

Coping with Caregiving

**How to Manage Stress
When Caring for the Elderly**



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This guide will help you maintain your personal well-being while providing quality care for a relative.



Each year over 25 percent of American families provide care to adult family members who are unable to fully care for themselves due to illness, disability, or advanced age. Sometimes the period of caregiving is short while the person recovers from surgery, a serious injury, or illness. Often, however, family members provide care to a relative for many years. Although this publication is focused on caring for older family members, the ideas will be useful to all long-term caregivers.

We offer ideas on how to maintain your personal well-being while providing long-term quality care. We discuss the common sources of stress and how you can master stress for your own benefit and that of the person for whom you are providing care. **As a caregiver, ignoring your own needs is not only potentially detrimental to you, it also can be harmful to the person who depends on you.** Many care facility placements are precipitated by the caregiver's exhaustion, illness, or

Are you caregiving? *We all do things for others, especially family members. When we begin doing things for others that they are no longer able to do for themselves, we are caregiving. If you go grocery shopping with your mom because it's convenient, saves gas, and it's enjoyable, you are not caregiving. The grocery trip is just part of your relationship. But if your mom is not able to get to the store without your help, you are caregiving.*



death. This publication can help prevent such a situation for you and your family.

WHO ARE YOU ... THE CAREGIVER?

You may be a spouse, son, daughter, neighbor, close friend, or distant relative. You may be young or older yourself. No matter your relationship or age, as a caregiver you are making concessions and personal sacrifices to provide care for another person. This can create areas of conflict and high levels of stress in your life.

If you're young or middle aged, you probably have competing responsibilities for children, spouse, and job. If you're older, you may be adjusting to age-related changes, such as retirement, reduced income, widowhood, declining health, or different living arrangements. At any age, you probably have important goals and plans that are interrupted or postponed because of caregiving responsibilities.

As a caregiver you may be providing care out of love or out of a sense of obligation. More often than not, you feel both love and

obligation. You may be providing the support alone or coordinating the work of others. You may find caregiving tasks satisfying and rewarding, or completely frustrating or even disgusting. This publication will help you understand your responses and will discuss ways to reduce the conflict and stress caused by the demands of caregiving.

WHAT IS CAREGIVING?

Caregiving can evolve slowly, over a long period of time, or suddenly, in the case of illness or accident. Caregiving can mean the person you care for lives with you, near you, or hundreds of miles away. He or she may be physically disabled or mentally incapacitated, or both. **Whether you are providing round-the-clock direct care or coordinating others who provide direct care, you are still the caregiver. You are responsible to some degree for another person's wellbeing.**

Depending on a person's specific needs, caregiving can involve many different activities, including:

- Listening, talking, and providing emotional support

Ambivalent feelings are common. Many people love the care recipient but hate the caregiving tasks.

- Shopping, cooking, and housekeeping
- Making regular contact in person or by telephone
- Traveling to and from your relative's home
- Maintaining two homes—yours and the care receiver's
- Managing financial and legal affairs
- Supervising others who provide direct care
- Arranging for health care and attending appointments
- Providing social activities
- Providing round the clock supervision
- Supervising medications
- Lifting, bathing, dressing, and feeding
- Managing incontinence

As a caregiver, you may feel a sense of accomplishment in helping the person you care for, and you may experience a new closeness in your relationship. Often a parent and child reach a higher level of acceptance and understanding when the adult child provides care for his or her mother or father. However, if you had a poor relationship with your family member prior to caregiving, you are likely to experience higher levels of stress from caregiving, and even more so if you felt you had no choice and became a caregiver out of a sense of obligation or duty or no one else was available to provide the care.

No matter how loving your relationship, caregiving almost always involves personal sacrifice and stress. Most caregivers say they

miss the freedom and activities they enjoyed before caregiving. You may feel that there are too many expectations and not enough time and energy to meet them all.

Ambivalent feelings are common. In fact, Dr. Barry Jacobs, an expert on family caregiving, reminds caregivers that “you can love the care recipient and hate the care tasks.” (See resource list on page 25.)

Unresolved, excessive, or prolonged stress results in what often is called “burnout.” When challenges and demands are too great, they drain our physical and emotional energy, time, health, and money. Caregiver stress and burnout can be seen in the following symptoms:

- Emotional or physical exhaustion
- Depression and anxiety problems
- Marital problems
- Family problems
- Alcohol or drug misuse
- Conflict among life roles—spouse, employee, parent, and caregiver
- Neglect or abuse of the older person

Becoming aware of how stress takes hold is the first step toward coping with it.

CAREGIVING STRESS—SYMPTOMS AND CAUSES

The warning signs of stress

When you experience an unusual level of stress, warning signals occur.

“If the levels of stress, distress, and illness found in caregivers were found in any other ‘profession,’ health agencies and workers’ compensation boards would undoubtedly be waging major prevention campaigns.”

— Nancy Guberman

Answering the following questions will increase your awareness of the stress signs you may be experiencing.

Yes No

1. Do you feel a loss of energy or zest for life?
2. Do you feel out of control or exhibit uncharacteristic emotions or actions?
3. Do you lack interest in people or things that were formerly pleasurable?
4. Are you becoming increasingly isolated?
5. Do you feel you need increased amounts of sleeping pills, medications, alcohol, caffeine, or cigarettes to manage the stress in your life?
6. Are you having increased health problems: for example, high blood pressure, ulcers, or difficulties with digestion?
7. Do you have difficulty falling asleep at night? Do

you awaken early or sleep excessively?

8. Are you experiencing appetite changes? Under or overeating?
9. Do you have problems with concentration or memory?
10. Are you increasingly irritable or impatient with others, including the care recipient?
11. Do you have thoughts of suicide?

A “yes” answer to even some of these questions can indicate stress that has become debilitating. Recognizing the cause of your stress is the next step in dealing with its destructive effects.

