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Loving Someone Who Has Dementia

Pauline Boss, Ph.D.

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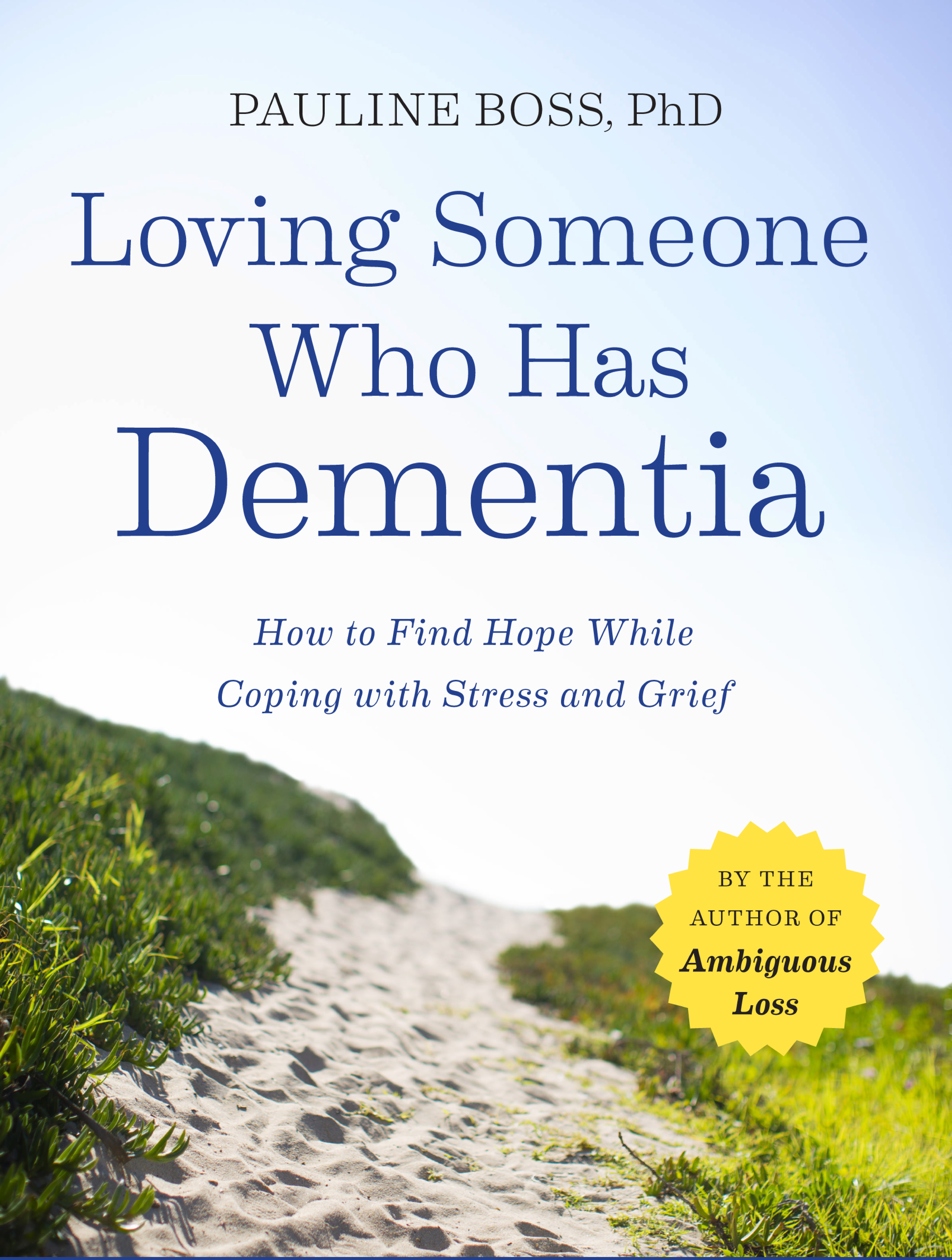

PAULINE BOSS, PhD

Loving Someone Who Has Dementia

How to Find Hope While Coping with Stress and Grief

BY THE
AUTHOR OF
Ambiguous Loss

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More Praise for *Loving Someone Who Has Dementia*

"With her work on ambiguous loss, Pauline Boss has shed much-needed light on a difficult human frontier. Now she brings her original insight to those caring for a loved one with dementia. Her knowledge is leavened by the rarer quality of wisdom. And so she truly offers a 'psychological journey toward meaning and hope' that practically addresses the hardest realities of life, love, self-care, and loss."

