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Caring for an Aging Loved One

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Introduction

According to the U.S. Department of Health and Human Services, approximately 9 million Americans age 65 and over needed long-term care in 2007, with that number expected to rise to around 12 million by the year 2020.

It's easy to see why most of us think of long-term care as something needed by older people. But an accident or illness can strike at any age. Historically, the extended family group provided care when needed. But today's families are smaller and often scattered across the country, adding an extra challenge to caring for an aging loved one. Despite these challenges, families and friends continue to provide a significant amount of long-term support and care.

According to a 2004 survey conducted by AARP and the National Alliance for Caregiving, an estimated 44.4 million caregivers age 18 and older in the U.S. provide unpaid care to an adult family member or friend. Many of these caregivers are also juggling family responsibilities and work, with 59% of caregivers working either full-time or part-time. A recent study from AARP estimates that in 2006 alone, the value of unpaid care provided by friends and family was \$350 billion.

It may or may not have crossed your mind that you may become a caregiver to a family member. Perhaps you have discussed changing needs with a loved one, have assumed more responsibilities for your aging parent or relative, or have even done some planning for the future. A more likely scenario is that an unexpected event—a visit to your loved one, or a call from a physician or neighbor—will alert you to the fact that assistance is needed.

The need for care may be related to a sudden event, such as a stroke, or to a gradual process, such as the onset of dementia. In either event, you may not be sure where to begin.

This brochure describes ways to assess when a loved one needs outside care. It covers developing a care plan, organizing important documents, and what you can do to provide support. The brochure also gives guidelines for providing home care for your loved one, finding and using services to assist older individuals, and options to consider when a person can no longer live at home. It emphasizes the importance of self-care for family caregivers and suggests ways that caregivers can take care of themselves.

How Will You Know?

Does Your Loved One Need Assistance?

Decline in mental and physical capabilities is inevitable as we age. People are living longer and healthier now, so changes are likely to be slower and more subtle than they were for our grandparents. In some ways, this increased longevity and health makes adjusting to the normal process of aging easier; in others, it makes it more difficult. You may be wondering what you can do if someone you know needs additional care or support.

Ask without being patronizing. You're likely to notice a general slowdown—a cue to ask general questions. If you see specific things that worry you, talk them over. Explain your concern. Listen! Propose solutions—if needed. Better yet, ask your loved one what he or she thinks the solution might be. It may not be appropriate to insist on your approach unless there is a threat to his or her safety or to the safety of others.

Observe carefully. If you notice her clothes are not as clean as they used to be, you might ask, "Mom, can I help with the laundry? I'm usually here on the weekend. How about I throw in a couple of loads for you?"

Many older individuals dread losing their independence. If you notice your Dad's refrigerator is often empty, your instinct might be to tell him you'll be doing the shopping from now on. He may, reasonably, see that as an intrusion. Instead, talk with him. Try to determine why the fridge is empty. There are dozens of possible reasons. Perhaps he has little appetite. Maybe he is uncomfortable driving to the store because he needs new glasses.

Pay Attention. Your loved one might tell you about a problem or concern. Although it's not always the case, some older individuals are comfortable telling their family when they need help. If your Mom tells you the grocery bags are too heavy for her to carry, you can offer to shop for her or go shopping with her. You may feel you know just how to help if your Dad asks, "These eyes aren't what they used to be. Would you look over my checkbook and bills before I mail them?" Perhaps helping with the bills and scheduling an eye exam is appropriate. Possibly, however, your Dad is not concerned about his vision; maybe he is worried that his mental alertness is deteriorating. Listening sometimes means reading between the lines.

As you focus on the issues, you can speak with other family members and friends about your concerns. They may be a good source of insight, especially if they see your aging loved one regularly.