The causes of your caregiver stress

The causes of stress vary with the responsibilities and the caregiver. What creates stress for you may not create stress for someone else. There are, however, some common sources of caregiving stress.

Finding your stress triggers

To identify your stress triggers, answer “yes” or “no” to the following questions

1. Are you experiencing multiple demands on your time, energy, or money? What are they?
2. Do you feel that your responsibilities conflict? Which ones?
3. Are there differences in expectations for your caregiving between your family members, your boss, the person you care for, yourself? What are these differences?
4. Are there disagreements about caregiving among family members?

5. Do you lack information and understanding about the care receiver’s mental or physical condition?
6. Do you have difficulty meeting your care receiver’s physical or emotional needs?
7. Are you pressured by financial decisions and lack of resources?
8. Do you feel a loss of freedom or a sense of being “trapped”?
9. Do you feel that other family members aren’t doing their share?
10. Does the older person place unrealistic demands and expectations on you?
11. Is there a lack of open communication between you

and other family members? Between you and the care recipient?

12. Do other family members have negative attitudes that you have trouble contending with?
13. Is there deterioration in your relative that is painful to observe?
14. Do you miss the relationship you once had with the person who now needs caregiving?
15. Are there other problems with children, marriage, employment, or health? What are they?

Look carefully at questions to which you answered “yes.” Focus your attention on your specific sources of stress as we talk about strategies to reduce stress.

STRATEGIES FOR MANAGING STRESS

Once you know the sources of your stress, you must determine which ones you can do something about and which are beyond your control. Successful coping involves acknowledging what you can and cannot change. For example, you will not be able to change a parent who has always been demanding and inflexible, but you can control how you respond to your parent's demands. If your father has a progressively debilitating illness, you can't change that. However, you can develop skills for coping with the changes brought on by his illness.

Usually some action can be taken to decrease stress. Changes do not need to be major to make an important difference. Sometimes letting go of unrealistic expectations or adjusting your standards of how frequently or how well you perform a task (such as housekeeping) will make a big difference in your level of stress.

In general, professionals who have extensive experience working with family caregivers agree on five basic strategies to help control the destructive effects of stress. They are:

Strategy 1: Set realistic goals and expectations

- Focus on achievable goals
- Develop realistic expectations

Strategy 2: Establish your limits

Strategy 3: Ask for and accept help

Strategy 4: Take care of yourself

- Express your feelings
- Acknowledge what you are doing right

- Maintain your health
- Take time for yourself

Strategy 5: Involve other people

- Hold a family conference
- Obtain professional guidance
- Explore and use your community resources

Strategy 1: Set Realistic Goals and Expectations

Focus on achievable goals

The basic goals of caregiving are to assure the care receiver's quality of life, physical comfort, and safety. These goals can be accomplished in many ways. For example, you may be the direct care provider or you may be a "care manager" who arranges, coordinates, and monitors the services your family member requires.

In setting goals it's important to consider how caregiving is likely to affect other areas of your life. How is your health? What is your relationship with your spouse and children? What other demands and obligations do you have? Are you employed?

In addition to understanding yourself, you also need to know how the illness, injury, or disability affects your family member. Objectivity about your situation is important . . . but is not always easy. You need to learn what is likely to occur medically and behaviorally now and in the future. For example, sometimes the behavior or moods of a person who is memory-impaired or has a mental illness can be baffling. It can appear that he or she is intentionally being difficult, acting helpless, or refusing to

Preventing caregiver burnout means accepting the limitations of what you can accomplish.



communicate. If difficult behavior occurs, consult with a professional who is knowledgeable about your family member's condition. A professional often can assess whether behavior is intentional or disease-related and therefore unintentional. By determining the reason for behavior, you can adjust your expectations and responses.

You will see positive results more often if you set goals that are specific and achievable. Specific goals are short term and focused on a clear problem. If you have only broad, long-range goals, you are more likely to experience frustration. You may have a long-range goal of getting your father back to his own home, if possible. Some specific, achievable, short-term goals might include:

- Keeping your father's spirits up by arranging for friends and family to visit
- Developing your father's physical strength by arranging for people to take him on daily walks

Professionals involved in the care of your family member can help you set realistic short-term goals. The degree to which short-term goals are accomplished

may also help you to assess the practicality of long-term goals that have been set. Goals also need to be considered in terms of the ill person's personality and capabilities.

Some caregivers are driven by vague goals such as "make mother happy." Given mother's personality or the accumulation of recent losses, this may be completely unrealistic and unachievable. Unachievable goals create a heavy emotional burden and feelings of failure. A more specific and achievable goal might be to provide a pleasurable activity at least once a week for your mother, perhaps spending two hours each week doing something enjoyable like visiting friends or working a puzzle. If you set such specific goals, you are more likely to feel satisfied with your progress.

Develop realistic expectations for the care recipient

How realistic are your expectations for the care recipient? The more you know about the person's health conditions, the better you will be able to develop realistic expectations. For example, if your father has a progressive dementia, he will not be able to remember the "simple" instructions you just gave him. You need to realize that he is not just being stubborn; the disease makes it impossible for him to remember.

Fully understanding the care recipient's condition will help you be realistic about his behavior and will allow you to focus on strategies that will work best within his abilities. Caregiver education and support groups can help you develop more realistic expectations and effective responses.

Develop realistic expectations for yourself

How realistic are your self-expectations? Do you often feel that if only you could do more, things would be better for your family member—your mother would be happier, your father less confused, or your spouse less depressed? Do you sometimes think, “Mother took care of me when I was a child, I should be able to care for her as well as she took care of me”?

Caregivers frequently struggle to balance their self expectations with what they actually can achieve. Sometimes we expect too much of ourselves and we get into a state of constant worry or anxiety because we think we are not doing what we should. Women caregivers are particularly vulnerable to “shoulds.” Because of the way females are raised in our society, women caregivers often believe they should be able to do everything themselves. When unable to do so, they often feel guilty or depressed.

