

So Far Away

Twenty Questions and Answers About Long-Distance Caregiving



Table of Contents

Introduction.....	1
Getting Started	4
Things You Can Do	12
Finding More Help	23
Support for Caregivers	36
Points to Remember	38
Resources	42



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 ballgame 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. *So Far Away: Twenty Questions and Answers About Long-Distance Caregiving* 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, this booklet 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. *So Far Away* often refers to caregiving for aging parents, but in fact, this booklet offers tips you can use no matter who you are caring for—an older relative, family friend, or neighbor.

The booklet 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 of these or even completely different solutions.

We hope these questions and answers stimulate helpful problem solving, but we understand you will mold your own best answers. If you have some good ideas—or questions—we haven't addressed, share them with us for consideration when we update the booklet.

Many resources are mentioned throughout this booklet. Sometimes we've included contact information in the text, but all the resources and more are included at the end of the publication.





GETTING STARTED

What does a long-distance caregiver do? How many other people are trying to help out from a distance, like me?

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.

If you are a long-distance caregiver, you are definitely not alone. There may be as many as 7 million people in your same situation in the United States. In the past, caregivers have been primarily working women in mid-life with other family responsibilities. That's changing. More and more men are getting involved; in fact, surveys show that men now represent almost 40 percent

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

FREE INFORMATION AVAILABLE FROM NIA

NIA has many free booklets and fact sheets that might be useful to caregivers. Here are just a few you might find of particular interest:

- *Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging*
- *Crime and Older People*
- *Depression*
- *End of Life: Helping With Comfort and Care*
- *Getting Your Affairs in Order*
- *Healthy Eating After 50*
- *Home Safety for People with Alzheimer's Disease*
- *Nursing Homes: Making the Right Choice*
- *Older Drivers*
- *Online Health Information: Can You Trust It?*
- *Talking With Your Doctor: A Guide for Older People*
- *There's No Place Like Home—For Growing Old: Tips from the National Institute on Aging*

All NIA resources can be ordered online at www.nia.nih.gov/health or by calling 1-800-222-2225 (toll-free) or 1-800-222-4225 for TTY (toll-free).

How will I know if help is needed? Uncle Simon sounds fine on the phone. How can I know that he really is?

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 in order 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

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

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 dinner 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. With Simon's okay, 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 should 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 house, 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.

What can I really do from far away? My sister lives pretty 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 who does what? 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 which tasks. 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 on a family vacation. 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 thought 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. They are a sort of “professional relative” to help you and your family to identify needs and how to meet them. These professionals can also help by leading family discussions about sensitive subjects. For example, Alice’s father might be more willing to take advice from someone outside the family.

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

- Are you a licensed geriatric care manager?
- Are you a member of the National Association of Professional Geriatric Care Managers?
- 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?

The National Association of Professional Geriatric Care Managers, www.caremanager.org, can help you find a care manager near your family member’s community. You can also call or write 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

My friends who have been caregivers say that a lot of what they did was organizing paperwork. Is that a good way to be helpful?

Yes. That's 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 check at the same time to make sure that all financial matters, including wills and life insurance policies, are in order. It will also help if someone also 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.

WHAT INFORMATION SHOULD A CAREGIVER KEEP TRACK OF?

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, 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

My parents are in their 70s and have not 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, talking with people about the kind of medical care they would want if they are seriously ill and unable to make decisions can be difficult. 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 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. Whoever is 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.

Whoever is chosen to be a 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? They 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 how much medical care 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. Here is an overview to help you get started.

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 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.cms.gov/home/medicaid.asp. 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 is a program providing care and services to people who otherwise would need care in a nursing home. SHIP, the State Health Insurance Counseling and Assistance Program, www.medicare.gov/Contacts, offers counseling and assistance to people and their families on Medicare, Medicaid, and Medigap matters.

If your parent is eligible for veterans benefits, don't forget to check with the Department of Veterans Affairs (VA), www.va.gov. Or, get in touch with the VA medical center nearest you.

For information about other 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 the name, address, or Social Security number in order to use this service.

If 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/find-a-plan/questions/home.aspx or call Medicare or SHIP. Also, the Partnership for Prescription Assistance, www.pparx.org, can provide a list of patient assistance programs supported by pharmaceutical companies.



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 the house safer for my mom who is a little frail. How can we make the best use of our time?

