

NOTES TOWARD A THEOLOGY OF DEMENTIA

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*“For my thoughts are not your thoughts, nor are your ways my ways, says the Lord.”
Isaiah 55:8*

It is not a prison, exactly, but a place of real though genteel incarceration from which no one escapes unless accompanied by family or friends, and then only temporarily, if at all. It is today’s sanitized version of bedlam, an asylum minus the roar and chaos, a place of antiseptic, medicated confinement where rehabilitation of the inmates is no longer even a dream. Euphemistically called a “memory care facility,” it is the last outpost of the cognitively bankrupt. It is Alzheimer’s Alcatraz, Parkinson’s Pelican Bay, senility’s Sing Sing. It is where ontological insecurity gazes out from every face, mute and palpable as a pulse.

An 83-year-old man has been living in one of these state-of-the-art facilities for several years. He is now in end-stage Alzheimer’s. His only child has been contacted and told that her father is actively dying, that she should come as soon as possible. Upon seeing her enter his room, he smiles faintly and gives her a look that she realizes is a flash of loving recognition. He has not known who she is for two years. He has not spoken a word. But now, there is this one fleeting moment when he realizes, perhaps, that this nice middle-aged lady who comes so often to visit is in fact his little girl, his daughter. How is this possible, she wonders. She imagines that she has been there in his mind all along, even when he has given her—and everyone else—no sign of anything at all going on, that his brain has retired as the command center of his life. What accounts for this momentary cognitive resurgence, this brief flash of connectedness, this terminal lucidity in which he knows who he is precisely because he knows who she is? He will die in four days, in her arms, never again to give her another sign of recognition.

Such phenomena occur not uncommonly in demented patients as they approach death. Despite the extensive brain damage characteristic of late dementia,¹ such phenomena raise the possibility that even in a mind that can no longer find external expressions of memory, indeed even in a brain where the seat of memory, the hippocampus, lies apparently beyond repair, some shred of memory and thus of the person remains,² and some apparently long-lost moment may be evoked from the genizah of all life’s memories. Is there still a person in there beyond the ability to feel pain; to suffer from fear, confusion, misery, rage, paranoia; a person who can still, if only for a nanosecond, remember and experience what it is to love and be loved?

Of course, we are not now and perhaps never will be able to fully answer these questions. But ask them we must, lest we succumb to despair at life’s cruel abandonment of the afflicted ones we love, at the ruthless exultation of decaying matter over immortal spirit.

Conceptually, it is impossible for us to separate memory from ourselves as persons. To make sense of a single sentence, we must remember not only its last word but also its first. Memory is essential to a moral sense because knowing right from wrong requires remembering past experiences. For the ancient

¹ I use “dementia” as an umbrella term for the many types of dementia, including but not limited to Alzheimer’s, frontotemporal dementia, Lewy Body dementia, and vascular dementia.

² Though memory constitutes a major part of who a person is, a person is more than their memory. Feeling, imagination, will, sentience, consciousness, relationships, among other personal characteristics, also have roles in defining who a person is.

Greeks, memory, *Mnemosyne*, was the mother of the Muses who made the creation and appreciation of all forms of art and beauty possible.

Given the centrality of memory to our ability to think, to communicate, to contribute to human flourishing and progress, to act ethically, to appreciate beauty, and to execute all human functions, the apparently inexorable erosion of a person's memory should evoke a fair amount of theological reflection.³ In the Christian tradition, Jesus's words, "take, eat, do this *in memory of me*" makes it clear that memory is crucial to the life of the person and to the life of the faith community. When one beholds the frightened, confused face of a demented person, one should acknowledge that in addition to physiological, psychological, and sociological questions, profound spiritual and religious questions arise when memory erodes. These questions have everything to do with what it is to be a human being who has a relationship with self, with other humans, with the natural world and its creatures, and with Ultimate Reality, the Ground of Being, God.

