National Institute on Aging

Long-Distance Caregiving

Twenty Questions and Answers

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Introduction

Five years ago, Dave's mother moved from their old house in Philadelphia to an apartment that was closer to his sister in Baltimore. Before the move, the 30-minute drive to visit his mom wasn't a big deal, and Dave had lunch with her weekly. Sometimes they'd go to a ball game together. After the move, neither Dave nor his mom expected much to change—what was another hour or so of drive time? But as time passed, the trip seemed to get longer, time together was harder to arrange, and as a result, they saw less of each other. Then his mom's health began to slide. When Dave's sister called to

say their mom had fallen and broken her hip, Dave needed and wanted to help. Should he offer to hire a nurse? Should he take a week off work and help out himself? After all the years his mom had devoted to caring for the family, what could Dave do from far away to help her—and his sister?

The answer for Dave, and for so many families faced with similar situations, is encouraging. Long-distance caregivers can be helpful no matter how far away they live. *Long-Distance Caregiving: Twenty Questions and Answers* focuses on some issues that are unique to long-distance caregiving. You will also find other information that is important to know whether you live next door or across the country.

Developed by the National Institute on Aging (NIA), part of the National Institutes of Health, *Long-Distance Caregiving: Twenty Questions and Answers* is a gateway to ideas and resources that can help make long-distance caregiving more manageable and satisfying.

But what is long-distance caregiving? It can be helping Aunt Lilly sort through her medical bills or thinking about how to make the most of a weekend visit with Mom. It can include checking the references of an aide who's been hired to help your grandfather or trying to take the pressure off your sister who lives in the same town as both your aging parents and her aging in-laws.

This resource often refers to caregiving for aging parents, but in fact, you can use the tips no matter who you are caring for—an older relative, family friend, or neighbor. The information is organized in a question-and-answer format. Each of these commonly asked questions has a brief answer. You can read them separately or together for a more complete picture of all the facets of caregiving from afar.

The most important thing to remember is that these are just ideas, suggestions, and observations from people with knowledge or experience in long-distance caregiving. Your situation might call for adaptations or even completely different solutions.

Keep in mind that healthcare providers and health plans are by law not required to share information with a person's family or friends unless they are the patient's personal representatives. For more information, visit *www.hhs.gov/hipaa/for-individuals/family-members-friends*.

The questions answered in this resource probably aren't the only ones you have about long-distance caregiving. If you would like more information, see the Resources section, which provides a sampling of other organizations that may be able to help you and your family answer your questions about long-distance caregiving.

GETTING STARTED

What is a long-distance caregiver?

If you live an hour or more away from a person who needs care, you can think of yourself as a long-distance caregiver. This kind of care can take many forms—from helping with finances or money management to arranging for in-home care, from providing respite care for a primary caregiver to creating a plan in case of emergencies.

Many long-distance caregivers act as information coordinators, helping aging parents understand the confusing maze of new needs, including home health aides, insurance benefits and claims, and durable medical equipment.

Caregiving, no matter where the caregiver lives, is often long-lasting and ever-expanding. For the long-distance caregiver, what may start out as an occasional social phone call to share family news can eventually turn into regular phone calls about managing household bills, getting medical information, and arranging for grocery deliveries. What begins as a monthly trip to check on Mom may become a larger project to move her to a new home or nursing facility closer to where you live.

Anyone, anywhere can be a long-distance caregiver. Gender, income, age, social status, employment—none of these prevents you from taking on at least some caregiving responsibilities and possibly feeling some of the satisfaction.

FREE CAREGIVER INFORMATION FROM NIA

NIA has many free resources for you. Some are available in Spanish. Here are just a few titles you might find of particular interest:

- *Alzheimer's Caregiving Tips*
- *Caregivers and Exercise—Take Time for Yourself*
- *Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging*
- *Crime and Older People AgePage*
- *End of Life: Helping With Comfort and Care*
- *Getting Your Affairs in Order AgePage*
- *Healthy Eating After 50 AgePage*
- *Home Safety for People with Alzheimer's Disease*
- *Nursing Homes: Making the Right Choice AgePage*
- *Older Drivers AgePage*
- *Online Health Information: Can You Trust It? AgePage*
- *Talking With Your Doctor: A Guide for Older People*

You can read these and other NIA resources online at *www.nia.nih.gov/health*. Print copies of some of the resources may be ordered for free on the NIA website or by calling 1-800-222-2225 (toll-free) or 1-800-222-4225 for TTY (toll-free).

How will I know if my aging relative or friend needs help?

Uncle Simon sounds fine on the phone, but I don't know if he really is okay.

Sometimes, your relative will ask for help. Or, the sudden start of a severe illness will make it clear that assistance is needed. But, when you live far away, some detective work might be necessary to uncover possible signs that support or help is needed.

A phone call is not always the best way to tell whether or not an older person needs help handling daily activities. Uncle Simon might not want to worry his nephew, Brad, who lives a few hours away, or he might not want to admit that he's often too tired to cook an entire meal. But how can Brad know this? If he calls at dinnertime and asks "what's cooking," Brad might get a sense that dinner is a bowl of cereal. If so, he might want to talk with his uncle and offer some help.

When you live far away, some detective work might be necessary to uncover possible signs that support or help is needed.

With Simon's permission, Brad might contact people who see his uncle regularly—neighbors, friends, doctors, or local relatives, for example—and ask them to call Brad if they have concerns about Simon. Brad might also ask if he could check in with them periodically. When Brad spends a weekend with his uncle, he can look around for possible trouble areas—it's easier to disguise problems during a short phone call than during a longer visit.

Brad can make the most of his visit if he takes some time in advance to develop a list of possible problem areas he wants to check out while visiting his uncle. That's a good idea for anyone in this type of situation. Of course, it may not be possible to do everything in one

trip—but make sure that any potentially dangerous situations are taken care of as soon as possible. If you can't correct everything on your list, see if you can arrange for someone else to finish up.

In addition to safety issues and the overall condition of the home, try to determine the older person's mood and general health status. Sometimes people confuse depression in older people with normal aging. A depressed older person might brighten up for a phone call or short visit, but it's harder to hide serious mood problems during an extended visit.

How can I really help from far away?

My sister lives close to our parents and has gradually been doing more and more for them. I'm halfway across the country. I'd like to help them and my sister, but I don't feel comfortable just jumping in.

