

GUIDE

The Caregiving Journey



Options and considerations for you and your loved one



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NATIONAL ALLIANCE FOR CAREGIVING

Established in 1996, The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. The Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients. www.caregiving.org

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This guide will help IF you or a loved one:

- Require ongoing care after a sudden illness, accident, or hospital stay.
- Cannot live independently anymore.
- Provide care or manages the caregiving process.
- Need to understand the costs associated with caregiving.
- Need to find help in caring for a family member.

WHAT IS A CAREGIVER?

You might shop for groceries once a week for a homebound relative or neighbor, help an aging parent with finances, or provide hands-on care for a member of your household. The need for care may have occurred suddenly or gradually. If you provide assistance to someone who is disabled or who needs help with day-to-day activities because of an accident, a chronic condition, or cognitive limitation, you, like many other Americans, are a caregiver.

Assess the Situation

THE CAREGIVING JOURNEY

No matter what kind of help you provide, caregiving is a journey with twists and turns along the way. Circumstances change. Care needs change. Options for care change. It is also a learning process. Sometimes you may doubt you're doing the right thing or if you're doing enough. Be patient with yourself and take it one step at a time. Give yourself credit for the effort you make in caring for someone important to you. And don't be afraid to ask for help along the way.

Caregiving by the Numbers

- More than 65 million Americans are family caregivers.
- More than 30% of U.S. households, or an estimated 36.5 million U.S. households, have at least one member who provides care for a family member, friend, or loved one.
- The average age of a caregiver is 48.
- Among caregivers, 66% are female and 34% are male.
- More than seven in ten work or have worked while providing care.
- Of those providing care, 22% are age 18–34; 29%, age 35–49; 35%, age 50–64; and 13%, age 65 and over.

Source: *Caregiving in the U.S.* National Alliance for Caregiving and AARP, funded by the MetLife Foundation, November 2009.

HOW TO ASSESS YOUR LOVED ONE'S CARE NEEDS

The needs of a care recipient will change with time. Your first step in developing an appropriate care plan is to do a thorough needs assessment to determine the extent and type of assistance your family member may require and the resources you'll need to provide. If your family member will need ongoing care, your plan may also be called a long-term care plan.

The assessment process may involve input from a variety of sources, both informal and formal. For instance, you may first notice subtle changes as you visit your family member. Making regular visits to aging parents or other relatives is one of the most effective ways to assess their abilities and any changes that may be occurring over time. Be observant and use your senses to help objectively assess the situation. Note any changes in your family member's appearance or abilities, or in the condition of his or her home.

Concerned neighbors, friends, or other family members who see your loved one more frequently than you do may also bring concerns to your attention. Use whatever resources are necessary to complete a thorough needs assessment.

Begin the assessment by taking the following steps:

- Speak with your loved one's physician to fully understand your family member's current medical diagnosis and prognosis. Bring any concerns you have, along with those your family member or others have expressed, to the attention of the physician for a complete evaluation.
- Differentiate assistance needs between personal care and supportive care. Personal care, sometimes called Activities of Daily Living, includes bathing, dressing, toileting, eating, and transferring from place to place, e.g., bed to chair. Supportive care, also called Instrumental Activities of Daily Living, includes activities such as laundry, meal preparation, shopping, managing finances, housekeeping, and transportation. Making these distinctions will be helpful once it's time to choose appropriate caregivers.
- Include an evaluation of your family member's cognitive status including the state of his or her memory, judgment, and ability to make decisions.
- Evaluate your loved one's desire for care. Does your loved one express any wishes for personal or household assistance? It is important to be a good listener, and listening sometimes means reading between the lines. Specific wishes along with your loved one's acceptance or resistance to care will be important factors in making decisions.

For additional help to make your assessment, check with the following:

- **Local senior center.** Senior centers often have social workers who can perform assessments or direct you to those who can.
- **Geriatric care manager (GCM).** This is often a nurse, social worker, or other professional who has special training in gerontology. GCMs can do in-home assessments, develop care plans, and monitor services. You can visit the National Association of Professional Geriatric Care Managers (NAPGCM) Web site (www.caremanager.org) to see if there is a care manager near your family member and to learn more about NAPGCM's services.
- **The Eldercare Locator.** This is a government-sponsored program (www.eldercare.gov) that can direct you to resources in your area to assist with the assessment and care plan development.
- **Social worker or discharge planner.** After an illness or accident that requires hospitalization, a social worker or discharge planner at the hospital will most likely work with you and your family member to plan for and implement follow-up care upon discharge.

