

Alzheimer's

*A Crash Course
for Friends and Relatives*

Mary McDaniel Cail, Ph.D.



Chapel Hill, North Carolina

*Disclaimer: This publication contains advice and information related to a medical condition. It is intended to provide helpful suggestions and information with regard to the subject matter. Neither the publisher nor the author are involved in providing psychological, medical, or other professional services. Although every effort has been made to ensure accuracy of material, the publisher and author assume no responsibility for omissions or errors. The ideas and suggestions are not meant to substitute for professional services. If a reader requires medical, psychological or personal advice, a competent professional person should be consulted. The publisher and author disclaim any liability, directly or indirectly, for advice or information presented herein. **Please be aware that websites and reference materials accessible at the time of publication may no longer be available when the book is read.** Names and identifying characteristics of the individuals whose stories are told have been changed to protect privacy.*

The present work appeared in an earlier version under the title *The All-Weather Friend's Guide to Alzheimer's Disease: Staying Connected to Loved Ones with Dementia and Their Caregivers*. ©2011 by Mary M. Cail. **The present work has been revised and updated.**

The All-Weather Friend and related logos and graphics are registered trademarks.

Truewind Press gratefully acknowledges permissions for quotations from Kris Bakowski, DaCapo and David Wolpe.

© Copyright 2014 by Mary McDaniel Cail. All rights reserved. No part of this book may be reproduced, stored in a retrieval system, or transmitted in any form or by any means whatsoever, except by a reviewer who may quote brief passages in a critical review, without written permission from the publisher.

For information: ckayser@kayserpierce.com.

Printed in the United States of America

Library of Congress Cataloguing-in-Publication-Data
is available upon request.

ISBN-13: 978-0-9825751-2-3

ISBN-10: 0-97825751-2-2

*In loving memory of
Greg McDaniel, my brother.
Thank you for the feathers.*

FOREWORD



My wife, Jan, was diagnosed with younger-onset Alzheimer's disease at age 55. Thus began a journey that was lonely, sad, exhausting, and physically dangerous to me as a caregiver.

This book has a lot to say about being a friend, both to caregivers and to dementia patients, at a time in life when friends are vital to survival. I have one supreme demand for any caregiver who is reading it: Survive.

Alzheimer's caregivers are usually selected not by training, but by geography. We are the closest person to the person with the disease. It could be a wife caring for her husband, or a daughter for a parent, or a brother for a sister. Caregivers often suffer depression that can spiral into even more serious health problems. Caregivers cope with endless, growing and sometimes irrational demands. One constant...as bad as it is today, it will almost surely get worse.

And here's the hardest part: Caregivers are alone. With almost any other disease, the person who is sick is part of the team. If someone you love is battling cancer, that person is part of the process, part of making decisions about their life, medicine, chemotherapy.

Not with Alzheimer's. If you are the caregiver holding this book, you're it. Doctors have few treatments and none that offer a cure or even slow the disease. The person with the disease will disappear ever more, making your struggle as a caregiver ever harder. It makes having friends who can begin to understand and listen with compassion all the more important.

If you're a friend or relative, seize the tools in this book. Learn the strategies. Read how others coped. Prepare for what is coming, but do so knowing that every Alzheimer's journey will be different.

And if you're a caregiver, most of all take care of you. You will be of no use to the person you are caring for if you are no longer here.

Survive. That will be your personal victory over this disease.

*Emmy Award-winning journalist and author **Barry Petersen** has been a CBS News Correspondent for more than three decades. He is the author of Jan's Story: Love Lost to the Long Goodbye of Alzheimer's.*

CONTENTS



A Note from the Author 1
About This Book 5
Alzheimer's 101 9

PART ONE

Mild Decline

- CHAPTER 1 ADELLE 19
- CHAPTER 2 A FRIEND IN THE EARLY STAGE:
EASY CHANGES YOU CAN MAKE 29
- CHAPTER 3 "I'M A CARE PARTNER NOW?"
HELP AT THE BEGINNING 49

PART TWO

Mid-Stage

- CHAPTER 4 NEAL 59
- CHAPTER 5 A FRIEND IN THE MID-STAGE:
COMMUNICATION TOOLKIT 69
- CHAPTER 6 HELP WHEN CAREGIVING GETS HARDER 81

