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.

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

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)

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.


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*.


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.uwateroo.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 V52 1E2 Ph: 604-681-6530.)

Information booklet for people diagnosed with AD. $1.50 per copy, available at Alzheimer Canada, 1320 Younge 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.


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

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


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


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


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


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


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

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.


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.


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


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.


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.


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.


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


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.


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.

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.

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.

Revised 09/09