



When Words Fail

Practical Ministry to People with Dementia and Their Caregivers

STUDY GUIDE

Introduction

Westminster Canterbury Richmond, a continuing care retirement community in Richmond, Virginia, dedicates itself to excellence and compassion and recognizes that memory care is a critical area of service to be explored and developed. The campus is home to 900 residents served by a workforce of 700. More than 100 residents per year receive financial aid through the organization's Fellowship Program. It is a place that takes its roots in faith seriously, nurtures a spirit of generosity and strives to break new ground as a national leader in senior living.

Dementia diseases are on the rise. This reality, and its implications, spurs the organization toward finding ways to help current and future residents, caregivers and church families deal with the impending wave. Westminster Canterbury is an incubator for effective therapies and a testing ground for supportive approaches for families, churches and residents alike. Through our collaborative work, we engage families, clergy, volunteers, interns and staff in discovering how to help residents cope with the real and devastating effects of dementia. It was into this unusually fertile soil that the *When Words Fail: Practical Ministry to People with Dementia and Their Caregivers* book and DVD were realized.

The project was made possible by Westminster Canterbury Foundation with an innovation grant from LeadingAge, a national affiliation of senior living providers, and a generous anonymous donor whose spouse suffered a long journey through Alzheimer's disease. In deciding to support this project our donor spoke this truth: "Dementia IS a spiritual issue. Regardless of your faith affiliation, it starts with a fear so deep it rocks you. And that is a spiritual experience in need of help!"

Five million are currently diagnosed with Alzheimer's disease and many more suffer from other forms of dementia. At least 50% of people over 85 have some form of dementia. 72% of people over 75 years of age consider their faith to be very important but memory loss makes it increasingly hard for people to participate in religious organizations or initiate faith practices which comfort and uplift

them. They need clergy, lay church leaders, fellow church members, professional and family caregivers to help them practice their faith. As the disease progresses, conversing verbally becomes increasingly difficult for people experiencing dementia. Words also fail for those who seek to serve them. We often struggle with how to respond and how best to support them.

When Words Fail: Practical Ministry to People with Dementia and Their Caregivers offers practices that are effective for providing holistic care – ministering to the mind, body and soul. You will receive practical suggestions on how to communicate – eventually even without words. Through viewing interactions with people experiencing dementia, you will obtain a better understanding of how to address people’s spiritual concerns and support not only people living with dementia, but their caregivers, too.

Whether watching the DVD for personal knowledge or to plan a seminar where people will watch, reflect, and discuss, this Study Guide will help navigate the DVD, which will enhance your understanding of dementia and its physical, emotional, and spiritual effects on individuals and families. All of our resources are available at the website: www.whenwordsfail.com.

Words may fail, but the Spirit of God continues to live within each of us. It is our hope that *When Words Fail: Practical Ministry to People with Dementia and Their Caregivers* will equip you to offer valuable spiritual care to people living with dementia and their caregivers.

Thank you for your interest in ministering to people living with dementia! As your compassion enables you to reach out and offer God’s blessings to others, you, too, will be blessed in immeasurable ways.

For Whom is the DVD Designed?

Clergy, lay church leaders or pastoral care visitors may feel the need to enhance an understanding of dementia and the ability to respond to the needs of congregants experiencing it. You may want to equip yourself and your congregants to see the needs and provide effective pastoral care to people and their caregivers.

Caregivers for someone experiencing dementia may be looking for ways to enhance the connection with a loved one. Learning how to better communicate through the different stages of dementia and how to nurture the faith of the person you’re caring for can strengthen day-to-day interactions and wellbeing. *When Words Fail*, the book and DVD, can help you discover ways to foster comfort and peace in the one you’re caring for on days when anxiety and frustration exist.

Those who work in a long term care or assisted living facility providing memory support care for people experiencing dementia may be interested in enhancing the spiritual care of residents. This book and DVD can help you and your co-workers better understand how to identify people’s spiritual strengths and needs as well as how to address them. By doing this, your facility will be able to provide better holistic care of residents with dementia. The DVD contains interactions which demonstrate effective spiritual care through interaction and engagement.

How to Use This Resource

Reading the full book, *When Words Fail*, is the best first step. The book provides information about dementia and a more complete understanding of providing spiritual care to people living with dementia and their caregivers. It contains practical ministry ideas and realistic case studies for reflection and application. The DVD covers highlights from the book and demonstrates what the book teaches. Reflect on how it applies to your situation as a direct caregiver, minister, professional or visitor seeking to serve people with dementia.

