

Bishop Kenneth L. Carder
Alzheimer's/Dementia:
Ministry with the Forgotten



Leader's Guide

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Note to Group Leaders

This resource is primarily written for older adult ministry leaders and pastors as they develop ministries with those living with dementia and their family/caregivers. Persons in early stages of dementia and their family will also be interested in these sessions. Learn from their insights and invite the group to provide care and support in their journey. The video, scripture study, discussions, and resources will provide you and your group with practical ideas to be in ministry within your local church and community.

As a group leader, your role is to facilitate the weekly sessions using the accompanying video, *Alzheimer's/Dementia: Ministry with the Forgotten* and this leader's guide. Each session begins with information for the facilitator including a lesson aim, key themes to develop in your group's discussion, a primary scripture passage, and a quotation from Bishop Carder that identifies a major theological theme.

Then, there are four movements in each session to guide the group's discussion:

1. Building Community in which group members connect and form community.
2. Going Deeper to view and discuss the video and to discuss the key scripture passage.
3. Equipped to Serve those who experience dementia and their families and caregivers.
4. Closing Worship which practices a way to worship with persons with dementia.

As you think about your time together, plan for 60 minutes per session to cover each session's components: Times for Building Community, Going Deeper, Equipped to Serve, and Closing Worship. Prior to each session, write the lesson aim, the primary scripture passage, and Bishop Carder's quotation introducing the major theological theme either on a handout for each participant or a whiteboard.

Note that the section, Equipped to Serve, guides the group to identify specific ways that they can be in ministry with those who live with a form of dementia, their family, and/or their caregivers. Each week, provide newsprint and markers to write down the group's thoughts and ideas. After the session, plan to compile the group's key ideas. This summary of ideas will be used in the fifth session to plan your next steps in ministry. In session five, there will be a process for individuals to use to plan their personal response and a process for the group to use to plan your congregation's response to persons with Alzheimer's/Dementia, their families, and their caregivers.

Please read through each session and preview the video prior to each session. Consider your words carefully, and if you know the participants, prayerfully consider what points of discussion will be most helpful for them and your congregation. The goal is to lead each person to take a next step in his or her own discipleship with Jesus Christ and ministry with older adults, particularly those with Alzheimer's or a form of dementia. This guide contains plenty of breadth, so you will need to be selective if you wish to go deep on one or two discussion questions or if you think it would be best to spend an extended period of time engaged with the scripture. Come to each session prayerfully prepared.

This guide includes an annotated bibliography of websites, books, and other resources that you or members of your group might find useful in further exploring ministries with those who experience dementia and their caregivers and families.

By leading this study, you are being faithful to Jesus' call to be in ministry with all persons, especially those who are often times forgotten or feel forgotten. God is always faithful. As you respond to God with faith, your life and the lives of others can be changed through this study. Pay attention, trusting that God is at work. Put what you learn into action. Name those times and places where God's story is making a difference in your own life and the lives of those who experience Alzheimer's/dementia and their families and caregivers.

Session I: Dementia Care: A New Vocation

Aim

To explore God's call to the church to be in ministry with persons who are living with Alzheimer's/dementia, their families, and their caregivers.

Key Themes

- To share personal stories of being with persons who are living with Alzheimer's and dementia, their families, and their caregivers.
- Using key statistics, consider why we need to be in ministry with those who experience Alzheimer and dementia, their families, and their caregivers.
- To discuss God's call to the church in light of God's call to Moses.

Key Scripture

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 from the Egyptians, and to bring them up out of that land to a good and broad land, a land flowing with milk and honey." (Exodus 3:7-8, NRSV)

Theological Focus

"In this story of the Exodus, God sees. And God hears. But God goes deeper. 'I **know** they're suffering.' It's knowing at the deepest level of connection, of covenantal relationship. It's the knowing a parent has when a child is sick, and the parent says, 'I wish I could be sick instead of my child.' That's how God knows.

God sees, God hears, God knows, and God sends. 'Come on Moses. Let's go down into Egypt, it's about to get messy.' And God delivers."

(Bishop Ken Carder, *Alzheimer's/Dementia: Ministry with the Forgotten*)

Building Community (10 minutes)

Introduction

Welcome the group to this study. Introduce yourself. Ask each person to share their name and name one reason they are part of this study.

Say: In this study, there are five sessions. Each session will include a video where you will hear Bishop Kenneth Carder share his experience as caregiver and chaplain and provide theological and practical implications for the church. Bishop Carder is a retired bishop of The United Methodist Church having served in the Mississippi and Nashville areas. He was the Ruth W. and A. Morris Williams Professor Emeritus of the Practice of Christian Ministry at Duke Divinity School. He became caregiver, when his wife, Linda, was diagnosed with frontal temporal dementia (Frontotemporal Dementia or FTD). He also now serves as chaplain at Bethany Memory Care Center at the Heritage at Lowman, which is the retirement community where they live, near Columbia, South Carolina.

The sessions will also include an examination of scripture in light of the session's theme and theological focus. Through our discussions, we will explore ways to apply insights and what we learn to start or enrich our ministry with those who are living with Alzheimer's or a form of dementia and their families and their caregivers. Each session will conclude with a way that Bishop Carder worships with the residents at Bethany Memory Care Center.

Opening Prayer

Pray:

Holy God, open our eyes to see your sacred presence.

Holy God, open our ears to hear you calling us to be in ministry with the forgotten.

Holy God, open our hearts to new understandings and insights of your love.

Conversation starter: Ask group members to turn to the person next to them. Invite each person to share a personal experience with a person who is living with Alzheimer's/dementia. What are the challenges? What are the gifts?

Going Deeper (30 minutes)

This section allows approximately 30 minutes for viewing the video and discussing the video and scripture. You will not have time to address every discussion question. Select questions in advance you believe will be most helpful for your group and address those questions first. If time allows, incorporate additional questions.

The Video

Say: This first video session introduces Bishop Kenneth Carder and how God called him into a new vocation as caregiver and chaplain. Encourage the group to pay attention to the ways Bishop Carder's story with Linda is similar or different from their stories with persons experiencing dementia. Encourage the group to consider which statistics presented in the video are surprising.

Play: Session 1: Dementia Care: A New Vocation (*running time is approximately 8 minutes*)

Ask and discuss:

- List the daily life difficulties of persons with dementia.
- List the challenges for family and caregivers.
- Which statistic surprised you the most? (*refer to the list of statistics at the end of this session*) Why?
- How are these statistics a call to the church to be in ministry with those who are living with Alzheimer's/dementia, their families, and their caregivers?

Scripture – Exodus 3: Nature and Presence of God

In advance: Become familiar with the text. Use a commentary to help you prepare to discuss the scripture. Add questions for discussion that emerge from your study in addition to those below.

Say: Bishop Carder says, "For people with dementia, cognitive disorders are a type of chaos of the brain. But God is forever bringing order, connection, and life. God is always present, moving from creation to new creation."

Read aloud: Exodus 3:1-12 asking the group to imagine that the passage is being read to those suffering from dementia or their families or caregivers.

Ask and discuss:

- How do you experience the presence of God? How do those with Alzheimer's or dementia experience the presence of God?
- God told Moses that he sees, he heard, he knows the Israelites suffering. What does it mean to say that God sees our suffering? What does it mean to say that God hears our suffering? What does it mean that God knows our suffering?

- God knew that the Israelites were suffering from bondage. How is dementia a form of bondage—where your thoughts are locked and imprisoned in your head?
- God called Moses to lead the Israelites from Egypt into the wilderness, a place of exile. They were taken away from their homes, the familiar to a new land—and, they thought, away from God. How is dementia a form of exile?
- Who is God to those who experience dementia? Their families and caregivers?

Equipped to Serve (15 minutes)

This section guides the group to identify specific ways you can personally and/or as a congregation be in ministry with those who live with dementia, their families, and/or their caregivers. Provide newsprint and markers to write down the group's thoughts and ideas. Plan to compile these ideas for session five.

