ALZHEIMER’S DISEASE STUDY

COMMUNICATION GAPS BETWEEN PRIMARY CARE PHYSICIANS AND CAREGIVERS
Conducted for:
The Alzheimer’s Association

With the support of:
Janssen Pharmaceutica

and
Ortho-McNeil Pharmaceutical

Conducted by:
Roper Starch Worldwide Inc.

May 2001
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METHODOLOGY AND INTRODUCTION

The purpose of the study was to ascertain the challenges and opportunities for improving communications between doctors and caregivers to help them provide effective treatment and care to people with Alzheimer’s disease, as well as to cope with the personal and emotional challenge of caregiving.

The findings reported are based on telephone interviews with 376 caregivers having a family member, relative or close friend with Alzheimer’s disease and 500 primary care physicians.

The basic sampling frame for the caregiver study component was a random digit dialing system that includes all telephone households in the United States, both listed and unlisted. The 222 interviews completed using this sampling frame were supplemented by 154 telephone interviews with caregivers of individuals having Alzheimer’s disease pre-identified from a national mail panel of over 500,000 households that is screened periodically for various diseases. The supplemental interviews were weighted to agree with the base sample’s incidence of caregivers living with the patient and those who were not, before being merged. The caregiver findings have a margin of sampling error of +/- 5 percentage points.

To be eligible as a caregiver, an adult had to have a family member, relative or close friend who had been diagnosed by a doctor within the past 10 years as having Alzheimer’s disease and to be the one who had regular contact with the doctor caring for that person. A profile of the caregivers is in the Appendix.

The sampling frame for the physician study component was the American Medical Association Directory that lists all physicians, both members and non-members, in the U.S. and their specialty. From this frame a sample of primary care physicians was drawn. The margin of sampling error of the physician findings is +/- 4 percentage points.

To be eligible for interview primary care physicians had to have at least 10% of their patient base over 65 years of age and have patients diagnosed as having Alzheimer’s disease.

All interviewing was conducted during April and May 2001.

The study was conducted on behalf of the Alzheimer’s Association with support from Janssen Pharmaceutica and Ortho-McNeil Pharmaceutical.

Copies of the questionnaires are in the Appendix.
EXECUTIVE SUMMARY

When caregivers first suspect a family member or close friend of having something like Alzheimer’s disease the most likely source they go to for information about the disease is a primary care physician (PCP). In a significant number of cases, when the possibility of Alzheimer’s disease is first discussed with a doctor, the doctor is the first to bring the subject up; indicating that a significant number of physicians recognize early signs of the disease among their older patients. The great majority of caregivers are of the opinion that the doctor was very or somewhat knowledgeable about the disease and its treatment when first discussed.

- 73% of caregivers suspected that a family member/close friend had Alzheimer’s disease
- 82% of those having early suspicions, sought information
- 58% of those having early suspicions went to a primary care physician for information about the disease; the next more common sources were magazine/newspaper articles (30%) and/or family/friends (29%)
- When the possibility was first discussed caregivers and PCPs agree that the caregiver/family member was the first to bring up the subject. However, 31% of the caregivers and 43% of the PCPs reported that the PCP first broached the subject
- 81% of caregivers said the doctor was very or somewhat knowledgeable about the disease and its treatment; 53% said very knowledgeable

PCPs have a positive attitude about Alzheimer’s disease, but this attitude is not being fully communicated to caregivers.

- 80% of PCPs believe the disease can be stabilized for a period of time, if treated early; 32% of caregivers report the doctor told them about this possibility
- 51% of the PCPs believe the condition can improve for a period of time, if treated early; 19% of caregivers report the doctor told them about this possibility
- Caregivers are more likely to say the doctor told them the condition could not be helped much, if at all, even with treatment (33% vs. 17%) and that the condition was just part of the aging process (21% vs. 9%)
Caregivers underestimate what they should know about the disease and its treatment while PCPs are aware of what caregivers need to know. However, such information is not being communicated effectively to caregivers.

- 57% of caregivers want information as to what they can expect as the disease progresses and 38% report the doctor provided it; 84% of PCPs say caregivers want it and 83% say they provide such information
- 52% of caregivers want to know the effect of the disease on the patient’s ability to do daily tasks and how to cope and 28% report the doctor provided it; 85% of PCPs say caregivers want it and 91% say they provide it
- 47% of caregivers want to know its effect on memory/thinking clearly and 31% report the doctor provided it; 88% of PCPs say caregivers want it and 90% say they provide it
- 46% of caregivers want information about medication treatments and what to expect from them and 41% report the doctor provided it; 91% of PCPs say caregivers want it and 91% say they provide it
- 42% of caregivers want information as to how to manage abnormal/difficult behavior and 23% report the doctor provided it; 85% of PCPs say caregivers want it and 81% say they provide it
- 40% of caregivers want to know how long the disease will last and 20% report the doctor provided it; 82% of PCPs say caregivers want it and 70% say they provide it

This disconnect also occurs for information needs relating to the role of caregivers.

- 45% of caregivers want information about where to find help/services and 31% report the doctor provided it; 88% of PCPs say they provide such information
- 43% of caregivers want to know how to manage changes in their life and 19% report the doctor provided it; 80% of PCPs report provided such information
- 41% of caregivers want to know what their responsibilities are and 28% report the doctor provided it; 78% of PCPs say they provide such information
- 32% of caregivers want to know how to handle financial/legal planning and 13% report the doctor provided it; 58% of PCPs say they provide such information

There is also a disconnect between caregivers and physicians on information sources provided/recommended by doctors to learn about the disease and its treatment.

- 80% of caregivers report the doctor provided/recommended information sources about the disease and its treatment versus 100% of PCPs saying they provide such information
• The gaps between what caregivers say the doctor provided and what PCPs say they provide are significant:
  • Alzheimer’s Association – 34% vs. 73%
  • Other physician/second opinion – 31% vs. 56%
  • PCPs educational materials – 30% vs. 76%
  • Alzheimer’s support group – 25% vs. 73%
  • Other health professional – 18% vs. 71%

There is yet another disconnect between PCPs and caregivers as to what doctors have recommended caregivers to do to help themselves cope with the challenge of caregiving. The gaps become more evident within the context of specific recommendations made.

• 60% of caregivers report PCPs did recommend what they should do to cope versus 97% of PCPs saying they make such recommendations.
• With respect to specific recommendations:
  • 24% of caregivers report the doctor recommending a support group versus 74% of PCPs saying they do
  • 16% of caregivers report the doctor recommending professional counseling versus 49% of PCPs saying they do
  • 14% of caregivers report the doctor recommending respite care versus 50% of PCPs saying they do
  • 12% of caregivers report the doctor recommending community services versus 76% of PCPs saying they do

Nearly all PCPs include medication in what they believe is the best treatment plan for Alzheimer’s disease. The best plan is one that includes medication, lifestyle changes and support services.