Select a viewing time which is appropriate for the group. The DVD is one hour and 17 minutes in length, presented in six video segments. You may choose to show the entire DVD in one session, pausing after each segment for discussion and application. You might prefer to schedule several shorter sessions.

To prepare to lead the sessions, review suggested questions so that you're prepared to facilitate the group discussion. If possible, have copies of the book available for people to read before viewing the DVD. You may want to make this resource available through your church library. Determine the best schedule for your group. Set up necessary equipment and be sure it is functioning correctly. Make copies of this Study Guide for each participant.

Guiding the Sessions

Welcome everyone and thank them for their interest in caring for, and ministering to, people living with dementia and their caregivers. Let participants know that a reflection and discussion period will follow each video segment. Encourage participants to voice their questions, observations and concerns after viewing. Explain that the DVD is designed to enhance understanding of dementia and its physical, emotional and spiritual effects on individuals and families. The DVD's real-life pastoral interactions with people in various stages of dementia will demonstrate how to effectively provide spiritual care. And, it will help each participant become better equipped to provide much-needed spiritual care for this population, which is too often neglected.

1. INTRODUCTION VIDEO (1:57)

This segment describes the DVD's purpose and the importance of providing ministry to people experiencing dementia. You'll be encouraged to reflect on the spiritual needs of people living with dementia and how to nurture their spirits as you remind them of God's presence and peace. Through such ministry, we have the opportunity to be ambassadors for God and to share God's love. Though words fail for people with dementia and they are frightened by loss of memories, God's love does not fade.

After viewing the introduction, facilitate discussion with questions such as the following: (5 minutes)

- Are people in our church and community experiencing dementia and/or caring for people with dementia? How so?
- What is our church doing to meet their needs?

2. DEFINING DEMENTIA AND EARLY-STAGE MINISTRY (20:17)

Nurse Educator Laura Mohun presents a definition of dementia, how the brain is compromised and how dementia physically affects people. Chaplain Kathy Berry highlights the emotional and spiritual challenges of dementia and demonstrates, through interaction with a woman in the early stages, how to provide pastoral care. Viewers receive information to help more effectively minister to people experiencing the confusion and struggles of dementia as it begins to impact someone's life.

After viewing the video, facilitate discussion with questions such as the following: (10 minutes)

- What new or interesting information did you learn as you viewed this video segment?
- What did you learn about dementia and how it affects people physically?
- Be prepared to give an overview of dementia, if participants haven't had a chance to read the book prior to the session. Should participants desire further information, you might consider inviting a representative from your area Alzheimer's Association or local memory support facility to present more extensive information about dementia's physiology.
- In what ways is our church dementia-friendly and doing a good job of reaching out to people who are newly experiencing dementia's affects? How can we do a better job?
- How are people affected emotionally in the early stages of dementia? What concerns did the resident express in the video?
- What pastoral care techniques did you see which encouraged the woman in the early stages of dementia to use her faith to help cope with losses she is facing? (For example: listening, gentle touch, encouragement to read sacred books, prayer, presence)
- What is a spiritual assessment? What questions would you ask someone to help discern his spiritual needs? A sample assessment is offered at the conclusion of this Study Guide.
- What is person-centered care and why is it important?

3. MIDDLE- STAGE MINISTRY (23:46)

Viewers learn about the indicators, emotional effects and struggles of middle-stage dementia. Through demonstrations of ministry to people experiencing this level of dementia, viewers receive practical tools to help them offer pastoral care more confidently and effectively. Watching and listening to the interactions enables viewers to understand how to respond to, and communicate with, people whose words may be failing.

After viewing the video, facilitate discussion with questions such as the following: (10 – 15 minutes)

- Are there people in our church who seem to be experiencing dementia in the middle stages? If so, how are they affected?
- How might their communication be affected in the middle stages?
- Why is it important not to ask too many questions when communicating with people experiencing middle-stage dementia?
- What does it mean to be prepared to do more narrative than dialogue when visiting?
- How can it affect the family as the person they love loses their memory?
- Why use music when ministering to people? What kind of music is preferred and why?
- Why is it important to create a trained care team specifically for ministry to people with dementia? What could team members do?
- What are some ideas for ministering to people in the middle stages of dementia?
- What could our church do?