Say: Throughout this study, we will be gathering thoughts, ideas, and insights on how to be in ministry with those who live with dementia, their families, and their caregivers. Each week, we will summarize our key ideas so that during the fifth session we can plan our next steps in ministry and/or personal caregiving of persons living with dementia.

Ask and Discuss: How do we hear our call, individually and/or as a congregation, to a new vocation of care with those who experience Alzheimer's or dementia? With their families and caregivers?

List: Invite the group to name the top three key ideas from today's discussion that you want to focus on or put into practice. Remember that you are not brainstorming ideas, rather, you are summarizing the key ideas from today's discussion. Each week's summary of key ideas will be used in prioritizing and planning ministries with persons living with Alzheimer's/dementia, their families, and their caregivers in session five.

After the session, have someone compile the group's key ideas. Each week the ideas will be summarized and compiled to use in the fifth session.

Closing Worship (5 minutes)

The session closes with a way that Bishop Carder worships with residents at Bethany Memory Care Center; it's a practice you can use in your own ministry to remind persons that they are not forgotten by your church or by God.

Say: Bishop Carder says, "God creates, God redeems, and God knows us by name." At the end of each worship service Bishop Carder leads at Bethany, he goes around and calls each person's name and says, "God bless you." He reminds us that "residents at Bethany don't have their names called very often. Or when it is, it's something like "OK Mary, it's time for your bath" rather than in a way of a blessing."

Stand in a circle. Turn to the person next to you, hold their hands, call them by name, and say, "God bless you." Continue around the circle till everyone has been blessed.

Note: *the next page contains Alzheimer's statistics. Feel free to make copies to hand out during your group's first meeting.*

Alzheimer's Statistics

- More than 5 million Americans are living with Alzheimer's. By 2050, this number could rise as high as 16 million.
- More than 15 million Americans provide unpaid care for people with Alzheimer's or other dementias.
- In 2016, caregivers provided an estimated 18.2 billion hours of care valued at over \$230 billion
- In 2017, Alzheimer's and other dementias will cost the nation \$259 billion. By 2050, those costs could rise as high as \$1.1 trillion.
- Thirty five percent of caregivers for people with Alzheimer's or another dementia report that their health has gotten worse due to care responsibilities, compared to 19% of caregivers for older people without dementia.
- One in three seniors dies with Alzheimer's or another dementia.
- It's the 6th leading cause of death and it kills more people than breast and prostate cancers combined.
- Currently, there is no cure for Alzheimer's.
- Since 2000, deaths from heart disease have decreased by 14 percent while deaths from Alzheimer's disease have increased by 89 percent.

Alzheimer's Association; <https://www.alz.org/facts/overview.asp?type=alzchptfooter>

Session II: More Than Our Memories

Aim

To affirm that the Incarnate Christ is always with us and that we model the Incarnate Christ through our ministry with persons living with Alzheimer's/dementia, their families, and caregivers.

Key Themes

- To name ways families experience grief and joy as their loved one loses their memories.
- To name ways persons with Alzheimer's/dementia are gifts to their families and the church even when they no longer remember.
- To experience Christ's Incarnation through *Lectio Divina*.
- Discuss how Christ's Incarnation is a model for congregations to be in community and to provide pastoral care to those with Alzheimer's/dementia, their families, and their caregivers.

Key Scripture

And the Word became flesh and lived among us, and we have seen his glory, the glory as of a father's only son, full of grace and truth. (John 1:14, NRSV)

Theological Focus

"God enters the messiness. God chose to come as a powerless, vulnerable, helpless infant born among the homeless—made homeless by another government's taxation policy. His mother was an unwed teenager. That can sound scandalous, can't it? But it is a scandal...a scandalous story. God moves into the outcast, broken, dark, dismal, dingy, hurting places of the world and claims them all, as a place of his presence. Jesus grew up in a working-class family; he worked with his hands. He reached out to the outcasts, the nobodies, the despised. He was executed using a government's form of capital punishment. He was a convicted felon...He also lives in dementia units, nursing homes, and in hospital wards. And he comes alive in cemeteries."

(Bishop Ken Carder, *Alzheimer's/Dementia: Ministry with the Forgotten*)

Building Community (10 minutes)

Introduction

Welcome the group. Invite the group to share a key thought or experience from the group's previous discussions. Introduce today's session title and aim.

Opening Prayer

Read: 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. (Psalm 139:1-3, NRSV)

Say: I invite you to close your eyes and imagine being held in the arms of Christ. If you wish, feel free to wrap your arms around yourself.

Pray: *Loving Christ, you are always with us. We cannot flee your presence. You never forget us even when we forget our own name or the name of others. You never forget us even when we are grieving the loss of one's memories. You enter our powerlessness, our vulnerability, and the messiness of our lives holding us in your loving presence. Amen.*

Conversation starter: Ask group members to turn to the person next to them. Invite each person to answer this question: Would you rather lose your memory or your life? Why?

Going Deeper (30 minutes)

This section allows approximately 30 minutes for viewing the video and discussing the video and scripture. You will not have time to address every discussion question. Select questions in advance you believe will be most helpful for your group and address those questions first. If time allows, incorporate additional questions.

The Video

Say: Bishop Carder says in today's video, "I am not my memory. I am more than my memory. I am more than my thinking. Whatever and whoever God says I am, then that's who I am." Listen for what that means for persons with Alzheimer's and dementia.

Play: Session 2: More Than Our Memories (*running time approximately 8 minutes*)

Ask and discuss:

- Think about persons you know who live with Alzheimer's/dementia. How have their family member's roles changed? How has it been painful? How has it been a blessing?
- From your experience, what do family members grieve?
- Bishop Carder stated that "John Swinton, a pastoral theologian, says people with dementia don't lose their sense of time, they lose their tense of time." How do you understand this change in "tense of time"?
- What is your identity beyond your work, how you look, or what you think?
- What does it mean to say, "I am more than my memory, whatever and whoever God says I am, then that's who I am."?

Scripture – John 1:1-18: Incarnation: A Paradigm for Community and Pastoral Care

In advance: Today's scripture reading leads the group through the meditative practice of *Lectio Divina*, a spiritual reading of scripture. If you are not already familiar with *Lectio Divina*, you may wish to do an internet search and spend time becoming familiar with this early meditative practice of our desert mothers and fathers. Please allow at least 10 minutes to fully experience this spiritual reading.

Say: Incarnation means "the act of being made flesh." We as Christians understand that Jesus, God's son, became human. Jesus came into the world as a vulnerable child and experienced all that we experience as a human being. Yet, Jesus was divine, God's son. Jesus enters into our lives and the world of others to bring God's redeeming grace.

Read Bishop Carder's quote: "God enters the messiness. God chose to come as a powerless, vulnerable, helpless infant born among the homeless—made homeless by another government's taxation policy. His mother was an unwed teenager. That can sound scandalous, can't it? But it is a scandal...a scandalous story. God moves into the outcast, broken, dark, dismal, dingy, hurting places of the world and claims them all, as a place of his presence. Jesus grew up in a working-class family; he worked with his hands. He reached out to the outcasts, the nobodies, the despised. He was executed using a government's form of capital punishment. He was a convicted felon...He also lives in dementia units, nursing homes, and in hospital wards. And he comes alive in cemeteries."

(Bishop Ken Carder, *Alzheimer's/Dementia: Ministry with the Forgotten*)

Say: Today we are going to practice *Lectio Divina*, a spiritual reading of scripture. Rather than reading and discussing the scripture text's meaning, we will prayerfully read today's text allowing God to speak to our hearts. We will read the text three times, allowing a time of silence after each reading. The first time, *lectio*, is reading the text. The second time, *oratio*, calls us into a time of meditative prayer. The

third time, *contemplatio*, we enter into the silence resting in God's comfort, presence, and power. Our hearts experience God and God fills our hearts.

