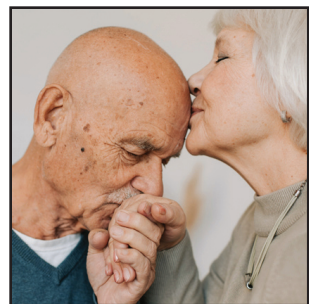
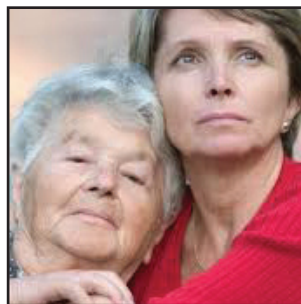
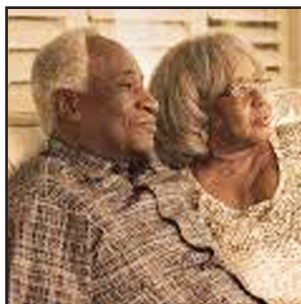
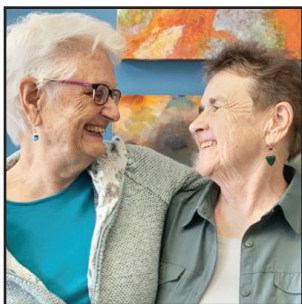




# Caregivers' Support Group Toolkit 2021



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The toolkit is generously funded by  
the Arthur N. Rupe Foundation.

Village Movement California thanks  
the Pasadena Village Caregiver Support  
Group for sharing its story and  
consulting on the toolkit.

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## INTRODUCTION

Most caregivers in the U.S. are family members and friends who are stretching to add the care of a loved one to their existing responsibilities. Initially, they may not see themselves as caregivers but rather as family or friends helping a loved one.


Caregiving is a continuum that often begins with being worried about a loved one and checking in frequently by telephone to be sure they are okay. Then, it may expand to taking on some of the daily tasks of living such as grocery shopping, errands, or transportation to appointments. Next, more personal tasks in the home may be added, from handling finances to physical help getting out of bed, dressing, bathing, etc. At each of these stages, the person providing help is a caregiver even when they don't see themselves this way.

Many people become long-distance caregivers as well, responsible for a loved one who is miles or even many states away. Their caregiving journey may begin with a crisis, a call from a hospital or concerned neighbor letting them know their loved one needs help right away. That can trigger upheaval in the caregiver's life and work, with increasingly frequent trips to deal with the loved one's changing needs and a scramble to find remote resources.

Village members care for spouses, children, parents, and friends. A Fall 2020 survey of villages found a spectrum of support for caregivers that includes: brief respite care, grocery delivery, errands, transportation, phone calls, referrals, and support groups.

Villages are mutual aid networks that connect older adults with the community, programs and resources they need to navigate the transitions of aging. Villages are uniquely positioned to give care to their caregiver members, supporting them and welcoming their loved ones to village activities.

Public health guidelines and shelter-in-place orders have isolated caregivers and care receivers. As a result, staying connected to



caregivers has been especially important during the COVID 19 pandemic. Zoom and online programs that enable people to make contact have opened doors to support that was previously unavailable and may well continue in post-pandemic times.

## **THE SUPPORT GROUP MODEL**


The support group model is designed to build a trusting community that helps members navigate the complexities and challenges of caregiving. Support groups offer respite from heavy duty caregiving demands. They provide non-judgmental understanding. Members may exchange information about resources or choose to explore one or more as a group. Located within a village, each group adapts to its own village criteria for group membership, meeting structure, and facilitation.

Support groups give their members regular opportunities to check in with each other and discuss their situations and concerns. Support groups can be led by members themselves, or by a facilitator experienced in group process and the subject at hand. If your village has this kind of group, you might check with them to learn about their operations.

## **CAREGIVER SUPPORT GROUPS**

Brooke Collison writes, “I believe the primary value of caregiver support groups is to provide a place where caregivers can give voice to stressful experiences, strong feelings and personal frustrations in the company of others . . . caregiver support groups should provide what most people in the caregiver’s larger circle cannot give – authentic empathic understanding.” (Collison, Brooke B., Facilitating Support Groups for Caregivers, *Counseling Today*, July 8, 2019) See link to article page 9.

If you decide to start your own, a village-based group has many advantages as it is founded on the affinity group members have developed through being a part of the village community. A village-based caregiver support group may be more appealing to potential members than one run by another organization because of this affinity. Having group members who know their partners or family members may add an extra dimension of compassion and support.



Eleven California Caregiver Resource Centers (CRCs) around the state provide services, including support groups, to caregivers. Your village should establish a relationship with your regional CRC for the benefit of members and volunteers. Check the website and enter your zip code to locate your regional center. Services include:

- Information and referrals
- Support groups
- Short-term respite care
- Retreats
- Education and training events
- Other services

## **HOW TO SET UP A GROUP**


Setting up a support group for caregivers in your village requires some basic research.

