Coping with Caregiving

HOW TO MANAGE STRESS WHEN CARING FOR OLDER RELATIVES

PNW 315

Reprinted June 2003

A Pacific Northwest Extension Publication
Oregon State University • Washington State University • University of Idaho

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Family members who play a major role in caring for elderly relatives frequently ignore their own needs. Some find themselves virtually homebound and consumed by caregiving tasks. When caregiving is prolonged over months and years, the self-sacrifice is particularly harmful.

We have prepared this publication to help you maintain your personal well-being while providing quality care for an elderly relative. We will discuss the sources of stress and how you can master stress for your own benefit and that of the person for whom you are providing care.

Many nursing home placements are precipitated by the caregiver's exhaustion, illness, or death. This publication can help prevent such a situation for you and your family.

Remember, it's just as important to take care of your own needs as to provide the best care for your family member. As a caregiver, ignoring your own needs is not only potentially detrimental to you, but also can be harmful to the person who depends on you. Many nursing home placements are precipitated by the caregiver's exhaustion, illness, or 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 a personal sacrifice to provide care for another person. This can create areas of conflict and high levels of stress in your life.

If you're young, you probably have competing responsibilities for children, spouse, and job. If you're older, you may be adjusting to age-related changes including 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. This publication will help you understand your responses and will show you ways to reduce the conflict and stress caused by the demands of caregiving.

What is caregiving?

Caregiving can evolve slowly, over a long time, or suddenly, in the case of illness or accident. Caregiving can mean having the older person live with you, near you, or hundreds of miles away. Your older relative may be physically disabled, mentally incapacitated or both. Depending on the specific need, caregiving can be a lot of different activities, including:

- Round-the-clock supervision
- Supervising others who provide direct care
- Shopping
- Telephoning
- Traveling to and from your relative's home
- Maintaining two homes—yours and your relative's
- Lifting, bathing, dressing, and feeding
- Managing incontinence
- Managing financial and legal affairs
- Providing social activity
- Supervising medication
- Arranging for health care
- Listening, talking, and providing emotional support

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 well-being. You may feel a sense of accomplishment in helping your dependent relative and may experience a new closeness in your relationship. Often a parent and child reach a higher level of acceptance and understanding when the child provides care for the mother or father. However, no matter how loving the relationship, caregiving almost always involves some personal sacrifice and stress, which can be seen in the following symptoms:

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

You may feel that there are too many expectations and not enough time and energy to meet them all. Unresolved, excessive, or prolonged stress results in what often is called burnout. When challenges and demands are too great, they drain our physical energy, time, health, and money. Becoming aware of how stress takes hold is the first step toward coping with it.

Caregiving can mean having the older person live with you, near you, or hundreds of miles away.

Strategies for managing stress

Once you know the sources of stress, you must determine which ones you can do something about and which ones are beyond your control. Successful coping involves accepting 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 general, professionals who have extensive experience working with caregivers agree on five basic strategies to help control

Caregiving Stress: Symptoms

When you experience an unusual level of stress, certain warning signals occur. Answering the following questions will increase your awareness of these signals.

Yes	No	
❑	❑	1. Do you feel a loss of energy or zest for life?
❑	❑	2. Do you feel out of control, exhibiting uncharacteristic emotions or actions?
❑	❑	3. Do you lack interest in people or things that formerly were pleasurable?
❑	❑	4. Are you becoming increasingly isolated?
❑	❑	5. Are you using more sleeping pills, medications, alcohol, caffeine, or cigarettes?
❑	❑	6. Are you having increased health problems; for example, high blood pressure, ulcers, or difficulties with digestion?
❑	❑	7. Is it hard to fall asleep at night? Do you awaken early or sleep excessively?
❑	❑	8. Are you experiencing appetite changes?
❑	❑	9. Do you have problems with concentration or memory?
❑	❑	10. Are you increasingly irritable or impatient with others?
❑	❑	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 source of this stress is the next step in dealing with its destructive effects.

the destructive effects of stress. They are:

1. **Set realistic goals and expectations.**
   a. Plan achievable goals.
   b. Develop realistic expectations.
2. **Establish your limits.**
3. **Ask for and accept help.**
4. **Take care of yourself.**
   a. Express your feelings.
   b. Maintain your health.
   c. Take time for yourself.
5. **Involve other people.**
   a. Hold a family conference.
   b. Get professional guidance.
   c. Use community resources.

