



Early Stage Books and Online Resources
Created by Individuals with Early Stage Dementia

Books Sharing the Experience of the Person with Early Stage Dementia

Baum, Mary Kay, Baum-Milius, Rosann, Baum-VanRyzin, Chris, Editors *Pathways of Hope: Living Well with Cognitive Changes*

Book edited by sisters diagnosed with dementia, includes personal stories of 12 younger onset individuals with dementia.

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.

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.

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.

O'Brien, Greg. *On Pluto: Inside the Mind of Alzheimer's.* Brewster, MA. Codfish Press, 2015.

The author is a former journalist diagnosed at the age of 59, who chronicles how his diagnosis and symptoms affect self and family. He shares information about his life, his community, and intertwines his experience in living with his diagnosis and symptoms.

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.

Smith, B and Gasby, Dan. *Before I Forget: Love, Hope, Help and Acceptance in our Fight Against Alzheimer's*. Harmony Publishers, 2016.

B. Smith is an accomplished businesswoman, celebrity chef, and author diagnosed with Alzheimer's disease. Dan Gasby, B. Smith's husband, is a television executive. Together they openly and courageously discuss how their lives have changed, and how they respond to new challenges in their life and relationship.

Snyder, Lisa. *Speaking Our Minds: What it's like to have Alzheimer's, revised edition*. Health Professions Press, 2009.

A collection of unique first-hand accounts, garnered from interviews by Ms. Snyder, of seven individuals with a dementia diagnosis.

Snyder, Lisa. *Living Your Best with Early-Stage Alzheimer's – An Essential Guide*. North Branch, MN: Sunrise River Press, 2010.

The author provides information on how to successfully cope with the challenges related to Alzheimer's while incorporating first person accounts, along with discussion questions useful for family members and early stage peer discussions.

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.

Newsletters for Individuals with early stage Alzheimer's or another dementia

Insight

<http://www.alzheimer.ca/en/bc/News-and-Events/Newsletters-and-updates/Insight>

A quarterly bulletin created by and for people with dementia, from the Alzheimer's Society of British Columbia.

Perspectives

<http://adrc.ucsd.edu/news.html>

A quarterly newsletter written for people with dementia that addresses the concerns, reflections, and coping skills of individuals with Alzheimer's disease or a related disorder. Written and edited by author Lisa Snyder, LCSW, published by the University of California, San Diego, Shiley-Marcos Alzheimer's Disease Research Center.

Short List of Online Websites

Alzheimer's Association Power+Purpose

<http://www.alzpowerpurpose.org/>

(Northern California and Northern Nevada Chapter)

Website created for individuals with early stage Alzheimer's disease. Includes information on early stage programs and services in local (Northern California and Northern Nevada) area, as well as resources, including early stage specific handouts, frequently asked questions, and helpful links.

Alzheimer's Association

www.alz.org

www.alz.org/norcal (Northern California and Northern Nevada Chapter)

The website for the Alzheimer's Association. Includes many online and local resources for the early stage individual and care partners.

Dementia Advocacy and Support Network International

<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.

Dementia Mentors

<http://www.dementiamentors.com>

Website created by people with a dementia diagnosis, for people with a dementia diagnosis. Includes the opportunity to speak with a mentor with dementia via video chat, videos, virtual social gatherings and a page with cognitive activities.

Message Boards

<https://www.alzconnected.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. Not all blog sites will appeal to all individuals.

My Journey with Alzheimer's:

<http://www.myjourneywithalzheimers.com/>

Pam M., diagnosed with Alzheimer's disease at the age of 61, is an advocate and a fund-raiser. She writes of her passion for raising awareness and making a difference, and life in general.

Creating Memories blog:

<http://creatingmemories.blogspot.com>

Kris B., diagnosed with Alzheimer's disease at the age of 46, writes of her experience in living with her disease and her participation in advocacy.

Sharing My Life with Lewy Body Dementia:

<http://parkblog-silverfox.blogspot.com/>

A 70 year old man, retired from the Navy and diagnosed with LBD in 2008, writes this award winning blog.