4. LATE - STAGE MINISTRY (21:42)

As people progress into this final stage of dementia, communication becomes nominal and eventually seems nonexistent. During this stage, people receive the fewest number of visitors. As their words fail, so do the words of people who wish to visit with them but don't know what to say or do. However, people continue communicating with more than words through sighs, raised eyebrows, facial expressions and body shifting. This section focuses on how dementia affects people in the late stages and how to look beyond the illness to focus on the person and her needs, especially when she may no longer be able to express them. Viewers are shown examples of ministry to people in the late stages and encouraged to use more than words when communicating. Demonstrations provide practical tools to help viewers provide compassionate ministry during this final stage of life.

After viewing the video, facilitate discussion with questions such as the following: (10 minutes)

- Why is it important to visit with people who are experiencing the late stage of dementia?
- Instead of worrying about the jumbled words people say, or the fact that they might not speak at all, what should you focus on when visiting someone in the late stages of dementia?
- What are some familiar religious practices you can share with people in the late stages?
- How can we infer what someone in the late stages of dementia is feeling?
- What are some other ways you can minister to people experiencing the late stages of dementia?

5. CARING FOR CAREGIVERS (6:40)

Caregivers provide invaluable care for their loved ones experiencing dementia. It is a consuming job with many ups and downs. In this section, real-life caregivers describe their challenges and joys as they journey with their loved one. This segment provides statistical information and suggestions for ministering to caregivers, helping lighten their load and bringing much-needed encouragement.

After viewing the video, facilitate discussion with questions such as the following: (10 minutes)

- How are caregivers affected when their loved one has a dementia disease?
- How can ministers and church visitors reach out to caregivers and partner with them in caregiving?
- What are some things ministers and church visitors can do to help if a caregiver decides to place her loved one in a specialized memory-care facility?

6. NURTURING THE SPIRIT (3:49)

There are many ways to enhance the lives of people experiencing dementia and bring them joy. In this segment, viewers receive ideas that can help inspire their churches and them to become dementia-friendly. Churches are encouraged to provide opportunities and ministries to enhance the faith and nurture the spirits of people living with dementia. What can your church do?

After watching the video, facilitate discussion with questions such as the following: (5 minutes)

- What are some things our church can do to create a dementia-friendly environment and minister to people living with dementia? What opportunities and special events could be adapted in order to include those with dementia and their caregivers?
- Spend time brainstorming together and making plans to act on new ways to support caregivers and those for whom they care.

7. CONCLUDING SESSION

Take time to break into smaller groups and look at the case studies found in *When Words Fail*. Give each group one case study to consider. After a time limit, invite each group to briefly summarize their case and findings. This exercise will help participants review and apply what they've learned from watching the videos.

Before participants leave, discuss how they would like to help continue or develop your church's ministry to people with dementia and their caregivers. Take time to set up a follow-up meeting to discuss people's interests and plan for the future.

We hope you will use the book and the DVD as on-going resources to return to as you offer faithful care for people throughout the disease's progression. Go forth and serve! And may God bless your ministry.



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SPIRITUAL ASSESSMENT

The following questions form the basis of an assessment that will strengthen your ministry. If possible, glean the answers to these questions directly from the people experiencing dementia and their loved ones for whom you provide spiritual care. In addition to these questions, get to know important aspects of their lives – family, pets, favorite vacation spots, hobbies and skills. These insights will enrich your visits and provide insights for sharing.

- What gives you hope?
- What gives you purpose?
- What helps you feel peaceful?
- What nurtures your spirit?
- Where and when do you feel closest to God?
- What religious practices and symbols are important to you? (For example: prayer, meditation, scripture reading, worship, reading The Book of Common Prayer, music, icons, candles, scents)

About the Author

Rev. Kathy Fogg Berry received a Masters of Religious Education from Southern Seminary in Louisville, Kentucky, and a Masters in Patient Counseling and a postgraduate certificate in aging studies from Virginia Commonwealth University in Richmond, Virginia. She serves as chaplain at Westminster Canterbury Richmond where she provides spiritual care for the residents with dementia diagnoses, their families, and the staff who care for them. For the last five years, Rev. Berry has offered the *When Words Fail* seminar for clergy and lay leaders throughout Virginia, and she speaks regionally and nationally about spirituality and dementia.

Please visit www.whenwordsfail.com for more information and resources.

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