



# AREA AGENCY on AGING THE FAMILY CAREGIVER SUPPORT PROGRAM SUPPORT GROUP HANDBOOK



## **Family Caregiver Support Program**

The South Plains Area Agency on Aging, Family Caregiver Support Program emphasizes support groups. Support groups beat isolation, and help caregivers find solutions. A support group strengthens families, nurtures independence and educates caregivers. We know the value of support groups. Our mission is to provide support and educational seminars for caregivers, and to help raise awareness among the fifteen county region, medical personnel and the public of the facts concerning caregiving and the resources available to help and assist caregivers.

In a support group, people share common problems and solutions with people who have had similar experiences. Non-caregivers cannot provide the same type of advice and support. Support groups are open to all caregivers, regardless of personal background, type of medical problem affecting the care-receiver, or type of connection the caregiver or care-receiver has to the local medical care system. The common bond of participants in support groups is their caregiving role.

Starting a support group takes a little preparation, and some hard work. Above all, the cardinal virtues of support group formation are patience and persistence. Support groups do not form overnight, and it takes time for people to get to know and trust the group and for the word to spread. But once it does the rewards are great. People really appreciate the work you are doing and you can easily see how much good you have done when a successful support group meeting concludes.

The Support Group handbook is broken down into simple steps. We know that each individual situation will be different, and no "cookbook" formula will always work - everyone needs to use good judgment and adapt to their local situation. But the issues that we talk about in each area are the ones that we think are most important to focus on for successful support group formation.

## **Networking**

There's no need to reinvent the wheel or go it alone. There are others out there who have knowledge and expertise that you can use and who want to help. Seek them out, contact them and learn from them - it'll make the process much easier. The information you gather during this stage and the experience you gain will be very helpful when the support group has been formed.

Linking with other support groups - there are lots of people who have organized support groups around the country, and it makes sense to talk to these people before beginning your own process. Forming a support group is not an extremely demanding or complex process, but there are some right ways and wrong ways to do it, and it helps to talk with others who have experience and can tell you what works for them and what doesn't.

Finding allies locally - while it is possible to do this entirely on your own, it really helps to have some friends. Each person you add to your core group brings resources, ideas and



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support for everyone, and makes the whole process run more smoothly. It will help you through the rough spots, because the process can be frustrating sometimes, and sharing ideas, inspiration, and work will really help.

So where do you find these allies? The first place to start is with your doctor, nurse, or other medical professional. Ask them to spread the word that you're trying to start a support group - ask if they know of any other caregivers or medical professionals that might be interested. By law they cannot directly give you the names of other caregivers. But they can pass on information to those caregivers, and then if the caregivers are interested they can call you. Medical professionals also talk a lot with their colleagues and can spread the word that a support group is forming.

So a crucial first step is to construct a list of names, addresses and phone numbers of physicians, public health people, social workers, etc., in your local area. If possible, try to find a medical professional who will mentor your group - i.e., act as a guardian angel and advocate with other professionals. Ideally this person will be someone with a strong interest in caregiving and one who recognizes the need for these groups and is willing to put time and energy into forming and supporting them. This person can help you in several ways - by contacting medical professionals and asking for their help, by contacting other caregivers to see if they'd like to join, and by attending your support group meetings later on, giving advice, and providing information. Your mentor is an invaluable ally, and it's worth spending some time trying to find one. Mentors can be physicians, or nurses who deal regularly with caregivers. They can be recruited in departments of public health or social work background.

But besides medical folks your primary need is to contact other caregivers. Sometimes flyers or other publicity can help to reach others. This can be as simple as printing up some 3X5 cards by hand and posting them in clinics where caregivers are likely to see them. Or you can use a home computer to crank out a simple notice, letting people know that there's a support group forming and giving them a way to contact you. As you drop these off in clinics, hospitals and treatment centers, be sure to stop by the desk and let people know what you're doing - they may remember to tell caregivers about it when they see them.