Know the Signs

Watch for these signs that may indicate your loved one needs extra assistance with:

Activities of Daily Living (ADLs)

- Do you notice a change in personal hygiene?
- Does there seem to be a change in weight?
- Does he or she appear unsteady when getting up or down from a chair?
- Are there any indications of incontinence on the part of your family member (e.g., an odor of urine in the apartment or home)?

Instrumental Activities of Daily Living (IADLs)

- Is there a change in tidiness or cleanliness in the home?
- Is dirty laundry piling up?
- Is mail stacked on tables or desks? Are bills unopened?
- Are there smells from spoiling food or garbage?
- Is there enough food in the refrigerator and cupboards? Is it fresh or has it gone bad?

Cognitive or emotional situations

- Does he or she seem to be increasingly forgetful?
- Are the shades drawn and the house dark when you arrive?
- Has your family member lessened his or her contact with family and friends?
- Does your family member appear withdrawn?
- Has he or she missed appointments or gotten lost in familiar places?
- Do there appear to be any safety risks, e.g., burnt pots in the cabinet or evidence that medications are not being taken properly?

If you answered yes to any of these questions, bring these concerns to your family member's physician so any changes can be properly evaluated.

COMMUNICATION IS KEY

Effective communication is a critical component throughout the caregiving experience: in the assessment process, the planning process, the monitoring of ongoing care, and any plan adaptations over time. Good communication skills help caregivers adapt to change by enabling them to obtain and share information, ask for what they need, and stay connected to others.

COMMUNICATE WITH YOUR LOVED ONE

It's important to remember at every step to include your family member in the decision-making process to the fullest extent that he or she is able to participate. You'll want to address the areas of concern and care options with him or her. If you have the services of a social worker, care manager, or discharge planner available, have that person present during your discussion.

Be sensitive to your family member's preferences and feelings. Acknowledge his or her desires even if they're different from yours. It is normal for even the closest of families to experience heightened levels of emotion and interpersonal strain during this period. Emotions such as fear and anger may cause confusion or create communication barriers. It is not unusual for family members in need of care to resist help initially. Fear of losing independence, a mistrust of "strangers," concerns about money, and resistance to change in general all play a factor in making decisions.

Remember the following and you'll have better success in communicating with your loved one and others in your family.

- Listen for the meaning behind your loved one's words. We all want to be heard, and by acknowledging your loved one's fears, concerns, or other emotions, you will provide a measure of comfort. Find common ground and express agreement whenever possible. If you can both agree on the problem, you will stand a better chance of coming up with solutions that are acceptable to everyone.
- Know your limitations as a caregiver. A family member, parent, or significant other may want you to be the only caregiver. However, he or she must understand that this is not always possible, and that you may need to enlist the services of others from outside the home. Setting limits may be difficult at first, but once you do, you may find that family members worry less, knowing that you're taking care of yourself. Also, by effectively communicating your limits, you will take much of the guesswork out of planning and problem solving.
- Ask for assistance from others. If your family member is resistant to receiving help or has an illness such as Alzheimer's disease that affects his or her judgment or ability to respond effectively, consider accessing the services of a trusted third party such as a doctor, clergyperson, or social worker to help in reviewing the options and mediating the situation.

BUILD YOUR CAREGIVING TEAM

Sometimes support will come from places you did not expect such as neighbors, friends, and other family members. Support from friends and other family members begins with informing them about the situation and the potential need for their assistance. Communicate regularly with all who are involved in assisting or providing care, including any paid care providers. This is vital to effective care planning, implementation, and monitoring.

As the primary caregiver:

- Ask direct questions.
- Do not make assumptions.
- Listen to what others have to say.

Be specific in what you ask, e.g., “Can you come every other weekend and mow the lawn?” “Can you stay with Dad next weekend? I have a wedding to attend out of town.” Don’t be offended if your request for help is declined. Family members or others may be unable or unwilling to help with a particular task, but ready and willing to do something else.

