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# *Coping with Caregiving*

How to Manage Stress  
when Caring  
for Elderly Relatives



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# Coping with Caregiving

## How to Manage Stress when Caring for Elderly Relatives

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

However, it is possible for you to maintain your personal well-being while providing quality care for an elderly relative. If you know the sources of stress as well as strategies for mastering them, you will benefit not only yourself but also the person for

whom you are providing care. Remember, it's just as important to take care of your own needs as it is to provide the best care for your dependent loved one.

When you are a caregiver, ignoring your own needs can harm both you and the person depending on you. Many people have been placed in nursing homes because of their caregivers' exhaustion, illness or death. By taking care of yourself and managing stress, you can help prevent such a situation for yourself 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 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, you probably have competing responsibilities for your children, your spouse and your 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. Regardless of your situation, there are ways to reduce the conflict and stress caused by the demands of caregiving.

# What Is Caregiving?

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

- ♥ providing 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 that of your relative
- ♥ lifting, bathing, dressing, toileting and feeding
- ♥ managing financial and legal affairs
- ♥ providing social activity
- ♥ arranging for health care and supervising medications
- ♥ 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:

- ♥ emotional or physical exhaustion
- ♥ depression
- ♥ marital and family problems
- ♥ alcohol or drug misuse
- ♥ conflict among life roles—spouse, employee, parent, 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 is often 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.



# Symptoms and Causes of Caregiving Stress

## Warning Signs of Stress

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

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.

	<b>Yes</b>	<b>No</b>
Do you feel a loss of energy or zest for life?	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel out of control, acting or behaving in uncharacteristic ways?	<input type="checkbox"/>	<input type="checkbox"/>
Do you lack interest in people or things that you once enjoyed?	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel increasingly isolated?	<input type="checkbox"/>	<input type="checkbox"/>
Are you consuming more sleeping pills, medications, alcohol, caffeine or cigarettes than usual?	<input type="checkbox"/>	<input type="checkbox"/>
Are you having increased health problems—for example, high blood pressure, ulcers or difficulties with digestion?	<input type="checkbox"/>	<input type="checkbox"/>
Do you have trouble falling asleep at night, or do you wake up too early or sleep too much?	<input type="checkbox"/>	<input type="checkbox"/>
Have you noticed a change in your appetite or eating habits?	<input type="checkbox"/>	<input type="checkbox"/>
Do you have trouble concentrating or remembering things?	<input type="checkbox"/>	<input type="checkbox"/>
Are you increasingly irritable or impatient with others?	<input type="checkbox"/>	<input type="checkbox"/>
Do you have thoughts of suicide?	<input type="checkbox"/>	<input type="checkbox"/>

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## The Causes of Stress

The causes of stress vary with the caregiver and his or her responsibilities. What creates stress for you may not create stress for someone else. There are, however, some common sources of caregiving stress, which can be identified in the next series of questions.

After you answer the questions, look carefully at those to which you answered “yes.” You will want to focus your full attention on these specific areas as you work to reduce stress.

	<b>Yes</b>	<b>No</b>
Are there many demands on your time, energy or money?	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel that your responsibilities conflict with each other?	<input type="checkbox"/>	<input type="checkbox"/>
Is there a difference in the expectations of your family, your boss, your dependent relative and yourself?	<input type="checkbox"/>	<input type="checkbox"/>
Do you believe that you do not fully understand the older person’s mental or physical condition?	<input type="checkbox"/>	<input type="checkbox"/>
Do you have difficulty meeting your relative’s physical or emotional needs?	<input type="checkbox"/>	<input type="checkbox"/>
Are you pressured by financial decisions and a lack of resources?	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel a loss of freedom, a sense of being “trapped”?	<input type="checkbox"/>	<input type="checkbox"/>
Is there disagreement among family members?	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel that other family members aren’t doing their share?	<input type="checkbox"/>	<input type="checkbox"/>
Does the older person place unrealistic demands and expectations on you?	<input type="checkbox"/>	<input type="checkbox"/>
Is there a lack of open communication between yourself and the older person or other members of the family?	<input type="checkbox"/>	<input type="checkbox"/>

Do other family members have negative attitudes that you must contend with?

