Dementia Through A Spiritual Lens

3. Dementia and God’s Nature and Action
4. Dementia and the God Who Is Incarnate
Primary Reference

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- Served as a pastor of United Methodist local congregations in Virginia and Tennessee for 35 years.
- **1992 to 2004:** Bishop in the United Methodist Church.
- **2004 to 2009:** Served on the faculty of Duke Divinity School.
- **Nov 2009:** his wife was diagnosed with frontotemporal dementia.
- He became his wife’s primary caregiver.
- As her disease progressed over the next 10 years, she eventually required institutional care at a memory care facility.
- He served as a chaplain at the memory care facility where his wife lived for 18 months.
November 29:
- 1. Dementia Through a Medical Lens
- 2. Dementia: Mind, Memory, and God

December 6:
- 3. Dementia and God’s Nature and Action
- 4. Dementia and the God Who Is Incarnate

December 13:
- 5. Dementia and the Meaning of Personhood
- 6. Dementia and the Meaning and Source of Salvation

December 20:
- 7. Dementia and Christian Discipleship
- 8. Dementia, Grieving, and Death
PowerPoint presentations from the series can be downloaded from:

Dementia And God’s Nature and Action
Questions

- What is God doing in the lives of those who have no cognitive grasp of God?
- What is God doing in the lives of those who can no longer comprehend the Bible, our creeds, our traditions, the writings of scholars, our hymns and liturgies – our primary pathways into the mystery of God?
Dementia and God’s Nature and Action

- **Dementia** can be described as a form of:
  - chaos, or
  - bondage, and/or
  - exile.

- The biblical stories of the Creation, the Exodus, and the Exile in Babylon provide biblical / theological lenses through which we can view God’s actions within the world, and in particular God’s actions and responses to those with dementia. God works to:
  - create order from chaos,
  - liberate those in bondage,
  - redeem those in exile.
Dementia And God’s
Nature and Action

The God Who Creates: Order from Chaos, Light from Darkness
The God Who Creates: Order from Chaos, Light from Darkness

- A husband at the Memory Care facility lamented as he listened to his wife’s incoherent babbling and watched her violently bang her fists against the wall, “How in the hell can a good God create or allow a disease that torments people like this? What has she done to deserve this?”

- The stories of creation and “the fall” (Genesis 1–3) are biblical / theological lenses through which we can view God’s actions and responses to the chaos of human frailty, suffering, and imperfection.
The prevalent interpretation in Western Christianity (from Saint Augustine of Hippo, 354-430) asserts that God created the world and everything in it as perfect – including human beings.

The earth was originally flawless, harmonious, and pure.

“The fall” resulted in the disordering, blemishing, corruption of creation’s goodness.

Sinfulness and disobedience distorted and disfigured the divine image originally bestowed upon human beings.

Banishment from paradise and the blighting of the whole creation resulted.

Humans became mortal, their nature infected with sin.

God’s presence and continuing action is the restoration of creation’s original perfection, including the reshaping of human beings in the divine image.
Eastern Tradition of Creation

- In the *Eastern* Christian tradition (from *Saint Irenaenius*, 130-202), the original *creation* was *incomplete* and naively *innocent*.
- **God created**, and *continues* to *create*, by bringing *order* from *chaos*, *light* from *darkness*, and *maturity* from *innocence*.
- Humans are *created* with the *potential* to reflect the *divine* image and *grow* into the fullness of *God’s* dream for them.
- However, wrong decisions and destructive actions *thwart* the fulfillment of *God’s* dream for humanity and the whole *creation*.
- *Creation* is the *arena* for soul-making.
- Suffering, struggle, challenges, and death are opportunities for spiritual *growth* and *maturity*.
- *God’s* presence and *continuing* action are directed toward the healing, molding, reconciliation, and consummation of the *divine* dream for *creation*. 
Dementia and The Eastern Tradition

- Bishop Carder finds the emphasis on incompleteness and innocence in the Eastern, or Irenaean perspective helpful when thinking of dementia.

- Genesis opens with: “In the beginning when God created the heavens and the earth, the earth was a formless void and darkness covered the face of the deep, while a wind from God swept over the face of the waters” (Genesis 1:1-2).