• 99% of PCPs include medication in their choice of the best treatment plan
• 84% consider a plan that includes all three components to be the best

Almost all caregivers and PCPs believe early diagnosis of Alzheimer’s disease is important. However, PCPs have not fully communicated to caregivers why it is important – in particular that the condition can be improved/stabilized for a period of time with treatment and that treatments are more effective when started early.

• 54% of caregivers say it is important since the condition can improve/be stabilized awhile with treatment versus 79% of PCPs giving this as a reason
• 53% of caregivers say it is important since treatments are more effective when started early versus 88% of PCPs giving this as a reason
SUMMARY OF FINDINGS
NEARLY THREE OF EVERY FOUR CAREGIVERS SUSPECTED THEIR RELATIVE/FRIEND HAD ALZHEIMER’S DISEASE BEFORE IT WAS ACTUALLY DIAGNOSED AS SUCH. THE GREAT MAJORITY (82%) SOUGHT OUT INFORMATION ABOUT THE DISEASE AND ITS TREATMENT WHEN HAVING SUCH SUSPICIONS. THE MOST COMMON SOURCE (58%) USED BY THOSE SUSPECTING IT WAS ALZHEIMER’S DISEASE WAS A PRIMARY CARE PHYSICIAN.

Base: All caregivers

Had suspicion before diagnosis 73%

Sought information* 82%

More common sources went to *:

PCP 58%
Media 30%
Family/friends 29%
Specialist 25%
Alzheimer’s Association 25%
Medical dictionary/reference book 23%
Others with relatives having Alzheimer’s 22%
Internet sites 15%

(* Percents based on caregivers having a suspicion before diagnosis)

“Did you suspect your relative might have something like Alzheimer’s disease before a doctor diagnosed it as such?” (CG Q. 7a) “When you first suspected your relative had Alzheimer’s disease did you seek out information about the disease and its treatment?” (CG Q. 8a) “Which, if any, of the following sources did you go to for information at that time?” (CG Q. 8b)
ALTHOUGH CAREGIVERS/FAMILY MEMBERS WERE MORE LIKELY TO BE THE ONES TO BRING UP THE POSSIBILITY OF ALZHEIMER’S DISEASE WHEN FIRST DISCUSSED WITH DOCTORS, A SIGNIFICANT NUMBER OF DOCTORS HAD THEIR OWN SUSPICIONS AND WERE THE FIRST TO BRING UP THE POSSIBILITY WITH THE FAMILY.

Base: All caregivers. All PCPs treating Alzheimer’s patients.

<table>
<thead>
<tr>
<th></th>
<th>CGs</th>
<th>PCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>First brought up:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver/family</td>
<td>47%</td>
<td>52%</td>
</tr>
<tr>
<td>PCP</td>
<td>31%</td>
<td>43%</td>
</tr>
<tr>
<td>Patient</td>
<td>11%</td>
<td>3%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>11%</td>
<td>2%</td>
</tr>
</tbody>
</table>

“When the possibility of Alzheimer’s disease was first discussed with a doctor, who first brought up the subject?” (CG Q. 10a) “When the subject is first discussed with the patient or his/her family, who usually initiates the discussion?” (PCP Q. 5b)
AT THE TIME THE POSSIBILITY OF ALZHEIMER’S DISEASE WAS FIRST DISCUSSED, CAREGIVERS WERE OF THE OPINION THAT THE DOCTORS WERE KNOWLEDGEABLE ABOUT THE DISEASE AND ITS TREATMENT.

Base: All caregivers

“Very knowledgeable” 53%

“Somewhat knowledgeable” 28%

“Not too knowledgeable” 7%

“Not knowledgeable at all” 4%

“Don’t know” 9%

“How knowledgeable did your doctor appear to be about Alzheimer’s disease and its treatment at that time? (CG Q. 10c)”
PCPs PERCEIVE ALZHEIMER’S DISEASE AS A CONDITION THAT CAN BE STABILIZED/IMPROVED, IF TREATED EARLY. BUT, THIS POSITIVE ATTITUDE IS NOT BEING FULLY COMMUNICATED TO CAREGIVERS.

Base: All caregivers. PCPs treating Alzheimer’s patients.

- **What CGs Told**
- **PCPs beliefs**

<table>
<thead>
<tr>
<th>Statement</th>
<th>PCPs beliefs</th>
<th>CGs Told</th>
</tr>
</thead>
<tbody>
<tr>
<td>There are treatments that can help, but only a little bit</td>
<td>35%</td>
<td>9%</td>
</tr>
<tr>
<td>Can’t be helped much, if at all, even with treatment</td>
<td>33%</td>
<td>17%</td>
</tr>
<tr>
<td>Can be stabilized for a period of time, if treated early</td>
<td>32%</td>
<td>80%</td>
</tr>
<tr>
<td>Just a part of the aging process</td>
<td>21%</td>
<td>9%</td>
</tr>
<tr>
<td>Can improve for a period of time, if treated early</td>
<td>19%</td>
<td>51%</td>
</tr>
</tbody>
</table>

(* Not asked)

“At the time of diagnosis which of the following did the doctor tell you about Alzheimer’s?” (CG Q. 14b) “What is your general attitude about Alzheimer’s disease? (PCP Q. 4d)
CAREGIVERS TEND TO UNDERSTATE THEIR OWN INFORMATION NEEDS ABOUT THE DISEASE AND ITS TREATMENT. PCPs ARE AWARE OF WHAT CAREGIVERS SHOULD KNOW, BUT THIS INFORMATION IS NOT EFFECTIVELY BEING COMMUNICATED TO CAREGIVERS. THIS DISCONNECT INCLUDES SUCH INFORMATION NEEDS AS MEDICATION TREATMENTS AND WHAT TO EXPECT FROM THEM, HOW DISEASE AFFECTS PATIENT, HOW THE DISEASE PROGRESSES AND HOW TO MANAGE ABNORMAL BEHAVIOR, AS WELL AS HOW LONG THE DISEASE LASTS.

Base: All caregivers. PCPs treating Alzheimer’s patients.