Ask: As I slowly read today's scripture text, what word or phrase gives you hope, particularly in your ministry with persons and families experiencing Alzheimer's or dementia.

Slowly read aloud: John 1:1-5, 14

Ask: Without comment or discussion, what word or phrase did you choose?

Say: As I reread today's text, consider what word or phrase that God is calling you to do or to pray more deeply about in your ministry with persons and families living with Alzheimer's or dementia. This may be the same word or phrase, or a different word or phrase.

Slowly reread aloud: John 1:1-5, 14

Silence

Slowly reread aloud: John 1:1-5, 14

Say: Take time to enter the silence resting in God's presence and giving thanks for God's grace.

Silence

Sharing: If you have time, invite persons to share insights or reflections from their prayerful meditation.

Equipped to Serve (15 minutes)

This section guides the group to identify specific ways you can personally and/or as a congregation be in ministry with those who live with dementia, their families, and/or their caregivers. Provide newsprint and markers to write down the group's thoughts and ideas. Plan to compile these ideas for session five.

Transition from the time of meditation to discussion by inviting persons to stand and stretch.

Say: Throughout this study, we are gathering thoughts, ideas, and insights on how to be in ministry with those who live with dementia, their families, and their caregivers. Each week, we will summarize our key ideas so that during the fifth session we can plan our next steps in ministry and/or personal caregiving of persons living with dementia.

Ask and discuss:

- John Swinton says, "The problem is not that people with dementia forget, the problem is they are forgotten." How is our congregation present with those who are often times forgotten?
- What are some practical ways we can be a dementia-friendly church?
- Our religion is thinking-oriented, what are some practical ways that we can incorporate persons who no longer think in the way that we do?
- How can we be present with persons who no longer have filters and can have outbursts like a child?

- Bishop Carder said, “We assume those with neurocognitive disorders or limitations have nothing to contribute. Don’t believe it. They have enormous gifts. My life is enormously enriched by Linda and the people that I now serve as a volunteer chaplain at Bethany Memory Care Unit. While Linda is now almost beyond communicating, her being still contributes. That’s her greatest gift and I would suggest that being is your greatest gift too.” How do we experience a person’s gift of “being”?
- How can our congregation be a community that provides spiritual support and care for persons whose cognitive abilities are diminished? To family members and caregivers?

List: Invite the group to name the top three key ideas from today’s discussion that you want to focus on or put into practice. Remember that you are not brainstorming ideas, rather, you are summarizing the key ideas from today’s discussion. Each week’s summary of key ideas will be used in prioritizing and planning ministries with persons living with Alzheimer’s/dementia, their families, and their caregivers in session five.

After the session, have someone summarize and compile key ideas from each week’s discussion to use in the fifth session. It might be helpful to organize the group’s thoughts and ideas under different headings, such as:

- Needs of persons with Alzheimer’s or dementia
- Needs of families and/or caregivers
- Ministry ideas
- Ways to advocate for persons with Alzheimer’s/dementia
- Community organizations to contact/partner

Closing Worship (5 minutes)

The session closes with one of the ways that Bishop Carder worships with those who experience dementia at Bethany Memory Care Center; it’s a practice you can use in your own ministry to remind persons that they are not forgotten by your church or by God.

Say: Music and Memory is a non-profit organization founded by Dan Cohen to provide personalized music to those struggling with Alzheimer’s, dementia, and other cognitive and physical challenges. On their website, it is stated “Even for persons with severe dementia, music can tap a deep emotional recall to reconnect with the world.” Through music, a person’s memory is triggered. Familiar hymns are songs of our faith that remind us that the Incarnate Christ is always with us.

Ask: What are some familiar hymns of our faith?

As each person names a hymn, invite the group to join in singing a verse. Even when a loved one or a member of your congregation cannot remember the name of a hymn, they can often times join you in singing the hymn or tapping to the music. Close your worship by singing “*Jesus Loves Me.*”

Session III: Created in God's Image: Identity in Community

Aim

To affirm and celebrate that persons with Alzheimer's/dementia find their identity in God through their baptism and their identity in community through the memory of their family and congregation.

Key Themes

- To affirm that all persons are created and claimed by God, even when one no longer remembers.
- To celebrate that faith communities, along with their families, hold the memories of those who no longer remember.
- To claim the church's responsibility to be stewards of story.

Key Scripture

So, God created humankind in his image, in the image of God he created them; male and female he created them. (Genesis 1:27, NRSV)

Theological Focus

"The Christian Gospel says that human identity, worth, and destiny are held in God in community. We are created in the image of God. That image is not in our physical appearance, psychological makeup, intellectual qualities, or our capacities. Our identity, our worth, and our value simply lies in the fact that we belong to God. It's all a gift."

(Bishop Ken Carder, *Alzheimer's/Dementia: Ministry with the Forgotten* video)

Building Community (5 minutes)

Opening Prayer

Read: But now thus says the Lord, he who created you, O Jacob, he who formed you, O Israel: Do not fear, for I have redeemed you; I have called you by name, you are mine. (Isaiah 43:1, NRSV)

Invite the group members to sit comfortably with both feet on the floor and their palms facing up on their lap. Take two to three deep breaths. Ask the group members to focus on their breathing. As you breathe in say: "*Loving God*". As you breathe out say: "*I know, I am yours.*" Slowly repeat three to four times. Sit in silence a few minutes. Conclude by saying, "*All God's children said, Amen.*"

Conversation starter: Ask group members to turn to the person next to them. Invite each person to answer this question: Why is it important for the church to be in ministry with persons with Alzheimer's/dementia, their families, and their caregivers?

Going Deeper (40 minutes)

This section allows approximately 40 minutes for viewing the video and discussing the video and scripture. You will not have time to address every discussion question. Select questions in advance you believe will be most helpful for your group and address those questions first. If time allows, incorporate additional questions.

The Video

In advance: Write on newsprint or marker board the three theological lenses through which to view dementia.

- The nature and presence of God
- The incarnation as a paradigm of community and pastoral care
- The identity in One to whom we belong as individuals and in community

Provide paper and pens for participants to take notes.

Say: Today's video session has a wealth of information as we theologically explore dementia. Bishop Carder presents three theological lenses through which to view dementia: the nature and presence of God; the incarnation as a paradigm of community and pastoral care, and the identity in One to whom we belong as individuals and in community. In our first two sessions, we have already discussed the nature and presence of God and the incarnation as a paradigm of community and pastoral care. As you watch today's video jot down any additional insights about these first two theological lenses. Also, write down key insights from the theological lens that our identity is in One to whom we belong as individuals and in community.

Play: Session 3: Created in God's Image: Identity in Community (*running time approximately 19 minutes*)

Ask and discuss:

- What new insights do you have about the nature and presence of God? Incarnation as a paradigm of community and pastoral care?
- What key insights did you gain from Bishop Carder's discussion about identity?
- What does it mean to see a person through a theological lens rather than through his or her medical symptoms?

Scripture – Genesis 1: Created in God's Image

In advance: Become familiar with the text. Use a commentary to help you prepare to discuss the scripture. Add questions for discussion that emerge from your study in addition to those below.

Divide the poem of God's creation found in Genesis 1 into seven parts – (1) Genesis 1:1-5; (2) Genesis 1:6-8; (3) Genesis 1:9-13; (4) Genesis 1:14-19; (5) Genesis 1:20-23; (6) Genesis 1:24-31; and (7) Genesis 2:1-3. Assign each section of the poem to a person to read.

Say: Bishop Carder says, "The Christian Gospel says that human identity, worth, and destiny are held in God in community. We are created in the image of God. That image is not in our physical appearance, psychological makeup, intellectual qualities, or our capacities. Our identity, our worth, and our value simply lies in the fact that we belong to God. It's all a gift."