Caregiving Stress: Causes

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, which we raise in this series of questions.

Yes	No	
❑	❑	1. Do you have multiple demands on your time, energy, or money? What are they?
❑	❑	2. Do you feel that your responsibilities conflict? Which ones?
❑	❑	3. Is there a difference in expectations between your family, your boss, your dependent relative, yourself? What are they?
❑	❑	4. Do you feel you don't understand the older person's mental or physical condition?
❑	❑	5. Do you have difficulty meeting your relative's physical or emotional needs?
❑	❑	6. Are you pressured by financial decisions and lack of resources?
❑	❑	7. Do you feel a loss of freedom . . . a sense of being "trapped"?
❑	❑	8. Is there disagreement among family members?
❑	❑	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?
❑	❑	12. Do other family members have negative attitudes that you have trouble contending with?
❑	❑	13. Is there deterioration in your family member that is painful to watch?
❑	❑	14. 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 these specific sources of stress as we talk about ways to reduce stress.

Set realistic goals and expectations

Plan achievable goals

What do you want to accomplish? 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? Preventing caregiver burnout means accepting the limitations of what you can accomplish.

In addition to understanding yourself, you also need to know how the illness or disability affects your family member. Objectivity about your situation is important—but not always easy. Find out what is likely to occur medically and behaviorally now and in the future. For example, sometimes a mentally impaired person's behavior or moods can be baffling. It can appear that he or she is intentionally being difficult, acting helpless, or refusing to communicate. If this 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'll see results more often if you select 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. 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

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

Also consider goals in terms of the ill person's personality and capabilities. Some caregivers are driven by goals such as "make mother happy." Given mother's personality or the accumulation of recent losses, this goal could be completely unachievable. Such a goal creates a heavy burden, and you'll probably never feel that you've attained it. A specific and achievable goal, however, might be to provide a pleasurable activity at least once a week for your mother. Perhaps that's spending 2 hours each week visiting friends or working on a puzzle. If you set specific goals, you are more likely to feel satisfied with your progress.

Develop realistic expectations

How realistic are your 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, 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 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. 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 one when the promise was made. You'll probably find the situation has changed considerably. If it hadn't, it might indeed have been possible to fulfill the promise.

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

Resistance to accepting help is a common cause of stress and depression among caregivers.

Establish your limits

You have a right to set limits on what you will do. It's all right to say "no." That can be difficult, however, especially if you must make painful choices. At times, of course, it's necessary to go beyond limits. In general, however, 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 to your ill relative. This may be particularly painful to do with a parent or spouse. But remember, *not* to do so will only increase your stress.

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

Ask for and accept help

How do you respond to offers of help? Is it difficult to ask for assistance? When you do, are you specific enough so people know exactly what you want? Do you expect close family members to know when you need help? Do you refuse offers of help, but feel exhausted or resent not receiving assistance? Do you feel "I should be able to do it alone"?

Resistance to accepting help is a common cause of stress and depression among caregivers. In our culture, with its emphasis on "independence" and "going it alone," it's not easy to request help. Some caregivers view it as a sign of helplessness, inadequacy, or failure. Actually, asking for needed help is just the opposite. 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 your family member.

Being a martyr benefits no one. Refusing help will not make you a better caregiver—it will make you exhausted and probably irritable.

Family members, neighbors, and friends often are willing to help. But sometimes people hesitate to ask if they can help because they are frightened by illness, feel uncomfortable around the ill person, don't want to interfere, or don't know what they can do. You may have refused earlier offers, or you may appear to have everything under control.

People can help best if you tell them exactly what you need and how they can help. Be specific and positive. When family or friends ask how they can help, make a specific suggestion. For example, say, "Could you visit

with mother for an hour so I can go to the store?" or "When you go to the store, could you pick up a few things I need?" Tasks unrelated to caregiving may be easier for some people. If you can be flexible, ask when would be the best time for them. It's also important to show appreciation for any help received. Let people know how much their support means to you.

People are always 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.

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.

Understand your emotions. Being a caregiver and seeing a loved one decline are 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 your family member's increased dependency and the multiple demands on your time, energy, and money. As your family member changes, you may grieve the loss of the person he or she used to be. Feeling unappreciated is sometimes a problem for the caregiver, particularly if the ill person expresses only dissatisfaction or can't show appreciation.