Addressing this erosion of memory, of personhood, requires clarifying the extent to which the theological understanding of the human person depends upon the brain, neuro-chemical processes, and matter itself. Already we are awash in mystery. Dementia poignantly raises the most fundamental questions about what it means to be "made in the image of God" and about the meaning of crucial terms found in the Christian creeds such as redemption, resurrection, soul. If these words refer to more than metaphors, if they refer indeed to realities, then dementia becomes an—maybe *the*—occasion to affirm religious beliefs and to reassess and realign theological discourse accordingly. If, on the other hand, words such *pneuma*, *psyche*, *nephesh* and the like are merely metaphors or ancient mythological notions, then we are in a difficult situation from a pastoral perspective, a cruel one in which avoiding existential despair seems impossible. In this latter case, our appropriation of the cry of Jesus on the cross, "My God, my God, why have you abandoned me?" seems justified. The pain and bitterness of caring for a loved one who no longer knows you, of praying to God in a world overflowing with pain, suffering, and death, raises the ultimate question: what hope can there be when there seems to be no person left where there was once a deep and complex personality with a long and rich history? Dementia, because it takes place in the body's command headquarters, the brain, pervades the entire body, integrates itself thoroughly into the body. Bodily processes as well as mental ones become deranged and eventually completely derailed. Your mind is you: your thoughts, your feelings, your skills, your ability to function, your character, your memory, your language, your self.

A firm grounding in doctrines of the soul and resurrection would seem essential to an adequate theological response to dementia. But are current theological agendas designed around personal experience and fulfillment adequate when confronted by the apparent disintegration of the self? Likewise, how adequate are theologies based on social justice? On narrative? Can we base theology on the subject if the subject crumbles when struck by the wrecking ball of dementia? Ultimately, when facing the devastating phenomenon of dementia, can we rest easily with anthropological, political, or economic frameworks for theologies of the human person?

An all-consuming disease such as dementia underscores the importance of doctrine and metaphysics. The theological problems raised by the specter of dementia appear to be most acute in

³ There are many handbooks out there that provide helpful information for the care of persons with dementia. Numerous as well are books and articles that analyze the medico-neurological causes and symptoms of the disease. Many also are the personal witnesses of caregivers. But theological works are sparse. In the English language, I have found three that qualify as theological works: 1) David Keck, *Forgetting Whose We Are: Alzheimer's Disease and the Love of God* (1996); 2) Dorothy Linthicum and Janice Hicks, *Redeeming Dementia: Spirituality, Theology, and Science* (2018); and 3) John Swinton, *Dementia: Living in the Memories of God* (2012). I believe that Swinton's is the best of the three, as do several reviewers.

theologies that have neither metaphysics nor confidence in creeds and creedal categories. Hence, dementia is a postmodern problem not only because we now live longer than our forebears did but also because of our reluctance to employ the central, sacred, and, in a post-Christian world, quickly evaporating terms needed to confront the disease adequately on all its levels.

I turn toward the end of this brief essay with an appeal to professional theologians (which I am not) who are also Christian believers (which I am) to deepen a comprehensive approach to dementia as an issue worthy of theological exploration. But I also turn to consider what I call the age-old temptation that entices anyone, theologian or not, who wrestles with the meaning of suffering—one's own or that of another or others. That temptation is theodicy. Theodicy is the attempt "to justify the ways of God to man" (John Milton), the attempt to vindicate divine providence and divine will given the existence of evil, the attempt to solve the conundrum of why bad things happen to good people. Theodicy is called upon to make suffering comprehensible. With the help of theodicy, suffering is supposed to make sense within the framework of some kind of original sin or the congenital contingency and finitude of human beings. Theodicy explains the evil and suffering that fill the world as part of God's grand design in which suffering atones for sin or announces some compensation or reward at the end of time. Such beliefs are invoked in order to discern, in a suffering that is essentially gratuitous and arbitrary and absurd, a clear meaning and an irrefutable order.

