WALKING EACH OTHER HOME

SPIRITUAL COMPANIONSHIP FOR DEMENTIA CAREGIVERS

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For Tom, in absentia,
and
For all who have supported Tom and me in our long walk
and
For dementia caregivers everywhere

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Preface

You might ask if we need yet another book about dementia. Many memoirs have been written with great tenderness honoring a loved one who has died from this mind-stealing disease. You can find poignant stories written in the voice of a person with dementia, telling what dementia is like from the inside. A great library of books is available to educate dementia caregivers about practical issues.

So why did I write this book?

I wrote because something significant was missing—something to do with spirit. Although some books acknowledge that dementia caregivers have spiritual needs, they rarely go beyond giving those needs a passing nod as the reader is directed to their religious upbringing. Not all people have a religious upbringing; for some who do, their early religious training may no longer be useful. The guidance offered in caregiving guidebooks is, unfortunately, too often superficial and is couched as self-care that would allow us to continue giving care rather than offering true care for our souls. Caregivers have spiritual needs intrinsic to all human beings. We have increased needs because we have taken on an enormous and often hidden role. Spiritual concerns (anger, loneliness, guilt, and hope) change over years of dementia caregiving as the disease landscape changes. New feelings and thoughts arise. These are serious matters that often aren't taken seriously enough. This book is an effort to begin addressing these matters.

I also wrote this book to remember Tom, my much-loved partner and husband of twenty years. Thirteen of those years were spent walking with Tom's younger-onset Alzheimer's. To "re-member" Tom means putting together again the parts of him and making him whole again in my heart. I don't want to lose him or the gifts that our life together gave me.

I also wrote hoping to find meaning in my years of dementia caregiving, a time when my professional options were constricted and my personal goals were put on hold. I often asked, “Why? What is the meaning in this? Why does a good God let a man suffer the indignity of losing his very self?” I struggled to find a way through the morass of feelings and questions. If what I learned can help lighten others’ struggles, this book will have been well worth the effort. Since I am a registered nurse, a spiritual director, and an ordained priest, Tom often teased that we had all the bases covered, but one never does. There’s always something new to learn, and I was often a reluctant learner,

My aim is to walk with you for a while on your journey and help you articulate your own spiritual story. As you explore what is true, what is not, what gives you purpose, and what keeps you caring, you will be mining gold.

Introduction

The thirteenth-century Turkish satirist and trickster Nasreddin Hodja told wonderfully provocative stories. Oral folk tradition has passed them down through the centuries and they are still told to children today. One of his stories is especially fitting to dementia caregivers as we seek to find the meaning of our experience. It goes like this:

> One night, Nasreddin was found by one of his followers searching under a streetlight. The follower asked, "Master, what are you doing?" Nasreddin responded that he was searching for his key. The follower joined in and eventually asked, "Where did you drop it?" Nasreddin replied, "Over there in the shadows," pointing to a spot several yards away. "But why aren't you looking over there?" "Because there is more light here," the master replied.[1]

The question of where to search for the key—where the light is best or where it has been dropped—may seem easy to answer, yet to step into the shadows is difficult. An ill-defined world where shapes shift demands a change from seeing clearly to sensing. This book will take you into the shadows, into dark, uncomfortable places. Searching for meaning here is not for the faint-hearted, but dementia caregivers are not a withering group.

The light that is shined on dementia caregiving is usually for the benefit of the person being cared for. It's obvious that people who carry dementia within their own bodies warrant as much light as possible—stalwart support, excellent research, and empathetic clinical care. I would not begin to compare our losses to those of people who literally lose their minds, but seeing our needs as only relating to the person for whom we care is limited and limiting. Too often we are not seen whole. Are we not just as human? Are our issues not also in need of attention? Are we not more than functionaries whose sole purpose in living is to care for one other who is terminally ill? Dementia changes us too: our inner being and even our bodies. We are too often a forgotten lot, and this writing seeks to change that.

What You Will Find in This Book

You will meet Tom, my husband and best friend. Our thirteen-year odyssey of younger-onset dementia is naturally unique to us. Your journey is your own, just as your loved one's dementia is not like that of any other. That said, I believe the poet Maya Angelou who wrote, "We are more alike, my friends, than we are unalike."[2] I believe we would do well to travel together as much as we can on this long and challenging journey.