Stress has fewer negative effects for people who admit their feelings and accept them.

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 your relative less. What is important is how you handle your feelings. Learning to express feelings and to deal with tensions in constructive ways is vital to your emotional and physical health.

Stress has fewer negative effects for people who admit their feelings and accept them. When you understand your emotions, you can control them. Repressing or denying feelings drains energy and can cause irritability, depression, or physical problems. Your feelings also can greatly influence your judgment.

Some feelings are very hard to share 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.

Use assertive communication techniques. Feelings should not be expressed in a manipulative or hostile way, to get even with someone or to create a sense of guilt. Such responses are not constructive and may indicate you are stuck in an "anger trap." To avoid the trap, use assertive communication. When conflicts arise, talk about them with those involved. Express yourself in terms of your own feelings. Use "I" statements and describe specifically what is bothering you. For example, "I'm upset that mother's doctor appointment wasn't made."

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. Saying "I feel, I need, I expect, I choose, I believe" is more effective and less threatening. Avoid terms such as "always" and "never"—the person usually will deny these statements because "never" and "always" are rarely true. Assertive communication encourages problem solving.

Recognition and appreciation are important needs. If you don't feel appreciated, let others know. Ask for positive feedback. If the care receiver can communicate, tell him or her your feelings.

Join a support group. Most people benefit from sharing their feelings with someone who is supportive and who listens nonjudgmentally. Sharing often relieves tension, helps give a new perspective, increases mutual understanding, and builds support.

Some areas have support groups for this kind of sharing. Some groups are oriented to specific diseases such as cancer, Parkinson's disease, lung diseases, or Alzheimer's disease. Others are for family caregivers in general. Many caregivers find that support groups help them feel less alone. Support groups give an opportunity to share openly with others who understand and to learn techniques for coping. Get information about local support groups from a local hospital or home health agency, the Area Agency on Aging, or disease-related associations such as the American Cancer Society or the Alzheimer's Association.

Maintain your health

To provide effective care, it's vital that you maintain your own 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.

Exercise has many benefits. It promotes better sleep, reduces tension and depression, lifts spirits, and increases energy. If you see exercise as just one more demand, think of ways to build it into your daily routine. If your family member is physically able, perhaps you could walk together. Do stretching exercises while talking on the telephone or watching television. Relaxation techniques are another way to reduce stress. Find activity you enjoy, so exercise is a pleasure 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.

To provide effective care, it's vital that you maintain your own health.

Take time for yourself

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?

All too often, caregivers place their own needs last. Helping an older relative should not mean giving up all activities and relationships with other people. Sacrificing oneself in the care of another and removing pleasurable events from one's life can lead to emotional exhaustion, depression, and physical illness. Taking breaks from caregiving is essential for both full- and part-time caregivers. You have a right—even a responsibility—to take time away from caregiving.

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 is more responsive with another person. For example, he or she may participate more actively in rehabilitation exercises in your absence.

Objective evaluation usually shows that 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're away, ask yourself, "What is the worst that could happen?" Then make contingency plans for handling "the worst."

Consider getting breaks early in caregiving. If you wait until you are burned out, these 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!

Finding appropriate substitute care takes time and preparation. In some areas, community respite care can 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 and/or home health services. It has the advantage of keeping the person in familiar surroundings. Out-of-home care includes adult day care programs or short stays in adult foster care homes, assisted living facilities, nursing homes, or hospitals.

Regardless of the respite care you select, prepare for the service by answering these questions.

- What type of help do I really need (regular or occasional)?
- What times are best for me?
- How much notice do I need to give the substitute care provider?
- What information should the respite provider have about the elder's special needs and routine?
- How should the respite provider deal with an emergency (who and where is backup)?
- How can I prepare the older person for my leaving?

If you've always been available, you may 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 your relative protests your leaving, acknowledge his or her feelings but 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.

Involve other people

Hold a family conference

Although care for an older person may be provided primarily by one person, all family members should be involved in the planning and continual support. One way to decide how to share caregiving responsibilities is to hold a family conference.

