



Southern Maine Agency on Aging

Family Caregiver Support Program

Caregiving as a Family

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Family Meetings

One of the best ways to get everyone's input on a problem and potential solutions is to hold a family meeting. With families scattered geographically, this may need to be done by conference call or online if an in-person meeting is not an option.

Here are some suggestions to help make the meeting smooth and productive:

Prepare

- Decide who to invite. Include immediate family and anyone else who is in close contact with the older adult
- If you anticipate a heated discussion, you can invite a facilitator or moderator as well (family friend, clergy, social worker, care manager)
- Choose a comfortable and neutral location
- Suggest that participants identify 3 or 4 priorities for discussion prior to the first meeting
- Identify which topics can be addressed at each meeting, making sure that everyone feels their concerns will be addressed at some point
- Establish a goal for every meeting that is agreed upon ahead of time
- Set and circulate an agenda. Plan to stick to it. Allow time for each member to participate

- Collect background information to share (for example, bring fact sheets on Alzheimer's Disease for someone newly diagnosed, or information on legal issues if that is a topic). Get materials to people ahead of time if possible

The Meeting

- Do not allow a family member to dominate the meeting. If necessary, use a timer and give each participant an agreed-upon amount of time to speak
- Create a list of concerns and prioritize them as a group. Tackle them in the order of urgency
- Set ground rules, such as
 - People may not interrupt each other
 - People will treat each other with respect
 - Everyone gets the chance to speak
 - Old family history will not be brought up
- Stick to the agenda
- Use "I" statements and avoid accusations
- Listen to the older adults' thoughts, opinions and concerns
- Remember that a competent older adult still has the right to make his or her own decisions, but family members have the right to say what they are willing and able to do to support those decisions
- Identify "acceptable risks" and ideas to devise a plan that is as safe and workable as possible
- Try to reach closure on each agenda item before proceeding to the next. If actual resolution isn't possible, at least set an action plan or next step
- Agree on which person will take on which responsibilities. It is best if everyone has some responsibility. Put it in writing and circulate. If meeting in person, have everyone sign off on their jobs. Agree to a follow-up date to make sure that the plan is working for everyone
- Before ending, agree on what to discuss at the next meeting, and schedule a time and date

After the Meeting

- Make sure everyone gets a copy of the plan
- You may want to agree on a "point person" to interface with providers and to relay information back to the family

- It is likely that a primary caregiver has emerged. Make sure that this person is comfortable with the role, and that plans are in place for respite and vacations for them

Getting Siblings Involved

What you can do to involve your sibling(s).

- Plan ahead and make a list to identify what help you need.
- Take the initiative to communicate with the sister or brother.
- Establish some boundaries around what you are willing to do.
- Set up a family conference in a neutral place such as a restaurant or library.
- Identify the needs of your parents as you see them and ask your siblings to do the same.
- Explain or update siblings on parents' current health status.
- Clearly identify some of the tasks that need to be done.
- Tell your siblings which tasks that you prefer to do yourself.
- Ask your siblings which ones they can do based on their abilities. Think about the 'best fit.'
- Communicate directly
 - Use "I" messages avoiding phrases like 'you should' 'you don't'. Instead say things like "When you don't come to visit or call and offer to help me with Mom, I feel overwhelmed by the responsibility."
- Clearly identify who is going to do what.
- Develop a communication schedule
 - How often?
 - By what means? Phone, email?
 - How often will you meet and where?
- If possible, let parents know how responsibilities will be shared.
 - Make sure that parents are comfortable with your plan.
 - Be flexible and willing to adjust the plan based parents' response.
 - Keep conflicts between siblings out of the discussion.
- Follow through. The best plans fail because they are too complicated, the parties do not really agree, or the parent does not consent.
- Change the plan if it does not work or needs adjustments.
- Avoid getting in the mindset that includes 'he should,' 'why can't she?' This wastes valuable energy.
- Communicate, communicate, communicate.

When A Spouse Provides Care

Generally, when we think of people who provide assistance with daily living tasks for seniors, we think of them as middle-aged adults. While many adults are employed as caregivers for older adults, much caregiving is provided by other senior adults. In fact, one-third of caregivers are older than 65 years of age themselves. Many of these caregivers are spouses of the older person needing assistance.