 

Can you see deterioration in your family member that is painful to watch?

 

Do you have other problems with children, marriage, employment or health?

 

## Strategies for Managing Stress

Once you know the sources of stress, you must determine which are ones you can do something about and which 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 don't have to be major to make an important difference. Sometimes, letting go of unrealistic expectations or adjusting your standards of how often or how well you perform a task (such as housekeeping) will make a big difference in reducing your stress.

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

♥ **Set realistic goals and expectations.**

- Plan achievable goals.
- Develop realistic expectations.

♥ **Establish your limits.**

♥ **Ask for and accept help.**

♥ **Take care of yourself.**

- Express your feelings.
- Maintain your health.
- Take time for yourself.

♥ **Involve other people.**

- Hold a family conference.
- Seek professional assistance.
- Use your community resources.

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### Set Realistic Goals and Expectations

**Plan achievable goals.** What do you want to accomplish? The basic goals of caregiving are to ensure 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. Although it is important to

be objective about your situation, it is not always easy. You need to know 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 can often assess whether the behavior is intentional or disease-related and therefore unintentional. By determining the reason for the behavior, you can adjust your expectations and responses.

You will see results more often if you select goals that are specific and achievable. Specific goals are short-term and focused on a clear problem. Having only broad, long-range goals is more likely to produce frustration. You may have

a long-range goal of getting your relative back to his or her own home, if possible. However, some specific, achievable, short-term goals might include:

- ♥ keeping your relative's spirits up by arranging for friends and family to visit
- ♥ developing your relative's physical strength by arranging for people to take him or her on daily walks

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

Goals should also be considered in terms of the ill person's personality and abilities. Some caregivers are driven by goals such as "make Mother happy." Given your mother's personality or the accumulation of recent losses (such as the death of her spouse or a move to a nursing home), this goal may be completely unachievable. Such an objective creates a heavy burden, and you'll probably feel that you'll never attain it.

A specific and achievable accomplishment, however, might be to provide an enjoyable activity at least once a week for your mother, perhaps spending a couple of hours each week visiting friends or working a puzzle. If you set specific goals like these, 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 often struggle to balance their self-expectations with what they can actually achieve. Sometimes we expect too much of ourselves and constantly worry that we are not doing what we should. Women caregivers are particularly vulnerable to "shoulds." Because of our society's expectations, 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. But such promises can prevent us from objectively assessing the current situation and can make us less able to make the best decisions for everyone concerned. It's important not to let old promises, "shoulds" or guilt guide your 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 that when the promise was made. You'll probably find that 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 your family member's health or in your life circumstances.

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## 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. There are times, of course, when it's necessary to go beyond limits. When additional resources simply are not available, you may not have a choice. 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 that not doing so will increase your stress.

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

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## Ask for and Accept Help

How do you respond to offers of help? Is it difficult to ask for assistance? When you do request support, 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 believe “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 self-sufficiency, it’s not easy to request help. Some caregivers view asking for help 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 are often 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 of assistance, or you may appear to have everything under control.

People can best help 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 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 for Uncle Joe?”

Tasks unrelated to actual 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 which limit the assistance they can provide.

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## Take Care of Yourself

**Express your feelings.** It’s vital that you find someone with whom you can talk openly about your situation and your emotions.

**Understand your emotions.** Being a caregiver and seeing the decline of a loved one 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, repugnancy, guilt, grief, fear, resentment, hopelessness or despair. You may feel angry about the increased dependency of your family member and the multiple demands on your time, energy and money. As changes occur in your family member, you may grieve for the loss of your relative as he or she used to be. Feeling unappreciated is sometimes a problem for the caregiver, 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 your relative less. What is important is how you handle your feelings. Learning to express your feelings and 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 acknowledge and understand your emotions, you can then control them. Repressing or denying feelings decreases energy and can cause irritability, depression or physical problems. Your feelings can also 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, or get involved in vigorous physical activity such as running, chopping wood or digging in the garden.

