

Kenneth L. Carder

The background of the cover is a flowing, translucent red fabric that appears to be blowing in the wind, creating soft, undulating folds and ripples. The color is a vibrant, slightly pinkish-red. The text is overlaid on this fabric.

Ministry
with the
Forgotten

Dementia through
a Spiritual Lens

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Chapter 1

Dementia through a Medical Lens

Introduction

The words exploded like a bombshell when spoken by the doctor: “frontotemporal dementia!” Though we knew something was amiss in Linda’s thinking, the word *dementia* had been avoided. The term conjured up too many fears, negative stereotypes, and foreboding possibilities to be used to identify the reason for Linda’s symptoms.

Many people I talk with confess they fear Alzheimer’s and other forms of dementia more than cancer or any other disease; and this fear increases with age and as they come to know people in their circles who are diagnosed. Denial, therefore, is an understandable response.

Furthermore, the stigma attached to dementia contributes to denial. “I’d rather lose my life than my mind” is a familiar expression. In a society that places priority on intellectual acumen and communication skills, cognitive and language degeneration are often viewed as worse than death itself. Frequently heard remarks by people in early-stage dementia include “I’m stupid,” “I’m crazy,” “I hate myself.”

The fear of lost relationships and isolation contributes to dread of the word *dementia*. Symptoms frequently include loss of social skills as behavioral filters weaken, making social interaction more difficult. The world becomes smaller as the circle of relationships diminishes. Potential loneliness and isolation loom ahead.

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Much of the explosiveness of the word *dementia* originates in misunderstanding or lack of basic knowledge of the diseases that fall under the term. Separated from medical information, the term can be demeaning. It is sometimes used to insult, discount, or negatively judge another. “She’s demented, so don’t pay attention to anything she says.” Or referring to a person who commits a serious crime as “demented” promotes the notion that people with cognitive diseases are dangerous. People with dementia are not criminals or “stupid” or without gifts and talents. They are individual persons with diseases of the brain.

A medical lens is an important means of countering such misunderstanding and perhaps lessening the denial and stigma associated with dementia.

Definitions: *Dementia* as an Umbrella Term

What is *dementia*? The term as widely used implies that dementia is a disease when, in fact, it is an umbrella term covering a constellation of symptoms of underlying diseases. The precise medical definition from the World Health Organization’s International Classification of Diseases and Related Health Problems, tenth edition (ICD-10), is as follows:

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behavior, or motivation. This syndrome occurs in Alzheimer’s disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.¹

The National Institutes of Health defines *dementia* based on the cognitive losses, as follows:

Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person’s daily life and activities. These functions include memory,

language skills, visual perception, problem solving, self-management, and the ability to focus and pay attention.²

These definitions for dementia include several important components. First, dementia is a *syndrome*, or group of related symptoms, that characterize a particular abnormality or condition of the brain. Therefore, dementia refers to symptoms or manifestations of underlying physiological conditions. Several diseases manifest themselves in the symptoms that fall under the umbrella of dementia.

Second, the symptoms that manifest themselves in dementia correlate with pathologies in the brain. They are diseases of the brain, as heart disease is a disease of the heart. There should be no more stigma assigned to people with diseases of the brain than to those with diseases of the heart or liver or kidneys. They are all impairments of bodily organs.

There is a difference in how dementia impacts a person, compared with other embodied diseases, however. Diseases of the brain adversely affect the person's thinking, perception, behavior, and control. In the early and middle stages of her disease, Linda was embarrassed that she couldn't remember people's names or keep up with conversations and that she would often say inappropriate things. She felt "stupid" and ashamed. Others may have considered her uninterested or even rude. But such behaviors were beyond my wife's control. Those negative behaviors were the disease, not Linda!

Separating the symptoms of disease from the identity of the person is crucial if the stigma is to be removed and for persons with dementia to be socially accepted. Much of the stigma attached to dementia results from the assumption that the negative symptoms reflect a lack of attentiveness, control, or volition on the part of the person with the condition. Medical information says otherwise.

Also, dementia is not to be confused with the normal cognitive decline that may accompany aging. The aging process affects the total physical organism, including the brain. So-called senior moments—temporary forgetfulness and lapses in recollection—are universal and normal. We all forget at times where we left our car keys; but a person with a brain disease may very well forget what a key or a car is. Furthermore, we can

compensate for aging's memory lapses, whereas a person with Alzheimer's or other forms of dementia will be unable to make such adjustments.

