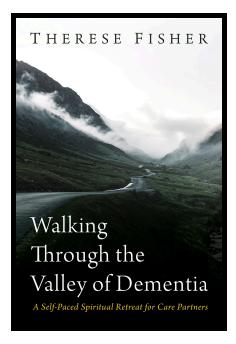
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Walking Through the Valley of Dementia:
A Self-Paced Spiritual Retreat for Care Partners
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New Title from Therese Fisher Walking Through the Valley of Dementia: A Self-Paced Spiritual Retreat for Care Partners



There are a multitude of challenges that care partners of People Living with Dementia (PLwD) face, which can leave them tired and depleted. They may not know where to turn for physical and emotional support, let alone spiritual care, which often goes untended.

This self-paced retreat is designed to support the care partner through various retreat exercises and scriptural reflections that create a space for them to engage in their relationship with God. The retreat begins with a discussion of what dementia is and the common challenges that care partners face. Within those challenges, readers will start to explore some of the many invitations God offers in the Valley of Dementia.

If, as care partners, readers have felt isolated from those around them, from society, community, church, and even family and friends, they are not alone. Therese Fisher offers this gift of spiritual exploration and relationship-building with the Divine to help nourish and sustain care partners and even help them find new life on the journey through the Valley of Dementia.

Therese Fisher is a graduate of the Jesuit School of Theology of Santa Clara University. She has more than fifteen years of experience in end-of-life care and is passionate about helping people increase their quality of life and find a deeper connection to the Sacred through direct care, spiritual direction, art, and song.



Interview with Therese Fisher

What inspired you to write the book?

Spirit inspired me to write this book. I honestly didn't know that I was writing a book until it was finished. The book is rooted in my experience of being a care partner both professionally and in my personal life along with my deep value in having a personal relationship with God. Walking Through the Valley of Dementia came out of my synthesis project for my Master of Theological Studies at the Graduate School of Theology of Santa Clara University. I wanted to create something that wouldn't just sit on a shelf somewhere, but that would actually have a life of its own ministering to people, bringing comfort in a time of need.

Who is your intended audience?

My intended audience is primary care partners of people living with dementia, those who are in this care partnership with a family member or loved one, or those who have chosen this field as a profession. This is also a wonderful resource for chaplains, clergy, and anyone doing pastoral care.

Why did you choose to write a book for care partners of people living with dementia?

Because I am a care partner of people living with dementia, both professionally and personally (my stepmom is at the end stages of Alzheimer's), and there are not a lot of resources out there for us in terms of spiritual support. All of my training in hospice care and as a nursing assistant didn't fully prepare me for walking this journey with my stepmom. I felt abandoned and alone, not only by my community, family, and friends but by the religious teachings I grew up with. I needed a place where I could lean into my big questions about what it means to be worthy of God's love and what it means to be of value as a human being. With this book, I offer care partners that space to dialogue with God about these and other big questions.

How did your journey with your stepmom influence this book?

When you read the book, you will get a taste of what this journey has been for me and some of the exercises that come from that lived experience. At some point, I hit a theological wall. If everything I learned about what it means to be a good Christian or even a good person, relies on doing things a certain way or on some form of intellect, what happens when those things aren't there? What happens when I can't be kind, I can't profess the name of Jesus, I can't engage in discipline, or I can't read or understand sacred scripture? What then does it mean to be human and to be worthy of God's love? This book came from leaning into the painful questions that challenged what I thought about being human and what I understood about religion and God.

Now that your book is out in the world, what do you hope people will get from it?

My hope is that people will find comfort in my book. I pray that they come to realize that they are not alone and that they will find a deeper, more intimate relationship with God as they encounter Spirit in these retreat exercises. I also hope that people will come to understand that we are all living with dementia because whether or not we have it, we are in a relationship with people who do, so we are living with it. That makes each of us care partners of people living with dementia even if we are not the primary care partner; even if we don't know the people around us have dementia.

What are your future plans? Will you continue to provide resources for caregivers?

I prefer to use the term "care partners." "Caregiver" implies doing something for or to someone instead of doing something with them. It sets up a power dynamic that I believe ultimately diminishes both parties. The term "care partner" honors our shared humanity and our interdependence, how we need each other for support and how we are a gift to each other. I plan to continue to partner with others through spiritual direction, hospice volunteering, and singing with the Threshold Choir. I plan to expand the retreat experience for care partners with additional retreat exercises, an expanded online presence on YouTube and possibly a podcast, and to offer some in-person programs. Who knows, maybe even another book!

What are some of your sources of inspiration as a writer?

Honestly, my dad is a huge source of inspiration. He is a wonderful writer and storyteller. Also, God is a source of inspiration. Every day when I sat down to write, I would ask God what God wanted me to write about and the whole experience was very prayerful. Another source of inspiration for this book in particular is Teepa Snow. I was at a workshop she was doing on dementia care and she said something along the lines of, "the world needs people with different levels of cognition." This flew in the face of my sense of expectations that we all be smart and strive for some sort of optimal level of cognition. I stayed after the workshop just so I could confirm that is what she really said. It broke my heart wide open. What would the world be like if we stopped villainizing dementia? Can we become people who acknowledge the suffering we experience while still being open to the gifts and graces that are around us?

