



SELECTED LIST OF RESOURCES FOR EARLY STAGE ALZHEIMER'S DISEASE

ALZHEIMER'S ASSOCIATION PUBLICATIONS

Basics of Alzheimer's disease: what it is and, what you can do.

http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf

Early Stage Alzheimer's: If you have Alzheimer's disease: what you should know, what you should do.

http://www.alz.org/national/documents/brochure_ifyouhave_earlystage.pdf

Know the 10 Signs

Web portal with access to multiple resources on early stage AD

http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp

Partnering With Your Doctor: A Guide for Persons with Memory Problems and Their Caregivers (20 pages)

http://www.alz.org/national/documents/brochure_partneringwithyourdoctor.pdf

ARTICLES

Available at Northern California Alzheimer's Association, Lafayette and Mountain View Offices 800-272-3900

Anthony, James W, *Ideas About Alzheimer's*, from *Perspectives*, a newsletter for individuals with Alzheimer's or a related disorder. May-July 1998.

Bakowski, Kris, *Living with Alzheimer's*, from *Perspectives*, a newsletter for individuals with Alzheimer's or a related disorder. August -October, 2008.

Benefits of Exercise from *Perspectives*, a newsletter for individuals with Alzheimer's or a related disorder. May-July, 2009.

Boden, Christine: *Caring Tips From the Perspective of a Person with Dementia*. Alzheimer's Association NSW, Australia.

Bryden, Christine and Friedell, Morris: *Dementia Diagnosis-Pointing the Bone*. A Paper presented by the authors, both of whom have a dementia diagnosis, at the National Conference of the Alzheimer's Association Australia, 2001. This paper argues that the manifestation of dementia is dependent on more than simply brain pathology, and likens the trauma of diagnosis to "bone-pointing" in Aboriginal culture.

Finding Meaningful Activity from Perspectives, a newsletter for individuals with Alzheimer's or a related disorder. August -October 2007.

Morhardt, Darby: *Top 10 Ideas for Enhancing Quality of Life by Diagnosed Individuals and Families Living with Alzheimer's Disease and Related Dementia*. Alzheimer's Care Today. April/May/June 2004.

Mulliken, Carole: *A Love Letter to Caregivers*. Text of presentation by author at international conference on Alzheimer's Disease.

Mulliken, Carole: *Forgiving, Forgetting and Building a Circle of Friends*. Author's blog reflecting her early stage experience, posted on DementiaUSA.com.

The Pleasure of Pets from Perspectives, a newsletter for individuals with Alzheimer's or a related disorder. May-July 2008.

Snyder, Lisa: *The Driving Controversy – Alzheimer's and the Automobile*.

Sterin, Gloria, Ph.D., retired. *Essay on a Word: a lived Experience of Alzheimer's disease*.

Things That Help in Tough Times from Perspectives, a newsletter for individuals with Alzheimer's or a related disorder. May-July 2009.

BOOKS/BOOKLETS

Alzheimer's Association of Northern California and Northern Nevada (2008)

Help and Hope

A handbook created for, and with the input and assistance of, people diagnosed with Alzheimer's or a related disorder. Available at Northern California Alzheimer's Association, Lafayette and Mountain View Offices, 800-660-1993 or 650-962-8111.

University of Waterloo, Canada, *By Us For Us Guides* Created by people with early-stage memory loss.

Managing Triggers

Enhancing Communication

Memory Work Out

Available from the Murray Alzheimer Research and Education Program, 1-800-888-4567 x36884, www.marep.uwaterloo.ca)

Alzheimer's Society of British Columbia (2000) *Memory Problems?*

Information booklet created by people with early stage dementia, for people with early stage dementia. Available at Alzheimer Society of British Columbia, 300-828 West 8th Avenue, Vancouver, British Columbia V5Z 1E2 Ph: 604-681-6530.)

Alzheimer Society of Canada (1995) *Just For You*. Toronto, Canada

Information booklet for people diagnosed with AD. \$1.50 per copy, available at Alzheimer Canada, 1320 Young St., Ste 201, Toronto, Ontario, CANADA M4T 1X2 Ph: 416-925-3552.

Baum, Mary Kay and Baum-VanRyzin, Chris. *Traveling with Hope: Sharing Our Experiences with Memory Challenges*.

Book edited by sisters, both diagnosed with Alzheimer's, who share their story and incorporate the experience of others.

Boden, Christine. *Who Will I Be When I Die?* North Blackburn, Victoria, Australia: Harper Collins Religious, 1998.

The author, diagnosed at the age of 46 with Alzheimer's disease, later changed to frontotemporal dementia, provides an account of her experience.