**Use assertive communication.** It is not constructive to express your feelings in a manipulative or hostile way, to get even with someone or to create a sense of guilt. Such responses may indicate that you are stuck in an “anger trap.”

To avoid the anger 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 whatever is bothering you. Say, for example, “I was upset when you didn’t make the doctor’s appointment for Mom that you said you would,” or “I felt frustrated when you didn’t show up to stay with Aunt Sallie so I could go to the grocery store.”

Also, avoid “you” or blaming statements that imply others are responsible for your feelings. Blaming statements, such as “You just 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 using terms such as “always” and “never”—the person will usually deny these statements because “never” and “always” are rarely true. Assertive communication encourages problem-solving.

Recognition and appreciation are important needs. If you do not feel appreciated, you need to let others know. Ask for positive feedback. If the care-receiver is able to communicate, tell your feelings to him or her.

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

In some areas, support groups have developed for this kind of sharing. Some groups are oriented to specific diseases such as cancer, Parkinson’s disease, lung disease or Alzheimer’s disease and related dementias. Others are for family caregivers in general.

Many caregivers find that support groups help them feel less alone. Support groups give you an opportunity to share openly with others who

understand and to learn techniques for coping. They also provide an opportunity to share your knowledge and to help other group members.

For information about local support groups, contact 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 also 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 think that exercising would be just one more demand, develop ways to incorporate it into your daily routine. If your family member 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.

To make exercise a pleasurable event for you, find an activity you enjoy. Do it at least 30 minutes per day most days of the week.

Humor is also 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.** 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?

All too often, caregivers place their own needs last. Helping an elderly relative should not mean giving up all activities and relationships with other people. Studies show that sacrificing yourself in the care of another and removing pleasurable events

from your life can lead to emotional exhaustion, depression and physical illness.

Taking breaks from caregiving is essential for both full-time and part-time caregivers. You have a right—and 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 yourself. It can increase the dependency of the care-receiver. The ill person who sees very 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.

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 are away, ask yourself, “What is the worst possible thing 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 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 or 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 or short stays in adult foster care homes, nursing homes, or hospitals.

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

- ♥ What kind of help do I really need (regular or occasional)?
- ♥ What times would be best for me?
- ♥ How much advance notice do I need to give the substitute care provider?
- ♥ What information should the respite provider have about the older person’s special needs and routine?
- ♥ How should the respite provider deal with an emergency (who and where is the back-up)?
- ♥ 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 there, 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’m exhausted and I need to get away for a while.” If your relative has impaired memory, it may help to leave a note indicating the time you will return.

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## 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 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. The conference can also clarify each person’s expectations and minimize misunderstandings.

**Include everyone.** Everyone who is concerned and may 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, 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, limited resources or family history with the older person. 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 will help them feel a part of the decision-making process. 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.

**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 the tasks they are willing to do.
- ♥ Hold the conference in a neutral place. Holding the conference in the older person's home will help 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 that 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.

- ♥ 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 it can better assure that needed tasks will be completed.

**Realize there may be conflict.** A family conference is not always easy, and in some families, it is impossible. It's most difficult for families who have never discussed feelings and family concerns.

Decision-making is difficult when conflicts already exist among family members or when family members come together after years of separation. Old conflicts can re-emerge regarding 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 believes that “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 that the impaired person should be kept at home, regardless of what needs to be done; another may think 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.

Bringing in an objective third party skilled in working with the elderly and their families can often help. If family conflicts or hidden resentments prevent rational discussion, seek professional guidance. A counselor, health or social service professional or a 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.

**Obtain professional guidance.** Receiving professional advice and assistance can help

reduce some stress. Consider seeking professional guidance in these situations:

- ♥ 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 can also result in neglectful or abusive behavior.
- ♥ You become depressed. Untreated depression can impair 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 find yourself feeling resentful or losing emotional control, or neglecting, humiliating or becoming physically rough with a family member. These behaviors are often 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 a conflict between caregiving and other responsibilities.