Read aloud: Genesis 1:1-2:3 (Have the seven assigned persons read their selected verses)

Ask and discuss:

- What does it mean to claim our identity in God?
- What does it mean to claim our identity in community?

Equipped to Serve (10 minutes)

This section guides the group to identify specific ways you can personally and/or as a congregation be in ministry with those who live with dementia, their families, and their caregivers. Provide newsprint and markers to write down the group's thoughts and ideas. Plan to compile these ideas for session five.

Say: Throughout this study, we are gathering thoughts, ideas, and insights on how to be in ministry with those who live with dementia, their families, and their caregivers. Each week, we will summarize our key ideas so that during the fifth session we can plan our next steps in ministry and/or personal caregiving of persons living with dementia.

Ask and discuss:

- How do people with Alzheimer's/dementia "fit in"?
- How do people with Alzheimer's/dementia contribute to the church?
- In the video, Bishop Carder shared about the importance of intergenerational ministry. What ways can your congregation enhance your intergenerational ministries, particularly with young adults whose parents live with Alzheimer's/dementia?
- Bishop Carder says, "Part of the church's responsibility is to be a steward of story. That's God's story, *the* story, but also the story of us. We all have gifts that the community needs, and we'll have those gifts until we die. And then, even our death can contribute to the community's memory." What does it mean for you to be a steward of a loved one's story? What does it mean for the church to be stewards of story?

List: Invite the group to name the top three key ideas from today's discussion that you want to focus on or put into practice. Remember that you are not brainstorming ideas, rather, you are summarizing the key ideas from today's discussion. Each week's summary of key ideas will be used in prioritizing and planning ministries with persons living with Alzheimer's/dementia, their families, and their caregivers in session five.

After the session, have someone summarize and compile key ideas from each week's discussion to use in the fifth session. It might be helpful to continue to organize the group's thoughts and ideas under different headings, such as: needs of persons with Alzheimer's or dementia; needs of families and/or caregivers; ministry ideas; ways to advocate for persons with Alzheimer's/dementia; community organizations to contact/partner; and so forth.

Closing Worship (5 minutes)

The session closes with one of the ways that Bishop Carder worships with those who experience dementia at Bethany Memory Care Center; it is a practice you can use in your own ministry to remind persons that they are not forgotten by your church or by God.

Say: Bishop Carder says, "The community holds our memories. We're not persons in and of ourselves, our identity is in community. We are baptized into Christ and that is our identity. And therefore, all have worth and dignity and all have hope."

Stand in a circle. Turn to the person next to you, hold his or her hands, call him or her by name, and share a fond memory of that person. It can be as simple as "I always appreciate your smile" or a brief story of an experience you shared together. End by saying the person's name and "You are a child of God." Continue around the circle until everyone has been blessed.

Session IV: Responding in Love

Aim

To affirm we always view dementia and all of life through the reality of love.

Key Themes

- To affirm that God always loves us, and we experience God's love through our relationships and interactions with one another.
- To name the ways that persons with Alzheimer's/dementia experience love and how we share our love with persons with dementia.
- To explore the church's responsibility to not only include persons with dementia but to discover ways that they can belong to their faith community.

Key Scripture

Love is patient; love is kind; love is not envious or boastful or arrogant or rude. It does not insist on its own way; it is not irritable or resentful; it does not rejoice in wrong doing but rejoices in the truth. It bears all things, believes all things, hopes all things, endures all things. Love never ends... And now faith, hope, and love abide, these three; and the greatest of these is love. (I Corinthians 13:4-8; 13, NRSV)

Theological Focus

"Tongues shall cease, language gets lost, but what abides? Faith, hope, love...but the greatest of these, is...I know you're thinking it...love. It really is! I mean that's the Gospel truth. Love is that which endures through dementia, cancer, and death itself."

(Bishop Ken Carder, *Alzheimer's/Dementia: Ministry with the Forgotten*)

Building Community (5 minutes)

Opening Prayer

Say: Hear this quote from Dietrich Bonhoeffer in his book, *God is in the Manger: Reflections on Advent and Christmas*:

"Only the humble believe him and rejoice that God is so free and so marvelous that he does wonders where people despair, that he takes what is little and lowly and makes it marvelous. And that is the wonder of all wonders, that God loves the lowly.... God is not ashamed of the lowliness of human beings. God marches right in. God chooses people as his instruments and performs his wonders where one would least expect them. God is near in lowliness; he loves the lost, the neglected, the unseemly, the excluded, the weak and broken."

Pray in Silence: Offer thanksgiving for God's love of persons with dementia and the ways that God is present with persons experiencing Alzheimer's, dementia, and other cognitive disorders.

Sing: *Great is Thy Faithfulness* (UM Hymnal, #140 or use a video clip from YouTube or VEVO)

Conversation starter: Ask group members to turn to the person next to them. Invite each person to answer these questions: How do we show God's love to those with dementia? How do we receive God's love from those with dementia?

Going Deeper (40 minutes)

This section allows approximately 40 minutes for viewing the video and discussing the video and scripture. You will not have time to address every discussion question. Select questions in advance you believe will be most helpful for your group and address those questions first. If time allows, incorporate additional questions.

The Video

In advance: Write on newsprint or a marker board the three previously discussed theological lens (see next paragraph for list) and add the fourth - Always view dementia and all of life through the reality of love.

Say: In previous sessions, we looked at three theological lenses through which the church can view dementia.

- The nature and presence of God
- The incarnation as a paradigm of community and pastoral care
- The identity in One to whom we belong as individuals and in community

Today, we look at another theological lens - *Always* view dementia and all of life through the reality of love.

Play: Session 4: Responding in Love (*running time approximately 23 minutes*)

Ask and discuss:

- How did the interaction between Naomi Feil and Gladys Wilson deepen your understanding of love?
- How has a person with Alzheimer's or dementia expressed love to you? How have you expressed your love to him or her?
- Bishop Carder says, "The heart remembers what the brain forgets." What does that mean to you?
- What does it mean for the church to love those Christ loves and to go where Christ goes?

Scripture – I Corinthians 13: Love Endures

In advance: Write each phrase on a slip of paper:

- Love is patient; love is kind
- Love is not envious or boastful or arrogant or rude
- Love does not insist on its own way
- Love is not irritable or resentful
- Love does not rejoice in wrongdoing but rejoices in the truth
- Love bears all things, believes all things, hopes all things, endures all things
- Love never ends

Say: Bishop Carder says, "Tongues shall cease, language gets lost, but what abides? Faith, hope, love...but the greatest of these, is... I know you're thinking it...love. It really is! I mean that's the Gospel truth. Love is that which endures through dementia, cancer, and death itself."

Read: I Corinthians 13

Discuss in pairs: Have persons find a partner. Give each pair one of the definitions of love from I Corinthians 13 and ask them to reflect on the definition and describe how family, friends, and/or caregivers can express love with a person who is living with dementia.

Share: Invite each pair to share a key insight from their discussion.

Ask and discuss: Is there a way that a person with dementia expresses one of these definitions of love?

Equipped to Serve (10 minutes)

This section guides the group to identify specific ways you can personally and/or as a congregation be in ministry with those who live with dementia, their families, and/or their caregivers. Provide newsprint and markers to write down the group's thoughts and ideas. Plan to compile these ideas for session five.

Say: Throughout this study, we are gathering insights on how to be in ministry with those who live with dementia, their families, or caregivers. Each week, we will summarize our key ideas so that during the fifth session we can plan our next steps in ministry and/or personal caregiving.

Ask and discuss:

- How can you or your congregation help persons with dementia move beyond feelings of isolation? Their families and caregivers?
- How can you enter the life of a person with Alzheimer's/dementia? How can he or she enter your life?

Say: John Swinton, author of *Dementia: Living in the Memories of God*, says, "There is a difference between being included and belonging." Bishop Carder gave the example that we can include persons with dementia in worship, but they may not feel like they belong, particularly when the service expects people to use print materials such as a bulletin or a hymnal.