Hold a family conference as early as possible after the need for caregiving arises. The conference gives everyone a chance to discuss caregiving concerns, identify potential problems and solutions, and negotiate the sharing of caregiving tasks. 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 — siblings, spouse, other relatives, housemates, neighbors, close friends, and the person for whom plans are being made—should be involved in the family conference. If illness prevents the care

Consider getting breaks early in caregiving. If you wait until you are burned out, these breaks will not be enough.

Don't exclude a family member from a family conference because of distance, personality, family history with the older person, or limited resources.

receiver from being involved directly, 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 age or illness.

Don't exclude a family member 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 to keep them informed helps them feel a part of the decision making. Involving all family members in developing a caregiving plan ensures greater success and support for the plan and helps prevent later undermining of decisions.

Consider a two-step conference. Sometimes it's helpful to hold a two-step conference. The first meeting, held without the older person, is to air ideas, feelings, and concerns, look at gaps in information, and discuss 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 held with the older person, who is involved as much as possible in looking at options and making decisions.

Plan for success. A family conference is most successful when you take these steps.

- 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 it in the older person's home helps give him or her a greater sense of control.
- 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, preferences, and suggestions without being "put down."
- Focus on the positive. Identify what each person can do, but encourage everyone to be honest about her or his limitations. Sharing information about other responsibilities can help others understand why the support must be limited.
- Prepare a written plan listing what each person will do and when he or she 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.

Realize there may be conflict. A family conference is not always easy; in some families, it is impossible. It's most difficult for families who have never discussed feelings and family concerns. Where conflicts exist among family members, decision making is difficult. When family members come together after years of separation, old conflicts about relationships, family roles, expectations, and even inheritance can reemerge.

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.

Beliefs about what is "best" often differ, creating conflict. One person may believe the impaired person should be kept at home, regardless of what 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 nursing home placement. If family conflicts or hidden resentments prevent rational discussion, seek professional guidance. A counselor, health or social service professional, or member of the clergy trained in family counseling can help you deal with family conflicts. He or she also may be able to guide the family conference.

Get professional guidance

Receiving professional advice and assistance can help reduce some of the causes of stress. Consider seeking professional guidance under the following circumstances.

Receiving professional advice and assistance can help reduce some of the causes of stress.

- You use alcohol or drugs to forget your problems, relieve stress, fall asleep at night, or get going in the morning. Substance abuse can impair your judgment and contribute to feelings of inadequacy and guilt. It also can result in neglectful or abusive behavior.
- You become depressed. Untreated depression can harm your health and your responses to the ill person.
- You don't understand your family member's behavior or don't know how to deal with specific care tasks.
- You feel resentment or lose emotional control, or you neglect, humiliate, or become physically rough with a family member. These behaviors often are caused by exhaustion, stress, or lack of resources.
- You are being physically or emotionally abused by your impaired family member.
- Your family cannot resolve problems or reach agreement on care decisions.
- You feel conflict between caregiving and other responsibilities.

A professional often can help you gain a clearer perspective. Don't be afraid to seek help and don't wait until a crisis overwhelms you. Getting help is a sign of personal strength, not weakness, and will enable you to be a more effective caregiver.

Get 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.

Use community resources

In recent years, a range of community services has developed to help older persons and their families. Specific programs designed for caregivers include respite care and support groups (see pages 11–13). Also, programs designed to serve older adults can help the caregiver, too. 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 your relative.

Available services vary by community. Following are some of the most common.

Companions or friendly visitors provide companionship, friendship, support, or supervision to older adults for a few hours at a time. In some areas, paid

companions are available to stay through the evening and night. For older people living alone, friendly visitors can provide a safety check as well as companionship. In general, they do not provide housekeeping or personal care.

A *telephone reassurance* program makes regular telephone calls to ill or disabled persons who are homebound.

In-home medical alert program ("Lifeline") participants wear an electronic device that sends a signal to a central dispatcher, often at a hospital, if the impaired person falls or needs help. Emergency assistance is summoned if the person does not answer the telephone.

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

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

Home health aides help with personal care activities such as bathing, feeding, and toileting. Aides from a certified home health agency are trained and supervised by a registered nurse.

Home-delivered meals are nutritious meals delivered to homebound elders, usually at midday. Days for home delivery of meals vary from one area to another.

Congregate meals are inexpensive, nutritious meals in a group setting in senior centers or other community places. Often, transportation is available for those unable to drive, and mealtime includes recreation and social activities.

