondents says all siblings share equal responsibility. Oldest children are significantly more likely than middle or youngest children to be part of this subset.

- The second-most commonly cited division of responsibility (12%) is that all siblings share responsibility equally. Significantly more oldest children (27%) than middle children (5%) or youngest children (3%) describe this type of division of responsibility.
- The involvement of siblings may explain why oldest children (41%) are significantly more likely than middle children (19%) or youngest children (19%) to report that they have developed closer relationships with their family since becoming a caregiver for a parent.

3. Some caregivers for a parent indicate that sibling relationships have suffered under the stress of caregiving.

- Some caregivers for a parent (25%) report that relationships with siblings have deteriorated after a parent was diagnosed. Those affected by fear of stigma and/or denial are significantly more likely than others (33% vs. 14%) to say that they grew farther apart from their siblings after the diagnosis. Overall, 86% describe their sibling relationships as somewhat or very close pre-diagnosis, decreasing to 75% post-diagnosis.

4. Most caregivers (with any relationship to the patient) report that their responsibilities are numerous and varied. Birth order does not have a significant impact on the type of responsibilities siblings carry out.

- Most respondents say their duties include attending appointments (79%), assisting in planning and organizing life events (76%), assisting or taking full responsibility for paying bills associated with care and treatment (76%), assisting in day-to-day activities (73%), helping to make important life decisions (67%), and providing “quality of life” care (60%).
- A large minority of respondents (39%) report that they perform full-time care activities.
- Female caregivers have more interaction with their loved one’s doctors: they are significantly more likely than males (83% vs. 73%) to attend appointments regularly. No other gender effects were noted in terms of responsibilities.

V. EXPERIENCE OF DIAGNOSIS

1. Respondents’ experiences indicate that it is not always easy to get a diagnosis of Alzheimer’s disease. On average, patients experienced symptoms for a few years and saw more than one doctor before receiving a diagnosis of Alzheimer’s disease. In some cases, the caregiver had been the one to initiate the topic of Alzheimer’s disease because of ongoing symptoms or a significant event.

- On average, patients experienced symptoms for roughly 2 years (26.1 months) and saw more than one doctor (2.3) before obtaining a diagnosis. Most caregivers (65%) would agree that Alzheimer’s disease can be difficult for doctors to diagnose.
- Fully three-quarters of caregivers (74%) said they noticed significant events or milestones prior to diagnosis that led them to believe their loved one might have Alzheimer’s disease. Unaided, caregivers are most likely to mention noticing memory loss (30%), getting lost (20%), short-term memory loss (20%) and repetitive speech (17%), among other symptoms/events prior to the diagnosis.
- Roughly half of the time (52%), the caregiver was the one to initiate the topic of Alzheimer’s disease. The caregiver’s relationship to the patient has a significant effect on the way the topic is brought up. Caregivers for a parent are more likely than caregivers for a spouse to be the initiator (62% vs. 43%), whereas caregivers for a spouse are more likely to let the doctor bring it up (41% vs. 25%).
- Overall, when caregivers bring up Alzheimer’s disease it is because of ongoing symptoms (54%) or a specific event or milestone (22%). This being the case, nearly half (45%) expressed that they were not surprised when the diagnosis was made.

2. At the time of diagnosis, most respondents say their loved ones were in the mild-to-moderate stages. Certain symptoms were present in most patients at the time of diagnosis, while other symptoms had occurred in some but not others.

- Most respondents report that their loved one had mild (43%) or moderate (23%) Alzheimer’s disease at the time of diagnosis. However, a minority (15%) say that the doctor didn’t indicate the stage. At the present time, most of the caregivers’ loved ones have moderate (44%) or severe (18%) Alzheimer’s disease.

