



National Institute on Aging

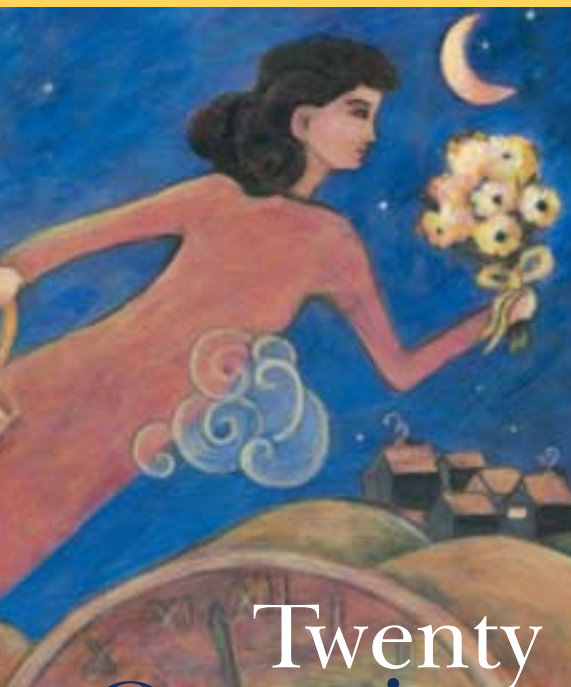
So Far Away

Twenty Questions for Long-Distance Caregivers



U.S. Department of
Health and Human Services

Table of Contents



Twenty Questions

Introduction	2
Q1. What is long-distance caregiving?.....	4
Q2. How will I know if help is needed?.....	6
Q3. What can I really do from far away?.....	7
Q4. How can my family decide who does what?.....	10
Q5. Are there things I can do that will help me feel less frustrated?.....	12
Q6. What is a geriatric care manager and how can I find one?.....	13
Q7. How can I keep up with my mom’s medical care?.....	15
Q8. How can I make the most of a visit with my parent’s doctor?.....	16
Q9. How on earth can my parents afford everything they need?.....	17
Q10. What kinds of documents do we need?.....	18
Q11. Should I encourage my parents to get more help?.....	19
Q12. How can we make the house safer for my mother who has Alzheimer’s disease?.....	21
Q13. How can I lighten the load for my mother?.....	23
Q14. How can I help my folks decide if it’s time for them to move?.....	24
Q15. What happens if my mother gets too sick to stay at home?.....	26
Q16. How is it that long-distance caregiving makes me feel so guilty all the time?.....	28
Q17. How can I be sure my father’s caregiver isn’t mistreating him?.....	29
Q18. How can I help my parents think about their future health care preferences?.....	32
Q19. What is the difference between an advance directive and a living will?.....	34
Q20. What if I’m told my mom only has a few months to live?.....	36
Resources: Where to Turn for Help.....	38



Introduction



Five years ago, Dave's mother moved from the old house in Philly to an apartment in Baltimore that was closer to his sister. Dave didn't give much thought to how the increased distance would affect their relationship. Until then, they'd only lived 30 minutes from each other. Dave had lunch with his mom about once a week; 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 over the years, the drive seemed to get longer and time together was harder and harder to arrange. Then his mom's health began to slide. When Dave's sister called to say 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 raising the family, what could Dave do from far away to help her?

The answer for Dave, and for so many families faced with similar situations, is simple: Lots! Long-distance caregivers can be helpful no matter how great the distance. *So Far Away: Twenty Questions for Long-Distance Caregivers* focuses on some of the issues unique to long-distance caregiving. 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.

Long-distance caregiving can be figuring out what you can do to help 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 her 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, be it an older relative, family friend, or former neighbor.

The booklet is organized in a question/answer format. Each of the 20 commonly asked questions has a brief, stand-alone answer. There's also a resource list at the end that can help you find more information.



What is long-distance caregiving? Am I the only one who's trying to help out from a distance?

Long-distance caregiving takes many forms—from helping manage the money to arranging for in-home care; from providing respite care for a primary caregiver to helping a parent move to a new home or facility. Many long-distance caregivers act as information coordinators, helping aging parents understand the confusing maze of home health aides, insurance benefits, and durable medical equipment.

Caregiving is often a long-term task. What may start out as an occasional social phone call to share family news can eventually turn into regular phone calls about managing health insurance claims, getting medical information, and arranging for respite services. What begins as a monthly trip to check on Mom may turn into a larger project to move her to a nursing facility close to your home.