Look and Listen

If you regularly visit a friend or relative, you may see changes in mental and physical capabilities. You may notice changes in behavior, or you might see signs of a physical problem. For example, depression, a common condition for many older people, can appear as a physical problem (e.g., tiredness or insomnia), a cognitive problem (e.g., forgetfulness), or both. Remember, if an older adult seems forgetful or takes longer to do some tasks, it may be a normal part of the aging process. Paying a bill a week later is not the same as forgetting to pay bills for three consecutive months. The most important consideration is whether the changes you see pose a threat to your loved one's medical or physical safety. Some changes that may signal the need for help are:

Behavior changes

- Changes in personal hygiene
- Change in tidiness or cleanliness of the home or yard
- Laundry piled up
- Mail and bills unopened or unpaid
- Odors (e.g. from spoiling food)
- Missed appointments
- Getting lost in familiar places
- Evidence of safety risks (e.g., burned pots in cabinet)
- Evidence that medications are not being taken properly

Physical symptoms

- Weight gain or loss
- Unsteadiness when walking or getting up / down from chair
- Evidence of incontinence (e.g., odor of urine in the home)
- Unusual thirst
- Unusual fatigue

Symptoms of depression

- Darkened house with the shades drawn when you arrive
- Decreased contact with family and friends
- More withdrawn, less conversational

When you have a concern, it may be tempting to rush to intercede. It's better, however, to avoid taking over. If your loved one is able to participate, don't make unilateral decisions and don't go over his or her head. Instead, discuss the issues that you've noticed and, if you have difficulty resolving problems, consider involving the professional community—a primary care physician, a gerontologist, or a senior care specialist. They are likely to ask you about your loved one's

behavior. They may also ask about his or her cognitive status. Questions you are likely to hear include:

- Is there difficulty with Activities of Daily Living (ADL) tasks such as bathing, dressing, toileting, eating, and transferring from place to place (e.g., bed to chair)?
- Are support tasks such as shopping, laundry, meal preparation, managing finances, housekeeping, and transportation being adequately managed?
- Are you noticing significant changes in memory, judgment, or ability to make decisions?

The objective is to jointly determine the cause of the problem(s) and decide on possible interventions. If an older person has an acute event, such as an illness or accident requiring hospitalization, the social worker or discharge planner may offer helpful guidance. You can begin to develop a care plan based on insights and considerations from your loved one, the medical community, friends, and relatives.

Developing a Care Plan

A care plan will define the services and support needed to provide appropriate care. Developing a care plan is a four-step process that you can adapt to your specific circumstances.

1. List the needs for support and additional care. These will generally fall into the areas shown in the table below:

Areas of Support Older Individuals May Need
Housekeeping - laundry, shopping, and household paperwork
Social and safety needs- transportation services, companionship, and daily telephone checks
Nutrition- meal planning, cooking, and meal delivery
Health care - nursing, social work, physical and rehabilitative therapy, and medication monitoring
Personal care- assistance with personal hygiene, medical equipment, dressing, bathing, and exercise

2. Figure out who can devote the necessary time/attention to provide support (e.g., siblings, friends, etc.).

3. Make a list of specific help needed (e.g., laundry once a week).

4. Get specific commitments (e.g., Cousin Julius will do the shopping every Saturday). These commitments need to include, as appropriate, a statement of who, what, when, where, and how.

Depending on the person's needs, the plan may simply outline a schedule for house visits by you and other family members. Or it may identify community resources that will provide additional support, including meals (e.g., Meals on Wheels), transportation services, and visiting nurses. Consider whether you or a family member may be able to handle the responsibility. In some cases, you may want to consider seeking other forms of support; nutrition or preventive health services and caregiver support services that are funded in part through the Older

Americans Act and administered by the U.S. Administration on Aging. For more information about local services, contact the Eldercare Locator at 1-800-677-1116 or at www.eldercare.gov. In some cases, you may need to employ a service to supply a live-in aide(s) to provide full-time care, or consider assisted living or nursing home placement.

No doubt, you'll need to revise the care plan as needs change. For example, you would need to adjust the plan when:

- Your loved one's needs increase or decrease (e.g., recovery from a stroke).
- A caregiver quits or withdraws.
- Your life situation changes (divorce, birth of children or grandchildren, unemployment, retirement).

Organizing Documents and Paperwork

Encourage your loved one to organize important documents and medical information. Offer your help. It's critical that this be done while your loved one is medically and mentally capable of participating in this process. For example, if he or she has specific wishes for end-of-life care, they need to be documented before they're needed. (See *Managing Your Loved One's Affairs*).