You will need to decide how people should get in contact with you. If using your personal phone number is a problem, you can try to get a medical professional to take the calls, or use a PO Box - those are relatively inexpensive and don't give away your personal information. You also will need to be sensitive to the privacy concerns of those who contact you. Many caregivers are reluctant to "go public" so you must be very careful not to release names and addresses without a really pressing need and appropriate permissions.

## **Design Your Support Group-Decide on a Meeting Format**

Once you have your core group, sit down and discuss how you want your support group to work. There are endless possibilities of structuring. However, integration is also an



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important ingredient. You don't have to do too much designing ahead of time. But here are some concerns that you may want to discuss ahead of time.

First, using a facilitator provides the group with a more formal structure than others. In some, one individual will chair the meeting and exercise some control over who gets to speak and topic highlights. Sometimes that facilitator is a medical person or therapist with formal training; other times simply a caregiver with a similar experience and/or knowledge about the caregiving. But the key element is control over the flow of the discussion in the group. An unstructured group can get chaotic, but it allows discussion to range over all the topics that the members want to address and everybody gets to talk. Facilitated groups are more concentrated and orderly, but pressing issues for certain individuals may be missed if they're not on the topic. Another perspective everyone share the responsibility. If one person is responsible for everything, that person may come to feel burdened and resentful. The group should understand from the beginning that it is self-sufficient, continuing to meet even if the "founder" cannot be there. A benefit of self-sufficiency is that people are allowed to grow and take responsibilities and feel they are each as important as every other member of the group.

Secondly, formal presentations - some groups like to focus on formal educational presentations by experts with Q & A periods following the presentation. In this kind of format, you find an expert in a particular topic and invite them to give a presentation, then advertise that to your support group membership to be sure that they know what kind of meeting you're having. You set the presentation up as a lecture/demonstration or discussion group - whatever the expert is comfortable with, provide some refreshments, and see how it goes. Sometimes it's good to have more open coffee and discussion sessions after the formal presentation to get the informal support that people need.

In addition, expert presentations can cover a variety of issues that are of concern to caregivers. The support groups can have experts talk about caregiver stress, treatments, research projects, insurance issues, disability law, medicine, living with chronic illness, diet and exercise, you name it. And attendance is usually good if there's an expert on hand - people like to hear from these folks. Most experts will do these talks free, at least once. However, the more often that you use professionals in your support groups, the more likely that costs are going to become an issue. In groups where professional facilitators are routinely used, the group has usually found a source of financial support, either a hospital, drug company, or other benefactor who is willing to pick up the costs of an honorarium or other compensation for at least the expert's travel time and sometimes an hourly charge. You can just charge for the meeting to cover the costs, but that will usually cut down on attendance - many caregivers are on a budget and can not handle much in the way of fees.

In rural or more remote areas, experts are harder to find or may even be unavailable, and travel and transportation often become a much larger issue. In these cases, printed literature, videotapes, medical libraries, and email or internet access can sometimes be used to provide expert information at a reasonable cost. And much information is now available over the internet which can be very useful. However, there is a caveat on



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internet sources - they are not verified in any systematic way, and you must be careful in using such sources to check that the information obtained is accurate and relevant before disseminating it to your support group.

But whether or not you use experts and facilitators, it's very important to allow time for people to mingle, network, and talk about their current situation, what their symptoms are, what their doctor said, and all the critical minutiae that help caregivers to feel that their issues are being heard by other sympathetic human beings. Many of caregivers are very worried about their situation, they need to hear from others and they need to express their worry and concern in a sympathetic environment, and they need to get new information if any is available. So having that chance to circulate, talk and listen, and carry something away is a very critical component of a successful support group. After everyone has received attention, the group finishes the business of the meeting such as short announcements, planning the date of the next meeting, and choosing who will facilitate it. A closing ritual such as a group hug, a song, or a round of appreciations is a good way to end.