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 how she seems to be and how she manages in her home.

- 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 have become most dangerous and discuss these with her primary caregiver, if there is one, and her

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

doctor. This is one way a long-distance caregiver can be helpful. 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. Don't wait until the next visit. 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 putting 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?
- Is the house clean?

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 website, www.nih.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 a release form that allows the doctor to discuss his or 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 appointment with a doctor allows them to seek more detailed information and answers to questions. 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 — *.gov* is a government agency, *.edu* is an educational institution, *.org* is a professional organization or a non-profit, and *.com* is a commercial website. Also look for the “About Us” page.
- Do you know who the author is? If so, what are his/her credentials? Will he or she profit from something recommended on the website?
- 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?

I'm visiting my dad for a week, and he has asked me to come along on his medical appointment. How can I make the most of this visit with his doctor? I don't want to waste the doctor's time.

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. Yet, even some health professionals seem to think it 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 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 basic neglect.

Sometimes the abuser is a hired caregiver, but other times it is someone your father knows. The stress that may happen when adult children care for their aging parents or when another older adult, like

a spouse or sibling, is a caregiver can take a toll on everyone. 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, contact 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 which 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 some may be hard to recognize during a short visit by a long-distance caregiver:

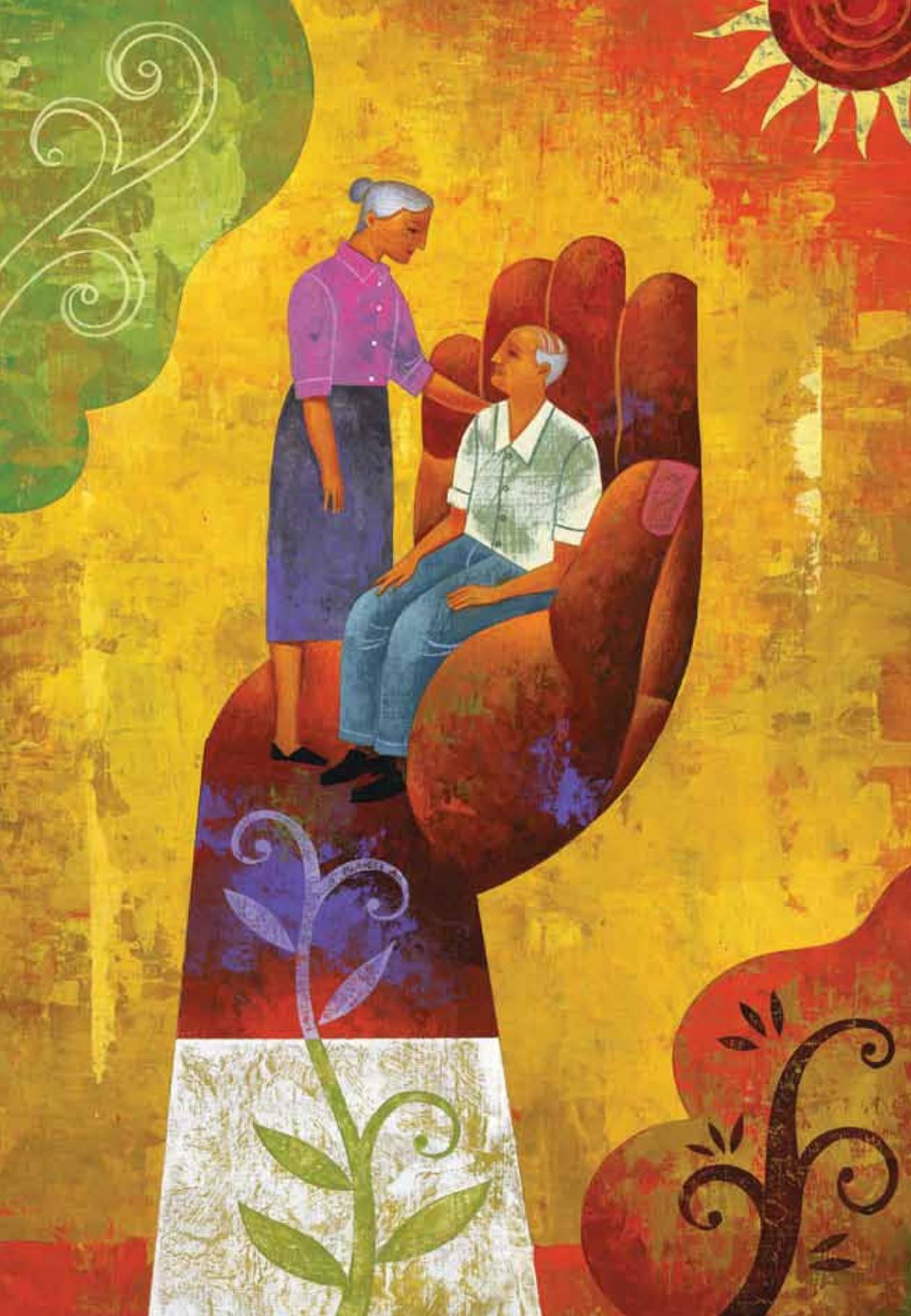
- Hoarding
- Failure to take essential medications or refusal to seek medical treatment for serious illness
- Leaving a burning stove unattended
- Poor hygiene
- Not wearing suitable clothing for the weather
- Confusion
- Inability to attend to housekeeping
- Dehydration