Important Documentation

The following documents should be assembled in one place so they're available when needed:

- Medicare card
- Social Security card
- All health insurance ID cards
- Copy of the birth certificate
- Names, phone numbers, and addresses of doctor(s). Note: If your loved one wants you to be able to discuss medical issues with a doctor, ask him or her to complete privacy release forms. Keep them on file with each doctor's office.
- List of health conditions
- List of current medications and the name and phone number of the corresponding pharmacy and prescribing physician.
- List of allergies to food or medications
- Will, Living Will, and Powers of Attorney: ask if you may make copies to retain. If these documents don't exist, encourage your loved one to prepare them. (See *Managing Your Loved One's Affairs*). If you're reluctant to do so, ask the doctor to discuss the medical issues and/or the attorney or financial advisor the other issues.
- Copies of insurance policies, including life insurance and long-term care insurance.
- Information about finances including the name and contact information for the tax preparer or accountant. Note: Ask your loved one where he or she keeps the financial records.

Create a laminated Reference Sheet

It is a good idea for every older adult to have a complete list of emergency telephone numbers and information. Laminate the list and put it in an obvious place (e.g., the refrigerator door, by the phone, in the top drawer of your desk, etc.) so it will be available for Emergency Medical Technicians (EMTs) or others who may need it. The sheet should contain at least the following information:

- Name, address, and telephone number, his or her birth date, social security number, and medical insurance information (e.g., Medicare and supplemental insurance information).
- Name and contact information for primary care giver.
- Primary physician's name and contact information.
- A list of all medications and dosages.
- Phone number of pharmacy.
- Names and contact information for other caregivers, relatives.
- Specialist medical personnel and their contact information (e.g., Cardiologist).
- Whether your loved one has a living will and/or a durable power of attorney that allows another person(s) to make financial and/or medical decisions if your loved one is unable to do so (if so include contact information).

Managing Your Loved One's Affairs

Although you may not like to think about it, your loved one may become unable to act on his or her own behalf. This can happen when one is nearing death or as the result of a physical or cognitive condition that may be either permanent or temporary. Many people assume their spouses or children will automatically be allowed to make financial and/or medical decisions for them, but this is not necessarily so. There are important legal and end-of-life decisions that need to be made while your loved one has the capacity to make these decisions.

Powers of Attorney

A power of attorney is a legal document that allows one person (called the principal) to appoint someone else—called the agent or attorney-in-fact—to act on his or her behalf. The powers that can be exercised by the agent can be broad or narrow; the principal stipulates them, in advance. Your loved one (the principal) might, for example, authorize you (the agent) to do a specific thing (e.g., sell the house). The principal can give the agent the authority to perform any legal act he or she would do. If an older person becomes incapacitated without having a power of attorney, the family may have to go through lengthy and expensive legal action so that someone can act on the individual's behalf.

The two main types of powers of attorney are:

- A conventional power of attorney gives the agent whatever powers the principal chooses for a specific period of time (e.g., 30 days) beginning when it is signed.
- A durable power of attorney stays in effect for the principal's lifetime—beginning when it is signed. **This power of attorney must contain specific language stating the agent's power is to stay in effect even if the principal becomes incapacitated.**

Signing a power of attorney does not mean a person gives up the right to act on his or her own behalf. The power of attorney assures the principal that the agent will be able to act when and how the principal directed, if it becomes necessary. Also, it's important to note that a person can revoke or cancel their power of attorney at any time.

Planning Medical Care and Treatment - Advance Directives

Advance directives are written documents that tell doctors what kind of treatment is desired if a person becomes unable to make medical decisions (e.g., falls into a coma). They can take many forms, and it's a good idea to understand state laws before writing an advance directive. Federal law requires hospitals, nursing homes, and other institutions that receive Medicare or Medicaid funds to provide

written information regarding advanced care directives to all patients upon admission.

Living wills are a kind of advance directive that come into effect when a person is terminally ill. A living will does not give one the opportunity to select someone to make decisions, but it allows the person to specify the kind of treatment wanted in specific situations. For example, your loved one might specify that she or he doesn't want to be treated with antibiotics if death is imminent.

A Do Not Resuscitate order (DNR) is a type of advance directive specifying that if a person's heart stops or if he or she stops breathing, cardiopulmonary resuscitation (CPR) is not to be given. Unless they are directed otherwise, hospital staff will try to help all patients who have stopped breathing or whose heart has stopped. A person can tell the doctor not to resuscitate and a DNR order will be entered on the medical chart.

