Dementia Through A Spiritual Lens

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

Dementia and Christian Discipleship
Dementia and Christian Discipleship:
Introduction
Introduction

- Each week Bishop Carter led a worship with 30 to 40 people, most of whom were in the mid-stages of dementia.
- Most of them had been participants in churches for six or seven decades.
- They had:
  - known the creeds,
  - participated in rituals and liturgies,
  - faithfully tried to fulfill their baptismal and membership vows to support the church.
- They had exhibited the marks of Christian discipleship.
But now for those 30 to 40 people in the mid-stages of dementia:

- Church participation has fallen by the wayside,
- Creeds have been erased from their understanding,
- For some, Jesus and God are meaningless concepts,
- Even behavior boundaries have weakened:
  - a straight-laced pastor now uses profanity,
  - a deaconess makes indiscriminate sexual overtures.
A pastor and chaplain with dementia laments, “I’m not any good to anybody! I can’t do anything anymore!” Instead of helping others, he is now dependent on others.

He is but one of many whose Christian discipleship and vocation seem in peril as their intellectual and language capacities fade.

Congregations largely view people with dementia as:
- recipients of ministries, not participants in ministries,
- objects of mission, not contributors to mission.

They are relegated to the “inactive roll,” with no expectations to contribute.
Questions

- Are people with dementia only emeriti Christian disciples?
- Can they follow a Jesus whom they have forgotten?
- Do they have a Christian vocation, a calling?
- How can their discipleship and vocation be nurtured, and their gifts celebrated and utilized for the church’s mission?
Dementia and Christian Discipleship:
The Meaning of Christian Discipleship
Some of the responses of a class of seminary students to the question, "What does it mean to be a Christian disciple?":
- To believe in the Apostles’ and Nicene creeds,
- To accept Jesus as Lord and Savior,
- To participate in the life and mission of the church,
- To trust in God’s mighty acts of salvation, supremely in Jesus Christ,

But all of these imply:
- intellectual understanding,
- conscious action or decision.
Is there a more *fundamental* answer to “*What does it mean to be a Christian disciple?*” one that can include those *dementia*?

John Swinton writes, “*Dementia does not affect discipleship or humanness; it reveals ‘hidden’ aspects of both.*”

Viewing *discipleship* through the lens of *dementia* can uncover “hidden” aspects of *discipleship*.
Christian Formation

- A **disciple** means a:
  - “follower,”
  - “student,” or
  - “apprentice” of a mentor.
- Jesus is called “rabbi,” or teacher, and his **disciples** learn about and from him.
- Christian education tries to **teach** and **form** people to be **disciples** of Jesus Christ.
Christian Formation

- Theological education prioritizes *intellectual understanding* of Christian:
  - doctrines,
  - history, and
  - tradition.

- Christian **discipleship**, however, also involves *formation* as well as such education.
Much of our formation occurs unconsciously.

We are formed by:
- relationships, experiences, practices within community, and
- the ethos, the prevailing spirit, the character of our community’s culture.

Christian formation is “caught” as well as “taught.”
Christian Formation

- One pastoral theologian writes: “Christian learning begins before we think about it and, by implication, it continues after we have ceased to think about it.”

- Another writes, “[Christian education] is a holistic endeavor that involves the whole person, including our bodies, in a process of formation that aims our desires, primes our imagination, and orients us to the world — all before we ever start thinking about it.”
Christian Formation

- Our “memory” is more comprehensive than the conscious recollection of events and facts.
- “Memory” is also formed by practices and experiences of which we are cognitively unaware.
- People with dementia embody behaviors and responses that reflect those past practices and experiences of which they were cognitively unawareness.
- Such “embedded” practices and behaviors can emerge in the actions and responses of those with dementia.
- They can “know” and “remember” in ways outside conscience recollection.
Broadening the Definition of Discipleship

- **Dementia** forces us to broaden the scope of discipleship *beyond* conscious loyalty to abstract creeds and doctrines.

