

© 2018 Dr. Elizabeth A. Shulman. All rights reserved.

No part of this book may be reproduced, stored in a retrieval system, or transmitted by any means without the written permission of the author.

Published by the author.

ISBN: 978-1-7328507-0-5

Cover Photo credits to Mya Young and to all the senior members of the author's family who posed for the picture: Molly Nash, Alla and Semyon Shulman, Beth and Joel Rabb, and David and Lilia Francis.

Because of the dynamic nature of the Internet, any web addresses or links contained in this book may have changed since publication and may no longer be valid.

To purchase additional copies, go to: www.sanctuaryinthemidst.com

Contents

Foreword.....	5	
Introduction.....	6	
PART I	PROVIDING SANCTUARY: A CURRICULUM FOR CONGREGATIONS.....	9
Lesson 1	“Impressions”.....	11
Lesson 2	“’Til Death Do Us Part”.....	15
Lesson 3	“Gifts to Give”.....	19
Lesson 4	“Synergy”.....	35
PART II	SEEKING SANCTUARY: SUPPORT FOR SPOUSES.....	39
Lesson 1	“God With Us”.....	41
Lesson 2	“You Shall Know the Truth”.....	45
Lesson 3	“Different Ways to Express”.....	49
Lesson 4	“Seeking the Peace”.....	53
PART III	CREATING SANCTUARY.....	59
Week 5	“Creating Sanctuary”.....	61
Final Words.....		63

“Seek the peace and prosperity of the city to which I have carried you into exile.
Pray to the Lord for it, because if it prospers, you too will prosper.”

- Jeremiah 29:7

sanc·tu·ary

noun \ 'saŋ(k)-chə-, wer-ē\

: a place where someone or something is protected or given shelter

: the protection that is provided by a safe place

: the room inside a church, synagogue, etc., where religious services are held

(Merriam-Webster)

Foreword

Spouses are now the most prevalent caregivers for persons with Alzheimer's disease.¹ Companionship, communication, shared experiences, and both physical and emotional intimacy are things valued by couples. When a marriage is impacted by Alzheimer's disease (or other forms of dementia), these characteristics of the relationship can become confusing and ambiguous as the feelings and interactions that made two people feel like a married couple slowly disappear from the relationship. As symptoms such as forgetfulness, confusion and personality changes take over the ill spouse, the well spouse is left to grieve for a loved one who is physically present, yet relationally disappearing. Research has shown that the majority of spousal caregivers of Alzheimer's patients struggle to make sense of their marriage as the disease progresses, contributing significantly to their level of stress.²

In the midst of confusion and anxiety, Christians, as well as persons of other faiths, often turn to their church or religious faith as a means of coping.³ However, most churches are not well-equipped to address the impact of dementia on the marital relationship. Studies have shown that caregivers often feel isolated from others; this includes feeling isolated from their church.⁴

In conducting research for my doctoral dissertation, I sought to better understand not only the experience of marriage for a spouse whose partner has Alzheimer's disease, but also how that caregiver's personal faith and their interaction with their faith community impacts that experience. I used the results of my research to develop *Sanctuary in the Midst of Alzheimer's*, a much-needed program of ministry for both spouses of dementia patients and for pastors and congregations who are seeking to minister more effectively to these spouses.

If you are a pastor or friend of a spousal caregiver, I hope this study propels you to explore innovative ways to reach out to the growing population of spousal caregivers. If you are the partner of a person with Alzheimer's disease or another form of dementia, I hope the scripture, personal narratives and study questions help you see that you are not alone. Ultimately, I pray that for everyone these pages bring you encouragement, strength and new-found meaning for your journey.

Blessings,

Elizabeth Shulman, D.Min., STNA

¹ Daley, Ryan T., O'Connor, Maureen K., Skirk Steven D., and Beard, Renée L., "'In this together' or 'Going it alone': Spousal dyad approaches to Alzheimer's." *Journal of Aging Studies* 40 (2017):57.

² LoboPrabhu, Sheila, Victor Molinari, Kimberly Arlinghaus, and Ellen Barr, "Spouses of Patients with Dementia: How Do They Stay Together 'Till Death Do Us Part?'" *Journal of Gerontological Social Work* 44, no. 3/4 (2005): 162.

³ Crystal L. Park, "Religion as a meaning-making framework in coping with life stress," *Journal of Social Issues* 61.4 (Winter 2005): 707.

⁴ Lisa P. Gwyther, *You Are One Of Us: Successful Clergy/Church Connections to Alzheimer's Families* (Duke University Medical Center, 1995), 3.