<table>
<thead>
<tr>
<th>What to expect as disease progresses</th>
<th>Wanted</th>
<th>PCP provided</th>
<th>PCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>57</td>
<td>38</td>
<td>84</td>
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</tbody>
</table>

Effect on ability to do daily tasks and how to cope

<table>
<thead>
<tr>
<th></th>
<th>Wanted</th>
<th>PCP provided</th>
<th>PCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>52</td>
<td>28</td>
<td>85</td>
</tr>
</tbody>
</table>

Effect on memory/think clearly and how to cope

<table>
<thead>
<tr>
<th></th>
<th>Wanted</th>
<th>PCP provided</th>
<th>PCPs</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>47</td>
<td>31</td>
<td>88</td>
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</table>

Medication treatments and what to expect from them

<table>
<thead>
<tr>
<th></th>
<th>Wanted</th>
<th>PCP provided</th>
<th>PCPs</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>46</td>
<td>41</td>
<td>91</td>
</tr>
</tbody>
</table>

How to manage abnormal/difficult behavior

<table>
<thead>
<tr>
<th></th>
<th>Wanted</th>
<th>PCP provided</th>
<th>PCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>42</td>
<td>23</td>
<td>85</td>
</tr>
</tbody>
</table>

How long the disease will last

<table>
<thead>
<tr>
<th></th>
<th>Wanted</th>
<th>PCP provided</th>
<th>PCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>40</td>
<td>20</td>
<td>82</td>
</tr>
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</table>

---As reported by:---

“What kind of information did you want?”  (CG Q. 16a)  “What kind of information did the doctor actually provide?”  (CG Q. 16b)  “On which of the following subjects do you provide information to family caregivers?”  (PCP Q. 11a)  “On which of these subjects do family caregivers want information?” (PCP Q. 11b)
THE SAME COMMUNICATION GAPS OCCUR WITH RESPECT TO INFORMATION NEEDS RELATING TO THE CAREGIVERS ROLE, SUCH AS WHERE TO FIND HELP/SERVICES, MANAGE CHANGES IN THEIR OWN LIVES, THEIR RESPONSIBILITIES AND HANDLING FINANCIAL/LEGAL PLANNING.

Base: All caregivers. All PCPs treating Alzheimer’s patients.

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<thead>
<tr>
<th></th>
<th>CGs</th>
<th>PCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Where to find help/services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wanted</td>
<td>45</td>
<td>87</td>
</tr>
<tr>
<td>PCP provided</td>
<td>31</td>
<td>88</td>
</tr>
<tr>
<td><strong>How to manage changes in their life</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wanted</td>
<td>43</td>
<td>74</td>
</tr>
<tr>
<td>PCP provided</td>
<td>19</td>
<td>80</td>
</tr>
<tr>
<td><strong>Responsibilities of caregivers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wanted</td>
<td>41</td>
<td>78</td>
</tr>
<tr>
<td>PCP provided</td>
<td>28</td>
<td>78</td>
</tr>
<tr>
<td><strong>How to handle financial/legal planning</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wanted</td>
<td>32</td>
<td>67</td>
</tr>
<tr>
<td>PCP provided</td>
<td>13</td>
<td>58</td>
</tr>
</tbody>
</table>

“What kind of information did you want?” (Q. 16a) “What kind of information did the doctor actually provide?” (Q. 16b) “On which of the following subjects do you provide information to family caregivers?” (PCP Q. 11a) “On which of these subjects do family caregivers want information?” (PCP Q. 11b)
THERE IS ALSO A DISCONNECT AS TO PCPs PROVIDING SOURCES OF INFORMATION THAT CAREGIVERS CAN USE TO LEARN MORE ABOUT THE DISEASE AND ITS TREATMENT. MORE THAN SEVEN OF EVERY TEN PCPs MENTION EDUCATIONAL MATERIALS THEY PROVIDE, THE ALZHEIMER'S ASSOCIATION, ALZHEIMER'S SUPPORT GROUPS AND OTHER HEALTH PROFESSIONALS. 34% AND FEWER OF CAREGIVERS REPORT BEING PROVIDED THOSE SOURCES OF INFORMATION. A SIGNIFICANT NUMBER (20%) OF CAREGIVERS REPORT THAT THEIR DOCTOR MADE NO SUCH RECOMMENDATIONS.

Base: All caregivers. PCPs treating Alzheimer’s patients.

“Which of the following information sources, if any, did the doctor provide or recommend to you to learn more about Alzheimer’s disease and its treatment?” (CG Q. 15a) “Which, if any, of the following information sources, if any, do you usually provide or recommend caregivers to educate themselves?” (PCP Q. 10a)
FOUR OF EVERY TEN CAREGIVERS DISCUSSING WITH THE DOCTOR
HOW CAREGIVING AFFECTS THEM PERSONALLY REPORT THE
DOCTOR DID NOT RECOMMEND ANYTHING TO HELP THEM COPE WITH
THE BURDEN OF CAREGIVING, WHILE ALMOST ALL PCPs (97%) SAY
THEY HAVE.

Base: All caregivers discussing personal needs. PCPs treating Alzheimer’s patients.

- **PCP made recommendation:**
  - CGs: 60%
  - PCPs: 97%

- **Alzheimer’s Association:** 26%

- **Participation in a support group:** 24%

- **Professional counseling:** 16%

- **Respite care:** 14%

- **Community services:** 12%

- **No recommendation made:** 3%

( *Not asked)

“What, if anything, has the doctor recommended that you, yourself, do to cope with the burden of taking care of your relative?” (CG Q. 22a) “Which, if any, do you recommend specifically to help family caregivers, themselves? Do you refer them...?” (PCP Q. 12)
THE GREAT MAJORITY (84%) OF PCPs BELIEVES THE BEST TREATMENT PLAN INCLUDES THREE COMPONENTS – MEDICATION, LIFESTYLE CHANGES AND SUPPORT SERVICES. VIRTUALLY ALL (99%) INCLUDE MEDICATION AS A PART OF A TREATMENT PLAN.

Base: PCPs treating Alzheimer’s patients.

Medication, lifestyle changes and support services 84%

Medication and support services 8%

Medication and lifestyle changes 6%

Lifestyle and support services 1%

Single component mentions 1%

“Which one of the following treatment plans do you believe is best for Alzheimer’s disease? Do you believe it is?” (PCP Q. 15a)
ALMOST ALL CAREGIVERS AND PCPs BELIEVE EARLY DIAGNOSIS OF ALZHEIMER’S DISEASE IS IMPORTANT. HOWEVER, PCPs HAVE NOT FULLY COMMUNICATED TO CAREGIVERS THE REASONS WHY IT IS IMPORTANT; SPECIFICALLY, THAT THE CONDITION CAN BE STABILIZED/IMPROVED FOR AWHILE (79% vs. 54%) AND THAT TREATMENTS ARE MOST EFFECTIVE WHEN STARTED EARLY (88% vs. 53%).

Base: All caregivers. PCPs treating Alzheimer’s patients.

- **Early diagnosis**
  - CGs: 90%
  - PCPs: 94%

- **Reasons why:** *
  - Condition can improve/be stabilized for awhile with treatment: 54% (79%)
  - Treatments more effective when started: 53% (88%)
  - Explains why patient is acting the way he/she is: 45% (68%)
  - Allows time for financial/legal planning: 40% (64%)

(*Percents based on caregivers/PCPs considering it important)

“Based on your experience, do you believe early diagnosis of Alzheimer’s disease is important, or not?” (CG Q. 23a) “Which, if any, of the following reasons best explain why you feel that way?” (CG Q. 23b) “Based on your experience, do you believe early diagnosis of Alzheimer’s disease is important, or not?” (PCP Q. 7b) “Why do you believe it is important?” (PCP Q. 7c)
72% OF CAREGIVERS REPORT THE DOCTOR DISCUSSED SPECIFIC MEDICATIONS. CHOLINESTERASE INHIBITORS WERE DISCUSSED MORE OFTEN THAN OTHER MEDICATION TYPES. HOWEVER, FEWER THAN FOUR OF EVERY TEN CAREGIVERS REPORTED THEM AS A TOPIC OF DISCUSSION WHEN ALMOST ALL PCPs PRESCRIBE THEM.