### **Find and Engage Caregivers**

Find out who your village's caregivers are and ask them if they would like to help start or participate in a support group. Some methods for finding and engaging them include:

- Ask your village's care team or staff about members they know of who are also caregivers
- Post a notice in your next newsletter inviting interested caregivers to respond to a specific contact person for more information
- Include a question about caregiving needs in your next village survey
- Include a blurb in your Village's membership application/intake form stating that you already have, or are interested in creating, a caregiver support group and ask if the prospective member would like to know more

You could interview caregivers separately or gather them together to explore the idea of starting a group. Five is a good number to start with but the group could be launched with as few as three or four members.



One issue that may arise is whether or not you will invite caregivers who are not part of your village to attend. The model described in this Toolkit assumes that all participants will be members or volunteers of your village. This common experience provides a foundation of trust, access to commonly shared resources, and the benefits of village educational and social activities.

## **Discuss and Design Group Logistics**

Group members will build the meeting structure together and make adjustments as the group forms and meets over a period of time. There are several areas to explore.

### **Facilitation**

Group meetings will need facilitation to run smoothly and ensure that participants' needs are being met. Facilitation can be shared by group members taking turns leading meetings or it can be provided by someone who is not a group member but who has an interest in contributing to the group. Is there a willing village volunteer with some kind of health care or social work experience available? Are there local social work programs, community service organizations, or interns seeking degrees in health services? Do you want a professional? If so, it may add a cost to running the group. See page 10 in the Tools section for Basic Facilitation Skills.

### **Meeting Structure**

Building a sound structure will set expectations and provide continuity. These contribute to the comfort level and emotional safety that allow group members to interact and be supportive of each other.

Here are some questions to consider when setting up the structure:

- How often will you meet? Once monthly? Twice monthly? Every week?

- What day and time will group meetings be held?
- Where will meetings be held? Village office, community room, online? Is there someone in the village or in the group who can help set up and run a Zoom call? Do organizers need technology training?
- How long will the meetings be? One hour? 1.5 hours? 2 hours?
- Do you want to focus on a pre-determined topic or two at each meeting? Do you want open discussions based on a period of “check-ins” during which members share what’s on their minds? Or perhaps a combination of the two with a time block set aside for sharing at every meeting?
- Will the group be open—that is people can join at any time? Will the group be closed—where the group commits to meeting over a period of time without adding new members during that time period? The Pasadena Group decided to start as a closed group for a period of 5 months and then re-evaluate.
- At what point does the group become too large? When should the group consider dividing into two to keep the size manageable? The ideal size for a group is 8 – 12 members.
- Is the village’s office able to handle sending out meeting reminders, or do the organizers want to handle this task? If within the group, who wants to volunteer?

## **Ground Rules**

Ground rules set the norms and establish the culture of groups. They describe a set of behaviors that build trust and ensure everyone can participate. They help the facilitator keep the meeting moving along and navigate difficult situations in a calm, rational manner. For example, it helps to refer to ground rules when one person is monopolizing the check-in time. The most basic ground rule is confidentiality. See page 12 in the Tools section for how to set and use ground rules.



## **MEETING AGENDAS**

Early meetings usually focus on members getting to know each other and establishing the group structure. The advantage of a village group is that members often already know each other. Meetings should begin and end on time. Ongoing meetings should follow a basic structure with the content determined by the group and should be fluid and flexible. See page 14 in the Tools section for a sample meeting agenda.

## **INCLUDING CARE RECEIVERS IN VILLAGE LIFE**

A core value of the village movement is inclusion. Village culture welcomes and values the life experiences and perspectives of its members and volunteers. Villages are adept at accepting and supporting the changes in members' circumstances, health, and wellness that are inherent in the aging process.

The village can support the caregiver by engaging the care receiver in its services and programming.

Here are some examples:

- Include the caregiver and care receiver in social events and treat them as a healthy duo. For example, a caregiver relayed their appreciation for being able to bring their spouse to a village dinner. The spouse had a stroke and sustained cognitive and speech injuries. The village is one of the only places where the couple can socialize within a group without stigma or judgement.
- Maintain the care receiver's participation in an ongoing program or group. For example, a care receiver with early dementia is still welcome at an ongoing village men's group.
- Offer one-on-one companionship and an activity of interest to the care receiver to coincide with a short respite period for the caregiver. One village offered respite to a caregiver and took the care receiver to play tennis, one of the few activities they still enjoy.

## COMMUNITY RESOURCES

Villages are trusted advisors and sources of information and recommendations about a range of services and supports provided outside the village. Over time many members will move into the role of caregiver, and villages can be prepared with relationships and resources from community organizations. Find out whether these organizations serve your village's area and if so, establish a relationship with a staff person or intake department.