Ask and discuss: What are some ways you can help persons with dementia "belong" not just be "included" in your congregation?

List: Invite the group to name the top three key ideas from today's discussion that you want to focus on or put into practice. Remember that you are not brainstorming ideas, rather, you are summarizing the key ideas from today's discussion. Each week's summary of key ideas will be used in prioritizing and planning ministries with persons living with Alzheimer's/dementia, their families, and their caregivers in session five.

After the session, have someone summarize and compile key ideas from each week's discussion to use in the fifth session. It might be helpful to continue to organize the group's thoughts and ideas under different headings, such as: needs of persons with Alzheimer's or dementia; needs of families and/or caregivers; ministry ideas; ways to advocate for persons with Alzheimer's/dementia; community organizations to contact/partner; and so forth.

Closing Worship (5 minutes)

The session closes with one of the ways that Bishop Carder worships with those who experience dementia at Bethany Memory Care Center; this is a practice you can use in your own ministry to remind persons that they are not forgotten by your church or by God.

Say: Scriptures in the Old and New Testament are stories of God's love for us and our love for God. It is through God's faithful love that we know and are claimed by God. It is through that same love that we view and respond to all of life in love. When we hear again those favorite scripture passages we have lived with and know in the depths of our soul, we are reminded of God's steadfast, enduring love.

Ask: What is your favorite scripture passage?

Respond after each scripture shared by saying together, "Thanks be to God."

Session V: Burden Bearing: Our Gift

Aim

To claim our God-given gift to bear one another's burdens.

Key Themes

- To explore and celebrate the gift of burden bearing.
- To identify our next steps in ministry with persons living with Alzheimer's/dementia, their families, and their caregivers.

Key Scripture

Bear one another's burdens, and in this way, you will fulfill the law of Christ. (Galatians 6:2, NRSV)

Theological Focus

"We bear one another's burdens because God bears our burdens. You'll find references to casting your burdens upon the Lord in Psalms, Proverbs, and 1 Peter. Through the cross, Jesus took upon himself the burdens of the whole world...and saved us through it. Bearing burdens is a means to salvation...it is the means by which we are saved, and we can contribute to the saving of others."

(Bishop Ken Carder, *Alzheimer's/Dementia: Ministry with the Forgotten*)

In advance: Take note that in this last session, the time for *Going Deeper* is only 15 minutes and the time for *Equipped to Serve* is 30 minutes. This allows time for the group to begin to prioritize and plan your congregation's ministry. It will be helpful to have copies of the group's summary of key ideas from the previous sessions compiled into a handout or on sheets of newsprint.

Building Community (10 minutes)

Introduction

Welcome the group. Invite the group to share key thoughts or experiences from the group's previous discussions. Introduce today's session title and aim.

Say: This is our last session. We will spend more time at the end of the session, beginning to prioritize and plan either our personal response or our congregation's ministry with those living with Alzheimer's/dementia, their families, and their caregivers. We will plan how we as individuals and as a congregation can bear one another's burdens.

Opening Prayer

In advance: Place chairs in a circle. In the center of the circle, place a large pitcher of water and a large empty ceramic or glass bowl on a small table. If you wish, you may add a piece of blue fabric crunched underneath the pitcher and bowl and/or light a white candle and set it next to the water.

Read: Bear one another's burdens, and in this way, you will fulfill the law of Christ. (Galatians 6:2, NRSV)

Say: Think about how every prayer offered mixes with the prayers of all of God's people around the world. Prayers do not know the boundaries of time or space and so all become one. In this way, each person's joys become the joys of others. And every person's concerns are our burdens. Consider a person, place, or situation you want to lift up in prayer. When you are ready, pour some of the water from the pitcher into the bowl to represent those prayers. Watch as they mix with the water added by others, representing your prayers mixing and becoming one with those of the whole group.

After each person has had a chance to offer their prayers sit in silence together.

Say: As we sit together in silence, imagine God reaching into the bowl of water and slowly, gently scooping up the water full of our prayers and washing over us with love and peace.

Close the time of silence by saying: All God's people said, Amen.

Conversation starter: Ask group members to turn to the person next to them. Invite each person to answer this question: How is bearing one another's burdens a gift?

Going Deeper (15 minutes)

Today, the discussion of the video is combined with the scripture discussion. This section allows approximately 15 minutes for viewing the video and discussion. You will not have time to address every discussion question. Select questions in advance you believe will be most helpful for your group and address those questions first. If time allows, incorporate additional questions.

The Video

Read: Bear one another's burdens, and in this way, you will fulfill the law of Christ. (Galatians 6:2, NRSV)

Say: Bishop Carder says, "We bear one another's burdens because God bears our burdens. You'll find references to casting your burdens upon the Lord in Psalms, Proverbs, and 1 Peter. Through the cross, Jesus took upon himself the burdens of the whole world...and saved us through it. Bearing burdens is a means to salvation...it is the means by which we are saved, and we can contribute to the saving of others." As you watch the video, consider how bearing one another's burdens is a gift.

Play: Session 5: Burden Bearing: Our Gift (*running time approximately 8 minutes*)

Ask and discuss:

- How is burden bearing a gift?
- Why is being present important?
- Think about your experiences with persons living with Alzheimer's or dementia. How have you experienced God?
- What are ways that we, as a congregation bear the burdens of those living with Alzheimer's/dementia? Their families? Their caregivers? (Add key ideas to a sheet of newsprint so that the group can use in *Equipped to Serve*.)

Equipped to Serve (30 minutes)

In this session, more time is allowed for discussion so that the group and/or individuals can plan your next steps in ministry with persons living with Alzheimer's/dementia, their families, and their caregivers.

In advance: Provide copies of the group's key ideas that have been compiled at the end of the previous sessions. You can choose to provide a handout for each participant and/or list ideas on sheets of newsprint and display around the room. Also provide copies of the worksheets at the end of this session, extra sheets of newsprint, and markers.

Say: Throughout this study, we have been exploring the theological lens in which to understand persons with Alzheimer's or dementia; the needs of persons with dementia and their families or caregivers; and ways that we can be in ministry with persons with dementia, their families, and their caregivers.

Choose ministry response: There are two ministry responses—a congregational response or a personal response. A congregational response leads the group through the first steps in planning your congregation’s ministry with persons with dementia, their families, and their caregivers. A personal response leads the group through a time of personal reflection and discernment to live into God’s call to be in ministry with persons with dementia, their families, and their caregivers.

Either decide for the group or ask individuals in the group to make a decision. If you wish, the group may work on the congregation’s response and individuals can choose to work on their personal response at a later time. Each process is outlined in a reproducible handout at the end of this session. Hand out the appropriate copy to the group.

Work through the worksheet for the ministry response that was chosen. Note that additional time and/or a smaller planning team for the congregation’s response will need to be scheduled to complete the planning process.

Closing Worship (5 minutes)

The session closes with one of the ways that Bishop Carder worships with those who experience dementia at Bethany Memory Care Center; this is a practice you can use in your own ministry to remind persons they are not forgotten by your church or by God.

Say: As we close our time together, our conversations have been rich and a blessing to all of us. As our personal relationships with persons with Alzheimer’s or dementia and their families or caregivers deepen, we will be a blessing to them, but we will also be blessed immeasurably.

Bishop Carder shares that he invites persons at Bethany Memory Care Center to offer their prayers of thanksgiving. One person might share that he is thankful for dentures or another thankful for her warm blanket or another thankful for God. No matter how small or how great, how simple or how complex, God hears our prayers.

Read: Psalm 100.

Pray: Today, I am thankful for.... (*Invite persons to share their prayers of thanksgiving.*)

Blessing: May God’s richest blessings surround us in our ministries as burden bearers. Amen.