Sometimes old promises drive us to do more than what is

realistic. Promises can get in the way of objectively assessing the current situation. They reduce our objectivity and ability to make the best decisions for everyone concerned now. It’s important not to let old promises, “shoulds,” or guilt guide caregiving decisions.

If an old promise, such as “Mom, I’ll never put you in a nursing home,” is creating difficulties for you, compare the current situation to the situation when the promise was made. You’ll probably find the situation has changed considerably. If it hasn’t changed, it might indeed be possible to fulfill the promise. However, a promise made under one condition may not be viable under the current situation because of changes in the care receiver’s health or in your life circumstances or health.

Strategy 2: Establish Your Limits

You have a right to set limits on what you will do! It’s all right to say “no.” Taking these steps, however, can be difficult, especially if you must make painful choices.



It's important not to let old promises or guilt guide decisions.

There are emergencies, of course, when it's necessary to go beyond your limits. Emergencies are immediate, short-term circumstances that demand immediate action. When additional resources simply are not available, you may not have a choice. Remember, however, that most caregiving is long-term and not an emergency that requires you to push past your realistic limits. In general, providing care at the expense of your mental and physical health or relationships with other family members does not benefit anyone!

When you set limits, it's important to communicate them to your family and, if possible, to the person for whom you provide care. This may be particularly painful to do with a parent or spouse. But remember, to not do so will only increase your stress and reduce your ability to provide the best care.

Discussing limits in caregiving is usually easier if you consider other ways in which the person's needs could be met. Share information about those options at the same time you talk about your limits.

Strategy 3: Ask for and Accept Help

How do you respond to offers of help from other people? How do you ask for help? Or, is it difficult for you to ask for assistance? Do you ever expect close family members to know when you need help and feel you should not have to ask for help? Family members, neighbors, and friends often are willing to help. But sometimes people don't offer to help because they are frightened by illness, feel uncomfortable around the ill person, don't want to interfere,

or simply don't know what they can do. Or, perhaps you may have refused earlier offers of help, or you may appear to have everything under control.

People can help best if you tell them exactly what your needs are and how they can help. Be specific and positive. When family or friends ask how they can help, make specific suggestions. For example, say, "Could you visit with mother for an hour this week so I can go to the store?" or "When you go to the store, could you pick up a few things that I need (or that Mom needs)? Here is a list..."

Tasks unrelated to direct caregiving are easier for some people. If you can be flexible, ask when would be their best time to provide assistance. It's also important to show appreciation for any help received. Let people know how much their support means to you.

People are less likely to respond to requests that are demanding, manipulative, or guilt provoking. One of the least productive attitudes a caregiver can have is to expect others "to know" when help is needed. People are not mind readers. Keep in mind, too, that others may have obligations or problems of which you are not aware, but that limit the assistance they can provide.

When you request support, be specific so people know exactly what you want. For example, it is unclear to say, "I need help!" or "Why don't you help?" or "Why don't you help more?" A clear, specific request is "Could you visit Dad at least once during the week and take him to church on Sunday?"

When someone does offer help, do you refuse, but feel exhausted or

resent not receiving assistance? Do you feel “I should be able to do it alone”? or “I am the only one that Dad (the care recipient) wants to do this”?

Resistance to accepting help is a common cause of stress and depression among caregivers. Many cultures emphasize “independence” and “going it alone.” This makes it more difficult to request help. Some caregivers feel that asking for or accepting help is a sign of failure. Actually, asking for and accepting needed help is a sign of good judgment. Knowing your limits and reaching out for assistance before you are beyond your limits is an important characteristic of a strong individual. It also helps ensure quality care for the person for whom you are providing care. Being a martyr benefits no one. Refusing help will *not* make you a better caregiver—it will only make you more exhausted and irritable.

Strategy 4: Take Care of Yourself

Express your feelings

It’s very important that you find someone with whom you can talk openly about your situation and your emotions.

First accept your negative emotions. Being a caregiver and seeing the decline of someone you care about is not easy. Almost every caregiver experiences a wide range of emotions, some of which are conflicting, confusing, and ambivalent. You may feel love, sadness, frustration, dislike, repugnance, guilt, grief, fear, resentment, hopelessness, or despair. You may feel angry about the increased dependency of the person you care for and the multiple demands on your time,

energy, and money. As changes occur in the care receiver, you may grieve for the loss of your relative as he or she used to be. Feeling unappreciated is common for caregivers, particularly if the ill person expresses only dissatisfaction or is unable to show appreciation.

These feelings are normal. They are neither “good” nor “bad,” nor do they reflect the degree of your caring. Feeling angry does not mean you love the person less. What is important is how you handle your feelings. Learning to express feelings and to deal with tension in constructive ways is vital to your emotional and physical health.

Stress has fewer negative effects for people who accept and express their feelings—both negative and positive. When you acknowledge and understand your emotions, you then can control them. Repressing or denying feelings leads to irritability, depression, or physical problems. Your feelings can also greatly influence your judgment.

Some feelings are very hard to express directly. If this is true for you, find an indirect way to do so—write them down, get involved in vigorous physical activity, chop wood, punch a pillow, yell in the garage.

Use assertive communication. Try to avoid expressing feelings in manipulative or hostile ways. The purpose of expressing your feelings is not to punish or “get even with someone,” or to create a sense of guilt. When negative feelings and conflicts arise, use assertive communication strategies to talk with those involved. Assertive

Asking for and accepting specific help is a sign of your strength and good judgment.

communication encourages problem solving.

