

A “Baker’s Dozen” Books for Your Consideration

1. ClergyAgainstAlzheimer's Network, *Seasons of Caring: Meditations for Alzheimer's and Dementia Caregivers*. CreateSpace, 2014.

Seasons of Caring offers the gifts of hope, encouragement, compassion and empathy to those on the difficult journey of caring for loved ones with Alzheimer's disease and other dementias. The book is organized around themes of seasonal transition, with each of the four seasons paralleling the various stages of life. The original writings by seventy-two authors representing a great diversity of spiritual traditions range from thoughtful meditations to poignant personal stories, moving poems and meaningful songs. Each meditation begins with an inspirational quote and ends with a prayer or words of encouragement.

2. ClergyAgainstAlzheimer's Network and Richard L. Morgan, Ph.D., *Leader's Guide for Seasons of Caring: Meditations for Alzheimer's and Dementia Caregivers*. Create Space, 2015.

The *Leader's Guide* is a companion volume to be used with *Seasons of Caring* by facilitators of support groups. Nationally renowned author, retired pastor, and founding member of ClergyAgainstAlzheimer's, Dr. Richard L. Morgan has drawn upon over 60 years of pastoral care for those with Alzheimer's, including his service as a hospice chaplain and a longtime facilitator for Alzheimer's support groups to write the *Leader's Guide* to help other facilitators in their groups. The *Leader's Guide* takes the original themes and metaphors of *Seasons of Caring* and delves deeper into caregiver concerns and stories, such as communicating with a loved one, dealing with guilt and forgiving oneself, using art and music to connect with a loved one and maintain relationship, and facing the difficult issues of death and grieving.

3. Kathy Fogg Berry, *When Words Fail: Practical Ministry to People with Dementia and Their Caregivers*. FaithHappenings Publishers, 2016.

More than 5.4 million Americans are living with Alzheimer's disease today and more than 15 million Americans provide unpaid care for those with Alzheimer's and other dementias. For faith communities, this represents a crucial opportunity for ministry and practical care - one that many aren't adequately prepared for.

All too often, as memories and abilities fade and the capacity to communicate weakens, those with dementia and their caregivers find themselves neglected or forgotten by the larger community. Despite good intentions, when words begin to fail for people with dementia, words also fail for those around them, who don't know what to say or what to do. But, like all of us, those suffering from dementia still need human connection and spiritual nourishment, and their caregivers need our understanding and support.

Rev. Kathy Fogg Berry is eminently qualified to address the many challenges presented by this disease and to offer practical suggestions, gleaned from years of ministering to people in various stages of dementia, for ways to meet the emotional, physical, social and spiritual needs of those impacted. In easy to understand terms, Rev. Berry provides information about each stage of dementia and offers constructive ways that individuals and the faith community at large can respond and minister to families in life-giving ways. In Chapter 9 of "When Words Fail" Rev. Berry lays out a church-wide response to this growing need. She urges us to use available resources to create and nurture dementia friendly congregations where members experiencing these diseases could stay engaged and included and not feel isolated and excluded. The case studies and personal examples help to alleviate our initial fear of serving persons living with dementia when we don't know what to expect or how to react. Rev. Berry reassures us that we don't have to interact perfectly; we just need to show up and be present.

"When Words Fail" is a manifesto for action and a must read for clergy, chaplains, laity, and faith organizations involved in caring for families impacted by dementia.

4. Louise Carey, *The Hedge People: How I Kept My Sanity and Sense of Humor as an Alzheimer's Caregiver*. Beacon Hill, 2009.

Caring for those with Alzheimer's can be emotionally depleting. Frustration often dominates the day as you try to bridge the gap between "real life" and a person who has lost touch with reality. Combine that with grief over the loss of the person you used to know and fear of what is to come and it seems as though life will never see laughter and joy again. But it does. In her collection of true stories, author Louise Carey provides perspective and techniques for treating loved ones with dementia with respect while also finding humor in the often trying situations encountered by the caregiver. Filled with humor, warmth, and encouragement, each chapter includes a caregiver prayer, a leading question for reflection, and space to journal.

5. Meryl Comer, *Slow Dancing with a Stranger: Lost and Found in the Age of Alzheimer's*. HarperOne, 2014.

Meryl Comer's *Slow Dancing With a Stranger* is a profoundly personal, unflinching account of her husband's battle with Alzheimer's disease that serves as a much needed wakeup call to better understand and address a progressive and deadly disease. When Meryl's husband was diagnosed with early onset Alzheimer's in 1996, she watched uncomprehendingly as the man who headed hematology and oncology research at the National Institutes of Health started to misplace important documents and forget clinical details that had once been cataloged encyclopedically in his mind. Detailing the daily realities and overwhelming responsibilities of caregiving, she sheds intensive light on this national health crisis, using her personal experiences—the mistakes and the breakthroughs—to put a face to an often misunderstood disease.

6. Joanne Koenig Coste, *Learning to Speak Alzheimer's: A Ground-breaking Approach for Everyone Dealing with the Disease*. Mariner Books, 2004.

Thirteen years after it was first released, this book remains a classic. Revolutionizing the way we perceive and live with Alzheimer's, Joanne Koenig Coste offers a practical approach to the emotional well-being of both patients and caregivers that

emphasizes relating to patients in their own reality. Her accessible and comprehensive method, which she calls “habilitation,” works to enhance communication and has proven successful with thousands of people living with dementia. *Learning to Speak Alzheimer’s* also offers hundreds of practical suggestions relating to such things as making meals and bath times as pleasant as possible, adjusting room design for the patient’s comfort, and dealing with issues of wandering, paranoia, and aggression.

