

## Praise for *Dementia and the Church*

*Dementia and the Church: Memory, Care, and Inclusion* is a treasure chest of insight, inspiration, and guidance for churches that seek to practice “informed compassion” for people affected by dementia. With sensitivity birthed from painful personal experience and knowledge gleaned from extensive research, Dr. Cail has provided a much-needed resource for faith communities and their leaders.

—Bishop Kenneth L. Carder, Ruth W. and A. Morris Williams Professor Emeritus, Duke Divinity School, and author of *Ministry with the Forgotten: Dementia through a Spiritual Lens*

Having been involved with ministry to dementia patients as a deacon and chaplain for over thirty years, I am so glad to have this book available. I teach pastoral care ministers and chaplains to the sick, and I wish this book had been available when I started many years ago. Dr. Mary McDaniel Cail’s book is a touching and yet very practical approach to understanding dementia and Alzheimer’s disease. It provides insight for those who are involved and are ministers to these wonderful and precious people. Having had my own family members go through these times in their lives, I have learned to value those who know how to minister to people in this time of their lives.

—Deacon Jack Conrad, director of spiritual care, CHRISTUS St. Vincent Regional Medical Center, Santa Fe, New Mexico

This is a deeply helpful and much-needed book, filled with powerful stories, important information, abundant resources, pastoral wisdom, and practical steps that all of us can take. It offers both an unflinchingly realistic account of what it is like to live with dementia and a hopeful way forward for pastors, individual church members, and congregations as we seek to do better at walking alongside people with dementia and those who care for them. I will be recommending it widely in my dementia ministry with churches and using it as a textbook in my seminary course on ministering to those living with dementia.

—Rev. Dr. Suzanne McDonald, professor of systematic and historical theology, Western Theological Seminary

Dementia is a complicated journey. It is one that we often fear as we anticipate it and wonder who will care for us and love us as we move into it. The church is a space of love within which Christians live out the beautiful truth that *nothing* can separate us from the love of God. In order to make the belief believable, we need a community who can live out that love and help us to live into it as we move on in our dementia journey. In this thoughtful, moving, and deeply practical book, Mary McDaniel Cail offers us maps, ways of thinking, and practical guides for the journey that can help us as individuals and communities to enable love, lament, and joy as we walk with one another along difficult roads. This is an important

book that offers new and exciting possibilities for creating communities where everyone truly belongs.

—Rev. Dr. John Swinton, professor in practical theology and pastoral care, King’s College, University of Aberdeen; Fellow, British Academy and Royal Society of Edinburgh; author of *Dementia: Living in the Memories of God*

Church congregations are aging. The aging process brings with it unique opportunities and some very specific challenges for churches. The opportunities are endless and include wisdom, a lived history, amazing stories, and an endless desire to help. One of the challenges of aging for both the congregation and the pastors and deacons who serve in congregations is the illness of dementia. Mary McDaniel Cail has not only given us a glimpse and a firsthand account of dementia in its main forms, but she has also presented us with a blueprint and model for what she refers to as “informed compassion.” This book gently guides the reader through the caring process for caregivers and for those who receive the care. This book is very practical in that it offers the definition of dementia, as well as the realities of those living with dementia and of those who care for someone with dementia. She guides the reader through the process of creating a caring ministry, including educating the congregation and preparing leaders and volunteers to carry out this important work. She provides vocabulary, programs, and activities that work. She even includes a comprehensive bibliography for additional study.

As someone who was a caregiver for a parent and a spouse, I highly recommend this book to all congregations, pastors, deacons, and anyone else caring for someone with dementia. This book is well on its way to becoming a seminal piece of literature for caring ministries.

—Deacon Dr. Cecelia Travick-Jackson, retired associate professor, California Lutheran University; Assistant to the Bishop for Senior Adult Ministry, Southwest California Synod (ELCA); and deacon for senior ministry, Mount Cross Lutheran Church, Camarillo, California

There’s no subtle way to put it: *Dementia and the Church* should be assigned reading for seminarians, clergypersons, pastoral care professionals, and counselors the world over. In it, Dr. Mary McDaniel Cail sheds desperately needed light on the crucible of cognitive decline and how best to care pastorally for those who live with it—which my decades in Christian ministry have shown me is many more people than we realize. This beautifully written, impressively well-researched, and deeply compassionate book is a gift to the church and all those who seek to embody the grace of God to sufferers.