Congregational Response

Say: Frederick Buechner in *Wishful Thinking: A Theological ABC*, says, “The place God calls you to is the place where your deep gladness and the world’s deep hunger meet.” Another way of saying this is that need + gifts = ministry.

During this study, we have explored the needs of persons with Alzheimer’s/dementia and the needs of their families and their caregivers. We have also explored many different ways that God might be calling our congregation to be in ministry with those with dementia and their families/caregivers. Today, we want to identify the needs of persons with dementia in our congregation and/or community, our individual gifts for ministry, and our next steps in ministry.

Reflect: Allow time for the group to read the summary of compiled key ideas that are recorded on newsprint or a handout.

Ask and discuss:

- What is the greatest need of persons with Alzheimer’s or dementia in our congregation and/or community?
- What are their families and/or caregivers deepest hunger or need?

List on newsprint the group’s responses. It will be helpful to list the needs of persons with dementia on one sheet of newsprint and the needs of families/caregivers on another sheet.

Prioritize: Invite the group to prayerfully consider the top three needs for your particular congregation/community. Using a colored marker, ask each person to vote by placing a checkmark by the top three needs he/she consider are most important. Tabulate the number of votes for each need to determine the group’s top three priorities.

Validate: If persons with Alzheimer’s/dementia, family members, or caregivers in your congregation and/or community have not been or are not part of the group’s discussions you need to validate your assumptions before moving forward with detailed planning. (**Note of caution:** Oftentimes, good ideas may not meet a need in your congregation or community. For example, one church started planning a respite program for families but there was already a successful program a mile away from their church. Even congregational members would not necessarily move their family member from one program to a new program if it caused further confusion.)

Suggest and list ways the planning team might have conversations with persons with dementia, their families, and/or their caregivers to validate the group’s priorities.

Identify gifts: Write each of the top three needs that the group has identified on a piece of newsprint. Divide the larger group into three small groups. Give each group a sheet of newsprint with one of the identified needs. Ask the group to list names of persons and/or specific, concrete ways your congregation can meet this identified need. It will be helpful to refer back to notes from previous discussions.

After two or three minutes, rotate the question to another small group. Encourage that small group to add additional ideas. Continue until all three small groups have had a chance to add ideas to each identified need. Collect each group’s ideas.

Ask: Does this group want to continue meeting or do we need a planning team to meet to refine and plan ways to implement our ministries with persons with Alzheimer's/dementia, their families, and/or their caregivers?

Identify planning team: List the names of persons who will be part of the planning team. Go ahead and set a date/time for your next meeting to begin formulating plans.

Ministry planning process: Your group may first need to plan how to validate the needs of persons with Alzheimer's/dementia and their families and caregivers within your congregation/community. Once the needs are validated, you can identify the gifts of specific persons in your congregation and plan the ministries your congregation will offer. The following chart, may be helpful in your planning:

Planning Chart

Ministry Idea _____

Mission/Purpose _____

Action Step	Person Responsible	Resources Needed	Budget/Cost	Timeline	Evaluation Method

Personal Response Worksheet

Frederick Buechner in *Wishful Thinking: A Theological ABC*, says, “The place God calls you to is the place where your deep gladness and the world’s deep hunger meet.” Another way of saying this is that need + gifts = ministry. During this study, we have explored the needs of persons with Alzheimer’s or dementia and the needs of their families/caregivers. God may have called you or may be calling you into ministry. This worksheet will help further discern where God is calling you and your gifts for ministry.

Reflect: If you a family member of someone who has been diagnosed with Alzheimer’s/dementia work together on this workshop. Otherwise, think about a person you already know with Alzheimer’s/dementia and their family/caregivers. Being with persons you already have a relationship with will be more natural and your offer to share your love and care will more likely be received.

Identify Needs: Read and reflect on the summary of compiled key ideas from the group’s discussions. Ask yourself:

- What is the greatest need(s) of the person with Alzheimer’s/dementia? Jot down your ideas.
- What is their family and/or caregivers deepest hunger or need? Jot down your ideas.

Identify gifts: As you prayerfully reflect on each need, identify your personal interest, skills, experience, and other ideas that you can offer for each need. This chart may be helpful.

Need	Interest	Skills	Experience	Ideas

Prayerfully prioritize the top two or three needs that match your interest, skills, experience, and/or ideas. List your top two or three ideas:

- 1.
- 2.
- 3.

Ask: Who might you wish to invite or be part of your team to assist in providing for the needs of the person experiencing Alzheimer’s/dementia and/or their family? You might also ask congregational leaders for ideas of persons who can assist.

Plan: If you are a family member, create a care team and plan of action naming the needs of your loved one and the persons who can assist with each need. Otherwise, set up a time to meet with the family and, if possible, the person with Alzheimer’s/dementia. Briefly share you experience in this study and your interest. Ask and carefully listen as they share their joys, struggles, and needs. Reflect on the needs of the person with dementia and their family and specific ways you can assist. (Your prayerfully written reflections can help you articulate and confidently share your ideas.) Suggest ways you can assist with their caregiving responsibilities. Determine if your ideas are feasible and ways they may need to be refined. Decide on specific, concrete plans.

Remember, calling or sending a card each week, providing a meal for the family on a regular basis, offering to be with their loved one while they attend a support group, assisting with a household chore, and so forth, can seem simple but can be extremely beneficial for the family. Start small and add ideas as your relationship grows deeper.

Annotated Bibliography of Resources

Recommended Resources

Dementia: Living in the Memories of God, John Swinton [ISBN-13: 9780802867162;

Publication Date: 10/2012]

Dementia is one of the most feared diseases in Western society today. In this book John Swinton develops a practical theology of dementia for caregivers, people with dementia, ministers, hospital chaplains, and medical practitioners as he explores two primary questions:

- Who am I when I've forgotten who I am?
- What does it mean to love God and be loved by God when I have forgotten who God is?

Offering compassionate and carefully considered theological and pastoral responses to dementia and forgetfulness, Swinton's *Dementia: Living in the Memories of God* redefines dementia in light of the transformative counter story that is the gospel.

No Act of Love Is Ever Wasted: The Spirituality of Caring for Persons with Dementia Jane Thibault and Richard Morgan [ISBN 13: 9780835899956; Publication Date: 09/2009]

With more than 5 million people in the United States living with Alzheimer's disease and nearly 10 million loved ones caring for them, addressing the concerns of these elders and their caregivers is a matter of increasing importance. Relying on their many years of experience in this area, Jane Thibault and Richard Morgan offer this book to provide a fresh, hopeful model of dealing with life and death in the realm of Alzheimer's and other forms of dementia. Caregivers have two basic needs: affirmation that caregiving is not in vain and reassurance that the lives of those for whom they care are not being lived in vain. Care receivers need more than medical attention; they need tender care, involvement in the community, and a sense of connection with a loving God. When patient and caregiver regard this shared experience as a "mutual spiritual path," each plays a role in deepening the spiritual life of the other. *No Act of Love Is Ever Wasted* is an excellent resource for individuals caring for loved ones as well as for counselors, support group leaders, pastors, and other professionals. In addition to offering practical ways to help, this book serves as a reminder that every act of love brings positive transformation to the recipient, to the giver, and to the world.

Ministry Resources

Coming August 2019

Ministry with the Forgotten: Dementia through a Pastoral Theology Lens (title tentative), Kenneth Carder [print ISBN: 9781501880247; ePub ISBN: 9781501880254; Publication Date: 08/06/2019]

Dementia diseases represent a crisis of faith for many family members and congregations. Magnifying this crisis is the way people with dementia tend to be objectified by both medical and religious communities. They are recipients of treatment and projects for mission. Ministry is done to and for them rather than with them.

Bishop Ken Carder confronts the deep personal and theological questions created by loving people with dementia diseases, demonstrating how living with dementia can be a means of growing in faith, wholeness, and ministry for the entire community of faith. He also reveals that authentic faith transcends intellectual beliefs, verbal affirmations, and prescribed practices.