- People with **dementia** can still “know” and “remember” in ways *outside conscience awareness*, through their “embedded” practices and behaviors.
Broadening the Definition of Discipleship

- **Love** is the most *fundamental* reality embodied in **Jesus** the Christ and in his **disciples**.
- **Love** is *not* the abstract *knowledge* of the creeds and doctrines.
- **Love** is a *way of being*, expressed in the conscious – and *unconscious* – dynamic of giving and receiving **love**.
Dementia and Christian Discipleship:
The Dance of Love: Essence of Christian Discipleship
The Shema

- The Hebrew Scriptures and the New Testament both declare that love for God and neighbor summarizes God’s expectations and goal for humanity.

- The Shema (Deuteronomy 6:4-5) is at the heart of Jewish daily prayer: “Hear, O Israel: The LORD is our God, the LORD alone. You shall love the LORD your God with all your heart, and with all your soul, and with all your might.”

- When asked to identify the greatest commandment, Jesus answered with the Shema, “You shall love the Lord your God with all your heart, and with all your soul, and with all your mind.” Then he added a commandment from Leviticus 19:18b, “You shall love your neighbor as yourself” (Matt 22:37-39).
Jesus not only taught about love, but was the incarnation of divine love.

His final commandment to his disciples is this: “Love one another as I have loved you” (John 15:12).

Paul:
- love is the ultimate gift and surpasses all other capacities, including knowledge and language (1 Cor 13).
- nothing in all creation, including dementia, can separate us from God’s love (Rom 8:38-39)

1 John: “God is love, and those who abide in love abide in God, and God abides in them” (4:16b).
Love at the Core of Discipleship

- The love at the core of discipleship is a covenantal commitment to seek the well-being of the Other with patience, humility, kindness, and perseverance.
- It is more than a sentiment: it involves acts of forgiveness, healing, justice, and advocacy.
- It also involves:
  - an acceptance of our dependency,
  - acknowledgment of our limitations,
  - a willingness to receive the gifts of others.
The Dance of Love

The essence of Christian **discipleship** is this: participation in the giving and receiving of **love**.

**Love** is defined by the **love** in the intimate relationship **within** the triune God, a dynamic **dance** of:
- creating,
- redeeming, and
- sustaining.

The **dance** moves with the unfolding drama of life’s transitions and challenges, always:
- **giving** and **receiving**,
- **holding on** and **letting go**.
Christian **discipleship**, then, consists of our *participation* in the triune God’s *dance of love*, whatever our status or capacity.

We are *part* of God’s drama, or *dance*, of **love**!

Identifying and fulfilling our *part* in that *dance* is the essence of Christian **discipleship**.

Our specific *roles* will *change* with our circumstances:

- Sometimes we take the “lead” in the *dance*; other times we are dependent.
- At times, we may perform “solo”,
- During other occasions, we may passively *receive* the gifts of others.
The Dance of Love

Before she developed dementia, the Bishop's wife’s role in the dance of love – in Christian discipleship – included teaching Sunday school and serving on Outreach projects.

Now her role is largely that of receiving the expressions of love from those around her.

As she receives expressions of love:

- her husband’s love grows,
- the love in the world grows,
- the triune God’s dance of love expands.
The Dance of Love

- The circle of the *dance* widens further as:
  - Caregivers skillfully, tenderly, and patiently care for the needs of another,
  - Neighbors stop in to lend support,
  - A couple from church brings in a meal.
We Love By Faith

- There may be a temptation to assume that our acts of love for those with dementia don’t really matter: “After all, she doesn’t even know I’m here!”
- Sometimes the acts of love are reciprocated with visible responses. At other times, there is no visible response.
- But if our love is a participation in God’s love, the full response is always beyond the visible or measurable.
- We love by faith: we trust that deep within the beloved, and in God’s economy, our love makes a difference.
We Love By Faith

