Books by People Living With Dementia

Special thanks to Dementia Alliance International (DAI) for allowing the National Council of Dementia Minds to share “Books By People Living With Dementia.” As part of Dementia Awareness Month 2021, DAI members Christine Thelker and Kate Swaffer created this list of books written and published by people living with dementia. To learn more about DAI visit https://www.dementiaallianceinternational.org/.

“In contrast to the vast number of books written by family members or care partners, we could only find about 3 dozen written by people with dementia. However, they are a unique and honest view into the real lives, of real people diagnosed with dementia.

If you know any that have been missed, please let us know!

Listed in chronological order, to highlight how long people with dementia have been speaking out:

My Journey into Alzheimer's Disease, by Robert Davis, 1989

Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's, by Diana Friel McGowin, 1994

Losing my Mind: An Intimate Look at Life with Alzheimer’s, by Thomas DeBaggio, 2002

When it Gets Dark: An Enlightened Reflection on Life with Alzheimer's, by
Thomas DeBaggio, 2003


*Dancing with Dementia: My Story of Living Positively with Dementia*, by Christine Bryden, 2005

*Alzheimer's from the Inside Out*, by Dr. Richard Taylor, 2006

*Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's*, by Diana Friel McGowen, 2011

*Silent Voices: My Battle With Alzheimers Rages on*, by Norman McNamara, 2011

*Who will I be when I die?*, by Christine Bryden, 2012

*From the Corner Office to Alzheimer's*, by Michael Ellenbogen, 2013


*Nothing About Us, Without Us!: 20 Years of Dementia Advocacy*, by Christine Bryden, 2015

*Before I Forget: How I Survived a Diagnosis of Younger-Onset Dementia at 46*, Christine Bryden, 2015

*What the hell happened to my brain?: Living Beyond Dementia*, by Kate Swaffer, 2016

*Diagnosed With Alzheimers Or Another Dementia: A practical guide to what’s next for people living with dementia, their families and care partners*, by Kate Swaffer & Lee-Fay Low, 2016

Dementia Activist: Fighting for Our Rights, by Helga Rohra, 2016

Five minutes of amazing: my journey through dementia, by Chris Graham, 2016

The Lewy Body Soldier: The Lewy Body Soldier, by Norman McNamara, 2016

Walk the walk, Talk the talk, by Keith Oliver, 2016

Before I Forget: Love, Hope, Help, and Acceptance in Our Fight Against Alzheimer's, B. Smith, Dan Gasby, et al., 2016

The Dancing Dementia Dude: An Urgent Conversation Between Dementia Folks, Care Partners and God, Dallas Dixon, 2017

Memory's Last Breath: Field Notes on My Dementia, by Gerda Saunders, 2017

"Was zum Teufel geschieht in meinem Hirn?: Ein Leben jenseits der Demenz, by Kate Swaffer, 2017

Dancing with Elephants: Mindfulness Training For Those Living With Dementia, Chronic Illness or an Aging Brain (How to Die Smiling Book 1), by Jarem Sawatsky, 2017

Somebody I Used to Know: A Memoir, by Wendy Mitchell, 2018

Will I Still Be Me?: Finding a Continuing Sense of Self in the Lived Experience of Dementia, Christine Bryden, 2018

認知症を乗り越えて生きる: “断絶処方”と闘い、日常生活を取り戻そう, by Kate Swaffer, 2017

A Doctor's Personal Journey of Hope, by Dr Jennifer Bute, 2018

Talking Sense: Living with Sensory Changes and Dementia, by Agnes Houston, 2018

Dear Alzheimer's: A Diary of Living with Dementia, by Keith Oliver, 2019
Dementia Strategies, Tips, and Personal Stories, by Myrna Norman, 2020

For this I am Grateful: Living well with dementia, by Christine Thelker, 2020

Slow Puncture: Living Well With Dementia, by Peter Berry, 2020

Sean’s Story: My five tips for living with frontotemporal dementia, by Sean Kelly, 2020

Dignity & Dementia: Carpe Diem: My journals of living with dementia, by Mary Beth Wighton, 2021

There are now many books that include chapters authored by people with dementia, e.g.

Dementia Rehabilitation, 1st Edition: Evidence-Based Interventions and Clinical Recommendations, Edited by Lee-Fay Low & Kate Laver, chapter 1, Rehabilitation: a human right for everyone, by Kate Swaffer.

The Routley Handbook of Disability Activism, Edited by Maria Berghs, Tsitsi Chataika, Yahya El-Lahib, Kudakwashe Dube, chapter 10, Dementia as a Disability, by DAI members, Kate Swaffer, Brian LeBlanc, Peter Mittler. This book was the 2019 Outstanding Handbook - Social Sciences - Award Winner."