Understand the Options

DETERMINE THE CARE SETTING: HOME, ASSISTED LIVING, OR NURSING HOME

Identifying the right care setting is an important first step in the care planning process. Sometimes the initial care setting is a temporary one. For instance, if a family member is hospitalized for a hip fracture, he or she may need to go to a skilled nursing facility for rehabilitation prior to returning home. Sometimes an individual will temporarily go to the home of a relative before returning home.

If you have questions or concerns regarding the care setting, it is often helpful to involve a professional such as the doctor or a social worker. Choosing the care setting can be very emotional and may involve differing opinions among family members. It can be especially difficult if the decision requires a lengthy or permanent move to a residential setting such as an assisted living community or nursing home.

Sometimes a sudden change in a loved one's physical or mental functioning does not permit time for extensive planning. However, where time permits, fully explore the options, especially if there are disagreements among family members. The right or wrong option may not be clear. Trust your instincts as you, your family member, and others weigh the options available. If a selected setting does not meet your family member's needs, another can be chosen in the future.

CARE AT HOME

Most people prefer to receive care in their own home, and family caregivers work with them, if possible, to allow them to do so. The extent of the care needs, the home setting itself, the preferences of the care recipient, and the availability of family, friends, and community-based services that will be able to address care needs in the home setting are clear factors in the decision. Sometimes modifications need to be made to adapt the home so it can serve as a care setting. The expansion of community-based and home care services has allowed many people, who would have otherwise required care in a residential setting, to remain at home.

While most people want to remain in their own homes, sometimes this is not realistic. An individual's home may not be able to serve as a care setting, even with modification, or he or she may not be able to obtain sufficient services at home to meet care needs. Moving to your home or the home of another relative may be another option. A number of factors would need to be considered including whether the home can be modified to serve as a care setting for your family member, whether sufficient care services would be available to meet his or her care needs, how the other members of the household feel about your family member moving in, and whether your loved one wants to move from his or her home and perhaps lose touch with a community of friends where he or she is currently living.

 **See also *The Essentials: Receiving Care at Home* and *The MetLife Aging in Place Workbook*.**

CARE IN A RESIDENTIAL SETTING

If a residential setting other than home appears to be the most appropriate place for care, an assisted living community or nursing home are the most common choices.

ASSISTED LIVING COMMUNITY

Assisted living is a residential housing option that combines independent accommodations such as an apartment or individual or shared rooms with support services such as dining, wellness, social activities, personal care, medication management, and more.

Assisted living helps older adults enjoy a lifestyle that allows for independence, dignity, and social involvement with the benefits of assistance to meet their daily needs. It generally includes 24-hour supervision, housekeeping, meal preparation, and assistance with personal care.

Assisted living is an option available for those who:

- **Do not need the skilled medical attention** that a nursing home would provide, but would benefit from being around others in a community setting and having assistance available 24 hours per day should they need it.
- **Have had a significant change in health** that has led to a major impact on lifestyle.
- **Have a cognitive disorder** that requires 24-hour supervision to protect their safety. Some assisted living communities specialize in care for those with dementia.

As is the case with nursing home care, planning ahead when you are not in a crisis will give you the opportunity to explore the assisted living option more thoroughly: the different populations served, the setting, and the available services. While assisted living is a more independent setting than a nursing home and some care recipients welcome a move to a setting where assistance is available 24 hours per day, others may resist this move as it is not living independently in their own home, the place they would prefer to be.

 **See also The Essentials: Assisted Living Communities.**

NURSING HOME

A nursing home is a residence that provides a room, meals, 24-hour nursing, rehabilitative care, medical services, and protective supervision for its residents. The goal is to help people regain or maintain as much of their independent function as possible in a supportive environment.

In many families, there is whole-hearted agreement that nursing home placement will never be an option. This is a promise made with love and conviction and is perhaps based more on feelings than on fact. There are times when a nursing home is the most appropriate setting.

Your family member's physical and mental changes, plus the care options available to meet his or her needs, will help you determine if nursing home care is needed. Your loved one may be able to receive needed care at home initially, but may have a condition that is progressive and may require nursing home care in the future. If so, it is helpful to plan early by exploring facilities in your area should they eventually be needed.

 **See also The Essentials: Choosing a Nursing Home.**

PAYMENT OPTIONS

No matter where your loved one lives, caregiving services can be costly. Unfortunately, most health insurance plans do not cover ongoing long-term care services.