—Krista Tippett, creator and host of public radio's *On Being*; author, *Einstein's God*

"The words in this book give caregivers a voice for what they feel and experience. They also give caregivers a 'place' to put their many emotions."

—Peggye Dilworth-Anderson, PhD; professor, Department of Health Policy and Management, Gillings School of Global Public Health, University of North Carolina-Chapel Hill

"This is more than a survival guide for unpaid caregivers and support groups for families of those with dementia. It is an easily understood self-care manual for living well that illuminates options for finding balance and resilience while managing the ambiguous loss of having a loved one with dementia."

—Macaran A. Baird, MD, MS; professor and head, University of Minnesota Medical School, Department of Family Medicine and Community Health

Loving Someone Who Has Dementia

How to Find Hope While Coping with Stress and Grief

Pauline Boss, PhD

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Dedicated to the many caregivers who inspired this book

and

to Elsbeth Elmer-Hammerli, who had dementia and
whom I loved

Contents

Preface

I often thought about writing a book for families, but I was busy writing for academicians and professionals. As a retired professor, however, I have more options—and this message on my voice mail cinched it:

> I'm calling to make an appointment. Basically I just have one question to ask you. [long pause and then continuing with a weary and sad voice] How does a caretaker care for oneself … when the work is soooo hard … to care for the other … [pause] I suppose that's the million-dollar question.

That caller convinced me that you all deserve an answer to this agonizing question. Yet many of you don't have the time or energy for therapy. I write this book then for the millions of you who now find yourselves asking the same question: "With the demands of caregiving, how can I possibly take care of myself?"

Researchers have found that caregiving can be dangerous to your health; it makes sense that in an aging society, caregiving becomes a public health issue. It's urgent that the rest of us help in any way we can to support you.

Toward this end, I write this book. It is not about how to give day-to-day-hands-on care; rather, it provides a new way to help you find meaning and hope in your relationship with someone you love who has dementia. The goal is to help you increase your resiliency—your ability to withstand and grow even stronger despite the stress and grief.

This book focuses specifically on a new lens or theory that can lessen the stress when a family member is here but not here. How did I get the idea for this new theoretical lens?

In the early 1970s, while studying family therapy with psychiatrist Carl Whitaker in my doctoral studies at the University of Wisconsin-Madison, I noticed that families with problem children often had psychologically absent fathers. They were *there but not there*, complaining (as fathers often did in the early seventies) that the child was the mother's business, not his, and didn't we know that he had to get back to work? Whitaker, of course, did not agree. Nor did I.

Relatively quickly, I came to see that any family member, not just a father, could be psychologically absent while physically present. In a sociology seminar, also at the University of Wisconsin-Madison, I began to develop the theory of ambiguous loss, and it became the topic of my doctoral dissertation in 1975, which focused on families of pilots missing in action after the Vietnam War. This was ambiguous loss of the *physical* type.

In the 1980s, now a professor at the University of Minnesota, I tested the theory of ambiguous loss again, this time with family caregivers whose loved ones had Alzheimer's disease. This was ambiguous loss of the *psychological* type. Ever since, in research and clinical work I've studied the effects on relationships when one person is psychologically absent—when a person you love is physically here, but gone psychologically.

Along with teaching, research, and clinical work, I have trained professionals who work with the psychological losses of dementia as well as those who work with families of the physically missing (in New York after 9/11, in Kosovo, in the Gulf Coast after Katrina, and in Miami after the Haitian earthquake). All continue to provide ideas that broaden guidelines to be more culturally inclusive. My training of professionals continues today.

The research today is conducted primarily by a second generation of scholars, some of whom studied with me at the University of Minnesota, but many from around the world are now testing the theory of ambiguous loss in other cultures.[1] I couldn't be happier about this.

In 2009, at the beginning of winter, I began writing this book, motivated by my long-standing belief that if people can understand a problem, they are better able to cope with it. The theory of ambiguous loss is grounded in that premise.

A year has passed, and snow is falling again. It's a welcome quiet in the midst of what are stressful times for the millions of people who are now caring for a loved one who has dementia. May this book and the ideas within it prove useful to you in your search for meaning and hope.

Pauline Boss
Saint Paul, Minnesota
December 2010

Acknowledgments

I am deeply grateful to the thousands of individuals, couples, and families who have shared their stories with me in either therapy or research. It is from you that I have learned about resiliency and how it can be found in the midst of ambiguity and adversity. Specifically, I thank the many caregivers of people with dementia with whom I have worked. It was you who inspired me to write this book.