—David Zahl, Director of Mockingbird Ministries and author of *Low Anthropology*

Dementia  
*and the*  
Church

MEMORY, CARE,  
AND  
INCLUSION

Mary McDaniel Cail

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Memory, Care, and Inclusion

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To my father, Jack P. McDaniel, M.D.

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## Introduction

With the Lord one day is like a thousand years, and a thousand years are like one day.

—2 Peter 3:8

I confess that for three decades, I was an inveterate church visitor, hardly ever missing a Sunday. I visited some churches a handful of times, some for years—Baptist, Catholic, Episcopalian, Methodist, Moravian, nondenominational, Presbyterian, Unitarian. I don't remember all of them. I supported these churches, at least the ones I attended regularly, and I served in their soup kitchens, Sunday schools, nurseries, altar guilds, missions, prayer groups, and committees. (They never wanted me in choir, but once I was invited to join the bell ringers, to hold the smallest, least audible bell.)

I didn't join a church until I was in my early sixties. I had been going to an old Episcopalian church with Tiffany stained-glass windows dating back a hundred years, that spread the story of the gospel around the nave like pages taken from a book. This would have kept me there for a while, just to watch those windows emerge in the sunlight on Sunday mornings. I joined, though, because I felt welcome; I felt at home, and I thought almost anyone would. The rector learned my name. I was one of hundreds of people to him, streaming in and out of four services. I joined because, even though I hadn't joined, the clergy took care of me through the deaths of both of my parents. They prayed for me. They visited me at the hospital. They allowed me to bury my mother's ashes in their memorial garden.

This book is about becoming a welcoming church to people with dementia and their caregivers and loved ones. My father died with vascular dementia and Parkinson's disease. His thinking and behavior were erratic. Sometimes

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he said things that were remarkably perceptive, but more frequently, toward the end, he fell into episodes of despondent weeping and silence when he couldn't seem to make sense of anything. He lost control of his body, reduced to almost an infantile state, in which he labored just to keep breathing. My father was a fighter.

During the church visiting years, I went through hard times, some of them unspeakable. I'm using this word, *unspeakable*, imprecisely. I mean by it that I cannot speak about them because they feel too deeply rooted, still, in pain; it's easier to say nothing. After the passage of time, I can talk about my late husband, a quiet, brilliant man who graduated first in his class in medical school. He took his own life a few months after undergoing surgery for a brain tumor. I found him in his office, hanging from a dog leash. A year before, during Christmas, I had miscarried our only pregnancy after five years of infertility treatment—sixty months, with hardly a break. My brother, born in the same calendar year as I was, dropped dead of an undiagnosed heart condition while he was raking leaves, at the age of fifty. I was going to a community church at the time. I sat in the same pew, week after week, with tears I could not control slipping down my cheeks. I know about grief.

The grief of dementia is different. It hurts in a different way to witness a loved one lose his mind, or her mind, in fragments, until you've become a stranger and they have, too, in many respects. Dementia is hard. It provokes a gamut of behaviors between people, from withdrawal to aggression and disinhibition. My father, who never failed to write a note to me without inscribing it with the acronym, SWAK (sealed with a kiss), could be menacing on nights when he struggled with sundowners, making violent, outlandish threats. I knew this arose from his brain dysfunction. It hurt nonetheless. He would find himself on other nights and tell me, as was characteristic of him, that I was the best little girl he ever had. A church's approach, whether through programs, ministries, or services, must be based on the understanding that one person at a certain stage may have very different needs and reactions from another and that people with dementia can be unpredictable. This book will give you an awareness of what the condition may bring about and how the church can help.

