



When taking care of an elderly parent or another relative, family members often need to work cooperatively. The more people participating in care, the less alone a caregiver feels in his/her role. Books and articles about caregiving often mention the family meeting as a way to facilitate this process. But how does one go about having such a meeting?

Who Should Attend?

Each family is different. In some families, only a husband/wife and their children are considered "family." In other families, aunts, uncles, cousins, current and ex-in laws and close friends may be included in the definition of family. When planning a family meeting, it is important to include everyone who is or will be part of the caregiving team, and this may include a family friend, neighbor or paid caregiver.

It is also sometimes helpful to engage the help of an outside facilitator, such as a social worker or minister to help the family communicate about difficult subjects during the meeting. (This is discussed in more detail below.)

A decision must also be made about whether or not to include the ill family member in the meeting. Family members usually do not want to be excluded from family events and their preferences for care must be considered. However, if someone has dementia or another condition where he/she might misunderstand the purpose of the meeting, it might be appropriate to hold at least the first meeting without him/her present. Also, other family members may need to share with each other thoughts or feelings that would be painful for the ill person to hear. Consider holding one meeting to focus on those matters, and holding a second meeting with the ill person present.

How Should We Begin?

Communication is the key to working successfully with a group of people. If it's difficult for some family members to travel to the location of the meeting, technology can help: a conference call or the use of a speaker phone can make it easier for them to participate. A videotape or an audiotape of the meeting can also be sent out to all family members who are unable to attend. With the use of email, even those who are not nearby can also be kept up to date on how things are going.

Prior to a meeting, you'll find it helpful to prepare an agenda. Someone in the family will generally introduce the idea of a meeting and arrange the date and location. That person can also create an agenda for the meeting and send it out to all the family members ahead of time. Family members can then share their ideas and suggest other items to include.

An agenda might include topics such as:

- The latest report from the physician
- Sharing of feelings about the illness/caregiving
- Fears:
 - About death and dying
 - About being overwhelmed
 - About what will happen to family members after the death
- Sadness, confusion, anger, guilt, shame
- What does the person who is ill want and need?
- Daily caregiving needs:
 - Should the sick person move in with us?
 - Does she/he need to be in an assisted living facility or nursing home?
 - How much time does each family member have to visit?
 - Other ways each person can help?
 - What other help might be available?
- Financial concerns in caregiving:
 - How much will it cost?
 - How much work can family members afford to miss?
 - What financial help might be available from outside?
 - Who will make decisions (e.g., financial, medical, hiring a caregiver, etc.) and how will they be made?
- What support role does each person want to play?
- What sort of support does the primary caregiver need?
 - Need for respite (a break from caregiving)
 - Help with meals, shopping, cleaning, laundry, etc.
 - Emotional support by telephone or email
 - Help with chores—i.e., taking the care recipient to doctor's appointments
- How will the caregiving and support needs change as the illness progresses?
- Problem Solving
 - List of tasks that need doing
- Summary of meeting and schedule for next meeting
- Written summary of what each person has agreed to
- Email or telephone tree for regular updates

It will probably be difficult to cover all these issues in one meeting, so additional meetings will be helpful. Each ensuing meeting should have a clear time table and a definite beginning and ending time. Be sure to stick to the time table; if meetings get to be too long, fatigue sets in, minds will wander, and people may resist coming to future meetings.

The Meeting

As with all high-level negotiations, deciding where to hold the meeting is as potentially controversial as the meeting itself. Whether you hold it in an office, a restaurant or someone's home, keep in mind that you want a setting that the majority of the participants will find

comfortable and convenient and that presents as few distractions as possible (e.g. noise, small children who need attention, etc.).

A successful family meeting gives everyone a chance to be heard. All feelings are appropriate and need to be expressed and acknowledged. People will be more willing to talk about their feelings regarding the situation if they feel safe. For example, the brother who is never present may reveal that he is unable to stand seeing someone sick, and the sister who is doing all the work may not realize how she pushes others away when they offer to help. Another sibling may be having marital problems which he or she has not yet shared with the family, and yet another sibling might be worried about losing a job. Each person needs to balance his/her own fears, concern, love and desire to help with available time, strengths, weaknesses and hopes.

Until the depth and breadth of the issues concerning the ill family member are explored, it is important to not try to solve the problems. Recording the problems in a list as they are shared, however, will be useful during the problem-solving portion of the meeting.

It is important for each family member to learn to use "I" messages, as well to say "I need..." rather than "You should..." Even when disagreeing, try to find the part of what is said that you can agree with. The goal of the meeting is to work as a team in caring for the person who is ill, even if there is conflict among family members in other areas.

At the conclusion of the meeting, make sure everyone has a clear understanding of the issues and considerations discussed. When the solutions to issues have been established, make sure that each person understands what he/she has agreed to do.

The most important thing for family members to remember is that the meeting is not a one-time event. Family meetings need to take place regularly. It is helpful to schedule them at a given time, perhaps at the same time each month. However, if this is not possible, they at least need to take place when the caregiving situation or other situations in family members lives change. Holding regular meetings puts less pressure on family members to get everything resolved in just one meeting, and allows more time for processing of information and decision-making. When a family member is unable to attend a meeting, keep in touch with them by phone, mail or email.

