Advance praise for *Redeeming Dementia*

"A profound and powerful re-framing, re-educating, and re-minding that the disease called dementia does not literally un-mind people or make them anything other than human beings with whom God remains in relationship. It is the supposedly healthy who do the un-minding, when we assume those with dementia have nothing to share or teach. This book is a labor of love and a deeply important pastoral and theological gift to all God's people. Don't read it and weep—read it and learn to see the loving possibilities of dementia."

—The Rt. Rev. Katharine Jefferts Schori,
Assisting Bishop of the Episcopal Diocese of San Diego
and former Presiding Bishop of the Episcopal Church

"Hicks and Linthicum go to the heart of the theological question of paradox that is dementia. Drawing on modern scholarship, lived experience, and contemporary best practice, they challenge the church to reflect afresh on the nature of personhood. They rightly conclude that 'by understanding and embracing the redemptive qualities of dementia, we can begin to see God's redeeming power in our own lives.'"

—The Rev. Dr. David Primrose, Director of Transforming
Communities, Diocese of Lichfield, The Church of England

"*Redeeming Dementia* is personal, practical, and profound. Dorothy Linthicum and Janice Hicks masterfully share wisdom from dementia-care experts and theologians to provide deeper understanding of God's all-encompassing love. Their practical ideas demonstrate how to better support and nurture relationships with people experiencing dementia and their care partners. Stories of journeying with their own parents personalize and validate the book's insights. An excellent read!"

—Kathy Berry, chaplain, and author of *When Words Fail*

"This book shows us—friends and family, pastoral caregivers, and congregations—how to have grace-filled relationships with people with dementia. Through these relationships we may all grow in our relationship with God. Linthicum and Hicks provide well-curated information, along with a solid theological underpinning, to equip the reader to overcome whatever obstacles there may be to fully embracing dementia ministry."

—Day Smith Pritchartt, Executive Director
of Episcopal Evangelism Society

Redeeming Dementia

SPIRITUALITY, THEOLOGY, AND SCIENCE

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Dorothy Linthicum and Janice Hicks

CHURCH
PUBLISHING
INCORPORATED

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Introduction

And now that I am old and gray-headed, O God, do not forsake me,
Till I make known your strength to this generation
And your power to all who are to come . . .
You have showed me great troubles and adversities,
But you will restore my life
And bring me up again from the deep places of the earth. —Psalm 71[1]

God's promise is full of redemption of all things, and dementia is no exception. How can dementia that is so frightening and debilitating also be redeeming? As daughters of parents with dementia, our journey from despair to a place of hope has been long and often winding. We began it years ago when our parents entered a world of confusion, isolation, and loss brought on by Alzheimer's disease. As caregivers, our experiences ricocheted from despair to joy as we became bystanders in their new worlds. We discovered the redemptive power of God's grace and love over and over when we bumped into walls only to turn and find new paths. Often it was a parent who, despite a fog of confusion, showed us the way.

We discovered that learning about scientific breakthroughs in brain research gave us a deeper understanding of the changes we saw in our parents. We found that the words of theologians brought us insight and comfort through their messages of human dignity, redemption, and God's extraordinary love. Our faith deepened as our spiritual journeys went in new directions, challenging us to look for God's abundance even in the midst of loss and despair.

Not every visit with our parents was filled with insight. Like anyone else, they could be testy, cranky, demanding, tearful, stubborn, or resistant. The need to be in control of one's life does not just go away because a person has dementia. Watching logic disappear along with memories is never easy. When we were patient and listened well, there were redeeming moments that lifted us above our anger, fear, and frustration. Observations from our parents that plumbed the depth of their wisdom and experience surfaced when we least expected them.

Perhaps it is hindsight, but we have concluded that there is little doubt that new viewpoints on Alzheimer's and related dementias are needed to deal with these illnesses in more productive ways. With the numbers of people who live with dementia growing and no cure at present, it is important that we find the best ways to treat, support, and care for those who are suffering and those who support them. On a deeper level, we need to put the phenomenon of dementia into perspective. We need to look beyond the losses, interruptions, grief, and inconveniences of neurodegenerative diseases to discover God in our lives and our human resilience that surpasses our loss.

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When my mother's Alzheimer's disease had progressed to a point where she was unable to put sentences together, she said, seemingly out of the blue, "I'm still the same." It was clearly a monumental effort to articulate the sentence, so I paid deep attention. She was letting me know that she felt the same inside. I realized that we were experiencing not a loss of her "self," but rather something that was at least in part a communication issue. Because of this spiritual gift from my mother, I changed the way I looked at her illness and learned to patiently wait to see more. I saw spiritual aspects of my mother that were so profound that they greatly changed me. She could, at times, be very complex and lucid, despite her general reduced level of cognition. As a scientist, I wanted answers to questions that science could not yet address. As a student of theology, I was also searching for what the Church says about human dignity in the face of suffering and illness.—*Janice*

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Some of the problems we face with dementia-related illnesses can be seen in the following two stories:

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A chaplain at a large continuum of care community recently reported meeting a local parish clergyperson in the elevator of the facility. Making small talk, the chaplain asked him who he had come to visit and how the visits went. "Well, I have three members here," the pastor replied, "but two are out of it so I just said hello and left my card." Undoubtedly, this pastor will dutifully report to his church council that he made three pastoral calls.[2]

A hospital doctor is standing at the bedside of an elderly woman who has severe Alzheimer's. Her adult children are also present. He is talking about hospice care with the children. "What are you keeping her alive for?" he asks them, as if she were not awake or not in the room. Then he moves closely toward her face and shouts (she is not hard of hearing), "What do you do for fun, Jane?" She cannot answer, but grimaces.

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The first story shows there is a basic unease with visiting people with dementia—even for clergy—that is not unlike that experienced visiting those with other mental or physical disabilities. This is why it is important to have a basic scientific understanding of illnesses with symptoms of dementia. This background removes prejudices that the person is malingering or is at fault in some way. No one knows what causes Alzheimer's disease or the related dementias. Scientific knowledge decreases the stigma of these diseases by helping us to see that it is a disease of the brain—nothing more and nothing less. Those who have diseases of some other organ, such as the heart or kidney, are not stigmatized, so why do we single out diseases of the brain? Scientific knowledge can be used to devise ways to increase communications with a person with dementia, such as knowing how the senses serve communication. For example, brain science is beginning to explain why music often reaches people with advanced dementia.

The second story shows that prejudice—even those of medical personnel—can severely harm people with dementia and their families. Bioethicist Stephen Post suggests that the stigma concerning dementia results from our society's overvaluation of rationality.[3] Whether it is due to their physical or mental limitations, a person with dementia is marginalized, and often their caregivers are pushed aside as well. The lack of respect for the "self" of the vulnerable patient is countered by arguments of many modern theologians and ethicists. A basic theological grounding and understanding of the illnesses lead to a treatment of people that maintains their full worth and wholeness. The person still holds a role in the context of his or her family and community. Others may hold important parts of their memory for them, but the person herself is entitled to exist and to be treated fully as a person until the end of her life.

Why This Book

There are 47 million people in the world who have Alzheimer's disease and related dementias, with nearly 10 million new cases each year.[4] Without a cure, this number is expected to grow to 132 million by 2050. In the U.S., currently 70 percent are living at home and most have mild to moderate dementia. You probably see them every day and don't realize it. To a certain extent they can function at home and in society with the help of family and other care partners.