Long-term care services are often financed through the individual's personal funds or assistance from family members.

- **Medicare** will cover some nursing home and home health care services but only if individuals have a need for skilled care that meets Medicare criteria for benefit reimbursement.
- **Medicaid** covers long-term care services for certain individuals with very limited income and assets.
- **Long-term care insurance** is intended to provide benefits for long-term care services. If your family member has such a policy, check to see what is covered. An individual is not eligible to purchase a policy if he or she is already in need of long-term care services.

Some care options are less costly than others. For instance, adult day services can be a cost-effective alternative for many people living at home who require significant amounts of care or supervision. There are some programs that receive government funding to provide services to older individuals, often on a sliding scale. Your local Area Agency on Aging (www.n4a.org) can be a resource for learning about these programs. You can also visit www.benefitscheckup.org, developed by the National Council on Aging (NCOA). It can assist you in determining benefit eligibility for services in your loved one's area, especially if he or she has limited income.

Payment Option	Description
Medicare	The federal government’s health insurance program for certain disabled individuals and individuals age 65 and over. It does not cover custodial care or ongoing long-term care services, but it will provide benefits for limited amounts of care in a nursing home or at home if an individual meets Medicare’s guidelines for skilled care.
Medicaid	Medicaid is a joint federal-state program that covers nursing home and other long-term care services, as defined by each state’s program, for individuals with limited income and assets who meet Medicaid eligibility requirements.
Long-Term Care	Private insurance specifically designed to pay for long-term care (LTC) services. If your family member has this insurance, it can be a good source of benefits. LTC insurance is medically underwritten and cannot be purchased once someone is already in need of long-term care services.
Veteran’s Benefits	In some instances, veterans are entitled to benefits for long-term care services.
Personal Financing	The resident’s or family’s personal funds.

Managing the financial aspects of long-term care can be difficult. Social workers in hospitals, home care, and residential settings can help you understand how the different insurances work and under what circumstances various services are covered.

 **See also The Essentials: Adult Day Services, and The Essentials: Medicare and Medicaid.**

Make a Plan

ESSENTIALS OF A LONG-TERM CARE PLAN

A clearly articulated and organized caregiving plan serves to provide quality care that will meet your loved one's needs and ensure good communication among those providing the care. Your plan should include:

- Where care will be given.
- What services are needed.
- Who will provide each service.
- When services are to be provided.
- How caregiving costs will be paid.
- What legal documents need to be gathered and/or created.

THE PLAN FOR CARE AT HOME

Most people prefer to receive care at home, and, where possible, family members work with them in developing a plan. A care plan defines the environmental adaptations, services, and support needed to provide appropriate care that will allow your loved one to live safely and securely in his or her own home or, if needed, in the home of a family member.

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

Common Support Areas	
Housekeeping	Laundry, shopping, managing household finances, household chores, and other supportive activities
Social and safety needs	Transportation services, companionship, activities and daily telephone checks, supervision to protect the safety of those with Alzheimer's disease or similar disorders, and home adaptations and equipment to support safety
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, dressing, eating, bathing, toileting and transferring (e.g., bed to chair)

2. **Identify any environmental changes or equipment that may be needed to support your family member.** If a family member has mobility problems, you may need to make home adjustments such as installing a ramp if a wheelchair is needed to get in and out of the home and grab bars in the bathroom if transferring and mobility are a concern. Physical and occupational therapists and visiting nurses can help in evaluating these needs. In the case of a hospital stay, the discharge planner can assist with ordering needed equipment such as hospital beds, walkers, and bedside commodes. If a family member has dementia, you may need to modify the environment to protect his or her safety. (See the Guide *Alzheimer's Disease: Caregiving Challenges*.)
3. **Identify informal resources to meet needs.** In addition to identifying the types of help your family member will need, you also need to:
 - Determine the amount of help needed and create a list of people who can provide it.
 - Have a conference with your family members and others, either in person or by phone, to discuss the extent of care needs and specific ways in which various people can help.
 - Create a list of what each person will do and when, e.g., your mother's neighbor agrees to check in on her each morning. Your brother will manage financial affairs such as bill paying and contacting insurance companies regarding claims.