- Thanks to the Wayne Caron Family Caregiving Center support group at the University of Minnesota and to Tim Harper for providing feedback on my original book proposal.
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- Thanks to my longtime assistant, Carol Mulligan, without whom I could not do this work. Her technical skills and penchant for detail make all of my books, and especially this one, possible.
- Finally, thanks to my dear husband, children, and grandchildren. Their constant support and love carry me through the inherent loneliness of writing.

Introduction

Here's the problem: as of 2011, there were 5.4 million Americans living with Alzheimer's disease.[1] The number increases if the other diseases and conditions that cause irreversible dementia are included. Every sixty-nine seconds, someone in America today develops Alzheimer's disease.[2] By 2050, the rate will increase to every thirty-three seconds.[3] Said another way, few families now—and fewer yet in the future—will be untouched by Alzheimer's or other dementias.

More women than men are susceptible to dementia, primarily because they tend to live longer.[4] In addition, race, ethnicity, education, and location also influence the prevalence of dementias.[5] One fact, however, is consistent: any increase in dementia leads to an increased need for caregivers. What do researchers tell us about them?

As of 2010, there were 14.9 million unpaid caregivers in the United States.[6] Not surprisingly, 60 percent are female—wives, daughters, daughters-in-law, granddaughters, and friends.[7] More surprising, the typical caregiver is relatively young. According to a 2011 report of the Alzheimer's Association, 67 percent of caregivers are between the ages of thirty-five and sixty-four. On either side of this largest group, caregivers range from very young (10 percent under the age of thirty-five) to very old (23 percent sixty-five or older).[8] Wives and daughters do most of the caregiving for persons with dementia; they also report the most negative effects on their own well-being.[9]

Many caregivers find themselves in what is called the sandwich generation, simultaneously caring for young children and elderly parents. Tending both to younger and older generations—and perhaps also to a marriage—such caregivers find themselves pulled from all sides, squeezed for time, and struggling with divided loyalties—a recipe for high anxiety and extreme stress.

◆ ◆

If someone you love has dementia, this book represents a psychological journey toward meaning and hope. We begin with ideas to help you understand why dementia can be so confusing and stressful, then follow with guidelines to help you cope and stay resilient. Throughout, my message to you is that participating in a less than perfect relationship can deepen your humanity.

My primary focus is on how to find meaning in dementia's unique kind of loss—what I call *ambiguous loss*. Dementia is a prime example of ambiguous (unclear) loss;

making sense of it is especially difficult because a loved one is simultaneously here and gone. It's as though there's a stranger in the house; the relationship you once had is thus deeply altered. Without clarity or clear finality, you're held in limbo, blocked from grieving and making sense of it all. Because of the incongruence between absence and presence, ambiguous loss is the most stressful kind of loss. Clients tell me that even a death in the family would be less painful. There is certainty in death, and thus more opportunity for finding meaning in it.

Who Is This Book For?

This book is meant for anyone who cares for—or cares about—a person who has some kind of dementia. It's for you if you're doing hands-on or long-distance caregiving. It's for you if you are experiencing sadness and anxiety due to caring about someone with dementia. It is also for others—friends, relatives, clergy, medical professionals—who want a resource that discusses the complexities of a caregiver's loss and what to do about it.

In an aging society, we are *all* vulnerable to the need either to give care—or to receive it. It's not an isolated problem. Until there is a cure, dementia, regardless of its source, remains a twenty-first-century epidemic—and we are all in it together.

With only a few degrees of separation, we now all know someone who has dementia or who is caregiving.

Yet even when it's close by, many people turn their heads and don't notice the frequency of what's happening. Until we all pay more attention, until we see caring as important, we are marginalizing and isolating the family caregivers who contribute so much to keeping dementia patients at home for as long as possible.

Until recently, families have tended to designate one family member (thus the term "primary" caregiver) to do the work of caregiving while the rest of the family and community carried on with their lives. They likely breathed a sigh of relief when they didn't have to put in what is called the "thirty-six-hour day."[10] But now it's time for all of us to acknowledge, appreciate, and directly help caregivers—the one down the street, the one in your congregation, the one in your family—because simply put, it takes a village. One person can't do it alone and stay healthy.

What often endangers the emotional and physical health of caregivers is their isolation. Unlike dementia, this problem can be fixed. We can do better. We can try harder to understand the caregiving experience. And that is what this book is for.