The growing challenge of caring for this large number puts great strain on society's medical and financial resources as well as on caregivers' time and livelihood. Medical and care costs worldwide were estimated in 2015 at $818 billion, which is 1.1 percent of the global gross domestic product, a large fraction for a single issue. According to the World Health Organization (WHO), the 2030 cost projection of two trillion dollars threatens economic development globally and could overwhelm health and social services. In its May 2017 report, "Global action plan on the public health response to dementia 2017–2025," WHO urges national and international partners to work to increase awareness of dementia, establish dementia-friendly initiatives, accelerate research and innovation, and increase support for caregivers.

Redeeming Dementia aims to provide a deeper vocabulary about dementia to raise awareness and insight among the faithful and enable them to better cope and advocate for themselves, loved ones, parishioners, or other people

who suffer from dementia. We will provide ways to embrace those living with dementia as well as their families and to help alleviate stigma. And we will challenge readers to find new ways of knowing God by embracing the "self" of all people, especially those who have dementia.

How to Read This Book

Organized first around the three themes of science, theology, and spirituality, the book then ends by focusing on how congregations can respond to people with dementia in their midst. The major parts of the book can be read in any order. Throughout the text we share personal stories from others as well as ourselves. Each chapter concludes with reflection questions as a way to emphasize what is important and perhaps controversial, and to give you a chance to reflect on your own stories and to take them further, either in a group or individually.

Chapter 1 begins by discussing the physical aspects of the healthy brain. It appears to be a coincidence that dementia-causing illnesses are spiking at a time when brain science is undergoing an exciting revolution. There is a new appreciation of the complexity of the human brain and its role in our evolution as a species. It is far more complicated than we realized. One human brain contains 100,000 miles of fiber, long enough to go around the earth four times. The potential capacity of the human brain has been estimated to equal the power of the entire Internet. New instrumentation and data-based approaches, as well as ideas about computation and consciousness, are producing some of the most rapid changes seen in any scientific field of our day.

The body is important in the Christian story and in the arguments here. Concepts such as the "self," "consciousness," and "spirituality" that were previously conjectures by philosophers and theologians are now aspects that researchers are beginning to measure. Important recent discoveries about memory, the senses, sleep, and aging add to the evolving picture of the healthy brain. At the same time, with all the advances in imaging, there is no one area in the brain identified as the "self" or "spirituality."

The media often write about breakthroughs in brain research and dementia. The terminology in this first chapter will help you to read and digest those reports with more clarity. Perhaps more importantly, we believe a scientific

understanding of the brain gives us hope, not only for a potential cure, but also for the awesome capacity of this extraordinary human organ.

Chapter 2 explains the latest scientific understanding of dementia as a symptom of various diseases that cause degeneration of brain cells and, therefore, interrupt connections in the brain that form the basis of central tasks such as memory, learning, and executive functions. The stages of Alzheimer's disease are described, with an emphasis on what *remains* at each stage. Even in advanced Alzheimer's, much of the brain is still working. Billions of pieces of information per second about vision, hearing, smells, touch, taste, and more are still being transmitted, perhaps not as well as before but usually still working. We do not know what the person is experiencing, and we should not presume. Again, there is no evidence that the diseases causing dementia destroy the "self" or "spirituality."

In chapter 3, we turn to theology about the human person to lay the groundwork for our response to dementia. Historically, the concept of rationality was central in explaining how humans differ from other higher animals. But this single criterion is problematic when it comes to people with dementia. When a person develops dementia, are they less of a person? Do they lose their connection to God? By citing contemporary theologians who are broadening concepts about what makes us human, we strongly answer "no" to these questions. David Kelsey believes human beings are who they are because of the way God relates to them. The basis for the value and relationship of the human being lies in God—that is, outside the human being themselves. Since this is mostly about divine characteristics, the relationship and therefore personhood are not affected by dementia or any human illness.

Chapter 4 applies several concepts of Kelsey's theology of the human person to the case of dementia. We are the glory of God—even if mute or paralyzed or lacking rationality. The most fundamental thing about us, Kelsey says, is our basic personal identity as grounded in God, not our everyday identity or health status. This chapter also cites other theologians writing on disability and dementia.

Chapter 5 focuses on aging in general, recognizing that most people with dementia are also facing the changes and losses of old age. The spiritual life is not disconnected from the changes that aging brings to bodies, including health and emotional stability. Depression and substance abuse are a reality for many older people coping with physical changes, financial challenges,

and difficult decisions that have no easy answers. Gerontologist Elaine Brody wrote when she was eighty-six that she was ready for old age intellectually but not emotionally. "Common experiences of old age, such as illness and losses, were unexpected, even though expectable."[5] At the same time, recent studies that measure happiness show that well-being increases with age, with older people outscoring younger people by a sizable margin.[6] Time is actually on their side as professional and personal demands lessen, giving them space to bring *being* rather than constant *doing* back into their consciousness. Supported by family and a community of faith, many older people embrace a new rhythm in their lives that leads to satisfaction and even joy.

Chapter 6 begins our discussion of what congregations can do to meet the challenges of dementia. Because the onset of dementia is often slow and difficult to detect, family and caregivers may be reluctant to share the information with others. Even though help may be desperately needed, many won't ask for it—even those who are long-term members of a congregation. Ironically, a faith community can ease the transitions we all face in life. Donald F. Clingan, who was instrumental in bringing the heritage of religion and spirituality into the field of gerontology, wrote, "Spiritual resiliency is nurtured in community. It is the experience of being knocked down and stunned by events and finding a hand of comfort, support, and encouragement that assists us in once again rising. It is the experience of faith, hope, and love shared through our various connections in life that nurtures our inner renewal."[7] Helping congregations understand dementia and giving them tools for communications and hospitality can lead to the full participation of those with dementia and their caregivers in community life. People with dementia keep reminding us that we need to be creating solutions *with* them rather than *for* them. They have much to teach us if we will only listen and pay attention.

How can congregations and other spiritual groups serve those with dementia? One of the challenges is that people with dementia and those who care for them tend to be isolated. Often due to misunderstandings about dementia and lack of knowledge about how to interact, friends and extended family pull back, creating a real deficit in the person's life. This has a negative effect in two aspects decreasing the person's well-being through grief about the losses of family and friends, and increasing fear on the part of the distancing friends. This fear can give rise to a stigmatizing attitude toward dementia.

Chapter 7 offers a variety of ways that congregations can get involved to serve those with dementia and their families. Following the Dementia-Friendly Church movement in England, congregations can hold special worship services, which can nurture the spiritual growth of people with dementia, as well as caregivers. They can also start a Memory Café, an informal get-together of those with dementia and their families that provides a relaxing respite from what might be an isolated care situation at home or more clinical environments. Memory cafés have been reported to reduce feelings of loneliness and increase quality of life.

Congregations and spiritual groups can provide people with dementia the opportunity to share their talents through service as appropriate, including participating in liturgy for as long as possible, accompanied by another person if needed. Providing a respite partner during services allows the caregiver to focus on worship, and also creates a meaningful ministry for volunteers. Individuals and congregations can also join with other efforts, such as the Stephen Ministry and Community of Hope International, as well as efforts by professional societies, medical staff, care facilities, hospitals, and governmental agencies, including the Dementia Friendly America movement. Finally, advocacy on behalf of those living with dementia and their caregivers is another possible role for congregations.