It's tempting, when you're with someone who has lost all ability to reason, who repeats himself over and over again or becomes agitated when he is separated from his caregiver, to see childishness. It's reasonable, when you are at the bedside of a person barely able to swallow and unable to speak, to think



of a return to infancy. But the Bible, as we know, is liberally sprinkled with references to our blindness, meaning our human proclivity to miss the main point of things. What we take in through our senses is unavoidably filtered by our understanding of what it means to us, usually in terms of either pleasure or problems. In an older person fumbling within a fog of dementia to interact with his or her surroundings, we cannot help but see dysfunction. We cannot help but imagine the impossibility of simple tasks—making a sandwich, zipping a jacket, sorting the mail—and feel overwhelmed by the idea of what each day must hold in terms of sheer frustration. We must also keep in mind, though, the achievements, griefs, hardships, and successes that distinguish a long life. It's our job to see a fraction of what God sees—through, with, and beyond the dementia. I wish the people who easily dismissed my father as a wasted old man slumped in a wheelchair could have seen him crouched in surgical scrubs, receiving with gloved, bloodied hands one of the ten thousand babies he brought into the world.

Churches strive to be inclusive, and as such, they attract a diversity of people, most of whom fit into groups around which ministries are organized: children, youth, singles, seniors, and so on. The word *dementia*, logically the choice for a ministry with this group, is stigmatizing, even if it modifies *friends* or *family* (referring of course to the church family). It shouldn't be, but it is. You don't need to look beyond a thesaurus to see why. It's a bit tricky to identify such a ministry with a descriptive term people will quickly recognize, while avoiding an unwelcome label. As a starting point, let me suggest the word *memory*, as in “memory ministry”—without the addition of the word *loss*. Dementia in all of its forms affects memory, a fact with which most are familiar. A church's outreach to people living with dementia will necessarily rekindle long-term memories of worship by employing the stories, hymns, and rituals that become engraved in our collective minds through frequent repetition. We can all share in this experience. Such a ministry should also seek to instill, at least in the minds of others, the memory of what these people accomplished in the past and a true sense of what they can offer to us in their present lives, so they are seen holistically by those around them. My father may have been frail and uncommunicative at the end; he was still a physician, and he deserved to be called “doctor,” not the belittling terms of endearment people used when he was no longer able to defend himself.

Old age makes us vulnerable, and in a culture that exalts youth, the elderly are easily nudged to the fringes, particularly when their minds are less sharp

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and words come less quickly. Too often, they are not protected in hospitals and nursing facilities, the very places we must, under common circumstances, entrust with their care. If I am ever able to reconcile my sadness and anger over the neglect my father suffered at the close of his life, no matter my fight to prevent it, it will be by God's mercy alone. I kicked against the goads. I contended as never before with feelings of hate. I was a solitary person, it seemed, struggling against a system set up to push him further and further into impairment and pain.

During this terrible time for my father and me, one of the ministers of that Episcopalian church, the final stop in my long church pilgrimage, showed up, to my surprise, at the hospital where Dad was slowly dying, and we sat outside the room, among muted wall coverings and furnishings meant, no doubt, to encourage calmness in people. I was a torrent of stress, sadness, anger, and helplessness beneath a veneer of exhausted control. In this man's steady presence, words surged from me as though they had burst from a dam. He didn't interrupt; he didn't talk about God, or salvation, or love, or faith, or courage. He simply listened, and back in my father's room, he prayed a tender, reverent prayer for us. It was comforting, strengthening, quieting. *I will quiet you*, God seemed to say in those minutes of his prayer, *with my love* (Zephaniah 3:17).

My work, my life's work, since those years occluded by grief, has been to advance what I call "informed compassion." We feel compassion when we are confronted by another's despair, but compassion alone does not give us an understanding of what to say and do to help someone whose life has been upended. Despair is dangerous, isolated despair even more so, and isolation can happen in the company even of people who care deeply, if those people are unaware or inadvertently insensitive. Informed compassion means taking the time to learn enough that you understand in broad brushstrokes what a difficult grief, loss, or diagnosis signifies. In this case, it means bringing the church as a whole to a point of understanding, so parishioners do not feel awkward, and programs and services are well tailored to the needs dementia engenders. It's about knowing how to accept, how to pray, how to relieve, and how to comfort—in these ways, showing to those who must live with the difficulties of dementia the soul-quieting God who says to each of us, *Can a mother forget the baby at her breast and have no compassion on the child she has borne? Though she may forget, I will never forget you. See, I have engraved you on the palms of my hands* (Isaiah 49:15–16, NIV).