There are six principles in assertive communication:

- 1. Express yourself in terms of your own feelings.** Use “I” statements and describe specifically what is bothering you. Say, “I feel, I need, I expect, I choose, I believe...” For example, “I’m upset that mother’s doctor appointment didn’t get made.”
- 2. Avoid “you” or blaming statements that imply others are responsible for your feelings.** Blaming statements, such as “You don’t care about Mom,” “You make me so angry,” “You never follow through on anything,” or “You always let me down” sound accusatory and tend to create defensive arguments. “I” statements are more direct, more effective, and less threatening than “you” statements.
- 3. Avoid “hidden you” statements.** For example, a hidden you message is “I felt disappointed when YOU didn’t take Dad to church.” Rather, say “I felt disappointed when Dad missed church on Sunday.”
- 4. Avoid using terms like “always” and “never.”** The person usually will deny these statements because “never” and “always” are rarely true.
- 5. Focus assertive communication on problem solving.** After you and the other person have expressed your feelings, try to end on a positive note, perhaps asking “How can we fix this so that Dad gets to church?”

6. Plan assertive communication ahead of time. Most people need to learn how to use assertive communication. The more intense your feelings, the more you need to think about how to express them constructively. Take time to think about how to express your feelings in terms of “I” statements, not “you” statements. When you use and practice assertive communication, you will get better at it.

In addition to conflict resolution and problem solving, assertive communication is useful in asking for what you need. For example, if you do not feel appreciated, you need to let others know. Ask for positive feedback. For example, you might say, “I feel overwhelmed because Dad can’t thank me for all I do. I could really use a thank you and a hug every week.” If the care receiver is able to communicate, use assertive communication to share your feelings with him or her.

Join a support group. Most people benefit from sharing their feelings with someone who is supportive and listens nonjudgmentally. Such sharing often relieves tension, helps give a new perspective on the situation, increases mutual understanding, and builds support. You will learn that negative feelings are normal and that you are not alone or crazy in how you feel. Support groups are especially helpful when a new diagnosis is given, when you are new to caregiving, and when caregiving becomes more demanding.

Support groups give you an opportunity to share openly with others who understand and to

learn about common challenges and strategies for coping. Many caregivers find that support groups help them feel less alone. They also provide an opportunity to share your knowledge and to help other group members. Information about local support groups may be obtained by contacting a local hospital or home health agency, the Area Agency on Aging, or the Aging and Disabilities Resource Connection centers (see page 20).

In some areas, support groups are offered for specific diseases such as cancer, Parkinson's disease, lung disease, or Alzheimer's disease and related dementias. These support groups meet in local communities but are often sponsored by national disease-related associations such as the American Cancer Society (<http://www.cancer.org/>), the National Parkinson Foundation, <http://www.parkinson.org/>, the Alzheimer's Association www.alz.org, and similar groups. Physicians and hospital social-work departments can often help guide you to support groups in your area. You can also identify support groups through Internet searches, such as at <https://www.caregiver.org>.

Acknowledge all that you are doing right!

All of us have an inner voice that can be very loud, harsh, and critical. That inner voice can be especially loud when we are doing hard things like providing long-term caregiving. Your inner critic can be the worst when there always seems to be more to do and the care recipient won't, or can't, say "thank you."

It's important to focus on what you are doing right and how you



make a positive difference for the care receiver. Focus on your small successes. Practice positive self-talk. At the end of every day, thank yourself for two or three things you did right that day. For example, "Mom liked dinner. I will make that again." Or "I did a good job of asking Tom for help with Mom. I was clear and specific and did not yell like I used to do." Some caregivers find it helpful to keep a daily journal and at the end of each day to write a statement about how they made a positive difference for their family member that day.

Be kind to yourself when you make mistakes or wish you had done something in a different way. "Sometimes I make mistakes, but I am only human and most of the time, I am doing OK with this hard job." Or, if you are late getting your mother to the doctor, say, "I did a great job of leaving work and getting mom ready, in the car, and here. Sure the traffic was horrible, but she is here now and safe. Next month, I will leave a half hour earlier."

As a caregiver you can only provide effective care for others if you care for yourself first.

Time away from caregiving—even for short periods—is needed to maintain friendships, social activities, health, and overall balance in life. Once these features are lost, they are difficult to regain.

— University of Utah caregiving researchers

Maintain your health

To provide effective care for others, it's vital that you maintain your own physical and mental health. Neglecting your health has long-range consequences, not only for you, but for the person who needs your care. Proper diet, sleep, exercise, and attention to your health problems are essential.

Without adequate nutrition and rest, you will feel exhausted, discouraged, and depressed. If interrupted sleep is a major problem, find someone who will provide occasional or even regular night duty.

Physical activity has many benefits—it promotes better sleep, reduces tension and depression, lifts spirits, and increases energy. If you feel that exercising would be just one more demand, think of ways to incorporate it into your daily routine. If the care receiver is physically able, perhaps you could walk together. While talking on the telephone or watching television, do stretching exercises. Relaxation techniques are another way to reduce stress. Find an activity

you enjoy, so exercise becomes a pleasurable event for you. Do it 20 to 30 minutes three times a week.

Humor is a powerful antidote to stress. Laughing quickens the pulse rate, stimulates the blood circulation, activates muscles, increases oxygen intake, and fosters physical relaxation. If you have forgotten how to laugh, try to be around people who still know how—it's contagious.

Take time for yourself regularly

Do you value yourself and your personal needs? What do you do for personal renewal? Do you save some time for yourself out of each day and take occasional extended breaks? Or are you so involved with caregiving tasks that you have little or no time for yourself?

Too often, caregivers place their own needs last. Helping another person should not mean giving up your enjoyable activities and relationships with other people. Studies show that sacrificing oneself in the care of another and removing pleasurable



events from one's life can lead to emotional exhaustion, depression, and physical illness in caregivers. Taking breaks from caregiving is essential for both full-time and part-time caregivers.

Refusing to take breaks for self-renewal can be detrimental to the care receiver as well as to you. It can increase the dependency of the care receiver. The ill person who sees few people regularly may benefit from being with others while you take a break. Sometimes, too, the care receiver will be more responsive with another person. For example, he or she may participate more actively in rehabilitation exercises in your absence.