More precise language with fewer negative connotations is needed. Some emerging possibilities in medical literature include "neurocognitive disorders," "cognitive impairment," "degenerative brain disease," or simply "brain diseases." Whatever term is used, it is important to emphasize that the symptoms manifested originate in the malfunction or degeneration of the brain and are not to be equated with behavioral choices or a person's character.

The Brain: Remarkable and Mysterious

Although it weighs only about three pounds, the human brain holds incalculable information and vast power, affecting every aspect of the human body. Our brains significantly initiate, regulate, and monitor our thoughts and actions. The brain's capacity to store and process information and experiences far exceeds its physical size. It, therefore, is understandable that the renowned Dutch neuroscientist D. H. Swaab would declare: "Everything we think, do, and refrain from doing is determined by the brain. The constructions of this fantastic machine determine our potential, our limitations, and our characters; *we are our brains*."³

Swaab's perspective as to the centrality of the brain in human identity mirrors the long-accepted hypothesis expressed by Hippocrates (c. 460–c. 370 BCE), considered the father of medicine:

It should be widely known that the brain, and the brain alone, is the source of our pleasures, joys, laughter, and amusement, as well as our sorrow, pain, grief, and tears. It is especially the organ we use to think and learn, see and hear, to distinguish the bad from the good, and the pleasant from the unpleasant. The brain is also the seat of madness and delirium, of the fears and terrors which assail us.⁴

Theology challenges the mechanistic view of the mind and human identity; nevertheless, the relationship between the brain and our feelings and actions is indisputable. The more we learn about the brain, the more questions emerge, and mystery deepens.

The brain consists of approximately one hundred billion neurons, even more glial cells, one hundred trillion synapses, and a hundred billion capillaries. It is an enormously complex organ, and scientists are only beginning to fathom its composition, functioning, and influence.

Medical imaging technology has significantly increased the ability to study the brain and the complex interactions taking place within. Nevertheless, the brain remains a profound mystery. Jeff W. Lichtman, MD and PhD, Professor of Molecular and Cellular Biology at Harvard, reflects in a *National Geographic* segment that we have only begun to understand the brain. He often asks students, “If understanding everything we need to know about the brain equals one mile, how far do you think we have walked?” The usual answers are “three quarters,” “one half,” or “one quarter.” The eminent researcher responds, “I think about three inches.”⁵

Dementia can be described as “brain failure” or “degeneration of the brain” or “malfunction of the brain.” The failure, degeneration, or malfunction results from diseases that affect the neurons, synapses, cells, and capillaries in the brain.

The one hundred billion neurons in the brain live to communicate with one another. Each neuron connects to thousands of other neurons through chemical messengers called neurotransmitters. During any one moment, millions of signals are passed from neuron to neuron and are speeding through pathways in the brain.

In order to stay healthy, neurons need to communicate with one another, receive adequate nutrition (oxygen and glucose) through blood supply, and be able to repair themselves. The disorders that cause dementia disrupt these functions of the neurons. While each disorder has a different mechanism or cause, dementia results because

- *connections* between neurons are interrupted or lost;
- neurons cannot metabolize nutrients and/or blood supply is interrupted;
- neurons cannot repair themselves; and
- neurons die.

The specific symptoms of the underlying diseases tend to reflect the areas of the brain being damaged. For example, damage in the hippocampus results in trouble forming and retaining memories. Damage to the frontal lobes results in difficulty with “executive functions” such as organizing, sequencing, and making decisions. Since much of the brain’s composition and functioning remains a mystery, scientists are only beginning to identify the various malfunctions underlying the symptoms.

Types of Dementia

When the doctor shared with us Linda’s diagnosis, we only heard the one word, *dementia*. We had never heard the term *frontotemporal dementia*. We recognized Alzheimer’s as a dreaded form of dementia, and we knew of elderly persons whose memory loss and confusion were attributed to “hardening of the arteries” or atherosclerosis. The moisture in the doctor’s eyes should have alerted us that *frontotemporal* added gravity to *dementia*. We were soon to learn that many diseases fall under the *dementia* umbrella.