Once you have figured out what friends and family can help with certain tasks and what tasks you are able to do, you can determine what other services are needed to complete the plan. You may find there is little informal support to assist you, or the informal support is not sufficient to meet all of the identified needs. It is important to be reasonable about what level of support others can provide, especially neighbors and friends. Depending on the extent of the care needs, it may be necessary to locate community resources and arrange for paid care.

 **See also *The Essentials: Adult Day Services* and *The Essentials: Receiving Care at Home*.**

4. **Identify and initiate formal (paid) care services.** Home care services and community-based services have grown significantly over the years, but finding the services that best meet your loved one's needs may not always be easy. This is an area where referrals and the assistance of professionals can be helpful. Ask any professionals with whom you are working e.g., a geriatric care manager or a hospital discharge planner to help you locate resources or consult the Eldercare Locator (www.eldercare.gov).

If services are ordered at the time of discharge from a hospital, the discharge planner can arrange for those services. As is the case with evaluating residential services, your input and evaluation and that of your family member, where possible, will be important in finding the services to best meet your family member's needs.

If you do not initially require outside services to support your family member, it is still helpful to explore the resources in your community because care needs or the availability of informal supports may change over time. Planning ahead by identifying and evaluating potential resources will help make plan adaptations easier and promote continuity of care.

Home-Based and Community Resources

Home care services provide a variety of care delivered in your home or your loved one's home, including home health aides to assist with personal care, homemakers to assist with housekeeping activities, nurses, therapists, and social workers.

Adult day services (ADS) provide social and health programs for physically frail, disabled, and cognitively impaired adults. Most programs offer transportation to and from the local senior center, in addition to meals, nursing supervision, therapeutic, recreational, and social activities, and health oversight.

Transportation services are offered by many communities, either public or privately hired. Your local senior center or Area Agency on Aging (www.n4a.org) is the best place to check for this referral.

Friendly visitors and telephone monitoring are usually provided on a volunteer basis through programs in the community. Churches, senior centers, or organizations such as the United Way or the local Area Agency on Aging sponsor such programs.

Personal Emergency Response (PERS) or Medical Emergency Response System is an in-home system that allows a person to obtain assistance in the event of a situation such as a fall, heart attack, or accident in the home. The individual wears a pendant or bracelet that he or she presses in the event of an emergency. This service can be very important for individuals who live alone or are alone for much of the time.

THE PLAN FOR RESIDENTIAL CARE

Once you determine that either assisted living or a nursing home is the appropriate option, matching the needs of your loved one with the most appropriate setting can seem overwhelming at first. However, there are steps you can take to assist with the choice.

- 1. Identify any special care needs and preferences.** Make certain that the preferences of your family member and his or her special care needs are taken into consideration.
- 2. Ask for referrals.** If you're choosing a residential setting for someone who is presently at home, your physician and other professionals such as nurses or social workers who may be providing home care services to your family member can provide referrals. If your family member is hospitalized, the discharge planner should be able to assist. Also speak with friends and family members.
- 3. Seek objective help.** Your local long-term care ombudsman (www.ltombudsman.org) may be able to assist in providing a list of area nursing homes and assisted living communities. He or she can provide you with information on any problems, strengths, or weaknesses with a setting, but the ombudsman cannot recommend a specific facility.
- 4. Evaluate the location.** When possible, visit those settings you are considering with your family member. Make unannounced as well as announced visits at various times of the day as you review options. There are tools to assist with your evaluation. Don't be afraid to ask questions and explore any areas of concern you may have. Be observant and speak with other residents and their family members as well as staff when you visit.

It may seem that you'll never find the right setting for everything that you want for your family member. But once you've looked at a few settings, compared them, and assessed the ability of each setting to meet your loved one's needs, then you'll be ready to make the decision.

After you make your decision, you may doubt yourself. Give yourself and your family member time. There will be a period of adjustment. Stay involved and visible in your family member's life. This will be beneficial to both of you. In some instances, you must be the voice for your loved one. Speak up for what you feel is important; ask about what you don't understand. Stay open to suggestions, and don't be afraid to reassess the situation and make changes if you feel they are appropriate.