You will meet me in this book, and I hope you will find in me an experienced companion, one who has compassion for others on the journey. I struggled with language to describe my experience and decided to call it dementia caregiving. I could have used other words (*care partner*, *caregiver to a person with memory loss*), but I decided on a commonly used phrase for consistency. Also, I use the word *dementia* knowing it is not one disease but multiple clinical processes with diverse causes. Some people find the word *dementia* offensive, but it is accurate. I chose to do my part to redeem the word.

If my goal is achieved, you will meet yourself in this book. I invite you to explore your own feelings and responses to what I share. We each develop our own meaning (even our own theology) as we encounter spiritual issues along this path. No one has "the" answers to spiritual questions, but each of us has our own hard-earned knowledge, our own valid perspective, and our own truthful understandings. The answers we find may change with time and more experience, but they remain our unique answers.

How This Book Is Organized

The book is divided into five parts:

- Part One: “Starting the Long Walk” introduces Tom and me as traveling companions, identifies dementia caregiver needs as the experts see them, and considers what it means to care. What is care, anyway? How is it valued, and by whom? Caring is a word and concept we seldom take time to examine.
- Part Two: “Companions” identifies your walking partners. No one goes on this risky journey alone. Your most intimate companion is the one for whom you care, but there are others. You walk with other dementia caregivers, most of whom are unknown to you. They are, nonetheless, very real companions on the very same journey. You also walk with your God, the One who has many names, based on your understanding and experience of the divine. Your original image of God was likely formed in your youth and either developed or discarded as you matured. We each carry a sense of the numinous, the “beyond.”
- Part Three: “Provisions for the Journey” offers nourishment for you along the way. I’ll share my perspective on prayer for your reflection. I’ll suggest some spiritual practices to support you for the long haul. These are not esoteric or foreign practices, but simple things that you might actually be able to fit into your overloaded day. Because the feelings you encounter can be confusing, I offer the concept of the *mandorla* as a way of handling contradictory feelings.
- Part Four: “Encounters along the Way” is a collection of possible feelings and experiences we confront in dementia caregiving. The encounters are not sequential, nor are these chapters necessarily meant to be read in any particular order. Rather, one day you may experience helplessness and want to explore that chapter. Another time, you might find your anger welling up and seek to explore that. Go where you are led on any given day. I make no claim that the encounters I have identified are experienced by all

dementia caregivers, nor do I see this list as comprehensive. My hope is that they will offer touchstones, a form of companionship to my fellow caregivers. "Encounters along the Way" may be where this book can be most valuable. It is where growth will come. You are invited to explore your own experiences in dementia caregiving and see them in a fuller way. By reflecting, you will be able to put yourself into this book. Your book will be written by you. I don't have the last word; you do. I don't have your answers, but you do, and they live inside your deepest self.

- Part Five: "Are We There Yet?" offers a conclusion that really is no conclusion. We will always carry memories and questions about the meaning of dementia and dementia caregiving. It's a part of our continuing spiritual growth.

What You Will Need to Use This Book

A Way to Record Your Thoughts

What I have written is intended to provoke you to think about your own caregiving experience, hopefully integrating diverse threads. Recording your thoughts can take different forms, like journaling or expressive art or recording your voice.

Reflecting on your experiences can help you rise above the daily grind. Getting ideas out of your head clears your mind of its endless, often circular, chattering about an issue. Mental blathering is silenced by the light of loving reflection. When we name feelings, they are out there in front of us; they can no longer lurk below consciousness or hide behind busyness. They become more real and also more pliable. Something can be done with them: they can be met, explored, sorted, and related to other feelings. They can be better understood, even embraced.

If you are journaling, you will want to invest in a blank book that you find attractive. It could be a spiral-bound notebook or a hardbound journal—whatever pleases you. Find a pen or pencil that feels good to your hand. Or use an electronic tool if that's preferable. Not everyone—and in particular dementia caregivers—can make time to do "proper" journaling. Instead of thoughtful paragraphs, maybe there is time only to jot down a few thoughts. Maybe all you can manage is one-word bullet points. At least these will leave a trail of your reflections. Later you can revisit the notes and expand on them if you like.