Potential Challenges

Families come with history: a history of how each person relates to the others, a history of what role each person has played and currently plays within the family, a history of how each person feels toward the person who is sick, and a history of how each person deals with illness and adversity. And in each family there are rules about what can and cannot be said, what emotions are okay and not okay to express. These factors can make family meetings difficult. This is why a third party facilitator can be helpful.

Family members play roles based on position in the family, relationship to the person who is ill, special talents, etc. The person who is the caregiver may be different from the one who handles the money, who may be different from the person who is the information gatherer, who is different from the one who is the decision maker or the one who has some medical background.

One person might play several roles. Also, often someone is the "blamer," and someone else the "blamed." One person may try to make peace, and another may try to sabotage the process. There will be secrets, old family rivalries, guilt, unequal burdens, differing investments, values and interests. Some will worry about past promises and about someone else not pulling his/her own weight. Everyone will need attention, power, love, control, and appreciation. It can help to acknowledge that there is probably no fair distribution of work and trying to make it even will fail.

A narrow focus for each meeting can help alleviate some of the pitfalls. Still, you will have to deal with some of the difficult issues when they get in the way of cooperation. Remember that you can't resolve long-standing family issues with one such meeting. The task is not to "fix" the family, but rather to have everyone on the same team, as much as possible, in caring for someone who is ill.

If alcohol will detract from the main focus of the meeting or will lead to conflict, it is better not to offer it. However, each family has different ways of communicating, and in some families a drink may make everyone more comfortable and more able to talk. In any case, over-consumption should be avoided.

Win/Win Situations

Consensus: Not all the issues inherent in caregiving and decision-making can be solved; sometimes it is important to accept approximations of a good solution. Try to work toward consensus building. Change happens slowly, but when families meet regularly, the seeds that are planted can grow into more productive solutions. Often things do not change until there is a crisis, but the work that has been done during the family meeting will make decision-making easier when the crisis does come. Agreements can be made on a time-limited basis to see if the agreed-upon action will work. Future meetings can be used to evaluate these trials and revise them as necessary.

Respecting each person's individuality and situation helps to create an atmosphere of acceptance and allows for creative solutions to problems. For example, Carol finds it difficult to be around sick people, so when her brother got lung cancer, she knew she couldn't take care of him. However, she was more than willing to make the pastas of their native Italy and take them to him to comfort him during his illness. Jesse lives a thousand miles away, but can get time off from work to be with her mother while her brother and his family take a vacation. When Ed's mother had surgery, Ed arranged to take care of his father with Alzheimer's, while his sister worked full time and helped with the expenses. Gina takes her parents to medical appointments while her sister makes sure they get their medicines properly every night.

Compromise: In order for these solutions to work, people have to learn to compromise. By being open to alternatives, you might get part—although maybe not all—of what you want or need. We often hold out for only one solution to a problem, we don't consider other possibilities that could assist us. Asking for help is one of the hardest things to do. Learning to graciously receive help offered can also be a struggle, not only for the person who is sick, but also for the person who is the primary caregiver. Being appreciative is the best reward you can give someone who is trying

to help you, even if the type of help he/she is offering isn't exactly what you wanted. When you make someone feel good about helping, he/she will want to help again. "Thank you" will take you a long way in working together. In creating the caregiving team, think about how each person should be acknowledged.

Put it in writing: A written agreement capturing the decisions and agreements made at the end of the meeting can be a helpful reminder for family members. Distributing a calendar with different days marked with responsibilities and commitments can also help each person honor the agreements made.

When Do You Need Outside Help? Where Can You Get It?

Although family meetings can be powerful and effective ways to connect and work with family members, they cannot magically solve all the problems of caring for an ill family member. When families have trouble working together or coming to agreements or when the family is divided on a big issue, it often helps to invite a neutral outside facilitator to attend. Sometimes a crisis precipitates the need for a meeting—perhaps someone is in the hospital and major life and death decisions need to be made. Time can be of the essence. Whatever work you have done together earlier will help you at these times of extreme stress.

Social workers from local caregiver organizations (such as Caregiver Resource Centers in California), as well as ministers, private case managers, social workers in home health or hospice, physicians, discharge planners in hospitals and nursing homes can help facilitate a family meeting or refer you to someone who can. Psychotherapists in private practice are trained in family counseling. If you find yourself in a difficult position, you might also want to see a psychotherapist privately. Don't forget the support you can find with friends, colleagues and support groups. Sharing experiences with other caregivers can help ease the feelings and frustrations often involved in being a caregiver.

Recommended Reading

Share the Care, Cappy Capossela, Sheila Warnock, Simon and Schuster, 1995.

I'll Take Care of You, Joseph Ilardo, Carole Rothman, New Harbinger Publications, Inc., 1999.

Taking Care of Aging Family Members, Wendy Lustbader, Nancy Hooyman, The Free Press, 1994.

The Caregiver Helpbook, Vicki Schmall, Marilyn Cleland, Marilyn Sturdevant, Legacy Health System, 2000.

How to Care for Aging Parents, Virginia Morris, Workman Publishing, 1996.

Resources

Family Caregiver Alliance
690 Market Street, Suite 600
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106
Web Site: www.caregiver.org
E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating disorders that strike adults.

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