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 regulations. 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: *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.



My mom is getting frailer, and my dad admits that keeping up with chores around their house is getting to be too much. How can I help my folks decide if it's time for them to move? I don't think they can stay in their own home much longer. What are their options? I'm at a loss.

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, bringing 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 another 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, even from a distance, you could 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, 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, or call Medicare for help.

What happens if my mother gets too sick to stay at home? She 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 is 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 wellbeing. Many people discover too late that promises they made (“*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 and talk to your own healthcare provider as well 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 them.

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 or a taped message, in addition to calling.

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 is, talk to 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? 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, are common experiences. 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 worry 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 already have many people who rely on you: your spouse, children, perhaps even grandchildren, as well as friends, coworkers, and colleagues. Adding one more “to do” to your 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 did visit 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 yourself might seem like the last thing you should be thinking about, but you have to take care of yourself before you can take care of anyone else.

You might find some consolation or comfort in knowing that you are not alone. 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, works through local and state Area Agencies on Aging. You can contact the Eldercare Locator at www.eldercare.gov or call 1-800-677-1116 toll-free. They might 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

My mom's 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. What are the most important points to remember as I begin?

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.

Some Good Ideas

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 be the one to talk with all healthcare providers. Try putting together a notebook, on paper or online, that includes all the vital information about medical care, social services, contact numbers, financial issues, and so on. Make copies for other caregivers, and keep it 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 to 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 rent 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. The human touch is important too. Try to find people 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. You can program telephone numbers (such as those for the doctors, friends, and yourself) into the phone for speed dialing contacts. (You might also provide a written key to the speed dial numbers to keep with the phone.)

Such simple strategies can be a lifeline. But be prepared—you may find you are inundated with calls from your parent. 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. Training can teach you how to safely move someone from a bed to a chair, how to help someone bathe, how to prevent and treat bed sores, as well as basic first aid, for example. Information about training opportunities is available online. Some local chapters of the American Red Cross might offer courses, as do some non-profit organizations focused on caregiving. Medicare and Medicaid will sometimes pay for this training. Contact the Eldercare Locator.
- **Gather a list of resources in the care recipient's neighborhood.** If you are familiar with computers, searching the internet is a good way to start collecting resources. Having a copy of the phone book for your parent's city or town can also be really useful. The "Blue Pages" provide an easy guide to state and local services. Also check with local senior centers for lists of sources of help. The National Institute on Aging's website, www.nia.nih.gov/health, offers an online list of more than 300 national health and aging organizations, including contact information.



Resources



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

**National Institute on Aging
Information Center**

P.O. Box 8057
Gaithersburg, MD 20898-8057
1-800-222-2225 (toll-free)
1-800-222-4225 (TTY/toll-free)
www.nia.nih.gov
www.nia.nih.gov/Espanol

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

Visit NIHSeniorHealth (www.nihseniorhealth.gov), a senior-friendly website from the National Institute on Aging and the National Library of Medicine. This website has health information for older adults. Special features make it simple to use. For example, you can click on a button to have the text read out loud or 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

P.O. Box 8250
Silver Spring, MD 20907-8250
1-800-438-4380 (toll-free)
www.nia.nih.gov/Alzheimers

Following is a list 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 on Aging

