



BEGIN A SUPPORT GROUP

A Step-by-Step Guide
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Loving Through Dementia

Begin A Support Group: A Step-by-Step Guide

By Sheila Welch: Coordinator/Developer, *Loving Through Dementia: Offering help, hope, inspiration, and dementia education to dementia families. Guiding communities of every faith to do the same.*

Why a Support Group?

Because God has called us to love...

*Inasmuch as you have done it unto the least of these, you have done it unto me.
(Matthew 25:40)*

Every 65 seconds another person is diagnosed with Alzheimer's. Another family is thrown into chaos having been given little or no instruction in providing care. Today, four out of five of those families fracture under the stress of caring for a family member who lives with Alzheimer's or related dementias. Relationships are broken, often never to be mended. How do we minister to these families?

Caregivers have taught me that a key to surviving the caregiving experience is coming face to face with others living similar lives. There is power in being with those who understand. Support groups ... formal or informal ... offer this power. They offer help, hope, and a particular healing that comes only when heart aches and hard lessons are shared. They offer life-saving laughter, forever friendships, and the peace that comes from knowing you are not alone. A support group is often the caregiver's greatest source of comfort and empowerment —the surest road to survival.

What Do I Do First?

Decide your mission...

Will you provide simply a safe and confidential environment in which caregivers can share experiences and resources ... or will you provide dementia education, as well? There is immeasurable value in both. There is immeasurable power in the latter.

Will I need a budget to begin a Support Group?

Quick answer: NO.

The first support group at my own faith community had no budget. *Loving Through Dementia* grew out of a simple conversation in the parking lot of our church. Two friends, each loving her mother through Alzheimer's, found life---saving comfort in talking with each other. They met once a month, and invited others to join them.

Following the death of my mother, they invited me to tell my family's story. I was struck by what I saw in those caregivers. My own life had been so very similar, yet as I listened to their stories, I heard a truth louder than I had ever heard it before. Caregivers need just as much care as the person who is living with dementia ... sometimes more.

What do I look for in a Support Group Leader/ Facilitator?

I can only tell you what works for my groups and for me. Sharing the lives of those who are loving a family member through dementia is an honor, a privilege...and for me...a calling.

For He gives us comfort in our trials that we in turn may give the same sort of strong sympathy to others in theirs. (II Corinthians 1:4)

1. As facilitators, we must be willing to learn about dementia. What it is, what it means to the person living with it, and what it means to the family loving that person through it. Our job then is to share that knowledge with dementia families who most often are desperate for information.

Still Standing found on the Home Page of lovingthroughdementia.org is a great place to start. It offers a basic dementia education for support group facilitators and also for the families they serve. It is free and downloadable. It begins with the 25 questions most often asked by caregivers. I have answered those questions succinctly. I then refer the reader to three books in which professionals offer more in- depth explanations. Because caregivers do not have lots of time for reading, I also provide the page numbers where the answers can be found.

2. We must be good listeners: We must manage the direction of the conversations allowing time for everyone to be heard. Note: there sometimes are those who feel the need to take up much of the time. It is our responsibility to keep that from happening, if possible. One thing you might try is to ask another member a related question at an opportune moment, changing the direction of the conversation. Often, if a member needs more time, I offer for the two of us to continue the conversation after the meeting or later in the week via phone or Zoom.

In addition to being a listener, I see my role as an energetic, empathetic, sympathetic, cheerleader. Passionate about caregivers ... about educating and empowering them to *know better* and *do better* as they love their family member through this journey.

3. We must decide the format for our support group: In my own groups, the needs and concerns of the caregivers determine the direction of conversation. I am there to listen, to follow their lead and to guide the conversation when needed. To answer questions and concerns from a base of dementia knowledge, awareness, and understanding. That is why a continuing dementia education is so important. The topics that care partners bring to the group most often require that I share the dementia education I have. I chose to be taught by dementia guru, Teepa Snow, and became a Certified Positive Approach to Care Trainer. Therefore, my format includes making time to share that training with our groups.
4. Personal experience is valuable: Caregivers, along with my own experience have taught me that dementia families most often identify with a facilitator who has walked this walk. Someone who has loved a family member or friend through dementia. Dementia families share a common bond. They understand each other's life, they "get it." That kind of understanding can offer great comfort and trust.

