

Plugging into Alzheimer's Disease: Finding the Best Internet Resources

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According to the Alzheimer's Disease Education and Referral Center (ADEAR), scientists estimate that close to 4.5 million Americans suffer from Alzheimer's Disease, the most prevalent form of dementia, with the onset usually beginning after age 60, and the risk increasing with age.¹ With the disease's prevalence in long term care settings—including assisted living—it is not surprising that AL practitioners, staff, family members, and even residents seek information, guidance, and resources about Alzheimer's disease (AD) on the Internet.

The problem is that there are hundreds of Web sites that offer information about AD, and not all of the information is accurate or useful. Knowing how to search the Web and recognize what sites offer the most reliable and practical data can make it easier for practitioners and others to help residents with AD enjoy optimal outcomes and quality of life.

This article looks at some of the key Internet sites for information about AD and how to navigate them most effectively.

PubMed

www.pubmed.gov

PubMed is the interface for the National Library of Medicine's Medline



Database. This free database is updated constantly and provides an avenue into approximately 15 million biomedical journal citations from around the world. It is a prime evidence-based health care tool and an excellent place to investigate both broad and specific topics. This tool is a boon for zeroing in on relevant information—and for excluding the extraneous. Novices and seasoned researchers alike will appreciate its navigability and compre-

hensiveness, as well as the many bells and whistles that are there to explore.

A detailed tutorial, brief help pages detailing specific topics, and an online manual are available on the site. For example, if a user was looking to find overviews covering the latest Alzheimer's drug therapies, he or she could narrow down the concepts he or she is seeking and simply type in "Alzheimer's disease AND drug therapy." It is a

PubMed search screen



good idea to always use uppercase “AND” and “OR.” (This is one of PubMed’s idiosyncrasies.) This simple search brings up—as of this writing—5,917 citations. Clicking on the right tab above the search results to limit to “Reviews” will reduce the retrieval significantly to about 2,100 articles. Users also may wish to execute the search pertaining to a specific drug. In that case, he or she should substitute the drug name (generic is best) for “drug therapy,” as in “Alzheimer’s disease AND donepezil.”

Additional search limits are available to help refine these results, among them language and publication type limits (including Practice Guidelines, Clinical Trials, and Meta-Analyses). To apply these, simply click on the “Limits” tab. Limiting the Alzheimer’s drug therapy search described above to English language and Practice Guidelines yields a result of four pertinent guidelines, including one from the Alzheimer’s Disease (AD) Managed Care Advisory Council, and another from the American Psychiatric Association. Running the same search, this time using the publication type “Clinical Trial” and English language, yields 880 articles overall, including 29 reviews. All references are listed as of their entry date into the database, so the most recent publications will be at the top of your results. To peruse the list with abstracts displayed, simply change the display default from

includes options to select etiology, therapy, diagnosis, prognosis, and clinical prediction guides. These criteria can be focused further to retrieve narrow and specific—or broad, more general—results. This can be a great time saver, enabling users to pinpoint needed information. For example, the search “Alzheimer’s disease AND physical therapy,” limited to Clinical Category “Therapy,” and opting for “narrow, specific” results yields a result of 12 relevant documents, ranging from electrostimulation and multi-sensory stimulation to exercise and massage.

Remember—there is no such thing as a “mistake” in re-searching on PubMed. All searches will be retained for the user’s session in “History,” so that he or she can view or re-execute searches by clicking on this tab.

To view a journal citation, simply click on a link to view it. In many cases, an abstract is available. If the user finds an article that is right on target, the “Related Articles” link to the right of the citation will automatically re-execute a search based on the terms included

“Summary” to “Abstract.”