But one cannot and I believe one should not try to find meaning in theodicy because in so doing one will find only the comfort of a false, easy inner peace ("God's in his heaven, all's right with the world") instead of the God-given, graced opportunity to give oneself over to the attention and the action that we can offer one another and that is incumbent upon each one of us to provide, wherever it is needed and whenever we can. One's consciousness of this inescapable obligation brings one closer, I believe, to the Reality we call God in a more difficult but also in a more truthful and spiritual, a more humble and prudent way than any confidence one might have in a divine, overarching plan. Now, faith, according to philosopher Emmanuel Levinas, is more difficult without the crutch of theodicy, it demands even more from one's deepest personal God-given resources than does theodicy. Theodicy is passive. Faith is active. Faith is a suffering inspired by the suffering of the other, a suffering inspired by the pain of the world, a suffering that is action, a suffering whose compassion, whose love, is a useful action that initiates and sustains relationship, a suffering that has immediate and irrefutable meaning.⁴

The *Book of Job* has something to offer us here. God does not allow Satan to visit Job with all manner of loss and affliction because Job is sinful. Job is a very good man. And, likewise, no one today ascribes a sinful life to the suffering of demented people. The importance of the story of Job for understanding innocent suffering remains—and remains a mystery. Job is everyman; his suffering is gratuitous and arbitrary and absurd, like ours. His story is not meant to give us an "answer" to innocent suffering. It is meant to show us what faith is and entails. The faith that Job comes to in the end is born when he rejects all the explanations and theodicies his "friends" urge him to accept, when he abandons all self-justification, when he is brought to confront his puny powerlessness as a human being in the face of the breathtaking immensities of the created world and of the ultimate inscrutability of God. The faith that Job comes to is, most simply put, a relationship with God. His friends do not have a relationship with God because they prefer their arguments to any relationship. They do not even have a relationship with Job. They do not speak to or with him; they talk at him. Job has a relationship with God because he is forever talking to God, asking for a response, some kind of explanation for his suffering. Job wants to

⁴ Levinas, a 20th-century Lithuanian Jew, lived in France and wrote his works in French, grounding philosophy in ethics. His thinking about faith inspires what I say here and is explained at greater depth in many passages of *Entre Nous: On Thinking of the Other*.

enter into a conversation with God, and God gives Job so much more in conversing with him than Job can ever have imagined. God chastises Job's friends by not speaking to them—a clear sign of non-relationship. God loves Job, speaks to him, tells him about Godself in thrilling, powerful, unforgettable language, and invites Job to respond—all signs of wanting a relationship with Job. Job's response is one of humility and silence: "See, I am of small account; what shall I answer you? I lay my hand on my mouth." It is only in this position, this stance, that Job can truly and honestly say, "I had heard of you by the hearing of the ear, but now my eye sees you." Job sees God, enters into a relationship with God when he sees and accepts his suffering-without-cause and his "nothingness" before the astonishing multitudinousness of creation and the awesome mystery of its Creator. And perhaps so it is when we see and accept the suffering-without-cause that is dementia, and place our energies on being-with, being-attentive-to, having-a-relationship-with the demented person.

Dementia makes us question not only theodicy but theology itself. Engaging dementia with theology will reveal more about the capacities and weaknesses of theology than it will about the disease itself. So, it will be instructive. Yet theology, for all our need to engage with it, falls as mute as Job before the gratuitousness, the arbitrariness, the absurdity of suffering. Perhaps the expectation that theodicy will provide the comfort of a certain kind of belief in a certain kind of meaning is one of the things—only one of the things—that once prompted Elie Wiesel to remark that "the tragedy of the believer is greater than the tragedy of the unbeliever." Perhaps theology also has a share in that tragedy. Perhaps a theology of the Incarnation, Passion, and Resurrection of the Christ can help us understand the nature of our relationship with the eternal Ground of our being who became flesh, and to enter more deeply into that relationship. But that's an essay for another time.

At the wake of the 83-year-old man mentioned at the beginning, the man who was my father, a friend led a prayer service, ending it with this passage from Teilhard de Chardin's *The Divine Milieu*. It is a passage on death, but one can apply it to dementia:

We must overcome death by finding God in it. In itself, death is an incurable weakness of corporeal beings, complicated in our world by the influence of an original fall. It is the sum and type of all the forces that diminish us, and against which we must fight without being able to hope for a personal, direct, and immediate victory. Now, the great victory of the Creator and Redeemer in the Christian vision is to have transformed what is in itself a universal power of diminishment and extinction into an essentially life-giving factor.