Washington, DC 20201
1-202-619-0724
www.aoa.gov

American Geriatrics Society

Foundation for Health in Aging
Empire State Building
350 Fifth Avenue, Suite 801
New York, NY 10118
1-800-563-4916 (toll-free)
www.healthinaging.org

ARCH National Respite Network and Resource Center

800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514
1-919-490-5577
1-919-490-5577 (TDD)
www.archrespite.org

BenefitsCheckUp

www.benefitscheckup.org

Caregiver Resource Directory

Beth Israel Medical Center
The Family Caregiver Program
First Avenue at 16th Street
New York, NY 10003
www.netofcare.org/crd/resource_form.asp

Centers for Medicare & Medicaid Services (CMS)

7500 Security Boulevard
Baltimore, MD 21244-1850
1-800-633-4227 (toll-free)
1-877-486-2048 (TTY/toll-free)
www.cms.gov
www.medicare.gov

Children of Aging Parents

P.O. Box 167
Richboro, PA 18954
1-800-227-7294 (toll-free)
www.caps4caregivers.org

Department of Veterans Affairs
Veterans Benefits Administration
Veterans Health Administration

810 Vermont Avenue, NW
Washington, DC 20420
VA benefits:
1-800-827-1000 (toll-free)
1-800-697-6947 (TDD/toll-free)
To speak with a healthcare benefits counselor:
1-877-222-8387 (toll-free)
www.va.gov
www.caregiver.va.gov

Eldercare Locator

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

Family Caregiver Alliance

180 Montgomery Street, Suite 900
San Francisco, CA 94104
1-800-445-8106 (toll-free)
www.caregiver.org

Family Caregiving 101

www.familycaregiving101.org

Hospice Foundation of America

1710 Rhode Island Avenue, NW
Suite 400
Washington, DC 20036
1-800-854-3402 (toll-free)
www.hospicefoundation.org
www.hospicedirectory.org

National Adult Day Services Association

1421 East Broad Street, Suite 425
Fuquay Varina, NC 27526
1-877-745-1440 (toll-free)
www.nadsa.org

National Alliance for Caregiving

4720 Montgomery Lane, 2nd Floor
Bethesda, MD 20814
www.caregiving.org

National Association of Professional Geriatric Care Managers

3275 West Ina Road, Suite 130
Tucson, AZ 85741
1-520-881-8008
www.caremanager.org

National Association of Social Workers

750 First Street, NE, Suite 700
Washington, DC 20002-4241
www.helpstartshere.org

**National Center on Elder Abuse
c/o Center for Community Research
and Services**

University of Delaware
297 Graham Hall
Newark, DE 19716
1-302-831-3525
www.ncea.aoa.gov

National Family Caregivers Association

10400 Connecticut Avenue, Suite 500
Kensington, MD 20895-3944
1-800-896-3650 (toll-free)
www.nfcacares.org

National Hospice and Palliative Care Organization

1731 King Street, Suite 100
Alexandria, VA 22314
1-800-658-8898 (toll-free)
www.caringinfo.org
www.nhpco.org

National Institutes of Health

9000 Rockville Pike
Bethesda, MD 20892
1-301-496-4000
1-301-402-9612 (TTY)
www.nih.gov

**National Library of Medicine
MedlinePlus**

www.medlineplus.gov

National Long-Term Care Ombudsman Resource Center

1828 L Street, NW, Suite 801
Washington, DC 20036
1-202-332-2275
www.ltcombudsman.org

**PACE (Program of All-Inclusive Care
for the Elderly)**

1-800-633-4227
www.pace4you.org
[www.medicare.gov/Nursing/
Alternatives/PACE.asp](http://www.medicare.gov/Nursing/Alternatives/PACE.asp)

Partnership for Prescription Assistance

1-888-477-2669 (toll-free)
www.pparx.org

SHIP (State Health Insurance Assistance Program)

1-800-633-4227
www.medicare.gov/Contacts

**Visiting Nurse Associations
of America**

900 19th Street, NW, Suite 200
Washington, DC 20006
1-202-384-1420
www.vnaa.org

Well Spouse Association

63 West Main Street, Suite H
Freehold, NJ 07728
1-800-838-0879 (toll-free)
www.wellspouse.org



National Institute
on Aging ■ ◆ ★ ✨



NIH Publication No. 10-5496
August 2010
Reprinted June 2011