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

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 cannot help you, ask for names of others who can.

**Use your 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 programs and support groups, as previously discussed. Programs designed to directly serve the elderly can also help the caregiver.

If you pay for outside assistance early in the caregiving process, it 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.

Services vary among communities, but some of the most common include:

- ♥ *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 people living alone, friendly visitors can provide a safety check as well as companionship.
- ♥ *Telephone reassurance* provides regular telephone calls to those who are homebound ill or disabled.
- ♥ *In-home medical alert programs* ("Lifeline") offer the impaired person an electronic device to wear that sends a signal if he or she falls or needs help. The signal is sent to a central dispatcher, often located at a hospital. Emergency assistance is summoned if the older person does not answer the telephone.
- ♥ *Chore services* provide help with yardwork, winterization and minor home repair. In some areas, chore services also include assistance with laundry, cleaning, household chores, grocery shopping and meal preparation.
- ♥ *Homemaker services* assist with shopping, laundry, light housecleaning 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 older people, usually around lunchtime. 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 may be available for those unable to drive.

- ♥ *Transportation services* provide vans or buses that can be called to transport the older person to and from doctors' appointments, rehabilitation sessions, congregate meal programs and sometimes grocery shopping and other activities.
- ♥ *Adult day care* is a special program for people who are physically or mentally unable to live independently and need protective services during the day. Programs vary, but they often offer health and medical monitoring, meals and recreational group activities. The program may enable some caregivers to continue their employment.
- ♥ *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 those needing nursing care at home. Other services such as physical therapy, speech therapy and home health aide services also can be provided.

Some of these programs require a fee, which may be calculated on a sliding scale that is determined by your ability to pay for them. 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 don't have time to make the necessary calls, enlist the help of other family members and friends. They can 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. Use the telephone prompter on the last page of this document to help you get the best information from agencies.

If an agency representative cannot answer your questions, ask to speak to the supervisor. Try not to become 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 then, 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 may need a service, and in a hurry.

## Strategies for Managing Stress

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 nearby.

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### 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 far away.

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## 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. Because 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, which can present major problems. The person may become entirely dependent on you for social

and emotional support. The move is more difficult if your family member does not make friends easily or is limited in mobility or verbal skills.

Also consider the move in light of your past relationship with the 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.

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## Support the Local Caregiver

If you live far from the family member needing care, it's critical to support, in whatever way you can, the caregiver who has day-to-day responsibility. Maintain regular contact. Call often 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.

People who provide daily support to an older family member often do not feel 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.

Because of their different perspectives, conflict can arise between family members who live near the older person and those who live away. 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 not 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 to make 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 believe it should be, it may not be that family members are neglectful. Your father may be refusing help with the household chores.

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## 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 occur gradually, family members who have daily contact are often not aware of the degree of change because they have gradually adjusted to them. When you live out of town, you have only two points of reference—the last visit and now. The changes can appear dramatic.

You can help by keeping your shock from placing 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 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.

## Placement in a Care Facility

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

Moving your 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, helping staff understand your family member’s needs and monitoring the care he or she receives.

The potential benefits of placement for your relative include increased social contact, rehabilitation services and recreational and social activities. 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 some of 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 special memories and give your relative a feeling of belonging and of being loved. These feelings add immeasurably to the older person’s quality of life.



## Legal Considerations

Although **guardianship** is not something that most people plan for, it can be an essential protection if for people who cannot take care of themselves or their property. The need may arise when an adult is brain injured in a car accident or when an older person loses the ability to make decisions because of dementia. If this happens, a court may decide if guardianship is necessary and may appoint a guardian to make decisions.

The court may decide how much authority to give to the guardian. A guardian might be appointed only to make decisions about living arrangements, personal needs and medical care. Or, a guardian might be appointed only to make decisions about finances and property. The same person or agency could be appointed to make both kinds of decisions.