- The caregiver’s **discipleship** amid **dementia** is often challenging.
- Our expressions of **love** may *not* be received with generosity or gratitude.
  - Response may appear to be the *opposite* of Christian **discipleship**: anger, hostility, violence, apathy, expressions of hate and disdain.
- Such **difficult** behaviors should be viewed as *manifestations* of the underlying **disease** rather than *intentional* responses to us.
- **Discipleship**, sharing in the *dance of love*, can require a lot of improvisation, discipline, and patience.
Dementia and Christian Discipleship: Discipleship as Communal
Discipleship as Communal

- **Discipleship** involves *community*.
- It is the *community* that engages in the *dance* of the triune God.
- The triune God’s *dance of love* is a communal *dance* of:
  - mutual support,
  - giving and receiving,
  - leading and following.
- Paul: we are to “**bear one another’s burdens, and in this way you will fulfill the law of Christ**” (Gal 6:2).
Our Mutual Dependency

- “I don’t want to be a burden” is a common dread in our society where personal autonomy is all important.
- One of the “hidden” aspects of discipleship exposed by dementia is our mutual dependency, our need of one another.
- To be human is to be a burden!
Our Mutual Dependency

- Psychiatrist/theologian Warren Kinghorn: “The remarkable thing about human life is not that humans are frequently a burden to each other, but that bearing each other’s burdens is simply what humans do. It is care and relationship, not isolation and individualism, which are normative in human life. So, while it is true that caring for people with dementia (or supporting the caregivers of people with dementia) can be burdensome, it is also true that in these seasons the person needing care becomes more, not less, paradigmatically human.”
Our Mutual Dependency

- Christian **discipleship** involves:
  - *bearing* one another’s *burdens*, and
  - *permitting* others to help bear our *burdens*.
- That’s the *dance* of *love*!
Our Mutual Dependency

- It also means the community worships, believes, and serves for the disabled disciple whose impairments prevent him or her from participating in some of the expressions of discipleship:
  - When persons with dementia can no longer recite the Apostles’ Creed, the community recites it for them.
  - When they cannot read the printed prayer, the community prays it for them.
  - When serving on committees or mission projects exceeds their abilities, others in the community serve on their behalf.
Dementia and Christian Discipleship: Dementia as Vocation
Our Christian Vocation

- Our **vocation** as Christians is to be:
  - recipients and **mediators** of God’s salvation,
  - **participants** in the triune God’s holy *dance* of *love*, compassion, and justice.
Our **vocational** calling as Christians takes place:
- within our own unique circumstances, and
- within a particular *community*.

*Each* member of the *community* plays a significant role.

The Apostle Paul’s description of the *community* as a “**body**,” with *each* part serving an important, *indispensable* function is noteworthy (1 Cor 12).

Paul: “**But God has so arranged the body, giving the greater honor to the inferior member**” (1 Cor 12:24b).
The Body of Christ

- The “weaker” or “less respectable members.” are indispensable members of the **Body of Christ**, and are given greater honor.
- God has *chosen* the “weak,” the “foolish,” and the “despised” as *mediators* of God’s power, wisdom, and reconciliation.
- Jean Vanier (founder of L'Arche): “*In some mysterious way, they [people with disabilities] are calling to me, to us all, to change,* ... *When we meet people with disabilities and reveal to them through our eyes and ears and words that they are precious, they are changed. But we too are changed. We are led to God.*”
Caregiving as Sacred Vocation

- Caregiving is a sacred **vocation**!
- Caregiving is the archetype of Christian **discipleship**.
- Jesus *defined discipleship* as **servanthood** (Matt 20:24-28).
  - The model is Jesus washing the feet of the **disciples** and calling the **disciples** into a life of humble service (John 13:1-20).
- Caregivers of the severely disabled are the epitome of **self-emptying** service:
  - entering the most vulnerable areas of a person’s life and
  - performing the most intimate and unglamorous of services.
Caregiving as Sacred Vocation

- In entering that world of total vulnerability, a unique bond of intimacy can develop:
- Some of Bishop Carter’s most profound moments of connection with his wife suffering from dementia came while:
  - brushing her teeth,
  - grooming her hair, or
  - feeding her favorite ice cream.
- In the dynamic of giving and receiving:
  - the bond between them grew, and
  - he could sense a transcendent presence.
- And his wife’s acceptance of his aid, her occasional smile or whispered “thank you,” were expressions of her discipleship.
The Discipleship of Those With Dementia

- Persons in the severe stages of dementia fulfill their discipleship in simply being and receiving the love of others.