PART THREE

The Last Years

- CHAPTER 7 VELMA 95
- CHAPTER 8 A FRIEND IN THE LATE STAGE:
ACCEPTING AND HONORING 103
- CHAPTER 9 Help As CAREGIVING DRAWS TO A CLOSE 109

PART FOUR

The All-Weather Friend

- CHAPTER 10 WILLA AND BERT 121
- CHAPTER 11 SEVEN WAYS TO STAY CONNECTED 131
- CHAPTER 12 A DIFFERENT DINNER PARTY 151

Beyond Dementia—A Man and Two Dogs 161

Notes 167

Further Reading 179

Acknowledgments 181

Works Consulted 183

Index 191

Topics and Questions for Discussion 197

“Terminus” by Ralph Waldo Emerson 201

About the Author 203

Alzheimer's

*A Crash Course
for Friends and Relatives*

“... We have a great deal more kindness than is ever spoken. [Even with] all the selfishness that chills like east winds the world, the whole human family is bathed with an element of love like a fine ether. How many persons we meet in houses, whom we scarcely speak to, whom yet we honor, and who honor us!”¹

— RALPH WALDO EMERSON (1803–1882)

We remember Emerson for his brilliant, complex mind. We remember him as a philosopher and writer of enduring essays, poems, and lectures. He entered Harvard as a student at age fourteen. What many of us may not know is that he died unable to write his own name, probably due to Alzheimer's disease.

A NOTE FROM THE AUTHOR



IF I HAD WRITTEN A MEMOIR ABOUT CAREGIVING, I would have entitled it simply, *Confessions*, and filled the pages with my regrets. Maybe I'd feel absolved, then, for having admitted the times when my patience had ground to a halt and I felt overrun with frustration at a situation I could not control. I've met and interviewed caregivers who inspire within me the kind of awe I reserve for remarkable musicians and athletes: They have reserves I lacked when confronted for the umpteenth time with an unsolvable problem involving my father, in the throes of dementia, or my mother, grappling with a bevy of age-related and chronic health ailments. When logic couldn't be applied, and there were no answers.

I spoke with many caregivers who do this work with little relief, night and day, seven days a week. I've transcribed their stories of heartache, need, occasional humor and small triumphs. But I didn't write the book for caregivers. It's a book of advice and information for

friends—the friends of caregivers and the friends of people suffering from dementia, from early stage to late. I wrote it because friends can help; in the smallest offerings of time and care, friendship makes a difference. I know this truth because I've lived it.

Dementia, whether it is caused by Alzheimer's or another neurological disorder, is isolating. Friends who don't know what to say or what to do drop out of sight, out of touch. Socially, life seems to go from the big screen to a small 1950s television set, a grainy little box with a temperamental antenna, perched atop a coffee table. The world shrinks. There are no more dinner parties and spontaneous outings, not when dementia has progressed beyond a certain point. Everything must be carefully planned, and even then, it may fall apart at the last minute.

Understanding friends, who've tailored their expectations to the realities of dementia for both patient and caregiver, can re-expand the world. Caregivers and people with dementia, especially in the earlier stages when symptoms are not quite so obvious, have support groups they can attend, but they need also to keep the connections and loves they've built over decades of living. It's up to friends to help. This is what my book is about.

AS MY FATHER LAY DYING, I sat beside him hour after hour, day after day, intermittently trying to comfort him. Nothing I said or did penetrated his mental fog. When I touched him, he cringed. When I tried to sing hymns to him, he grimaced (which, admittedly, was understandable). He said few intelligible words. He screamed like he was being tortured when the nurses changed his gown or sheets, and I had to leave the room and clap my hands over my ears. But periodically, friends arrived with chicken salad sandwiches, coffee, chocolate and even, once, whiskey. A minister from a church I had visited for a few months stopped by, unannounced, and invited me to talk—or rather wail—for what seemed like a long time, sitting stoically through it, like he was stuck in the middle row of a bad movie. They took me out of that bleak scene,

with the dangling lines and vinyl furniture, the air reverberating with my father's labored breathing, and reminded me, over and over again, that life, for all its unavoidable sadness, is good. This is the power of friendship and connection to the bigger world.