What makes your book stand out from others?

The subject matter combined with the format of the retreat make this book special. There are lots of books on dementia, but not on spiritual care for care partners. There are also retreat-style workbooks on various aspects of life and spirituality, but there aren't resources like this that try to meet the care partner where they are at and invite them into a deeper relationship with the Divine. I think the spirituality of care partners is often neglected. We often struggle with so much shame around the experience of dementia that it is sometimes hard to get the courage to dive into other vulnerable places like our own spirituality. This book is a safe place to do that.

How do you think spirituality can change the approach to dementia care on a broader scale?

Dementia care is changing and becoming more person-centered and more compassionate. For those with a faith background, it also needs to be inclusive of spirituality. I don't think that we can fully address our humanity unless we honestly acknowledge our complex spirituality. Bringing spirituality into the equation enhances care partnering. Studies have shown that if care partners have a better quality of life, they are able to offer a better and more positive partnership experience, improving the quality of care for the person living with dementia and delaying placement into assisted living facilities. Spirituality can help transform the whole experience of dementia into one that is more positive and life-affirming.

An Excerpt from Walking Through the Valley of Dementia: A Self-Paced Spiritual Retreat for Care Partners

Rationale and Purpose

I have created this retreat because I love God. This loving relationship has sustained me as a care partner professionally and personally when society, community, church, and sometimes even family and friends have not been able to. I want to offer other care partners a space where they can explore their relationship with God. I believe that through this relationship, care partners can find nourishment and sustenance for their journey through life in general and specifically through the Valley of Dementia.

God's greatest commandments are to love God with all your heart, soul, and mind and to love your neighbor as yourself (Matt 22:34–40). The generosity that this passage suggests is easy to get lost in, particularly in a care partnering environment. For example, it is "easy" to identify with giving generously to a care partner, to believe we must care for them with every ounce of our being and even that we must suffer for their sake, for the Bible says, "And not only that, but we also boast in our sufferings, knowing that suffering produces endurance, and endurance produces character, and character produces hope." (Rom 5:3–4 NRSVCE) We know God did not promise us an easy road, so we carry on in God's name and forget to care for ourselves.

My firsthand experience and observation of others over the last fifteen years have shown me that the multitude of challenges care partners face often leave them tired and depleted. They (we) don't know where to turn for physical and emotional support, let alone spiritual care, which often falls completely by the wayside. Spirituality and a relationship with God can begin to feel like a luxury that one can abstain from or "put off until after."

The idea of a spiritual retreat might sound refreshing and nourishing. Still, the reality is there often just is not time, or there are no resources available to take an afternoon off, let alone an entire weekend. Studies have shown that successful interventions for caregivers of People Living with Dementia (PLwD) generally have the quality of being individually tailored to them. For that reason, I have compiled this retreat program with various exercises that you, the care partner, can adapt to your own life and use anytime, day or night, at your own pace.

Since most care partners are not professionally trained, my primary focus is on everyday people (family, friends, or acquaintances of the PLwD) who have found themselves in the role of care partner for one reason or another. Though not my primary intended audience, I hope the retreat is also helpful for paid professional care partners.

Goals

The retreat's primary goal is to nourish and support you, the care partner, through spiritual explorations (such as prayers, meditations, rituals, and journaling) that create a space for you to engage in your relationship with God. Secondary goals include offering some basic education and providing a resource that is easily accessible, low-cost, and self-paced, inviting you to tend to your spirituality in a way that considers your time constraints and other potentially limited resources.

Praise for Walking Through the Valley of Dementia: A Self-Paced Spiritual Retreat for Care Partners

"When you are a care partner for a person living with dementia, finding effective spiritual support is often a challenge. Therese Fisher noticed this and thoughtfully created a tool to help meet this need. For those in the Christian faith, this is an excellent resource for care partners, as well as church communities, chaplains, and other faith-based organizations."

—Teepa Snow, founder, Positive Approach to Care®

"Whether you are a care partner for a family member with dementia or a lifelong care partner of dementia patients, ultimate questions of life, its purpose, and its destiny surround you. To find meaning or even to behold God in this work may be a daunting task. Therese Fisher's outstanding book which seamlessly blends current research, personal experience, and sound theological insights offers a self-guided, self-paced retreat for compassionate care partners that strengthens, supports, and nurtures one's spirituality amidst this challenging work."

—Gina Hens-Piazza, professor of biblical studies, Jesuit School of Theology of Santa Clara University

"Therese Fisher has brought heaven to earth in this offering. The challenges of being a care partner are often misunderstood, and the options to receive support are few and far between. Bringing her own years of experience as a care partner and understanding of the stresses related to being a carer, Fisher has created a truly usable and easily accessible gift to anyone who seeks respite while walking through the Valley of Dementia."

—Anne House, volunteer services manager, Providence Community Health Napa Valley

"This is the kind of book I wish I could have offered to many care partners over the years I worked as a hospice chaplain. Therese Fisher is a compassionate, knowledgeable guide through the terrain of the Valley of Dementia and draws on deep wells of lived experience, advanced study, and Christian wisdom to create much-needed retreat for those on a similar path. I know this book will be a beloved companion to many."

—Heather Isaacs, board-certified chaplain