Many long-distance caregivers provide emotional support and occasional respite to a primary caregiver. Staying in contact with your parents by phone or email might also take some pressure off your sister. Long-distance caregivers can play a part in arranging for professional caregivers, hiring home health and nursing aides, or locating care in an assisted living facility or nursing home (also known as a skilled nursing facility). Some long-distance caregivers find they can be helpful by handling things online—for example, researching health problems or medicines, paying bills, or keeping family and friends updated. Some long-distance caregivers help a parent pay for care, while others step in to manage finances.

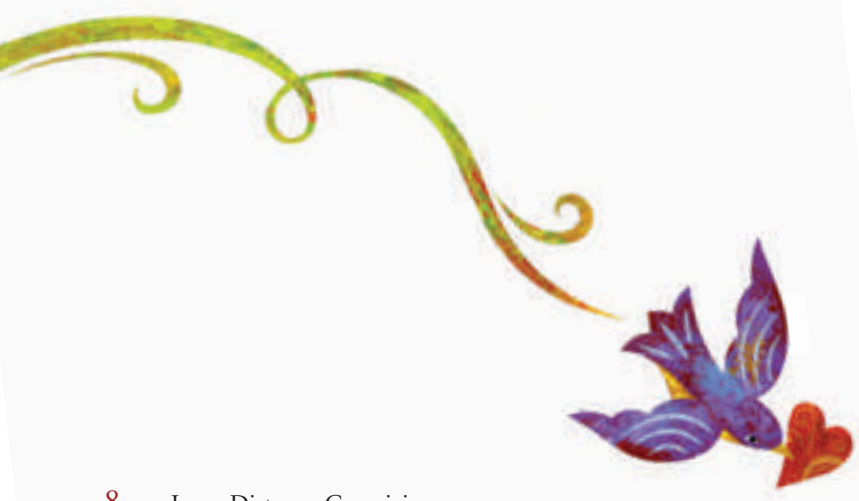
Caregiving is not easy for anyone—not for the caregiver and not for the care recipient. There are sacrifices and adjustments for everyone. When you don't live where the care is needed, it may be especially hard to feel that what you are doing is enough and that what you are doing is important. It often is.

How can my family decide about sharing responsibilities?

My brother lives closest to our grandmother, but he's uncomfortable coordinating her medical care.

This is a question that many families have to work out. You could start by setting up a family meeting and, if your grandmother is capable, include her in the discussion. This is best done when there is not an emergency. A calm conversation about what kind of care is needed in the present and might be called for in the future can avoid a lot of confusion. Ask your grandmother what she wants. Use her wishes as the basis for a plan. Decide who will be responsible for each task. Many families find the best first step is to name a primary caregiver, even if one is not needed immediately. That way the primary caregiver can step in if there is a crisis.

Think about your schedules and how to adapt them to give respite to a primary caregiver or to coordinate holiday and vacation times. One family found that it worked to have the long-distance caregiver come to town while the primary caregiver was away. Many families report that offering appreciation, reassurance, and positive feedback to the primary caregiver is an important, but sometimes forgotten, contribution.



Know Your Strengths and Set Your Limits

If you decide to work as a family team, it makes sense to agree in advance how your efforts can complement one another. Ideally, each of you will be able to take on tasks best suited to your skills or interests. For example, who is available to help Mom get to the grocery store each week? Who can help Dad organize his move to an assisted living facility? After making these kinds of decisions, remember that over time responsibilities may need to be revised to reflect changes in the situation, your parent's needs, and each family member's abilities and limitations. Be realistic about how much you can do and what you are willing to do.

When thinking about your strengths, consider what you are particularly good at and how those skills might help in the current situation:

- **Are you good at finding information, keeping people up to date on changing conditions, and offering cheer, whether on the phone or with a computer?**
- **Are you good at supervising and leading others?**
- **Are you comfortable speaking with medical staff and interpreting what they say to others?**
- **Is your strongest suit doing the numbers—paying bills, keeping track of bank statements, and reviewing insurance policies and reimbursement reports?**
- **Are you the one in the family who can fix anything, while no one else knows the difference between pliers and a wrench?**

When reflecting on your limits, consider:

- **How often, both mentally and financially, can you afford to travel?**
- **Are you emotionally prepared to take on what may feel like a reversal of roles between you and your parent—taking care of your parent instead of your parent taking care of you? Can you continue to respect your parent's independence?**
- **Can you be both calm and assertive when communicating from a distance?**
- **How will your decision to take on caregiving responsibilities affect your work and home life?**

Alice lives in Phoenix, and her father, Zhuang, lives alone in a Los Angeles apartment. She visits him several times each year. When she began to notice that her dad was starting to have problems managing some things on his own, Alice called the Area Agency on Aging. The Agency staff helped her to set up daily meal delivery and a home health aide. A few months later, Zhuang fainted in church and was taken to a local hospital. He was there for a day before someone was able to track Alice down. The hospital discharge planner wanted Alice to come in person to discuss what her father needed—but Alice couldn't get away immediately. Her husband suggested hiring a geriatric care manager, someone based in LA who could keep tabs on her dad more efficiently. Now, a care manager visits Zhuang once a month and calls Alice with updates and recommendations.

What is a geriatric care manager, and how can I find one?

A friend of mine suggested that having a professional on the scene to help my dad would take some of the pressure off me.

Professional care managers are usually licensed nurses or social workers who specialize in geriatrics. Some families hire a geriatric care manager to evaluate and assess a parent's needs and to coordinate care through community resources. The cost of an initial evaluation varies and may be expensive, but depending on your family circumstances, geriatric care managers might offer a useful service.

A geriatric care manager is a sort of "professional relative" who can help you and your family to identify needs and find ways to meet your needs. These professionals can also help by leading family discussions about sensitive subjects.

When interviewing a geriatric care manager, you might want to ask:

- Are you a licensed geriatric care manager?
- How long have you been providing care management services?
- Are you available for emergencies around the clock?
- Does your company also provide home care services?
- How will you communicate information to me?
- What are your fees? Will you provide information on fees in writing prior to starting services?
- Can you provide references?

There are organizations that can help you find a care manager near your family member's community. You can also call or write to the Eldercare Locator for recommendations. In some cases, support groups for diseases related to aging may be able to recommend geriatric care managers who have assisted other families.

THINGS YOU CAN DO

Could it help for me to organize Mom's paperwork?

My friends who have been caregivers say that a lot of what they did was to organize paperwork. I'm thinking of taking on that task to help my mother and sisters.

Organizing paperwork is one way that a long-distance caregiver can be a big help. An important part of effective caregiving depends on keeping a great deal of information in order and up to date. Often, long-distance caregivers will need access to a parent's personal, health, financial, and legal records. If you have ever tried to gather and organize your own personal information, you know what a chore it can be.