Others can provide adequate care, at least for a short time. If you hesitate to leave because you are concerned about what might happen while you are away, ask yourself, "What is the worst possible thing that could happen?" Then make contingency plans for handling "the worst."

Finding appropriate substitute care takes time and preparation. In some areas, community respite care has been developed to provide in-home or out-of-home support. Respite services may be available for a few hours, a day, overnight, weekends, a week or longer, and on a planned or emergency basis. Respite providers may be trained volunteers or paid staff.

In-home respite care can include companion type or supervision services or the temporary use of homemaker or home health services. It has the advantage of keeping the person in familiar surroundings. Out-of-home care includes adult day centers or short stays in adult foster-care homes, nursing homes,

assisted living or memory care facilities, or hospitals.

Regardless of the respite care services you select, you will want to prepare for the service by answering these important questions:

- What type of help do I need (regular or occasional)?
- What can I afford to pay? You may need to pay for substitute care. Remember, it is worth it! Ask about per-hour charges if that will be more manageable than full-time help.
- What times would work best for me for respite care?
- How much notice do I need to give a substitute care provider?
- What information does a respite provider need to have about the care receiver's special needs and routine?
- How should the respite provider deal with an emergency (who and where is the backup)?
- How can I prepare the care receiver for my leaving?

If you've always been available, you will need to prepare your family member for your leaving. You might try a "trial period." Have the substitute care provider visit a few times while you are present or take only a brief break in the beginning to see how the arrangement will work. If the care receiver protests your leaving, acknowledge his or her feelings, but calmly state your need for a break. For example, you might say, "Dad, I know it's hard to have me leave, but I am exhausted and I need to get away for a while." For the memory-impaired person, it may help to leave a note indicating the time you will return.

Start taking regular breaks early in caregiving. Remember, caregiving is a marathon, not a sprint. You need to protect yourself for the long haul. If you wait until you are “burned out,” short, regular breaks will not be enough. It’s important to make a plan for regular breaks, decide on the time, date, and activity—then follow through!

Strategy 5: Involve Other People

Hold a family conference

Although care for an older person is most often provided primarily by one person, it’s important to involve all family members in the planning and continual support. One strategy for deciding how to share caregiving responsibilities is the family conference.



A family conference should be held as early as possible after the need for caregiving arises. The conference gives everyone an opportunity to discuss caregiving concerns, identify potential problems and solutions, and negotiate the sharing of caregiving tasks and costs. The conference also can clarify each person’s expectations and minimize misunderstandings.

Include everyone. Everyone who is concerned and might be affected by care decisions should be involved in the family conference. Siblings, spouse, other relatives, housemates, neighbors, close friends, and the person for whom plans are being made should be involved. If illness prevents the care receiver from being involved directly, it’s important to get his or her input and keep him or her informed. Remember, having as much control as possible over our lives is important to all of us, regardless of our age or illness.

A family member should not be excluded from a family conference because of distance, personality, family history with the older person, or limited resources. It’s just as important to include a difficult, argumentative family member, or one who never visits, as it is to involve those who are supportive.

Telephoning distant relatives to get their input and keeping them informed will help them feel a part of the decision making. Involvement of all family members in developing a caregiving plan ensures greater success and support for the plan and helps prevent later undermining of decisions. Ask for help in making these calls.

Consider a two-step conference. Sometimes families

find it helpful to hold a two-step conference. The first meeting is held without the older person for the purpose of airing ideas and feelings, identifying concerns, looking at gaps in information, and discussing responsibilities for each family member. The purpose should not be to make the decision or to “gang up” on the older person. A second meeting is then held with the older person, who is actively involved in looking at the options and making decisions.

Plan for success. A family conference is most successful when you give attention to these considerations.

- Before the conference, ask family members to list their concerns and tasks they are willing to do.
- Hold the conference in a neutral place. Holding the conference in the older person’s home may help give a greater sense of control to the care receiver.
- Create a feeling of support and confidentiality.
- Keep the conference focused on the current concern rather than on other issues or past conflicts.
- Be certain everyone has the opportunity to express feelings, voice preferences, and offer suggestions without being “put down.”
- Focus on the positive. Identify what each person can do, but encourage everyone to be honest about their limitations. Sharing information about other responsibilities can help others understand why the support must be limited.

- Remember there are many ways family members can help—regular direct care, substitute care, financial assistance for substitute care providers, or other costs.
- Prepare a written plan listing what each person will do and when they will do it. Keep it flexible. A written plan can prevent later disagreements about who agreed to what, and can better assure that needed tasks will be completed. Make copies of the written plan and distribute them to all involved parties.

Realize there may be conflict.

A family conference is not always easy, and in some families, it may be impossible. It’s most difficult for families who have never discussed feelings and family concerns. Where conflicts already exist among family members, decision making is difficult. When family members come together after years of separation, old conflicts can re-emerge with regard to relationships, family roles, expectations, and even inheritance.

Family members often have different perceptions about the care needs of an older person, the best care option, the division of care tasks, and how money should be spent. For example, one brother might not want a parent’s resources—his potential inheritance—spent for in-home services. He may prefer that the family provide the needed care, while another brother feels “Mom’s money is there to spend on her” and prefers to purchase care services. One person may feel that the impaired person should be kept at home, regardless of what

Getting help is a sign of personal strength, not weakness, and will enable you to be a more effective caregiver.

needs to be done; another may feel that a different living arrangement is needed for the person's health and safety. Intense conflicts often result when one person insists that the older person be maintained at home and another is fighting for moving the person to a care facility.

Bring in an objective third party. An objective facilitator for a family conference is especially helpful when family conflicts or resentments prevent rational discussion. A counselor, health or social service professional, or member of the clergy trained in family counseling can often help you deal with family conflicts.