Base: All caregivers. PCPs treating Alzheimer’s patients.

- **CGs reporting**
  - Cholinesterase inhibitors: 39%
  - Anti-psychotics: 23%
  - Vitamin E: 21%
  - Anti-depressants: 18%

- **PCPs reporting**
  - Cholinesterase inhibitors: 92%
  - Anti-psychotics: 71%
  - Vitamin E: 52%
  - Anti-depressants: 82%

“Which, if any, of the following medications for treating Alzheimer’s disease and related symptoms did the doctor discuss with you? (CG Q. 17a) “Which, if any, of the following medications for treating Alzheimer’s disease do you sometimes prescribe?” (PCP Q. 13a)
NEARLY SIX OF EVERY TEN CAREGIVERS FEEL VERY COMFORTABLE DISCUSSING HOW CAREGIVING IS AFFECTING THEM PERSONALLY. STILL, A SIGNIFICANT NUMBER (39%) DO NOT FEEL VERY COMFORTABLE ABOUT DISCUSSING IT OR THE SUBJECT IS NEVER DISCUSSED.

Base: All caregivers.

<table>
<thead>
<tr>
<th></th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>Is discussed</td>
<td>92%</td>
</tr>
<tr>
<td>Feel very comfortable</td>
<td>58%</td>
</tr>
<tr>
<td>Feel somewhat comfortable</td>
<td>19%</td>
</tr>
<tr>
<td>Feel somewhat uncomfortable</td>
<td>7%</td>
</tr>
<tr>
<td>Feel very uncomfortable</td>
<td>5%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>3%</td>
</tr>
<tr>
<td>Never discussed</td>
<td>8%</td>
</tr>
</tbody>
</table>

“How comfortable are you personally in discussing with the doctor how caregiving affects you personally? Do you feel?” (CG Q. 21)
CAREGIVER PROFILE

LENGTH OF TIME CHARGE HAS HAD ALZHEIMER’S:

- Less than 3 years: 46%
- 3 to less than 5 years: 26%
- 5 to less than 10 years: 27%

RELATIONSHIP:

- Parent: 34%
- Spouse: 27%
- In-law: 12%
- Other: 26%

LOCATION OF INDIVIDUAL WITH ALZHEIMER’S:

- Lives in a care facility: 33%
- Lives with caregiver: 24%
- Lives with someone else: 24%
- Lives alone: 13%
- Other: 6%

LOCATION OF CAREGIVER:

- Lives with Alzheimer’s patient: 24%
- Not living with Alzheimer’s patient: 76%
  - Same city/town: 43%
  - Same county, not same city/town: 9%
  - Out of county, same state: 10%
  - Out of state: 14%

AGE:

- Under 50: 34%
- 50 to 64: 29%
- 65 + older: 37%

GENDER:

- Male: 28%
- Female: 72%

EMPLOYMENT:

- Employed: 48%
- Not employed: 52%
PCP PROFILE

POPULATION OF PATIENTS OVER AGE 65:

10% to less than 25% 23%
25% to less than 50% 38%
50% and over 39%

MEAN NUMBER OF PATIENTS DIAGNOSED WITH ALZHEIMER’S DISEASE:

60.2

LENGTH OF TIME IN ACTIVE PRACTICE:

Less than 10 years 34%
10 to less than 20 years 29%
20 years and more 37%

LENGTH OF TIME TREATING ALZHEIMER’S PATIENTS:

Less than 10 years 42%
10 to less than 20 years 34%
20 years and more 23%

AGE:

Under 35 years old 13%
35 to 49 50%
50 and older 37%

SEX:

Male 82%
Female 18%
CAREGIVERS SURVEY

Hello, my name is ___ and I am calling from Roper Starch, a national survey research firm. We are conducting a survey and would like to ask you a few questions. We’re not selling anything and anything you tell us will be completely confidential.

A. First we’d like to know how you feel things are going for you and your family. Compared with one year ago, would you say that, overall, things are going better, going worse, or are about the same for you and your family?

Better 1
Worse 2
About the same 3
Don’t know 7
Refused 8

1. Do you have any living family members, relatives or close friends who have been diagnosed by a doctor as having one of the following diseases or health conditions?

<table>
<thead>
<tr>
<th>Disease</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arthritis</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>1</td>
<td>2  (TERMINATE)</td>
</tr>
</tbody>
</table>

2a. We’re trying to learn more about people’s experiences and opinions about helping care for people with Alzheimer’s disease – the kinds of problems they might have and so forth. Thinking about the family member or close friend who has Alzheimer’s disease, we would like to talk to someone who has regular contact with the doctor caring for that Alzheimer patient. Would that be you or someone else in your household?

YES, ME 1 (GO TO Q. 3)
YES, SOMEONE ELSE IN HOUSEHOLD 2 GO TO Q. 2b)
NO, SOMEONE NOT IN HOUSEHOLD 3 (GO TO Q. 2c)

2b. May I speak with that person?

YES, WILL GET 1 (GO TO Q. 2d)
NOT AVAILABLE NOW (SCHEDULE CALLBACK AND DISPO AS “QUALIFIED CALLBACK”) 2
NO, REFUSED 3

2c. Could you give me that person’s name and phone number so I could call him or her to ask some questions about their experiences?

YES (RECORD NAME AND PHONE NUMBER) 1
NO, DON’T KNOW 2
NO, REFUSED 3

2d. Hello, my name is ___ and I’m calling from Roper Starch, a national survey research firm. We’re conducting a survey to learn more about the experiences and opinions of people who are caretakers for people with Alzheimer’s disease. Do you have regular contact with the doctor caring for a family member or close friend who has Alzheimer’s disease?

Yes 1 GO TO Q. 3)
No 2 (GO TO Q. 2a)
Refused 3 (TERMINATE)
3. Approximately how long ago was your family member diagnosed as having Alzheimer’s disease?

- Less than one year ago 1 (ASK Q. 4)
- 1 to less than 3 years ago 2 (ASK Q. 4)
- 3 to less than 5 years ago 3 (ASK Q. 4)
- 5 years to less than 10 years ago 4 (ASK Q. 4)
- 10 years ago or more 5 (TERMINATE)
- Don’t know (vol.) x (TERMINATE)

4. What is your relationship to the family member with Alzheimer’s? Is he/she your…. (READ LIST)

- Spouse 1
- Parent 2
- In-law 3
- Other relation (SPECIFY) 4

5. Does that family member live alone, with you, with someone else or in a residential care facility?

- Alone 1
- With caregiver 2
- With someone else 3
- In a care facility 4
- Other (SPECIFY) 5

6. (IF NOT LIVING WITH CAREGIVER, ASK) Do you, yourself, reside in the same (READ LIST. STOP AT FIRST ‘NO’) as the family member with Alzheimer’s?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>State</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>County</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>City/town</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

7a. Did you suspect your (RELATIVE) might have something like Alzheimer’s disease before a doctor diagnosed it as such?

