

Winter August 2012

Unraveling the Uncertainties of Alzheimer's Disease: Internet Resources for Attorneys and Clients

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Repository Citation

Henisak, Kathryn (2012) "Unraveling the Uncertainties of Alzheimer's Disease: Internet Resources for Attorneys and Clients," *Marquette Elder's Advisor*. Vol. 4: Iss. 3, Article 8.

Available at: <https://scholarship.law.marquette.edu/elders/vol4/iss3/8>

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ON-LINE

Unraveling the Uncertainties of Alzheimer's Disease: Internet Resources for Attorneys and Clients

By Kathryn Hensiak

*Alzheimer's is a deadly,
mysterious disease that
affects millions of people.
At this time, there is no
known cure. People
diagnosed with the disease,
their families and
caregivers, and their
attorneys need quality
information about
Alzheimer's, its symptoms,
and possible treatments.
Here are some helpful
Internet resources.*

Alzheimer's disease is a debilitating and deadly brain disease affecting millions of people. Up to four million Americans suffer from Alzheimer's disease, and that number is expected to grow.¹

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Former President Ronald Reagan has been battling the disease for years.

Most of us personally know someone who has the disease, or know a family member who is coping with the disease of a loved one. My own family dealt with the horror of the disease when my grandfather was diagnosed with Alzheimer's in 1988. We sat by helplessly and watched him gradually deteriorate mentally and physically. He eventually succumbed to the disease in 1990.

Unfortunately, when my grandfather was battling Alzheimer's disease and my grandmother was struggling with her role as the primary caregiver, the Internet and its many web resources did not exist as it does today. Although my family had access to books and pamphlets provided to us by healthcare providers, these resources were limited and static. The Internet has changed all this; if there are any bright lights in this otherwise bleak scenario, perhaps this is one of them.

Although researchers have not found a cure for Alzheimer's disease, at least there are organiza-

tions on the Internet reaching out to patients and caregivers. Websites provide information to two important audiences: people diagnosed with Alzheimer's disease and family members affected by the disease. More important, the information is available at the click of a button at any time it is needed. When a new issue arises or a caregiver has a question, information is immediately available. Websites also provide a community in which patients and caregivers can overcome feelings of isolation or despair by connecting with others who are having similar experiences. Finally, practicing elder law attorneys frequently need information about Alzheimer's disease to effectively advise clients on legal matters.

Here are some of the many web resources that deal with Alzheimer's disease.

AARP

<http://www.aarp.org>

Founded in 1958, AARP is a nonprofit organization dedicated to serving the needs of people over 50 years of age.² With more

than 35 million members,³ AARP is a powerful and respected organization. Accordingly, the website of AARP is an excellent research and informational tool for older people. In particular, the AARP website has some good resources related to Alzheimer's disease. These resources are accessed by selecting "Health & Wellness" on the navigation bar on the left-hand side of each page.

Although the focus of this section of the website is not strictly limited to Alzheimer's disease, there are some useful articles on the disease and articles about caring for a loved one stricken with Alzheimer's. In addition, there are articles devoted to health insurance, Medicare, nursing homes, healthcare legislation, current research, and legal issues.

It is easy to browse around this section of the website, but for quick access to the Alzheimer's disease resources, type "Alzheimer's" into the search box at the top of the page and the website will produce a list of relevant pages. Finally, the Health & Wellness section links to a list of relevant books as well as a list of related websites.

Alzheimer's Association

<http://www.alz.org>

The Alzheimer's Association is the largest nonprofit organization in the United States devoted to finding a cure for Alzheimer's disease and reaching out to caregivers who are affected by the disease.⁴ The Association has a network of local chapters throughout the country.

The Association's website is divided into different sections. There are individual pages for people suffering from Alzheimer's, caregivers and family members, healthcare professionals, researchers, and the media. Each section provides quality information about Alzheimer's disease. In fact, this website is one of the best sites available to the public. Both attorneys and clients will benefit from the information available on this site.

In addition to the information available on the Association's website, the organization also sponsors the Benjamin B. Greenfield Library and Resource Center. The library has a wide variety of materials in its collection, including books, videos, audiocassettes, and CD-ROMs. Anyone may use the library's materials by placing an interlibrary loan request through his or her local public library. The library's catalog is searchable on the website. There are also links to reading lists and a link to request information from the library.

Alzheimer's Disease Core Center

<http://www.brain.nwu.edu/core/index.htm>

The Alzheimer's Disease Core Center (ADCC) is part of the Cognitive Neurology and Alzheimer's Disease Center at the Northwestern University Medical School. Funded by the National Institute on Aging, the mission of the ADCC is to provide support for research on the etiology, diagnosis, and treatment of Alzheimer's disease.