A durable power of attorney (sometimes called a durable medical power of attorney) names the person who is to make medical decisions for another person. It is activated any time the person is unconscious or unable to make medical decisions. State laws vary, but most states disqualify anyone under the age of 18, the person's health care provider, or employees of the health care provider. The individual named as the agent must:

- Be willing to speak and advocate on the older person's behalf.
- Be willing to deal with conflict among friends and family members should it arise.
- Know the person well and understand his or her wishes.
- Be someone the individual trusts with his life.

Spiritual or religious beliefs may have bearing on the types of advance directives one chooses to prepare. Although death is often a difficult subject to raise, it is a good idea for you, your family members and your loved one to discuss these issues to ensure everyone understands the older person's values and beliefs. The more communication there is, the easier it will be for the family to respect your loved one's wishes.

Advance directives don't have to be complicated legal documents; they can be relatively short statements about what one wants done when one can't speak on their own behalf. Any advance directive must, however, comply with state laws. It's also a good idea to have written advance directives reviewed by the senior's doctor and lawyer to make sure that all instructions are understood as intended. Once advance directives are finalized, copies are distributed to the family, medical power of attorney agent, and the doctor.

When Your Loved One Needs Skilled Care

While, as discussed earlier, you may gradually notice changes in your loved one that lead to the need for long-term care, in other instances the need may arise without warning. Sometimes a sudden event, such as a hip fracture or stroke, will lead to the need for long-term care for an individual who had previously been independent. Sometimes the worsening of an existing medical condition, such as heart disease or diabetes, will result in the need for long-term care, where previously the individual required no assistance. In each instance, a loved one may first require “skilled care,” which is care delivered by professional staff, such as nurses and therapists. Often a hospital stay followed by a period of rehabilitation or treatment in a short-term rehabilitation facility or nursing home is needed to treat and stabilize the medical condition or injury. For some, rehabilitation may take place at home. Medicare or other insurance may cover care for rehabilitation either at home or in a nursing facility. Services might include nursing care, therapy services and home health aide services as long as the person meets Medicare criteria for receiving skilled care. A referral for these services would likely be to a Medicare-certified home health care agency or skilled nursing facility.

When Your Loved One Needs Long- Term Care

Some individuals will return to independent living following a period of rehabilitation or treatment, but some will continue to need care with daily activities on an ongoing basis. This long-term care, often referred to as “custodial care” may be provided in one’s home or at another location. Whether the need for custodial care arises gradually or suddenly following an episode of skilled care, the goal is to help the person remain as independent as possible with the help of supportive services. These may include help with the activities of daily living (ADLs) such as bathing, dressing, and toileting and/or assistance with what are called instrumental activities of daily living (IADLs) such as shopping, transportation, laundry and finances. These services may be provided by family members—who may require training for certain activities such as assistance with getting someone in and out of bed following a stroke—or by paid caregivers.

Decisions will need to be made based on family preferences and availability, the financial situation, and the amount and type of care needed. You will have to look at the costs for custodial care services and determine how they will be covered. Costs will vary depending upon the type of care your family member requires. Some agencies may have a sliding fee schedule or there may be other resources in the community that would be available to provide some services. Medicare as well as most health insurance policies do not cover longterm care services.

It is important to understand that some individuals who need longterm custodial care may also need some skilled services on an ongoing basis. Others may need skilled care intermittently to treat an illness or injury. Their long-term care needs

will continue to need to be addressed and perhaps re-evaluated following episodes of skilled care, as needs may have changed. Needs may also gradually change over time and the care plan will need to be adjusted to meet changing needs. Sometimes care providers who had been assisting may no longer be available. If your loved one's need for care increases, you could find that informal caregivers are no longer able to meet all the care requirements. In this situation, you may need to increase the amount of service given by paid care providers. Or you may find that your loved one's needs may best be met in another location such as your home, an assisted living facility or a nursing home.

The various types of longterm care services and resources to help you locate needed care are described in this brochure. The information looks at what could be called a "continuum" of long-term care services which are available based on the needs of the individual requiring the care. It provides options to consider as your loved one's needs change over time.

Providing Home and Community-Based Care

When you know what support is needed, and who among family and friends can provide help, you and your loved one can begin developing the care plan. Most often, care for an older adult begins in the person's own home; he or she remains in a comfortable, familiar environment, and retains a measure of independence. This is what is often referred to as "aging in place."

Sometimes a supporting relative or friend will have unique qualifications. For example, if your sister Susie is a freelance writer working from home, she may be the best person to deal with unscheduled emergencies. If Aunt Sally, the nurse, is comfortable talking with the medical community, she might agree to be the medical liaison.