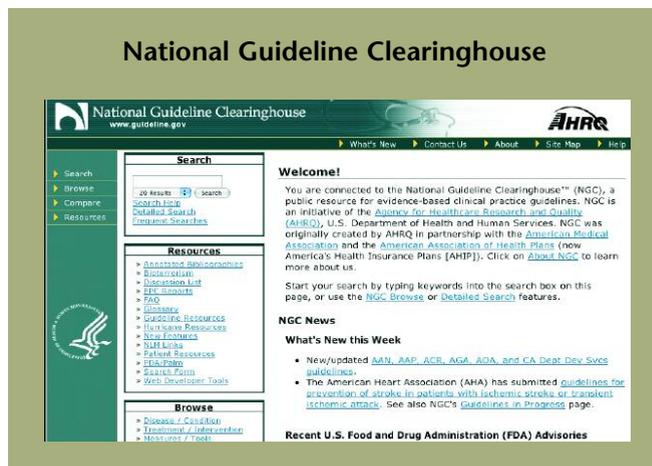
Another way to limit search results effectively is to use the “Clinical Queries” filters, which can be found on the left side-bar. Here the user will be prompted to Search by Clinical Study Category, which in-

in that particular paper. If the user needs to locate the full article, he or she can click on “Links,” then “Link Out,” which will provide access to online full text providers, as well as libraries holding the journal.

Many health sciences libraries will allow access to their collections, and alumni also may be supported in their research by their affiliated institutions. If users want to find out if there is a health sciences library in their area, they can go to the National Library of Medicine’s MedlinePlus, (<http://www.medlineplus.gov/>) and click the link for “Other Resources” for a listing of libraries, local resources, and more.

National Guideline Clearinghouse www.guideline.gov/

What if someone is specifically seeking clinical practice guidelines? There is no better place to search for—and find—this type of information than the National Guideline



Clearinghouse (NGC) database offered by the Agency for Healthcare Research and Quality (AHRQ). Summaries and links to the full text provide a wealth of authoritative information. (Contact information on obtaining print copy is provided if no electronic version is available.)

The layout of this site is clean and easy to navigate. Enhancements, including an assortment of display options, a “My Collection” cubby, a detailed search option

featuring numerous criteria, and a guideline comparison tool improve its utility. One can search specific terms, perform a detailed search, or browse by category such as Disease/Condition, or Treatment/Intervention. For example, putting the word “Alzheimer” (Tip: Databases can be particularly quirky when it comes to punctuation, so in diseases named after persons, try the name alone), this search yields a result of 34 related guidelines, spanning a wide extent of guidelines relating to Alzheimer’s and other dementia. Parameters for screening, diagnosis, caregiving, and treatment have been developed by well-respected and diverse groups including state medical societies, research institutions, hospitals, and national and international professional organizations.

ADEAR, the Alzheimer’s Disease Education & Referral Center
www.alzheimers.org

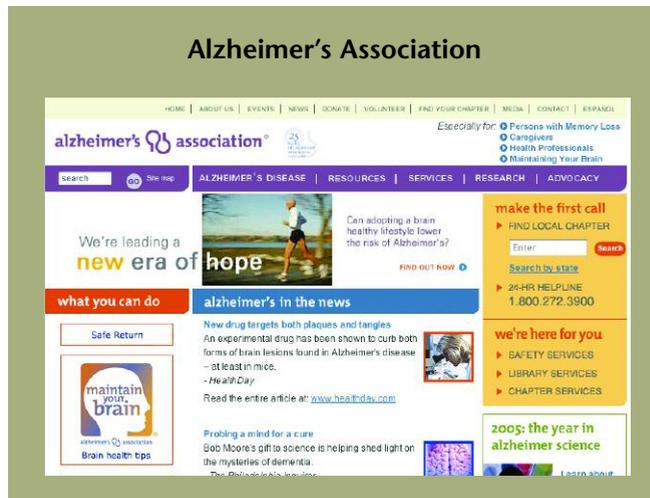
ADEAR provides “comprehensive Alzheimer’s disease (AD) information and resources from the U.S. Government’s National Institute on Aging (NIA).” Users will find a repository of information geared to

are available to access general and specific topics, including causes, symptoms, and diagnosis and treatment options pertaining to AD. Quality information for professionals includes links to the Center’s “Connections Newsletter,” training materials, and the option to sign up for automatic e-mail alerts. Should a user require additional information, a toll-free number and e-mail link are provided to facilitate contact with the Center’s information specialists. In addition, helpful links to automated searches in CHID (“Combined Health Information Database, a bibliographic database produced by agencies of the National Institutes of Health) are a mouse click away and comprise topics including medications, professional caregiving, and multimedia materials. Easy to navigate, well organized, and resource-rich, this site

rates highly as a “one-stop shopping” site that provides inroads to quickly keep you up-to-date.