I wish I could come to terms with what happened to my father, with the slow unraveling of his mind and with the ways I failed him in my own distress and fear, and within the context of a culture that too often fails its most vulnerable, needy members. Despite bad times in my life—the miscarriage of my only pregnancy after five years of infertility treatment, my husband's brain tumor and, a short time later, his suicide, my brother's sudden death, an abusive relationship, a brief but terrifying brush with ovarian cancer—nothing prepared me for what it would be to have my father, in a tight voice, threaten to cut open my head on a difficult, memorable night; my father, who signed every note he ever wrote to me with SWAK (sealed with a kiss). Nothing made me less heartsick at seeing him sit with his shoulders slumped and head drooped, still despondent with grief years after my brother's death, a grief from which dementia mercilessly did not free him, or to find his scribbled, undecipherable attempts at writing. When I produced the first draft of this book, he glowingly pronounced it a masterpiece. By the very end of his life, his brain and his eyes had all but failed. He sometimes squinted at headlines out of lifelong habit, holding a crumpled newspaper inches from his nose, unable to read the words.

My father was a physician. He delivered ten thousand babies. He combatted his fatigue from the perpetual middle-of-the-night dashes to the hospital by singing—awfully, but with great enthusiasm. I remember him carrying me into the ocean, back when I wore a frilly swimsuit, and my hair was twisted into long blonde braids. I wish I had been able to carry him through his struggles during the final years of life, when waves of loss, so much stronger than an ocean, crashed relentlessly, and within the turmoil of his own mind, he could not make sense of what his life had become.

FRIENDS CAN'T FIX THINGS, but they can bring comfort and relief when you feel less like a fortress and more like a flimsy dam, straining against a surge of problems. My friends couldn't have assuaged my grief or guilt. They couldn't make my father well. They couldn't undo the dysfunctions in our parent-child relationship, made indelible by the ink of age and ingrained disparities. They could and did, however, offer me a place to go, where the force of the adversity receded for a while.

I sat on the deck of a friend's vacation house one evening, as the sun slipped beneath the sky, and a row of cottages, lit from within, formed a bracelet around a darkened lake. I had spent most of the day in a police station and an attorney's office, trying to stop a fraudster from pilfering my father's accounts. Dad didn't understand what he had done, writing check after check for thousands of dollars, and I didn't know how to keep it from happening again, not then, anyway. I can still see my friend's face as she listened compassionately, like that minister. Years later, I can reclaim the comfort I felt, eating a dinner I did not make, my napkin ruffling in the late spring breeze. Friends are life saving.

Circumstances can become one huge, relentless storm, and every one of us slips into a muddy kind of despair at times. A compassionate, sensitive friend—an all-weather friend, so to speak—is a godsend. The rain stops for a while. You can dry off, warm up and maybe even laugh.

Dementia is one of worst storms life can impose, pelting one problem and loss after another for years on end. This book is about how to be a friend with an umbrella.

ABOUT THIS BOOK



DOES SOMEONE YOU LOVE HAVE ALZHEIMER'S DISEASE (AD)? Is one of your friends, relatives, or neighbors a caregiver? You can make the most of your relationship from the early stage, when changes are not so obvious, through the last. If a person in your world is dealing with dementia, whether as a patient or a caregiver, this book is for you. It will guide you through steps you can take to be supportive in the months and years ahead. You can help more than you may believe possible just by learning new ways to connect.

The book can best be described as a crash course for people who have not experienced this situation themselves. In a crash course, information is practical, often used to tackle a crisis. It breaks the surface and invites a more in-depth investigation. Most of us, however, are quite familiar with Alzheimer's disease, given the intense media coverage in recent years. We don't want so many details. The neurobiology is thoroughly complicated. What we can readily see—the relentless loss of intellect and life skills—is grim.

A man I met at a party was more candid than most when I told him I was writing about friendship and dementia. He paused for a moment and asked, smiling politely, "Why would I want to read that?" as if to say, Why would anyone? His hesitation was not surprising. An affliction that slips in with the stealth of a cat burglar and destroys neurons frightens us. We are tempted to push the threat to the fringes of conscious thought, eat salmon and blueberries (linked to a lowered risk of cognitive decline), and hope for the best. We abandon, sometimes, the people who must squarely face the disease.