Currently, there is no single test to diagnose any of the diseases that cause dementia. Rather, they are diagnosed primarily through the person’s symptoms and by ruling out other causes. Sometimes a person can have symptoms that appear to be dementia but are caused by other conditions. Medication, infections, nutritional deficiencies, an injury such as a concussion, depression, or severe emotional trauma can each result in acute or chronic confusion, memory impairment, and language difficulties. These treatable conditions must first be ruled out before a diagnosis of Alzheimer’s or a related disease is made.

A thorough evaluation involves recording a detailed medical history, conducting physical and neurological exams, and administering psychological and cognitive tests. Laboratory tests can help find treatable causes such as thyroid problems or vitamin deficiencies. Brain scans such as magnetic resonance imaging (MRI) can reveal tumors, strokes and other vascular changes, and shrinkage within the brain.⁶

Advancement is being made in identifying biomarkers that signal the disease, but these are now used primarily in research settings. They include

advanced brain imaging techniques such as positron emission tomography (PET) scans to identify glucose metabolism in the brain and cerebrospinal fluid (CSF) evaluation to identify proteins that are characteristic of Alzheimer's disease. Genetic testing may be ordered if there is a strong family history of disease or if a rare form of dementia is suspected.⁷

Treatments and Medical Challenges

No cure or effective treatments currently exist for Alzheimer's and other dementias. Medications commonly prescribed for Alzheimer's disease, such as Aricept (donepezil) and Namenda (memantine), may decrease symptoms and enhance functioning for a time in some people. Other medications are used to control behavioral and mood symptoms such as agitation, anxiety, aggression, and depression.⁸

While research increasingly reveals the complexities of the genetic, environmental, and lifestyle factors that contribute to degenerative brain diseases, the underlying causes are not yet fully understood. Known risk factors for developing Alzheimer's and related diseases include: advancing age, vascular disease, diabetes, Down syndrome, head injury, and genetics.⁹ How these and other factors under investigation influence disease progression and interact with each other are questions yet to be answered by the researchers.

The most promising current efforts are directed toward prevention and delaying the onset of the diseases. Protective factors are summed up in what the physician advised us, "What's good for the heart is good for the brain." Maintaining good cardiovascular health through exercise and a healthful diet, engaging in lifelong learning, and staying active and involved with others appear to play a role in maintaining brain health.¹⁰ It is important to note that genetics and other factors can result in brain disease despite our best efforts at prevention.

Characteristics and Consequences

All sensations, movements, thoughts, and feelings result from signals transmitted through billions of neurons in the brain.¹¹ Our perception of

and interaction with the world depends upon the functioning of the brain. Therefore, every aspect of our existence is potentially impacted when disease invades the brain—self-image, memory, capacities, and relationships.

As stated previously, the specific consequences of the pathology depend on the portion of the brain affected. The diseases are progressive, and the severity of the symptoms increases as cells die. The diseases are fatal with the life expectancy after diagnosis as brief as two years and as long as twenty years.¹² Death often occurs as the indirect consequence of the underlying pathology, such as a fall, pneumonia or other infection, or inability to swallow.

While there are common manifestations of brain pathologies, each person with dementia is unique. A common adage is “if you’ve met one person with dementia, you’ve met one person with dementia.” Multiple factors affect the symptoms and manifestations, and each person must be dealt with as an individual. Furthermore, the symptoms vary in their duration and persistence. Even persons in the severe stage of Alzheimer’s or another form of dementia may mysteriously have short lucid moments. “[Kissing] the joy as it flies by”¹³ is the challenge of caregivers and family members as they journey with the person with dementia.

The consequences of dementia far exceed those experienced by the person diagnosed. Alzheimer’s and other forms of dementia significantly impact families, communities, and the broader society. In fact, the Alzheimer’s Association reports that “more than 16 million Americans provide unpaid care for people with Alzheimer’s or other dementias.” The vast majority of these are family members. Many of these caregivers are so-called sandwich generation caregivers who are responsible not only for an aging parent’s care but also for children.

According to that same 2019 report from the Alzheimer’s Association, the healthcare and long-term care costs for individuals with Alzheimer’s and other forms of dementia are estimated at \$290 billion.¹⁴ The total out-of-pocket expenses for these family caregivers is expected to exceed \$63 billion, or 22 percent of their medical payments.¹⁵ The lifetime cost of caring for an individual with dementia is estimated at \$357,650.¹⁶ With the

significant increase in the number of people with Alzheimer's and other forms of dementia, the monetary costs will dramatically escalate.