- Yes 1 (ASK Q. 7b)
- No 2 (GO TO Q. 10a)

7b. What triggered your suspicion that it might be something like Alzheimer’s disease? Was it (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

- Forgetting things 1
- Behaviour was odd, erratic, wasn’t him/herself 2
- Getting lost 3
- Repeating things said 4
- Difficulty with routine tasks 5
- Not seeming to care about his/her appearance 6
- Something else (SPECIFY) 7

8a. When you first suspected your (RELATIVE) had Alzheimer’s disease, did you seek out information about the disease and its treatment?

- Yes 1 (ASK Q. 8b)
- No 2 (GO TO Q. 9a)
8b. Which, if any, of the following sources did you go to for information at that time? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

- Primary care physician
- Specialist
- Alzheimer’s Association
- Other people with relatives having Alzheimer’s
- Medical dictionary or reference book
- Magazine or newspaper articles
- Religious/spiritual advisor
- Internet sites
- Family or friends
- Other (SPECIFY)

8c. Were you able to get…(READ LIST)

- All the information you needed
- Most of it
- Some of it
- Very little
- None

9a. Thinking back to when you first suspected (RELATIVE) might be suffering from Alzheimer’s, how long was it before you discussed his/her condition with a doctor? Was it (READ LIST)

- Less than 3 months
- 3 to 6 months
- Over 6 months to one year
- Over 1 year to 2 years
- Over 2 years
- Don’t know (vol.)

If ‘LESS THAN 3 MONTHS’, GO TO Q. 10a

9b. Which of the following best explain why (TIME) went by before the possibility of Alzheimer’s disease was discussed with a doctor? Was it because (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

- You were waiting for the doctor to bring up the subject
- You were unwilling or afraid to ask the question
- You were unsure of your suspicions
- You thought nothing could be done about your (RELATIVE’S) condition
- You did not want to offend your (RELATIVE)
- Your (RELATIVE) did not want you to
- Some other reason
- Don’t know (vol.)

10a. When the possibility of Alzheimer’s disease was first discussed with a doctor, who first brought up the subject? Was it you, your (RELATIVE) or the doctor?

- You, yourself
- Your (RELATIVE)
- Doctor
- Don’t know (vol.)
10b. Did you feel the doctor wanted to hear your concerns and other questions you had, or not?

- Yes, doctor wanted to hear 1
- No 2
- Don’t know x

10c. How knowledgeable did your doctor appear to be about Alzheimer’s disease and its treatment at that time? Was the doctor (READ LIST)

- Very knowledgeable 1
- Somewhat knowledgeable 2
- Not too knowledgeable 3
- Not knowledgeable at all 4
- Don’t know (vol.) x

11. How long did it take from the time your (RELATIVE’S) condition was first brought to the doctor’s attention until he/she was diagnosed as having Alzheimer’s disease? (READ LIST)

- Less than one month 1
- One month 2
- 2 to 3 months 3
- Over 3 to 6 months 4
- Over 6 months to 1 year 5
- Over one year 6

12. How knowledgeable were you about Alzheimer’s disease at the time your (RELATIVE) was diagnosed with it? Were you (READ LIST)

- Very knowledgeable 1
- Somewhat knowledgeable 2
- Not too knowledgeable 3
- Not knowledgeable at all 4

13. Which of the following were your greatest concerns at the time? Did they include (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

- What to expect from the disease as it progresses 1
- Whether anything could be done to treat the disease 2
- What to expect from various medications available 3
- Your (RELATIVE’S) ability to cope 4
- Your ability to cope 5
- Impact on your (RELATIVE’S) other health problems 6
- Availability of services to help/finding care 7
- Cost of care/difficulty in getting reimbursed 1
- Time it would take to care for him/her 2
- Whether he/her could drive, live alone 3
- Impact on your health 4
- Other (SPECIFY) 5
- None (vol.) 0
14a. At the time of diagnosis, which, if any, of the following describe your belief about the disease? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

14b. At the time of diagnosis which of the following did the doctor tell you about Alzheimer’s? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

<table>
<thead>
<tr>
<th></th>
<th>(a)</th>
<th>(b)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A condition that can improve for a period of time, if treated early</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>A condition that can stabilize for a period of time, if treated early</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>A condition that can’t be helped much, if at all, even with treatment</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>There are treatments that can help, but only a little bit</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>It is just a part of the ageing process</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Do not know (vol.)</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Nothing (vol.)</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

14c. After the diagnosis was made, did the doctor talk to you about what was likely to happen as the disease progressed, or not?

- Yes, said what was likely to happen: 1
- No: 2

15a. Which of the following information sources, if any, did the doctor provide or recommend for you to learn more about Alzheimer’s disease and its treatment? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

<table>
<thead>
<tr>
<th></th>
<th>(a)</th>
<th>(b)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other physician/second opinion</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other healthcare professional</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Alzheimer’s Association</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Other people having relatives with Alzheimer’s</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Medical reference book</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Magazine or newspaper articles</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Internet sites</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Educational material provided by doctor</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Alzheimer’s support group</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Other (SPECIFY)</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>None (vol.)</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

15c. (IF SOURCES USED – Q. 15b, ASK) How helpful were the source(s) used? Did they provide (READ LIST)

- All the information you wanted: 1
- Most of it: 2
- Some of it: 3
- Very little of it: 4
- None of it: 0
16a. What kind of information did you want? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

16b. What kind of information did the doctor actually provide? Did it include (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

Rotate

- How long the disease will last
- How it will affect memory and the ability to think clearly, and how to cope
- How it will affect the ability to do daily tasks and how to cope
- What to expect as the disease progresses
- How to manage abnormal or difficult behavior
- Medication treatments and what to expect from them
- Responsibilities of family caregivers
- Where to find help, services
- How to handle financial/legal planning
- How to manage the changes in your life
- None (vol.)