Getting all this material together is a lot of work at first, and from far away it can seem even more challenging. But once you have gathered everything together, many other caregiving tasks will be easier. Maintaining current information about your parent's health and medical care, as well as finances, home ownership, and other legal issues, lets you get a handle on what is going on and allows you to respond more quickly if there is a crisis.

If you do not see your parent often, one visit may not be enough time for you to get all the paperwork organized. Instead, try to focus on gathering the essentials first; you can fill in the blanks as you go along. You might begin by talking to your parent and his or her primary caregiver about the kinds of records that need to be pulled together. If a primary caregiver is already on the scene, chances are that some of the information has already been assembled. Talk about any missing information or documentation and how you might help to organize the records. It is also a good idea to make sure that all financial matters, including wills and life insurance policies, are in order. It will also help if someone has a durable power of attorney (the legal document naming one person to handle financial and property issues for another).

Your parents may be reluctant to share personal information with you. Explain that you are not trying to invade their privacy or take over their personal lives—you are only trying to assemble what will be needed in the event of an emergency. Assure them that you will respect their privacy, and then keep your promise.

If your parents are still uncomfortable, ask if they would be willing to work with an attorney (some lawyers specialize in elder affairs) or perhaps with another trusted family member or friend. Keep in mind that healthcare providers and health plans are by law not required to share information with a person's family or friends unless they are the patient's personal representatives. For more information, visit *www.hhs.gov/hipaa/for-individuals/family-members-friends.*

WHAT INFORMATION SHOULD A FAMILY CAREGIVER ORGANIZE?

The answer to this question is different for every family. You might want to help organize the following information and update it as needed. This list is just a starting point.

- Full legal name and residence
- Birth date and place, birth certificate
- Social Security and Medicare numbers
- Employer(s) and dates of employment
- Education and military records
- Sources of income and assets; investment income (stocks, bonds, property)
- Insurance policies, bank accounts, deeds, investments, and other valuables
- Most recent income tax return
- Money owed, to whom, and when payments are due
- Credit card account names and numbers
- Safe deposit box key and information
- Will and beneficiary information
- Durable power of attorney
- Living will and/or durable power of attorney for health care
- Where cash or other valuables might be kept in the home

Should I talk with my aging parents about the kind of care they'd like to have in the future?

My parents are in their 70s and haven't said anything about their future healthcare preferences. Since they are still relatively healthy, do we need to talk about that now?

For most of us, it is hard to talk with others about the kind of medical care they'd want if seriously ill and unable to make decisions on their own. But, when the conversation is with someone close to you, it can be many times harder for everyone. Yet, it's important to be prepared, especially in case of unexpected illness.

As a long-distance caregiver, you might want to wait until you are face to face with your parents, rather than try to handle this sensitive subject on the phone. During a visit, you could try saying that you have just made your living will, or you could tell them you've chosen someone to make your healthcare decisions. A friend or neighbor's illness might also jumpstart a conversation about healthcare preferences.

For some families, a conversation about, for example, who would like Grandma's china could be a gentle way to start the discussion. Would you rather begin on a less personal note? Discussing a topical TV show, newspaper article, or movie might be the way to start.

When talking about medical care, assure your parents that as long as they are alert, they will be the ones to make decisions. But documenting their healthcare wishes is important. Healthcare providers can't know your parents' preferences unless they are included in their medical records.

Having these wishes on the record allows your parents to receive the care they want. It may also help avoid some of the conflicts that can occur when family members disagree over treatment decisions.

Advance care planning is often done through an advance directive, which includes verbal and written instructions about future medical care. There are two types of advance directives—a living will and a durable power of attorney for health care.

A living will states in writing what kinds of life-sustaining medical treatments, if any, a person wants if he or she is unable to speak or respond and at risk of dying.

A durable power of attorney for health care names someone to make medical decisions in that same type of situation. This person, called a healthcare proxy, can decide on care based on what he or she knows the patient would want. It is vital for your parents to discuss their wishes with the healthcare proxy.

Naming a healthcare proxy is an extremely important decision. Living nearby is not a requirement to be a healthcare proxy, also called "healthcare agent" or "surrogate." Even a long-distance caregiver can be one. Most people ask a close friend or family member to be their healthcare proxy. Some people turn to a trusted member of the clergy or a lawyer. The person chosen should be able to understand the treatment choices, know your parents' values, and support their decisions.

Advance directives are not set in stone. You might want to let your parents know that they can revise and update their instructions as often as they wish. Patients and caregivers should discuss these decisions—and any changes in them—and keep the healthcare team informed. Consider giving copies of advance directives to all caregivers and to your brothers and sisters. Keep a copy at home as well. Because state laws vary, check with your Area Agency on Aging, your state department of aging, or a lawyer for more information about advance directives.

The person chosen as the healthcare proxy should be able to understand the treatment choices, know your parents' values, and support their decisions.

How can I find information about financial assistance for my parents who live across the country from me?

My parents saved money for retirement, but the cost of their medical care is really high, and they are worried.

You and your parents are not alone in worrying about healthcare costs. These expenses can use up a significant part of monthly income, even for families who thought they had saved enough. Your parents may be eligible for some healthcare benefits. As a long-distance caregiver, one way you can be helpful is by learning more about possible sources of financial help and then assisting your parents in applying for aid as appropriate. The internet can be a helpful tool in this search.

There are several federal and state programs that provide help with healthcare-related costs.

The Centers for Medicare & Medicaid Services (CMS), the federal agency responsible for Medicare, offers several programs. Over time, the benefits and eligibility requirements of these programs can change and they differ from state to state, so it is best to check with CMS, *www.cms.gov*, or the individual programs directly for the most recent information.

People on fixed incomes who have limited resources may qualify for Medicaid, *www.medicaid.gov*. This program covers the costs of medical care for people of all ages who have limited income and meet other eligibility requirements.

Under Medicare, some states have PACE, Program of All-Inclusive Care for the Elderly, *www.pace4you.org*. This program provides care and services to people who otherwise would need care in a nursing home.

SHIP, the State Health Insurance Assistance Program, *www.medicare.gov/contacts*, offers counseling and assistance to people and their families on Medicare, Medicaid, and Medicare supplemental insurance (Medigap) matters.

If your parent is eligible for veterans benefits, remember to check with the Department of Veterans Affairs (VA), *www.va.gov*. Or, get in touch with the VA medical center nearest you.

For more information about federal, state, and local government benefits, go to *www.benefits.gov*. If you don't have a computer, call 1-800-FED-INFO (1-800-333-4636).