Transportation services provide vans or buses for travel to and from doctors' appointments, rehabilitation sessions, congregate meal programs, and sometimes 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 helps 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 persons who need nursing

Possible community resources

- Companion or friendly visitor
- Telephone reassurance
- In-home medical alert
- Chore service
- Homemaker service
- Home health aide
- Home-delivered meals
- Congregate meals
- Transportation service
- Adult day center
- Day treatment
- Home health nurse

When calling an agency, state your needs as clearly as possible and remember to ask about eligibility requirements and costs.

care at home. If needed, other services such as physical therapy, speech therapy, and home health aide services are provided.

Some of these programs charge a fee, which may be 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. Use the telephone prompter on page 19 to help you get the best information from agencies.

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.

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.

If an agency representative can't 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.

Whether or not you need assistance now, 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 might need a service, and in a hurry.

Caregiving from a distance

Distance can make caregiving more complicated. You may get calls from neighbors and friends who are concerned about your relative's health or living situation, but it's difficult to know how well your older relative is functioning without being near.

Establish a network

You may be driving or flying back and forth to repeated crises or spending long weekends and vacations "getting things in order" for your family member. If so, you will need to establish a network of neighbors, friends, and professionals in your relative's community who can help assess your relative's needs and arrange for services. In some communities, health care professionals in public agencies and private businesses offer the service of coordinating the care of older persons whose primary relatives live at a distance.

Think 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.

Whether or not you need assistance now, explore community services for future needs.

Telephone Prompter

Place this prompter by 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 no):

Can you give me another name to call?

(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 whom am I speaking?

Do I need to speak to anybody else?

If you live at a distance, it's critical to support, in whatever way you can, the caregiver who has day-to-day responsibility.

A move also should be considered in light of 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 your older family member, paying for a housekeeper or respite care provider once a week, or inviting your older family member 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 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 on a day-to-day basis.

Conflict can arise between family members who live near the older person 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 they would if you had 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, someone will "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 a 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.

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 have not been told "just how bad Mom or Dad is." When changes are gradual, family members who have daily contact often are not aware of the degree of change because they have adjusted to it gradually. When you live at a distance, you have only two points of reference—the last time and now. The changes can appear dramatic.

You can help by concealing your shock which could place an additional burden on the caregiver. Unloading on the primary caregiver may create just one 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 the needs and request specific help rather than resent them for "not doing more." And, remember, show appreciation for any help you receive.

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.

You are doing many things right. Don't fail to give yourself the credit you're due.

Placement in a care facility

A time may come when you or other family members cannot provide direct care, or in-home services no longer meet your older relative's needs. Placing the frail older person in adult foster care or a care facility is sometimes the best decision for everyone. However, it might be one of the most difficult decisions you will ever make.

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

Potential benefits of placement for your relative include increased social contact, recreational and social activities, and rehabilitation services. Also, when you're no longer devoting your time to meeting the physical and safety needs of your family member, you'll be better able to meet some of his or her emotional and social needs, which is very important. Almost any trained person can assist your relative with activities of daily living—dressing, bathing, and feeding. Family and friends, however, are in the best position to share special memories and give your relative a feeling of belonging and of being loved. These feelings add immeasurably to the person's quality of life.

Conclusion

Caregiving decisions should not be based only on the needs and desires of the older person. Also consider the consequences of caregiving decisions for yourself and other family members. Making these decisions is an essential part of self-care, which in turn will help you provide effective care for others.

Even if you follow the suggestions provided here, not everything will be as you like. At times you will wish you had done things differently. You are only human. If you make a mistake, admit it, learn from it, and then go on. There is no advantage in carrying feelings of guilt.

Too often caregivers focus on what they have not done well. Remind yourself of the many things you have done well—that 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.

For more information

PNW publications

Sensory Changes in Later Life, PNW 196

Aging Parents: Helping When Health Fails, PNW 246

Hiring and Working Successfully with In-home Care Providers, PNW 547

Depression in Later Life: Recognition and Treatment, PNW 347.

Driving Decisions in Later Life, PNW 510

Helping Memory-impaired Elders, PNW 314

Making Decisions about a Nursing Home, PNW 563

Oregon publications

Talking to Your Family and Doctor about Difficult Health Care Decisions, EC 1386

If You Became Incapacitated, Who Would Make Decisions for You?, FS 332

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