However, personal experience is NOT a requirement. Finding a facilitator with personal experience is not always possible. If you have not loved someone through dementia yourself, then perhaps, you might find a former care partner willing to co-facilitate ... or willing to at least sit in on meetings and share his/her perspective occasionally.

Bottom line: It is the heart of the facilitator(s) that will carry the day.

How Do I Prepare to Lead?

The Alzheimer's Association offers facilitator training. Additionally, you might be allowed to visit a support group in your area. We allow those who hope to facilitate to visit our groups as long as they sign our confidentiality statement.

AND, you can prepare to begin by utilizing *Still Standing: A Guide for Loving Through Alzheimer's and Related Dementias*, found on this website. The Guide will provide you with a good basic dementia education.

- Educate yourself. Begin by reading the three resource books that *Still Standing* uses to answer the 25 Most Asked Questions, and frequent the "Websites to Live By." Show and use their videos for discussion.
- Learn the answers to the top 25 questions asked by caregivers.
- Use the 25 questions, anecdotal stories, and all materials in the Guide as topics in your meetings.
- Attend as many dementia education events, as possible.
- View Dr. Peter Rabins' free YouTube videos.

Once you have educated yourself with the guide and its resources, then you are ready to provide *Still Standing* to each member as their own basic resource. Use it to facilitate discussions. *Loving Through Dementia's* Family Conferences, along with its *Multi-Faith and Community Leaders' Workshops* are posted and available for your use. Links to additional valuable resources are found on our website.

How do I let caregivers know the group is available?

- Publish meetings in your church's monthly newsletter or e-newsletter, Sunday bulletins, and on all church social media. See Appendix of this document for examples of each.
- Announce the Support Group from the pulpit

- Visit Sunday School classes and groups in your church that might have individuals caring for family members or friends who are living with dementia. Tell each group that your support group offers help, hope, inspiration, and dementia education. Invite them to come...and ask them to help spread the word.
- Visit assisted living and skilled nursing residences to meet the directors. Leave flyers with Support Group information. Ask the director to allow you to announce your support group at their next gathering of the families. Inviting in person is always good. Finally, ask the director to put your Support Group info in the monthly newsletter and on all social media.

How often do we meet, and for how long?

My Family Support Groups meet once a month, which is typical. My Spouse Support Group is a different story. We began once a month with 5 husbands loving their wives through dementia. That number grew to three times a month, with 15 –20 spouses attending regularly. Note: Professional Support Group facilitators recommend a limit of 12 persons in order that everyone gets the attention they need. Spouse Support Groups are rare. I cannot turn away a caregiver. My answer is simply to meet more often.

My Support Group typically meets for an hour and a half.

When caregivers lose their loved ones, are they still allowed to come to meetings?

As the loved ones of our Support Group members have passed, I have been very pleased that many of our caregivers continue coming to meetings. They tell me:

- We are family.
- They want to help others who are still in the trenches
- Helping others is a constructive, meaningful way for them to heal during the grieving process.

Why offer a separate group for spouses?

I have learned many truths about loving a family member through Alzheimer's and related dementias while loving my mother, my aunts, and uncles, and a beloved cousin through this journey. Family Support Groups have taught me even more.

However, it is our Spouse Support Group, that has provided new and tender insights into what it means to love a husband or wife through this illness ... new and tender insights into what it means to love.

My education began one night after a Family Support Group meeting. One of the four spouses who were members of that group said to me, "'Sheila, I'm tired of sittin' here listening to a bunch of women talk about their mamas!" He smiled when he said it, even laughed a little, but he meant it. I heard him loud and clear. That comment has resulted in one of the greatest educations and blessings of my life.

The loss of the relationship between a husband and wife is different from the loss of the relationship of any other family member ... the grief is different ... the guilt even more profound.

I want to encourage you to offer two separate support groups, if at all possible ... a Family Support Group for those who are loving a family member or friend through this illness and a Spouse Support Group, for those who are loving a husband or wife.