The National Council on Aging website, *www.benefitscheckup.org*, is another good place to start. By providing some general information about your parent, you can see a list of possible benefits you might want to explore. You don't have to give a name, address, or Social Security number in order to use this service.

If your family member's prescription medicines cost too much, ask the doctor if there is a less expensive medication or a generic choice. Learn more about Medicare insurance for prescription drugs at *www.medicare.gov/part-d*, or call Medicare or your state SHIP. Also, the Partnership for Prescription Assistance, *www.pparx.org*, can provide a list of patient assistance programs supported by pharmaceutical companies.

How can my brother and I ensure our aging mother's safety at home?

This year, my wife and I decided to spend our vacation with my mom at her house. My brother and his partner will also be there. We'd like to see how we can make things safer for Mom, who is a little frail.

You can't anticipate every problem, but go through the house room by room and check. Some things will need to be taken care of right away. Pay careful attention to your mom—especially her safety and overall health, and how well she manages in her home. For example:

- If your mom is still driving, can you assess her road skills?
- How is your mom's health? Is she taking several medicines? If so, could the pills be better organized?
- What about her mood? Does your mom seem depressed or anxious?

If you feel that your mother is unsafe alone because of her health, make note of which behaviors or activities have become most dangerous and discuss these with her primary caregiver, if there is one, and her doctor. This is one way a long-distance caregiver can be helpful. Remember, you will need your mother's permission to discuss her health with the doctor.

Discuss your concerns and offer to help adapt the environment to meet your parent's changing safety needs.

You can provide a fresh look when evaluating the situation. Behavior that is unsafe or unhealthy may have become familiar to the primary caregiver. Discuss your concerns and offer to help adapt the environment to meet your parent's changing safety needs.

There are a variety of things you can do that will make your mom's surroundings safer, more accessible, and more comfortable. First, quickly

correct any real dangers. Once the urgent issues are addressed, you and your brother can start working on other ways to make sure your mom will be out of harm's way. Use these home safety suggestions as a starting point:

- Are the stairs manageable, or is a ramp needed?
- Are there any tripping hazards at exterior entrances or inside the house (throw rugs, for example)?
- Are any repairs needed?
- Is the house well lit, inside and out? Do any bulbs need to be replaced?
- Is there at least one stairway handrail that extends beyond the first and last steps on each flight of stairs?
- Is there carpeting or safety grip strips on stairs?
- Is there clutter, which can cause disorientation and confusion and increase the risk of falling?
- Are all walk areas free of furniture and extension and electrical cords?
- If a walker or wheelchair is needed, can the house be modified—perhaps put in a ramp to the front door?
- Is there food in the fridge? Is any of it spoiled? Are there staple foods (such as cereal, sugar, canned soup) in the cabinets?
- Are bills being paid? Is mail piling up?

It is sometimes easier to change a place than to change a person. For someone like Rhea, who is helping her mom make the house safer for her dad to live comfortably in spite of his memory problems, some steps include:

- Talking with her mom about ways to remember to lock all doors and windows to prevent her dad from wandering.
- Making sure all potentially harmful items, such as medications, weapons, machinery, or electrical cords are put away in a safe, preferably locked place when they're not in use.
- Using child-resistant caps on medicine bottles, childproof latches on cabinets, and childproof plugs in unused outlets.

How can I keep up with my mom's medical care?

I don't know where to start.

Healthcare experts recommend that you start by learning as much as you can about your parent's illness, its likely course, and current treatments. This information will be essential as you help your parent and the primary caregiver cope with day-to-day concerns, make decisions, and plan for the future. You can do this by discussing your mom's diagnosis with your own healthcare provider or gathering reliable health information.

Contacting a government agency, like the National Institutes of Health (NIH), or visiting its MedlinePlus website, *www.medlineplus.gov*, is a good way to find information you can trust.

When you visit your parent, consider going along on a doctor's appointment—first check that your parent does not mind having you there. You must have your parent's permission to have any conversation with his or her doctor or to discuss healthcare bills with Medicare or other health insurance. Ask your parent to complete the required privacy release form so the doctor can discuss his/her medical care with you. Be sure the release is up to date and that there's a copy in your parent's medical records, in addition to keeping a backup copy for your files.

When you visit your parent, consider going along on a doctor's appointment.

Some long-distance caregivers say that making a separate doctor's appointment lets them seek more detailed information and answers to questions. You will need your parent's written permission. You might have to pay for these appointments yourself. Or, see if the doctor will agree to provide email or telephone updates to you or other family members who live out of town.

Evaluating Health Information Online

Many people search online to learn more about medical concerns. But not all health information online is of equal quality. The following questions may help you decide if the source you find on the internet is reliable:

- **Who is responsible for the content? Part of the web address may tell you—for example, *.gov* is a government agency, *.edu* is an educational institution, *.org* may be a nonprofit organization, and *.com* may be a commercial website. Also look for the website's "About Us" page.**
- **Can you identify the author? If so, what are his/her credentials? Will he or she profit from something recommended on the website?**
- **Who reviews the information? Does the website have editors?**
- **Is the purpose and goal of the sponsoring organization clearly stated? Is it selling something?**
- **Is there a way to contact the sponsor for more information?**
- **Is the website supported by public funds or donations?**
- **Do the contents of the articles encourage you to buy specific products as part of providing general health information?**
- **How new is the information? Is the information based on strong scientific evidence described in the article, or does it express personal opinions?**
- **Does the website ask for personal information about yourself? Does the website clearly state its privacy policy?**

How can we make the most of everyone's time during my dad's medical appointment?

I'm visiting my dad for a week, and he asked me to come to his medical appointment. I want to make the most of this visit.

If you go with your parent to see the doctor, here are a few tips that will help you be an ally and an advocate:

- Bring a list of questions, starting with what is most important to you and your parent, and take notes on what the doctor recommends. Both the questions and the notes you write down can be helpful later, either to give information to the primary caregiver or to remind your parent what the doctor said.
- Before the appointment, ask your parent, the primary caregiver, and your siblings if they have any questions or concerns they would like you to bring up.
- Bring a list of ALL medicines and dietary supplements your parent is taking, both prescription and over-the-counter, and include the dosage and schedule. If your parent sees several different doctors, one may not necessarily know what another has prescribed.
- When the doctor asks a question, let your parent answer unless you have been asked to do so.
- It's easy to get into a two-way conversation between the doctor and yourself—try not to do this. Always include both your parent and the doctor when you talk.
- Respect your parent's privacy, and leave the room when necessary.
- Talk to the doctor about how you can keep up to date on your parent's health since you live out of town.
- Ask the doctor to recommend helpful community resources.
- Larger medical practices, hospitals, and nursing homes may have a social worker on staff. The social worker may have valuable suggestions about community resources and other information.

