

Sanctuary in the Midst of Alzheimer's

A Ministry for Families Facing Dementia

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ISBN: 978-1-7328507-1-2

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“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 \ 'sɑŋ(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)

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Foreword

Family members provide most of the care for persons with Alzheimer's disease and other forms of dementia. As symptoms such as forgetfulness, confusion and personality changes take place, caregivers are left to grieve for a loved one who is physically present, yet relationally disappearing. Research has shown that adult children caring for parents often report a deep sense of loneliness and increased conflict with other family members.¹ Many spousal caregivers of Alzheimer's patients struggle to make sense of their marriage as the disease progresses.²

During times 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 families. Studies have shown that caregivers often feel isolated from others; this includes feeling isolated from their church.⁴ A person is diagnosed with Alzheimer's disease every 65 seconds.⁵ With communities supporting an increasing number of aging citizens, it only makes sense that our churches would become centers of support for persons with dementia and their family members. Yet, so far little has been done to address this growing need in our congregations.

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 Ministry for Husbands and Wives Caring for a Spouse with Dementia* (originally published in 2018). Over the past year, I received feedback from many that they wished this program also included children and other family members who are caring for a loved one with dementia. This updated book includes an additional four-week section for children caregivers and has been renamed to reflect this more comprehensive ministry.

This program is meant to offer hope and prompt meaningful discussion. While I have used the Bible as the spiritual framework, I hope that people of all backgrounds will benefit from this ministry and from the assurance that there is a higher power overseeing, loving and providing a sense of meaning, regardless of religious (or non-religious!) background.

If you are a pastor or friend of a caregiver, I hope this study propels you to explore innovative ways to reach out to the growing population of caregivers. If you are the partner, child or other family member caring for 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.

~ Elizabeth Shulman, D.Min.

¹ Hwang, A. S., Rosenberg, L., Kontos, P., Cameron, J. I., Mihailidis, A., & Nygård, L. (2017). *International journal of qualitative studies on health and well-being*, 12(sup2), 1389578. doi:10.1080/17482631.2017.1389578

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.

⁵ Alzheimer's Facts and Figures Report, 2019.

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 congregation who are caring for a family member with dementia. The other purpose is to create a safe place for family members to gather and share their experiences in a spiritually-based environment. (Note: Because each section is self-contained, this book can be broken down and tailored for individual groups such as senior centers, assisted living facilities, or support groups that would like to integrate a spiritual component.) The goal of this ministry, when executed in its entirety, is to create a program that results in churches becoming an important resource for the growing number of dementia caregivers in their community.

Three Parallel Studies

This complete ministry is comprised of three separate groups that each meet for four weeks. Each lesson is designed so that anyone can facilitate it. The only requirements to lead are making sure there are large sheets of paper and markers and a willingness to read out loud if there are no volunteers. Allow one hour for each lesson. After the four weeks, the three separate groups come together for a fifth week where the results from each individual group are discussed and a plan of ministry begins to be created. The three groups are:

Providing Sanctuary - for church members or individuals who want to better understand the experience of caregiving and learn how to better support dementia caregivers.

Seeking Sanctuary: Children Caring for Parents – for adult children or other family members facing such challenges as: role-reversal, loneliness and isolation, self-care and asking for help.

Seeking Sanctuary: Support for Spouses – for spouses encountering the unique challenges of caring for a husband or wife with dementia. This section explores the commitment of marriage while offering encouragement to spouses.

Bringing It All Together

In the fifth week, *Creating Sanctuary*, participants from the *Providing* and *Seeking* groups meet. Using the information that each group has compiled during their separate gatherings; the combined group of *Providers* and *Seekers* will discuss the challenges and needs currently present in their church and explore how the gifts that have been identified can be used to meet these needs. Because each group will be presenting information unique to their participants, the ministry created out of this gathering will be unique to that congregation.