Your plan, of course, depends not only on the needs of your loved one, but also on your specific situation. Options are limited when a friend or relative doesn't live nearby. For example, if your friend Ellie (who lives 100 miles away) can no longer drive or handle her own housekeeping activities, you have few choices. In such situations, you may be able to assist by asking a friend of Ellie's to buy the groceries. Perhaps you can arrange for Ellie to employ a house cleaner or other service to do housekeeping tasks.

Home care includes a multitude of medical and personal services provided in your loved one's own home. Home assistance is available through some hospitals, home care agencies, and public health departments.

Arranging a home and community-based care program requires investigation and organization. The Eldercare Locator Service— 1-800-677-1116—can connect you with the local Area Agency on Aging, which can provide information on most aspects of home care, including how to find competent caregivers. You may also want to ask for referrals from friends and relatives, physicians, and hospital discharge planners. You will probably have to coordinate services from more than one source.

Finding Community Resources

For additional assistance in locating community resources, check with a local senior center, local volunteer programs, or local and national disease associations such as the Alzheimer's Association. (See "For More Information").

The table below lists types of services available in many communities.

Community Resources for Older Adults
<ul style="list-style-type: none">• Supportive services (handyman, chore, personal care, telephone reassurance, friendly visitors)• Adult day services that provide respite care (i.e., to give family and friends time off)• Transportation Services• Meals (congregate and home delivered) and nutrition screening and counseling• Preventive Health Service• Home health care• Hospice Care (e.g., local hospitals)• Nursing and therapies

Most of these services are *not* free, although they may be covered by insurance and / or Medicare. If you are a caregiver, help may be available to you under the **National Family Caregiver Support Program**. This program, which is part of the **Older Americans Act**, provides the following services:

- Information about available services
- Assistance in gaining access to services
- Counseling
- Support groups
- Caregiver training
- Respite care
- Supplemental Services

Help is available for finding the most appropriate resources through information and referral services like the Eldercare Locator service. Still, finding and coordinating services can be a challenging task. One possible option is to employ the services of a Geriatric Care Manager (GCM). A GCM is often a nurse or social worker who can help assess needs and arrange services for older people.

The GCM can make an initial assessment of care needs and suggest options for meeting those needs, including referrals to local resources. This may be especially helpful if your loved one is at home and you are uncertain what he or she needs, or what services are available. You may find a GCM through a local senior center, Area Agency on Aging, an elder care attorney, or a gerontologist. Be sure to check references. Verify that paid caregivers have the appropriate

licenses or certifications. Determine the cost for the GCM's services and find out how they are billed.

Adult Day Care Centers

These programs are an adjunct to home care. They offer social and health services in a group setting to individuals who are frail, physically challenged, or cognitively impaired. They provide a safe, protective setting during daytime hours. Services may include medical care, rehabilitation therapies, nutrition therapy, and health monitoring. Adult day services are often a cost-effective option. The centers offer a respite to family and other caregivers, helping them avoid burnout and, perhaps, helping loved ones avoid admission to a residential care facility. (See For More Information for sources to help locate adult day-care centers in your community).

If your loved one is receiving care through a home care agency or another community resource such as an adult day center, keep the name and phone number of a supervisor available in case you have questions. Also, make certain the supervisor or nurse who will be overseeing your loved one's care has your phone number should there be an emergency or should any questions arise.

Maintaining Dignity

It's important to help your loved one maintain a sense of personal dignity. If she or he understands what is happening and can communicate, this may involve primarily being respectful and patient. In situations where an older adult has problems performing daily tasks, communicating or understanding due to either a physical condition such as a stroke or a cognitive disorder such as Alzheimer's disease, the most generous gift you can give may well be enabling him or her to maintain dignity. Some of the things you might do to help preserve your loved one's dignity:

- Be patient and calm.
- If an older person has difficulty hearing, speak slightly slower and use a lower pitch. Use simple, short sentences, and let your loved one see your face and expressions when speaking. Repeat and clarify when necessary—without being patronizing.
- Encourage him or her to be as active and independent as possible; reading, hobbies and helping out around the house can be marvelous therapy.
- Welcome visitors and encourage continued participation in groups, clubs and organizations, card games and discussing memories.
- Be sensitive to feelings and preferences. Acknowledge his or her desires even if they are different from your own.
- Be aware that your efforts may not always be appreciated.