If you are worried that your parent might be depressed, you might want to discuss this with the doctor before the appointment. Depression is not a normal part of aging. Emotions like sadness, grief, and temporary "blue" moods are normal, but continuing depression that interferes with daily living is not okay.

Even some health professionals seem to think depression is a normal response to the illnesses and other problems that can happen as we grow older. Make sure the doctor is taking action in response to your concerns.

FINDING MORE HELP

How can I be sure my elderly father's caregiver isn't mistreating him or taking his things?

Everything has been fine so far, but I'm worried that if Dad's memory deteriorates, something might happen.

From a distance, it can be hard to assess the quality of your father's caregivers. Ideally, if there is a primary caregiver on the scene, he or she can keep tabs on how things are going. Perhaps you have already identified friends or neighbors who can stop in unannounced to be your eyes and ears. Sometimes, a geriatric care manager can help.

You can stay in touch with your father by phone and take note of any comments or mood changes that might indicate neglect or mistreatment. These can happen in any setting, at any socioeconomic level. Abuse can take many forms, including domestic violence, emotional abuse, financial abuse, theft, and neglect.

Sometimes the abuser is a hired caregiver, but he or she can also be someone familiar. Stress can take a toll when adult children are caring for aging parents, or when an older person is caring for an aging

spouse or sibling. In some families, abuse continues a long-standing family pattern. In others, the older adult's need for constant care can cause a caregiver to lash out verbally or physically. In some cases, especially in the middle to late stages of Alzheimer's disease, the older adult may become difficult to manage and physically aggressive, causing harm to the caregiver. This might cause a caregiver to respond angrily. But no matter who is the abuser or what is the cause, abuse and neglect are never acceptable responses.

If you feel that your parent is in physical danger, contact the authorities right away. If you suspect abuse, but do not feel there is an immediate risk, talk to someone who can act on your behalf: your parent's doctor, for instance, or your contact at a home health agency. Suspected abuse must be reported to adult protective services.

SIGNS OF SELF-NEGLECT

Self-neglect describes situations in which older people put themselves at high risk. People who neglect themselves may have a disorder that impairs their judgment or memory. They may have a chronic disease. Knowing where to draw the line between a person's right to independence and self-neglect can be hard.

Here are some signs that may mean it's time to intervene, although they can be hard to recognize during a short visit:

- Hoarding
- Failure to take essential medications or refusal to seek medical treatment for serious illness
- Leaving a burning stove unattended
- Poor hygiene
- Not wearing suitable clothing for the weather
- Confusion
- Inability to attend to housekeeping
- Dehydration

ELDER ABUSE

Elder abuse is causing physical, emotional, or financial harm to an older person, whether intentionally or unintentionally. There are many possible signs of abuse:

- Bruises, pressure marks, broken bones, abrasions, and burns may be signs of physical abuse, neglect, or mistreatment.
- Unexplained withdrawal from normal activities, a sudden change in alertness, and unusual depression may indicate emotional abuse.
- Sudden financial losses may be the result of exploitation.
- Bedsores, unattended medical needs, poor hygiene, and unusual, unexplained weight loss might be signs of neglect.
- Behavior such as belittling, threats, and other uses of power and control by spouses or other adults may signify verbal or emotional abuse.
- Strained or tense relationships and frequent arguments between the caregiver and older person can suggest mistreatment, either by the caregiver or the person receiving care.

If your parent is in a long-term care facility, the facility must take steps to prevent (and report) abuse. Nursing homes and hospitals are subject to strict state licensing requirements and federal regulation. Even so, neglect and abuse can occur. Physical abuse by other residents is also possible.

For more information, contact the National Center on Elder Abuse. You might also talk with your state or local long-term care ombudsman; contact your state government, your Area Agency on Aging, or the National Long-Term Care Ombudsman Resource Center.

How can I lighten the load for my mother?

Over the years, Dad's condition has worsened, and now when we talk, Mom sounds exhausted.

Your mother may be hesitant to ask for help or to say that she needs a break. Be sure to acknowledge how important her care has been for your father. Also, discuss the physical and emotional effects caregiving can have on people. Although caregiving can be satisfying, it also can be very hard work. Offer to arrange for respite care.

Respite care will give your mother a break from her caregiving responsibilities. Respite care can be arranged for just an afternoon or for several days. Care can be provided in the family home, or your dad may spend the time in an adult day services program or at a skilled nursing facility.

The ARCH National Respite Locator Service can help you find services in your parent's community. You might suggest your mother contact the Well Spouse Association—it offers support to the wives, husbands, and partners of chronically ill or disabled people and has a nationwide listing of local groups.

Your parents may need more help from home-based care to continue to live in their own home. Some people find it hard to have paid caregivers in the house, but most also say that the assistance is invaluable. If your mother is reluctant, point out that with an in-home aide, she may have more energy to devote to your father's care and some time for herself. Suggest she try it for a short time, and then decide.

In time, your father may have to move to assisted living or a nursing home. If that happens, your mother will need your support. You can help her select a facility. She may need help adjusting to his absence or to living alone in their home. Just listening may not sound like much help, but often it is.

Should I encourage my parents to get more help?

The last time I visited, my mom seemed very confused, like she just wasn't quite there. Dad didn't seem to notice and didn't want to talk about it when I asked him.

If you do not see your parent often, changes in his or her health may seem dramatic. In contrast, the primary caregiver might not notice such changes or realize that more help, medical treatment, or supervision is needed. Or, the primary caregiver might not want to accept the fact that the health of his or her spouse or parent is failing. Sometimes a geriatric care manager or other professional is the first to notice changes.

For families dealing with Alzheimer's disease or another dementia, it can be easier to cover for the patient—doing things for him or her, filling in information in conversations, and so on—than to acknowledge what is happening.

A few good conversation starters are:

- If you thought there might be a change in Aunt Joan's condition, whose opinion would you seek?
- I didn't notice Dad repeating himself so much the last time I was here. Do you remember when it started?

Some changes may not be what you think. Occasional forgetfulness does not necessarily indicate dementia. Before you raise the issue of

what needs to be done, talk to your parent and the primary caregiver about your concerns.