Another approach is a goal-pursuing support group. The group helps each other develop doable steps towards each caregiver's current hopes and dreams. They then help each other take those steps. Each meeting ends with each person making a commitment to do at least one task towards their goal that month. Each meeting begins with a check-in about how each person fared during the month before. Sometimes group members agree to call each other for support during the month as well. Amazing things happen in groups like this. It's very empowering to make progress towards something you care about and inspiring to see other people do so.

At this point, decide the structure of your meeting. Select a facilitator or expert speaker if necessary, line up any resources you'll need such as handouts and documentation. Think about your requirements for audio-visual equipment, refreshments - all the details of the meeting. Then decide what kind of space you'll need for a meeting like that.

## **Location**

When selecting a space, you need to look at the factors that will tend to influence whether people come to your meeting or not. Is the meeting place convenient, does it have free parking, is it easy to find, is the distance from the parking to the meeting place reasonable for people who are disabled or not physically strong? Is the area safe, is it well-lit, is there sufficient security for the attendees? All of these factors can affect attendance. It's important to check out the space ahead of time before deciding to use it - changing meeting locations always creates confusion, so it's better to be sure you can use it before committing.

As to the space itself, you want a room that has the amenities that are required for your group, or you need to be able to bring them. You may need a podium, a screen, overhead projector, slide projector, television and VCR, or computer system for some presentations. Or you may just want a comfortable quiet room for informal conversation,



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with chairs that can be arranged in a circle for a more casual atmosphere. It's better if the space is not too large to start with, since early group meetings tend to be small - you don't want to make people feel like they're in a huge barn. Having food nearby can be helpful. Some groups get rooms near a hospital cafeteria, for example, so people can get refreshments easily. If no food is nearby, at least an outlet or two for coffee machines is helpful.

Try to get a commitment to use the room on a regular basis, at whatever interval you've decided to meet. Many groups have monthly meetings, but others prefer semi-monthly or even weekly if there's enough need. It's good to have a regular meeting time known in advance, so you can put out flyers and people can get the regular meetings on their calendars well in advance. For your first meeting, be sure to leave yourself enough time to get the arrangements made and get the word out. The time of day is important, too. Most people would rather meet in the evenings after work. Give people enough time to leave work, travel to the meeting and get any food they need before the meeting starts. Weekends are usually not too popular - people want their time off to be uninterrupted.

## **Set-up a Regular Time**

Set a time for the meeting. If you know other people like yourself, work together to come up with a good time to meet. A day-time meeting may work, but if some members work, early evening may be better.

## **Get the word out**

Most newspapers have free sections for club meeting notices. Simply type up the type of meeting along with the meeting date, time (many support groups find an hour is a good length of time for meetings), place and the telephone numbers of one or more contacts whom people can call for information. Make sure to utilize family or senior monthly magazines such as the *Golden Gazette* or *Home & Family*.

## **Preparing for The Meeting**

Hopefully several people are involved in starting up the meeting, but even one person can get it going. You'll want to create an agenda. It doesn't have to be long, structured or inflexible, but it will give you an opportunity to get the meeting rolling and keep it going. You'll introduce yourself, then go around the room and ask people to give their names (name stickers are a great idea). For an icebreaker you may want to pair people off and have each find out something about the other and then introduce their partner to the group. An example of this: "This is Jean and she's cares for her husband for seven years. She's no longer able to work. Jean has three grown children and two grandchildren and wishes this thing would get easier." Next you may want to talk about what people would like the meeting to do. Some groups are purely talking and sharing, others have professional speakers, and still others go to conventions and seminars together.

Refreshments: This is optional. Perhaps people will want to chip in to have coffee and/or soda and take turns bringing snacks. Many meeting places have coffee pots available, but your group should supply everything: coffee, sweetener, cups, napkins, sugar, creamer,



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etc. Donations: This is also optional. No one person should have to bear the cost of making photocopies, long distance calls, etc.