- Be honest if you have concerns, and don't make promises you can't keep; take your loved one's concerns seriously.
- No matter how helpless a loved one appears, don't reverse roles. Treating an aging loved one like a child can crush any remaining feelings of dignity and independence.
- Encourage him or her to be as active and independent as possible; reading, hobbies and helping out around the house can be marvelous therapy.

Monitoring Care

When an ailing, older person lives at home, it's important to monitor how things are going. This is true even if there is full-time home care in place.

- Get updates from neighbors or relatives who may be assisting or who visit on a regular basis.
- Communicate regularly with your loved one. Give him or her a chance to tell you who or what is wrong, even when signs of dementia are present.
- Make visits, both planned and unplanned, to see all aspects of his or her care (e.g., at meal time, at bed time, during recreational times).
- Talk with the individual care providers (e.g., the aides), and the agencies providing the services.
- Trust your instincts, especially if your loved one is unable to communicate what he or she needs or what may be wrong. If you are uncomfortable, or if your loved one complains about a specific person, it may be time for a change. Always err on the side of caution.

In certain situations, you may feel that more oversight is needed than you or nearby family members can provide. If you choose to work with a GCM, he or she can formally monitor your loved one's care, at your request. This approach may be especially important if you live far away and cannot visit on a regular basis.

When Your Loved One Can No Longer Live at Home

If a person's care needs cannot be met in his or her own home, a permanent change in living environment may be necessary. Moving to a new living situation will involve a period of adjustment for your loved one. This adjustment time will be needed regardless of whether he or she is moving to a nursing home, an assisted living facility, an apartment closer to you or into your home.

When a Loved One Moves in with You

If you've decided care in your home is appropriate, you'll probably need to make some changes around the house. Changes can be as complex as adding another bathroom or converting a first-floor den into a bedroom. Or changes could be as simple as attaching a safety rail to the shower or having an amplified receiver installed on the telephone. In addition to making necessary physical changes in your home, you'll want to make sure your loved one feels welcome in your home by displaying favorite possessions—particularly mementos and photographs—in plain sight.

Assisted Living Facilities

Those who need care beyond what they can receive at home but not requiring the level of care provided by a nursing home may find the help they need in assisted living facilities. Many of these residential facilities provide a home-like atmosphere, and some are structured so that individuals have their own apartments. Staff is available to assist twenty-four hours a day. Depending on specific needs, residents can receive assistance with housekeeping, meals, and personal care, including help with daily activities such as eating, bathing, and dressing. There are no federal regulations for assisted living facilities, and the licensing requirements vary from state to state. Assisted living facilities may be referred to by other names such as personal care home, residential care facility, and adult group living facility.

Nursing Homes

Nursing homes, also referred to as nursing facilities, are residential facilities that provide round-the-clock care and supervision. Nursing homes offer a range of services from skilled care for seriously ill people who require close supervision by a licensed nurse to custodial care, often provided by nursing assistants supervised by a nurse.

All states have licensing requirements for nursing homes and perform surveys to evaluate the quality of care. Most states maintain databases you can access to get general information about a facility (e.g., number of beds), resident details (e.g., percent of residents who are physically restrained), and staffing details (e.g., staff hours/resident ratio). You can also see the results of state evaluations

and often summaries of complaints lodged by residents and families. This information can provide a starting point for selecting a nursing home.

Choosing a Nursing Home or Assisted Living Facility

Before selecting a nursing home or assisted living facility, investigate several. You can use your state's database and get recommendations from friends. You can tell a lot about a facility by walking around and observing the residents and staff. You should also, where possible, try to speak with residents or their family members to see what their experience has been.

In addition to what you see, you'll need answers to many important questions to determine if a facility will meet your needs and expectations. There are excellent resources available to help you identify the information you need to evaluate a residential facility; some provide a checklist. One such resource is the National Citizens Coalition for Nursing Home Reform website. (See For More Information for links to this and other helpful websites).

Who Pays for Long-Term Care?

Long-term care is expensive. Even a temporary stay in a nursing home can derail years of careful financial planning. Although costs may vary significantly depending upon where you live, the average national cost for care in a nursing home is more than \$75,000 a year for a private room and more than \$66,000 for a semi-private room.