Try not to sound critical when you raise the subject. Instead, mention your particular worry, for example, "*Mom, it looks like you don't have much food in the house—are you having trouble getting to the store?*" and explain why you are asking. Listen to what the primary caregiver says about the situation and whether he or she believes there are problems.

Discuss what you think could be done. For example, you could ask:

- Would you like me to arrange to have groceries delivered on a regular basis?
- Do we need to get a second opinion about the diagnosis?
- Can you follow the medication schedule?
- Would you like some help with housework?

Try to follow your suggestions with practical help, and give specific examples of what you can do. For example, you might arrange to have a personal or home health aide come in once a week. You might schedule doctors' appointments or arrange for transportation.

In some cases, you may have to be forceful, especially if you feel that the situation is unhealthy or unsafe. Do not leave a frail adult at risk. If you have to act against the wishes of your parent or the primary caregiver, be direct and explain what you are going to do. Discuss your plan, and say why you are taking action.

How can I help my parents decide if it's time for them to move from their home?

My mom is getting frailer, and my dad admits that keeping up with chores around their house is getting to be too much. I'm at a loss about what to do.

The decision about whether your parents should move is often tricky and emotional. Each family will have its own reasons for wanting (or not wanting) to take such a step. One family may decide a move is right because the parents can no longer manage the home. For another family, the need for hands-on care in a long-term care facility motivates a change.

In some cases, a move frees up cash so that the parent can afford a more suitable situation. For others, the desire to move to a safer location is hampered by a lack of funds to cover the cost of the new home.

In the case of long-distance caregivers, the notion of moving can seem like a solution to the problem of not being close enough to help. For some caregivers, moving a sick or aging parent to their own home or community can be a viable alternative. Some families decide to have an adult child move back to the parent's home to become the primary caregiver.

Keep in mind that leaving a home, community, and familiar medical care can be very disruptive and difficult for the older parent, especially if they are not enthusiastic about the change. You might first want to explore what services are available in your parents' community to help them in their home—including home health care, housekeeping, personal care, and transportation services.

Check with your parents' friends and doctors, a local social worker, senior centers, and other resources in their area and on the internet for possible sources of help.

Older adults and their families have some options when it comes to deciding where to live, but these choices can be limited by factors such as illness, ability to perform activities of daily living (for example, eating, bathing, using the toilet, dressing, walking, and moving from bed to chair), financial resources, and personal preferences.

Making a decision that is best for your parent—and making that decision with your parent—can be difficult. Try to learn as much as you can about possible housing options.

Older adults, or those with serious illness, can choose to:

- stay in their own home or move to a smaller one
- move to an assisted-living facility
- move to a long-term care facility
- move in with a family member

Some families find a conference call is a good way to talk together about the pros and cons of each option. The goal of this call is to come up with a plan that works for everyone, especially your parent. If the decision involves a move for your mom or dad, you could, even from a distance, offer to arrange tours of some places for their consideration.

Experts advise families to think carefully before moving an aging adult into an adult child's home. There are a lot of questions to consider, for example:

- Is there space in your home?
- Is someone around to help the older person during the whole day?
- What are your parents able to do for themselves?
- What personal care are you willing and able to provide—moving your parent from a chair to a bed or toilet, changing adult diapers, or using a feeding tube, for example?
- What kinds of home care services are available in your community?
- What kind of specialized medical care is available nearby?

HOW DO WE FIND A NURSING HOME?

If the decision is made that your parent needs the intensive care found in a nursing home (skilled nursing facility), you could talk with his or her doctor or a social worker about which facilities would be appropriate. Once you have the names of several places, the primary caregiver could visit them and meet with staff there. Then, when you have narrowed down the list, you can compare the quality of the remaining homes at Nursing Home Compare on the Medicare website, *www.medicare.gov/nursinghomecompare*, or call Medicare for help.

What happens if Mom gets too sick to stay at home?

My mother is terrified of ending up in an institution and has asked me to promise that I won't "put" her in a nursing home. It's hard for me to figure out what to say.

If you are over 40, chances are you've had a similar conversation with someone you love. It might come up if you see a segment about nursing homes while watching the evening news. "*I never want to be in a nursing home,*" your mother says. This thought usually reflects what most of us want: to stay in our own homes, to maintain independence, to turn to family and friends for help.

Sometimes, however, parents want their adult children to promise that they won't go to a nursing home. Think carefully before doing so. According to the Centers for Medicare & Medicaid Services, "Quality of care means doing the right thing, at the right time, in the right way, for the right person, and having the best possible results."

Agreeing that you will not put someone in a nursing home may close the door to the right care option for your family. It requires you to know that no matter what happens you will be able to care for your parent. The fact is that for some illnesses and for some people, professional health care in a long-term care facility is the only reasonable choice.

When faced with a parent who is truly ill or frail, long-distance caregivers may find that some promises hamper their ability to do what is necessary, either for their own health or for their parent's well-being. Many people discover too late that promises they made, such as, "*Of course you will be able to die at home*," cannot be kept.

Try to focus your commitments on what you know here and now. If asked to make a promise, you could say something like, "*Dad, I will make sure you have the best care we can arrange. You can count on me to try and do what's best for everyone. I can't think of a situation where I'd walk out on you.*"

Base your promises and decisions on a realistic assessment of the current situation or diagnosis, and realize that you might need to revisit your agreement. Your father's condition might change. Your circumstances might change. You truly do not know what will happen in the future—disease and illness can necessitate enormous adjustments. And, of course, it's not only your parent's health that changes—your own health may alter over time.

Base your promises and decisions on a realistic assessment of the current situation or diagnosis, and realize that you might need to revisit your agreement.

If you've already made a promise to your parent, remember you can bring the subject up again. You can modify your answer to something more specific, something you feel you can undertake. As hard as that conversation might be, it may be better than risking the guilt of a promise not kept.

When Linda's father, Neil, was diagnosed with congestive heart failure, she was 4 months into her second pregnancy. Her mother had died several years earlier. During her mother's illness, Linda, then single, had gone home almost every weekend to help her father and be with her mother. After her mother's death, she stayed close to her dad, even helping him move to an assisted living facility in his own town. Neil settled easily into the facility. Over time, Linda did her best to visit. With two young children, she couldn't get there regularly, but she made a point of calling her dad twice a week. Eventually, it became harder for Neil to catch his breath, and on some days he was too tired to get out of bed. He died quietly one night in his sleep. Linda said she had few regrets; she had done everything she could do to let her father know how much she cared. Knowing this comforted her.

What if I'm told Mom only has a few months to live?

I can't fly out to be with her for that long, but I want her to know that I am here for her.