Sanctuary in the Midst of Alzheimer's

PART I

Providing Sanctuary

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A Curriculum for Congregations

Providing Sanctuary

Lesson 1

“Honor Thy Mother and Father”

Summary: This initial lesson explores your assumptions and impressions of what it is like for an adult child caring for a parent with Alzheimer’s or another form of dementia. The first gathering is designed to guide participants to better appreciate these challenges through reading aloud and discussing the personal accounts of caregivers.

Goals

- assess the current level of participants’ knowledge of dementia caregiving
- begin to create a list of challenges encountered by caregivers of Alzheimer’s patients

Materials

- large sheets of paper or poster board
- marker
- nametags (if needed)

Lesson

A. Introductions

1. Go around the room and introduce yourselves by sharing your first name and who you know caring for someone 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 family members caring for a loved one with dementia. (Save this list and have it available for future lessons.)

B. Have a volunteer read I Corinthians 13:1-13: ¹ If I speak in the tongues of men or of angels, but do not have love, I am only a resounding gong or a clanging cymbal. ² If I have the gift of prophecy and can fathom all mysteries and all knowledge, and if I have a faith that can move mountains, but do not have love, I am nothing. ³ If I give all I possess to the poor and give over my body to hardship that I may boast, but do not have love, I gain nothing. ⁴ Love is patient, love is kind. It does not envy, it does not boast, it is not proud. ⁵ It does not dishonor others, it is not self-seeking, it is not easily angered, it keeps no record of wrongs. ⁶ Love does not delight in evil but rejoices with the truth. ⁷ It always protects, always trusts, always hopes, always perseveres. ⁸ Love never fails. But where there are prophecies, they will cease; where there are tongues, they will be stilled; where there is knowledge, it will pass away. ⁹ For we know in part and we prophesy in part, ¹⁰ but when completeness comes, what is in part disappears. ¹¹ When I was a child, I talked like a child, I thought like a child, I reasoned like a child. When I became a man, I put the ways of childhood behind me. ¹² For now we see only a reflection as in a mirror; then we shall see face to face. Now I know in part; then I shall know fully, even as I am fully known. ¹³ And now these three remain: faith, hope and love. But the greatest of these is love.

Providing Sanctuary

Lesson 1 – Personal Narratives

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

#1

My mom is the person I went to with all my problems. Now that she has dementia, I miss that about her. I miss so many things, actually. She taught me how to sew on buttons, showed me how to cook, babysat my kids. Now, I do all of these things for her. Don't get me wrong, I'm glad to do it, but I miss having my “mom” as I knew her for so many years.

#2

To be honest, dad and I have not had the best relationship. He wasn't one to express his feelings and left it to mom to handle most of the work of raising me and my sister. However, he *was* the one to dole out the punishment, and he firmly believed in the “spare the rod, spoil the child” philosophy; sometimes to the extreme, in my opinion. My sister moved hundreds of miles away right after high school. Mom died 4 years ago and I've been the one who stayed close to home, so now he's my responsibility. I really don't like it, but what else can I do?”

#3

I took mom to the doctor's office and he had all the facts together on x-rays and psych tests and all and he looked at mom and said, “Mrs. B, we think you're in the early stages of Alzheimer's disease.” And Mom 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, I just took my cue from her and told people. I've always believed in open communication. 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 then learned to adapt to Mom.

#4

It's gotten too difficult to take dad places, even places where everyone knows him. He'll either wander around or, if I try to keep him with me or sitting in one spot, he'll get combative and tell me to leave him alone. It's embarrassing when I'm out in public. People who don't understand my situation will just watch, they don't know what to say or how to help - even with his old buddies. I tried to take him to the diner where he used to gather with the guys. They greeted him and everything, but he didn't seem to remember them, although he can be good at covering it up; laughing and making very generic statements like, “Is that so?” Even still, they knew something was off and you could tell they were a little uncomfortable which then made me uncomfortable.