Our hope for this book is that reflecting on the scientific, theological, and spiritual aspects of dementia will lead to helpful insights that will eventually shift some of the focus about these illnesses from devastation, dehumanization, and loss to an embrace of the selfhood, coping, and spiritual gifts that come from any challenge before us. In the long run, we hope for better inclusion and care for people with dementia and their families and friends in our society, especially the empowerment of congregations to continue ministry through the end of life.

Notes

1. The Book of Common Prayer (New York: The Church Hymnal Corporation, 1979), 684.
2. Susan H. McFadden, Mandy Ingram, and Carla Baldauf, "Actions, Feelings, and Values: Foundations of Meaning and Personhood in Dementia," *Journal of Religious Gerontology* 11 (2001): 3-4, 67-86.

3. Stephen G. Post, *The Moral Challenge of Alzheimer's Disease* (Baltimore: The Johns Hopkins University Press, 1995), 3.
4. World Health Organization, accessed January 10, 2018, http://www.who.int/mediacentre/factsheets/fs362/en/.
5. Elaine M. Brody, "On Being Very, Very Old: An Insider's Perspective," *The Gerontologist* 50, no. 1 (February 2010): 2-10, doi.org/10.1093/geront/gnp143.
6. *State of American Well-Being: State Well-Being Rankings for Older Americans*. Gallup-Healthway Well-Being Index, 2015, accessed December 27, 2017, http://www.well-beingindex.com/hubfs/Well-Being_Index/2014_Data/Gallup-Healthways_State_of_American_Well-Being_Older_Americans_Rankings.pdf?t=1508795566327.
7. Donald Clingan, "Foreword," in James A. Thorson, ed., *Perspectives on Spiritual Well-Being and Aging* (Springfield, IL: Charles C. Thomas Publisher LTD., 2000), xiii.

CHAPTER 1

The Healthy Brain

The body is very important in our story. Christians believe in the Incarnation, that the second person of the Trinity assumed human form in the person of Jesus Christ. We are embodied, too. This chapter begins our discussion about the physical body, and in particular, the healthy brain.

Brain and Mind

Many today believe that it is the human brain that makes us different from other forms of life. It is immense and more complex in comparison to that of other species, giving rise to an unprecedented human consciousness with abilities such as self-awareness, intelligence, language, self-control, extensive planning, emotion, the ability to cooperate, and other attributes observed only to a lesser degree, if at all, in the species closest to us. Rather than believing in the traditional concept of the soul, some theologians believe that it is consciousness,[1] or the "information pattern,"[2] that survives after death. (See chapter 3 for more information on this topic.)

Those holding to the scientific-secular model for what makes us human would say that it was the surging size of the brain about two hundred thousand years ago that marked the transition from human ancestors to human beings

that were largely like us.[3] Because the brain is affected by dementia, those characteristics that some believe make us human can also be affected. This is why theologian David Keck referred to Alzheimer's disease as the "theological disease," because it calls into question beliefs about what makes us human.[4]

Another layer of the theological and scientific discussion is about the subtle differences between brain and mind. For the purposes of our discussion, *brain* is the physical organ made of brain cells (neurons), fed by circulating fluids and chemicals, full of energy, which as a system generates electrochemical signals. The brain is an object you could hold in your hand. The *mind* includes intangibles such as thoughts, processing, perceptions, emotions, spirituality, and even relationships. The mind is like the software, yielding laws and theories, yes, but also changing in time and difficult to categorize.

Jeannette Norden articulates the common belief among neuroscientists that "the brain is the biological substrate [substance] of the mind."[5] To complicate matters, it has been discovered that the human heart has forty thousand neurons, and the gut has a billion neurons,[6] so even the physical organ "brain" may not be as contained (just in our heads) as we once thought.

Basics about the Brain and Neurons

The 3-pound human brain is much more complex than previously thought. It consists of 100 billion neurons—brain cells—packed together in a consistency like that of firm tofu. The human brain uses a very large amount (20 percent) of your body's energy when you are at rest. The brain has two hemispheres and all but one of the substructures are paired left and right. The figure on the next page shows a slice through the brain from the forehead to the back of the head, revealing one hemisphere.

There are three major parts of the brain. The brain stem includes the spinal cord, cerebellum (which controls balance and rote motions), and medulla oblongata (which controls heart rate, blood pressure, and breathing, among other activities). It is called the stem because it connects to the rest of our body, as if the brain were the fruit. The brain stem is evolutionarily the oldest part that we share in common with animals. In addition to the functions already named, it is also responsible for digestion, reflexes, sleeping, and arousal. It is the first to develop in a fetus, and the last to be affected by Alzheimer's.

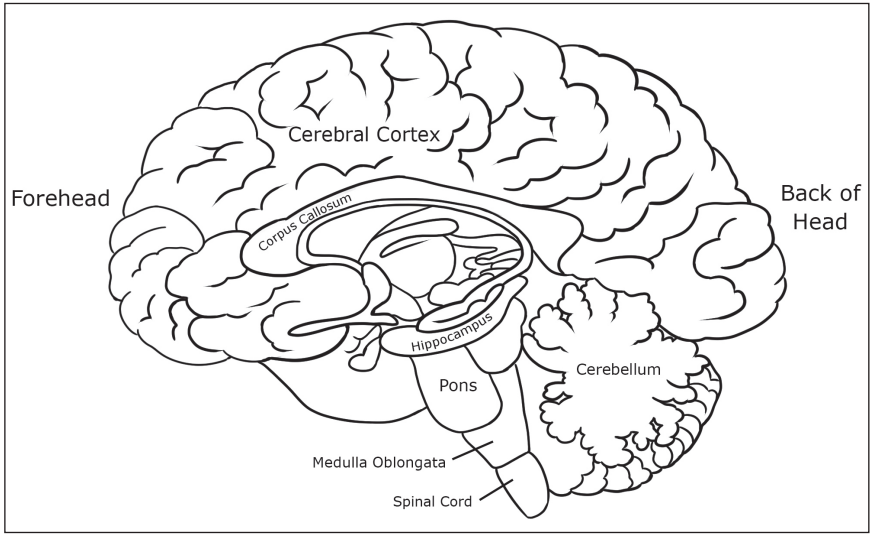
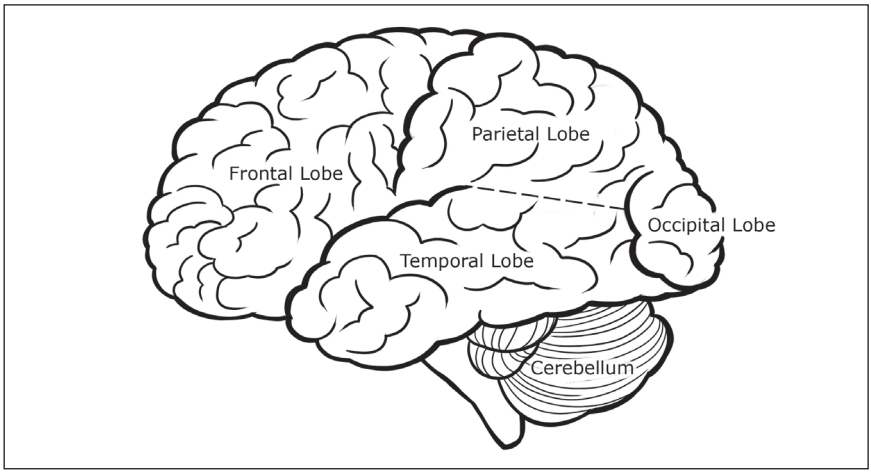


Diagram of slice through the brain from forehead (left) to back of head (right) revealing one hemisphere.