Medicare: What It Can and Can't Provide

Medicare is the federal government's health insurance program for the disabled and for people age 65 and over. Many Americans believe Medicare will pay their long-term care bills. In fact, Medicare pays only under certain conditions and only for a limited number of days. Currently, Medicare may cover skilled care in a nursing home for (up to) the first 20 days, and a portion of the cost for (up to) the next 80 days if admission follows (at least) a three-day hospital stay and the individual needs skilled care. The "need" for skilled care is determined according to specific Medicare criteria. To receive home care benefits from Medicare an individual must also meet specific Medicare guidelines.

The biggest gaps in Medicare coverage are:

- No coverage for "custodial" care, either at home or in a nursing home. (Care is considered custodial when an individual's condition is stable, care needs have not changed over a period, and care needs are not expected to change.)
- No coverage in a nursing home unless it immediately follows hospitalization of at least three days.
- No coverage for nursing home care after 100 days.
- Coverage only through a facility or home health care agency approved by Medicare.

(See "For More Information" for links to obtain more information about Medicare benefits and Medigap Plans, which are supplements to Medicare sold by insurance companies. They pay for some of the costs not covered by Medicare, including co-payments and deductibles. They do not, however, provide coverage for long-term care).

Medicaid

Medicaid is a joint federal/state program that pays for health care for people with limited income and assets. The federal government has established broad national guidelines under which each state can establish its own eligibility standards. In order to receive Medicaid benefits, the recipient must meet the state's guidelines for income and asset eligibility. This means, for example, that most of your loved one's assets will need to be "spent down" or used up before

he or she becomes eligible. To obtain information about the Medicaid program, contact your local Medicaid office or Department of Social Services.

Taking Care of You

If you are to be the coordinator, the primary care giver for a loved one, it can be a big job! Many of the demands on you could be unscheduled and could disrupt your normal routine. When Uncle Harvey can't make it to Mom's, you'll have to go. If Dad calls you when he falls and sprains his ankle, you'll be the one to take him to the doctor or hospital. If a paid caregiver is unsatisfactory or quits, you may have to sleep at your loved one's house until you can find a replacement. Beyond the unexpected, you may also have extensive routine responsibilities. You may need to manage finances or deal with medical, legal, community, or government bureaucracies. It can be a big job. Although, as a family caregiver, you may often be under a huge strain, you can do things to ease the pressure.

Balancing Caregiving and Other Responsibilities

Most caregivers juggle work responsibilities as well as two households. It can be especially difficult if your loved one doesn't live near you. Below are some things to think about as you figure out how to balance these responsibilities.

Your Household. As you plan, implement, and monitor care for your loved one, don't forget to plan for your own household

- Keep your family informed about your caregiving responsibilities and how it may impact them
- Try to provide your home family with at least a general schedule of your caregiving commitments.
- If you find yourself spending a lot of unscheduled or additional time as a caregiver, figure out how you'll fill the gap in your responsibilities (e.g., can your spouse help the children with homework, carpool, etc.)?

Your Job. The responsibilities of caregiving can have a significant impact on work obligations, sometimes more than anticipated. Caregivers may be concerned that requesting changes to work schedules and obligations can threaten job security. Many times, however, creativity and flexibility on the job are necessary to fulfill caregiver and employee responsibilities.

Employers are finding that the caregiving responsibilities of their employees impact productivity in the workplace. Today, an employer may have programs in place to assist employees in caregiving roles. As a caregiver, you may want to research what is available to you in your workplace. Some options might be:

- **Flex time.** You may be able to work part-time or to work longer hours on some days and shorter hours on others.
- **Telecommuting.** Your employer may have a program for working from home one or two days a week.

- **Employee Assistance Programs.** These programs provide information and support for employees. Some employers have Eldercare Referral programs which provide employees with access to a Geriatric Care Manager to assist them in locating resources and services for their loved one. Usually the Human Resources Department can provide information on this.

