

## 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
- Useful Tip
- 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](http://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.*

Chicago, IL: Alzheimer's Association, 2003.

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

### Useful Tip

Identify material that may bring hours of reading enjoyment to persons with Alzheimer's. Visit your public library and ask to see "high interest, easy readability" books in topics of interest to the person with dementia. Also see our resource list: [Reading Material for Persons Living with Dementia.](#)

### Articles

Ellenbogen, Michael. The realities of Alzheimer's and overcoming stigma. *ADI World Alzheimer's Report*, 2012.

Full-text: <http://www.alz.co.uk>

Green-Field Library does not own.

Frank, Christopher. A patient's experience in dementia care. *Canadian Family Physician*. Jan 2017; vol. 63(1), pp. 22-26

Full-text: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5257215>

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 Research and Practice*. Oct 2002; vol. 1(3), pp. 359-366.

Full-text: <http://morrisfriedell.com>

Green-Field Library owns.

Gillies, Brenda. A memory like clockwork: accounts of living through dementia. *Aging & Mental Health*. Nov 1, 2000; vol. 4(4), pp. 366-374.

Abstract: <http://www.tandfonline.com/doi/abs/10.1080/713649961>

Green-Field Library does not own.

Halperin, Alexander "Sandy"; Brummel-Smith, Kenneth. Patient-centered care for people with cognitive impairment is possible in primary care. *Generations*. Fall 2013; vol. 37(3), pp. 87-91

Sandy Halperin, member of the Early Stage Advisory Group, Alzheimer's Association National Headquarters, 2013.

Abstract:

<https://www.ingentaconnect.com/content/asag/gen/2013/00000037/00000003/art00017>

Green-Field Library owns.

Murakami, S; Halperin, Alexander "Sandy". Alzheimer's patient feedback to complement aging and dementia. *Frontiers in Genetics*. Aug 6, 2014 [online].

<http://journal.frontiersin.org/Journal/10.3389/fgene.2014.00269/full>

Green-Field Library does not own.

Mjorud, Marit; Engedal, Knut; Rosvik, Janne, et al. Living with dementia in a nursing home, as described by persons with dementia: a phenomenological hermeneutic study. *BMC Health Services Research*. Jan 31, 2017

Full-text: <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-017-2053-2>

Green-Field Library does not own.

McKillop, James; Wilkinson, Heather. Make it easy on yourself! *Dementia*. Jun 2004; vol., 3(2), pp. 117-125.

Abstract: <http://dem.sagepub.com>

Green-Field Library owns.

## **Books**

Bakowski, K. Really early onset. IN: Maria Shriver, M , Angela Geiger, et al. *The Shriver Report*, pp. 94-95.

Chicago, IL: Alzheimer's Association, 2009.

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

Beckklenberg, MA. Early stage Alzheimer's: the fear is losing yourself. IN: Maria Shriver, M , Angela Geiger, et al. *The Shriver Report*, pp. 4-5.

Chicago, IL: Alzheimer's Association, 2009.

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

Bryden, C. *Dancing with dementia*.  
Philadelphia, PA: Jessica Kingsley, 2005  
Contents: A roller coaster journey since early 1998 – Coming out with dementia –  
Let's talk about having dementia – I know who I'll be when I die.  
Green-Field Library Call No.: WM 220.5 B666s 2005

Davis, R.. *My journey into Alzheimer's disease: a story of hope*.  
Wheaton, IL: Tyndale House, 1989.  
A former pastor chronicles his personal spiritual and emotional journey as he  
experiences memory loss and confusion from Alzheimer's disease.  
Green-Field Library Call No.: WM 220.5 D35 1989

DeBaggio, T. *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

DeBaggio, T. *When it gets dark: an enlightened reflection on life with Alzheimer's*.  
Flavored with correspondence, poetry, and quotes, Thomas DeBaggio in his second  
book goes deeper into the past with gentle observations about Alzheimer's disease  
and descriptions about his success as an herb grower.  
New York, NY: The Free Press, 2003.  
Green-Field Library Call No.: WM 220.5 D286w 2003

