persons with alzheimer’s disease

a selected list of personal narratives

Persons with Alzheimer’s describe how the disease affects their lives and the coping strategies that offer them support.

The list is a reviewed collection of items prepared by the Alzheimer’s Association Green-Field Library staff. Contact your local chapter or local library for availability of the items.

On this resource list:

- Alzheimer's Association Publications
- Tips
- Articles
- Books
- Newsletters
- Videos
- Blogs
- Web Sites
- Other Dementias

Alzheimer’s Association Publications

I have Alzheimer’s: my story.
Read personal stories written by people with Alzheimer’s disease. Also visit the Tributes section on alz.org, which allows you create and update your own special Web page to share your story or the story of a loved one with your family and friends. Through your page, others can share their memories and also make online donations to help support the Alzheimer’s Association mission. You can also share your story on our Message Boards.
Voices of Alzheimer’s.
1 videocassette (83 min)
A panel of individuals with Alzheimer’s disease and family members
discuss early symptoms, the disease’s impact on their lives and their
hope for the future.
Green-Field Library Call No.: WM 220.5 DVD no.7 2003

Tips:
Identify material that may bring hours of reading enjoyment to persons
with Alzheimer’s. Visit your public library and ask to see “high interest,
low vocabulary” books in topics of interest to the person with dementia.

Search Amazon.com using the following terms:
dementia coloring book, to find coloring books that may bring hours of
entertainment to a person with Alzheimer’s.

Articles

Ellenbogen, Michael. The realities of Alzheimer’s and overcoming
Full-text: http://www.alz.co.uk
Green-Field Library does not own.

Friedell, Morris. Awareness: a personal memoir in the declining quality
of life in Alzheimer’s. Dementia: The International Journal of Social
Full-text: http://morrisfriedell.com
Green-Field Library owns.
Abstract: [http://www.tandfonline.com/doi/abs/10.1080/713649961](http://www.tandfonline.com/doi/abs/10.1080/713649961)
Green-Field Library does not own.


Abstract: [http://dem.sagepub.com](http://dem.sagepub.com)
Green-Field Library owns.

**Books**

Green-Field Library Call No.: WM 220 S561 2009

Newmark, A; Geiger, AT. *Chicken soup for the soul: living with Alzheimer's and other dementias. 101 stories of caregiving, coping, and compassion.*
Cos Cob, CT: Chicken Soup for the Soul, 2014.
Contains stories about living with the disease, including those written by alumni members of the Alzheimer’s Association National Early Stage Advisory Group. They are: Nancy King Barnes; Tracy Crump; Jean Ferratier; Jennie Ivey; Crescent LoMonaco; Jeri McBryde; Robert S. Nussbaum; and Samantha Duclox Waltz.
Green-Field Library Call No.: WM 220.75 N551 2014


DeBaggio, Thomas. *Losing my mind: an intimate look at life with Alzheimer’s.* New York, NY: The Free Press, 2002. This account was begun on the day of diagnosis and is described as an autobiography, a medical history, and a testament to the beauty of memory. Green-Field Library Call No.: WM 220.5 D286 2002


http://www.amazon.com
Green-Field Library Call No: W 85 H195 2014

The author provides a view of what it is like to have Alzheimer's disease with photographs by Nancy Andrews.
Green-Field Library Call No.: WM 220.5 H496 1998

Green-Field does not own.

The author candidly reveals her thoughts and emotions through numerous health situations before getting the accurate diagnosis of Alzheimer's disease.
Green-Field Library Call No.: WM 220.5 L478 2003.

The author, who has early-onset, offers a candid picture of the mental struggles inherent in Alzheimer's, the daily challenges that she and her family face, and how they cope.
Green-Field Library Call No.: WM 220.5 M687

Request a PDF copy at:
https://www.kickstarter.com/projects/768788456/blueriverapple/posts/96
Green-Field does not own.