Introduction

Sanctuary in the Midst of Alzheimer's is a five-week program. The entire curriculum is two-fold in its ministry objectives. One purpose of the curriculum is to educate and train pastors and church members to more effectively and compassionately minister to those in their congregations who are caring for a spouse or significant other with Alzheimer's. The other purpose is to create a safe place for spouses to gather and share their experiences in a Biblically-based environment. Note: there are many forms of dementia. For an excellent description of the various kinds of dementia, please see www.alz.org. I will be using "dementia" and "Alzheimer's" interchangeably because Alzheimer's is the most common form of dementia, and it is projected to affect over 14 million Americans (131 million, worldwide) by 2050.⁵

Two Parallel Studies

This ministry is comprised of two separate but parallel studies subtitled, "Providing Sanctuary" (for pastors and congregation members) and "Seeking Sanctuary" (for spousal caregivers). Ideally, these studies occur simultaneously. Both studies use scripture and personal narratives as the foundation for discussion.

The narratives have been gathered from spouses I interviewed for my research. Several of the same narratives are used in both studies. I also include quotes from journal articles that recount the many types of scenarios that husbands and wives experience while caring for a spouse with dementia. Dorothy Snyder was extremely helpful to me in my research, and with her permission, I also include several of her reflections which she has beautifully shared in her book, *Our Journey Through Alzheimer's* (AuthorHouse, 2003). Her book not only recounts situations that are common to caregivers, she also incorporates scripture and the role her faith played in her caregiving. Spousal narratives are included as part of the curriculum for each lesson to give the reader the opportunity to "walk in another's shoes." Additionally, reading anonymous stories aloud provides the benefit of participants hearing personal accounts without feeling pressure to share their own. (Or, it might also *encourage* sharing!)

Each study includes Pre-Study and Post-Study questionnaires to evaluate the effectiveness of the curriculum. The congregational Bible study questionnaire is designed to measure for increased understanding of the experience of caring for a spouse with Alzheimer's. The spouse questionnaire measures the helpfulness of the program. These pre- and post-tests will provide valuable information to congregations.

Providing Sanctuary: A Curriculum for Congregations

Providing Sanctuary is for the general church congregation. It is intended to increase awareness of the experience of caring for a spouse with Alzheimer's and seeks to find ways to minister to this growing population.

The first week begins with the lesson, "Impressions." During this initial session, participants will explore their own assumptions and impressions of what it might be like to care for a spouse

⁵ <https://www.alz.org/alzheimers-dementia/facts-figures>.

with Alzheimer's. The first gathering is designed to help participants better appreciate the challenges experienced by spouses caring for a husband or wife with dementia. Passages from I Corinthians 13:1-13 and John 13:1-17 and 34-35 frame this week's discussion as guidance for how God calls us to love each other.

The second lesson, "Til Death Do Us Part," builds upon the previous week with more personal stories from spouses and a discussion of Jesus' description of marriage in Matthew 22:23-33. Married participants spend time considering how their own marriage would be affected if they or their spouse were diagnosed with Alzheimer's. During this lesson, the group continues to consider the list of challenges they made from the previous lesson and makes additions if necessary.

Week three, "Gifts to Give," is based on I Corinthians 12:1-11 as Paul talks about spiritual gifts. Participants review experiences of spousal caregivers and explore how the church can better respond to spouses' needs by taking the Spiritual Gifts Inventory (SGI),⁶ a very thorough tool developed by Michael Anne Haywood and her colleagues to help discern one's spiritual gifts.

In the fourth lesson, titled "Synergy," participants review the lists of challenges and needs compiled in the previous sessions in light of the gifts represented from their SGI results. A discussion of the word "synergy" and its meaning begins the lesson to discover the synergy between the needs of spousal caregivers and the gifts the participants have to offer. Creative "gift-giving" is encouraged as participants are asked to come up with as many ways possible to "synergize" one's needs with the provision of another's gifts. The discussion concludes with James 2:14-26, which speaks of faith and works and encourages participants to act on their faith by putting their gifts into action.

Seeking Sanctuary: Support for Spouses

Seeking Sanctuary is designed for spousal caregivers and addresses the themes culled from the literature reviews and personal interviews. The goal in this group is for spouses to feel safe as they interact with scripture, anonymous narratives and each other. The ultimate intention of the study is for spouses to feel a greater sense of peace through processing their experience and knowing that they are not alone.

The first week, "God with Us," is an introductory lesson on the overall experience of having a spouse with Alzheimer's. The scripture for this lesson is Luke 24:1-35. These passages establish that God is with the group as they seek to make sense of a situation that in many ways makes little sense. This initial lesson also introduces personal narratives from spousal caregivers. Two caregivers share their decisions to keep a journal, and at the end of the lesson participants are encouraged to try this.