Ellenbogen, M. *From the corner office to Alzheimer's*.  
Seattle, WA: Amazon Digital Services, Inc., 2013.  
Green-Field Library Call No: on order

Halperin, A "Sandy;" Davidson, G; Green, D.; et al. *Becoming an activated patient:  
how to take control and enhance your level of health care*.  
Seattle, WA: CreateSpace, 2014  
Green-Field Library Call No: W 85 H195b 2014

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Henderson, Cary Smith. *Partial view: an Alzheimer's journal*.  
Dallas, TX: Southern Methodist University Press, 1998.  
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

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Hornback, Paul. *God still remembers me: devotions for facing Alzheimer's disease with faith.*

Goshen, IN: CrossBooks, 2013

Green-Field does not own.

Houston, A with Christie, J. *Talking sense: living with sensory changes and dementia.*

Sydney, AU: HammondCare, 2018

[Download](#)

Green-Field does not own.

Lee, JL. *Just love me: my life turned upside down by Alzheimer's.*

West Lafayette, IN: Purdue University Press, 2003.

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.

McNamara, N. *The Lewy body soldier*

Presents a positive approach to living with Lewy body disease.

Seattle, WA: CreateSpace, 2016

Green-Field does not own.

McNamara, N. *Me and my Alzheimer's: join me as I fight the fight of my life against this awful illness.*

Seattle, WA: CreateSpace, 2011

Green-Field does not own.

Mitchell, W. *Somebody I used to know: a memoir.*

New York, NY: Ballantine Books, 2018.

Green-Field Library Call No.: On order

Mobley, T. *Young hope.*

Hazelwood, MO: Emerald Falcon Press, [2004].

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 2007

Nelson, N. *Blue.River.Apple: an exploration of Alzheimer's through poetry.*

Blue River Apple, 2014

Request a PDF copy at:

<https://www.kickstarter.com/projects/768788456/blueriverapple/posts/962233>

Green-Field does not own.

O'Brien, G. *On Pluto: inside the mind of Alzheimer's*

South Dennis, MA: Codfish Press, 2014

Green-Field Library Call No.: WM 220.75 O13 2014

Oliver, K. *Dear Alzheimer's: a diary of living with dementia.*

London, UK: Jessica Kingsley, 2019.

An activist and speaker with direct insight into what it is like to live with dementia day-to-day.

Green-Field does not own.

Prosch, T. *The other talk: a guide to talking with your adult children about the rest of your life.*

New York, NY: McGraw Hill Education

Green-Field Library Call No: HQ 1063 P966 2014

Quaid, K. *Lewy body dementia survival & me: book written by a patient with Lewy body dementia diagnosed at 53.*

Seattle, WA: CreateSpace, 20128.

Green-Field does not own.

Raushi, TM. *A view from within: living with early onset Alzheimer's.*

Albany, NY: Northeastern New York Chapter, Alzheimer's Association, 2001.

Reflects the author's inner thoughts and feelings about living with Alzheimer's disease.

Green-Field Library Call No.: WM 220.5 R248 2001

Rohra, H. *Dementia activist: fighting for our rights*

A person living with young onset Lewy body dementia explains changes and challenges in her every day and shares tips on living well with dementia.

London, UK: Jessica Kingsley, 2016.

Green-Field does not own.

Rose, L. *Larry's way: another look at Alzheimer's from the inside.*

New York, NY: iUniverse, Incorporated, 2003.

Larry Rose shares his feelings and insights about having Alzheimer's disease with a positive outlook.

Green-Field Library Call No.: WM 220.5 R796I 2003

Rose, L. *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.

Green-Field Library Call No.: WM 220.5 R796 1996

Russell, S. *Silly Mr. Scott.*

Bloomington, IN: Inspiring Voices, 2013

Available through bookstores.

Green-Field Library does not own.

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Sawasky, J. *Dancing with Elephants.*

Toronto, OM: Red Canoe Press, 2017

Green-Field Library Call No.: WM 200 S271 2017

Schneider, C. *Don't bury me...it ain't over yet.*

Bloomington, IN: AuthorHouse, 2006.