 **See also the tools: Assisted Living Checklist, Assisted Living Cost Calculator, and Nursing Home Assessment.**

KEEP LEGAL AND FINANCIAL AFFAIRS IN ORDER

Sitting down with your family member to discuss financial and legal matters may be uncomfortable at first, but it is important to honor his or her wishes, even at a point when he or she is no longer able to make them known. Topics for discussion might be wills, living wills, estate planning, and powers of attorney for health and financial matters. Documents you will need to find include health, life, and other insurance information, bank information, and investment information. Certain documents need to be executed by your loved one when he or she has the capacity to understand the issues and make decisions.

With proper documents in place, loved ones will legally have their say should the time come when they might not otherwise be able to communicate their wishes.

- Learn what is important to your loved one in making additional financial and health care decisions so personal wishes can be carried out.
- Determine the location of each document so that it can be accessed if needed.
- Make copies of health insurance cards, living will, and durable power of attorney documents. Make caregivers aware of their location so they can be given to emergency personnel should your family member need to go to the hospital.
- Encourage the use of a qualified attorney or financial planner if your family member is reluctant to discuss personal matters with you.

Once formal documents have been created, make sure their location is readily available and plan to review them at least every two years. Remember that estate planning and terminology can vary from state to state. Enlisting the help of a qualified elder law attorney may be beneficial.

 **See also The Essentials: Legal Matters.**

Elder Law Attorneys

When you need legal help and advice, elder law attorneys have experience with older adults and an appreciation for many of the physical and mental challenges associated with the aging process.

These lawyers can assist older persons and their families with such issues as Social Security, Medicaid, Medicare, estate planning, and preservation of assets. They can also help your family member with completing important legal documents such as wills, living wills, and durable powers of attorney for health and financial matters.

Monitor and Adapt

MAINTAIN A WATCHFUL EYE

Your advocating skills are critically important to your loved one's care. Do not assume that information about your family member's health conditions, personal likes, abilities, or style of living has been passed along to in-home caregivers or the staff at a nursing home or adult day services center, even if you are told it was. It is smart to give information twice, particularly about medications, allergies, special precautions, and abilities.

Remain actively involved with your family member's care. Speak with him or her frequently to determine how he or she feels about the care plan and the care providers. Understand that there will be a period of adjustment for your loved one — whether the care is being provided at home or in another residential setting. The adjustment may take longer if the plan involved a move from the family member's home.

As you monitor the care of your loved one, be sure to:

- 1. Take your loved one's concerns seriously and encourage him or her to express feelings, concerns, or questions.** Observe how your family member appears to be doing. Has his or her mood changed? How does he or she appear physically? Sometimes individuals are fearful of expressing their concerns, and your observations can help bring them to light.
- 2. Maintain contact with the care team to get their perspective on how your family member is doing,** to keep them updated on any changes in your family member's health, and to let them know you are available should concerns arise.
- 3 Bring any concerns based on your observations or conversations with your family member to their attention.** Early attention to a concern can help prevent a crisis in the future.
- 4. Provide positive feedback directly to caregivers and their supervisors when things are going well.** Also, let the friends and families who are part of the care team know how much you appreciate their contributions.

Over time, the needs of your loved one will likely change, and you may need to make adjustments in the care plan. You can often receive assistance from the care providers in place should additional services be needed. Providers in the community are often aware of other available resources and can help you implement them.

Monitoring Care in the Home

- Keep the entire care team apprised, both informal and paid providers, of changes in your loved one's health or medications.
- Get to know the paid care providers who are assisting your family member and keep regular contact with your informal care team. They both can be important resources as to how your loved one is doing.
- Visit on a regular basis at different times of the day if possible. Make unannounced visits.
- Keep a list of important phone numbers and information you need as a caregiver in an accessible location. You may need to keep a copy at your work location as well as in your home.
- Keep a list of important information and contact information related to your family member in his or her home should an emergency arise or he or she needs to see a new doctor.
- Keep a list of pertinent information available for individuals giving direct care to your family member. Often, new caregivers will be introduced if the regular caregiver is ill or no longer available, and this can be a resource for them.