But the single biggest risk factor for AD is age. By placing ourselves well within the orbit of modern medicine and complying with the roster

of recommended health screenings, most of us try earnestly to become old. Ironically, our success in prolonging life is related to the disease's prevalence. In the year 2050, one in eight people worldwide will be over the age of sixty-five. At present, ten percent of people over age sixty-five have Alzheimer's disease. The longer you live, the greater the chance Alzheimer's will affect your life in a significant way, if it hasn't already.

THIS BOOK IS MEANT TO HELP YOU to have what I term 'informed compassion,' and to navigate the changes AD brings to relationships with dementia patients and their caregivers. Most of us feel sympathetic toward others when they are mired in hardship. To a limited extent, we can imagine what they're going through, but therein lies the rub: If you have not dealt with this or a closely comparable situation yourself, you can only *imagine* what it entails. Taking the time to learn about a friend's



The effort to bring others up to speed about a problem can add to the stress: It is exhausting to repeat the same information over and over, even when you are grateful for people's interest and concern.

condition and figure out how you can genuinely help is the difference between having *informed compassion* and feeling sympathetic but powerless to make a real difference.


Consider this: Although listening patiently to a beleaguered friend is an act of true kindness, such a friend may be too tired to talk. The effort to bring others up to speed about a

crisis can add to the stress. It's exhausting to repeat the same information over and over to different people, even when you are grateful for their interest and concern. And no one wants to speak in a way that seems meant to invoke the pity of others, the goal of being understood set aside. We just want those with whom we interact to get it, and unfortunately, they can't—not without help.

THE FIRST THREE PARTS OF THE BOOK are about life with the disease after it has passed the preclinical (or asymptomatic) stage, in which changes are occurring in the brain, but outward signs are not yet evident.* People's stories are followed by suggestions that explain how to support both the friend with memory loss and the caregiver.

Keep in mind, although the focus is on Alzheimer's, the most common form of dementia, there are many other causes, and the resulting needs are much the same. For the purposes of this book, the terms are almost interchangeable.² Realize, too, that every person's experience of dementia is different. The scientific study of disease is methodical, if imperfect; relationships are more of an unpredictable creative art. The tips and strategies are meant to serve as guidelines. Do the best you can. A caregiver whose husband in mid-stage AD tends to sit for long stretches, disconcertingly silent and somber, has this advice: "People fear his lack of a response. They feel responsible and afraid if it doesn't go well. I want to say to them, 'Don't be afraid. It isn't your fault. I know he enjoys your company, even if he can't show it. And it means a lot to me when you spend time with him.'"

YOU CAN MAKE A UNIQUE CONTRIBUTION to the lives of dementia patients and their caregivers. You understand the history—the important people, events, and places—upon which your relationship is based. You can reminisce with a friend suffering from Alzheimer's, and you can relate meaningfully to the broader circumstances of the caregiver's life. As someone who does not directly bear the problems and challenges, but can come and go at will, you bring a different strength and energy to the circumstance.

 *"People fear his lack of a response. They feel responsible and afraid if it doesn't go well. I want to say to them, 'Don't be afraid. It isn't your fault.'"*

*For clarification, the first three parts of this book correspond to the main stages you'll find listed on the Alzheimer's Association website (www.alz.org) which contains detailed information on the symptoms of each stage.

We choose friends initially out of a sense of mutual benefit and enjoyment, avoiding, as a rule, people who talk too much or too little, people with overwhelming needs, and people with whom we do not share common interests and activities. However, we remain involved with friends caught up in trouble who may, for a time, seem wholly self-focused and perpetually serious because we care about them: They've become a part of our lives; the relationship has deepened. When Alzheimer's affects the way a person can respond within a relationship or the way a caregiver can participate, the concept of reciprocity must be redefined. We stay connected as an expression of commitment and care. During the most difficult points of life, every person needs the unselfish attention of friends and loved ones who are willing to put aside some of their own needs and allow the relationship to adapt to the changing circumstances.

If you want to be prepared for the changes Alzheimer's brings, this book will help you view the gathering clouds as a reason to stick around rather than run for cover. Read it slowly, as the changes unfold. Give your friend the freedom to change in an atmosphere of acceptance. Whether you have a lot of time or a little, you will make a difference.