The ADCC website serves

multiple audiences, including patients, caregivers, and healthcare professionals. A goal of the website is to create a registry of Alzheimer's patients to aid in further research and hopefully, one day, to find a cure for the disease.

One of the most helpful sections of this website is the list of links to related websites. By selecting "Other Research and Information," visitors to this site will find a comprehensive list of websites related to Alzheimer's disease. The links are broken down by categories, which include university-affiliated sites, nonprofit organizations, local organizations, research sites, and clinical/medical sites.

Alzheimer's Disease Education and Referral Center

<http://www.alzheimers.org>

The Alzheimer's Disease Education and Referral (ADEAR) Center is one of the leading resources available on the Internet. Established by the National Institute on Aging in 1990, the mission of ADEAR is to provide access to information about Alzheimer's disease, its effect on caregivers, and research on causes and possible cures.⁵

The website is divided into several sections. The "What's New" section highlights recent developments dealing with Alzheimer's, including research developments and testimony before Congress. This section is updated monthly. In addition, there is a section devoted solely to recent developments on the research front. Visitors have the

option to subscribe to an e-mail service that will alert them to new developments. The site has a section that provides information about NIA Alzheimer's Centers located around the country. The section devoted to ADEAR publications is excellent.

Visitors can access user-friendly pull-down menus to find fact sheets, research and technical reports, training programs, and the ADEAR newsletter entitled CONNECTIONS. This section also provides a link to an alphabetical list of all ADEAR publications. The multimedia section has links to video and audio available for download on a variety of subjects related to Alzheimer's disease. In addition to these sections, the site has links to other federal resources, a bibliographic database, information about clinical trials, and a calendar of events. In sum, this website is worth a visit.

Alzheimer's Disease International

<http://www.alz.co.uk>

Located in England, Alzheimer's Disease International (ADI) is an international organization composed of sixty Alzheimer's associations.⁶ The goal of ADI is to build and strengthen Alzheimer's associations around the world.⁷

The ADI website has several useful sections. Visitors can learn about possible causes of Alzheimer's disease, treatments, diagnosis, and help for caregivers. The site also provides a section on where to find help, including a comprehensive list of Alzheimer's disease associations. One unique feature of this site is

a section devoted to the global impact of Alzheimer's disease.

Alzheimer's Research Forum

<http://www.alzforum.org/default.asp>

Funded by grants and individual donations,⁸ the Alzheimer's Research Forum is an exceptional website devoted to developing treatments and preventions for Alzheimer's disease. The site provides "resources for researchers and produces discussion forums to promote debate, speed the dissemination of new ideas, and break down barriers across the numerous disciplines that can contribute to the global effort to cure Alzheimer's disease."⁹

The primary audience for this website is researchers. Much of the information is complex and geared toward professionals with extensive medical knowledge. For instance, the Research and Resources sections include topics such as Alzheimer's-related patents, molecular genetics, and a drug company directory.

Even though the information on this website is targeted to researchers, Alzheimer's patients and caregivers may find some useful information on this site. In particular, patients and caregivers looking for technical information about the disease or detailed information on current research would benefit from visiting this website.

Alzheimer Society of Canada

<http://www.alzheimer.ca/english/index.htm>

Founded in 1978, the Alzheimer's Society of Canada is the leading

nonprofit organization in Canada dedicated to helping people with Alzheimer's disease and caregivers of those with the disease.¹⁰ The organization provides support and information to caregivers and engages in extensive public awareness campaigns. The Society's website has extensive information about the disease, caring for someone with the disease, treatment options, and updates on current research.

The section of the website entitled "Alzheimer Care" is particularly instructive. This section contains frequently asked questions, an option to "Ask the Expert", ethical guidelines, guidelines for care, as well as support for families including children and teenagers.

The Alzheimer's Society also has an extensive library accessible from its website. The Library page has information on various types of resources such as books and videos. The Society website also has links to other related websites.

Alzheimer's Society (UK)

<http://www.alzheimers.org.uk>

This is the website of the Alzheimer's Society located in London, England, which serves the needs of England, Wales, and Northern Ireland. The Society is the leading care and research organization for people who suffer from Alzheimer's disease. The website has good information on dementia for both caregivers and people who suffer from dementia. The section aimed at caregivers is particularly helpful. This section has articles devoted to caring for

someone with dementia, dealing with financial worries, and placing someone in a long-term care facility.

The site is easy to use because of a detailed, yet straightforward navigation bar on the left-hand side of the screen. Each topic is broken down into narrower topics and related topics listed in the navigation bar.

American Academy of Neurology

<http://www.aan.com/professionals/practice/guidelines.cfm>

This site provides detailed guidelines for patients, family, and friends. The guidelines address how to recognize the signs of Alzheimer's, how medical professionals will diagnose the disease, what treatment and care options are available to patients and caregivers, and where to find more information.