Because it is often easier for a person to transfer legal authority himself or herself rather than having the transfer ordered by a court, it is important to review your legal options when providing care for an older adult before it is actually needed. Although many aspects of caregiving involve allowing the individual to function independently for as long as possible, legal considerations should be reviewed at the outset of caregiving.

For more information on legal documents and decision making, visit <http://www.lawhelp.org>.

As legal guidelines and information vary from state to state, be sure to select the particular state of residence in which you are interested.

**Advance care planning** is the legal process of helping people:

- ♥ understand their medical condition and potential future complications
- ♥ understand the options for future medical care
- ♥ discuss choices with family, loved ones and providers
- ♥ reflect upon these choices in light of personal values, goals and religious or cultural beliefs.

This planning process is vitally important, not only for older adults or those who have a serious and/or progressive illness, but also for healthy younger adults who may lose the ability to speak for themselves because of trauma or a sudden unexpected illness.

For more information on end-of-life decision making, visit the Texas Cooperative Extension Planning for Later Years website: [http://fcs.tamu.edu/families/aging/planning\\_for\\_later\\_years/index.php](http://fcs.tamu.edu/families/aging/planning_for_later_years/index.php). Because laws governing end-of-life decisions vary from state to state, forms and documents to execute these decisions may vary as well. Contact the state unit on aging in the particular state of residence for information on the rules and regulations in that state.

## Review

Caregiving decisions should not be based only on the needs and desires of the older person. You must 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 though you follow the suggestions 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. There is no advantage in allowing yourself to be plagued by feelings of guilt.

Too often, caregivers focus on what they have not done well. 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.

## For More Information

These publications are available from Texas Cooperative Extension's Bookstore: <http://tcebookstore.org>

### **Adult Children and Aging Parents Series**

- L-2115, *Helping When Health Fails*
- L-2116, *Building Positive Relationships*
- L-2117, *Brothers, Sisters, and Aging Parents*

### **Training Program Materials**

- B-1603, *Training Respite Caregivers for Alzheimer's Family Support Manual*, \$10.00 per copy.

### **Caring for Disoriented Elderly Series**

- B-1484, *Therapy for the Disoriented*
- L-2118, *Helping the Disoriented Elderly*
- L-2119, *Caring for the Disoriented Person*

## Other Resources

Texas Cooperative Extension – Aging:  
<http://aging.tamu.edu>

Texas Cooperative Extension – Caregiver  
Education and Support [http://fcs.tamu.edu/  
families/aging/elder\\_care/index.php](http://fcs.tamu.edu/families/aging/elder_care/index.php)

Department of Aging and Disability Services  
<http://www.dads.state.tx.us>

Area Agencies on Aging of Texas (AAA) [http://  
www.dads.state.tx.us/contact/aaa\\_directory.html](http://www.dads.state.tx.us/contact/aaa_directory.html)  
or by phone 1.800.252.9240  
2-1-1 Texas  
Dial 2-1-1 from a home telephone.

Texas Partnership for End of Life Care  
<http://www.txpec.org>

U.S. Administration on Aging <http://www.aoa.gov>

U.S. Department of Health and Human Services  
– Eldercare Locator  
<http://www.eldercare.gov>  
or by phone: 1.800.677.1116

American Association of Retired Persons (AARP)  
<http://www.aarp.org/families/cargiving>

Family Caregiver Alliance – National Center on  
Caregiving <http://www.caregiver.org>

National Hospice and Palliative Care Organization  
– Caring Connections <http://www.caringinfo.org>  
or by phone: 1.800.658.8898

# Telephone Prompter

Keep this prompter by your telephone when you call about community services. It will remind you of the questions you should ask.

My name is \_\_\_\_\_

I'm caring for \_\_\_\_\_

I need \_\_\_\_\_

Can you help me? \_\_\_\_\_

**If the answer is no:**

Can you give me the name of another person to call? \_\_\_\_\_

**If the answer is 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? \_\_\_\_\_

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Extension publications can be found on the Web at: <http://AgriLifeBookstore.org>.

Visit Texas AgriLife Extension Service at <http://AgriLifeExtension.tamu.edu>.

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Revised