The second lesson, "You Shall Know the Truth," uses passages from I Corinthians 13:8-13 and John 8:31-32 to provide the foundation for spouses to identify what they know to be true for

⁶ *The Spiritual Gifts Inventory*, developed by Michael Anne Haywood with assistance from Genie Carr, Steve Gambino, The Reverend Virginia Herring, Margaret Moore, Marjorie Northup, Mary at Stillpoint and Jean Woods, (c) June 1998. Used with permission from the author. Available from <http://home.earthlink.net/~haywoodm/SpiritualGiftsDiscernment.html>; accessed 4 March 2007 at 7:30 P.M.

themselves as try to live through their challenges in life and how marriage to a spouse with dementia is framed by those beliefs.

Participants are given a list of emotions to refer to while listening to personal narratives from other spouses. The idea of “projection” is highlighted with a caution for you to be careful not to project your own feelings and opinions onto someone else’s story. This lesson focuses on the uniqueness of each spouse’s situation despite, somewhat similar circumstances. It is stressed that what works for one spouse in caring for a partner may not work for another. As participants begin to identify how they interpret their own situation, you may discover that what is “true” for you may not be for a fellow spouse. Acknowledging these truths and claiming their uniqueness can give participants a sense of freedom from the pressure to feel a certain way about their circumstances.

The third week’s lesson, “Different Ways to Express Commitment,” focuses on marriage; specifically, how Jesus viewed marriage. Matthew 22:23-33 provides the basis for this discussion. Participants are asked to list changes (both good and bad) that occur in a marital relationship after Alzheimer’s sets in. As in previous weeks, written narratives are read aloud to initiate discussion. Participants discuss ways that spouses may understand and express commitment differently.

The fourth lesson, “Seeking the Peace,” proffers hope for participants as they continue in their journey. Looking at John 14:27 and Jeremiah 29:4-14 participants see how these scriptures offer promise and explore where they are currently finding peace. Jeremiah’s theme of ambassadorship is introduced to offer support in your role as spousal caregivers.

Research showing that caregivers are reluctant to seek help is presented for discussion. The group is asked to list ways others can support them so that they might have more peace in their lives. You will be encouraged to share these needs with your church. By presenting a list that comes out of the whole group, no one person is singled out, and the church has a clearer understanding of how they can minister more directly and efficiently to its spousal caregivers.

Week Five: Creating Sanctuary

After participants have finished the four weeks in their separate studies, both the *Providing Sanctuary* and the *Seeking Sanctuary* groups come together in a fifth week titled *Creating Sanctuary*. Groups are asked to bring the results of the Pre- and Post-Study Questionnaires, their respective lists that were compiled from their individual studies and explore present needs that exist in their congregation. This final meeting is a much less structured gathering intended to share feedback from what was learned, brainstorm ideas for ministries and commit to a plan of action.

Sanctuary in the Midst of Alzheimer's

PART I

Providing Sanctuary

∞

A Curriculum for Congregations

Providing Sanctuary

Pre-Study Questionnaire

*** Please make copies of the questionnaire to pass out and collect once they are completed. You may also download copies from www.sanctuaryinthemidst.com**

Please circle the statement that best describes your response.

1. How important do you think it is for churches to provide a ministry for spouses of Alzheimer's patients?

Very important

Somewhat important

Not very important

Not at all important

2. Are you married? Yes No

3. How well do you think you understand the experience of caring for a spouse with Alzheimer's disease?

I understand the experience well.

I understand a little about what that experience is like.

I have no clue.

4. Do you feel your church is doing enough for those who are affected by Alzheimer's?

Yes

No

5. If you answered "no" to question 4, in what ways could your church be more helpful?

Providing Sanctuary

Lesson One

“Impressions”

Summary: This initial lesson explores your assumptions and impressions of what it is like to care for a spouse with Alzheimer’s or another form of dementia. The first gathering is designed to guide participants to better appreciate the challenges of caring for a husband or wife with Alzheimer’s through reading aloud and discussing personal accounts given by spouses. During this lesson, you will compile a list of challenges that spouses experience. Passages from I Corinthians 13:1-13 and from John 13:1-17 and 34-35 frame this week’s discussion.