Spouses certainly have provided care for one another throughout their married lives. That's part of being married! As partners age, however, the type of care necessary often changes. When chronic diseases and disabilities take their toll, some spouses remember their vows of "... in sickness and in health" but never thought it would be like this! Such responsibility can create conflicting emotions for the caregiving spouse. Loyalty and commitment to the partner in need can be powerful values driving our caregiving decisions.

Sometimes our values can interfere with sound decision-making. Consider the following examples:

Learning New Roles. In most marriages, each partner manages specific tasks around the house, in specific ways. When an illness upsets these roles, stress between the partners usually results. Washing dishes, mowing the lawn, folding laundry - these and other daily tasks can trigger criticism and arguments. The disabled partner is often frustrated that he cannot be more help; the healthier partner resents criticism when she is doing the best she can under trying circumstances.

Coping With Guilt. It's bad enough when we feel guilty over some real mistake, but some partners experience guilt over issues such as being healthier or more active than a disabled spouse. Or guilty for not spending 24 hours a day caring for a spouse. Or guilty for resenting the demands of a partner whose personality has changed. Or guilty over just about any responsibility that has not been perfectly fulfilled, as if that were ever possible. Guilt is a negative motivator, unhealthy for both the caregiver and receiver over time.

Needing to Feel Useful. Whenever a relationship develops unbalanced dependence of one partner on the other, it can become difficult to reestablish balance. The relationship between caregiver and receiver can become so entrenched that both partners resist change. Ironically, caregivers may subconsciously undermine improvements in a disabled partner's condition if it threatens her role as caregiver. This situation can really be tough when the disability reverses previous power balances; for example, when a husband had

made all the family decisions for years, suffers a disabling condition, and now the wife must assume the major decision-making role.

Having Too Much Time Together. Most relationships eventually settle into a routine that includes a balance of together-time and alone-time that both partners find comfortable. A disabling condition requiring one partner to become a major caregiver can upset that time balance. Loss of privacy or time for community involvement can fan the flames of resentment and guilt discussed above.

Most caregiving spouses feel tremendous responsibility to "be strong," never sharing the feelings of worry and stress that lie just beneath the surface. Like a pressure cooker, however, without some relief, something is going to explode! Even in healthy relationships, serving as a caregiver can create serious stress. In troubled relationships, the added stress of caregiving can result in angry outbursts, depression, and even violence.

How can we avoid, or at least minimize, these stresses of caregiving? To paraphrase Dirty Harry, a man's got to recognize his limitations. Caregivers may see themselves as noble martyrs when they devote their lives to caring for partners in need. There is nothing noble, however, about destroying one's emotional health and a formerly loving relationship in the process. Recognize when you, the caregiver, need some care yourself! Develop a network of friends with whom you can share your burden when the pressure seems overwhelming. If necessary, find some paid support such as temporary visiting nurses. Finally, recognize that declining physical abilities with aging are a normal, expected part of most of our lives. Coming to terms with that reality, making the necessary accommodations, and going on with our lives is a sign of healthy aging.

The University of Georgia and Ft. Valley State College, the U.S. Department of Agriculture and counties of the state cooperating. The Cooperative Extension Service offers educational programs, assistance and materials to all people without regard to race, color, national origin, age, sex, or disability. For large print, taped or Braille editions of this publication, contact the author.

Who Will Help?

This worksheet can be helpful when you're communicating with others about what can be done to assist someone and can also be used for family meetings.

Date	Task/Responsibility	Who will do	Signature	Reassess
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Some examples of tasks/responsibilities you may need support with include:

- Help with chores, laundry, yard work and household maintenance
- Help with grocery shopping
- Meals delivered at home or fixed and served there, clean-up
- Personal care, such as help dressing or bathing
- Transportation to places important to your relative, such as church or social gatherings
- Transportation to the pharmacy and doctors' appointments
- Assistance at medical appointments, and/or consultation with doctors and other health professionals
- Assistance with paying the bills, banking, budgeting or other money matters
- Financial assistance to make ends meet
- Referral to an attorney experienced in elder law issues; for example, to establish Durable Powers of Attorney or to address estate planning concerns

- Dispensing of medications and ensuring they are taken on time
- A safety inspection of the house (e.g., smoke alarms, uneven flooring, loose rugs, lighting).
- Installation of grab bars or a ramp to make the home safer and easier to navigate
- Trips out of the house, perhaps to an adult day care or senior center
- Visitors who make sure all is well on a weekly (or twice weekly or even a daily) basis
- Additional social visits from friends, family and other volunteers
- Emotional support, reassurance and someone to talk to