The second part, the midbrain, is the emotional brain, regulating sex hormones, sleep cycle, hunger, emotions, and addictions. The midbrain also contains the pleasure center that makes us feel good, and the amygdala, which is responsible for the fight-or-flight impulse, anger, and fear. The hippocampus—the name in Greek means "seahorse" because it was imagined to resemble such an animal—is thought to consolidate short-term memory into long-term memory and enable spatial memory. The hippocampus is the first place that is affected by Alzheimer's, which is why the first symptoms of this disease are usually loss of short-term memory, difficulty forming new memories, and disorientation in space.

The third part of the brain is the wrinkly, folded exterior, the cerebral cortex (or cerebrum), which is the thinking brain. It is evolutionarily the newest part, and in humans its size is massive compared to in other animals. Whereas a mouse brain is 40 percent cerebral cortex, a human brain is 80 percent.[7] Here is the seat of our thoughts, reasoning, language, planning, and imagination. Parts of the cerebral cortex also process our senses, temperature, movement, reading, music, and mathematics. It is affected in the middle and late stages of dementia.



Lobes of the cerebral cortex (or cerebrum).

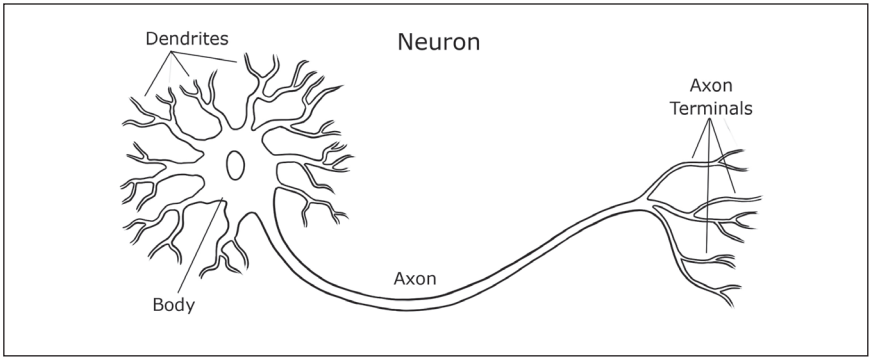


Diagram of a brain cell (neuron), usually microscopic in size (the size of the cross section of a human hair).

The cerebral cortex is divided into four lobes. The frontal lobe is responsible for executive functions such as concentration, planning, and problem-solving. The parietal lobe is associated with understanding speech and using words. The temporal lobe interprets sensory stimuli and contains memory of visual and auditory patterns. The occipital lobe interprets visual information and recognizes visual images.

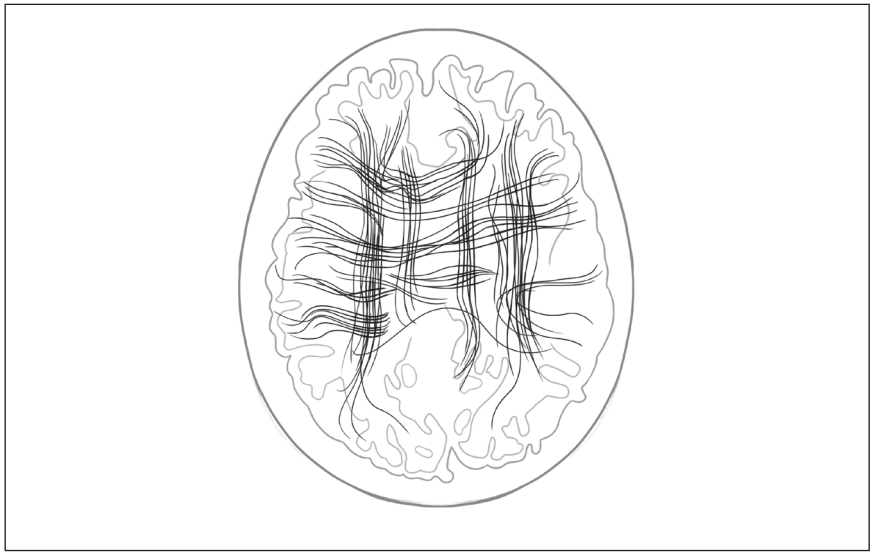
Of the 100 billion neurons making up the brain, there are thousands of different kinds: multipolar, unipolar, bipolar, pyramidal, and so on. Most

have a microscopic cell body, a long projection (or fiber) called the axon, and dendritic terminals, like tree branches, that connect with nearby neurons. Axons are usually microscopic but can be as long as several feet, reaching down the spinal cord to activate muscles, for example.

The cell bodies gather to form substructures, called gray matter because of their gray coloring. The axons join to form adjoining layers called white matter, so named because the axons are coated with a waxy protective substance called myelin, which appears white. There are an astounding 100,000 miles of axonal fibers in one human brain, enough to circle the Earth four times.[8]

A method called diffusion spectrum imaging, invented only in the past few years, produced the image shown in the figure below, which reveals a grid-like order of the fibers that astounded even most neuroscientists. Most expected a more tangled anatomy.

In addition to neurons, the brain also has as many *glial cells* that provide support for neurons, such as cleaning their environments. We will see later



Drawing of the fiber pathways of a living female human brain, mapped noninvasively with diffusion spectrum imaging. The image shows a view from above (front of the brain is at the top of the picture). The fibers of white matter (axons of brain cells) are arranged in major grid-like pathways.[9]

on how this is an important process during sleep and is possibly a point of deficiency in illnesses causing dementia.

The Brain as an Electrochemical System

Feelings, thoughts, sensations, and muscle actions all are thought to result from particular neural pathways involving neurons and chemical changes. Neurons communicate by sending electrical pulses that travel down their axons. The rate of the pulses—faster or slower—and the intensity of the pulses—strong or weak—contain the information the brain is trying to transfer. The pulses stimulate the release of chemicals (neurotransmitters), which travel a short distance from one cell to the next across *synapses*, passing the signal and wiring the two cells together. It's been said that "neurons that fire together, wire together."[10] This concept of networking among cells is thought to be important in memory as well as in many other brain processes.

The neurotransmitters released at the synapses have various effects. Some, for example, are excitatory—triggering wakefulness, attentiveness, anger,

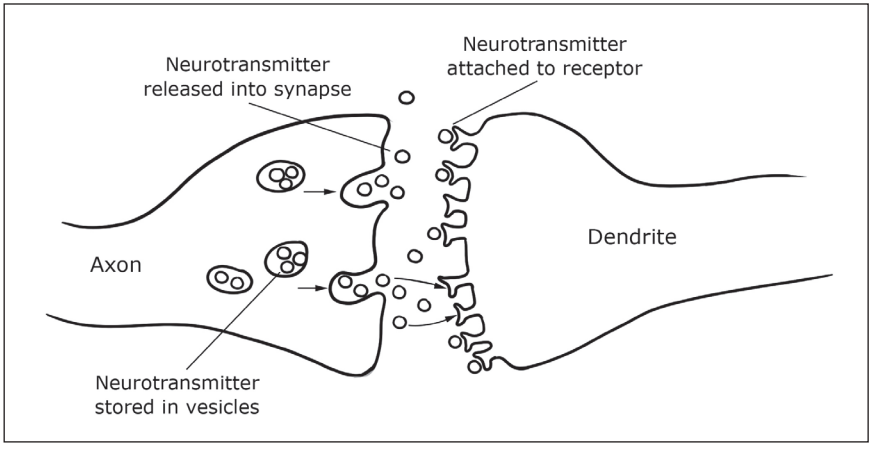


Diagram of a neuronal synapse showing neurotransmitters (dots) leaving the end of the neuron on the left as the result of an electrical pulse that came down the axon, and becoming attached to receptors on the dendrite of the neuron on the right, creating the pulses in that neuron to pass on the information.

aggression, etc.—while others are inhibitory—calming anxiety, inducing sleep, etc.

