

A How to Guide Starting and Maintaining a Caregiver Support Group Care Partner Tool Kit

One of the most effective ways that a church or faith community can help caregivers/care partners is to give them support. Support can come in several ways but one of the easiest is to start and sponsor a caregiver support group and if possible, offer respite care for the care receivers. Following this easy "How to Guide" for starting and maintaining a caregiver support group can get you started serving your church and community.

THE BASICS

THE PLAYERS/THE TEAM/ THE MANAGEMENT

Who has the vision? Who needs to be involved? Who has the money? Where are the people?
One person has the dream; two or more can make it a reality.

DEFINE THE PURPOSE OF YOUR SUPPORT GROUP

Why you do what you do it. Goals, objectives (when, where, what and who)

IDENTIFY POTENTIAL GROUP MEMBERS

Who is going to come? How do you find them? What are your boundaries?

PUBLICITY

How can they find you?

MEETING PREPARATION AND TIME

Deciding when to meet is critical to success. How often do we meet? Each meeting should have a plan or agenda. Keeping to a set time frame is critical.

PROVIDE RESPITE OR CHILDRENS ACTIVITIES

The success of your group could rely on the status of the care receiver? (Grandparents Raising Grandchildren support groups are another need.)

SPECIAL SPEAKERS/ WORKSHOPS (if appropriate for your group)

When starting a group provide a list of possible topics for discussion to each participant and have them rank the importance of each topic. Revisit and add to the list as needs indicate. It is not necessary to have a speaker or topic identified each meeting...some of the best sessions are those in which people are just able to share and provide support to others.

CONTACT BETWEEN MEETINGS

The leader can share this responsibility with all the support group members.

INVOLVING GROUP MEMBERS

Ownership=Continued Involvement

SURPRISES

Be prepared for the unexpected.

ADDITIONAL THINGS TO CONSIDER

Ask around your community to learn from others how they do support groups.

Think about how to get to know each other.

Confidentiality

Sign-in sheets and email address sharing

Information forms

THE DETAILS

THE PLAYERS/THE TEAM/ THE MANAGEMENT

Who has the vision? Who needs or wants to be involved? Who has the money? Where are the people?

With the concern of a specific population...caregivers, grandparents raising grandchildren, those in grief, etc... or the commitment to "walk through their lives" with them, a support group will work. Are you people in your church, in your neighborhood? Also consider it might take money, space, meals/snacks, etc. One person has a dream; two or more can make it a reality.

Start talking... just because you think it is a good idea doesn't mean it is...do not duplicate services...Keep Talking...locate people with talents to help you (geriatric nurses, parish nurses, counselors, social workers, experienced caregivers)...lots to do...Keep Talking...keep eyes open for possible funding sources...Keep Talking...if looking to start a support group for grandparents raising grandchildren (GRG's) for instance then you have to find the caregivers, talk to local schools, especially counselors.

DEFININE THE PURPOSE OF YOUR SUPPORT GROUP

Why you do what you do. Write a mission statement, your goals, objectives, etc.

Here is an example:

Caregivers Support Group Fact Sheet

When and Where and What:

- We meet the 3rd Tuesday of each month.
- We meet in the church parlor on the second floor (the same floor the sanctuary is on.)
- We meet virtually or have a hybrid meeting.
- We begin at 7:00 p.m. and end around 8:30.

The objectives of this support group are:

- Provide a place where people feel understood in the special way that only others who have faced or are facing a similar situation can understand.
- Provide respite from caregiving situations (time away) - a safe place.
- Help caregivers achieve a sense of perspective on their problems.
- Provide an opportunity to share resources.
- Provide verbal rewards (pats on the back) for good decisions or problems solved.
- Energize caregivers to extend themselves into the community to advocate for caregiver rights.

Who should come?

- Spouse caregivers, children's caregivers, grandchild caregivers, friend caregivers - in home or in community, long distance caregivers, those who share caregiving duties, or grandparents raising grandchildren.

The Do's and Don'ts (rules)

- What is said in this group is confidential unless the person gives you permission to tell.
- No requirements for attendance. Don't put the burden of attendance on the caregivers. Keep it very informal.
- Participants will be asked not to dominate conversations.

Meeting Agenda possibilities:

- Start with a devotion or prayer (take turns).
- Catch up on what is going on with each person, ask to share challenges, and joys.
- Sometimes have a short program provided by a professional.
- Include a problem sharing/solving session.
- If the group is in agreement serve refreshments (take turns).
- Maybe a potluck dinner every once and awhile.

Support Group Facilitators: Jane Doe is facilitator for the group. Jane comes to the group with 46 years of experience in the aging field having worked with caregiver groups for 20 years.

IDENTIFYING POTENTIAL GROUP MEMBERS

Who is going to come? How do you find them? Are you going to outreach into your community? Word of mouth is the best method to spread the word. Church admin, membership chair, deacons, Stephen's ministry, health ministry, parish nurses, etc. Talk to people in other faith communities (any denomination).

