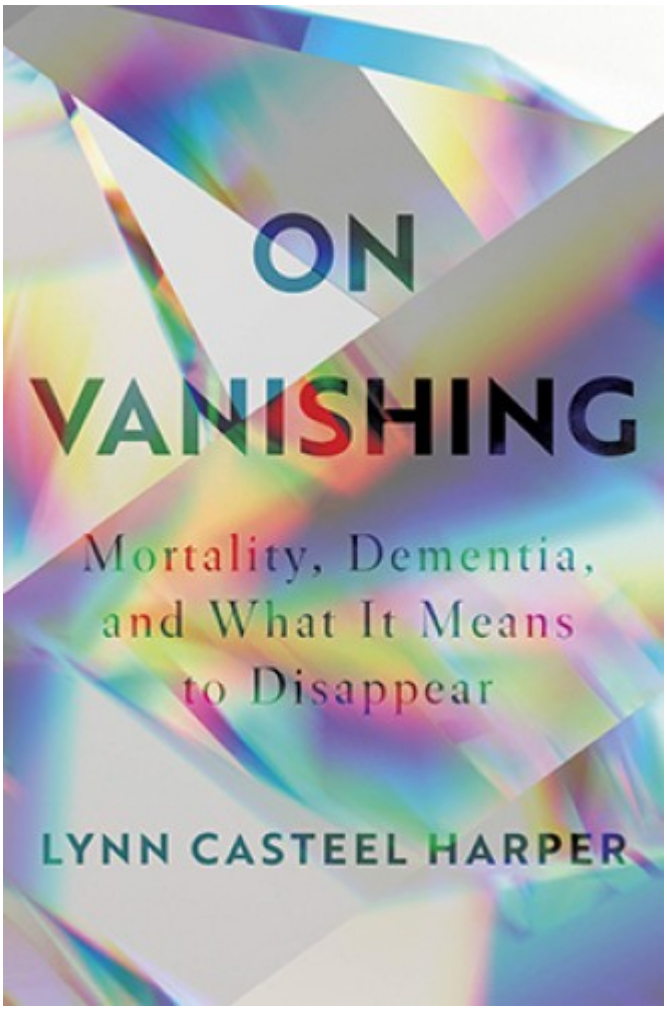
Toward a more generous way of thinking about dementia

Two very different books provide guidance for family, caregivers, and clergy.

by Sophie Lefens in the May 20, 2020 issue

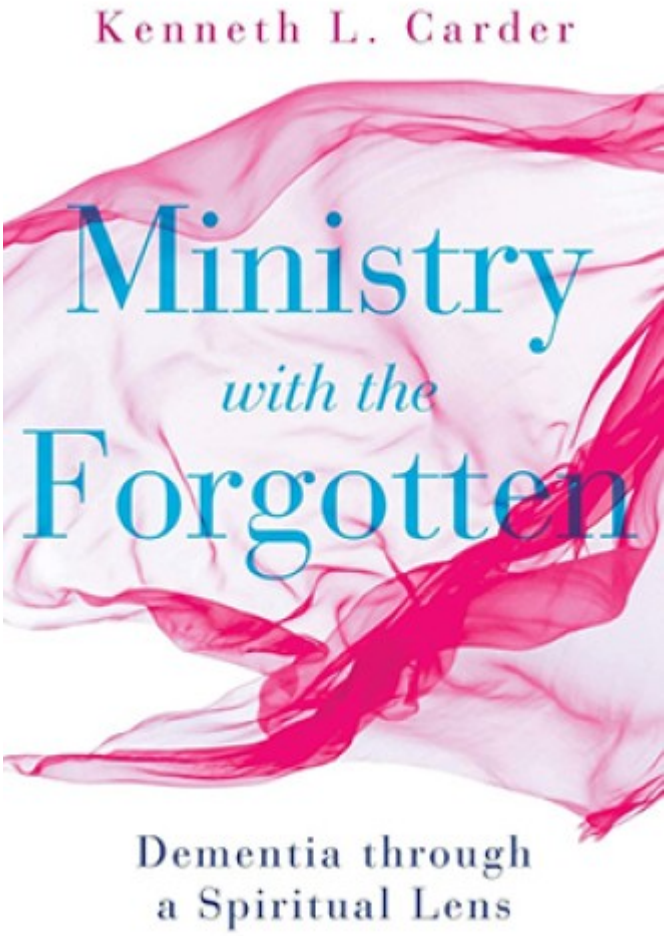
In Review



On Vanishing

Mortality, Dementia, and What It Means to Disappear

By Lynn Casteel Harper
Catapult



Ministry with the Forgotten

Dementia through a Spiritual Lens

By Kenneth L. Carder
Abingdon

Few diagnoses evoke the kind of hushed terror that regularly accompanies Alzheimer’s disease. The ambiguous nature of the disease confronts us with difficult questions of selfhood, mortality, dignity, love, and discipleship. Lynn Casteel Harper and Kenneth L. Carder address these questions head-on in their candid and compassionate explorations of the role of dementia in our communities and culture. They each draw from their family experiences with dementia and their professional lives as Christian ministers. Together they advocate for a greater awareness and

generosity in how we speak and think of dementia.