What if only one caregiver attends?

This is an opportunity to learn more about their loved one, about the caregiver, and about the family. I have held many meetings with only one caregiver present. I was blessed by that caregiver and believe that we were both where God wanted us to be. I also believe that if you "build it, they will come." The *Loving Through Dementia* program grew out of a small support group at our church. However, over the last 13 years, we have served locally over 2000 families facing dementia through our support groups, conferences, workshops, and private consultations. Today, our website offers resources for many more families, globally. Its *Action Plan: A Guide for Ministering with the Forgotten* continues to result in new dementia ministries.

"It is not important how big the beginning ... it is beginning that is important."

What do I look for in a meeting place?

Cheery. Bright. Warm. Welcoming. I have tried several rooms in my own church. They felt institutional and lacked warmth. Attendance doubled when we began meeting in my home. A neighborhood clubhouse works well. Local coffee shops often offer conference rooms that provide a fun atmosphere, as well.

When meeting in a home, offering of coffee and dessert or a meal is optional. I find it works wonders for bonding with one another and making caregivers feel welcome and at home.

A support group will reflect the personality of its members and its facilitator. I love to cook, so I offer a snack or meal at every meeting. You may not choose to do that. This is simply what works for me.

What resources will help my group to get started?

A great beginning: Use the questions and stories and other materials in *Still Standing: A Guide for Loving Through Alzheimer's and Related Dementias*. In addition, the speakers featured on lovignthroughdementia.org are excellent resources. Our speakers always include an advocate who lives with dementia. They are the true dementia experts and educators.

How do I communicate between meetings?

I offer free phone or Zoom private consultations. I send a monthly calendar at the first of each month containing meeting information, news, and special events or speakers coming up. I send all Support Group meeting reminders a few days before each meeting. Caregivers are under tremendous stress. Reminders are necessary and appreciated.

I also email helpful dementia resources and encourage them to attend all dementia education events, including other support groups.

You might decide to do a private Facebook page for your group.

What about speakers?

All of our support group speakers donate their time. Even so, I only occasionally invite a speaker to join us. Caregivers need time to share and time for dementia education information.

When we do have a speaker, I notify the members ahead of time. I invite them to come during the last half of the meeting, allowing members to discuss their concerns during the first portion without the speaker present.

No solicitation. Caregivers are vulnerable. Our speakers are always gracious in understanding that, as a matter of courtesy, they are with us to provide dementia information only. This is not a time for solicitation.

What about confidentiality?

Meetings are a safe haven. Confidentiality is crucial. All present know that everything said during the meetings is to be kept in confidence. Members are reminded of this in our monthly meeting reminders. We honor and respect each other's privacy.

What are sources for free speakers?

Alzheimer's Association: A wonderful free resource for knowledgeable speakers.

Elder Care Attorneys: Caregivers are particularly interested in "How Do I Pay For Care?" The discussion should cover Medicaid and Medicare benefits; Veterans benefits; Health Care Powers of Attorney; and Financial Powers of Attorney.

Hospice Representatives: Hospice is a frequently misunderstood subject. Ask your local hospital to provide a hospice representative. I am aware that hospice discussions can be tender. I try to determine where our members' loved ones are in the course of the disease. If our group is made up primarily of loved ones in early stage, this discussion could be daunting for the caregivers. I would therefore, not choose Hospice as my subject. As is true in other conversations, listening to your members will guide you.

Senior Services organizations: If your county or town has a Senior Service organization, it might prove to be a good resource for speakers.

Caregivers: Those who have already gone through the whole journey can be powerful inspirations to other caregivers. Of course, you would want to know the caregiver and about his/her journey before inviting that person to speak.

A Personal Note of Encouragement to Those Who Might Lead

Leading support groups is one of the greatest blessings of my life. Families facing dementia teach me, bless me, inspire me to do more and learn more...so that I might love...better. I am particularly amazed as I see them together choosing laughter as a healing balm for their broken and lonely hearts. With each other, they slowly walk this journey...putting one foot in front of the other...heroically...lovingly. I thank God that they allow me to walk with them.

Thank you for what you are about to do for these often forgotten families.

- Sheila Welch