- Their receiving of care:
  - expands the caregivers’ capacity to love without reciprocity,
  - enables growth in patience and kindness,
  - calls forth gentleness and attentiveness,
  - facilitates the presence of God in “the least of these.”
The Discipleship of Those With Dementia

- Those with severe dementia:
  - are means of grace, giving God’s presence and power to those who choose to be present with them;
  - teach us what it means to be a person made in the divine image and loved by God,
  - enable us to grow more fully in love for God and neighbor,
  - woo us to love one another as Christ loves us.
Dementia, Grieving, and Death
Dementia, Grieving, and Death:
Introduction
Grief is “the constant yet hidden companion of Alzheimer’s disease and related dementias.”

The Bishop describes his acute awareness of his own grief as spouse and caregiver:

- “I’m losing her a brain cell at a time,”
- “It is as though a brilliant, multicolored light is gradually fading into an encroaching darkness.
- There are short periods of stability with only subtle changes, allowing time for adjustment to the losses, then inexplicably the rate of decline accelerates, and the dramatic losses surface more grief.”
- “The radiant light grows dimmer and dimmer, with occasional, fleeting flickers of brightness.”
Introduction

- His wife’s personal **grieving** over her **dementia** becomes less identifiable as her ability to perceive and articulate thoughts and feelings disintegrated.

- Signs of **grief** and sadness occasionally emerge, sometimes openly, other times subtly:
  - Sorrow in her eyes, a whimper in grieving tones.

- But is she aware of her losses, since only the **present moment** seems real?
  - Do the tears flow from mourning, or is there another explanation?
Questions

- How are we to understand the grief of persons with dementia?
- How does the grief vary from stage to stage?
- How can we aid in the process?
- What about the grief of caregivers?
- What are sources of hope and comfort from the Christian faith?
Dementia, Grieving, and Death: Grief of the Person with Dementia
Grief of the Person with Dementia

- During the early stages of dementia, the grief of the person with dementia can be visibly expressed: shock, denial, anger, and guilt.
- For example, the Bishop’s wife’s:
  - anger and denial at failing the exam for renewal of her driver’s license.
  - frustration at being unable to dress herself,
  - tears when she realized she couldn’t recall a grandchild’s name,
  - anger at perceived shunning by friends,
  - exasperation at the inability to find words or comprehend words,
  - defensiveness when offered help with a task she can no longer complete.
- Each lost capacity is accompanied by grief.
Grief of the Person with Dementia

- As the disease *advanced*, her ability to comprehend and reflect on the losses faded, as did her capability to express her feelings verbally.
- Her *grief* seemed to go *underground*, erupting in behaviors and expressions *unrelated* to specific incidents or losses.
- She became combative and hostile for no apparent reason, as though life itself was against her, stripping away everything she valued.
Grief of the Person with Dementia

- Restlessness, withdrawal, searching, crying, waning appetite, and a forlorn look in her eyes were among the outward signs of underlying grief.
- “I want to go home” became a frequent plea – when they were at home.
- “Home” was more a feeling, an emotion, than a place; a longing for life as it once was, for a sense of security, connectedness, belonging, comfort.
Grief of the Person with Dementia

- *Attentiveness* to the feelings *beneath* the behaviors is the appropriate response to the *grief* of the person with *dementia*.

- A reassuring *presence* is the most helpful *counter* to their *grief*:
  - Entering the person’s world with empathy and compassion,
  - gently mourning with him or her.

