MedicineNet Health Research Survey Report

Coping with Alzheimer’s Disease in the Internet Age
Survey Results

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Executive Summary

Alzheimer’s disease is a growing health concern. There are 4.5 million Americans currently suffering from Alzheimer’s disease with that number expected to swell as the population ages. There is no single cause for the disease, and diagnosis can only be confirmed upon autopsy. Alzheimer’s disease is irreversible and current treatments focus on improving the symptoms or managing the disease’s psychiatric manifestations.

Alzheimer’s disease is frustrating for patients and caregivers. Taking care of the Alzheimer’s disease patient places a burden on the family since the caregiver must be vigilant 24-hours per day. Caregivers themselves frequently suffer depression and are overwhelmed by the responsibilities attendant with caring for the Alzheimer’s disease patient.

While network coverage of the Reagan family and funeral highlighted the pain that this one high-profile family and patient suffered, this survey plumbs how the average American family copes with this disease in the Internet Age:

- The quest for information on disease treatment and management
- The support resources used by caregivers in the Internet Age
- Patient compliance in the face of treatments that provide no cure

This survey was conducted during the time frame of September 29, 2004 and October 11, 2004. The data reflects the opinions of a self-identified panel of 387 individuals visiting MedicineNet.com who have or care for or about someone with Alzheimer’s.

The data shows that the Internet has become a primary source for Web users seeking information on Alzheimer’s disease be they caregivers, family members or health care professionals. The survey also showed that those consulting health care professionals are almost twice as likely to have accessed Internet information as the health care professionals themselves.

Whereas health professionals rely on community health organizations for support, the caregivers and families still rely largely on family and friends. The mobile lifestyles and small families prevalent today in the United States may weaken the support system for the growing caregiver population dealing with Alzheimer’s disease.
Methodology

MedicineNet.com used a six-question pop-up online survey to query 387 individuals responding to the question: “Do you or someone you care for have Alzheimer’s disease?” All were visitors to the Alzheimer’s content of the MedicineNet.com site.

Less than 2% of respondents had been diagnosed with Alzheimer’s disease (See Figure 1: Survey Respondent Population). Caregivers and spouses (19%) and family members (42%) predominated. Health care professionals represented 15% of the population, and other individuals interested in Alzheimer’s disease (students, friends or educators) represented 23% of the sample.

All responses were completely anonymous, and no visitor received the survey more than once, so the aggregated results represent unique individual respondents.

Figure 1: Survey Respondent Population

![Bar chart showing survey respondent population distribution]

- Patients: 42%
- Caregivers: 19%
- Family: 15%
- Health Professionals: 23%
- Others: 2%
Findings

To develop a clear picture of the impact of Alzheimer’s disease on families and caregivers, it was necessary to segment the data and tease out the nuances. For example, 23% of survey respondents were only interested in Alzheimer’s disease and have a different point of view than the 61% that are caregivers/spouses (19%) or family (42%) of Alzheimer’s patients. The findings that follow are consequently broken out by segment.

PATIENTS

Only 6 of the 387 respondents to the survey indicated that they had been diagnosed with Alzheimer’s disease. Because of the small size of the sample, no statistically valid significance can be attached to the findings.

It is interesting to observe that although small in number the patients surveyed are active online. They were three-times more likely to rely on Internet groups and forums for support (See Figure 2: Reliance on Internet Support Groups and Forums).

Figure 2: Reliance on Internet Support Groups and Forums

![Bar Chart]

- Patients: 21.43%
- Caregivers: 7.06%
- Family: 7.21%
- All Survey Respondents: 8.40%
CAREGIVERS AND SPOUSES

Caregivers and spouses represented 19% of the survey respondents. These individuals bear the heaviest burden from Alzheimer’s disease since they must be ever vigilant and bear firsthand witness to the inevitable deterioration of their loved one.

Disease Information – When these individuals first suspected that their loved one might have Alzheimer’s disease, most began looking for information on the disease; only 4% indicated that they disregarded or denied the possibility of Alzheimer’s.

