

Grieving Someone Who Is Still Here

If you need help right now

Emergency

911

988 Suicide and Crisis Lifeline

Call or text 988, any hour, or chat at 988lifeline.org. For anyone in distress, or worried about someone who is.

Eldercare Locator

1-800-677-1116, Monday through Friday, 8 a.m. to 9 p.m. Eastern, or eldercare.acl.gov. A public service of the U.S. Administration on Aging that connects older adults and caregivers with local help anywhere in the country.

From
The Sitting Room Series

**BOOK 9 • GRIEF AND
MEMORY LOSS**

Grieving Someone Who Is Still Here

*When Someone You Love Has Progressive
Memory Loss*

Stephen Deason



Alder
Creek
EDITIONS

Grieving Someone Who Is Still Here

*When Someone You Love Has Progressive
Memory Loss*

Book 9 of The Sitting Room Series

Copyright © 2026 Stephen Deason

All rights reserved. No part of this book
may be reproduced in any form without
written permission from the publisher,
except for brief quotations in reviews.

Published by Alder Creek Editions, LLC
aldercreekeditions.com

ISBN 979-8-952410-18-3 (paperback)

First edition, 2026

This book is general information for adults.
It is not medical, legal, financial, or tax
advice, and reading it does not create a
professional relationship with the author
or the publisher. The author is not a
physician, nurse, counselor, lawyer, or
financial adviser. Decisions about health,
treatment, legal documents, benefits, and

money belong to the person and the professionals named in this book.

About This Book

Other than the author's own companies, which are named in the preface and in About the Author, the author and publisher are not connected to, do not endorse, and are not paid by any organization, provider, or service named in this book, apart from the booksellers that sell it. Phone numbers, websites, and programs were checked in October 2026 and can change. Confirm them before you rely on them.

The named examples, such as Carol, Lamar, and Bernice, are composites drawn from many families and written to teach, with names and details changed. They are not case histories, and real situations often resolve less cleanly. The author's accounts of his own family and work are drawn from his experience.

To the fullest extent the law allows, the author and publisher are not liable for any loss, injury, or damage arising from the use of this book. In an emergency, call 911. In a crisis, call or text 988.

Contents

Preface.....	9
1. Who This Is For and How to Use It.....	14
2. Grief Before a Death.....	20
3. What You May Feel.....	25
4. Keeping Yourself Going.....	31
5. The Losses Along the Way.....	42
6. Who They Are Now.....	47
7. Your Marriage.....	52
8. Changes to Report to the Doctor.....	57
9. When It Is Not Safe.....	64
10. When Home Is No Longer Enough.....	72
11. Toward the End.....	80
Part Two: For the Rest of the Family.....	87
12. What the Care Partner Carries.....	88
13. Taking Part of It.....	94
Sources.....	102
Where to Get Help.....	121

Index.....	126
The Sitting Room Series.....	130
Also by Stephen Deason.....	133
About the Author.....	139

Preface

This book is personal for multiple reasons. I have spent about forty years working inside health care. I began volunteering in a hospital at fifteen and was working as an orderly by sixteen, helping care for patients in hospitals and nursing homes while I worked my way through college. Later, I spent more than twenty years building and running systems for hospitals, insurers, Medicaid programs, and other health care organizations before returning to direct care through healthcare staffing, home care, and skilled nursing. Today I am an Administrator of a licensed health care facility that delivers care in patients' homes.

That facility is OPA Home Care, which I founded and run. In Georgia it is a licensed Private Home Care Provider, or PHCP. My healthcare staffing company employed

nurses and aides across hundreds of health care facilities around the country, including through the COVID years, and our home care operations have recruited, hired, and managed caregiving staff for hundreds of families. I have watched older adults and their families face what this series covers, often in a hurry and usually at a difficult time.

What I kept seeing was this. Families meet the information in pieces, after they already need it, from people who each answer a different piece. The hospital owns the discharge. The insurer owns the benefit. The home care provider owns its services. Each of them may do that job well. The family still has to put the puzzle pieces together.

It happened to my own family. My mother was found wandering the parking lot of a hospital, looking for her car. She had a

urinary tract infection that urgent care and the hospital both missed, and she was sent home with severe delirium and a new diagnosis of mild cognitive impairment. It took two weeks, and a nurse practitioner and a doctor we knew who were willing to look again, before anyone found the cause. She stayed with us for two months and then moved into independent living. She has kept improving, and she is driving again. The infection was ordinary. The months that followed were the cost of catching it late.

Much of the information in this series is already available somewhere. Medicare publishes Medicare's rules. The VA explains VA benefits, and each state explains its own programs. Having information spread across so many places is part of the problem. Families do not meet these questions one provider or agency at a time. The questions arrive together. I wrote this

series to put many needed pieces in one place, in the order people tend to need them, with a way to record or otherwise act on each answer.

The facts and program rules in this book come from the sources listed at the back, each with the chapters that use it. The judgment about which facts matter, how they fit together, what families often discover too late, and what questions to ask comes from years of doing this work. Chapters 4 and 10 draw on that work most: what happens when the care partner is the one who gets sick first, and the move to more care.

This book is written to you, the person caring for someone whose memory is going. Part Two, at the end, is written to the rest of the family. They are welcome to read all of it. You remain the person it is written for.