The site also has a list of the top ten warning signs of Alzheimer's disease. Although the summary is short, it is a good starting place for patients and caregivers who are seeking basic information about Alzheimer's disease.

Elderweb

<http://www.elderweb.com>

Created in 1994, Elderweb is designed to be a research tool for professionals and family members who are seeking information about eldercare issues. The site has numerous links to legal, financial, and medical information. The site also has links to

policy information and statistics. In addition, the site has extensive information about Alzheimer's disease.

Visitors to the site should click on "Body and Soul" and then select "Alzheimer's" from the index. On this page, visitors will find links to articles about Alzheimer's appearing in the Elderweb Newsletter. Articles address issues like the cost of Alzheimer's disease, developments on vaccines, and information for caregivers. The page also has links to other helpful documents from other Alzheimer's organizations. Karen Stevenson Brown operates Elderweb.¹¹ She is a certified public accountant who has over nineteen years of experience with long-term care, finance, and technology.¹² The site is self-funded.

Family Caregiver Alliance

<http://www.caregiver.org>

This website provides a great deal of information about Alzheimer's disease. In addition to providing information about caregiving, the site also has many publications such as newsletters, statistics, fact sheets, research, and diagnoses. Recently updated, the fact sheet on Alzheimer's disease is very helpful. The fact sheet details symptoms of Alzheimer's during the early, middle, and late stages. It also provides information on diagnosing the disease and treatment options. The fact sheet concludes with an excellent discussion about issues facing caregivers during the early, middle, and late stages of Alzheimer's disease.

The Family Caregiver Alliance was founded in 1977.¹³ The Alliance focuses on providing support to caregivers who are caring for loved ones suffering from Alzheimer's disease, stroke, traumatic brain injuries, and other cognitive disorders. Although each of these conditions is unique, caregivers have similar challenges such as isolation, lack of quality information, and significant changes in family roles.

National Institute on Aging

<http://www.nia.nih.gov>

Formed in 1974 as one of the federal National Institutes of Health, Congress directed the National Institute on Aging (NIA) to be the leading organization on research, training, health information dissemination, and similar programs related to aging and older citizens.¹⁴ Since its inception, the NIA has become the primary federal agency that is responsible for Alzheimer's disease research. The (NIA) website also provides access to ADEAR (Alzheimer's Disease Education and Referral), which was discussed earlier in this column.

In addition to ADEAR, the NIA website provides links to a complete list of its publications including age pages, fact sheets, booklets, videos, and directories. The site also has a link to a resource directory for older people and links to other related federal websites. Another part of the website has links for research programs sponsored by the NIA.

Endnotes

1. National Institutes of Health, U.S. Department of Health and Human Services, Alzheimer's Disease Fact Sheet, NIH Publication No. 01-3431, *available at* <http://www.alzheimers.org/pubs/adfact.html> (last visited Sept. 11, 2002).
2. http://www.aarp.org/what_is.html (last visited Sept. 11, 2002).
3. *Id.*
4. <http://www.alz.org/AboutUs/overview.htm> (last visited Sept. 11, 2002).
5. <http://www.alzheimers.org/ir.html> (last visited Sept. 11, 2002).
6. <http://www.alz.co.uk/adi/> (last visited Sept. 11, 2002).
7. *Id.*
8. <http://www.alzforum.org/abo/mis/default.asp> (last visited Sept. 11, 2002).
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10. <http://www.alzheimer.ca/english/society/mission.htm> (last visited Sept. 11, 2002).
11. <http://www.elderweb.com/default.php?PageID=163&Version=0&Font=0> (last visited Sept. 11, 2002).
12. *Id.*
13. <http://www.caregiver.org/who.html> (last visited Sept. 11, 2002).
14. <http://www.nia.nih.gov/about/history.htm> (last visited Sept. 11, 2002).

Websites Mentioned in this Column

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| • AARP | http://www.aarp.org |
| • Alzheimer's Association | http://www.alz.org |
| • Alzheimer's Disease Core Center (ADCC) | http://www.brain.nwu.edu/core/index.htm |
| • Alzheimer's Disease Education and Referral (ADEAR) Center | http://www.alzheimers.org |
| • Alzheimer's Disease International | http://www.alz.co.uk |
| • Alzheimer's Research Forum | http://www.alzforum.org/default.asp |
| • Alzheimer Society of Canada | http://www.alzheimer.ca/english/index.htm |
| • Alzheimer's Society (UK) | http://www.alzheimers.org.uk |
| • American Academy of Neurology | http://www.aan.com/professionals/practice/guidelines.cfm |
| • Elderweb | http://www.elderweb.com |
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