O'Brien, Greg. *On Pluto: inside the mind of Alzheimer's*
South Dennis, MA: Codfish Press, 2014
Green-Field Library Call No.: WM 220.75 O13 2014

Prosch, Timothy. *The other talk: a guide to talking with your adult children about the rest of your life.*
Green-Field Library Call No: HQ 1063 P966 2014

Raushi, Thaddeus M. *A view from within: living with early onset Alzheimer's.*
Reflects the author's inner thoughts and feelings about living with Alzheimer's disease.
Green-Field Library Call No.: WM 220.5 R248 2001

Larry Rose shares his feelings and insights about having Alzheimer's disease with a positive outlook.
Green-Field Library Call No.: WM 220.5 R796l 2003

Rose, Larry. *Show me the way to go home.*
The author, diagnosed at the age of 54, writes of his day-to-day experiences in coping with Alzheimer's disease.
Green-Field Library Call No.: WM 220.5 R796 1996

Russell, Scott. *Silly Mr. Scott.*
Bloomington, IN: Inspiring Voices, 2013
Available through bookstores.
Green-Field Library does not own.
Sabat, Steven R. *The experience of Alzheimer's disease: life through a tangled veil.*
Highlighted with dialogue and interviews with persons in various stages of Alzheimer’s, this book covers topics related to communication and selfhood.
Green-Field Library Call No.: WM 220 S113 2001

Schneider, Charles. *Don’t bury me…it ain’t over yet.*
Bloomington, IN: AuthorHouse, 2006.
A former policeman and current fireman explores the first signs of the disease and the pivotal moments that contributed to the onset of his illness at age 52.
Green-Field Library Call No.: WM 220.5 S358 2006

Provides the perspective of both the person with AD and his spouse.
Green-Field Library Call No.: WM 220.5 S613 1999

Sparrow, Emma Rose.
Available on Amzon.com
Green-Field Library does not own.
Green-Field Library Call No.: WM 220 S561 2009

Seven individuals of various ages and backgrounds express their thoughts and feelings about what it is like to have Alzheimer’s disease.
Green-Field Library Call No.: WM 220.5 S675 1999

Green-Field Library Call No.: ND 237 U89 2008

The mother, a newspaper reporter, began a diary when diagnosed with Alzheimer’s disease. The diary continued until she was no longer able to read and write. The daughter took over with her artwork and some narrative.
Green-Field Library Call No.: WM 220.5 Z12 1996
Newsletters

**Insight.**
A newsletter whose content is written mostly (85%) by people with dementia.
Call: (800) 667-3742.
http://www.alzheimerbc.org
Green-Field Library does not own.

**Living with dementia.**
Exeter, Devon: Alzheimer’s Society.
Bi-monthly newsletter for people with dementia. Subscribe:
http://www.alzheimers.org.uk
Green-Field Library does not own.

**Perspectives: a newsletter for individuals diagnosed with Alzheimer’s disease.**
La Jolla, CA: Lisa Snyder, 1995-
Call (858) 622-5800
Green-Field Library owns.

Videos

**Alzheimer’s disease: inside looking out.**
1 videocassette (18 min.)
Features persons with Alzheimer’s disease sharing their experiences.
Green-Field Library Call No.: WM 220.5 DVD no.52 1994

Alzheimer’s disease: the patient’s perspective.
Baltimore, MD: Video Press, University of Maryland, School of Medicine
Green-Field Library Call No.: WM 220.5 DVD no.33 2006

**Early onset memory loss: a conversation with Letty Tennis.**
1 videocassette (22 min.)
Tennis and her husband relate how she learned about and copes on a
daily basis with memory loss due to early onset Alzheimer’s disease.
Green-Field Library Call No.: WM 220.75 DVD no.238 1992

*The longest loss: Alzheimer’s disease and dementia*
Stack, Kathy and Simons, Joyce
Washington, DC: Hospice Foundation of America, 2009
Green-Field Library does not own.

*My challenge with Alzheimer’s disease.*
1 videocassette (16 min.)
Beverly Wheeler describes in a very personal way experiences that are common to people who know they have Alzheimer’s disease. She shows that life goes on after diagnosis.
Green-Field Library Call No.: WM 220.5 DVD no.227 1995

*Stranger in the home.*
1 videocassette (25 min)
This interview with a woman who has Alzheimer’s—and who understands her diagnosis—offers a frank discussion about how it feels to experience the disease and to be told what the diagnosis is.
Green-Field Library does not own.