If you are a long-distance caregiver, you are not alone. Approximately 7 million adults are long-distance caregivers, mostly caring for aging parents who live an hour or more away. Historically, caregivers have been primarily mid-life, working women who have other family responsibilities. That's changing. More and more men are becoming caregivers; in fact, men now represent over 40 percent of caregivers. Clearly, anyone, anywhere can be a long-distance caregiver. Gender, income, age, social status, employment—none of these prevent you from taking on caregiving responsibilities. 🌿



Caregiver Basics

What You Should Do (or Think About Doing)

- 1** Seek out help from people in the community: the next door neighbor, an old friend, the doctor. Call them. Tell them what is going on. Make sure they know how to reach you.
- 2** Take steps to identify options to help the primary caregiver. He or she may not need the help now, but having plans and arrangements in place can make things easier if there is a crisis.
- 3** Try to find a directory of senior resources and services by checking with a library or senior center for lists of resources. Get several copies—one for yourself and one for the primary caregiver. This helps everyone learn what’s out there and perhaps to start “plugging into the networks.” Don’t forget to check for updates.
- 4** Pull together a list of prescriptions and over-the-counter medications. Get doses and schedules. This information is essential in a medical emergency. Update it regularly.
- 5** When you visit, go through the house looking for possible hazards (such as loose rugs, poor lighting, unsafe clutter) and safety concerns (such as grab bars needed in the bathroom). Stay for a weekend or week and help make needed improvements.
- 6** Find out if your parent has an advance directive stating his or her health care treatment preferences. If not, talk about setting one up. If so, make sure you have a copy and you know where a copy is kept. You might want to make sure the primary caregiver has a copy. The doctor should also have a copy for the medical record.


Adapted with author’s permission from *How to Care for Your Parents: A Practical Guide to Eldercare* by Nora Jean Levin.

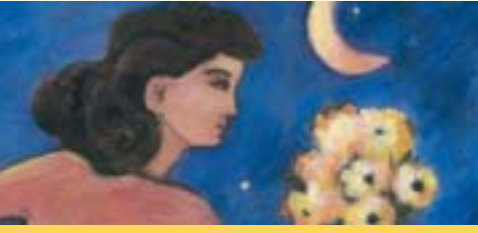


How will I know if help is needed? Uncle Bill sounds fine on the phone. How can I trust that?

In some cases, the sudden start of a severe illness will make it clear that help is needed. In other cases, your relative may ask for help. When you live far away, you have to think carefully about possible signs that support or help is needed. You might want to use holiday trips home to take stock.

Some questions to answer during your visit include:

- Are the stairs manageable or is a ramp needed?
- Are there any tripping hazards at exterior entrances or inside the house (throw rugs, for instance)?
- If a walker or wheelchair is needed, can the house be modified?
- Is there food in the fridge? Are there staple foods in the cupboards?
- Are bills being paid? Is mail piling up?
- Is the house clean?
- If your parents are still driving, can you assess their road skills?
- How is their health? Are they taking several medications? If so, are they able to manage their medications?
- What about mood: Does either parent seem depressed or anxious? 





What can I really do from far away? I don't feel comfortable just jumping in.

Many long-distance caregivers provide emotional support and occasional respite to a primary caregiver who is in the home. Long-distance caregivers can play a part in arranging for professional caregivers, hiring home health and nursing aides, or locating assisted living and nursing home care. 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. From a distance, it may be especially hard to feel that what you are doing is enough, or that what you are doing is important. It usually is. 🧘



Free Information Available from NIA

NIA has many free publications including the popular *Age Pages*—informative fact sheets for older people. There are over 40 titles in the series, many of which are available in Spanish. The Resources section of this booklet has information on how to contact NIA.

Long-distance caregivers might find the following titles of particular interest:

- *Home Safety for People with Alzheimer's Disease*
- *Good Nutrition: It's a Way of Life*
- *Older Drivers*
- *Caregiver Guide: Tips for Caregivers of People With Alzheimer's Disease*
- *Long-Term Care: Choosing the Right Place*

Some Good Ideas

- **Know what you need to know.** Experienced caregivers recommend that you learn as much as you can about your parent's illness and treatment. Information can help you understand what is going on, anticipate the course of an illness, prevent crises, and assist in disease management. It can also make talking with the doctor easier. Learn as much as you can about the resources available. Make sure at least one family member has written permission to receive medical and financial information. Try putting together a notebook, or something similar, that includes all the vital information about health care, social services, contact numbers, financial issues, and so on. Make copies for other caregivers.
- **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. This may help you set clear-cut and realistic goals for the visit. For instance, does your mother need to go to the mall or to 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 visit with old friends or other family members. Perhaps your aunt or uncle 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.