The news that a family member is dying is difficult to hear—and yet, it is a basic part of life. When you hear that a parent has a terminal illness, you may be flooded with emotions: sorrow, disbelief, anger, anxiety. It can be hard to know what to do or what to say. Fortunately, many organizations are working to improve the lives of dying people and their families. Think about a hospice program. Hospice provides special care for people who are near the end of life. Check with Medicare for information on hospice benefits.

Talk to your own friends, clergy, or colleagues. Many have probably experienced the serious illness and death of a beloved friend or family member. Exchanging stories can help you cope with your own impending loss and might provide some ideas as you try to decide what to do.

Contact your parent's doctor to find out what will need to be done, the kinds of care that your mother or father is likely to need, and how you can arrange for it to happen. And if there is a primary caregiver, ask what you can do for him or her. Remember, you will need your parent's permission to discuss his or her health with the doctor.

Be there for your parent when you can. Spend time with your mom or dad and let your parent know the important part he or she has played in your life. When you can't be there, you can send notes or cards, videos, or audio messages, in addition to calling or using video chat.

Some people find that it is very hard to talk about death and dying and will go to great lengths to avoid the subject. Difficult as it may be, try to talk with your parents about what is going on. But, if you can't have that conversation, don't let that add to your worry. There is no single right way to approach the death of a loved one.

SUPPORT FOR CAREGIVERS

Why do I feel so frustrated and guilty as a caregiver?

I didn't realize that not being nearby every day would be so stressful.

You might think that being far away gives you some immunity from feeling overwhelmed by what is happening to your parent, but long-distance caregivers report otherwise. Caregiving, especially from a distance, is likely to bring out many different emotions, both positive and negative. Feeling frustrated and angry with everyone, from your parent to the doctors, is a common experience. It can be hard to acknowledge that you feel this way, but try not to criticize yourself even more. Anger could be a sign that you are overwhelmed or that you are trying to do too much. If you can, give yourself a break: take a walk, talk with your friends, get some sleep—try to do something for yourself.

Although you may not feel as physically exhausted and drained as the primary, hands-on caregiver, you may still be worried and anxious. And you might feel guilty about almost everything—about not being closer, not doing enough, not having enough time with your parent, and perhaps even feeling jealous of those who do. Many long-distance caregivers also find that worrying about being able to afford to take time off from work, being away from family, or the cost of travel increases these frustrations. Remember that you are doing the best you can given the circumstances and that you can only do what you can do. It may help to know that these are feelings shared by many other long-distance caregivers—you are not alone in this.

If you are like most long-distance caregivers, you may also have many people who rely on you: your spouse, children, perhaps even grandchildren, as well as friends, coworkers, and colleagues. Adding one more item to your to-do list may seem impossible.

As one caregiver noted, "*When I was growing up, my mother and I weren't very close. As an adult, I ended up across the country. When Mom got sick, my sister took on most of the caregiving. Because I'm hours away, I couldn't be at Mom's bedside regularly, but I did call her more often. I worked it out with my sister, so I took care of handling Mom's monthly bills. I visited several times and always encouraged my sister to take a break from caregiving while I was there. Now that Mom's gone, I'm dealing with the estate, closing out accounts, and deciding what to do with the house. We all do what we can.*"

What can I do to take care of myself?

Taking care of myself seems like the last thing I should be thinking about, but I've heard you have to take care of yourself before you can take care of anyone else.

Consider joining a caregiver support group, either in your own community or online. Meeting other caregivers can relieve your sense of isolation and will give you a chance to exchange stories and ideas.

Support groups can be a great resource and a way to learn caregiving tips and techniques that work—even from afar. Some people find the camaraderie and companionship helpful. Perhaps an online support group is more your style. By focusing on what you have been able to contribute, you may be able to free yourself from some of the worry. The Eldercare Locator may be able to help you find a local group.

ELDERCARE LOCATOR

The Eldercare Locator, a service of the Administration on Aging, is a nationwide service that connects older Americans and their caregivers with information on senior services. You can contact the Eldercare Locator at *www.eldercare.gov* or call 1-800-677-1116 toll-free. They may have information about nutrition programs, preventive health services, elder rights, caregiver training, and support services for older people and their caregivers that are available in your area.

POINTS TO REMEMBER

What are the most important things to remember as I become more involved in my mom's life?

My mother is a widow, and I realize that it's time for me to become more involved in her life. So far, my sister has been doing most of the work.

Start by checking with your sister; ask what would help her the most. And talk to your mom to see if there is something special you can do for her.

Learn. Ask your friends who are involved in caregiving if they have suggestions about ways to help. Find out more about resources where your mom and sister live that might be useful for them. Develop a good understanding of your mom's health issues and other needs.

Caregiving can be difficult and time-consuming, but it can also be rewarding.

Visit as often as you can. Not only might you be able to notice something that needs to be done and can be taken care of from a distance, but you can also relieve your sister for a short time.

Caregiving—whether long-distance or hands-on—can be difficult and time-consuming, but it can also be rewarding. Even from a distance, you can help make your mom's life easier.

More Ideas for Caregivers

If you find yourself in the long-distance caregiving role, here is a summary of things to keep in mind:

- **Know what you need to know.** Experienced caregivers recommend that you learn as much as you can about your parent's illness, medicines, and resources that might be available. Information can help you understand what is going on, anticipate the course of an illness, prevent crises, and assist in healthcare management. It can also make talking with the doctor easier. Make sure at least one family member has written permission to receive medical and financial information. To the extent possible, one family member should handle conversations with all healthcare providers. Try putting all the vital information in one place—perhaps in a notebook or in a shared, secure online document. This includes all the important information about medical care, social services, contact numbers, financial issues, and so on. Make copies for other caregivers, and keep the information up to date.

- **Plan your visits.** When visiting your parent, you may feel that there is just too much to do in the time that you have. You can get more done and feel less stressed by talking to your parent ahead of time and finding out what he or she would like to do. Also check with the primary caregiver, if appropriate, to learn what he or she needs, such as handling some caregiving responsibilities while you are in town. This may help you set clear-cut and realistic goals for the visit. For instance, does your mother need to get some new winter clothes or visit another family member? Could your father use help fixing things around the house? Would you like to talk to your mother's physician? Decide on the priorities and leave other tasks for another visit.

- **Remember to actually spend time *visiting* with your family member.** Try to make time to do things unrelated to being a caregiver. Maybe you could find a movie to watch with your parents, or plan a visit with old friends or other family members. Perhaps they would like to attend worship services. Offer to play a game of cards or a board game. Take a drive, or go to the library together. Finding a little bit of time to do something simple and relaxing can help everyone, and it builds more family memories. And keep in mind that your parent is the focus of your trip—try to let outside distractions wait until you are home again.

