# Recommended Reading from The Dementia Sherpa Bookshelf

People often ask what books I recommend, so I made a list...with commentary, of course.;)

I've organized the books into four categories. Several of these books fit into more than one category, but I've only listed them once. Don't mistake a book under the podcast categories as something I'm recommending just because they were featured on the show. Unless I believe an author has something of value to offer the audience, they never even make it to the show.

- 1. Featured on The Alzheimer's Podcast 2020
- 2. Featured on The Alzheimer's Podcast 2019
- 3. Some Classics
- 4. A Few Personal Faves

A cautionary note: Some books contain information about Medicare/Medicaid and/or Medicaid planning that is now out of date or incomplete. Please consult an elder law attorney or financial planner for the most current and accurate information.

Affiliate disclosure: As an Amazon Associate I earn a small commission from qualifying purchases, <u>at no/zero/none/nada additional cost to you.</u> If you've heard/read/seen something helpful on <u>The Alzheimer's Podcast</u> or the <u>Dementia Sherpa blog</u> or <u>YouTube channel</u>, purchasing through the links below is a way to show support (thank you!).

#### Featured on The Alzheimer's Podcast 2020

Any Game for Any Brain, by Mikaela Wilson & Spencer Coombe. Mikaela & Spencer are featured on *The Alzheimer's Podcast* episode #145: "We can laugh and have fun and be silly" discussing the book, its inspiration, and why having fun is important for both your person and you.

Radical Alignment: How to Have Game-Changing Conversations That Will Transform Your Business and Your Life, by Alexandra Jamieson & Bob Gower. Alexandra & Bob talked to us on episode #142: The All-In Method for Difficult Conversations, in which they walk us through how AIM provides a framework for difficult conversations and what having one sounds like.

Donna Thomson is the co-author (with Dr. Zachary White) of <u>The Unexpected Journey of Caring: The Transformation from Loved One to Caregiver</u>, which she discusses in episode <u>#134: The Unexpected Journey of Caring</u>. If you're looking for people who *get it*, check out this book.

A soulful meditation on care partnering, <u>The Four Walls of My Freedom: Lessons I've Learned From a Life of Caregiving</u> by Donna Thomson, is one of the best books I read in 2020. Donna goes deep in discussing her experiences on episode <u>#135</u>: "Where isolation and solitude come in handy". Just the sound of her voice is soothing.

<u>I Love Someone with Dementia...So Why Am I Losing My Mind? A Practical Guide</u> by Beth Friesen (a fellow Certified Dementia Practitioner) is the result of Beth's experiences during her mother's battle with dementia, when Beth realized that if she--a professional familiar with both the system and the lingo--was struggling, others must be too. Beth talks more about what the experience taught her and the passion it ignited within her in episode #125: <u>Using A Placement Agent AKA Your Secret Weapon</u>.

If you've ever wished you could create joy-filled visits for your person, well...<u>Creating Joy-Filled Visits in the Midst of Alzheimer's: A step by step guide for engaging fun for family caregivers</u> by Julie Bigham is definitely the book for you. Julie's an award-winning activities professional with decades of experience. Her first book is <u>Gifts from Gramps: My Joy-Filled Journey from Granddaughter to Grandmother</u>, and she discusses both on episode #133: Joy-Filled Visits...in Your Own Home.

Dr. Deborah Bier's book, <u>From Crisis to Calm: A Family Guide to Handling Dementia Behavior</u>, gives you concrete steps in alignment with what we talk about in The Dementia Sherpa tribe. As a person with a traumatic brain injury (TBI), she brings unique insight. And she discusses how staying stuck in shame from making mistakes can keep us from great care partnering in episode <u>#127: Learning What You Need to Learn</u>.

## Featured on The Alzheimer's Podcast 2019

My UK soul sister, Dr Jane Mullins, brings a wealth of experience, knowledge, and practicality to <u>Finding the Light in Dementia: A Guide for Families, Friends and Caregivers.</u> For even more (in her lovely Welsh accent), check out episode #120: <u>Finding the Light in Dementia</u>.

Looking for <u>Sanctuary in the Midst of Alzheimer's</u>? Dr Elizabeth Shulman explains how in her book and talks about what led her to write it in episode <u>#105</u>: <u>Sanctuary in the Midst of Alzheimer's</u>.

Jamie Tyrone has two copies of the ApoE-4 gene, which puts her at a 91% lifetime risk of getting Alzheimer's disease, along with 2% of the US population. She's also the co-author, with Dr Marwan Sabbagh, of Fighting for My Life: How to Thrive in the Shadow of Alzheimer's. Jamie discusses how she became an advocate and author in episode #104: I Call it a Gift. She shares personal care partnering stories in episode #100: Enjoy Us in the Moment.

<u>Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End</u> by Dr Tia Powell discusses her personal experience with her mom, the history of how people living with dementia have historically been treated by society, and shares a vision of how things can be both different and better. If that doesn't already convince you it's a must-read (it is!), check out <u>episode #87</u> (in which I go from Dr Powell skeptic to total fangirl) and <u>episode #88</u> for more from Dr Powell.