- Typical symptoms at the time of diagnosis include memory problems or forgetfulness (87%), trouble thinking clearly (such as poor or decreased judgment, disorientation to time and space) (65%) and repetitive words/questions (59%). Many also reported general personality changes (47%), getting lost while driving (40%), depression (38%), and trouble performing activities of daily living (personal hygiene, using the bathroom, eating) (34%). At the present time, with the progression of the condition, even more caregivers report that their loved ones demonstrate these symptoms.
- 3. At the time of diagnosis, many caregivers felt sad and/or scared thinking about what the future might bring. Other emotions were felt by some and tended to vary by caregiver gender. Level of preparedness at the time of diagnosis varied from respondent to respondent.**
- When their loved one was diagnosed, the most common feeling caregivers expressed was sadness knowing that things were only going to get worse (65%). A large minority (39%) felt scared as to what the future would bring. Those who were afraid of stigma and/or in denial at the time of diagnosis were significantly more likely to feel scared as to what the future would bring (47% vs. 28%).
 - As mentioned earlier, nearly half (45%) expressed not feeling surprised by the diagnosis. This was significantly more common among female caregivers (52%) than among males (30%).
 - One-quarter (25%) felt angry that this was happening to someone they love. This was significantly more common among those who experienced fear of stigma/denial (30%) than others (18%).
 - Slightly fewer (22%) say they felt a sense of relief to have an actual diagnosis. Females (26%) were significantly more likely than males (14%) to feel a sense of relief.
 - More practical worries such as the amount of care their loved one would need (19%) and concerns about the cost of healthcare (7%) were not at the forefront of most caregivers' minds at the time of diagnosis. Those few concerned about the cost of healthcare were more likely to be male (12%) than female (5%).
 - At the time of diagnosis, level of preparedness varied by respondent. Respondents were slightly more likely to say they felt somewhat/very unprepared (48%) than they were to indicate feeling somewhat/very prepared (39%). Females (37%) were significantly more likely than males (25%) to have felt prepared.
 - Caregivers indicate that certain types of support or information could have helped them to feel more prepared to deal with their loved one's future. At the time of diagnosis, caregivers wish they had received more general information about Alzheimer's disease (29%), more information about treatment options (27%), more support from family/friends (23%), more emotional support (19%), more financial support (16%), and more support/advice from experienced caregivers (15%). Caregivers who said that fear of stigma and/or denial were reasons for a delayed diagnosis are significantly more likely to say they could have used more emotional support at the time of diagnosis (23% vs. 14%).

VI. BENEFITS OF TREATMENT

- 1. The physician who is primarily responsible for treating the loved one with Alzheimer's disease may be a generalist or a specialist. Respondents tend to be highly involved in their loved one's medical care and are likely to interact with the primary physician often.**
 - A general/family practitioner is the primary healthcare professional for roughly half of respondents (46%).
 - The rest report that a neurologist (20%), internal medicine specialist (15%), geriatrician/gerontologist (11%), psychiatrist (5%), or other type of physician (3%) is primarily responsible for care. Roughly three-quarters of caregivers report that they always (59%) or usually (15%) attend Alzheimer's-related doctor's appointments with their loved one.
- 2. Caregivers are largely aware that treatment options exist that can slow the progression of symptoms. They have heard the name of one or more medications that are available, and in most cases their loved one has already used prescription medications for Alzheimer's disease.**
 - The vast majority (92%) say they are aware that there are medications available that may slow the progression of symptoms. Nearly all (96%) have heard of some of these medications by name, with the vast majority (91%) reporting that their loved one has used prescription treatments for Alzheimer's disease.
 - Of the treatments studied, caregivers are most likely to have heard of Aricept/donepezil (77%), Antidepressants (55%) and Namenda/memantine (50%). A minority have heard of Razadyne/Reminyl/galantamine (30%), Exelon/rivastigmine (29%) or Antipsychotics (28%).
 - Among those 91% whose loved one has taken prescription medications, loved ones are most likely to have ever taken Aricept/donepezil (73%). Half or fewer have ever taken Namenda/memantine (48%), Antidepressants (41%), Exelon/rivastigmine (20%), Razadyne/Reminyl/galantamine (19%), and/or Antipsychotics (19%).
 - Among those 91% whose loved one has ever taken prescription medications, half or fewer are currently taking any given treatment. Loved ones are most likely to currently be taking Aricept/donepezil (47%), Namenda/memantine (40%), or Antidepressants (32%), while a few are taking Razadyne/Reminyl/galantamine (13%), Exelon/rivastigmine (12%), or Antipsychotics (12%). A small group (12%) reports that their loved one has tried medications in the past but is not currently taking them.
- 3. Some caregivers are not currently aware of the opportunity for combination therapy, but most would be at least somewhat open to having their loved one try it, especially if it were shown to reduce the amount of time spent caregiving.**
 - Roughly half of caregivers (49%) were not aware of the opportunity for combination therapy. Caregivers for a spouse (60%) are significantly more likely than caregivers for a parent (47%) to be aware.
 - However, a large majority of caregivers (85%) say they would be at least somewhat open to having their loved one try taking two medications to address their symptoms.
 - And a similarly large proportion (85%) express enthusiasm toward a medication that could help reduce the amount of time spent caregiving.