Caregivers are a devoted army of family and friends who provide most of the dementia care and who work for no pay and no benefits. They save our government (and taxpayers) millions of dollars by reducing the time dementia patients spend in institutional care settings. Surely we can pay closer attention to their contributions.

Policymakers, community leaders, neighbors, friends, and relatives need to acknowledge their work—and lend a hand so that caregivers can stay more socially connected. After all, human connection is what keeps us healthy.

What I Mean by "Dementia"

Dementia, whether from illness or injury, is a condition of the brain that leads to the loss of remembering, thinking, reasoning, and judgment. Gradually, even the simplest tasks of daily living—dressing, feeding, and toileting—require help. Dementia itself is not a disease, but rather a group of symptoms that results from other diseases or conditions. The most common is Alzheimer's disease, a fatal disease that accounts for over half of all cases of dementia.[11] Dementia changes one's personality, mood, and behavior, so existing relationships are strained. Thus dementia is more than a physiological condition. It is a *relational* condition that deeply affects those who care *for* and care *about* the patient.

What is relevant to the thesis of this book is the factor of incurability, which creates the deepest and longest-lasting ambiguity and stress for caregivers. Approximately fifty causes of dementia exist now, some treatable, some not. In this book, I limit my discussion to those that are as yet *not* curable—Alzheimer's disease, vascular dementia (tiny strokes), Lewy body dementia, frontal lobe dementia, Huntington's disease, Parkinson's disease, AIDS dementia complex, and Creutzfeldt-Jakob disease (what is also called mad cow disease), among others.[12]

The lack of resolution is what makes the case of dementia so compelling in the study of human resiliency. How do people live with a loved one who is gone psychologically but still here physically? In the absence of a cure—or the finality of death—how do people live in this shadow land? These are the questions that I will try to answer in subsequent chapters.

Before we proceed, I need to add a note about traumatic brain injury, which can also lead to dementia. After much thought, I have decided not to address the ambiguous loss of traumatic brain injury in this book, even though it is the signature wound from our wars in the Middle East. Why? Because progressive dementia is not always the outcome of traumatic brain injury, and because younger patients and their spouses or parents differ from older patients and their families in their dynamics and developmental life stages. Having worked with the families of these young people wounded in Iraq and Afghanistan, I see them very differently. They are not families in the last half of life, but young families trying to build a life together despite terrible wounds in both body and mind. Although there are commonalities, their story deserves a book of its own.

Why I'm Writing This Book

Although dementia at any stage is a difficult experience for anyone, it is especially stressful for those of us who like to be in charge of our own destinies. Accustomed to being in control, we feel helpless about dementia. Yet there is a way to feel better. When we can't control the dementia, we can still control how we perceive and manage the situation. And therein lies a caregiver's window for hope.

Although I'm not technically a boomer, I relate to their generation of can-do people accustomed to finding solutions to problems. As a Swiss American Protestant professor who was socialized to believe that I could solve anything if I worked hard enough, I too have struggled with feelings of helplessness, as I watched dear ones slip away with illnesses that had no cure—my grandmother's dementia, my little brother's polio, and my sister's cancer. Today, polio is prevented and cancer has better treatments, but we still face problems that have no solution, and dementia remains one of them. There are many ways to feel less helpless with this kind of loss, and I will share them with you. Instead of offering a how-to caregiving book (there are already many good ones), I've developed a new lens through which to make sense of your situation so that you can manage it—and thereby feel stronger for this journey with dementia.

How to Read This Book

This book is designed to be read alone or with a group. It is your guide for self-reflection as well as discussion with others. Each chapter can stand alone and has its own topic. Read it in any way you wish. Although related themes run throughout the book, you may, if you are busy or exhausted, want to focus on only one chapter at a time. I hope you find the information useful and calming for what is likely to be a long and painful journey.

Know that I do not discuss the illnesses and conditions that cause dementia, nor do I discuss the medical technicalities of dementia. Rather, I focus on the challenges you face *relationally* when someone you love has dementia.

Here is a brief summary of the chapters, so that you can best decide which area to focus on as you read:

Chapter One, "The Ambiguous Loss of Dementia," explains what ambiguous loss is, how it relates to you, and why it can cause depression and anxiety.

Chapter Two, "The Complications of Both Loss and Grief," makes the case that unresolved loss causes unresolved grief. What this means for you is that your complicated grief is to be expected. It is not your fault. The complicated grief is caused by ambiguous loss—in this case, by the dementia, which requires a special kind of grieving.

Chapter Three, "Stress, Coping, and Resiliency," helps you identify your own stress issues more specifically.