7. Nancy L. Mace and Peter Rabins, *The 36 Hour Day: A Family Guide to Caring for People with Alzheimer’s Disease, Other Dementias, and Memory Loss in Later Life*. John Hopkins, 2007 (5th edition).

Originally published in 1981, *The 36-Hour Day* was the first book of its kind. Years later, with dozens of other books on the market, it remains the definitive guide for people caring for someone with dementia. Now in a new and updated edition, this best-selling book features thoroughly revised chapters on the causes of dementia, managing the early stages of dementia, and finding appropriate and safe living arrangements for the person who has dementia when home care is no longer an option. A perennial best seller, and for good reason.

8. Richard L. Morgan, *At the Edge of Life: Conversations When Death is Near*. Upper Room Books, 2014.

Drawing on 60 years of experience as pastor, hospice chaplain, volunteer, and friend to dying persons, Richard Morgan offers perspective and advice to people coping with a family member, friend, or patient who is approaching the time of death. In only 72 pages, Dr. Morgan’s wise counsel takes us from accepting our own mortality and the impending death of someone we care about through “making preparations,” “finding closure,” and “dying moments.” His use of personal stories and scripture lead into reflective questions and prayer. The result is a sense of peace that gives readers confidence as companions to the dying.

9. Greg O’Brien, *On Pluto: Inside the Mind of Alzheimer’s*. Codfish Press, 2014.

This is a book about living with Alzheimer’s, not dying with it. It is a book about hope, faith, and humor. Greg O’Brien, an award-winning investigative reporter,

was diagnosed with early-onset Alzheimer's 8 years ago at age 59. Acting on long-term memory and skill coupled with well developed journalistic grit, the author decided to tackle the disease and his imminent decline by writing frankly about his journey. Greg is a master storyteller whose story is unvarnished, wrenching, and soul searching. Told with candor and courage, *On Pluto: Inside the Mind of Alzheimer's* is a trail-blazing roadmap for a generation - both a "how to" for fighting a disease, and a "how not" to give up!

10. Daniel C. Potts, M.D. and Ellen Woodward Potts, *A Pocket Guide for the Alzheimer's Caregiver*. Dementia Dynamics LLC, 2011.

This book is the place to turn for initial information and perspective on Alzheimer's disease, and to return for practical advice as problems arise. Dr. Potts is a noted neurologist, author, educator, and champion of those with Alzheimer's and their caregivers. His wife Ellen has over 25 years experience in healthcare management and teaches at the University of Alabama. Together they have had 8 close relatives with dementia for whom their immediate families provided care. And, together Danny and Ellen offer clear, concise, practical, and most importantly, compassionate information and advice to help care for and improve the lives of patients with Alzheimer's and those who care for them. Their book is divided into two sections - the first with discussions of common issues and problems, and the second with an alphabetical quick reference of problems and listed responses. This is a perfect format for the often weary and distraught caregiver who has many concerns and little time.

11. Jane Marie Thibault, Ph.D. and Richard L. Morgan, Ph.D., *No Act of Love Is Ever Wasted: The Spirituality of Caring for Persons with Dementia*. Upper Room, 2009.

Relying on their many years of experience in the areas of aging, dementia and spirituality, authors Jane Thibault, a clinical gerontologist, and Richard Morgan, a retired Presbyterian minister, offer this book to provide a fresh, hopeful model of dealing with life and death in the realm of Alzheimer's and other forms of dementia. The authors suggest that caregivers have two basic needs: affirmation that caregiving is not in vain and reassurance that the lives of those for whom they care

are not being lived in vain. They further state that care receivers need more than medical attention; they need tender care, involvement in the community, and a sense of connection with a loving God. Their perspective that caregiving is an extension of spiritual life will aid families and professionals to look beyond day-to-day routines and chores and accept their role as an opportunity to serve the total person in body, mind, and spirit. In addition to offering practical ways to help, this book serves as a reminder that every act of love brings positive transformation to the recipient, to the giver, and to the world. *No Act of Love Is Ever Wasted* is an excellent resource for individuals caring for loved ones as well as for counselors, support group leaders, pastors, and other professionals.

12. Max Wallack and Carolyn Given, *Why Did Grandma Put Her Underwear in the Refrigerator?* Puzzles to Remember 2013.

Why Did Grandma Put Her Underwear in the Refrigerator? is a sensitive, light-hearted children's story that seamlessly provides its young readers with a toolbox to help them overcome their fears and frustrations. It shares easy-to-understand explanations of what happens inside the brains of Alzheimer's patients, how to cope with gradual memory loss, with a missed holiday, or even a missing Grandma! This 40-page fully illustrated children's book is told from a second-grader's perspective in her own style and vocabulary, but it lovingly shares real strategies, scientific insights and lessons of dignity from which adult caregivers may also benefit.

13. Don Wendorf, Psy.D., *Caregiver Carols: a Musical, Emotional Memoir.* CreateSpace, May 2014.

Get help managing your feelings from this musical memoir of Dr. Don Wendorf's emotional struggles as caregiver for his wife, Susan. Written in song lyric (rhyming verse) form to be easily absorbed and recalled, Don shares his personal feelings such as anxiety, anger, sadness, uncertainty, sexuality and compassion, to help other caregivers understand and better handle their own emotions. Selections are humorous, chatty, moving, informative, creative and practical. He has written

Caregiver Carols to encourage other caregivers that their own feelings are tough but normal and manageable and that they are not alone.