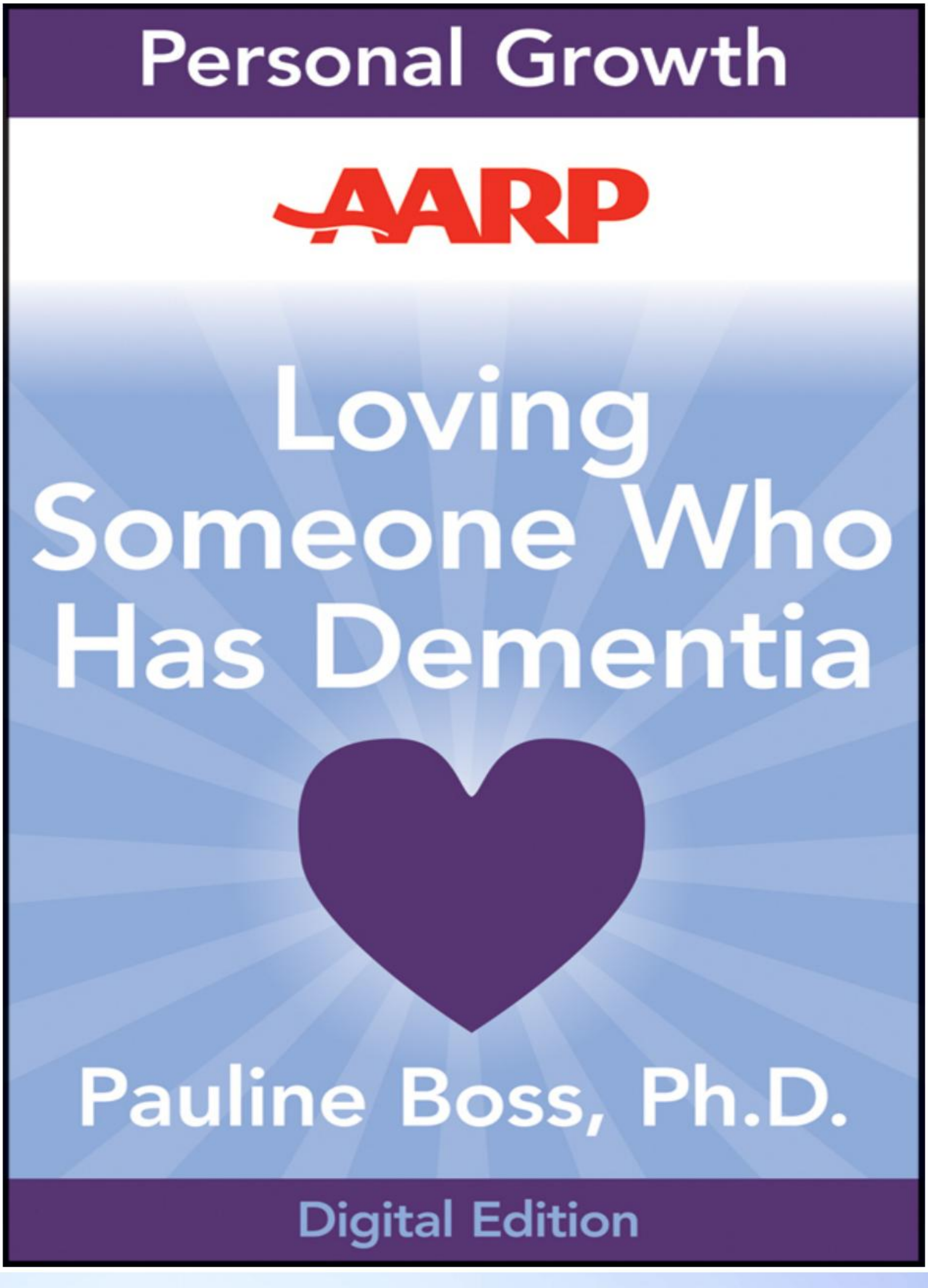

PAULINE BOSS PhD

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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

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.
- Thanks to my agent, James Levine, who guided me in the transition from academia to writing for the general public.
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- Finally, thanks to my dear husband, children, and grandchildren. Their constant support and love carry me through the inherent loneliness of writing.