- Overall, the vast majority (94%) wish there were more treatments available.

VII. IMPACT OF LONG-TERM CARE (LTC) PLANNING (OR LACK THEREOF)

1. Caregivers often find that additional resources are needed, even when their loved one had some type of LTC plan(s) in place.

- Roughly half of respondents (47%) indicated that their loved one had made some type of plans before he/she developed Alzheimer's disease.
- Among those 47% whose loved one had made plans, most (69%) say that a will had been in place. Far fewer (32%) indicate that financial planning had occurred, that their loved one had discussed his/her residence preferences (29%), that their loved one had discussed who will provide care and how (27%), or that their loved one had purchased long-term care insurance (27%).
- Among those whose loved one had made plans, just over half (57%) say that the plan has been sufficient to provide care thus far. A large minority say that additional resources have been necessary on top of the plan, whether a small amount of resources (18%) or a large amount (25%).

2. When no plans have been made, the caregiver and his/her family are often negatively impacted.

- Roughly half of all respondents (53%) report that their loved one had not made any plans for long-term care.
- Lack of any long-term care planning most often (80%) has some impact on the caregiver and his/her family. Caregivers for a parent (85%) are significantly more likely than caregivers for a spouse (68%) to indicate that there has been some impact. Overall, among those caring for a loved one who had not made plans, a large minority indicate that the most significant impact has been the emotional toll (38%), while others indicate a significant financial burden (19%), a physical toll on the health of the caregiver and family (12%), or the stress and costs of having to relocate family members (11%) has been the most important impact of not having plans in place.
- In terms of the emotional impact, those who loved one made no plans are significantly more likely to report that they have less time for themselves (68% vs. 55%) and that they have felt abandoned by family (31% vs. 19%).
- At the time of diagnosis, when no plans are in place, caregivers may feel less prepared to face the future. Those whose loved one had not made any plans are significantly more likely to be concerned about what to expect from the disease as it progresses (94% vs. 78%), and are more likely to experience fear at the time of diagnosis as to what the future will bring (45% vs. 31%).
- As a more practical concern, lack of LTC planning is significantly associated with a parent living with his/her caregiving child (73% vs. 53%). While some families may favor this arrangement, it is possible that limited financial resources make sharing a home a necessity for some who would prefer the parent lived elsewhere.

3. Most caregivers are unaware of organizations that could help them to plan for long-term care in the case of illness.

- Just two in five caregivers (41%) report being aware of these organizations, while the rest are not aware (40%) or are not sure (19%).

VIII. PERSONAL QUALITIES THAT ARE IMPORTANT TO CAREGIVING

1. Overall, caregivers think that the most important qualities associated with caregiving are patience, compassion, and inner strength. Relationship to the patient may have an effect in which traits are considered most important.

- Most respondents (73%) say that patience is highly important to caregiving. Caregivers for a parent (82%) are significantly more likely than caregivers for a spouse (64%) to cite patience as a key trait.
- Compassion is rated as one of the most important traits by a large minority of respondents (43%) with all types of relationships to the patient.
- Inner strength is cited by one-third (33%) of caregivers. Those who care for a spouse (41%) cite this significantly more often than those caring for a parent (28%).
- While it is not one of the overall top mentions, caregivers for a spouse (9%) are significantly more likely than caregivers for a parent (3%) to mention that loyalty is important.

2. Most caregivers feel they embody patience, compassion, and strength to some extent, though many would not claim to completely embody these personal traits.

- The vast majority see themselves as at least somewhat patient (92%), strong (97%), and compassionate (98%).
- Of these three key traits, caregivers are most likely to say they completely embody compassion (67%). Roughly half (53%) say they are completely strong, and slightly fewer (42%) would describe themselves as totally patient.
- While the vast majority (92%) see themselves as at least somewhat patient, only about half of these (42%) say this completely describes them.
- While even more (97%) say they are at least somewhat strong, only about half of them (53%) say this completely describes them. Caregivers for a parent (58%) are significantly more likely than caregivers for a spouse (42%) to describe themselves as completely strong.
- Likewise, while nearly all (98%) describe themselves as at least somewhat compassionate, two-thirds say this completely describes them. Caregivers for a parent (73%) are significantly more likely than caregivers for a spouse (60%) to say this completely describes them. Female caregivers (72%) are more likely than males (58%) to describe themselves as completely compassionate.