Obtain professional guidance

Receiving professional advice and assistance can reduce some of the conflict and stress during a family conference. Besides facilitating a family conference, a professional can help you gain objectivity and a clearer perspective of the situation. Don't be afraid to seek help and don't wait until you are overwhelmed by a crisis. Seeking professional guidance is especially recommended under the following circumstances.

- You find yourself using alcohol or drugs to forget your problems, relieve stress, fall asleep at night, or get yourself going in the morning. Substance abuse can impair your judgment and contribute to your feelings of inadequacy and guilt. It also can result in neglectful or abusive behavior.
- You become depressed. Untreated depression can negatively affect your health and your responses to the ill person.
- You don't understand the care receiver's behavior or don't

know how to deal with specific care tasks.

- You find yourself feeling resentment, losing emotional control, or neglecting, humiliating, or becoming physically rough with a family member. These behaviors often are caused by exhaustion, stress, or lack of resources and support.
- You are being physically or emotionally abused by the impaired person.
- Your family cannot resolve problems or reach agreement on care decisions.
- You feel a serious conflict between caregiving and other responsibilities.

You can obtain the names of individuals skilled in working with older adults and their families through senior centers; hospitals; and health, family, and social service agencies. When you call a professional, state your specific need and ask the person about his or her training and experience with your problem. If the person is unable to assist you, ask for names of others who can help.

Explore and use your community resources

In recent years, community services have become available to help older people and their families. Specific programs designed for caregivers include respite care programs and support groups, as previously discussed. In addition, programs designed directly to serve older adults can help the caregiver. Paying for outside assistance early in the caregiving process is generally less expensive than if you wait until you become overwhelmed

and exhausted. At that point, your options are likely to be fewer and more expensive, and you may be paying health bills for yourself as well as for the care receiver.

Available services vary between communities, but some of the most common include the following.

Companions or friendly visitors provide companionship, friendship, support, or supervision to older adults for a few hours. In some areas, paid companions are available to stay through the evening and night. For older persons living alone, friendly visitors can provide a safety check as well as companionship. In general, they do not provide housekeeping or personal care services.

Telephone reassurance provides regular telephone calls to homebound ill or disabled persons.

In-home medical alert programs (sometimes called a “Lifeline” service) that link the care recipient to help in an emergency or crisis. The person wears an electronic device that sends a signal to a central dispatcher, often located at a hospital, if he or she falls or needs help. Emergency assistance is summoned if the care receiver does not answer the telephone.

Chore services provide help with yardwork, minor home repair, and winterization. In some areas, chore services also include assistance with household chores, grocery shopping, laundry, meal preparation, and cleaning.

Homemaker services assist with light housecleaning, shopping, laundry, and food preparation.

Home health aides provide help with personal care activities, such as bathing, feeding, walking, and toileting. Aides provided by



a certified home health agency are trained and supervised by a registered nurse.

Home-delivered meals are nutritious meals delivered to homebound elders, usually around the lunch hour. The days for home delivery of meals vary from one area to another.

Congregate meals provide inexpensive, nutritious meals in a group setting in senior centers or other community settings. Transportation is often available for those unable to drive. Frequently, the mealtime includes recreational and social activities.

Transportation services provide vans or buses that can be called to transport a person to and from doctors’ appointments, rehabilitation sessions, congregate meal programs, and sometimes for grocery shopping and other activities. Transportation services must be scheduled in advance.

Adult day centers are for people who are physically or mentally incapable of independent living and need a supervised environment during the day. Programs vary but often offer health and medical monitoring,

meals, and recreational group activities. The program enables some caregivers to continue their employment and care for their relative at the same time.

Day treatment provides assistance to individuals who are mentally ill or have a mood or thought disorder that significantly impairs judgment or behavior. Psychosocial rehabilitation is provided to assist these people in their daily lives.

Home health nurses offer health assessment and home health care to people who need nursing care at home. If needed, other services such as physical therapy, speech therapy, and home health aide services are provided.

Some of these programs require a fee, which may be calculated on a sliding scale that is determined by ability to pay. Other services may be free or have a voluntary donation because they are provided by volunteers, government, or charitable organizations. Some programs also have age, income, or other eligibility requirements.

When calling an agency, state your needs as clearly as possible and remember to ask about eligibility requirements and costs. Contacting agencies requires considerable time and energy. If you feel you don't have time to make the necessary calls, enlist the help of other family members and friends. They can help make the contacts or provide care for your family member while you call.

- Contact county and state health and social service agencies that serve older people, adult communities or senior centers, local offices of the U.S. Social Security Administration, and (if the impaired person served in

the military) the Veterans Administration. Home health and home care agencies can help with personal care and housekeeping chores. Meal delivery, transportation, and shopping services also may be available.

- The Aging and Disabilities Resource Connection (ADRC) is a nationwide initiative that serves communities across America. ADRC centers are staffed by local experts who help connect older adults and people with disabilities with needed services and assistance. ADRCs are very helpful when families are providing care and support to someone in a different community. You can locate ADRCs by searching "ADRC and your state name." For example, ADRC listings for Oregon, Washington, and Idaho are:
 - Idaho: <http://www.aging.idaho.gov/adrc> or call 1-800-926-2588
 - Oregon: <https://www.adrcoforegon.org> or call 1-855-ORE-ADRC (855-673-7332)
 - Washington State: In 2015, Washington State's ADRC System was renamed Community Living Connections (CLC). From this link you can connect to local CLCs across Washington state: <http://www.adrcofwashington.org/>

Your local Area Agency on Aging is a good place to find out about programs and services in your community. It also may be called Senior Service Division, Aging Services, or the Office on Aging. Use the telephone prompter on page 25 to help you get the best information from agencies.

If an agency representative cannot answer your questions, ask to speak to the supervisor.

Avoid becoming irritated or angry. Say something like, “I appreciate your assistance, but I’d like to ask your supervisor some additional questions.” If the supervisor is not available, ask for the best time to call back. Before you hang up, ask if there is a direct telephone number for the supervisor.

