HOW DO I BEGIN A SUPPORT GROUP?

A Step-by-Step Guide
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What Do I Do First?

Understand your mission...

A support group provides a safe and confidential environment in which caregivers can share experiences and resources, support each other and lift each other up. It can also provide dementia education, empowerment for the caregiver.

Why a Support Group?

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)

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 lifesaving laughter, forever friendships, and the peace that comes from knowing they are not alone. A support group is often the caregiver’s greatest source of empowerment—the surest road to survival.

Will I need a budget to begin a Support Group?

Quick answer: NO.

The first support group at Due West UMC had no budget...our Dementia Ministry 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 speak. 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...and most often they do not even know it.

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

I can only tell you what works for my groups and for me. My job is to listen. I answer questions. If I do not have the answers, I look for them.

The needs and concerns of the caregivers determine the direction of conversation in my support groups. I am there to follow their lead and to guide the conversation when needed. To encourage ... and to provide dementia education.

In addition to being a listener, I see my role as an energetic, empathetic, sympathetic, cheerleader. Passionate about caregivers...about empowering them to *know better and do better* as they love their family member through the journey. This requires a willingness on the part of the facilitator to gain dementia knowledge in order to provide the tools caregivers need to protect their loved one, their families, and themselves along the way.

Caregivers and my own experience have taught me another valuable quality in a facilitator: Though not a requirement...caregivers most often identify with a facilitator who has walked this walk...someone who has loved a family member through dementia. Caregivers share a common bond. They understand each other’s life, they “get it. That kind of understanding can offer great comfort.

Finding a facilitator with that kind of experience is not always possible. If that is the case, then perhaps your facilitator could find a former caregiver willing to sit in on meetings and share his perspective as needed.

Regardless, it is the heart of your facilitator that will carry the day.
How Do I Prepare to Lead?

The Alzheimer’s Association offers facilitator training. Additionally, you might find a support group in your area. Or, you can begin by simply using 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.

Follow these simple steps.

- Read the three resource books it recommends.
- Learn the answers to the top 25 questions asked by caregivers.
- Use those questions, stories, and all materials in the Guide as topics in your meetings.
- Frequent the three websites offered: Alz.org; teepasnow.com; and nih.gov.
- View Teepa Snow’s free YouTube videos. Attend her conferences and workshops whenever possible.
- Seek other dementia education events, as available.
- 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 a basic resource. You will be able to use it as a means of facilitating discussions. 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, Sunday bulletins, and on all church social media.
- 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 if you could come to their next gathering of the families to invite those caregivers in person. 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. Today, we meet three times a month, with 15 – 20 men and women 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, and I do not want to turn away a caregiver. My answer is simply to meet more often. My Support Group meetings are from one and one half to two hours.

As the loved ones of our Support Group members have passed, I have been sweetly surprised and 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 own family through this journey. Family Support Groups have taught me even more.

However, it is our Spouse 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 any other family member lost to this illness...the grief is different...the guilt, perhaps even more profound.

I could write a book about what this group has taught me, but for now, 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.

We began small. You can, too. Five men sat around a table in a coffee shop. A friend who had lost her husband to Alzheimer’s and I sat with them. We met once a month. As the number grew, we met twice a month. Today we meet three times a month with an average of 18 men and women at each meeting.

“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 lacked warmth. Attendance doubled when we began meeting in my home. A neighborhood clubhouse works well also. An offering of coffee and dessert or a meal is optional, but I find it works wonders for bonding and making caregivers feel welcome and at home.

A support group reflects 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 materials will help my group to get started?

*Still Standing: Loving Through Alzheimer’s and Related Dementias.* A simple beginning would be to use the questions and stories and other materials in that guide as the basis for your conversations.

How do I communicate between meetings?

I send a monthly calendar at the first of each month containing meeting information, news, and special events or speakers coming up. I send Family Support Group meeting reminders 7 days before the meeting. I send a Spouse Group reminder 2-3 days before the meeting. Caregivers are under tremendous stress. Reminders are necessary and appreciated.

I notify members of other Support Group opportunities, and encourage them to go, when possible. I notify and encourage them to attend all dementia education events available.

What about speakers?

All of our speakers for our support group meetings 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 invite them to come during the last half of the meeting. Members can discuss their concerns during the first portion without the speaker present.

Caregivers are vulnerable. Our speakers are always gracious in understanding that they are with us to provide information and that this is not a time for solicitation.

Confidentiality is crucial. All members are assured in our monthly email reminder that everything said during our meetings is kept confidential. We respect each other’s privacy. I make sure that our speakers understand and agree.
What are sources for free speakers?

**Alzheimer’s Association**: An excellent resource for 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 try to be aware that hospice discussions can be tender. I try to determine where our members’ loved ones are in the course of the disease. If your group is made up primarily of loved ones in early stage, this discussion could be daunting for the caregivers. 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** who have gone through this journey can offer powerful encouragement and personal stories.

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.