IX. CAREGIVER EXPECTATIONS AND GENDER

1. The perception that expectations differ between male and female caregivers exists among roughly half of caregivers.

- Roughly half of males (51%) and females (56%) perceive that expectations differ.
- Caregivers of both genders perceive that female caregivers are expected to demonstrate a more caring personality (18%), to be more compassionate (13%), and to be more adept at daily caregiving activities such as cooking, cleaning, and hygiene (12%).
- Caregivers of both genders perceive that male caregivers are expected to be less involved in caregiving (10%), are less comfortable helping with personal hygiene activities (5%), and are more detached in caregiving (5%).

2. For certain caregiving activities, the perception exists that a same-gender caregiver ought to tend to the patient.

- Some caregivers of both genders (5%) think the perception exists that a same-gender caregiver should be the one to help a loved one with intimate activities like bathroom and bathing.

X. CAREGIVER AND PATIENT PROFILES

1. Alzheimer's caregivers tend to be white females who are middle-aged or older. They typically share a household with their loved one with Alzheimer's disease.

- Overall, roughly two-thirds of caregivers (66%) are female, and one-third (34%) are male. The caregivers in this study tended to be white (87%) though blacks (6%) and Hispanics (3%) are also represented.
- On average, caregivers are 56.2 years old. Caregivers for a spouse tend to be significantly older than caregivers for a parent (69.4 vs. 51.7 years).
- Roughly two-thirds of caregivers (63%) are currently married, including half (52%) of those caring for a parent. Male and female caregivers are equally likely to say they are currently married.
- A large minority of all caregivers are employed in some capacity, whether it be full time employment (26%), self-employment (10%) or part time employment (9%). Being older, caregivers for a spouse (62%) are significantly more likely than caregivers for a parent (15%) to say they are retired.
- Two-thirds of caregivers (66%) say they share a household with their loved one who has Alzheimer's disease. The vast majority of caregivers (94%) say they live in the same community as their loved one (within 50 miles). Caregivers are more likely to live in a suburban (56%) or rural (26%) area than they are to live in an urban area (18%).

2. These caregivers are most likely to care for a female patient who is in her late 70s.

- Overall, over half of caregivers' loved ones are female (61%), with a minority who are male (39%).
- On average, caregivers' loved ones are 78.0 years old. Some are in their late 80s or early 90s.

Appendix A: Methodology

Harris Interactive conducted *I CAN: Investigating Caregivers' Attitudes and Needs* on behalf of the Alzheimer's Foundation of America (AFA) and sponsored by Forest Pharmaceuticals, Inc.

Sample

Potential online respondents were drawn from individuals registered with Harris Interactive's HPOL database and also individuals registered through an outside vendor's database. Email invitations were sent to these individuals inviting them to participate in the survey.

Interviewing Procedures

Online interviewing was conducted utilizing Harris' proprietary web-based technology. This technology enables large numbers of respondents to simultaneously complete surveys online, and has the ability to tailor question sequences based on how an individual responds during the course of the interview, as well as online data entry by the respondents and online data editing for each interview.

In order to maintain the reliability and integrity of the online sample, each invitation email contained a URL encrypted with a password that was uniquely assigned to a potential respondent. Each respondent was required to use this link at the beginning of the survey in order to gain access into the survey. Password protection ensures that a respondent completes the survey only once.

Editing and Cleaning the Data

The data-processing staff performs machine edits and additional cleaning for the entire data set. The edit programs act as a verification of the skip instructions and other data checks that are built into the web-based interviewing programs. The edit programs identify errors that are subsequently resolved by programming personnel (and when appropriate, project staff), who inspect the original file and make appropriate corrections. Complete records are kept of all such procedures.

All data are tabulated, checked for internal consistency and processed by computer. A series of computer-generated tables is then produced for each of the key sample groups showing the results of each survey question, both by the total number of respondents and by important subgroups.

Weighting

The data were weighted to represent the general population of U.S. Alzheimer's disease caregivers with respect to age, gender, education, income and region. The weighting parameters were derived through previous research conducted by Harris Interactive, as well as from statistics generated by the Current Population Survey.

In theory, with samples of this size, one could say with 95 percent certainty that the overall results have a sampling error of plus or minus 4 percentage points. Sampling error for the sub-samples of caregivers of parents (310), caregivers of spouses (138) , those who mentioned fear of stigma and denial as a reason for a delay in diagnosis (279) and those who did not mention fear of stigma or denial as a reason for a delay in diagnosis (260) is higher and varies. This online sample is not a probability sample.