Finding Time for Yourself

All too often, caregivers focus on everything but their own needs. At any given moment, it may be the kids, the job, the care recipient, or the family finances. Rarely does a caregiver step back to see how he or she is doing, and all too frequently a caregiver's family and friends forget to ask. As selfish as it may seem, and even as guilty as it may make you feel, take time for yourself. Caring for you is not being selfish. The following list has some important things for you as a caregiver to think about:

- Sometimes it's helpful to speak with others in situations similar to yours. You may want to consider a support group either online or in person. As awkward or reluctant as you may feel at first, you will find that most support group participants are experiencing or have experienced many of the emotions and frustrations that you may be feeling. www.caregiver.org provides a link where you may search for both local caregiver support groups and community resources by state, county and zip code. They also offer an online caregiver discussion group.
- Take care of your physical health. Don't ignore physical symptoms such as continual headaches, backaches, or stomach pains.
- Your emotional health is as important as your physical health. Give yourself credit for what you are doing. Recognize what you can and can't change and act on what you can.
- Be aware of your diet, and work exercise into your life. Exercise can help reduce stress and ward off depression.
- Set limits and learn to say no—to friends, family and your loved one.
- Don't let yourself become isolated from friends, family and activities that you've always enjoyed. If necessary, let people know that you need them to include you, and not to be put off if you decline an invitation.
- Check with a health care professional or counselor if you have concerns about either your physical or emotional health, or if others are voicing concerns about you.

Taking good care of yourself is important not only for you, but also for your aging loved one.

For More Information

References

How To Care for Aging Parents
by Virginia Morris
Published by Workman Publishing Company, Inc.

The Comfort of Home: A Complete Guide for Caregivers
by Maria M. Meyer and Paula Derr
Published by CareTrust Publications, LLC

& Thou Shalt Honor: The Caregiver's Companion
B. McLeod, Editor
Published by Rodale Books

The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer
Disease, Related Dementing Illnesses, and Memory Loss in Later Life
by Nancy L. Mace, M.A. and Peter V. Rabins, M.D., M.P.H.
Published by Mass Market Paperback

Caring for Yourself while Caring for your Aging Parents:
How to Help, How to Survive
Claire Berman and Deborah Brody, Editors
Published by Owl Books, Henry Holt & Co., LLC.

Caring for Your Parents: The Complete AARP Guide
by Hugh Delehanty and Elinor Ginzler
Published by Sterling Publishing Company, Inc.

Helpful Websites

www.cms.hhs.gov

Centers for Medicare and Medicaid Services (formerly Health Care Finance Administration) has information about the Medicare and Medicaid Programs.

www.alz.org

The Alzheimer's Association offers information and supportive services to families and individuals dealing with Alzheimer's disease.

www.alzheimers.org

The Alzheimer's Disease Education and Referral (ADEAR) Center is a service of the National Institutes of Health. The Center provides information to patients, families, and professionals about Alzheimer's disease and services.

www.alzfdn.org

The Alzheimer's Foundation of America (AFA) provides information about brain health, Alzheimer's disease, and other forms of dementia. It gives tips for caregivers, as well as information about local resources to assist individuals with Alzheimer's disease and their families.

www.benefitscheckup.org

The Benefits Checkup site was developed by the National Council on Aging (NCOA) to assist seniors and their families in determining benefit eligibility for services in their area.

www.caregiving.org

The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. The website includes helpful information and resources for caregivers.

www.aahsa.org

The American Association of Homes and Services for the Aging website contains a consumer section with information about long-term care services, a searchable service provider directory for both home care and facility care and links to other important resources for caregivers.

www.caregiver.org

Founded in 1977, Family Caregiver Alliance (FCA) serves as a public voice for caregivers, illuminating the daily challenges they face, and offering them assistance. The website has information related to a variety of caregiving topics and a state by state searchable resource directory.

www.nccnhr.org

The National Citizens' Coalition for Nursing Home Reform (NCCNHR) was formed because of public concern about substandard care in nursing homes. The website includes the ability to search for the nursing home ombudsman in your area should you have questions or concerns about nursing facilities in your area.

www.aarp.org

AARP provides information on caregiving, long-term care, and many other topics related to aging.

www.medicare.gov

The official government Medicare site includes many topics important to Medicare beneficiaries including planning for long-term care, and a nursing-home search tool and comparison guide. It also has consumer publications related to many of the aspects of Medicare as well as useful tools and calculators to help when making Medicare decisions.

www.aoa.gov

Administration on Aging (AOA) is maintained by the U.S. Department of Health and Human Services, and provides resources, news, and information for older adults as well as links to the Eldercare Locator and the National Long-Term Care Clearinghouse, which contains important information related to planning for long-term care.

www.eldercare.gov

Funded by the Administration on Aging, the Eldercare Locator assists older persons and their caregivers with access to support services in the geographic area in which they live (1-800-677-1116).