- The image is one of chaos and darkness; and God’s creative action is in the form of bringing order from chaos and light from the darkness, out of which rise the conditions making possible life, beauty, and abundance.
Dementia as a Form of Chaos in an Unfinished Creation

- **Chaos** and **darkness** are apt descriptions of what happens in the brain as nerves die and connections become tangled.

- In **dementia**, thoughts and words are jumbled and incoherent. Vision and perception are distorted. Boundaries crumble, filters disintegrate, controls deteriorate, memories fade. Life is **chaotic**.

- The diseases causing **dementia** are examples of the **unfinished** nature of **creation**.

- God acts within the **unfinished creation** by **continuing** to bring **order** from the **chaos**.
Minimizing the disorder and disorientation are desirable goals of intervention in those with dementia.

Forms of relaxation, meditation, and music are often effective means to restore order.

Music may be an especially effective in fostering calm and orientation in people with dementia.

Bishop Carder frequently observed that the order, rhythm, and harmony of familiar hymns and music seem to help put people with dementia in touch with the God-created harmonies and order within creation itself.
Summary. The God Who Creates: Order from Chaos, Light from Darkness

- Christian theology views the **cosmos** as an expression of **God’s** love.
- **God’s** love continues to heal, reconcile, and harmonize the often turbulent, **chaotic creation**.
- Academic discussions of the origin of suffering and disease are perhaps less important than the affirmation that a loving and **creating God** is **aware** of, and **involved** in, the **totality** of human experience,
  - bringing **order** from **chaos**,  
  - **light** from **darkness**,  
  - **harmony** from **dissonance**, and  
  - **life** from **death**.
Dementia And God’s Nature and Action
The God Who Liberates from Bondage
The Prison of Dementia

- Memory care facilities are locked for the safety of residents.
- Bishop Carder once gently apprehended a resident trying to escape through a side door, and led her back to the facility. She asked him, “Where are you taking me? Back to that damn prison?”
- In dementia, the ability to make simple decisions and perform simple tasks diminishes, stripping away independence and freedom of action. One person in the early stage of Alzheimer’s disease remarked, “I feel like I’m being imprisoned within my own diseased brain.”
Questions

- Our culture *highly* values individual autonomy, self-sufficiency, and personal choice.
- The *inability* to exercise such values is viewed as a form of bondage, of imprisonment.
- Where is God, and what is God doing when human beings are in bondage?
The God Who Liberates from Bondage

- The story of the *Exodus* is a *biblical / theological lens* through which we can view *God’s* relationship to those in *bondage*.
- The deliverance of *God’s* chosen people from Egyptian slavery is a pivotal event in the story of *God’s* mighty acts of salvation.
- Exodus 3:7-8: “Then the LORD said, ‘I have *observed* the misery of my people who are in Egypt; I have *heard* their cry on account of their taskmasters. Indeed, I *know* their sufferings, and I have *come* down to deliver them.’”
- God *sees, hears, knows, and comes* to deliver those in *bondage*!
"To Know" in the Old Testament

- The Hebrew word knows (knowledge, yada) has several nuances in the Old Testament:
  - Genesis 4:1, “Now the man knew [yada] his wife Eve, and she conceived and bore Cain.”
    - In this context, to know yada is a deep, intimate, covenantal knowing that produces life!
  - Proverbs: “The righteous know [yada] the needs of their animals, but the mercy of the wicked is cruel” (12:10).
    - To know is to identify the needs of others and to respond in mercy.
  - Jer 22:16 “Did not your father .. do justice and righteousness? Then it was well with him. He judged the cause of the poor and needy; ... Is not this to know [yada] me? says the LORD.”
    - To know involves more than intellectual awareness of the poor and needy, it means to act wisely on their behalf.
Where is God, and what is God doing among those made captive by dementia?

God is aware of, present with, showing mercy and compassion, seeking justice, and delivering them from the captivity and isolation of their diseases.