With electrical signals traveling all of the possible synapses in the many neurons and the many chemicals involved, the agility of the brain is enormous. The brain has potentially forty quadrillion synaptic connections, making one human brain potentially more powerful than the entire Internet (that is, a storage potential of one petabyte.)[11]

Neurotransmitter receptors are not just restricted to the brain, but rather are found throughout the body. Neuropsycho-immunologists Candace Pert and Michael Ruff termed this "a network of communication between brain and body"[12] or, colloquially, "liquid brain." This fact, together with the knowledge that the heart and gut have neurons of their own, shows that the information system in our body extends beyond the boundaries of what we traditionally call the brain.

Neurotransmitter	Functions
Acetylcholine	excites cells activates muscles wakefulness
Glutamate	helps learning assists memory
GABA	slows down and regulates anxiety
Endorphins	reduce pain increase pleasure
Dopamine	provides motivation gives pleasure
Epinephrine (adrenaline)	maintains alertness energizes
Serotonin	regulates body temperature, memory, emotion, sleep, appetite, and mood
Oxytocin (found during labor and in breast milk)	elicits "motherly" love elicits romantic love increases trust

A few of the major types of neurotransmitters in the brain and their functions.

> The interaction of the mind and body has been a philosophical quandary at least since Ancient Greece. Pert's contemporary neuroscientific description of "liquid brain" recalls Gregory of Nyssa's description in 300 CE: "the mind approaching our nature in some inexplicable and incomprehensible way, and coming into contact with it, is to be regarded as both in it and around it, neither implanted in it nor enfolded with it, but in a way which we cannot speak or think."[13]

It is natural that some of the first therapies for dementia focus on the brain chemicals that can affect brain activity. One common Alzheimer's medication, Aricept (donepezil), increases acetylcholine in the brain to increase activity. Namenda (memantine) is thought to block excess glutamate that can kill neurons.

Long ago we were taught in school that once the brain reaches maturity, it no longer makes new neurons, but in 1998 Peter Eriksson showed this is wrong: the brain does make new neurons in some areas.[14] A chemical named brain-derived neurotrophic factor (BDNF) causes brain cells to grow. How do we increase BDNF? Arthur Kramer and Kirk Erickson demonstrated in 2011 that physical exercise increases the size of the hippocampus and improves memory.[15]

Other studies also indicate the brain can be altered even into adulthood in a process termed neuroplasticity. This includes forming new substructures on the neurons (e.g., spines), new connections between neurons (synapses), and new receptors on neuron surfaces. For example, researchers believe that the brain can remap and rewire in response to injury and training. Yet the assignment of brain regions to functions is thought to be fairly stable. Rodrigo Quian Quiroga found that one particular neuron fired when a patient was shown different photographs of television actress Jennifer Aniston, but not for photographs of others. Quiroga suggests that it is the abstract identity that is stored and that there may be an "invariant, sparse and explicit code."[16] He suggests the situation is likely more complicated than a one-to-one correspondence between a face and a neuron, but the result indicates certain stability between function and structure. It is still the early days of research in understanding structure, function, and memory in the brain.

The Senses

The five senses of vision, hearing, smell, taste, and touch increase the richness of our interaction with the world. Each is an immeasurable gift not only helping our survival but also yielding sensual pleasures like the appreciation of beauty. As inputs to the brain, the senses are vital for communication. To communicate most effectively with a person with dementia, it is helpful to understand what is happening with each of the senses, as they might be altered with the illness.

Touch is the first sense in a newborn, and often the last to be lost to dementia. Our bodies are covered with a network of six to ten million sensors; more than half of those sensors are located on our hands, feet, and faces. Where possible and with permission, touch is an important, pastoral way to communicate. A light touch on the shoulder or holding hands can be very effective. If a person is lying down, touching the feet can also be effective. Passive touch, like the sun or breeze on bodies and faces, is also a pleasure that is not to be underestimated.

With the sense of smell, the signal pathway is a direct line to the brain, separated by just two or three synapses to the hippocampus. This is why smells can be quickly and strongly associated with memories and emotions. We can harness the power of smell in liturgies through the use of incense, for example, or use specific smells through aromatherapy to benefit particular symptoms. A 2002 study showed that the scent of lemon balm significantly decreased agitation in people with severe dementia.[17] In some cases, however, dementia sufferers may experience a loss of smell.[18]

Through the sense of vision, retinal cells transmit one billion pieces of information to the brain every second. The brain then has to sort through this astounding amount of information to decide what to pay attention to. People tend to pay more attention to *changes* in their visual field. Because people with Alzheimer's often lose peripheral vision, it is important to approach a person from the front rather than the side. Getting eye contact before speaking is also important. People with Alzheimer's may lose contrast between colors and cannot see blue and purple tones. Using red, orange, and yellow will enhance contrast for clearer vision.

The ear has the fewest sensory cells of any sensory organ, only about 3,500. People with dementia may have hearing loss, similarly to any person who is aging. If a person's response is lagging, however, it may not be a hearing issue, but rather a longer processing time. Shouting at people with dementia won't shorten that processing time. Professionals suggest that directions or questions be as short and simple as possible, followed by thirty seconds of waiting. By waiting, an answer may come.

Memory and Forgetting

Memory is everywhere. We are often asked, "Do you remember this?" When we are with family or old friends, we hear ourselves say, "Remember when . . . ?" Even in church we are told, "Do this in remembrance of me."

Memory is required for our identities, learning, relationships, and decision-making. Photographs and souvenirs memorialize holidays, vacations, and special celebrations. National observances and monuments help us remember critical events in our history. Forgetfulness is also everywhere. In our busy lives, we cling to calendars to boost our memories. We want to remember the intense feelings from joyous moments of our lives—falling in love, recovering from a serious illness, the birth of a child. We tend to think deeply about memory only when it lapses and serious problems start to infringe on our everyday lives. These lapses could be due to medication, stress, or illness, but we most fear an irreversible degenerative brain disease such as Alzheimer's disease.

While not completely understood, the resulting neural pathways consisting of hundreds of neurons may be the basis of long-term memory. When cells fire together, there is a chemical trace left behind called "long-term potentiation." The repetition of information during study, for example, strengthens these pathways, resulting in easier recall.