Not many books have so swiftly dismantled my default mode of thinking as Harper's *On Vanishing*. Harper, a minister for older adults at New York City's Riverside Church, rigorously uproots the stigmatizing language shrouding Alzheimer's. By identifying the dominant metaphors surrounding the disease—"thief, kidnapper, slow-motion murderer" leaving behind "shells," "darkness," and "the walking-dead"—Harper begins a deft interrogation into the deeper cultural ills perpetuating this marginalization. Her book calls for a robust reimagining of Alzheimer's and the way we care for each other in its presence.

Implicit in Harper's argument and writing is a deep respect for language and its ability to create new realities. Though she writes from sociological and theological perspectives with manifesto-like urgency, *On Vanishing* has the emotional complexity and richness of language of any great work of literary nonfiction. Like the Romantic poets and writers she references throughout, Harper masterfully translates complex abstractions into crystalline distillations.

For instance, on the relationship between dementia and the body, she writes: "I sense that our culture is fearful both of the body's powerlessness and its power." On dementia patients' experience of exile: "The story is a familiar one: the strong subjecting the weak—the strong eradicating their fears through expulsion of the weak." On the cultural perception of mental slipping: "We want madness . . . to shut up, to turn vacant, to put on some clothes; we want to neutralize its danger and muzzle its unsettling truth."

In a few hundred pages, Harper covers an awesome breadth of inquiry while bringing to the fore her own relationship with her grandfather and his experience with Alzheimer's. The book is a genre unto its own: it begins with Harper standing in front of Jacques de Gheyn's painting *Vanitas Still Life* and includes a hike up Mount Sinai as well as a brief biography of Ralph Waldo Emerson's final years. Throughout this eclectic journey, Harper offers new language and metaphors that show Alzheimer's to be a deeply human experience in which we all participate.

Though the book is full of real-life anecdotes, there is a noticeable absence of negative depictions of the disease. The project is aimed at stripping away the tragic language encasing Alzheimer's, so perhaps Harper fears undermining her own argument by speaking to some of the grittier truths of the disease. *On Vanishing*

would be even more compelling had Harper not flinched from the full spectrum of experience. Still, it is an excellent book for anyone, regardless of age or creed, who wants to seriously examine what it means to be mortal.

Ministry with the Forgotten is aimed at a narrower audience. Kenneth Carder, a retired Methodist bishop and Duke Divinity School professor, writes from within the linguistic and theological scope of mainline Protestantism. Reflecting on his experiences with his wife Linda's Alzheimer's disease, Carder takes readers through his personal journey of making peace with what is. He draws upon the Bible and a number of theologians, most heavily the Scottish theologian John Swinton, to explore what it means to be a disciple of Christ when you can't remember who Christ is.

Much of the book aims to correct what Carder sees as an incomplete understanding of discipleship and salvation. He emphasizes the communal nature of salvation when he writes, "Mediation of God's salvation requires entering solidarity and presence with the other, as God has entered solidarity with humanity in Jesus Christ." At the same time, he continually draws attention to God's mercy and love as an unconditional gift.

Resisting the duality frequently imposed on dementia patients as either fully present or fully absent, Carder broadens common assumptions of selfhood and affirms the humanity of all individuals regardless of mental acuity. He writes, "There seems to be a widespread assumption that people with dementia . . . are void of spiritual needs, longing, or wishes. Yet, if human beings bear the divine image into whom God has breathed God's own Spirit, we are 'ensouled bodies, embodied souls.'"

Carder speaks frequently of the emotional and spiritual devastation of Alzheimer's. He does so in order to sympathize with and offer solace to his readers. The book's ultimate message is one of Christian hope. He writes, "God's memory is the inexhaustible source, the infinite fountain from which flows all existence. It is within God's memory that 'we live and move and have our being.'" The emphasis on God's goodness makes *Ministry with the Forgotten* a comforting read.

Some readers may find the book intellectually thin. In a section titled "Mediating God's Salvation" Carder tells the story of a woman who shares with her priest her reluctance to care for her mother. The priest responds, "But your salvation may depend on your care for her; she may very well be the means to your salvation." Carder elaborates, "This is not to imply that we earn our salvation by our service to

the vulnerable and powerless. Rather, it is the recognition that we encounter the living God in those with whom God in Christ is in solidarity and we are thereby changed.” Here God becomes a kind of syllogism, and Carder risks turning individuals with dementia into vessels of others’ salvation.

But this kind of simplifying of complex social and theological ideas into accessible, sectioned chapters could also be seen as the book’s strength. Carder’s voice throughout is warm and generous, and the book reads very much like a sensitively written self-help book. In a later chapter titled “Dementia, Grieving, and Death,” Carder even includes a section on “Tasks of Grieving.” While some might balk at the enumeration of something as complex as grief, for those who find clarity and rest in practical solutions and outlined steps, Carder’s book will serve as a welcome companion.

In very different ways, both *On Vanishing* and *Ministry with the Forgotten* rejuvenate the collective conversation surrounding dementia and reify the enduring humanity in us all.