And as God called Moses, we are also called to participate in God’s knowing (yada), to join in their deliverance, and act justly on their behalf.
The "Knowing" of Those with Dementia

- Bishop Carder was frequently asked, “Does your wife know you?”
- She no longer recognized him as her husband. She did not recall their past together.
- Yet the expression in her eyes, the occasional smile on her face, the slight squeeze of the hand — all suggested a knowing more profound than intellectual comprehension.
- Bishop Carder suggests many people with dementia “know as God knows.” They know with the heart what the brain cannot comprehend or process.
How Those With Dementia Free Us From Bondage

Those living with dementia can be a means by which God frees us from our bondages. They can:

- **free** us from the enslaving concept that knowing is only an intellectual awareness,
- **free** us from bondage to an excessive reliance on our capacities as the source of identity and worth,
- **free** us to live joyfully in the moment, appreciating the simple experiences,
- **free** us from the distractions that prevent us from seeing that love is the only enduring reality.
- **free** us from the distractions that prevent us from knowing God as the One who works within creation to set the captives free.
Dementia And God’s Nature and Action

The God Who Redeems From Exile
“I want to go home” is a frequent comment from people in the memory care facility.

“Who is at your home? Who will you see there?” Bishop Carder would ask.

If the short-term memory had been erased, the person thinking of their childhood home might answer, “My momma and daddy.”

A frail ninety-six-year-old woman answered his question with: “Jesus!”
Our Longing for Home

- Frederick Buechner suggests that there is a *longing* within the human spirit for *two* homes:
  - the home of our *past* where we first experienced life and love, and
  - the home of the *future* where dreams of wholeness are fulfilled.
- We persistently live with “*homesickness,*” as *exiles* in a strange land:
  - remembering what *has been* but *is no more,* and
  - longing for a *future* home where we will be restored and made whole.
Exile is an appropriate metaphor for the experience of dementia:

- People with dementia are often away from their homes, their families and friends, their congregations.
- Their daily routines are determined by strangers who seldom know their life stories.
- The people they live with behave strangely, speak incoherently, and unknowingly enter their private space.
- They are cut off from their past experiences, roles, recollections, and ways of relating.
- In the advanced stages, once familiar people become strangers, sometimes even perceived enemies.
- Their isolation increases as family members and friends visit less and less.
The story of the **Babylonian exile** in the sixth century BC is a **biblical / theological lens** through which we can view **God’s** relationship to those in **exile**.

In the sixth century BCE (~586 BC), Jerusalem was destroyed by Babylon’s army, and the Jewish people lost their temple and their homeland.

Many of the leaders – those with influence – were taken to Babylon.

Those who remained were **exiles** in their own land.
In Psalm 137:1-4 we read: By the rivers of Babylon — there we sat down and there we wept when we remembered Zion. On the willows there we hung up our harps. For there our captors asked us for songs, and our tormentors asked for mirth, saying, “Sing us one of the songs of Zion.” How could we sing the LORD’s song in a foreign [strange] land?

The experience of exile led the Jewish people to reinterpret their tradition, rediscover their identity as the people of covenant, and envision a new future with hope.

Exile would finally end with Cyrus II’s of the Persian Empire (600-530 BC) conquest of Babylon in 539 BC, allowing the Jews to return home and rebuild the temple in Jerusalem.
Insights from the Exile for Dementia

There are several insights we can take from the stories of the exile for those with dementia:

1. God’s presence transcends all borders.
2. Need for lament.
3. Concept of the “the suffering servant.”
4. Hope for Return.
1. God’s presence transcends all borders

- The ancient exiles learned experientially that God knows no exile. God’s presence *transcends all* borders, is *not* confined to specific places:
  - God lives in Babylon as surely as Jerusalem,
- God’s sovereignty extends over *all* peoples and transcends *all* barriers – *including* the limitations of the human mind.
- Those with dementia may be exiles in a strange land, and may have even forgotten God, but God has not forgotten them.
- In that affirmation lies their identity, their worth, and their hope.
2. Need for Lament

- The poets of the **exile** knew that the first step in coping with **suffering** and **loss** is to acknowledge its **ugliness** and **meaninglessness**.
- Denial only compounds the destructiveness and slows the journey toward **healing** and **peace**.
- Laying the anger, despair, desolation, and weariness before the **God** is one avenue into **God’s** **healing** **presence**.
- Individual and communal expressions of **lament** dominate the one hundred and fifty psalms – many specifically referencing the destruction of the **exile**.
- The **book of Lamentations** gives voice to the suffering, despair, grief, and longing of the Babylonian captivity.
2. Need for Lament

- My God, my God, why have you forsaken me? Why are you so far from helping me, from the words of my groaning? O my God, I cry by day, but you do not answer; and by night, but find no rest. (Psalm 22:1-2)