This book will help you name what you are going through, keep yourself going, know when to call the doctor and when to call for help, and let the rest of the family carry part of the load. Start with Chapter 1, or with whatever brought you here.

1. Who This Book Is For and How to Use It

This book is for you if you are caring for someone whose memory is going: a husband or wife, a parent, a brother or sister, or a friend. You may live with them, or you may drive over every day, or you may manage their care from another state.

Many of the families I work with never got a clear diagnosis. They just knew their mother was not the same. This book is for them too.

Some memory loss keeps getting worse over time, as it does in Alzheimer's disease and most other kinds of dementia. Some stays about where it is, as it can after a stroke or a brain injury. You may not know yet which kind your person has. Most of this book is for you either way. Chapters 10 and 11 are about what comes when memory

loss keeps getting worse, and you can skip them until they apply.

What this book does

It gives a name to the grief that comes before a death, and describes the feelings care partners report. It helps you keep yourself going, notice the changes a doctor should hear about, and know who to call when the house is not safe. It walks through the move to more care, if that comes, and the last months. Part Two tells the rest of the family what you carry and how they can take some of it.

It does not diagnose anything, and it does not judge how you feel. The feelings in this book are the ones families describe. Yours may be some of them, all of them, or different ones.

Read it in pieces

You do not have to read this book in order, or all at once. Each chapter stands on its own. A chapter takes about as long to read as a cup of coffee. Start with the one that answers the question in front of you.

Where to start

- If you are worn out, start with Chapter 4.
- If something changed suddenly in the last few days, start with Chapter 8.
- If someone in the house has been hurt, or you are afraid someone will be, start with Chapter 9.
- If you are thinking about a move to memory care or a nursing home, start with Chapter 10.
- If you are a son, daughter, or other relative who wants to help, start with Part Two, which begins with Chapter 12.

If the diagnosis is new and the person can still make their own decisions, Book 6 in this series, *While You Can Still Decide*, covers the papers to sign and the conversations to have while there is time.

A word about the people in this book

The named examples in this book, such as Carol, Lamar, and Bernice, are composites drawn from many families, with names and details changed. Real families' stories are often messier. The accounts of my own family and my own work are mine.

Who to call or ask first

Who to call or ask: The Alzheimer's Association 24/7 Helpline, for any question about memory loss or caregiving, any hour. The 988 Suicide and Crisis Lifeline, if you are in distress. The person's doctor, for any question about their health.

How to reach them: The Alzheimer's Association Helpline is 1-800-272-3900, free, any hour, every day. Call or text 988, or chat at 988lifeline.org.

What you can say: I am taking care of my husband, who has memory loss, and I do not know where to start. Can you help me think it through?

NOTES

1. *Who This Book Is For and How to Use It*

“Come unto me, all ye that labour and are heavy laden, and I will give you rest.”

Matthew 11:28, King James Version

2. Grief Before a Death

Spouses and grown children have told me they started grieving long before the death, while the person was still sitting at the kitchen table.

That grief has a name. Pauline Boss, a family therapist and researcher, calls it ambiguous loss: a loss that stays unclear. When memory goes, the person is here in body, in the chair they always sat in, and is also going, a little at a time, in the ways you knew them. Boss describes this kind of loss as the person being psychologically absent while physically present, and she names Alzheimer's disease and other dementias as causes of it. Some people call this anticipatory grief.

Why this grief gets so little room

When someone dies, people come. They bring food, send cards, and take time off

work. There is a service, and a date to remember.

Grief before a death has none of that. Nobody brings a casserole because your husband called you by his sister's name. There is no day off for the afternoon your mother asked when her own mother was coming to pick her up. You may not even tell anyone, because the person is still alive and saying you are grieving can feel like giving up on them.

Many care partners grieve what has changed and keep caring for the person who is here, both on the same day.

Grief does not come in stages

You may have heard that grief comes in five stages, in order. Researchers who have reviewed the evidence say grief does not work that way, and that expecting it to can leave people thinking they are grieving the wrong way. Your grief may come in waves,

go quiet for months, and return on an ordinary Tuesday. The order it comes in tells you nothing about how much you love them.

Holding two things at once

Boss writes about holding two opposite ideas at the same time, absence and presence, because most relationships are both. The person is here, and the person is going. Care partners describe loving the person and, some days, resenting what caring for them has done to their life. They describe wanting the person to live, and some nights wanting it to be over. Each pair can be true at the same time.

What has changed

What is still here

Some care partners fill in this page once and never look at it again. Others come back to it every few months, and find that the second list is longer than they expected.

Carol has been married to Gene for fifty-one years. He still knows her, most days. He no longer remembers their son's wedding, or that he retired, and every morning he asks whether he is late for work. Carol says she lost her husband two years ago and still has him. She has not told her sister that, because her sister would say she is being morbid.

NOTES

2. Grief Before a Death

“A time to weep, and a time to laugh; a time to mourn, and a time to dance;”

Ecclesiastes 3:4, King James Version

End of the preview

You have read the first two chapters of Grieving Someone Who Is Still Here, Book 9 of The Sitting Room Series. The full book has 13 chapters, in large print.

The book's page at aldercreekeditions.com has the buy links for the paperback and Kindle editions once they are on sale. The ISBN below is the paperback's.

ISBN 979-8-952410-18-3

The worksheets from this book are free to print at aldercreekeditions.com, where the other books in the series are listed too.

You are welcome to share this preview with anyone it might help.