PUBLICITY

How can they find you? The potential participants have to know you are out there and how to find you. Using social media is a great tool to let people know you are starting a group. Visit Sunday school classes, if possible, get announcement in church bulletin and in church newsletter every session. If you regularly meet the 2nd Tuesday do not assume everyone is going to remember it...work to get the word out every month. If expanding outside the church send emails, letters and follow-up with letters, emails, and calls. Grandparent groups can publicize at schools, DRs Offices, apartments, laundry mats, corner 7-11's, senior centers, etc.

Print up an information flyer to distribute outside of the church and to have posted in the church. Remember your best publicity is word of mouth by satisfied participants.

MEETING TIME AND MEETING PREPARATION**Deciding when to meet. Getting ready for the meeting and setting up the space.**

Deciding when to meet could be critical in the success of your support group. Of course, the time you pick will not always be good for everyone. Try to be flexible. Check the church calendar for nights or days that are not very busy...then check to see why they are not busy. Ask potential members what a good time for them is... making them realize that what they tell you does not commit them to anything. If the time you pick does not seem to be working pick another time.

Decide how often to meet...if too often people will not come if too far apart you will lose continuity.

If you are bringing in a speaker secure them as far ahead as possible and confirm with them closer to the meeting. Try to publicize the topics that will be covered over a 6-7 meeting time span. Send an

email with the topics to all potential participants; you never know when one topic may pique their interest. Don't assume anything!

Then Grandparent groups, for example, have found that having a meal for grandparents and grandchildren helps so consider adding that to the support group. Also, with GP groups the children need to have their own space away from the support group meeting. You will have to have screened volunteers to be with the children too.

Another option is an online support group which provides flexibility for those who may not drive at night, live a further distance from the church building, have work conflicts, or other family obligations that make in person difficult.

TIPS FOR DURING THE ACTUAL MEETING

Start and end on time. If folks do not know each other, then make up permanent name badges that you keep and give out each time. Always have everyone sign in and list any changes in address, email, etc. This will give you a record for future planning.

If you are having a speaker let participants know what to expect at the meeting, who the speaker will be, how the group time will be structured. Be sure to inform the speaker of their time limit. Allow time for discussion.

Do not cancel meetings unless absolutely necessary...you do not want people to get use to not coming! Even if only one person comes, they came because they really needed the support.

PROVIDING RESPITE OR CHILDRENS ACTIVITIES

If necessary, try to provide respite care for the spouse or parent the caregiver is caring for. An adult day center might agree to provide respite during your caregiver support group. For a Grandparents group offer children's activities that are appropriate.

SPEAKERS / WORKSHOPS

Work up a list of possible speaker topics and present it to each new member. Using a list will help you determine what topics the caregivers are interested in. Their needs change so revisit the list occasionally. Here some example topics:

- When do you know when someone needs help/care?
- Nutrition
- Caregiver duties- your and other family members
- Benefits, i.e., Medicare/Medicaid, SS, SSI, etc.
- Communicating with other family members
- Resources for caregivers
- Role reversal- when the child becomes the parent
- The aging process
- Quality of life issues
- Mental health and Wellness
- Dementia/Alzheimer's Disease
- Respite care
- Geriatric evaluations
- Death and dying
- Depression/ emotional instability
- Medication management
- Dealing with grief
- Fraud and Exploitation
- Spouse Caregivers
- Problem solving
- Spirituality and aging
- Housing options
- Safety in the home
- Homecare options- How to find good help?
- End of life issues (spiritual) End of life documents (advance directives, medical power of attorney, durable power of attorney, wills)

This is not an all-inclusive list as there are lots of topics out there to touch on. Remember you do not always have to have a topic. Just being there to talk and support each other may be enough.

CONTACT BETWEEN MEETINGS

Keep the ball rolling if at all possible. Try to talk to support group members between meetings... make one on one contact to those who seem to need more reinforcement, need to talk. It will be well worth your time because they will not come so full...over brimming...to next group meeting.

INVOLVING GROUP MEMBERS

Ownership= Continued Involvement

Offer opportunities for members to do something...bring refreshments, speak about an issue they are experts in, have members call each other for added support. Do lots of informal networking. Ask participants about speakers they might think are good for the group. Encourage activities outside the group...special seminars on caregiving, conferences, etc.

SURPRISES

Who Knew?

Be prepared for the unexpected. Someone that dominates the conversation can be a problem...what do you do? Do not feel that low attendance means there is no need for a support group. If 1 comes or 12 come, they are all coming to be supported and the numbers should not matter. Give it time to grow and mature. It is difficult to predict what topics people will respond to.

MISCELLANEOUS

- Sign in sheets, information forms (non-threatening), email as a support group.
- Confidentiality is critical!
- Participants having an opportunity to ask knowledgeable people that they feel comfortable with not strangers...a big factor in the success of a support group.

This Quicksheet is part of the [Care Partner Tool Kit](#) where you can find additional Quicksheets on other Care Partner topics and a Resource Roadmap with websites and books. For additional resources, see the resource library page for the partners in this project [POAMN \(www.poamn.org\)](http://www.poamn.org) and [APCE \(www.apcenet.org\)](http://www.apcenet.org) or the [Office of Christian Formation \(www.pcusa.org/formation\)](http://www.pcusa.org/formation)

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