- The great tragedy is that the *difficult* behaviors emerging from the *grief* often drive people away, precisely at the time their *presence* is most *needed*. 
Dementia, Grieving, and Death: The Grieving Caregiver
The Grieving Caregiver

- The grief of the caregiver is like a constant companion.
- Sometimes the companion keeps a manageable distance; other times, it is like a violent intruder.
- Often it is like a cumulus cloud floating silently and unobtrusively nearby; other times, is a thunderbolt followed by a storm of sobbing.
- The lament of the psalmist surfaces throughout the journey: “My tears have been my food day and night” (Ps 42:3a).
Ambiguous Loss

Pauline Boss (a professor emeritus at the University of Minnesota), describes the grief of loved ones of people with dementia as ambiguous loss.

Ambiguous Loss is “a loss that is unclear; it has no resolution, no closure.”

The person with dementia is both:
- present and absent,
- gone but still there,
- beside you but far away.

Boss: “With dementia, absence and presence coexist. . . . When someone you love has dementia, the task is to increase your tolerance for the stress of ambiguity.”
Ambiguous Loss

- **Ambiguous loss** makes the caregiver’s grief particularly confusing and lonely.
- It is a roller coaster of conflicting emotions:
  - *holding on* and *letting go*,
  - *yearning* for an end to the anguish while *resisting* the final goodbye.
Disenfranchised Grief

- The ambiguous loss accompanying dementia contributes to a form of grief Kenneth Doka identifies as disenfranchised grief: “losses that are not appreciated by others.”

- Doka writes: “The individual has no perceived ‘right’ to mourn; the loss is not openly acknowledged or socially sanctioned and publicly shared. Others simply do not understand why this loss is mourned and may fail to validate and support the grief.”

- Society fails to acknowledge that the “long goodbye” is a legitimate grief process, thereby denying those on the journey support.
Layered and Multifaceted Grief

- Caregiver *grief* is layered and multifaceted.
- The Caregiver *grieves*:
  - for the losses experienced by the one with dementia,
  - their own personal losses.
- The uncertainty, fear and yet anticipation of the journey’s end adds another layer of ambiguity and *grief*.
Layered and Multifaceted Grief

- The nature of the *past relationships* affects the **grieving**.
- Spousal **grieving** is a continuous process of:
  - *letting go* of the person who *was*, and,
  - *learning to love* the person who *is*,
  - while at the same time *anticipating* the final separation of death.
- Families characterized by open communication and mutual support can **grieve** with solidarity.
  - But when there is a history of tension and alienation, the **dementia** will likely intensify the family stresses and complicate the **grieving**.
Layered and Multifaceted Grief

The decision to place a loved one in a facility intensifies and complicates grieving:
- guilt that you have failed and abandoned the person with dementia,
- anger at real and perceived neglect at the institution,
- frustration with systemic institutional problems,
- loneliness at the absence of the person with dementia.

It is largely disenfranchised grief: few people understand the trauma involved in admitting a loved one to an institution:
- “You must feel relieved,” a neighbor told the Bishop after he had admitted his wife to a Memory Care Facility.
- On the contrary, he felt devastated!
Dementia, Grieving, and Death: Grieving the Final Goodbye
Grieving the Final Goodbye

- The death of the person with dementia changes the focus of the grief.
- As with other phases of the journey, the grieving is individualized and multifaceted.
- Some people experience a liberating loss, feelings of relief and emancipation:
  - the caregiving responsibilities and suffering by both the patient and family have ended.
- Others may grieve the loss of the caregiving role and experience a sense of meaninglessness and lack of purpose.
Grieving the Final Goodbye

- Guilt is a common component of all grief, but it may be especially intense upon the death of a family member with dementia:
  - guilt over times when more patience and empathy could have been shown, when difficult behaviors could have been better tolerated;
  - guilt for institutional placement;
  - guilt for failing to provide more assistance;
  - guilt for not visiting more often;
  - guilt over having feelings of relief.
Grieving the Final Goodbye

- The grief at the death of the loved one is sometimes a disenfranchised grief, or minimized by others who assume that the grieving has already taken place.