Not everyone enjoys using words. Maybe a collage is your way of tracking what's going on inside you. Your tool might be clay, colored pencils, or another medium. Any of these can be the means of getting your inner experience out into the light. Use whatever suits your time and inclinations. Gather the tools that you'll need and store them in a place where you can access them without having to assemble them each time you want to use them.

Recording your experience is personal, helping you to hear and see yourself. No one else is listening or watching; your reflections are yours and yours alone. You need safety in order to be honest and vulnerable. Your reflections don't have to be well constructed or thoroughly formed. They don't need to be clear. They only need to be true and real.

A Bit of Time

Time, of course, is that all too scarce commodity. It doesn't have to be a lot of time; maybe ten or twenty minutes. The time needn't be rigidly set, and it can be taken intermittently when you find it. On the other hand, it might be a regular appointment you have with yourself, marked on your calendar as you would a doctor's appointment. If you have respite care for a day, you might want to take yourself to a quiet place and really delve in. Use what time you can afford. How I wish I could give you more time in your overly packed day, but each of us gets just twenty-four hours each and every day, no matter what demands are put on our time. It is ultimately our choice as to how to spend them.

A Curiosity

You'll need to foster a curiosity about yourself and your experience of dementia caregiving. You'll be thinking as well as feeling. Curiosity requires a willingness to step back and to take a long, loving look at your life. This curiosity is an investment in yourself and a way to honor your experience.

An Openness to Difficult Feelings

This is the hardest part: welcoming the parts of life that hurt. Our minds are programmed to hide from us the things we don't want to face. When they crop up, we push the feelings away, hoping they will die from neglect. But our rational, thinking selves know they won't disappear. They will smolder and erupt into flames when we least want or expect them. Take courage; remember that anxiety is only increased by not wanting to feel what we feel. The pain is worth the effort. Remember too that feelings are embodied. Whatever is going around in your head is also going around in your body. Listen to your body.

Practically Speaking

These guidelines will support your reflection.

- Choose a place you find comfortable—a favorite chair or a place near the light from a window.
- Quiet yourself with some consciously deep breaths to help empty your mind. Offer a short affirmation or prayer. Be both patient and ready at the same time.
- Pick up this book and let your eyes fall on a topic that engages you or mirrors where you are at the moment. Look over what I wrote about my experience, read the "Reflections" section that elaborates on the encounter, and consider the "Wisdom" that is offered to engage your imagination.
- Notice what memories, questions, and feelings bubble up inside you. Feel your feelings and notice them in your body.
- Express your responses in writing or in your chosen mode. Use one or more of the questions posed in the "For Your Consideration" sections as prompts or, if you prefer, work free form.

- Date the entries to help document your journey. Dementia caregiving can make life a busy blur, and dates help put your experiences into the context of your full life.
- Follow your reflecting with silence, and maybe a prayer.

Patterns of your life may be revealed as you reflect. You may see repetition. If so, that's important. Responses recur until we get to the bottom of our feelings and questions. While some patterns are cherished, others are imprisoning. But patterns can be changed. This is an opportunity for unexpected beginnings.

Part One

Starting the Long Walk

Chapter One

"We Have Dementia"

Believing that life is fair used to be easy for me. It just seemed common sense that we reap what we sow. Tom's dementia disabused me of that. Dementia was not a just reward for a life lived with compassion and integrity.

Tom and I were supposed to be leading spiritual retreats from our home near Laramie, Wyoming, where the mountains would invite us out for frequent visits, the university would offer cultural and intellectual stimulation, and the cathedral would offer solace. There was to be a large round table in the kitchen for conversation and humor shared with guests and friends over home-cooked meals. There was to be lots of space outside with a small chapel, a sweat lodge, and a yurt to house guests. We were going to lead discussions of global issues and weighty matters of justice and spirituality.

Yet here we were instead, silently sitting in the zinnia-filled courtyard in an Indiana care home, Tom in his wheelchair and me on a bench next to him, my journal open and my pen in hand. I had tried to make Tom comfortable, able only to guess how to do that, because he no longer had words. He couldn't express himself with facial gestures, now that his facial muscles were flaccid. I released the back of the wheelchair so he could lie flat, and I put a small pillow under his head, a pillow I made from soft denim fabric that was once part of his well-worn blue jeans.