A former policeman and current fireman explore 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

Shorthouse, T. *I am still me.*

Bloomington, IN: AuthorHouse, 2017.

Dementia is not the main focus but includes a wide variety of poems about life, nature, and stories within a poem.

Green-Field Library does not own.

Simpson, R. *Through the wilderness of Alzheimer's: a guide in two voices.*

Minneapolis, MN; Augsburg: Northam; Roundhouse, 1999.

Provides the perspective of both the person with AD and his spouse.

Green-Field Library Call No.: WM 220.5 S613 1999

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Snyder, L. *Speaking our minds: personal reflections from individuals with Alzheimer's*.  
Baltimore, MD: Health Professions Press, 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 2009

Steel, L. *See with your eyes – hear with your heart: expressions of Alzheimer's disease*.  
Twin Falls, ID: Marian Steel, LLC  
Book of artistic illustrations produced by LaVar Steel, person living with dementia.  
Green-Field Library Call No: WM 220.5 S813 2018

Steffen, M. Slowing Alzheimer's down. IN: Shriver, M, Geiger, AT; Morgan, O; Meyer, K; et al. *The Shriver Report*, pp. 88-89.  
Chicago, IL: Alzheimer's Association, 2009.  
Green-Field Library Call No.: WM 220 S561 2009

Summitt, P.; Jenkins, S. *Sum it up: 1,098 victories, a couple of irrelevant losses, and a life in perspective*.  
New York, NY: Crown Archetype, 2013  
Green-Field does not own

Swaffer, K. *What the hell happened to my brain?*  
London, UK; Jessica Kingsley, 2016.  
Green-Field Library Call No.: WM 220.75 S971 2016

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Utermohlen, W. *Portraits from the mind: the works of William Utermohlen – 1995 – 2000: a retrospective of the artist's work before and after diagnosis with Alzheimer's disease* / presented by the Alzheimer's Association Salt Lake City, UT: Myriad Pharmaceuticals, 2008  
Green-Field Library Call No.: ND 237 U89 2008



Zabba, KH. *Painted diaries: a mother and daughter's experience through Alzheimer's.*

Minneapolis, MN: Fairview Press, 1996.

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.*

Vancouver, BC: Alzheimer Society of British Columbia.

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.*

UC San Diego, Shiley-Marcos ADRC

<https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/perspectives-newsletter>

## Videos

*Alzheimer's disease: inside looking out.*

Chicago, IL: Terra Nova Films, 1994.

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

*Dementia from the inside*

London: UK: Social Care Institute for Excellence

<https://www.understandtogether.ie/news-and-events/news/video-aims-to-show-what-dementia-feels-like.html>

*Early onset memory loss: a conversation with Letty Tennis.*

Durham, NC: Duke University, 1992.

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.

*Stranger in the home.*

Toronto, Ont.: Alzheimer Society of Canada, 1995.

1 videocassette (25 min).

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>

Blough, Rod  
(2017) ?  
<http://www.sunnysideofalzheimers.com>

Borghoff, Jeff  
(2016)  
<https://www.borghoff.com>

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

Ellenbogen, 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>

Guzman, Cynthia  
(2014)  
<http://blog.alz.org>

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

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

Kaufman, Tim  
(2014)  
<http://blog.alz.org>

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>

### **Blogs – general**

DementiaDaze.com  
Laurie  
<https://dementiadaze.com/about-me>

Early onset Alzheimer's Blog  
Linda Fisher  
<http://earlyonset.blogspot.com>

Hear our voices: people with dementia in their own words.

Alzheimer's Society

<https://www.alzheimers.org.uk/blog/hear-our-voices-people-dementia-their-own-words>

Sharing my life with Lewy body dementia

Silverfox

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

WhichMeAmIToday

Wendy Mitchell

<https://whichmeamitoday.wordpress.com>

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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*

Closely affiliated with Dementia Action Alliance below

<https://www.dasninternational.org>

*Dementia Action Alliance*

"We: educate about stigma and misperceptions; support well-being and a focus on the whole person rather than just their dementia symptoms"

<https://daanow.org/hear-our-voices>

*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>

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

A selected list of references

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Updated 2019