Regardless of whether you now need assistance, explore community services for future needs. Find out about services offered by public and private sectors, and record the information for future use. You never know when you may need a service, and need the service in a hurry.

For more guidance on finding community long-term care services, see *Making Decisions about Long-term Care Options* (PNW 563).

CAREGIVING FROM A DISTANCE

Distance can make caregiving more complicated. You may get calls from neighbors and friends who are concerned about your older relative’s health or living situation, but it’s difficult to know how well your relative is functioning without being near. As a long-distance caregiver, you can take these four steps to better manage your situation:

- Establish a local network
- Be prepared for dramatic changes
- Think carefully before you move a family member
- Support the local caregiver

Establish a local network

Are you driving or flying back and forth to repeated crises or spending long weekends and vacations “getting things in order”



for your family member? If this is true for you, you will need to establish a network of neighbors, friends, and professionals in your relative’s community who can help assess your relative’s ongoing needs and arrange for services. In some communities, health care professionals, often called “geriatric care managers,” in public agencies and private businesses offer the service of coordinating the care of older adults whose primary relatives live at a distance.

Be prepared for dramatic changes

If you live at a distance and are unable to visit regularly, you may be shocked at the deterioration in your relative when you do visit. You may become upset because you feel that you have not been told “just how bad Mom or Dad is.” Or you may have been told, but did not actually believe how conditions had changed.

When changes occur gradually, family members who have daily contact are often not aware of the degree of change because they have adjusted to them gradually. When you live at a distance, you have only two points of reference—the last time and now.

The changes can appear dramatic.

Keep your shock from placing an additional burden on the local caregiver. Unloading on the primary caregiver may create more stress. The caregiver may begin resenting your visits or struggle to make the ill person appear better than he or she really is.

If you are a local family member, try to understand the different perspective of out-of-town relatives. Keep them informed and involved in decisions. Let them know what the needs are and request specific help, rather than resenting them for “not doing more.” And, remember, show appreciation for any help you receive.

For other guidance on long-distance caregiving, see: <https://www.caregiver.org>

Think carefully before you move your family member

If you are an only child or have primary responsibility for your family member, or if there are no relatives living nearby, you may face the tough decision of whether to move your relative closer to you. If you are considering moving a parent to your community or into your home, carefully weigh the advantages and disadvantages for your relative, yourself, and your family. Since needs change over time, weigh the decision for the future as well as for the present.

A move can separate your family member from long-established roots that are not easily replaced. This can present a major problem. The person may become entirely dependent on you for social and emotional support. This is more difficult if your family member does not make friends

easily or is limited in mobility or verbal skills.

It's also very important to consider your past relationship with your family member. Can you tolerate increased and intensified contact with your relative? Relationships that have been difficult in the past or succeeded because of geographic distance often require extensive adjustment when the distance is removed. Remember, arranging for needed services for a family member is sometimes the most appropriate means of caregiving.

Support the local caregiver

If you live at a distance, it's critical to support, in whatever way you can, the caregiver who has day-to-day responsibility. Maintain regular contact. Call frequently rather than expecting the caregiver to call you. Ask, “What can I do to help?” Make a list of tasks you are willing and able to do and share this list with the caregiver. Perhaps you can give the caregiver a break by spending a week with the care receiver, paying for a housekeeper or respite care provider once a week, or inviting the care receiver to visit you. Calling your older relative weekly, making frozen meals, or managing the person's finances may provide needed relief for the primary caregiver.

Caregivers who provide daily support to an older family member frequently feel they are not appreciated. The person receiving care sometimes takes out his or her feelings of loss and frustration on those providing the day-to-day support and talks in glowing terms about sons and daughters who live at a distance. If this happens, do not allow the older person to put down the primary caregiver in

your presence. It will help if you also let the primary caregiver know you understand the situation and appreciate what he or she does from day to day.

Conflict can arise between family members who live near the care receiver and those who live at a distance, because of their different perspectives. If you spend only a few days with your relative, the care needs may not seem as great as if you have daily responsibility. Sometimes, too, the older person will “perk up” in response to a visit by a rarely seen family member and will fail to display the symptoms and difficult behavior that occurred before the visit. At times, the person may “dump” on one person and show a cheerful side to another. This behavior can be related to distance or to past relationships.

Don't let apparent differences in behavior between what you see and what the caregiver has told you discredit the caregiver. To accurately assess your relative's functioning, you may need an extended visit and to talk with professionals involved in your relative's care.

Remember, too, that local caregivers often have to compromise with the older person and accept imperfect solutions to problems. For example, if you find your father's home is not as well kept as you feel it should be, it may not be that family members are neglectful. Your father may be refusing help with the household chores.

MOVING A FAMILY MEMBER TO A CARE FACILITY

There may come a time when you or other family members cannot provide the needed care, or in-home services are no longer appropriate to meet your older relative's care needs. Moving a frail older person to an adult foster care home, assisted living residence, memory care, or other care setting is sometimes the best decision for everyone. However, it may be one of the most difficult decisions you will ever make. Families facing this difficult decision must realize they have not failed, broken a promise, or abandoned a loved one. They have given to health-care professionals only the physical chores of daily care.

Moving a family member to a care facility does not mean your caring relationship ends. It merely changes the relationship, and often for the better. It signifies an extension, rather than a termination, of your caring. You become a valuable member of the health-care team by participating in planning care, assisting staff to understand your family member's needs, and monitoring the care he or she receives.

The potential benefits of a move to a group care setting for your relative include increased social contact, recreational and social activities, and rehabilitation services. Also, when you are no longer devoting your time to meeting the physical and safety needs of your family member, you will be better able to meet

When you are no longer devoting your time to meeting the physical and safety needs of your family member, you will be better able to meet some of his or her emotional and social needs.

his or her emotional and social needs. Meeting these needs is very important. Almost any trained person can assist your relative with the activities of daily living—dressing, bathing, and feeding. Family and friends, however, are in the best position to share the special memories that give a person a feeling of belonging and of being loved. These feelings add immeasurably to someone’s quality of life.