When I first met him, Tom owned no other clothes than denim jeans, T-shirts, and a fleece-lined jacket, appropriate wear for working outdoors at the retreat center where he and his partners offered hospitality to city slickers like me. The Antelope Retreat Center offered guests a window into rural life—irrigating hay fields, bottle-feeding the bum lambs discarded by the professional shepherds, shopping once a week in the supermarket sixty miles away. The Center had introduced me to Native American spirituality taught by elders from Yankton Reservation in South Dakota. Guests participated in sweat lodge ceremonies, which proved to be profound prayer meetings, and we experienced solo vision quests in the high sun-soaked Red Desert.

The same bright sun was shining on us, but the earth had shifted. His sun-bleached ponytail had been cut off. His blue eyes were no longer sparkling, nor were they focused. The mouth that had easily sung and whistled now hung open. His once powerful upper body was disfigured: the contractions in his neck caused his head to be permanently twisted toward his left shoulder. His legs and arms (and sometimes his torso) shuddered with unpredictable muscular spasms. The myoclonic movements, like mini seizures, were with him constantly except when he was in a deep sleep. Outside in the open air that he loved so much, sleep did come to him as the cicadas chirped their seasonal music and the wind gently ruffled the leaves above us. Before his own diagnosis, Tom, aware of his father's dementia, told me, "If I ever lose my mind, take me to the Red Desert and leave me. Don't come to find me." He got only part of his wish. There was no Wyoming desert in the care home, only the wilderness that dementia created for him.

And I couldn't find him, no matter how hard I tried.

Reflections

Dementia is not an altogether solo experience. Shortly after his diagnosis, Tom said, "I don't have dementia. *We* have dementia." He spoke a truth I only learned as I lived into it. How wise he was!

No dementia is solitary, especially for those whose lives have intertwined. We walk together, caregiver and care recipient, each having a different experience with the same dementia. We walk together even if we are living apart. We walk each other home, even though dementia takes us to different destinations.

During Tom's illness, I intermittently wrote in my journal. I did not want to lose the complicated, multilayered, bittersweet experience of loving him through it all. In reading the entries later, I watched myself going through the ordeal of Tom's moving further and further away from me. I noticed how I responded, amazed at my varied reactions. Some of the responses were quite gratifying. Some, just as strong and frequent, made me feel embarrassed. Some responses seemed antithetical to each other, yet they were all there and all mine.

We are given hints as to how to manage the journey of dementia caregiving, but we have no dependable road map to tell what to expect. We all learn by doing. We are confused amateurs, trailblazing through unchartered territory. At times, we catch a surprise glimpse of the former personality of the one we care for. At times, we find things inside our hearts that we didn't expect and find them quite mysterious. Few other people seem to notice that we "have dementia" too, that we are being changed by it. Our dreams and former expectations are forfeited to the realities of dementia.

The journey, both the inner exploration and the public odyssey, is not one we chose or wanted, but one we were given. We live it, step by step, because there is no alternative route.

Wisdom

Traveler, your footprints
are the only road, nothing else.
Traveler, there is no road;
you make your own path as you walk.
As you walk, you make your own road,
and when you look back
you see the path

you will never travel again.
Traveler, there is no road;
Only a ship's wake on the sea.

—Antonio Machado[1]

The bad news is we don't have any control. The good news is we can't make any mistakes.

—Chuck Palahniuk[2]

Maps only get you to destinations already discovered, but to discover the unknown you need to burn your maps and walk free, unrestrained and unconditioned like the wind.

—Abhijit Naskar[3]

Though your destination is not yet clear
You can trust the promise of this opening;
Unfurl yourself into the grace of beginning
That is at one with your life's desire.

—John O'Donohue[4]

For Your Consideration

- What future had you hoped for in your relationship with the one for whom you care? Let your imagination take you to that dreamed-of place.
- In what ways has dementia changed the relationship you had?
- What changes do you foresee coming? What fears do those anticipated changes bring?
- Is there a compass you look to for navigating through life? Are you finding it dependable on the journey of dementia caregiving?