17a. Which, if any, of the following medications for treating Alzheimer’s disease and related symptoms did the doctor discuss with you? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

<table>
<thead>
<tr>
<th>Medication</th>
<th>(a)</th>
<th>(b)</th>
<th>(c)</th>
<th>(d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognex (tacrine), Aricept, Exelon or Reminyl</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Risperdal, Zyprexa, Seroquel or Haldol (haloperidol)</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>An anti-depressant such as Prozac or Paxil</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Vitamin E</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Other (specify)</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>None</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

17b. Which ones, if any, had you been aware of before your doctor discussed medications with you? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

17c. Which ones, if any, were you the first to bring up and ask him/her about them? (MULTIPLE RESPONSES ACCEPTABLE)

17d. Which, if any, were ever prescribed for your (RELATIVE)? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

<table>
<thead>
<tr>
<th>Medication</th>
<th>(a)</th>
<th>(b)</th>
<th>(c)</th>
<th>(d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognex (tacrine), Aricept, Exelon or Reminyl</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Risperdal, Zyprexa, Seroquel or Haldol (haloperidol)</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>An anti-depressant such as Prozac or Paxil</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Vitamin E</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Other (specify)</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>None</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

18. Which of the following, if any, did the doctor tell you to expect from the drug prescribed? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

<table>
<thead>
<tr>
<th>Expectation</th>
<th>(1)</th>
<th>(2)</th>
<th>(3)</th>
<th>(4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Could improve or stabilize memory loss for a period of time</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Could maintain (RELATIVE’S) ability to perform normal daily activities for a period of time</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Could help prevent or reduce difficult behavior</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Could delay progression of the disease</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Probably would not do much, but worth a try</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (SPECIFY)</td>
<td>6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not mention what to watch for or expect (vol.)</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know (vol.)</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

19a. Is your (RELATIVE) still taking that medication, or not?

- Yes, still taking | 1
- No | 2
19b. In your opinion, how effective is/was the medication? Would you say it is/was (READ LIST)
   - Very effective 1
   - Somewhat effective 2
   - Somewhat ineffective 3
   - Very ineffective 4
   - Don’t know (vol.) x

   [IF YES TO Q. 19a, GO TO Q. 20]

19c. How long did your (RELATIVE) take that medication before stopping?
   - Less than 1 year 1
   - # ___ years 2
   - Don’t know x

19d. Why did he/she stop taking it? Was it because of (READ LIST. MULTIPLE RESPONSES
   ACCEPTABLE)
   - Side effects 1
   - Cost 2
   - Helped for a little while then stopped 3
   - Some other reason (SPECIFY) 4

19e. Was your (RELATIVE) switched to another medication, or not?
   - Yes, switched 1
   - No 2

20. In addition to medication, what other things did the doctor recommend to your (RELATIVE)
    to treat his/her Alzheimer’s disease? Did the doctor recommend (READ LIST. MULTIPLE
    RESPONSES ACCEPTABLE)
   - Adult day care or respite care 1
   - Professional counselling 2
   - A support group 3
   - Other (SPECIFY) 4
   - Nothing (vol.) 0

21. How comfortable are you personally in discussing with the doctor how caregiving affects you
    personally? Do you feel (READ LIST)
   - Very comfortable 1
   - Somewhat comfortable 2
   - Somewhat uncomfortable 3
   - Very uncomfortable 4
   - Don’t know (vol.) x
   - Wasn’t discussed (vol.) 0

   [IF WASN’T DISCUSSED, GO TO Q. 23a]

22a. What, if anything, has the doctor recommended that you, yourself, do to cope with the burden
    of taking care of your (RELATIVE)? Did it include (READ LIST. MULTIPLE
    RESPONSES ACCEPTABLE)

22b. Which ones, if any, have you received, done or participated in? (MULTIPLE RESPONSES
    ACCEPTABLE)
   (a) (b)
   - Professional counselling 1 1
   - Respite care 2 2
   - Community services such as Meals On Wheels 3 3
   - Participation in a support group 4 4
   - Alzheimer’s Association services/information 5 5
   - Other (SPECIFY) 6 6
   - Nothing (vol.) 0 0
23a. Based on your experience, do you believe early diagnosis of Alzheimer’s disease is important, or not?

   Yes, important 1 (ASK Q. 23b)
   No 2 (GO TO Q. 23c)
   Don’t know x (GO TO Q. 24a)

23b. Which, if any, of the following reasons best explain why you feel that way? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

   Have more time to plan (RELATIVE’s) care 1
   (RELATIVE) can improve or be stabilized for awhile with treatment 2
   Treatments are most effective when started early 3
   Explains why (RELATIVE) is acting the way he/she is 4
   Allows time for financial and legal planning 5
   Other (SPECIFY) 6

   [GO TO Q. 24a]

23c. Which, if any, of the following reasons best explain why you feel that way? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

   The diagnosis is too traumatic to the patient 1
   The diagnosis is too traumatic to his/her family 2
   Cost of treatment is too high/cannot get medical reimbursement once diagnosed 3
   There is no cure 4
   There is no effective treatment 5
   Social stigma 6
   Some other reason (SPECIFY) 7

24a. How often do you usually talk to the doctor about your (RELATIVE’S) condition?

   Once a month or more often 1
   Once every other month 2
   Once every 3 months 3
   Once every 6 months 4
   Once a year 5
   Less often 6

24b. What is your usual method of communication? Is it (READ LIST)

24c. What method of communication with the doctor do you prefer?

<table>
<thead>
<tr>
<th>(b)</th>
<th>(c)</th>
</tr>
</thead>
<tbody>
<tr>
<td>In person</td>
<td>1</td>
</tr>
<tr>
<td>By telephone</td>
<td>2</td>
</tr>
<tr>
<td>By mail</td>
<td>3</td>
</tr>
<tr>
<td>By e-mail</td>
<td>4</td>
</tr>
<tr>
<td>Through the nurse</td>
<td>5</td>
</tr>
<tr>
<td>No preference (vol.)</td>
<td>0</td>
</tr>
</tbody>
</table>

25. Do you feel the doctor usually spends enough time with you in discussing your (RELATIVE’S) condition, or not?

   Yes, spends enough time 1
   No 2
26a. How satisfied are you with the doctor’s ongoing communication about your (RELATIVE’S) Alzheimer’s disease? Would you say you are (READ LIST)

Very satisfied 1
Somewhat satisfied 2
Slightly dissatisfied 3
Very dissatisfied 4

26b. In what ways, if any, could your relationship with the doctor be improved? (PROBE) In what other ways?

26c. Do you believe the doctor feels it is in his/her best interest to have you involved in your (RELATIVE’S) care, or not?

Yes, best interest 1
No 2
Don’t know x

Now for statistical purposes

D1. In which of the following age ranges are you? (READ LIST)

18 to 24 1
25 to 34 2
35 to 49 3
50 to 64 4
65 and older 5

D2. Are you employed either full time or part time?

Yes, employed 1
No 2

D3. What was the last grade of school you completed?

Less than high school 1
High school graduate 2
Some college 3
College graduate and more 4

D4. Are you (READ LIST)

Married 1
Single, living alone 2
Single, living with another adult 3

D5. Gender: Male 1
Female 2

D6a. Do you consider yourself to be of Hispanic or Latin American origin, or not?