**Blogs**

*Written by Alumni Members of the Alzheimer’s Association National Early-Stage Advisory Group*

Bordisso, Lou
(2011)
http://alzreflection.blog.com

Bakowski, Kris
(2007)
http://creatingmemories.blogspot.com

Berry, Terry
(2013)
http://blog.alz.org/advocacy-why-it-matters
Borghoff, Jeff
(2016)
https://www.borghoff.com

Burke, Rae Lyn
(2011)
http://www.alznorcalblog.org

Ellenhogen, Michael
(2012)
http://blog.alz.org

Ferrero, Lee.
(2011)
http://blog.alz.org

Frost, Bill
(2011)
http://blog.alz.org

Fox, Kaye
(2012)
https://alzheimersspeaks.wordpress.com/2013/04/05/6701

Gillmore, Vern
(2014)
http://blog.alz.org/in-their-own-words

Guzman, Cynthia
(2014)
http://blog.alz.org/you-dont-look-like-you-have-alzheimers

Henley, Dennis
(2012)
http://blog.alz.org

Hornback, Paul
(2015)
http://www.faithfulfoggyliving.com

Kaufman, Tim
(2014)
http://blog.alz.org/i-am-more-than-my-diagnosis

Kursonis, Brian
(2017)
https://www.withalzmyheart.com
LeBlanc, Brian  
(2015)  
http://abitofbriansbrilliance.com

Lehmann, Ken  
(2013)  
http://blog.alz.org

Montana, Pam  
(2017)  
http://www.myjourneywithalzheimers.com

O’Brien, Greg  
(2015)  
https://onpluto.org/blog

Russell, Scott  
(2011)  
http://blog.alz.org

Uronis, Joan  
(2012)  
http://mariashriver.com

Warner, Charles  
(2013)  
http://blog.alz.org/making-plans-for-the-future-after-an-alzheimers-diagnosis

Wolfert, Paula  
(2014)  
http://blog.alz.org/cooking-with-alzheimers-food-family-the-nontraditional

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**Web Sites**

*By Us For Us© Guides.*  
University of Waterloo; Ontario, Canada  
PDF guides created through the Kenneth G. Murray Alzheimer Research and Education Program (MAREP) at the University of Waterloo by persons with dementia for persons with dementia. The guides are practical tools to help enhance well-being and manage daily challenges.  
http://marep.uwaterloo.ca
DASN International: Dementia Advocacy and Support Network.
“A worldwide organization by and for those diagnosed with dementia working together to improve our quality of life.”
http://www.dasninternational.org

Patient voices: Alzheimer’s disease.
Five persons with Alzheimer’s and alumni members of the Alzheimer’s Association National Advisory Group, describe what the disease means for them and how they cope. They are: Gwen Richards (2010), John Macinnes (2009), Pat VanDyke (2009), Sue Roby (2009), and Laura Mercer (2010)
http://www.nytimes.com

Picture books for those with dementia.
Lynn Palmer, Reference Librarian, Davenport Public Library
“Reading suggestions for caregivers and for those in the latter stages of dementia.”
http://libguides.davenportlibrary.com/content.php?pid=674272

Other Dementias

Boden, Christine. *Who will I be when I die?*
Christine Boden was 46 when she was diagnosed with Alzheimer’s disease. Her diagnosis has since been changed to frontotemporal dementia.
Green-Field Library Call No.: WM 220.5 B666 1998

Bryden, Christine. *Dancing with dementia: my story of living positively with dementia.*
Second book by Christine, who has married and taken the name Bryden.
Green-Field Library Call No.: WM 220.5 B666d 2005
Skloot, Floyd. *A world of light.*
Lincoln, NE: University of Nebraska Press, 2005.
Brain damage caused by a virus impairs the cognitive abilities of this author who describes how he pieces his memory back together. His mother has Alzheimer's which plays a major part in his own journey and deepens his understanding of the disease.
Green-Field Library Call No.: PS 3569 S628 2005

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**Persons with Alzheimer’s disease: a selected list of personal narratives**

A selected list of references

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