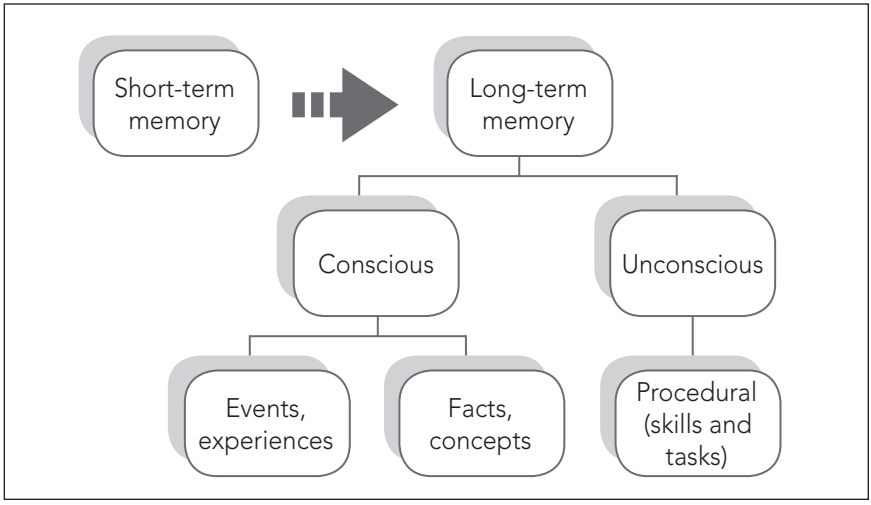
There is more than one kind of memory. Memory begins when our senses feed stimuli to our brains, many of which are ignored. When we pay attention, *sensory memory* is retained almost automatically, taking less than a second.[19] The information goes into *short-term memory*, which is like a temporary scratch pad. Short-term memory is a nerve impulse, not a well-worn track, and can hold about seven items for ten to fifteen seconds or sometimes up to one minute. The information can be quickly lost if more information

comes in. The hippocampus (located in the figure on page 3) coordinates the conversion of short-term memory to long-term memory, functioning like a memory control center. For example, a childhood memory of a worship service might have sounds, smells, and emotions stored in their respective parts of the brain. The hippocampus ties these together from various parts of the brain (auditory, olfactory, emotional) to form a single episode.

Transfer to long-term memory occurs in a few seconds and is aided by repetition or by adding meaning or association. This is why recalling the name of someone new is easier if you repeat the name and associate it with another person you know.

Long-term memory is robust. In a healthy brain, the ability to recall may degrade, but memories remain intact. Long-term memory can be conscious (explicit), such as episodic memories of what you had for lunch or experiences such as your first kiss. These generally have associated feelings. Memories with a lot of emotion tend to last a long time. For example, many remember clearly what they were doing on September 11, 2001, but few remember what they were doing the day before that. We store our autobiography through long-term memory, orchestrated by the hippocampus.

Conscious memory also includes semantic memory, which is a collection of facts with no feelings or memories attached, such as the multiplication



Types of memory

tables. Long-term memory can also be unconscious (implicit), including procedures, skills, and tasks such as riding a bike, tying a shoelace, reading a clockface, or playing the piano, requiring little thought to perform.

Different types of long-term memory are stored in different regions of the brain. Conscious long-term memory involves the hippocampus plus other areas throughout the brain. Procedural memories do not involve the hippocampus but rather are stored in motor control areas of the brain. Amee Baird and Séverine Samson found that a musician with Alzheimer's, for example, can still play the piano (using their unconscious procedural memory), but cannot recognize familiar melodies, which involves conscious memory.[20]

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Mr. Polanski was a neighbor in my mother's memory care facility. His daughter and I first met while talking about Polish food, and then I learned that her father had played piano every Saturday night in a Polish club for over thirty years. A widower, Mr. Polanski had a cheerful disposition and a charming smile. He sometimes recognized his family, but due to Alzheimer's he required 24-7 care. The residents, who were mostly women, enjoyed his weekly piano performances, where for an hour he masterfully played and sang old songs with a joy that was felt by all.—*Janice*

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What is forgetting? For short-term memory, it means that a nerve impulse has ceased being transmitted through a particular neural network. For long-term memory, it means that the synaptic connection among the neurons in a network becomes weakened. The structure that was modified decays because of a random event or because the cells that have the chemical information die through illness. Another possibility is that the hippocampus that recreates the episode from information in different parts of the brain is damaged. The memories may still be there, but not accessible.

Even the healthy brain prunes itself, getting rid of connections not often used, thus the phrase, "Use it or lose it." There is evidence that brain gym exercises (for example BrainHQ from Posit Science) help keep the mind active.

Sleep and Memory

The biological reasons for sleep and dreaming are not fully understood and are still being debated. From an evolutionary point of view, the loss of consciousness during sleep puts a person or animal at very high risk in terms of safety. Because humans need a significant amount of daily sleep, it must be extremely important. What does sleep have to do with memory?

There are two main theories about the purpose of sleep. During the phase of sleep known as rapid eye movement (REM), the hippocampus shows synchronized waves that some believe is memory consolidation.[21] The second, discovered only in the past few years, is about cleaning. Glial cells clean out all the molecular toxins and metabolites that build up from thinking and learning functions during the day.[22] These helper cells remove the excess proteins that are thought to be linked to Alzheimer's disease. Sleep is important for both memory consolidation and the removal of unwanted proteins. Dementia is associated with disturbed sleep, but we don't know if the lack of sleep contributes to the illness or if the illness disrupts sleep.

Sleep researchers recommend sleeping eight to nine hours daily. Naps should be ninety minutes in duration to complete an entire sleep cycle to maximize the cleaning function. If ninety minutes isn't possible, researchers recommend a twenty-minute nap as a good alternative for getting some rest.

The Long-Term Memory of Music

In the best and worst of times, music reaches our hearts in ways that other communication cannot. Alice Parker says, "Song is a right and a need."[23] Music obviously involves the auditory areas of the brain, but also taps into its emotional center. It boosts endorphins and other feel-good molecules that can lift spirits and even cause euphoria. The whole brain is involved when we listen to music. For nonmusicians, the right hemisphere is dominant for appreciation of melody and harmony and the left for rhythm and language. People who dance or play an instrument use even more of the brain, for example, the motor system that controls movements and coordination.

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> I was fortunate to be able to observe a worship group led by a chaplain with six women with moderate to advanced dementia. When the a capella singing began, many of the women, though not fluid in conversation, could sing all the verses of familiar hymns, many more than I could. These verses were probably memorized when they were young. Especially popular among this group were "Amazing Grace," "Holy Holy Holy," "How Great Thou Art," "What a Friend We Have in Jesus," "Mine Eyes Have Seen the Glory," "Sweet Hour of Prayer," "Fairest Lord Jesus," and "Blessed Assurance."—*Janice*

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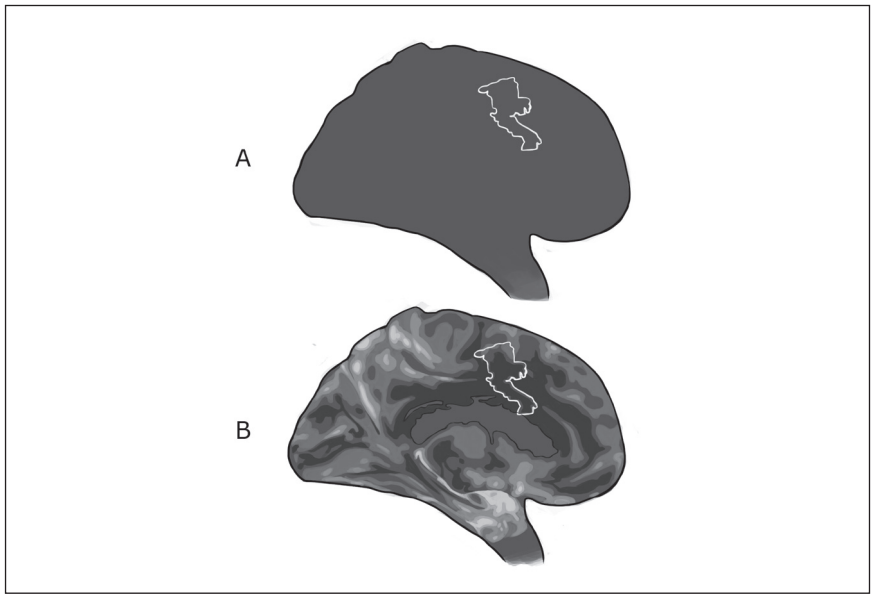
There are several famous videos of people with advanced dementia who are uncommunicative but then become animated and talkative, reacting happily when hearing beloved music.[24, 25] These effects can last for hours or days and can stimulate memories. A 2015 study focused on how musical memory from people's youth can be preserved even in the case of advanced Alzheimer's. The researchers arranged for people in their late twenties to hear music from their youth while their brains were scanned. The scans revealed the primary area for long-term musical memory, superimposed on the brain sketch in Scan A on the next page.[26] This same area is surprisingly spared in the brains of those with Alzheimer's, as shown in Scan B.