- **Get in touch, and stay in touch.** Many families schedule conference calls with doctors, the assisted living facility team, or nursing home staff so several relatives can participate in one conversation and get up-to-date information about a parent's health and progress. If your parent is in a nursing home, you can request occasional teleconferences with the facility's staff. Sometimes a social worker is good to talk to for updates as well as for help in making decisions. You might also talk with a family member or friend in the community who can provide a realistic view of what is going on. In some cases, this will be your other parent. Don't underestimate the value of a phone and email contact list. It is a simple way to keep everyone updated on your parents' needs.

- **Help your parent stay in contact.** For one family, having a private phone line installed in their father's nursing home room allowed him to stay in touch. For another family, giving Grandma a cell phone (and then teaching her how to use it) gave everyone some peace of mind. These simple strategies can be a lifeline. But be prepared—you may find you are inundated with calls or text messages. It's good to think in advance about a workable approach for coping with numerous calls.

- **Learn more about caregiving.** Whether you are the primary caregiver or a long-distance caregiver, getting some caregiving training can be very helpful. As with a lot of things in life, many of us don't automatically have a lot of caregiver skills. For example, training can teach you how to safely move someone from a bed to a chair, how to help someone bathe, and how to prevent and treat bed sores, as well as basic first aid. Information about training opportunities is available online. Some local chapters of the American Red Cross might offer courses, as do some nonprofit organizations focused on caregiving. Medicare and Medicaid will sometimes pay for this training.
- **Gather a list of resources in the care recipient's neighborhood.** Searching the internet is a good way to start collecting resources. Check with a local library or senior center, the Area Agency on Aging, or the Eldercare Locator *(www.eldercare.gov)* to find out about sources of help.

Resources

The National Institute on Aging offers free information about health and aging in English and Spanish.

National Institute on Aging
Information Center
1-800-222-2225 (toll-free)
1-800-222-4225 (TTY/toll-free)
niaic@nia.nih.gov (email)
www.nia.nih.gov
www.nia.nih.gov/Go4Life (exercise and physical activity information)

To order publications (in English or Spanish) or sign up for regular email alerts, go to: *www.nia.nih.gov/health*.

Visit *www.nihseniorhealth.gov,* a senior-friendly website from the National Institute on Aging and the National Library of Medicine. This website has health and wellness information for older adults. Special features make it simple to use. For example, you can click on a button to make the type larger.

NIA's ADEAR Center offers free information about Alzheimer's disease, including specific caregiving information:

Alzheimer's Disease Education and Referral (ADEAR) Center
1-800-438-4380 (toll-free)
1-800-222-4225 (TTY/toll-free)
adear@nia.nih.gov
www.nia.nih.gov/alzheimers

The following list is a sampling of groups to contact to learn more. Some have more detailed information related to caregiving and the health of older people. Others can direct you to help in your community.

Administration for Community Living
1-202-401-4634
aclinfo@acl.hhs.gov (email)
www.acl.gov

Aging Life Care Association
1-520-881-8008
info@aginglifecare.org (email)
www.aginglifecare.org

American Geriatrics Society
Health in Aging Foundation
1-800-563-4916 (toll-free)
info@healthinaging.org (email)
www.healthinaging.org

ARCH National Respite Network and Resource Center
1-703-256-2084
www.archrespite.org

BenefitsCheckUp
www.benefitscheckup.org

Benefits.gov
www.benefits.gov

Caregiver Action Network
1-202-454-3970
info@caregiveraction.org (email)
www.caregiveraction.org

Caregiver Resource Directory
Beth Israel Medical Center
www.netofcare.org/crd/resource_form.asp

Centers for Medicare & Medicaid Services
1-800-633-4227 (toll-free)
1-877-486-2048 (TTY/toll-free)
www.cms.gov
www.medicare.gov
www.medicaid.gov

Department of Veterans Affairs
Veterans Benefits Administration
Veterans Health Administration
1-877-222-8387 (toll-free)
VA benefits:
1-800-827-1000 (toll-free)
1-800-829-4833 (TDD/toll-free)
To speak with a healthcare benefits counselor:
1-877-222-8387 (toll-free)
www.va.gov
www.caregiver.va.gov
www.va.gov/healthbenefits

Eldercare Locator
1-800-677-1116 (toll-free)
www.eldercare.gov

Family Caregiver Alliance
1-800-445-8106 (toll-free)
info@caregiver.org (email)
www.caregiver.org

Hospice Foundation of America
1-800-854-3402 (toll-free)
info@hospicefoundation.org
www.hospicefoundation.org
www.hospicedirectory.org

National Adult Day Services Association
1-877-745-1440 (toll-free)
info@nadsa.org (email)
www.nadsa.org

National Alliance for Caregiving
1-301-718-8444
info@caregiving.org (email)
www.caregiving.org

National Association of Social Workers
www.helpstartshere.org

National Center on Elder Abuse
1-855-500-3537 (toll-free)
ncea@med.usc.edu (email)
www.ncea.aoa.gov

National Hospice and Palliative Care Organization
CaringInfo
1-800-658-8898 (toll-free)
caringinfo@nhpco.org (email)
www.caringinfo.org

National Institutes of Health
1-301-496-4000
1-301-402-9612 (TTY)
NIHinfo@od.nih.gov (email)
www.nih.gov

National Library of Medicine
MedlinePlus
www.medlineplus.gov

National Long-Term Care Ombudsman Resource Center
1-202-332-2275
www.ltcombudsman.org

Nursing Home Compare
Centers for Medicare and Medicaid Services
1-800-633-4227 (toll-free)
1-877-486-2048 (TTY/toll-free)
www.medicare.gov/nhcompare

PACE (Program of All-Inclusive Care for the Elderly)
1-703-535-1565
info@npaonline.org (email)
www.pace4you.org
www.npaonline.org

Partnership for Prescription Assistance
www.pparx.org/about_us/contact_us (email form)
www.pparx.org

SHIP (State Health Insurance Assistance Programs)
1-877-839-2675 (toll-free)
info@shiptacenter.org (email)
www.shiptacenter.org

Visiting Nurse Associations of America
1-888-866-8773 (toll-free)
vnaa@vnaa.org (email)
www.vnaa.org

Well Spouse Association
1-800-838-0879 (toll-free)
info@wellspouse.org (email)
www.wellspouse.org

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