Planning ahead for care

Many families hesitate to plan for the possibility of care in a health-care facility until a crisis occurs; for example, a change in the person’s health, or the caregiver’s unexpected illness or death. The Alzheimer’s Association says placement may be desirable if the impaired person wanders, is a danger to himself or others, is unable to care for himself in the most basic ways, or frequently interrupts another’s sleep.

Being informed and prepared will help you make the best decisions. Before a crisis occurs, discuss with your family and medical providers under what conditions a care facility would be the best option for your family member and for you, the caregiver. What would the care mean financially and personally? Explore the resources—including long-term care insurance, Medicare, Medicaid, and the Veteran’s Administration—that may help with costs.

Meeting with an attorney who specializes in elder law can help protect resources for spouses. Visit some facilities, especially those that specialize in dementia or “memory care” if your relative has Alzheimer’s disease or a related

dementia. Look for facilities and programs where staff are friendly and calm and where residents appear calm and engaged in activities that match their abilities. All of these steps take time, so plan ahead of a crisis.

Adapting to a new care setting

You and your family member will need time to adjust to a care facility. Adjustment to a move usually takes anywhere from 30 to 90 days, and may take longer for some people. A few treasured items from home can help make a care facility feel more familiar and comfortable. Ask the staff for advice on how to make the transition smoother. They have been through this many times and will have good ideas on adjustment.

It is important to visit or call to monitor the transition and to help staff learn about your family member. Following a move, it’s often helpful to keep visits short so the person gets into activities and the new routine of the facility. Family members who visit too often or for long hours can make a transition more difficult. Spending time with family is important, but if all of the person’s time during the transition period is spent with family, it will be more difficult for him or her to make new friends and get involved in the community. The person needs time and space to adjust to his or her new home.

Staff play a very important role in a new resident’s adjustment. In some facilities, staff members meet with each new resident to explain their particular role in the facility and what that means to the resident. In other facilities, new resident orientations are held to

help residents get acquainted with their new home.

After a period of adjustment, most families find that family relationships improve. Families can focus on being supportive loved ones rather than focusing on caregiving tasks. As one nursing home administrator said, "Anyone can give a bed bath or help a person to dress, but only a family member knows the favorite treats, events, and memories that are meaningful to the person."

For more information about long-term care settings, see *Making Decisions about Long-term Care Options* (PNW 563).

CONCLUSION

It's important to base caregiving decisions on the needs and desires of the older person, the caregiver, and the family. Remember, as a caregiver you can only provide effective care for others if you care for yourself first.

The suggestions in this guide can help you. However, even if you follow the suggestions we have provided here, not everything will be as you would like. There will be times when you wish you had done things differently. You are only human. If you make a mistake, admit it and learn from it, and then go on. Too often caregivers focus on what they have not done well. There is no advantage in being plagued by feelings of guilt.

Remind yourself of the many things you have done well. It will make you feel better about yourself. Ask yourself: What are my personal strengths? *How have I made a difference for my family member? What things have I done that I feel good about?* You are doing many

things right. Don't fail to give yourself the credit you're due.

ADDITIONAL EXTENSION RESOURCES:

Helping Memory-impaired Elders (PNW 314)

USEFUL BOOKS FOR FAMILY CAREGIVING

Jacobs, B. and J. L. Mayer. 2016. *AARP Meditations for Caregivers: Practical, Emotional, and Spiritual Support for You and Your Family*. AARP Bookstore

Morris, V. 2014. *How to Care for Aging Parents: A One-Stop Resource for All Your Medical, Financial, Housing, and Emotional Issues*. Workman Publishing

Schmall, V. et al. 2013. *Powerful Tools for Caregiving*. Third Edition. Available through www.powerfultoolsforcaregivers.org/

Hartley, C. P. and P. Wong. 2015. *The Caregiver's Toolbox: Checklists, Forms, Resources, Mobile Apps, and Straight Talk to Help You Provide Compassionate Care*. Rowman & Littlefield

Loverde, J. 2009. *The Complete Eldercare Planner: Where to Start, Which Questions to Ask, and How to Find Help*. Potter/TenSpeed/Harmony

Jacobs, B. 2007. *The Emotional Survival Guide for Caregivers: Looking After Yourself and Your Family While Helping an Aging Parent*. Guilford Press

BOOKS RELATED TO ALZHEIMER'S DISEASE AND RELATED DEMENTIAS:

Bell, V. and D. Troxel. 1997. *The Best Friends Approach to*

TELEPHONE PROMPTER

Place this prompter next to your telephone when you call about community services. It will remind you of the questions to ask.

My name is _____

I'm caring for _____

I need _____

Can you help me? _____

If yes:

What services do you provide?

What are the costs?

How are they paid?

What are the eligibility requirements?

How long must we wait?

Can you send a brochure or application to me at:

To whom am I speaking?

Do I need to speak to anybody else?

Thank you!!

If no:

Can you give me another name or agency to call?

To whom am I speaking?

Thank you!!

Alzheimer's Care. Baltimore. Health Professions Press.

Hatchigan, J. 2013. *The Alzheimer's and Dementia Caregiver's Helpbook: 101 Tips, How-to's & Great Ideas to Help a Mildly Impaired Loved One Live 'Independently' Longer*. Nostina

Coste, J.K. . 2004. *Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease*. Houghton Mifflin Harcourt

Rabins, P.V. and N. L. Mace. 2008. *The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Related Dementias, and Memory Loss*. Johns Hopkins Press

Brackey, J. 2015. *Creating Moments of Joy for the Person with Alzheimer's or Dementia: A Journal for Caregivers*. Fourth Edition. Purdue University Press



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