Bryden, Christine (formerly Christine Boden). *Dancing with Dementia: my story of living positively with dementia*. Philadelphia, Pennsylvania: Jessica Kingsley Publishers, 2005.

Also the author of "Who Will I Be When I Die," expands upon living life with a diagnosis of dementia.

Davies, Helen D., and Michael P. Jensen. *Alzheimer's: The Answers You Need*. Forest Knolls, CA: Elder Books, 1998.

Written for people in the early stages of Alzheimer's and their caretakers. Out of print, but may be available in libraries and through Amazon.com

Davis, R., with help from Davis, B. *My Journey into Alzheimer's Disease*. Wheaton, IL: Tyndale House publishers, 1989.

A former pastor chronicles his personal spiritual and emotional journey as he experiences memory loss and confusion from Alzheimer's disease.

DeBaggio, Thomas. *Losing My Mind: An intimate look at life with Alzheimer's*. New York: The Free Press, 2002.

A 57 year old man chronicles his experience with early onset Alzheimer's disease, beginning on the day of his diagnosis.

Harris, Phyllis Braudy. *The Person with Alzheimer's disease: pathways to understanding the experience*. Baltimore, MD: Johns Hopkins University Press, 2002.

A collection of edited chapters covering multiple aspects of the experience of the person with dementia, often in the first person perspective.

McGowin, Diana.F. *Living in the Labyrinth: a personal journey through the maze of Alzheimer's*. San Francisco: Elder Books, c1993.

The author writes of her own experience as a person in the early stages of Alzheimer's disease.

Mobley, Tracey. *Young Hope: The broken road*. Outskirts Press, 2007.

The author, diagnosed with Alzheimer's disease at age 38, chronicles her journey with Alzheimer's disease including the impact on her role of wife, mother and advocate for herself and others.

Raushi, Thaddeus, Ph. D. *A View From Within: Living with early onset Alzheimer's*. Northeastern NY Chapter, Alzheimer's Disease and Related Disorders Association, Inc. 2001.

To order: (800) 303-2218. The author has early stage, early onset Alzheimer's disease as well as other life challenging illness. This book chronicles his experience in living with the frustrations that Alzheimer's disease brings, while continuing to live life fully.

Rose, Larry. *Show Me the Way to Go Home*. Forest Knolls, CA. Elder Books, 1996.

The author, diagnosed at the age of 54, writes of his day to day experiences in coping with Alzheimer's disease.

Rose, Larry. *Larry's Way: Another look at Alzheimer's from the inside*. Lincoln, NE: iUniverse, 2003.

The author continues to provide details of how his life has changed since his diagnosis. His personal relationships and challenges are described, as well as how he copes with the changes Alzheimer's brings.

Simpson, Robert and Anne. *Through the Wilderness of Alzheimer's: A guide in two voices*. Minneapolis, MN: Augsburg, 1999.

The authors share their experience of Bob's younger onset Alzheimer's disease through their individual perspectives, using journal entries, conversations, letters and prayers.

Snyder, Lisa. *Speaking Our Minds: Personal reflections from individuals with Alzheimer's disease*.

The author skilfully reports on her conversations with individuals diagnosed with Alzheimer's disease.

Taylor, Richard. *Alzheimer's from the Inside Out*. Baltimore, MD: Health Professions Press, Inc., 2007.

The author, a former psychologist, courageously shares his account of how his life is affected by an Alzheimer's diagnosis at age 61.

VIDEOS

Alzheimer's Disease: Inside Looking Out. Chicago, IL.

18- minute video featuring people with early stage AD who participate in support groups and their families. Ph: 1-800-779-8491.

Early Onset Memory Loss: A conversation with Letty Tennis. Durham, NC: Duke University Medical Center, Joseph and Kathleen Bryan Alzheimer's Disease Research Center, c1992.

1 videocassette, 22 minutes.) Call the Alzheimer's Association, National office (800) 272-3900 Call no.: WM 220 VC no. 82 1992.

Early-Stage Advisory Group Highlights (video clip)

Chicago, IL: Alzheimer's Association National Office; action@alz.org channel.

3-minute montage featuring interview clips from people with early stage Alzheimer's and their families.

<http://www.youtube.com/actionalz#p/u/10/nf6PEuLvJxw>

Forget Me Never. New York: Filmmaker's Library, 1995.

1 videocassette, 15 minutes. ABC/Primetime Live interview with Diana Friel McGowin) Call the Alzheimer's Association, National office (800) 272-3900. Call no.: WM 220 VC no. 323 1995.

My Challenge with Alzheimer's Disease. Chicago: Terra Nova Films, 1995.

1 videocassette, 16 minutes. Beverly Wheeler describes her experiences with AD) Call the Alzheimer's Association, National office (800) 272-3900. Call no.: WM 220 VC no. 374 1995.