I. Materials

- Bibles
- large sheets of paper or poster board
- marker
- nametags (if needed)
- copies of the Pre-Study Questionnaire
- a large envelope to collect questionnaires

II. Goals

- assess the current level of knowledge of Alzheimer’s and caregiving among the group
- explore assumptions, impressions and opinions currently held regarding marriage and Alzheimer’s
- be exposed to actual experiences of spouses through personal narratives
- begin to create a list of challenges encountered by spouses of Alzheimer’s patients

III. Lesson

- A. Distribute Pre-Study Questionnaires and complete. You do not need to put your name on the questionnaire. Collect and save the questionnaires in a manila envelope to compare to the Post-Study Questionnaires after the study.
- B. Introductions
 1. Go around the room and introduce yourselves by sharing your first name and whether you know a spouse who is caring, or has cared for, a husband or wife with Alzheimer’s or another form of dementia.
 2. On a large sheet of paper, write the heading “Challenges.” Take turns sharing what you perceive to be challenges for spouses of Alzheimer’s patients and write them down. **(Save this list and have it available for future lessons!)**
- C. I Corinthians 13:1-13
 1. Read aloud the scripture.
 2. Ask:
 - a) During what ceremony is this passage often read?
 - b) Within the situation of marriage, how does verse 12 apply?

Providing Sanctuary

Lesson One – Selected Narratives

After each narrative, ask yourself, “What stands out to me about this narrative?”

#1

Assign two people to read the “Interviewer” and “Participant” roles

I = Interviewer

P = Participant

I: You knew that she had a problem.

P: Yes. Our daughter is a nurse practitioner and she said, “Daddy, if I could get her an appointment, do you think you could bring her down here?” And I said, “Well, let me talk to her and see.” And I asked Peggy and she said, “Oh if I could just do something to help my memory.” And all the testing they did on her! After we went down the second time she said, “I want you to promise you will never bring me down here again.” You do this all day long, they test you and check you. I told Peggy we’d have to come down at least one more time. We’d need to get all the facts that they had gathered and get a diagnosis. So, we did and they had gotten them all back and when they told us it was Alzheimer’s. She just went ballistic. In fact, we couldn’t even go out to visit my daughter, we just drove home. She cried all the way home. I wanted to die. The big thing is you have to go to work, you know, and try to find the medications. And I was thinking today we have gone through so many kinds of medications trying to slow this thing down. They told us to expect - because she’s so young - that could be a fast-moving thing. And it was for her.

I: You said she was diagnosed five years ago?

P: Almost six. And here we are.

I: And you placed her into the facility...

P: Three months ago. She has to have twenty-four hours of care. And I drug my feet an extra year too long. I thought, “Well, I can take care of her.” Well, that made me develop a heart problem, which they have taken care of. But she would get up in the middle of the night and wander, and I hadn’t slept the night in five years. I still can’t. You get used to listening. I’d lock the doors so she couldn’t get out. I’d look up and she’s sitting in the middle of the floor, and she’s gaining weight. She’s gone up from 120 to 170 lbs. And I, you know, I couldn’t lift her. I’d have to swing her to the bed. I had taken off the rails and put them down on the floor so I didn’t have too far to lift her. But I still go to the chiropractor three times a week to try to get my back straightened out. But you know, that’s not my problem. I’m going to be alright.

I: It’s just one more way Alzheimer’s affects the spouse.

P: Yes, it affects everything. And it's hard to talk today to someone who hasn't been affected in some way by some sort of dementia.

#2

Selfishly, I kind of wish God would just go ahead and take me. Seventy- four years in this world is long enough. But then who would take care of Mary? Those are the thoughts that keep me awake at night.

#3

One time he told me to just throw him out; he was no good to anyone anymore. What a confusing world it must have been for him to know he was not in control of his actions, but still able to understand some of the things he did was wrong. As caregivers, we hurt when we see such agonizing and frightening confusion overtake our loved ones.

(Our Journey Through Alzheimer's, p.38)

#4

We went into the doctor's office and he had all the facts together on x-rays and psych tests and all and he looked at her and said, "Mrs. B, we think you're in the early stages of Alzheimer's disease." And Rose didn't panic or anything. She just said, 'Well, I want everyone to know about it. I don't want the people at church saying, 'what's wrong with her?!' So that really – I knew what to do from the very beginning. I've always believed in open communication, you know. We get into trouble when we try to fake things and cover up and all that. It's best just to let it out. So, the people at church learned to adapt to Rose.

#5

I'm starting a new life. And it's without [my wife] and we had planned to do so many things in our lives. And it won't happen now... You know, I don't know how many different things we had planned to do upon retirement.

#6

Can you imagine how that would be to be locked up in that mind? And want to tell me something and can't? I think sometimes that's why people don't go see them. There are people who haven't had a visitor, and I've been out there ninety days, and haven't had but one or two visitors. But, where I felt I got hurt, because I'm a people guy, always have been and probably always will be. And I saw things happen, particularly with the church and friends, not necessarily our church but other friends. And after a while you get ignored, even from your family.

Notes: _____

