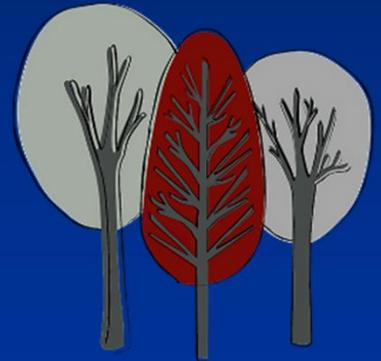


Dementia Through A Spiritual Lens

3. Dementia and God's Nature and Action

4. Dementia and the God Who Is Incarnate



ST. JOHN IN THE WILDERNESS

Kenneth L. Carder



Ministry
with the
Forgotten

Dementia through
a Spiritual Lens

Primary Reference

- **Ministry With The Forgotten: Dementia Through A Spiritual Lens**, Kenneth L. Carder. 2019, Abingdon Press, ISBN 978-1-5018-8024-7.





Kenneth Carder

- 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. ■

Outline

■ **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:**

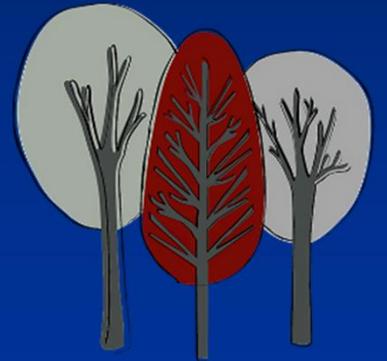
- 5. Dementia and the Meaning of Personhood
- 6. Dementia and the Meaning and Source of Salvation

■ **December 20:**

- 7. Dementia and Christian Discipleship
- 8. Dementia, Grieving, and Death ■

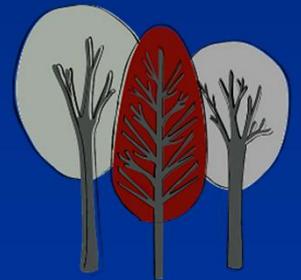
- PowerPoint presentations from the series can be downloaded from:

www.StJohnAdultEd.Org/dementia.htm



ST. JOHN IN THE WILDERNESS

Dementia And God's Nature and Action



Questions

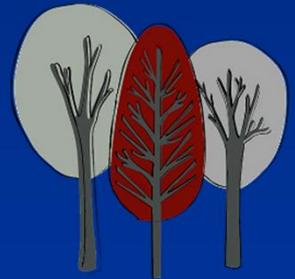
- What is **God** doing in the lives of those who have *no* cognitive grasp of **God**?
- What is **God** doing in the lives of those who can *no longer* comprehend the Bible, our creeds, our traditions, the writings of scholars, our hymns and liturgies – our primary pathways into the *mystery* of **God**?

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*.

Western Tradition of Creation

- 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 Irenaenus**, 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 *Irenaeian* 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**.

Practical Means of Minimizing Dementia's Chaos

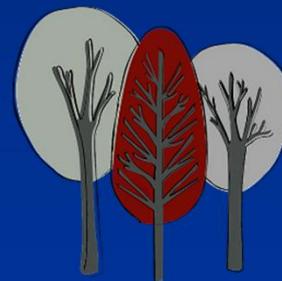
- Minimizing the **disorder** and **disorientation** are desirable goals of intervention in those with **dementia**.
- Forms of relaxation, meditation, and music are often effective means to restore **order**.
 - **Music** may be an especially effective in fostering calm and orientation in people with **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 *justly* on their behalf.

The God Who Liberates from Bondage

- 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

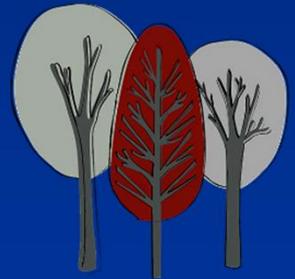
- Bishop Carder was frequently asked, “**Does your wife *know* you?**”
- She *no longer* recognized him as her husband. She did *not* recall their past together.
- Yet the expression in her eyes, the occasional smile on her face, the slight squeeze of the hand — all suggested a **knowing** more profound 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



ST. JOHN IN THE WILDERNESS

“I want to go home”

- **“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.

Dementia as a Time of Exile

- **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 God Who Redeems From Exile

- 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.

The Babylonia Exile

- 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.

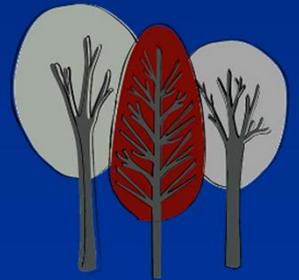
4. Hope for Return

- 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.”

A Different World

- 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** chooses 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