Yes 1
No 2

D6b. Do you identify yourself as (READ LIST)

White 1
Black 2
Asian 3
Other 4
Hello, my name is ___ and I am calling from Roper Starch Worldwide, a national survey research firm. We are calling today to ask you a few questions about Alzheimer’s disease. Please understand that we are not selling anything and are only interested in your opinions. The survey will not exceed 15 minutes and we have provided an honorarium of $50. First I have a few qualification questions.

1. What proportion of your patient base would you estimate to be over the age of 65?

   - Less than 10% 1
   - 10% to less than 25% 2
   - 25% to less than 50% 3
   - 50% to less than 75% 4
   - 75% or more 5

   **IF UNDER 10%, TERMINATE**

2a. Approximately how many of your current patients have been diagnosed with Alzheimer’s disease?

   # _____ having Alzheimer’s None 0 (TERMINATE)

2b. For what percent of those patients were you the first to notice the early signs of Alzheimer’s disease and for what percent did you become aware only after family members reported changes in patient behavior? Please give your best estimates.

   ___ % doctor first to notice
   ___ % family reported

   **Must add to: 100%**

3a. And, approximately how many of your patients do you suspect may have Alzheimer’s disease, but have not yet been diagnosed?

   # _____ suspected to have None 0 (GO TO Q. 4a)

3b. What usually triggers your suspicion that a patient might have Alzheimer’s disease? Is it (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

   Rotate
   Memory lapses 1
   Erratic behavior 2
   Repetition of things said 3
   Missing appointments 4
   Seem less concerned about their appearance 5
   Don’t follow your instructions 6
   Mix up medications 7
   Just seem different 8
   Can’t seem to adjust to stress or strain 9
   Other (SPECIFY) 0

4a. How confident are you in your ability to identify early signs of Alzheimer’s disease? Are you (READ LIST)

   - Very confident 1
   - Somewhat confident 2
   - Not very confident 3
   - Not at all confident 4
4b. Do you conduct any regular screening procedures for Alzheimer’s disease among your older patients, or not?

Yes, conduct 1 (ASK Q. 4c)
No 2 (GO TO Q. 4d)

4c. What kind of screening do you do? _______________________________________________

4d. What is your general attitude about Alzheimer’s disease? Would you say it is (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

- A condition that can improve for a period of time, if treated early 1
- A condition that can stabilize for a period of time, if treated early 2
- A condition that can’t be helped much, if at all, even with treatment 3
- It is just a part of the aging process 4
- An illness that affects the memory and not much else 5
- Do not know (vol.) x

5a. What steps, if any, do you take when you first suspect a patient has Alzheimer’s disease and the family or patient has not raised the possibility? Do you (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

- Immediately discuss your thoughts with the patient 1
- Immediately discuss your thoughts with patient’s family 2
- Raise the subject indirectly with the patient to gauge receptivity 3
- Raise the subject indirectly with patient’s family to gauge receptivity 4
- Monitor the symptoms without informing the patient or family 3
- Wait for the patient or family to express concern 4
- Something else (SPECIFY) 6

5b. When the subject is first discussed with the patient or his/her family, who usually initiates the discussion? Is it (READ LIST)

- Family member 1
- Patient 2
- You, the physician 3
- Don’t know (vol.) x

6a. How confident are you in your ability to diagnose Alzheimer’s disease? Are you (READ LIST)

- Very confident 1
- Somewhat confident 2
- Not too sure 3
- Not sure at all 4

6b. Do you typically make the diagnosis yourself or does a specialist make it?

- Make diagnosis yourself 1 (ASK Q. 6c)
- Specialist 2 (GO TO Q. 6d)
- Both (vol.) 3 (ASK Q. 6c)
- None (vol.) 0 (GO TO Q. 7a)

6c. Which of the following do you do to make a diagnosis of Alzheimer’s disease? (READ LIST)

- A written or verbal mental status test 1
- A thorough patient history 2
- Blood and other lab tests 3
- An imaging test such as CT scan or MRI 4
- Something else (SPECIFY) 5

[IF SPECIALIST DOES NOT MAKE DIAGNOSIS, GO TO Q. 7a]
6d. Why do you refer Alzheimer’s patients to a specialist? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

   **Rotate**
   Not confident in your ability to diagnose it 1
   When your own findings are not definitive, need another opinion 2
   When patient and/or family is not satisfied with your diagnosis 3
   You do not have enough time 4
   You do not get reimbursed for it 5
   Some other reason (SPECIFY) 6

7a. About how much time usually passes between the time a patient’s condition first comes to your attention and the actual diagnosis of Alzheimer’s disease?

   - Less than one month 1
   - One month 2
   - 2 to 3 months 3
   - Over 3 to 6 months 4
   - Over 6 months to 1 year 5
   - Over one year 6

7b. Based on your experience, do you believe early diagnosis of Alzheimer’s disease is important, or not?

   - Yes, important 1 (ASK Q. 7c)
   - No 2 (GO TO Q. 7d)
   - Don’t know 3 (GO TO Q. 8a)

7c. Why do you believe it is important? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

   - Patient and/or family need explanation of what they are seeing/experiencing 1
   - Can stabilize the disease for awhile 2
   - Can start treatment early, when it is most likely to be effective 3
   - Allows time for financial and legal planning 4
   - Other reason (SPECIFY) 5

    GO TO Q. 8a

7d. Why is it not important? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

   **Rotate**
   The diagnosis is too traumatic to the patient 1
   The diagnosis is too traumatic to his/her family 2
   Patients/families cannot get reimbursement for treatment, once diagnosed 3
   Your time constraints of dealing with the family/patient 4
   Social stigma 5
   There is no effective treatment 6
   There is no cure 7
   Some other reason (SPECIFY) 0
8a. What are your usual concerns or interests when a patient is first diagnosed with Alzheimer’s disease? Do they include the (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

8b. What are the usual concerns of the family member who will be the primary caregiver? Do they include (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

Rotate
(a) (b)
Pros and cons of various medications available 1 1
Patient’s ability to cope 2 2
Family’s ability to cope 3 3
Impact on patient’s other health problems 4 4
Availability of services 5 5
Difficulty in getting reimbursed 6 6
Time it will take to manage/care for the patient 1 1
Practical issues such as whether patient should continue to drive or live alone 2 2
Impact on caregiver’s other health problems 3 3
Something else (SPECIFY) 4 4
Don’t know (vol.) x x

9a. At the time of diagnosis, how knowledgeable about Alzheimer’s disease is the typical family member who will be serving as the primary caregiver? Is he/she (READ LIST)

Very knowledgeable 1
Somewhat knowledgeable 2
Not too knowledgeable 3
Not knowledgeable at all 4

9b. Which of the following, if any, do you think describe what a typical family caregiver believes about the disease at the time of diagnosis? Does he/she believe it is (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

Rotate
A condition that can improve for a period of time, if treated early 1
A condition that can stabilize for a period of time, if treated early 2
A condition that can’t be helped much, if at all, even with treatment 3
It is just a part of the aging process 4
An illness that affects the memory and not much else 5
Do not know (vol.) x

10a. Which of the following information sources, if any, do you usually provide or recommend for family caregivers to educate themselves? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

Second opinion from another physician 1
Access/referrals to other healthcare professional 2
Alzheimer’s Association 3
Interaction other people caring for Alzheimer’s patients 4
Medical reference book 5
Magazine or newspaper articles 6
Internet sites 1
Educational material provided by your office 2
Alzheimer’s support group 3
Other (SPECIFY) 5
None (vol.) 0

IF ALZHEIMER’S ASSOCIATION MENTIONED, GO TO Q. 11a

10b. Do you ever refer patients to the Alzheimer’s Association, or not?