It's also good the first month to have writing materials available for people to make notes and share phone numbers. After that, the members should be responsible for bringing their own.

In addition, you may want to make signs to post in the building to help people find the room.

### **The First Meeting**

The time is here. You're prepared. You have your agenda, writing materials available, maybe some books or handouts on the subject. The signs are up. You are ready to go. Perhaps one or more should be posted at the door to watch for people wandering around looking lost and to personally greet them as they enter. People seem to straggle in a few at a time, often up to half an hour after the meeting starts. You can determine to allow ten minutes or so and then start the meeting. It's up to the group how rigid it will be on starting and ending times.

One person should call the meeting to order, explain why the meeting was started, and introduce the other "founders." One of other founders should then start the ice-breaker exercise, and get the "introductions" going.

Once people are relaxed, you can ask what they would like to get out of the meeting, what they're willing to do, and from that point the meeting will start to gel.

A phone list is very helpful. To have someone to call when things are rough is priceless. Ask people how they feel about that, pass around a sign-up sheet, and arrange to have it photocopied for the next meeting.

The group should determine how often they would like to meet, which people will take care of arranging for the room, refreshments, donations, getting a speaker, etc. Forming committees to manage these arrangements can help build unity in the group and ensure no one person has to be responsible.

And time should be set aside for anyone who's having a crisis or just needs to talk. You may want to go around the room and let everyone have up to five minutes to share.

Before leaving, set the next meeting date. Leave the room the way you found it. You've all just started something very special!

### **Review of First Meeting**

When the first meeting is over, sit down, review the situation and decide how to go forward. What was particularly successful about this first meeting? What fell short of your expectations? How will your next meeting be organized? Is there anything you can



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learn from this first one? Should you publicize differently? Use a different format? Organize in a different way? Everything you're doing should be reviewed based on this new experience.

Don't be too disappointed if the initial turnout isn't as large as you hoped. In our experience it takes time for a support group to take root and begin to draw large turnouts consistently month after month. Initial meetings can be poorly attended, but as the word spreads and as people get to know your group the turnout will increase. It's important to stay with it - remember that there is tremendous need out there, but most caregivers have few sources of information and it will take time for them to find you. Don't give up.

And be sure to let others know about your group. Plug into the national caregiver groups. Subscribe to the newsletters of other groups, and get yourself on the email lists and world wide web sites that advertise caregiver support groups. You'd be surprised how many people learn about your group from sources like that. Place ads in church bulletins, Caregiver Newsletter, etc.

Finally, once you're an experienced veteran of support group formation, don't forget to help others in your area and elsewhere to set up their own groups. The need is enormous all over the country, so help others to get started. Remember how you felt when you began, and reach out to others who are just beginning.

## **Additional Options**

As the group grows, you may need to make some decisions about how to organize it more formally. Several options are available to you. You can take a very formal approach, incorporate as a non-profit corporation in your state, and seek tax-exempt status and donations from large companies or foundations to support your work. You can ally yourself with another organization in your area which has tax-exempt status. You can set yourself up as a chapter of another organization - several national caregiver organizations are seeking to form local chapters and will work with you to do that. Or you can just keep your informal arrangements going.

A lot depends on whether you want to seek grants or other support from foundations or charitable organizations in your area or nationally. Granting agencies will want a formal declared tax-exempt status for your organization before they will fund it. You will need to incorporate, get a tax ID number, and file paperwork with the IRS to gain tax-exempt status under section 501(c)3 of the Internal Revenue Code. All of this takes time and money. It often can take a year or more to get all this set up, so it's a considerable undertaking and should not be done lightly. However, it does give you substantial advantages when dealing with physicians, hospitals, charitable organizations, corporations, foundations or other large granting agencies - they can routinely make small grants to your organization once they know it has achieved formal tax exemption.

## **Assistance**

In addition, if you have any comments or needing assistance please contact us. We will



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be content to assist you developing a caregiver support group. Contact us at our regular mail address, by email, or by phone.

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