While acknowledging the devastation of dementia diseases, the author draws on his own experience as a caregiver, hospice chaplain, and pastoral practitioner to portray the gifts as well as the challenges accompanying dementia diseases. Readers will appreciate that persons diagnosed with dementia maintain their identity and worth as beloved children of God who are made in the divine image and an integral part

of the community of faith. They will also learn how people with dementia contribute to the community and the church's life and mission, discovering practical ways those contributions can be identified, nurtured, and incorporated into the church's life and ministry. Pastors and congregations will be better equipped to minister with people affected by dementia, receiving their gifts and responding to their unique needs.

Alzheimer's/Dementia from the Experiences of a Caregiver, Frederick Trunk [ISBN-13: 9781619965843; Publication Date: 02/2012]

If you are a caregiver, or know someone who is, you owe it to yourself to read this book. It is very important to know the phases of Alzheimer's as well as the effects it has, not only on the patient, but on those who care for, or live with the patient. This book will give insight into the challenges of dementia and Alzheimer's from the perspective of a caregiver who started attending caregiver's meetings shortly after he realized that his wife was having unusual challenges and behaviors.

Dementia: Pathways to Hope: Spiritual Insights and Practical Hope for Caregivers, Louise Morse [ISBN-13: 9780857216557; Publication Date: 01/2016]

To be diagnosed with dementia is "like being blindfolded and let loose in a maze". There is no clear treatment to follow because each case is unique. But once thickets of misunderstanding and misinformation are brushed aside, there are pathways to hope. *Dementia: Pathways to Hope: Spiritual Insights and Practical Advice* is packed with examples of what works, as well as practical advice and accessible medical information.

Do This, Remembering Me: The Spiritual Care of Those with Alzheimer's and Dementia, Colette Bachan-Wood [ISBN 13: 9780819232519; Publication Date: 03/2016]

This book provides a hands-on manual that will give clergy, spiritual care providers, and family members an understanding of the ongoing spiritual needs of individuals with dementia, and practical tools such as how to create a religious service in a memory care unit and how one might plan a nursing home visit. It is accessibly written, with real-life applications and sample services for a variety of settings. The shared stories that are tender, sad, funny—sometimes all three at once—encourage readers to develop spiritual care ministries for people with memory loss in congregations, homes, nursing facilities, or other communities. These ministries will only gain in importance in the coming decade as Baby Boomers age and the number of people with Alzheimer's and dementia skyrockets.

Finding Grace in the Face of Dementia: Experiencing Dementia—Honoring God, John Dunlop, MD [ISBN 13: 9781433552090; Publication Date: 07/2017]

When a patient is diagnosed with dementia, it impacts not only the patient but also those who care for him or her. It can be devastating to watch loved ones lose the independence, personality, and abilities that once defined them, knowing there is no cure. How should Christians respond to a diagnosis of dementia? Experienced geriatrician Dr. John Dunlop wants to transform the way we view dementia—showing us how God can be honored through such a tragedy as we respect the inherent dignity of all humans made in the image of God. Sharing stories from decades of experience with dementia patients, Dunlop provides readers, particularly caregivers, with a biblical lens through which to understand the experience and challenge of this life-altering disease. *Finding Grace in the Face of Dementia* will help you see God's purposes as you love and care for those with dementia.

Sanctuary in the Midst of Alzheimer's: A Ministry for Spousal Caregivers and their Churches, Dr. Elizabeth Young [ISBN 13: 9781496965004; Publication Date: 01/2015]

When a spouse is diagnosed with Alzheimer's disease, chances are the husband or wife has suspected something is "not right" for some time. Denial, embarrassment, the decision to tell others, and additional issues—some that feel too private to share—can have a significant impact on the marriage. Spouses often look to their church for emotional, physical, and spiritual support; however, research shows that most

churches are not well-equipped to minister to those caring for a spouse with Alzheimer's. *Sanctuary in the Midst of Alzheimer's* is a resource for both spouses and their churches, encouraging congregations to walk in the shoes of a spousal caregiver while providing the opportunity for spouses to find meaning and a sense of peace in their role as a caregiver.

Personal Stories

A Path Revealed How Hope, Love and Joy Found Us in a Maze Called Alzheimer's, Carlen Maddux (husband of the patient) [ISBN 13: 9781612617848; Publication Date: 10/2016]

This is a story about a young family's sudden shift from a comfortable, middle-class American life into an alien world shaped and defined by Alzheimer's disease. Just days after turning 50, Martha Maddux was hit with this diagnosis. This is not a story about hopelessness. The story traces a path that emerged during their family's darkest hours, a path they did not foresee. Only a few books explore the painful spiritual and emotional issues that are sure to surface with a crisis like Alzheimer's. You or a loved one may be staring at a different crisis—cancer, stroke, job loss, diabetes, heart attack, home foreclosure, you name it. Regardless of the crisis, the potential for emotional and psychological upheaval—alienation, depression, fear, guilt, anxiety attacks, and a cold numbness—is much the same for victim and family alike, for care-receiver and caregiver. The author says: “Our story's focus is the spiritual path that emerged out of a threatening darkness.”

Before I Forget: Love, Hope, Help, and Acceptance in Our Fight against Alzheimer's, Michael Shnayerson, Dan Gasby and B. Smith [ISBN 13: 9783447156; Publication Date: 11/2016]

I know where I'm going. I'm still myself. I just can't remember things as well as I once did. On short trips, I work hard not to be confused. I'll say to myself: What are we going to do? How long are we staying? It's like I'm talking to my other self, the self I used to be. She tells me, this is what we need to buy—not that. I'm conscious of that other self, guiding me. Restaurateur, magazine publisher, celebrity chef, and nationally known lifestyle maven, B. Smith is struggling at 66 with a tag she never expected to add to that string: Alzheimer's patient. B, her husband, and other editors, unstintingly share their unfolding story. Readers learn about dealing with Alzheimer's day-to-day challenges: the family realities and tensions, ways of coping, coming research that may tip the scale, as well as lessons learned along the way. At its heart, *Before I Forget* is a love story: illuminating a love of family, life, and hope.

Chicken Soup for the Soul: Living with Alzheimer S & Other Dementias: 101 Stories of Caregiving, Coping, and Compassion, Amy Newmark and Angela Geiger [ISBN-13: 9781611599343; Publication Date: 04/2014]

Caring for a loved one with Alzheimer's or another form of dementia? You are not alone. This collection, a joint project with the Alzheimer's Association, is filled with 101 stories of love and lessons from others like you. These stories will support and encourage you as you care for your loved one.

Moving Miss Peggy: A Story of Dementia, Courage and Consolation, Robert Benson [ISBN-13: 9781426749575; Publication Date: 05/2013]

When the vibrant, beloved Miss Peggy began the agonizing descent into the “darkness” of dementia, her family faced what an estimated 35.6 million people around the world live with each day. *Moving Miss Peggy* is an intimate look at what dementia means for a family—how do you organize your mother's new life, how do you move her from her cherished home...how do you come to terms with the fact that the woman who, as Benson writes, “once seemed to hold the whole world in her hands, now does not know the day of the week?” With his signature style, Benson's artistic touch lends a warmth and softness to a harsh reality in this powerful story.

Soulful Reflections from a Daughter's Heart: Inspirational Insight for the Caregiver of a Loved One with Dementia, Jan Blakely (ISBN-13: 9781512755763; Publication Date: 09/2016]

Dementia steals the memory, mental capacity, and very life of the one affected. It cheats the family of quality time with their loved one. Being a caregiver for a family member with dementia is consuming and demanding. It is a condition and position that no one can truly understand unless you have been through it. It is the most extreme roller coaster ride you will ever take. This book provides stories that are common among by dementia patients and includes inspirational wisdom from God through scripture for the journey.