- How long, O LORD? Will you forget me forever? How long will you hide your face from me? How long must I bear pain in my soul, and have sorrow in my heart all day long? How long shall my enemy be exalted over me? Consider and answer me, O LORD my God! Give light to my eyes, or I will sleep the sleep of death. (Psalm 13:1-3)
2. Need for Lament

- **Laments** were often Bishop Carder’s *primary* forms of **prayer** during his wife’s illness.
- They gave **voice** to his *anguish* at being separated from his wife, at seeing her *agony* and *confusion*.
- They also allowed him to interpret *her own* expressions of agitation, frustrations, and resistance as *her own laments*.
- He came to view her angry outbursts as **prayers of lament** to be accepted with patience and kindness.
3. Concept of the “the suffering servant”

- During the exile, Israel’s understanding of its mission and of God’s way of being in the world progressed to encompass suffering, weakness, and vulnerability:
  - they saw the exile as a judgment on their failure to fulfill their calling to be a community of compassion, justice, and hospitality.
  - they could not ignore God’s solidarity with, and continued presence among them – even though they were powerless, vulnerable, and dislocated,
  - they began to understand their own mission to be among the powerless and vulnerable.
3. Concept of the “the suffering servant”

- Isaiah 52:13–53:12 portrays God’s “servant” as “a man of suffering and acquainted with [yada] infirmity; and as one from whom others hide their faces.”

- Those exiled by dementia are contemporary “suffering servants” of God who know sorrow and illness, and are those from whom others often hide their faces.

- Entering their world of dislocation and frailty therefore is a pathway into the presence and steadfast love of the God.
  - For God claims the vulnerable and despised as means of divine grace and transformation.
4. Hope for Return

- The image of **exile** provides *hope* for return!
- The final return from **dementia’s exile** is “eschatological,” in **God’s** time.
- Yet, there are **intimations** of the final restoration of those with **dementia** in:
  - the *temporary* times of remembrance, connection, and recognition,
  - in *fleeting* expressions of love, joy, and peace.
Summary: Dementia and God’s Nature and Action

- The diseases causing dementia are examples of the unfinished nature of creation.
- The biblical/theological stories of creation, exodus, and exile provide lenses through which we can better view dementia.
- God is present and active in creation, and God is present and active within those with dementia, working to:
  - create order from chaos,
  - liberate those in bondage,
  - redeem those in exile.
Dementia and the God Who Is Incarnate
A Different World

A friend and hospice chaplain suggested to Bishop Carder in his journey with his wife’s dementia: “She’s moving to another world, ... Being present in her world is hard and sometimes impossible; but your presence in her world is important for both of you. There will come a time when you will have to let go and give her permission to enter a totally new world, but accompanying her as far as you can will bring you both sorrow and joy.”
How does one enter a world composed of chaotic thought processes, sporadic comprehension, and jumbled language?

His wife’s world was filled with confusion, agitation, combativeness, apathy, sadness, and withdrawal.

The temptation was to avoid that world, argue with it, deny it, resist it, escape it.

As he struggled to get inside her realities and those of other residents of the Memory Care facility where he was chaplain, Bishop Carder encountered anew the Incarnate God.
Incarnation, God Entering a Different World

- At the heart of the Christian tradition is the **Incarnation**, the **Word made flesh**.
- **God**, the Creator of the universe, became **flesh** in **Jesus** of Nazareth.
- **God** chose to **enter** human existence with all its **frailty**, **dependency** and **vulnerability**.
- **God** chose to experience, in the **flesh**, **human love**, **weakness**, **confusion**, **pain**, **suffering**, **loss**, **grief** and **death**.
Incarnation, God Entering a Different World

- **Jesus** was the *Word made flesh*:
  - as a whimpering, dependent infant nursing at Mary’s breast,
  - as well as an adult presenting himself for baptism at the Jordan.

- **Jesus** was the *Word made flesh*:
  - while carving wood and accidentally cutting his hand as a youth in Nazareth,
  - as well as an adult being nailed to a wooden cross on Golgotha.
Incarnation, God Entering a Different World

- **God** entered the *entirety* of the **human flesh**, claiming *every* cell, organ, and function as a vessel of *divine* presence.