A lesson for anyone visiting someone with Alzheimer's: play music from the person's youth, including hymns, Top Ten hits, oldies, and popular tunes.

The Self from a Neuroscientific Point of View

Despite all the neuroscientific research gains of the past decades, scientists have not identified a part of the brain that is the center of self or "soul." Modern neuroscience has shown progress in understanding both the anatomy and some of the function of the human brain. This has led to therapies for addiction, strokes, depression, trauma, seizures, tumors, dementia, and other major brain diseases. Yet even the most recent map of the brain[27] shows no one part that is associated with "self." A journal editor writes:

> Most of us share a strong intuition that our own self is an irreducible whole, that there must be some place in our brains where our perceptions



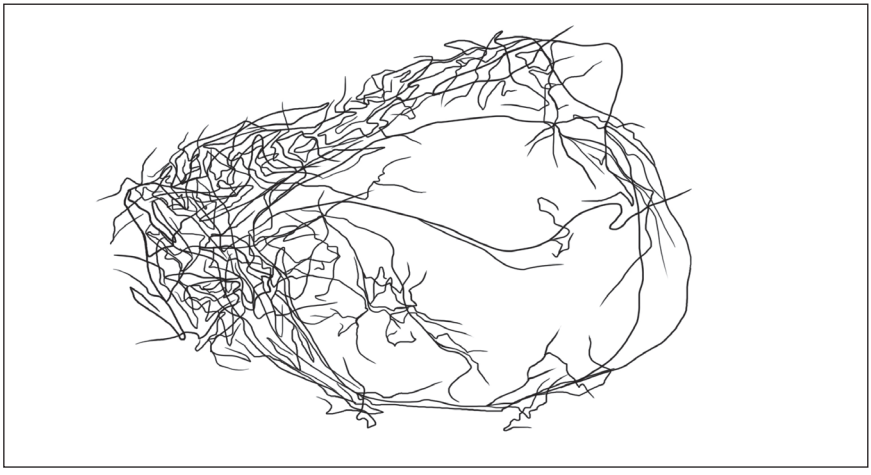
Drawing based on brain scans from a study on memory of music.[28] Scan A shows the area of the brain that correlates with long-term memory of music. Scan B shows Alzheimer's damage based on gray matter atrophy. The lighter areas represent more damage, and the darker areas less or no damage. It can be seen that the musical memory area corresponds to an area that has no to low Alzheimer's damage.

> and thoughts all come together and where our future actions are decided. Yet this view is now known to be incorrect—different mental processes are mediated by different brain regions, and there is nothing to suggest the existence of any central controller.[29]

When you wake up in the morning, how do you know it's you? There are structures that are associated with parts of what we call "self."[30] The hippocampus handles experiences and stories and, therefore, our autobiography. In the midbrain, our amygdala and emotional system unconsciously act on our behavior and shape who we think we are. This includes our demeanor, emotional temperature, tendency to worry or get angry, and how we find pleasure. The cerebral cortex establishes who we think we are because it is the seat of thought and, in addition, our likes and dislikes.

Further subdivisions contribute to the "self" in specific ways. The prefrontal cortex originates our thoughts, plans, imagination, and ability to solve problems. The orbitofrontal cortex gives us goals, as well as a sense of morality and ethics, and is possibly the seat of conscience. The posterior parietal cortex is associated with distinguishing self from non-self; it is thought to establish the borders of the self. The temporal lobe allows us to recognize scenes and objects, and to process sounds and language. There are particular structures for recognizing faces.[31] Our talents—music, art, and sports, for example—which are in various parts of the brain, also constitute part of who we think we are. Because there is no one part of the brain that defines "self," there is no evidence that dementia can destroy our "self."

By studying brain-damaged subjects who experienced unconsciousness or coma, neuroscientists have identified some of the physical structures that correlate with consciousness. They ascertained that areas of the thalamus and cerebral cortex are associated with awareness, attention, and self-reference.[32] A "crown of thorns"–shaped cell that wraps continuously around the brain of a mouse was recently discovered. The authors propose that it is a tantalizing candidate for a linkage to consciousness because of its unusual circular shape and apparent connections to sensory inputs and outputs, but this is only a conjecture at this point.[33]



A giant neuron from a mouse's brain that is a continuous loop around the circumference of the brain. The authors named this the "Crown of Thorns Neuron."

Understanding why humans have subjective experiences is even more challenging. It is straightforward to understand how red light can be absorbed by the eye, resulting in a signal that travels to the brain and that the brain learns to call "red." What is not understood is why the person *experiences* the color red. This is an example of "qualia," the person's subjective experience associated with stimulation to the brain. Norden writes, "it is challenging to examine why consciousness appears to be 'something' that is happening to a 'me.' "[34]

Spirituality from a Neuroscientific Point of View

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At a time in the progression of her Alzheimer's when my mother was no longer articulating sentences, she once said (with perfect fluidity), "I know he knows me." I could only make sense of this if the "he" referred to God. Despite what we would characterize as her condition of chaotic confusion, to be so certain and lucid that God knew her was an astounding pronouncement. I was in awe at the quality of her aliveness and wondered what experience had moved mom to say this.—*Janice*

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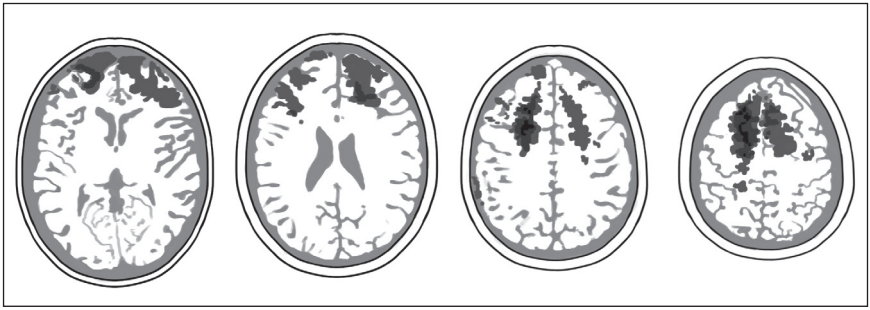
Before it was possible to image the brain, researchers articulated two radically different hypotheses about spiritual experiences. The first is that no signal would show up in the brain because a spiritual experience occurs at the soul level, not the brain level. The second is that a specific module in the brain exists for spiritual experience that evolved for psychological evolutionary reasons. While it is early in this research, it appears that both hypotheses are incorrect.