Websites

Alzheimer's Association; <https://alz.org>

The Alzheimer's Association was founded in 1980 by a group of family caregivers and individuals interested in research. Jerome H. Stone was our founding president. Today, the association reaches millions of people affected by Alzheimer's across the globe through its headquarters in Chicago, a public policy office in Washington, D.C., and a presence in communities across the country. It is one of the leading voluntary health organizations in Alzheimer's care, support, and research.

Clergy Against Alzheimer's; www.usagainstalzheimer.org

The mission of ClergyAgainstAlzheimer's is to promote dignity, compassionate care, and quality of life for individuals with Alzheimer's disease, and to provide support for families, friends, and caregivers as we work together to stop Alzheimer's by 2020.

Memory Bridge; www.memorybridge.org

Memory Bridge is established for the purpose of promoting communication with and memory preservation for individuals with Alzheimer's disease.

Music and Memory; www.musicandmemory.org

A non-profit organization that brings personalized music into the lives of the elderly or infirm through digital music technology, vastly improving quality of life. They train nursing home staff and other elder care professionals, as well as family caregivers, how to create and provide personalized playlists using iPods/MP3 Players and related digital audio systems that enable those struggling with Alzheimer's, dementia and other cognitive and physical challenges to reconnect with the world through music-triggered memories.

Additional Resources

100 Simple Things You Can Do to Prevent Alzheimer's and Age-Related Memory Loss, Jean Carper [ISBN-13: 9780316086844; Publication Date: 01/2012]

After best-selling author Jean Carper discovered she had the major susceptibility gene for Alzheimer's, she was determined to find all the latest scientific evidence on how to escape it. She discovered 100 surprisingly simple scientifically tested ways to radically cut the odds of Alzheimer's, memory decline, and other forms of dementia. Did you know that vitamin B 12 helps keep your brain from shrinking? Apple juice mimics a common Alzheimer's drug? Surfing the internet strengthens aging brain cells? Exercise is like Miracle-Gro for your brain? Even a few preventive actions could dramatically change your future. *100 Simple Things You Can Do to Prevent Alzheimer's* will change the way you look at Alzheimer's and provide exciting new answers from the frontiers of brain research to help keep you and your family free of this heartbreaking disease.

Coach Broyles Playbook for Alzheimer's Caregivers: A Practical Tips Guide, Frank Broyles [ISBN 0692007679; Publication Date: 01/2006]

When our work began in 2006, our approach was simple—we wanted to create a comprehensive and affordable guide for Alzheimer's caregivers. With the help of professionals from many different backgrounds, we created the *Coach Broyles Playbook for Alzheimer's Caregivers*. The playbook helps caregivers understand the disease and how to provide better care for their loved one.

I'll Have It My Way: Taking Control of End of Life Decisions: A Book about Freedom & Peace, Hattie Bryant [ISBN 13: 9781942945000; Publication Date: 01/2106]

Few people choose to contemplate critical illness or the inevitability of death until their time comes. Because possibilities are rarely discussed, many people are unprepared or unable to make critical end-of-life decisions and spend their last days in over-medicalized and unnecessarily painful and protracted situations. Breaking frankly through the taboo of discussing death, Hattie Bryant shows that we have a choice. Inspired by the peaceful death her mother was almost denied, Bryant began gathering information from national experts in palliative care, geriatrics, oncology, bio-ethics, psychology, and spirituality. *I'll Have It My Way* credibly and passionately presents the case for personal responsibility in the healthcare, legal, and procedural decisions that all of us must make if they are not to be made for us. By making our wishes known and communicating them effectively, we remove the burden from our loved ones of making the deeply personal choices that will enable us to live our lives more fully to the end. *I'll Have It My Way* provides useful information from experts throughout healthcare, real-life examples that illustrate the consequences of decisions made or not made, and a thought-provoking guide that takes the reader on a journey of discovery to learn what a life well lived means to them.

The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Related Dementias, and Memory Loss, Nancy L Mass and Peter V. Rabins [ISBN 13: 9781455521159; Publication Date: 09/2012]

When someone in your family suffers from Alzheimer's disease or other related memory loss diseases, both you and your loved one face immense challenges. For over 30 years, this book has been the trusted bible for families affected by dementia disorders. Now completely revised and updated, this guide features the latest information on the causes of dementia, managing the early stages of dementia, the

prevention of dementia and finding appropriate living arrangements for the person who has dementia when home care is no longer an option. You'll learn:

- The basic facts about dementia
- How to deal with problems arising in daily care-meals, exercise, personal hygiene, and safety
- How to cope with an impaired person's false ideas, suspicion, anger, and other mood problems
- How to get outside help from support groups, friends, and agencies
- Financial and legal issues you must address

Broken Brain Series by functional medicine physician Dr. Mark Hyman. See episode #3 on Alzheimer's and dementia. This resource is no longer free to download but you can purchase one or more episodes. For more information, visit <https://brokenbrain.com/trailer/>.

Acknowledgements

Thanks, and appreciation are extended to the persons and agencies listed below. They have made this project possible so clergy, congregations, and family members can hear God's call to a new vocation with persons with Alzheimer's and dementia, their families, and their caregivers. It is their prayer that everyone claims his or her gifts to be burden bearers and that no one is forgotten.

Bishop Kenneth L. Carder is a retired bishop of The United Methodist Church having served in the Mississippi and Nashville areas. He also served as the Ruth W. and A. Morris Williams Professor Emeritus of the Practice of Christian Ministry at Duke Divinity School. He became caregiver, when his wife, Linda, was diagnosed with frontal temporal dementia (Frontotemporal Dementia or FTD). He now serves as chaplain at Bethany Memory Care Center at the Heritage at Lowman, which is the retirement community where they live, near Columbia, South Carolina.

Kent McNish, executive director of the Golden Cross Foundation since 2006, develops and implements annual campaigns and oversees planned gifts and donor relations for the benefit of benevolent care of seniors and senior ministries. He has also served as director, Connectional Giving, for United Methodist Communications in Nashville and was senior vice president for Hart & Company Advertising & Public Relations in Nashville, Tennessee.

Reverend Susan Groseclose is a deacon in The United Methodist Church serving in the Holston Annual Conference. She is a spiritual leader with a passion for leading persons—from cradle to grave—to grow deeper in their relationship with God and one another and to be in ministry and service within their communities. Groseclose, whose father lived with Alzheimer's for almost seven years before his death, continues to be a caregiver and pastor to persons living with dementia.

Cindy Solomon, video script writer and project manager for *Alzheimer's/Dementia: Ministry with the Forgotten*, is a marketing consultant and content writer from Franklin, Tennessee. Both her mother and maternal grandmother suffered from various forms of dementia before their deaths. For Solomon, working on this project was personal and one of the highlights of her career.

United Methodist Communications staff for their generous support for this project in providing hospitality to the studio audience, graphics and staging, and expertise in filming and editing the video sessions.

Members of the **Golden Cross Foundation, ENCORE Ministries, and Adult/Older Adult Committee of the Tennessee Conference** who envisioned and provided financial support for this project making it available to all churches in the Tennessee and Memphis conferences as well as other United Methodist and ecumenical churches.

Evaluation

Thank you for participating in the study *Alzheimer's/Dementia: Ministry with the Forgotten*. We hope you were informed, blessed, and inspired. So that we may tweak the leader's guide for future group studies (or possibly develop follow-up materials or resources), please take a minute to provide your thoughts and input. Please send your responses to kmcnish@goldencrossfoundation.org. Thank you in advance for your time and insight.

1. What did you like best about the study?

2. What could be improved?

3. Did you find any of the questions or activities confusing or hard to follow? How might they be improved?

4. Was there anything you felt was missing from the study?

5. Did you group come up with congregational and/or personal ministry response(s) that you would like to share?

6. If we'd like to know more about your response(s) to question five above (possibly for future articles or website blogs), who can we contact for additional information (name and email address)?

7. Do you have any other comments or suggestions?

Name and email address (optional):