## **Some Classics**

As you might imagine, there are lots of books that could fall into this category. This isn't a definitive list, but they're all on my bookshelf.

The 36-Hour Day, sixth edition: The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Other Dementias, and Memory Loss (A Johns Hopkins Press Health Book)

Paperback Caution! Do not read this book as a novel. Rather, think of it as a handy encyclopedia when something comes up.

Jolene Brackey shows you how to create moments of joy. And as we often say around here, joy isn't optional; it's *necessary*. <u>Creating Moments of Joy Along the Alzheimer's Journey: A Guide for Families and Caregivers, Fifth Edition, Revised and Expanded Fifth Edition, Revised and Expanded.</u>

<u>Alzheimer's from the Inside Out</u>. Dr Richard Taylor's essays explain what it's like to have, as he calls it, "senile dementia, probably of the Alzheimer's type." I've used sections of it for staff training for years.

<u>I'm Still Here: A New Philosophy of Alzheimer's Care</u>. John Zeisel speaks my language, focusing on relationship building, communication, environmental cues, and more. Plus, the guy who wrote *Emotional Intelligence* calls it "a must-read."

<u>Dementia Beyond Drugs: Changing the Culture of Care</u>. I think I highlighted darn near every word the first time I read this. Dr Allen Power is a pioneer in how people living with dementia are cared for in congregate settings. Every time someone tells me drugs are the answer, it's a tell they haven't read this book.

<u>Dementia Beyond Disease: Enhancing Well-Being</u>. Dr Powers's follow up to *Dementia Beyond Drugs*.

What's Happening To Grandpa? Maria Shriver had both a dad living with Alzheimer's disease and young kids she needed to explain it to, so she wrote this book.

Along the same lines as *What's Happening to Grandpa?*, <u>Grandma and Me: A Kid's Guide for Alzheimer's and Dementia</u> is for young kids who need an assist in understanding what's going on.

A Dignified Life: The Best Friends™ Approach to Alzheimer's Care: A Guide for Care Partners by Virginia Bell & David Troxel. by Virginia Bell & David Troxel. This is the seminal book in dementia care. First published in 2002, it was one of the first things I read when I realized I didn't have a clue but needed to get better fast. Successful memory care communities—those that have high resident, family, and staff satisfaction and tend to win awards and have long wait lists—are based on The Best Friends™ Approach. And yes, I have fangirled David at a live event.

<u>Learning to Speak Alzheimer's A Groundbreaking Approach for Everyone Dealing with the Disease</u>. Joanne Koenig Coste's book came out a couple years after *A Dignified Life*, and delivered yet another nail in the coffin of the "reality orientation" nonsense that was so prevalent in long-term care at the time.

<u>Passages in Caregiving Turning Chaos Into Confidence</u>. Gail Sheehy weaves her own story of caring for her husband into the comprehensive help she offers in this book. It's so comprehensive, in fact, that I used to teach an 8-week course based on it. This isn't specific to dementia, though.

<u>Coach Broyles' Playbook for Alzheimer's Caregivers</u> is my recommendation if you 1) have only 10 minutes to learn anything about Alzheimer's or dementia and/or 2) you're the type of person who isn't so much interested in the why of it all, but more the 'What do I do about it? type. At the time it was first published, I was a memory care director working for a large national company that snapped this up by the case. I handed out *Playbook*s like Gideons hand out Bibles, and still always had people telling me they'd heard from a friend I had a book they should get....

## A Few Personal Faves

<u>Still Alice</u>, Lisa Genova's masterpiece debut novel, is the only book ever endorsed by the Alzheimer's Association and it's better than even Julianne Moore's acting. A bold claim, I know, but it's the truth. The first sentence will stay with you for a long, long time. And yeah, I fangirled Lisa too at a live event, unexpectedly bursting into tears because I was so overwhelmed in the presence of someone who so viscerally *gets it*.

A Deep Breath of Life doesn't have anything at all to do with dementia, but it's my morning go-to for getting centered.

In <u>Remembrance of Things Present: Making Peace with Dementia</u>, poet and playwright Peter Maeck takes us through a brief but touching photographic journey accompanied by his words.

And of course the <u>2021 Monthly + Daily Planner for Dementia Care Partners with Pro Tips from The Dementia Sherpa</u>. It's a planner, it's a journal, it's a reminder I'm rooting for you. <3

And just in case you missed it, here are three complimentary pdf downloads I've created for care partners over the years:

<u>Words Matter: The Dementia Sherpa's Guide to Dementia-Friendly & Preferred Language</u>. Because words really do matter and we've got to eliminate the stigma our people face.

<u>Talking to Professionals Guide with Doctor Appointment Template</u>. This also includes a glossary decoding common geek-speak phrases in long-term care and scripts to use in common situations.

<u>How to Know When it's Time for Memory Care</u> gives you some tools to help answer one of the toughest questions care partners face.