The survey results showed that the key sources of information for Web-savvy caregivers are the Internet and their physicians. The Internet far outweighed traditional media sources and the library. Respondents were 10 times more likely to seek information online than at the library (See Figure 3: Internet versus Library as Information Source).

Of particular note is at what point in the process of obtaining an Alzheimer’s disease diagnosis caregivers sought information. Of the surveyed caregivers, 37.29% discussed the disease with a health professional after seeking information on the disease; whereas, 45.76% did their research after a discussion with a health care professional. The implications for health professionals is that they should become aware of and familiar with the sources their patients’ caregivers are consulting so that they can address any misconceptions and errors in understanding of data gleaned from these sources.

Figure 3: Internet versus Library as Information Source
Treatment Information – Caregivers, who use the Internet, rely most heavily on health care professionals and the Internet for treatment and disease management information (See Figure 4: Information Source Most Frequently Relied upon by Caregivers). Health care professionals were the most-relied-on source with 83.6% of caregivers, seeking information from health professionals, relying on them “always” or “often.” Of those indicating their use of the Internet for information on treatment, 61.6% “always” or “often” relied on the Internet. Health organizations such as Alzheimer’s Association were relied on “always” or “often” by 60.5% of those indicating their use of these organizations. Print publications are relied on “always” and “often” 42.5% of the time; family and friends 39.4%, broadcast media 35.1% and other sources such as the library 31.2%.

Figure 4: Information Source Most Frequently Relied upon by Caregivers
Support – When caregivers were asked where they turned for support, family and friends were far and away the most frequently cited source (See Figure 5: Caregivers’ Sources of Support). The data clearly shows the role of family in support the Alzheimer’s care giver:

- Family and Friends 43.53%
- Community Health Resources 16.47%
- Can't Find Support 11.76%
- In-Person Support Groups 9.41%
- Faith-Based Organizations 9.41%
- Internet Support Groups 7.06%
- None Needed 2.35%

There are several implications. With smaller, more mobile families, reducing the proximity and availability of family members to provide support, many caregivers in the future will need to find sources of support beyond their families. Already, 11.76% of caregivers indicate that they cannot find support. This number may grow in the future.
FAMILY

Those with an Alzheimer’s patient in their family were the largest segment of the survey population (42%).

Information – Web-savvy family members’ patterns of information seeking parallel those of the caregivers. They too relied heavily on the Internet (30.74%) for information once they suspected that a family member might have Alzheimer’s disease. Family members were less likely than caregivers to have discussed the disease with health professionals before or after seeking information from other sources (See Figure 6: When Does the Health Professional Enter the Information Search Process?).

Figure 6: When Does the Health Professional Enter the Information Search Process?
**Treatment Information** – Where family members rely on for information on disease treatment and management varies slightly from the caregivers (See Figure 7: Sources Most Frequently Relied on for Treatment Information by Family and Caregivers).

![Figure 7: Sources Most Frequently Relied on for Treatment Information by Family and Caregivers](chart.png)

Family members with less access to the health professionals managing their loved one’s care must rely on the Internet and other family members for information. The data showed that family members overall were active seekers of information.

**Support** – Where family members seek support is not surprising. The bonds of family are strongest with 48.08% of respondents who had a family member with Alzheimer’s indicating that they rely on family. This is similar to the caregivers. Only 4.81% of family members indicated that they cannot find needed support as opposed to 11.76% of caregivers who indicated a lack of support. This is hardly surprising given the tremendous needs of the caregivers. The entire family suffers and needs support, but the caregivers suffer the most.
HEALTH CARE PROFESSIONALS

Health care professionals represented a significant portion (14.51%) of the survey population. The opinions of this group are interesting when contrasted with those of the caregivers, a group with whom they might have regular contact.

**Disease Information** – Less than half as many of these Web-savvy health professionals indicated that they consulted the Internet for information on Alzheimer’s disease than caregivers. Because of their professional training, the health care professional does not need to rely on the Internet for disease information. The data suggests, however, that health care professionals should routinely scan the Internet sources relied upon by their patients and caregivers if they expect to understand their patient families’ research.