The most traumatic consequences, however, are less quantifiable. They have to do with the changes and demands placed on family members and caregivers. In addition to the added stress of financially caring for a family member, the physical and emotional demands are enormous. Evidence exists linking dementia-caregiving to increased levels of depression and anxiety, social isolation, and potential physical health decline.¹⁷

The consequences of dementia for both patients and caregivers are influenced by more than the pathology of the brain. Additional factors include the support systems in place, degree of stigma attached to Alzheimer's and other forms of dementia, and how personhood is defined. If we are our brains, then degeneration of the brain means diminished personhood, loss of self.

Reducing people to their brains is an unwarranted medical conclusion rooted largely in the outdated Cartesian mind/body dichotomy and notion of individual autonomy. Emerging neuroscience, the social sciences, and theology push against the notion that we are our brains and that memory is far more complex than the functioning of brain cells.

Conclusion

"I hate myself" was Linda's often-repeated expression following that fateful November afternoon in 2009 when we heard the doctor pronounce the diagnosis of frontotemporal dementia. Frequently thereafter, as she struggled to think and speak clearly, she called herself "stupid," "crazy," "no good," "worthless." Her self-image and confidence as well as her recollections waned. Her self-concept, relationships, social networks, abilities, and capacities diminished: all the result of what was taking place in the small organ called the *brain*.

The negative consequences have been far-reaching. Yet, there have been positive consequences as well resulting from several factors. First, accepting that her dementia is caused by a disease increases my perspective and patience. Gradually, when she was confused and unable to express her thoughts, she would say, "My brain isn't working right." That was progress!

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It wasn't that she was inattentive or unconcerned; her brain wasn't working properly! As I persistently reminded her, "You have a disease of the brain; I have a disease of the heart! But together we make a whole."

We also learned that even the mind and memory are more than the mechanisms operating in the brain. Memory is more than the recollection of data. The mind includes more than recall of events, information, and experiences. As we shall see in the next chapter, memory is complex and multifaceted with numerous physiological, biological, relational, and theological components.

Never Underestimate a Ministry of Presence

Ministry with the Forgotten: Dementia through a Spiritual Lens . . .

“. . . will become a classic about ministry to people with dementia and their caregivers. Carder describes his decade of trust-in-faith caregiving for his wife, afflicted with dementia. What makes this book unique is how Carder shows how theology goes beyond the medical lens to a spiritual lens that values the vulnerable, forgotten souls of persons with dementia who ‘know God by heart.’ Carder offers helpful suggestions for how the church, often silent on this issue, can initiate relational support for caregivers. Carder’s book needs to be read and practiced by pastors as an invaluable guide to a much-needed ministry.”

—**Richard L. Morgan**, PhD, retired Presbyterian Church (USA) pastor; founder of the ClergyAgainstAlzheimer’s network, Pittsburgh, PA

“. . . is a magnificent book, beautifully written, deeply felt, and enormously rewarding. It is a gentle, if sometimes searing, guided journey through the pain of dementia. The book invites everyone to prepare for the journey with the guidance of one who has traveled the road himself; for no family is immune from the consequences of dementia. Professionals and laypersons alike will be bowled over by the honest vulnerability of an esteemed theologian and bishop so deeply committed in his faith and theology. There are no easy answers here. But every reader will be blessed by a profound testimony to God’s grace creating a love that steadfastly refuses to succumb to dementia.”

—**M. Douglas Meeks**, PhD, Cal Turner Chancellor Professor of Theology and Wesleyan Studies, Emeritus, Vanderbilt University Divinity School, Nashville, TN

“. . . shares Bishop Carder’s lessons learned from ten years of struggle with his wife’s brain disease. He shows how the experience of caregiving and receiving can be both a source of profound grace and a mutual way to continue glorifying God. This book provides guidance and comfort to all whose lives are touched by dementia—personally, professionally, and congregationally.”

—**Jane Marie Thibault**, PhD, professor emerita and clinical professor of family and geriatric medicine, School of Medicine, University of Louisville, Louisville, KY

“. . . is a lovely, thoughtful book, awakening all of us to what our life in Christ is really like. Who better than Bishop Ken Carder to probe, with such wisdom and eloquence, how we think about dementia and Christian faith?”

—**James C. Howell**, PhD, senior pastor, Myers Park UMC, Charlotte, NC

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