 **See also the tools: Family Caregiver Emergency Information, Important Information for Caregiving, and Personal Health Information.**

Monitoring Care in Assisted Living Facilities or Nursing Homes

- Learn the personnel structure of the facility and the name of the person to contact for giving and getting information about your family member. Keep that person's contact information handy in the event that questions or concerns arise.
- Develop good communication with the staff. It is helpful to get to know the head nurse on the floor or wing where your loved one is residing as well as the nurse on the evening shift. Introduce yourself to the social worker and other members of the care team including the therapists and nursing assistants who are caring for your loved one.
- Find out the procedures for sharing your concerns.
- Visit on a regular basis at different times of the day if possible.
- Maintain regular telephone communication with a staff member familiar with your loved one's care. Be certain to also identify an alternate staff member should your usual contact person be unavailable.
- Attend care planning conferences or ask for one if you feel it is needed.

Individuals whose families are involved in a positive way generally have higher spirits and receive better care. With your watchful eyes and active involvement, you can rest better knowing your family member is recognized, understood, and treated well.

TAKE CARE OF YOURSELF

It can be easy to lose sight of your physical and emotional needs when you are performing the rewarding but often difficult task of providing care. Emotions such as guilt, anger, regret, and hopelessness —“burnout”— can erode your physical and emotional state if you don’t allow time for your own needs.

It is critical to maintain your own life, complete with social, physical, and emotional interactions. You need it and deserve it. When you are at your best, you will be more effective in carrying out your caregiving responsibilities.

Be aware of the signs that you may need more help with your duties:

- Excessive use of alcohol, medications, or sleeping pills.
- Appetite changes—either eating too much or too little.
- Depression — hopelessness, feelings of being alone, lack of energy to do new things.
- Increased irritability.
- Trouble falling or staying asleep.
- Chronic fatigue.
- Difficulty concentrating or missing appointments.
- Physical symptoms such as continual headaches, backaches, or stomach pain.

Check with a health professional or a counselor if you have concerns or if others are voicing concerns about you. It is not a sign of weakness to ask for assistance, but rather an indication of a strong individual who is willing to accept limitations and reach out to those people and services that will help them provide the very best for themselves and the person they care for.

PROTECT YOUR PHYSICAL HEALTH

Try to limit your consumption of soft drinks, sweets, high-carbohydrates, high-fat foods, and alcohol. Make time for exercise, even if it's only 10 to 15 minutes each day. Exercise helps you feel better, keeps your muscles strong, and can help prevent disease. Exercise doesn't need to be intense or difficult. Taking a walk, riding a bike, dancing, or doing low-impact aerobics in your home are good ways to stay physically active. Get enough rest. A good night's sleep and allowing yourself to relax during the day are both critical to your overall health and effectiveness as a caregiver.

MAINTAIN YOUR PSYCHOLOGICAL HEALTH

Social connections and support groups are keys to maintaining your psychological health. Don't let yourself become isolated from friends, family, and activities that you've always enjoyed. Respite care offers temporary relief, giving caregivers greatly needed breaks. Check out adult day service centers, home care agencies, assisted living communities, or nursing homes that offer respite care. Finding respite care for your loved one allows you the freedom and time to relax and invest in your own health and emotional well-being.

Achieving Balance

- Learn to set limits on how much you can do.
- Ask other family members to help.
- Consider respite care for your family member.
- Consider a caregiver support group.
- Ask your employer if working from home on occasion, flexible scheduling, or employee counseling are available.
- Try to balance caregiving with your work, your other family responsibilities, and your own needs.

Resources for You

Alzheimer's Association

www.alz.org / 1-800-272-3900

This is a not-for-profit national organization that provides information and supportive services to families and individuals dealing with Alzheimer's disease. The organization offers print and online educational materials and caregiver guidance. Its help line is available 24 hours a day, seven days a week. In addition, it provides information about local chapters that can assist families in finding support groups and other services in their communities. The Web site also includes an "online community," which connects caregivers with other caregivers from all across the country.

BenefitsCheckup

www.benefitscheckup.org

BenefitsCheckup is a Web site developed by the National Council on Aging (NCOA) to assist older Americans and their families in determining eligibility for benefits and services in their area.

Commission on Law and Aging (American Bar Association)

www.abanet.org/aging

The Web site provides valuable information for consumers, including A Consumer's Tool Kit for Health Care Advance Planning, which can be downloaded and printed from the site. Search under "Publications" and click on "Consumer Publications online" to access the tool kit. You also can search for legal and other aging resources on a state-by-state basis at the site.

