

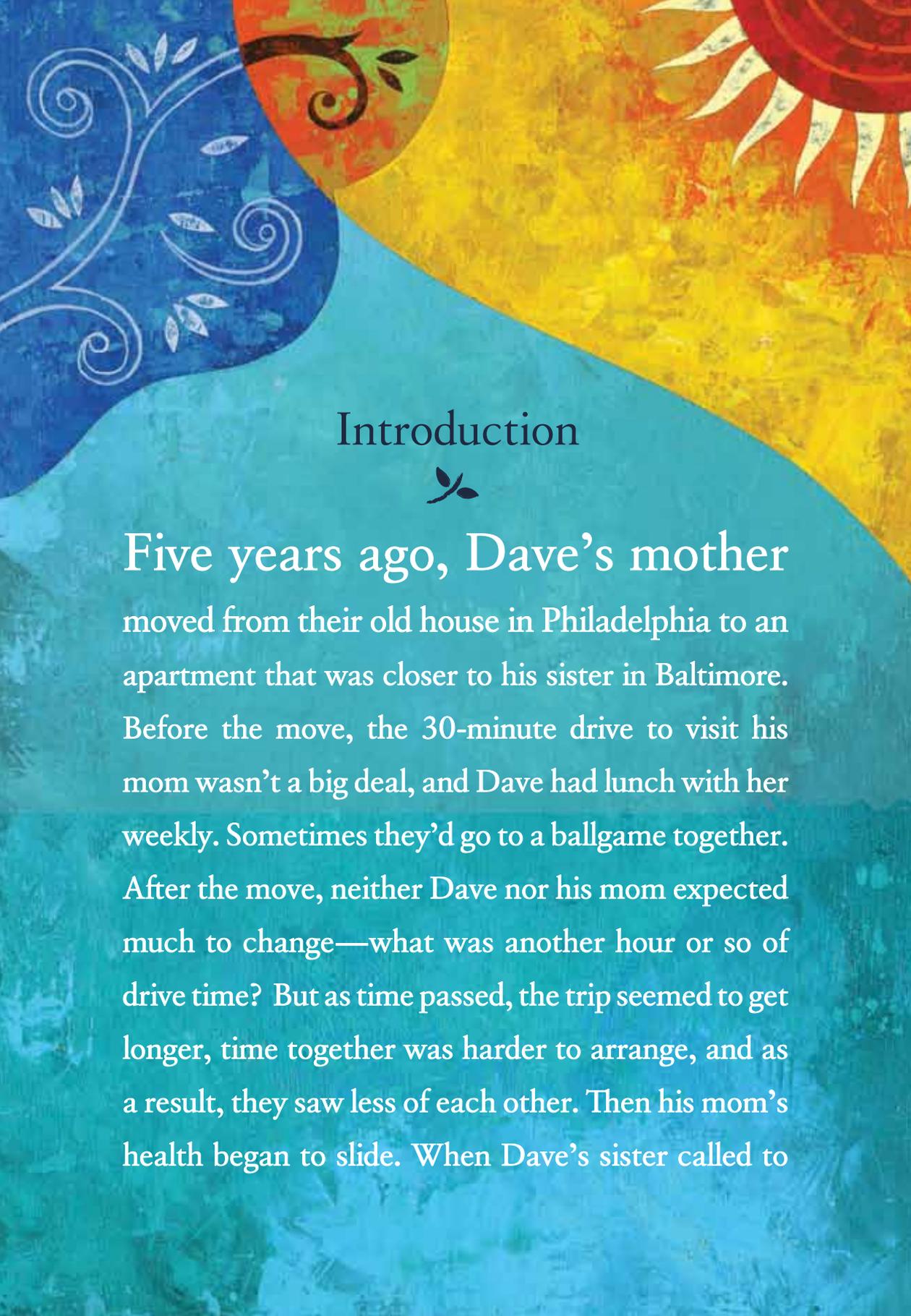
So Far Away

Twenty Questions and Answers About Long-Distance Caregiving



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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 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

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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.

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