- 211 – Local information & referral phone line – check your county for the sponsoring agency
  - AARP Caregiving Resources
  - AgingNext
  - Alzheimer's Association
  - Alzheimer's LA
  - Area Agency on Aging – check for your county
  - Caring Across Generations
  - Department of Aging and Adult Services
- 
- Diverse Elders Coalition
  - Family Caregiver Alliance
  - National Resource Center on LGBT Aging
  - Regional Family Caregiver Center
  - Rosalynn Carter Caregivers Institute
  - Tri-City Mental Health

## TOOLS

### *Facilitating Support Groups for Caregivers*

By Brooke B. Collison

This article is an excellent introduction to the dynamics of caregiver support groups. It describes the author's experiences as a facilitator, counselor, and caregiver, and the timeline of the group he was part of. The full article is **here**.

Brooke B. Collison is an emeritus professor of counselor education at Oregon State University. He is a fellow and a past president of the American Counseling Association. For the past several years, he has served as a facilitator for caregiver support groups as a volunteer activity in his retirement.

## **BASIC FACILITATION SKILLS**

Successful meetings are highly dependent upon the skills of the person leading the meeting—the facilitator. Here are the basic skills a facilitator needs to be effective. Use them as a checklist for the facilitator(s) you designate within your Caregivers Support Group or to help evaluate the suitability of a facilitator from outside your group.

### **The facilitator:**

Communicates ideas clearly and concisely

- Lucidly articulates the group's purpose and easily explains the agenda
- Ably re-states and re-phrases ideas when clarity is needed
- Succinctly presents information
- Models active listening

Ensures visuals enhance meeting content

- Provides easy-to-understand charts, slides, or other media
- Creates a record of key decisions and action items visible to all
- Ensures handwriting is easily read
- Asks questions effectively
- Engages all participants with questions to ensure all ideas are heard
- Uses open and closed-end questions to control the discussion flow

Uses established ground rules to manage group dynamics

- Controls side conversations, dominating speakers
- Stops interruptions
- Diplomatically handles difficult questions and challenging participants

Models appropriate meeting behaviors

- Personally follows established ground rules
- Ensures all participants are involved
- Demonstrates relaxed control of the meeting

### Enables Group Understanding

- Repeats questions so all can hear
- Clarifies questions when needed, checking to be sure the intended meaning is retained
- Re-states and re-phrases as needed
- Provides clarifying examples

### Manages Time

- Establishes a time-frame for any agenda items at the meeting's outset
- Ensures all members have an opportunity to speak
- Sets discussion time limits during the meeting as needed
- Stays focused on the meeting's purpose

### Demonstrates Flexibility

- Is well-prepared
- Alters or re-routes the agenda or meeting activities to accommodate new information or group needs

### Summarizes Effectively

- Closes the meeting by reviewing the agenda and what was accomplished
- Calls out action items and other assignments
- Sets date and time for the next meeting

## **SETTING GROUND RULES**

When a group meets to solve a problem, develop an action plan, explore options, or otherwise share ideas it is useful to establish ground rules. These are behavioral guidelines that help discussions of all kinds succeed and allow all participants to respectfully contribute.

Ground rules are most effective when the group develops them together rather than having them imposed by the group leader. Rules set by the group are owned by the group and enforced by them as well. The group leader is then able to focus on the meeting content rather than policing behavior.

### **How to Set Ground Rules**

- Before the first meeting, make a basic list of ground rules you would like to see
- At the start of the meeting, right after introductions, introduce the value and importance of ground rules
- With a white board or flip chart pad available, ask the group to think about how they want to be treated in this meeting and ask them to specify ground rules
- List each rule as it is offered, asking for clarification when needed
- After the list is written, go back and restate each rule, simplifying as needed and getting the group's agreement for each suggested change
- Offer any additional rules from your list, if needed

### **How to Use Ground Rules**

- Ground rules are a living document that should be updated as circumstances warrant
- Send a copy of the final list of rules to each group member
- At each subsequent meeting, ensure the rules are posted where all can see them\*

- Periodically remind the group that if someone abuses a rule, anyone can point that out

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\*For Zoom meetings, consider taking a photo of the ground rules and using it as your background for each meeting

### **Sample Ground Rules**

Here are some typically established ground rules to get you started. The order of the rules doesn't matter:

- Maintain confidentiality
- Allow everyone a chance to be heard
- Do not interrupt
- Listen with an open mind
- Think before speaking
- Be prepared
- Attack the problem, not the person
- Stay on point and on time

## **SAMPLE AGENDA**

Here is an all-purpose structure for a meeting agenda. It can be altered from meeting to meeting to suit the purpose of getting together and the needs of the group.

- Welcome and settle in
- Check-in (defined amount of time for each person to share what's on their mind)\* – this will be the core of the meeting
- Discussion – topic can come from the check-in or it could be predefined
- Additional Items (resources, announcements, events, other)
- Closing & thanks

*\*Note that time allocation may depend upon the immediate needs of a member—crisis in the lives of caregivers is a common occurrence.*