Eldercare Locator

www.eldercare.gov / 1-800-677-1116

The Eldercare Locator, a public service of the Administration on Aging (AOA), U.S. Department of Health and Human Services, provides older individuals and family caregivers with information on state and community resources in their local area.

Family Caregiver Alliance (FCA)

www.caregiver.org

FCA provides information, education, services, research, and advocacy for the nation's caregivers. Based in California, it provides national, state, and local levels of support. The site includes a 50-state searchable resource map: Family Care NavigatorSM, which provides state-specific information on resources and programs to assist individuals and their caregivers. Also on the site are downloadable fact sheets, tools, and publications. You can call FCA at 1-800-445-8106 Monday–Friday, 9 a.m.–5 p.m. PST. (Note the office is closed from noon to 1 p.m. PST.)

Family Caregiving 101

www.familycaregiving101.org

This educational Web site is co-sponsored by the National Alliance for Caregiving and the National Family Caregivers Association with support from Eisai Inc. It provides assistance and information for family caregivers on a variety of issues related to caregiving as well as resources for locating needed services.

Foundation for Health and Aging (The American Geriatric Society)

www.healthinaging.org

The Foundation for Health and Aging (FHA) is a national, nonprofit organization established in 1999 by The American Geriatrics Society (www.americangeriatrics.org) to advocate on behalf of older adults and their special health care needs. The FHA Web site contains a comprehensive online guide, *ElderCare at Home*, which addresses physical and mental/social problems, problems in managing care, and contains specific chapters on dementia. The site also offers a "What to Ask" series with questions to ask health care providers about various care issues. A hard copy of the guide can be ordered for \$19.95 by calling 1-800-334-1429 ext. 2529.

National Academy of Elder Law Attorneys (NAELA)

www.naela.org / 520-881-4005

This Web site is for attorneys who deal with the many issues facing older adults and the disabled. NAELA attorneys can assist clients with estate planning, long-term care issues, powers of attorney, wills, and trusts. Within the site is a search field to find an elder law attorney in your area and a helpful question-and-answer section to assist you in your search.

National Alliance for Caregiving (NAC)

www.caregiving.org

The NAC Web site contains research on caregiving as well as practical assistance for caregivers, including a guide to hospital discharge planning, a guide for caring for aging parents, and a palliative care guide. It also has a database called the Family Care Resource Connection that can be accessed in the "Caregiver Tips & Guides" section. This database allows caregivers to search for information on specific topics and includes reviewed and rated books, videos, and Web sites related to a wide variety of caregiving issues.

National Association of Area Agencies on Aging (n4a)

www.n4a.org

The National Association of Area Agencies on Aging (n4a) is the umbrella organization for our nation's 629 area Agencies on Aging and a champion for the 246 Title VI Native American aging programs. At the Web site, you can search for your local Area Agency on Aging. Area Agencies on Aging were established under the Older Americans Act (OAA) in 1973 to respond to the needs of Americans age 60 and over in every local community. They provide a range of options that allow older adults to choose the home care and community-based services and living arrangements that suit them best. The goal is to help older adults remain in their homes and communities as long as possible.

The National Long-Term Care Ombudsman Resource Center (NORC)

www.ltombudsman.org

The NORC is a resource to help find a nursing home or assisted living community if your loved one needs this level of care. An ombudsman can help with any concerns or complaints you may have related to care in a facility. At the site, you can search for the contact information for the ombudsman program in your state.

So Far Away: Twenty Questions for Long-Distance Caregivers

www.nia.nih.gov/HealthInformation/Publications/LongDistanceCaregiving/

This free guide from the National Institute on Aging, National Institutes of Health is specifically designed for long-distance caregivers and looks at 20 key areas to think about in a question-and-answer format. In addition to providing helpful information and tips, it includes a list of useful resources with contact information. It can be downloaded and printed or ordered by calling toll-free 1-800-222-2225. The NIH Publication number is No. 05-5496.

Strength for Caring

www.strengthforcaring.com

The Strength for Caring Web site provides a wealth of information for caregivers on topics such as medical diagnoses, financial planning, legal issues, insurance, and daily care. You can download and print caregiving brochures from a variety of organizations. It also has a listing of statewide and local caregiving and health care resources as well as support information for each of the 50 states.

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