The Alzheimer’s Association
www.alz.org

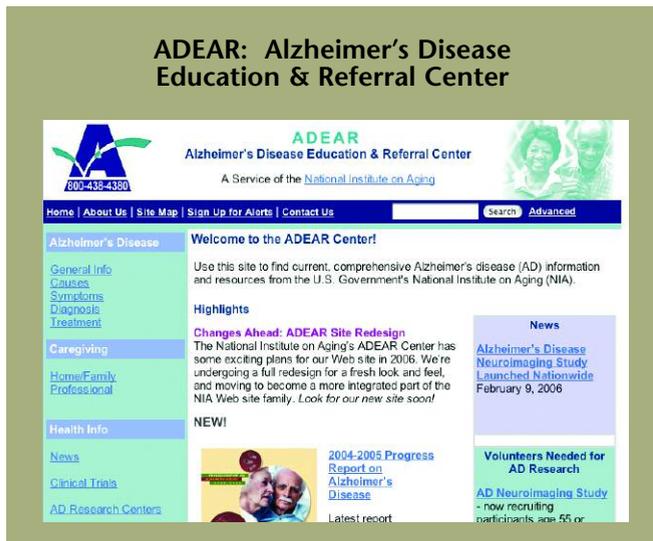
This non-profit organization actively supports Alzheimer’s research. In pursuit of its mission to find a cure, the Association has



caregivers, and researchers. While not providing comprehensive information, it does fill a niche that those working in the field of assisted living will find valuable. News and research updates, volunteer opportunities, and legislative and advocacy links are part of the practical grassroots information found here. Under “Research,” users will find links to the Association’s new peer-reviewed, interdisciplinary publication, *Alzheimer’s & Dementia: The Journal of the Alzheimer’s Association*, which covers “the entire research spectrum from laboratory science to experimental drugs and innovations in care and practice.” The table of contents and abstracts are provided free to non-subscribers, and individual articles may be purchased.

With specially tailored sections for patients, health professionals, and caregivers, users will be able to quickly identify resources addressing their needs. Clicking on the “Health Professionals” link provides general and specific information on the disease in general, plus a number of practical tools. Such tools are among this site’s strengths. For example, the “Diagnosis” area contains a detailed differential diagnosis workup with deeper links to additional information. “Treating Alzheimer’s” goes much further than the basics in addressing cognitive and behavioral

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health care professionals and caregivers across all disciplines, as well as to family members and those suffering from the disease. Quick links

established this high-quality site with the aim of bringing together the diverse community of persons suffering from memory loss, clini-

and practitioners to recognize when sleep disorders are present and to address these in a way that restores residents' ability to sleep well and maximizes their quality of life.

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Author bios to come.

References

1. Foley D, Monjan A, Brown S, et al.: Sleep complaints among elderly persons: an epidemiologic study of three communities. *Sleep* 1995; 18: 425-432.
2. Ohayon M: Epidemiology of insomnia: what we know and what we still need to learn. *Sleep Medicine Reviews* 2002; 6(2): 97-111.
3. Stepanski E, Rybarczyk B: Emerging research on the treatment and etiology of secondary or comorbid insomnia. *Sleep Medicine Reviews* 2006; 10: 7-18.
4. Morin CM, Colecchi C, Stone J, et al: Behavioral and pharmacological therapies for late-life insomnia: a randomized controlled trial. *JAMA* 1999; 281: 991-999.
5. Ancoli-Israel S, Gehrman P, Kripke D, et al.: Long-term follow-up of sleep disordered breathing in older adults. *Sleep Med* 2001; 2: 511-516.
6. Bliwise DL: Sleep in normal aging and dementia. *Sleep* 1993; 16: 40-81.
7. Coleman RM, Pollak CP, Weitzman ED: Periodic movements in sleep (nocturnal myoclonus): relation to sleep disorders. *Ann Neurol* 1979; 8: 416-421.
8. Ancoli-Israel S, Kripke DF, Klauber MR: Periodic limb movements in sleep in community-dwelling elderly. *Sleep* 1991; 14: 496-500.
9. Pollak CP, Perlick D: Sleep problems and institutionalization of the elderly. *J Geriatr Psychiatry Neurol* 1991; 4: 204-210.
10. Jacobs D, Ancoli-Israel S, Parker L, Kripke DF: Twenty-four-hour sleep-wake patterns in a nursing home population. *Psychology and Aging* 1989; 4: 352-356.
11. Lenzer J: FDA warns about using antipsychotic drugs for dementia. *BMJ* 2005; 330: 922.
12. Ancoli-Israel S, Gehrman P, Martin J, et al.: Increased light exposure consolidates sleep and strengthens circadian rhythms in severe Alzheimer's Disease patients. *Behavioral Sleep Medicine* 2003; 1: 22-36.
13. Alessi C, Yoon E, Schnelle J, et al: A randomized trial of a combined physical activity and environmental intervention in nursing home residents: do sleep and agitation improve? *J Am Geriatr Soc* 1999; 47: 784-791.