Primary Degenerative Dementia of the Alzheimer Type "I am not my own person anymore." St. Louis, MO: St. Louis University Medical Center, 1998.

1 videocassette. Dr. and Mrs. Bronson share their experiences with Alzheimer's disease. Call the Alzheimer's Association, National office (800) 272-3900. Call no.: WM 220 VC no. 294 1988.

A Thousand Tomorrows: Sexuality, intimacy and Alzheimer's disease. Chicago, IL: Terra Nova Films, 1995.

Videocassette, 31 minutes. Available from Terra Nova Films, 800/779-8491. People with Alzheimer's disease and their spouses discuss the effect of Alzheimer's disease on their personal and sexual relationships.

NEWSLETTERS

Alzheimer's Association of Northern California and Northern Nevada
Available at (800) 272-3900 or www.alz.org/norcal

Perspectives: A Newsletter for Individuals with Alzheimer's or a related disorder. La Jolla, CA: Lisa Snyder.
Available via email: lsnyder@ucsd.edu, (858) 622-5800.

Alzheimer's from the Inside Out by Richard Taylor, Ph.D. (individual living with probable Alzheimer's disease).
Available at <http://www.richardtaylorphd.com/news/>

INTERNET SOURCES

Alzheimer's Association

<http://www.alz.org>

National website. Updates on research and treatment, tips on providing care, information on programs and services at the local chapters. A search of the site using the keywords, "early stage" will produce additional resources.

<http://www.alz.org/norcal>

Website of the Northern CA & Northern NV chapter. Articles, announcements of upcoming events, support group schedules, and information about community resources.

Alzheimer's Association Message Boards/Chat Rooms

<http://www.alz.org/messageboards>

24 hour/7 day support community for people with Alzheimers, family caregivers, professional caregivers.

Alzheimer's Australia

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

Information for people with dementia and fact sheets that can be downloaded.

Alzheimer Research Forum

<http://www.alzforum.org>

This independent nonprofit organization was founded in 1996 to create an online scientific community dedicated to developing treatments and preventions for Alzheimer's disease. It is free and open to the public.

Alzheimer's Disease Education and Referral (ADEAR) Center

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

Sponsored by the national Institute on Aging (NIA), this site offers news on research and clinical trials and has a link to the Combined Health Information Database (CHID), a bibliographic service containing health education and information materials.

Alzheimer's Society, United Kingdom

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

The primary Alzheimer's resource in the UK. Includes information for the person with dementia and their caregivers. Sections for comments by people with AD and families. Includes an online discussion forum and research information.

Canadian Alzheimer Society

<http://www.alzheimer.ca>

The web site for the Canadian Alzheimer's Society has a very helpful section devoted to persons with AD.

Specific to the Early Stage Individual:

<http://www.alzheimer.ca/english/haveAD/intro.htm>

Clinical Trials

<http://www.clinicaltrials.gov>

The U.S National Institutes of Health, through its National Library of Medicine, developed this website to provide patients, family members and members of the public current information about clinical research studies.

Dementia Advocacy and Support Network

<http://www.dasninternational.org>

Includes information on advocacy, research, other dementias, and a chat room for people with early stage Alzheimer's Disease. Includes links to other sites. This resource is run primarily by people with Alzheimer's disease or a related disorder, many with a younger onset.

Family Caregiver Alliance

www.caregiver.org

www.link2care.net

Caregivers of persons with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's disease, ALS, and related brain disorders can find practical information on topics such as care planning, stress relief, and community resources. The related website, www.link2care.net, includes an e-mail based support group for caregivers in California.

For Memory

www.formemory.org

Created by sisters, both diagnosed with younger onset Alzheimer's. Provides information, links, advocacy information and contact with others.

SHORT LIST OF ONLINE CHAT/BLOG WEBSITES:

Message Boards

<http://www.alz.org>

<http://www.Dasninternational.org>

Blogs by Individuals with Early Stage Dementia

Note: information expressed in blogs is as varied as the individuals that share their experience. Please be aware that not all blog sites will appeal to all individuals.

<http://im-mike.blogspot.com>

<http://lcc-thoughtsfromtherollercoaster.blogspot.com/>

<http://www.usatoday.com/community/profile.htm?plckPersonaPage=PersonaBlog&plckUserId=1b7035cf54d97057&UID=1b7035cf54d97057>

www.wheretobud.blogspot.com (some adult themes)

<http://youngerjourney.com>

PRODUCTS

Attainment Company

www.AttainmentCompany.com

Various Products, including mentally stimulating activities and games for people with MCI and Early Dementia.

Attainment Company, Inc. (800) 327.4269.

AlzStore

www.alzstore.com

An online store featuring products designed for all degrees of dementia impairment.

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