- *Every* cell, organ and function of **human flesh** became a dwelling place – indeed a part – of **God**.

- *Every* cell, organ, and function of **human flesh** was thus made *holy* and *sacred*, a **temple** where **God** could dwell.
Incarnation, God Entering a Different World

- Note the flesh made holy and sacred was not just the particular flesh of Jesus’s human body, but included the human flesh in all of the creation. All human flesh became sacred and holy; temples where God could dwell.

- In Eastern Christianity, they describe this by saying “God became human so we can become divine.”
  - In the Incarnation, human flesh became “divinized.”
Incarnation and Dementia

- What does the **Incarnation** mean for those who live in the world of **dementia**?
- Through the **Incarnation**, the human body has been made a **temple**, a dwelling place for **God**.
- **God** dwells in the bodily **temples** of those with **dementia**, and thus **God knows** their human world of **frailty** and **vulnerability**.
Incarnation and Dementia

- How do those with dementia experience the divine presence when their mind cannot comprehend God’s presence?
- People with dementia maintain sensory capacities; some capacities can be heightened as the disease progresses.
- Since the totality of the human person is a temple of God, they can experience God’s presence through:
  - gentle touches,
  - glimpses of beauty,
  - sounds of music,
  - the fragrance of fresh flowers,
  - the taste of familiar foods.
- Abstract thoughts vanish and words disappear, but God’s presence remains.
The Incarnation as Model for Relationships

- **God** chose to be with us (Emmanuel) in the most conceivably intimate way:
  - by becoming one of us in the flesh as Jesus,
  - by being present with us through our lives in our confused, broken, and vulnerable world.

- We in turn are invited to be “Christlike,” using the Incarnation as a model, and try to enter into, be present within the world of others, in their confusion, ordinariness, brokenness, and vulnerability.
"Being With" a Person with Dementia

- How can we try to “be with” a person with dementia?
- **(1) Be physically present.**
- Isolation and loneliness are common to the elderly in general, and even more so among those with dementia. A major contributing factor to the isolation of people with dementia is fear and discomfort on the part of family members and friends. “She doesn’t recognize me when I visit, and she forgets I was there, so why visit?”
- John Swinton poignantly states that the tragedy isn’t that people with dementia forget; it is that they are forgotten.
- **Presence** proclaims value. As God is present with humanity, thereby declaring our worth and dignity, so we are present with one another as a declaration of the worth and dignity of the other.
"Being With" a Person with Dementia

- How can we try to “be with” a person with dementia?
- (2) Be attentive.
- The psalmist declared “O LORD, you have searched me and known me. You know when I sit down and when I rise up; you discern my thoughts from far away. You search out my path and my lying down, and are acquainted with all my ways. Even before a word is on my tongue, O LORD, you know it completely.” (139:1-4)
- Jesus declared that even the hairs of our head do not escape God’s attention, and that a lamb cannot wander unnoticed from the fold.
- Many people with dementia are hypersensitive to nonverbal communications, voice tone, and touch. Communication requires attentiveness to their individualized mannerisms, expressions, and feelings.
"Being With" a Person with Dementia

- How can we try to “be with” a person with dementia?
- **(3) Affirm the mystery of their life.**
  - Every person is an ineffable mystery to be approached with a degree of reverence and awe.
  - Openness to the wonder and mystery in the Other avoids reducing one another to our physical, behavioral, and intellectual characteristics.
  - **Mystery** is the appropriate place to begin when relating to people with dementia. It “sees the extensive disability and profound irreversible, advancing illness as a mystery and not as a problem. It doesn’t treat them as fundamentally needy, miserable, or pitiable. It doesn’t define people by what they’re not.” (Samuel Wells, *Incarnational Ministry: Being With the Church*)
"Being With" a Person with Dementia

How can we try to “be with” a person with dementia?

(4) Find Delight in the Other.

Dementia is accompanied by the persistent stripping away of capacities, and the tendency is to focus exclusively on the resulting deficits rather than on gifts that frequently surface unexpectedly.

Some capacities recede; others – gifts – emerge. For example: a childlike delight in simple things:
- jet stream in the blue sky,
- a small insect crawling on his/her shirt,
- a cone of ice cream that is new each time he/she eats it.
Next Week:

5. Dementia and the Meaning of Personhood
6. Dementia and the Meaning and Source of Salvation