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symptoms, alternative treatment, monitoring, assessment, and more, providing information and associated tools. Residential care, insurance coverage, and coordinated care are also areas detailed in the "Health Professionals" content area.

Alzheimer's Foundation of America

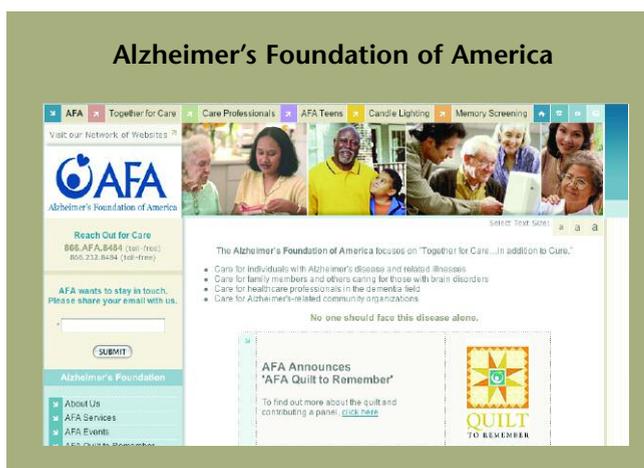
www.alzfdn.org/index.shtml

This is another organization devoted to providing "optimal care and services to individuals confronting dementia, and to their caregivers and families—through member organizations dedicated to improving quality of life." Formed in 2002—and still growing—the Foundation comprises a consortium of interdisciplinary or-

Symptoms, Treatment, Research, Statistics, and Medicare issues. In many cases, associated links are included for further information. Several of the sections, such as "Education and Care," are fairly detailed, and include practical tips and strategies for providing effective care.

Two quality publications are also available through this site. *Care Advantage*, published especially for the caregiving audience, contains pertinent, timely articles, addressing a gamut of issues. There is no charge to view current or past issues, and a free subscription is only a mouse click away. A second publication, the AFA Voices newsletter, also is available here and provides information about the Foundation and its activities, plus articles of interest to those involved in Alzheimer's and dementia care.

In order for busy clinicians, administrators, pharmacists and others to make wise use of limited time, easy access to timely, authoritative information is essential. A wealth of free information exists at their fingertips, and knowing how to navigate



organizations. With the unifying aim of improving patient care and quality of life for those afflicted, these groups collaborate across a wide range of issues and initiatives. A state-by-state directory of member organizations is available here; and it provides a convenient networking tool. Additionally, an e-mail newsletter containing current information on Alzheimer's, dementia, and related illnesses, as well as coverage of sponsored events and legal and Medicare-related issues, are offered.

Content on the Web site for non-members is organized under topical headings including Diagnosis,

the Internet provides background information to answer questions and critical evidence that can aid in decision making.

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Reference

1. Alzheimer's Disease Education and Referral Center [homepage on the Internet]. Silver Spring, MD: The Center; 1990-2006 [updated 2005 Sep; cited 2006 Feb]. Available from <http://www.alzheimers.org/generalinfo.htm#howmany>.