**Treatment Information** – When asked where they turn to for information on the treatment and management of Alzheimer’s disease, surveyed health professionals are more reliant on the Internet than caregivers with 73.68% indicating that they rely primarily on the Internet for this type of information (See Figure 8: Sources Most Frequently Relied on for Treatment Information by Health Care Professionals and Caregivers). Health professionals also rely more on the library as a resource than the caregivers.

![Figure 8: Sources Most Frequently Relied on for Treatment Information by Health Care Professionals and Caregivers](chart)

[Other (Library, etc.)][Broadcast Media][Friends/Family][Print Media][Health Organizations][Internet][Health Professionals]
Support – Health care professionals indicated that they relied heavily on community health resources for support for those with Alzheimer’s disease. Given the large number of caregivers that considered themselves needing additional support, the survey points out a need for increased communication of available health resources (See Figure 9: Community Health Resources – Reliance for Support).

Figure 9: Community Health Resources – Reliance for Support
OTHER FINDINGS

The survey panel was asked to indicate the current treatment used by the respondent or the patient(s) cared for. The survey offered choices of five branded medications and alternative medications. Figure 10: Medication shows that Aricept (donepezil) was the leading choice:

- Aricept (donepezil) 44.86%
- Namenda (memantine) 14.02%
- Reminyl (galantamine) 13.08%
- Exelon (rivastigmine) 8.88%
- Cognex (tacrine) 3.74%
- Alternative medications 11.21%

Many Alzheimer’s patients, who are prescribed medication, discontinue their use. This anonymous survey shows that the two most frequently given reasons that patients discontinue taking a prescribed medication for Alzheimer’s disease were:

- Experienced side effects
- Noticed no change in condition even with treatment
Figure 11: Reasons for Discontinuing Medication shows the entire range of reasons cited.

- Expected more improvement: 10.32%
- No change in condition: 23.81%
- Side effects: 31.75%
- Treatment plan difficult: 6.35%
- Could not afford: 15.08%
- Other: 12.70%
Conclusions

The following conclusions can be drawn from this survey:

- Caregivers and spouses, who use the Internet, are ten times more likely to seek information online than at the library.
- 37.29% of caregivers discussed the disease with a health care professional after seeking information on the disease, and 45.76% did their research after a discussion with a health care professional. Health care professionals should become familiar with the sources their patients’ caregivers are consulting.
- The Internet and health care professionals are the two most relied on sources of information on disease treatment and management by Web users.
- Caregivers and family members predominantly rely on family and friends for support.
- 11.76% of caregivers indicated that they cannot find support, a number which will probably grow because of our mobile society and smaller families will reduce or weaken the support available.
- Web-savvy family members with less access to the health professionals managing the care of their loved one rely heavily on the Internet for information on treatment and management.
- Family members of Alzheimer’s patients are active seekers of information.
- Half as many health professionals as caregivers indicated that they rely on the Internet for disease information.
- For treatment and management information, surveyed Web-savvy health professionals turn to the Internet and library resources.
- Health care professionals were more reliant on community health organizations than any other group and may need to effectively communicate the availability of such help to their patients.
- Aricept (donepezil) is the most frequently mentioned treatment used by the survey panel.
- Side effects and no change in condition were the reasons most frequently given for discontinuing medication.
MedicineNet.com – Additional Resources

Below are links to additional information available on MedicineNet.com.

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**MedicineNet.com’s Alzheimer’s disease Overview**
http://www.medicinenet.com/alzheimers/focus.htm

**MedicineNet.com’s Alzheimer’s disease Main Article**
http://www.medicinenet.com/alzheimers_disease/article.htm

**MedicineNet Home Page**
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**Diseases and Conditions**
http://www.medicinenet.com/diseases_and_conditions/article.htm

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http://www.medicinenet.com/symptoms_and_signs/article.htm

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http://www.medicinenet.com/procedures_and_tests/article.htm

**Medications (non-prescription and prescription drugs)**
http://www.medicinenet.com/medications/article.htm

**MedTerms™ Online Medical Dictionary**
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