Yes, refer 1 (GO TO Q. 11a)
No 2 (ASK Q. 10c)
10c. Why not? (DO NOT READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

- Do not know what services they offer
- It just funds research
- No particular reason
- Some other reason (SPECIFY)

11a. On which of the following subjects do you provide information to family caregivers? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

11b. On which of these subjects do family caregivers want information? Do they want to know (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

<table>
<thead>
<tr>
<th>(a)</th>
<th>(b)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How long the disease will last</td>
<td>1</td>
</tr>
<tr>
<td>Effect it will have on memory, ability to think clearly and how to cope</td>
<td>2</td>
</tr>
<tr>
<td>Effect it will have on ability to do daily tasks like shopping, dressing and how to cope</td>
<td>3</td>
</tr>
<tr>
<td>What to expect at different stages of the disease</td>
<td>4</td>
</tr>
<tr>
<td>How to manage abnormal or difficult behavior</td>
<td>5</td>
</tr>
<tr>
<td>Medication treatments and what to expect from them</td>
<td>6</td>
</tr>
<tr>
<td>Responsibilities of family caregivers</td>
<td>7</td>
</tr>
<tr>
<td>Where to find help, services</td>
<td>8</td>
</tr>
<tr>
<td>Financial/legal impact of the disease</td>
<td>9</td>
</tr>
<tr>
<td>How family/caregiver’s quality of life will be affected</td>
<td>0</td>
</tr>
<tr>
<td>None (vol.)</td>
<td>x</td>
</tr>
</tbody>
</table>

12. What, if anything, do you recommend specifically to help family caregivers, themselves? Do you refer them to (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

- Professional counseling
- Respite care
- Community agencies for services
- Support group
- Other (SPECIFY)
- Nothing (vol.)

13a. Which, if any, of the following medications for treating Alzheimer’s disease or related symptoms do you sometimes prescribe? (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

- Cholinesterase inhibitor (Cognex, Aricept, Exelon, Reminyl)
- Anti-psychotic
- Anti-depressant
- Vitamin E
- Other (specify)
- None

IF CHOLINETERASE INHIBITORS MENTIONED, GO TO Q. 14a

13b. Why do you not prescribe Cholinesterase inhibitors at the time of diagnosis? (DO NOT READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

- When condition has progressed too far for medication to be effective
- When patient is very old
- Don’t believe they are effective
- Concern about side effects
- Patient/family cannot afford them
- Other reason (SPECIFY)
- Don’t know (vol.)

GO TO Q. 15a
14a. What do you tell patients and family caregivers to expect from Cholinesterase inhibitors that you prescribe? Do you say they can (READ LIST. MULTIPLE RESPONSES ACCEPTABLE)

**Rotate**
- Improve or stabilize memory loss for a period of time 1
- Improve quality of life 2
- Delay the progression of the disease 3
- Maintain ability to perform activities of daily living for a period of time 4
- Help prevent or reduce difficult behaviors 5
- Probably would not do much, but worth a try 6
- Other (SPECIFY) 7
- None (vol.) 0

14b. How effective do you believe cholinesterase inhibitors are for most patients? Are they (READ LIST)

- Very effective 1
- Somewhat effective 2
- Somewhat ineffective 3
- Very ineffective 4

15a. Which one of the following treatment plans do you believe generally is the best for Alzheimer's disease? Do you believe it is (READ LIST. ACCEPT ONLY ONE RESPONSE)

- Medication only 1
- Lifestyle changes only 2
- Support services only 3
- Medication and lifestyle changes 4
- Medication and support services 5
- Medication, lifestyle changes and support services 6
- Lifestyle changes and support services 7
- None 8
- No opinion (vol.) 0

15b. Which one of the following do you consider to be successful treatment of the disease? Is success (READ LIST. ACCEPT ONLY ONE RESPONSE)

- Visible signs of improvement for a period of time 1
- Stabilization of the symptoms for a period of time 2
- An actual slow down or halt of the disease, itself 3
- Better ability of patient and caregiver to cope 4
- Other (SPECIFY) 5

16a. How often do you usually consult with the family caregiver about a patient's condition?

- Once a month or more often 1
- Once every other month 2
- Once every 3 months 3
- Once every 6 months 4
- Once a year 5
- Less often 6

16b. What is your preferred method of communication with family caregivers? Is it (READ LIST)

- In person 1
- By telephone 2
- By mail 3
- By e-mail 4
- Through your nurse 5
16c. Do you have enough time to consult with family caregivers and respond to their questions and concerns, or not?

- Yes, have time: 1
- No: 2
- Don’t know: x

17. Does the typical Alzheimer’s patient require more, less or about the same amount of your time, compared to other elderly patients?

- More: 1
- Less: 2
- Same: 3

18a. How satisfied do you believe family caregivers are with their ongoing communication with you about their relative’s Alzheimer’s disease? Are they (READ LIST)

- Very satisfied: 1
- Somewhat satisfied: 2
- Somewhat dissatisfied: 3
- Very dissatisfied: 4
- Don’t know (vol.): x

18b. In what ways, if any, could your relationship with family caregivers be improved? (PROBE)

In what other ways? _________________________________________________________

19. How important to the care of the patient is a good relationship between you and the family caregiver? Is it (READ LIST)

- Very important: 1
- Somewhat important: 2
- Somewhat unimportant: 3
- Very unimportant: 4
- Don’t know (vol.): x

Now for statistical purposes

D1. How long have you been in active practice?

- Less than 5 years
- Five years to less than 10 years
- 10 years to less than 20 years
- 20 years to less than 30 years
- 30 years or more

D2. And, how long have you been treating patients with Alzheimer’s disease?

- Less than 5 years
- Five years to less than 10 years
- 10 years to less than 20 years
- 20 years to less than 30 years
- 30 years or more

D3. In which of the following age ranges are you? (READ LIST)

- 18 to 24: 1
- 25 to 34: 2
- 35 to 49: 3
- 50 to 64: 4
- 65 and older: 5

D4. Gender:

- Male: 1
- Female: 2
This completes the interview. We would like to thank you for your time and effort by sending you a gift of $50. In order to do so we will need to know your name, address, and telephone number. All information will remain strictly confidential.

Name _______________________________

Address _______________________________

____________________________________

____________________________________

Phone # _______________________________