- Intended statements of support may complicate the process, failing to acknowledge its complexity:
  - “This must be a blessing,”
  - “You must feel relieved.”
Dementia, Grieving, and Death:
Tasks of Grieving
Psychologist J. William Worden classifies four tasks of mourning:

1. **Accept** the reality of the loss.
2. **Work through** the pain of grief.
3. **Adjust** to an environment in which the loved one is missing.
4. **Find** an enduring connection with the person while **moving forward** with a new life.
(1) Accept the Reality of the Loss

- Accepting the reality of the losses occurring throughout the journey with dementia is an ongoing challenge for both the person with dementia and their caregiver.
- The incremental and often subtle nature of the losses makes denial possible.
- However, as the disease progresses, the losses can no longer be denied.
Rituals exist to mark the grief of the final loss, but no rituals exist for marking the gradual, more subtle losses of dementia.

A practice the Bishop found helpful in both in accepting the reality, and working through the pain of grief was the use of lament.

After his wife experienced a specific loss, he wrote a prayer to express his grief, sadness, even anger.

Following the lament, the prayer could turn into thanksgiving for having previously been the beneficiary of the gift of what had been lost.
(2) Work Through the Pain of Grief

- Expressing one’s pain within a supportive community can also help.
- Participation in support groups can also counters the sense of being alone:
  - Pain shared is pain diminished.
(3) Adjust To An Environment In Which The Loved One Is Missing.

- The grief accompanying dementia requires persistent adjustment to an environment in which the person is different rather than “missing.”
- The person you miss is still with you, but dementia is ever altering their behavior, abilities, and interactions.
- The losses from dementia are open-ended, and the adjustments to the new reality are ongoing.
(4) Find An Enduring Connection With The Person

- When death occurs, the bereaved remains connected with the deceased primarily through memories.
  - One moves forward by integrating those memories with new experiences, relationships, and activities.
- The grieving task for those living with dementia requires continually:
  - finding new ways of connecting with the changed person as he or she is now,
  - while letting go of former ways of connecting.
Dementia, Grieving, and Death:
Love: The Bond That Endures
At the core of the Christian tradition is the affirmation that love is the dominant and eternal reality in all creation.

Human beings were created to participate in the triune God’s dance of love.

1 John: “God is love, and those who abide in love abide in God” (4:16b).

Paul: nothing “in all creation, will be able to separate us from the love of God in Christ Jesus our Lord” (Rom 8:39).

This theological lens broadens the perspective and provides comfort and hope.
Love

- **Love** is the *paradoxical* reality throughout grief’s journey:
  - **Love** creates the pain of grief,
    - and *love* motivates care and support amid the pain.
  - **Love** mourns the cascading losses,
    - while *embracing* the inherent worth of *being* itself.
Love laments the shattering of the world as it has been while opening pathways into the world as it is becoming. Love struggles to hold close the one who is drifting away, and love yearns for his or her ultimate peace. Love bewails the powerlessness to prevent the inevitable, and love dares to trust that “weeping may linger for the night, but joy comes with the morning” (Ps 30:5b).
Hope

- **Hope** lies in the final triumph of **love** over all that threatens God’s intention for creation:
- All wounds will finally be healed.
- Death does not have the last word.
- *Intimations* of the final triumph of **love** abound for those who remain attentive as memories fade:
  - glimmers of coherence amid confusion,
  - flickers of joy within the surrounding gloom,
  - traces of harmony amidst dissonance.
Hope

- **Grief** is **love** mourning.
- In **loving** the vulnerable Other, we are participating in the transcendent **love** of the triune God.
- In such moments of **love**, the eternal can:
  - enter the transitory and
  - fill it with enduring promise and a peace that passes understanding.