Like the "self," spirituality is an experience that is not localized to one place but is found throughout the brain. Andrew Newberg and other neurotheologians have attempted to "measure" spirituality in the brain by searching for correlations between spiritual experiences and brain data. Whether they are observing monks meditating or nuns performing centering prayer

during a brain scan, there is a consistent but distributed set of brain structures that change during these spiritual experiences. No one has identified a clear substructure that is the internal "cell phone" to God. Some areas of the brain that show an increase in activity ("light up") during spiritual experiences are associated with focus and emotion. But interestingly, significant *decreases* in activity are also noted. The observed decrease in activity in the posterior parietal cortex, which creates the boundary between self and others, could account for the feeling of unity with the world and/or God.[35] According to Newberg, sudden decreases in the frontal and parietal lobes are associated with "incredible shifts of perception and experiences of unity consciousness."[36] He proposes, "When the frontal lobe activity drops suddenly and significantly, logic and reason shut down, everyday consciousness is suspended, allowing other brain centers to experience the world in intuitive and creative ways."[37] One of the challenges of the research, practitioners report, is that spiritual experiences are not uniform and each type could result in a different brain signature. Further, the measurements are state of the art and sophisticated but still limited in capturing information; for example, it is not yet possible to map neurotransmitter patterns. While the scans capture some physical changes in the brain, it is by no means clear that this is all that is happening.

The idea that spiritual experiences are correlated with a decrease in brain activity, as if the brain in its resting state is throttling down something, is very interesting. Irene Cristofori studied Vietnam veterans who had bullet wounds in their brains and attempted to correlate their level of spirituality with the location of the wounds.[38] The idea is that the area of the brain that is wounded would "permanently" have less activity. The study is the first of its kind and is notable for having a large sample (116 persons with brain injury and 32 healthy controls). They measured spirituality using the M-scale standardized survey, which includes "the experience of profound unity with all that exists, a felt sense of sacredness, a sense of the experience of truth and reality at a fundamental level, deeply felt positive mood, transcendence of time and space, and difficulty explaining the experience in words."[39] Of those veterans routinely having the most spiritual experiences (highest M-scale scores), it is astounding that the brain damage was in similar areas, located in the front of the brain (just behind the forehead) in the dorsolateral prefrontal cortex (dlPFC), as shown in the following figure.[40]



The cross-sectional scans of the entire brain are shown averaged for fourteen patients with the highest M scores. The forehead is toward the top of the figure. The first scan on the left is at the widest part of the brain (for example, nose level), and each successive scan slices through the brain moving up to the top of the head. The darkest shading corresponds to the number of patients with brain damage in the same location, and it can be seen that those with the most spiritual experiences had damage toward the front of the brain.

This result is consistent with Newberg's findings. The front of the brain is associated with executive functions, such as planning, working memory, inhibition, and abstract reasoning. Cristofori proposes that decreased functioning of the prefrontal cortex (in this case from bullet damage) is correlated with spiritual experiences. The researchers go beyond the data to propose that normal executive functioning inhibits spiritual experiences. This makes intuitive sense. During the practice of Buddhist meditation, monks inhibit their executive functions to clear their minds and allow "being," not "doing." This practice seems to allow the spiritual to arise.

Another famous example is the left hemisphere stroke experienced by neuroscientist Jill Bolte Taylor. A stroke would cause a decrease in brain activity in the affected region. Of this experience, she wrote, "And here, deep within the absence of earth temporality, the boundaries of my earthly body dissolved and I melted into the universe. . . . In the absence of my left hemisphere's analytical judgment, I was completely entranced by the feelings of tranquility, safety, blessedness, euphoria, and omniscience."[41]

While these new results are still being discussed, the remarkable suggestion here is that lowering activity in the front part of the brain can actually increase spiritual experiences. Damage in the brain due to dementia is not like stroke or bullet damage, but in principle there could be parallel effects.

Indeed, neurologist Bruce Miller found emergence of musical talent in some people with frontotemporal dementia that he attributes to damage in the left anterior temporal lobe areas. He writes, "Loss of function in one brain area can release new functions elsewhere."[42] We posit here that dementia does not categorically terminate spirituality, and it is not beyond the understanding of modern science that spirituality might increase.

Conclusion

Music, spirituality, the self, and humor are spread throughout the brain, and the diseases that cause dementia do not necessarily remove them. We cannot presume to know all the subtleties the person with dementia is experiencing. But concepts such as the "self," "consciousness," and "spirituality" that were previously conjectures by philosophers and theologians are now aspects that researchers are beginning to measure in the brain. There is much controversy, but the work of this chapter shows that the brain is far more complex than most of us imagined. We should not underestimate its abilities, even in the face of damage due to disease. Alzheimer's disease and related dementias are due to disease in an organ of the body, no more, no less. The stigma that surrounds them is not logical.

The brain is indeed an amazing phenomenon and is a wondrous part of creation, truly a sign of God's glory. Cognitive psychologist Steven Pinker expresses the views of many when he proposes that the human brain may ultimately be too limited for us to understand ourselves:

> The brain is a product of evolution, and just as animal brains have their limitations, we have ours. Our brains can't hold a hundred numbers in memory, can't visualize seven-dimensional space, and perhaps can't intuitively grasp why neural information processing observed from the outside should give rise to subjective experience on the inside. This is where I place my bet, though I admit that the theory could be demolished when an unborn genius—a Darwin or Einstein of consciousness—comes up with a flabbergasting new idea that suddenly makes it all clear to us.[43]

Psychologist and theologian J. Harold Ellens writes, "You could say that we live in a matrix of forces that looks natural and mundane but is in fact transcendental."[44] In the end we are left to marvel at the origin of the brain's

orderliness, and how the beauty and complexity that is our brain is reflective of the greatness of the one Holy God.

Reflection Questions

- Does the recent discovery of the memory capacity of the healthy human brain change your view of human potential? Freud said that even before what we say is our first memory, our brains have stored a huge amount of previous experience. What is your earliest memory, and has the answer to this question changed over your adult life? Why do you think you chose this as your earliest memory? How might we honor the gift of memory?
- Do you think about keeping your brain healthy, as we have been taught to keep our hearts healthy? How do you take care of your mental health, cherish it, and appreciate it, as much as your physical health?
- When you pray, what do you pray with? Jesus said to love God "with all your heart, and with all your soul, and with all your mind" (Matt. 22:37). Back in the day, they believed the heart, rather than the brain, was the "thinking center." How does it feel to love God with all your brain, your soul, and your mind?
- We don't know if all spiritual experiences have a physical basis. The ones discussed in the Cristofori study seem to. Does it lessen spiritual experiences if it's true they have a physical basis? Are they totally generated by our intentions—by our consciously or subconsciously manipulating a part of our brain? What about the ones that we don't ask for, the ones that just come spontaneously, "without any warning or desire on our part" (as St. Teresa of Avila described)?
- If we broaden our thinking, can we conclude that in order to experience God spiritually, we need to surrender our strong egocentric tendencies to be in control? ("For we do not know how to pray as we ought, but that very Spirit intercedes with sighs too deep for words" [Rom. 8:26].)

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> The real me is not the ever-changing atoms of my body, but it is the immensely complex, information-bearing pattern in which those atoms are organized. It is that pattern that is the soul, an idea that fits in with what twenty-first-century science is beginning to discover from the study of complex systems, that information is as fundamental a category as energy.

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