God must, in some way or other, make room for himself, hollowing us out and emptying us, if he is finally to penetrate into us. And in order to assimilate us in him, he must break the molecules of our being so as to re-cast and re-model us. The function of death is to provide the necessary entrance into our inmost selves. It will make us undergo the required dissociation. It will put us into the state organically needed if the divine fire is to descend upon us. And in that way its fatal power to decompose and dissolve will be harnessed to the most sublime operations of life. What was by nature empty and void, a return to bits and pieces, can, in any human existence, become fullness and unity in God.

The rabbis taught that God gave not only the words of Torah ("the black fire"), but the white spaces ("the white fire") between the words, which means that God is the author of wordlessness as well as words. One needs to read the white spaces in the text, in the story, of a human life (ours and others') along with the words (our thoughts, our words, our deeds) because it is not only thoughts and words and deeds that make up the story of that life. We are a divinely inspirited and divinely sustained text, a text of black *and* white fire. There would be no legible, understandable story without the white spaces—the emptiness between the words, the open spaces, the spaces that allow God to enter more deeply into

relationship with us, the spaces that we mistakenly interpret as “worthless,” as “nothing.” Those white spaces represent what remains of the human story when there is no more “black fire,” when there are no more thoughts to be thought, no more words to be spoken, no more deeds to be done. God is as much the author of these spaces, which are often filled with deep and silent suffering, as God is of the words. When the altar of life has been stripped, when everything has been ripped away, when body and soul have been crucified, what remains? “If I make my bed in hell, You are there” (Psalm 139). We may in life eventually forget who we are; we will surely forget, and eventually be forgotten, in death. But *whose* we are, that we are beings-in-relationship who belong absolutely to the Love who has loved us unto death and who will raise us up in “the new heaven and the new earth,” in that Love we will live forever.

POSTSCRIPT

Dear Reader:

You may have noticed that plagiarism has received quite a bit of press lately. You may also have noticed that my essay has several quotations for which I have not provided full citations. This postscript aims to clarify some issues by making a useful distinction.

My piece is a personal essay, a form or genre of creative nonfiction in which one shares personal experiences, thoughts, and feelings on a particular topic. The personal essay has always distanced itself from a scholarly article or a treatise. Virtually all the essays of Michel de Montaigne are mosaics, his own sentences riddled with quotations—always attributed to one or another classical author, but hardly, if ever, accompanied by a reference to the source. Montaigne said he did it to get a free ride on other men’s brains, and to hide his weakness “under great authorities.” He may also have quoted so extensively in order to urge his readers to locate his sources and read them at length.

Much the same can be said of Henry David Thoreau’s personal essays: I’m thinking particularly of his well-known essay on walking. But Thoreau dispenses altogether with even mentioning the authors of his quotations, perhaps to invite his readers to the hunt. And who can read Annie Dillard’s Pulitzer-Prize-winning Pilgrim at Tinker Creek without getting enmeshed in quotations from the works of many naturalists who preceded her? She too does not provide sources nor even, at times, authors.

So, why quotations are given without full references in footnotes or endnotes in the personal essay? One reason may be to lend authority to the author’s thoughts. Another reason may be that quotations simply spring from an author’s well-stocked, liberally educated mind—perhaps one used to keeping “commonplace books” filled with favorite quotations. And yet another reason may be to give the reader the added pleasure of hearing a second, third, fourth mind engaging the topic. It is also always possible that a quotation was given to the author in a special circumstance (such as a funeral) without benefit of full scholarly citation. Admittedly, and sadly, there is no longer a commonly recognized body of quotable culture (not even of the Bible or Shakespeare) in our information-saturated age.

Whatever the reason or reasons, the personal essay has always striven to graciously share experiences, thoughts, and feelings with the reader by avoiding what, in that genre, would look like playing the pedantic schoolmaster. What Virginia Woolf called “the common reader” may or may not exist any longer, but in the personal essay every reader is always invited to partake. ■

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