- **Get in touch and stay in touch.** Many families schedule conference calls with doctors, the assisted living facility team, or nursing home staff to 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. Some families schedule conference calls so several relatives can participate in one conversation. 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 your parent's community who can be your eyes and ears and provide a realistic view of what is going on. In some cases, this will be your other parent.
- **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 the grandmother a cell phone (and then teaching her to use it) gave everyone some peace of mind. You can program telephone numbers (such as doctors', neighbors', and your own) into your parent's phone so that he or she can speed-dial contacts. Such simple strategies can be a life-line for you and your parent. 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.
- **Get a phone book, either hardcopy or online, that lists resources in your parent's neighborhood.** Having a copy of the phone book for your parent's city or town can be really helpful. The "Blue Pages" can provide an easy guide to State and local services available in your parent's hometown. 📖



How can my family decide who does what? My brother lives closest to our grandmother, but he's uncomfortable coordinating her health care.

Be sure to talk with other family members and decide who will be responsible for which tasks. 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. And remember, if you aren't the primary caregiver, offering appreciation, reassurance, and positive feedback is also a contribution. 🚲



Know Your Strengths/Set Your Limits

If you decide to work as a family team, it makes sense to agree in advance how your skills can complement one another. Ideally, each of you will be able to take on tasks best suited to each person's 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 or your parent's needs. 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 that skill might help in the current situation:

- Are you best on the phone, finding information, keeping people up-to-date on changing conditions, and offering cheer?
- 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?

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—and to respect your parent’s autonomy?
- Can you be both calm and assertive when communicating from a distance?
- How will your decision to take on care responsibilities affect the rest of your family and your work?

5

Are there things I can do that will help me feel less frustrated? What can I do to take care of myself?

Feeling frustrated and angry with everyone, from your parent to his or her doctors, is a common caregiving experience. It can be hard to acknowledge that you feel this way, but try not to criticize yourself even more. Caregiving, especially from a distance, is likely to bring out a full range of human emotions, both positive and negative. If you feel angry, it 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, join a support group—try to do something for yourself.

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. By focusing on what you can do, you may be able to free yourself from some of the worry and focus on being supportive and loving.

Most caregivers report feeling guilty about almost everything—about not being closer, not doing enough, not having enough time. Worrying about being able to afford to take time off from work or the cost of travel can increase frustration.

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.”* ❧



6

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.

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

Professional care managers are usually licensed nursing or social work professionals 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 geriatric care managers can 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 be helpful in leading family discussions about sensitive subjects.

Continues



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?
- Does your company also provide home care services?
- How will you communicate information to me?
- What are your fees? Will you provide them in writing prior to starting services?
- Can you provide references?


The National Association of Professional Geriatric Care Managers 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, local chapters of the Alzheimer's Association may be able to recommend geriatric care managers who have assisted other families. The Resources section of this booklet has information on how to contact these organizations. 📞



How can I keep up with my mom's medical care? I don't know where to start.

Health care experts recommend that you start by learning as much as you can about your parent's illness, current treatments, and its likely course. 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.

When you visit your parent, consider going along on a doctor's appointment (check that your parent does not mind having you there). Some long-distance caregivers say that making a separate appointment with a doctor allows them to seek more detailed information and answers to questions. These appointments must be paid for out-of-pocket.

You must have permission to have any conversation with your parent's doctor. Ask your parent to complete a release form that allows the doctor to discuss his or her health care with you. Be sure the release is up-to-date and that there's a copy in your parent's records in addition to keeping a back-up copy for your files. 



Evaluating Health Information Online

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


- Who is responsible for the content?
- What are the author's credentials?
- Is the purpose and goal of the sponsoring organization clearly stated?
- Is there a way to contact the sponsor for more information?
- Is the website supported by public funds or donations?
- Is advertising separate from content?



How can I make the most of a visit with my parent's 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 advocate:

- Bring a prioritized list of questions and take notes on what the doctor recommends. Both 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 medications your parent is taking, both prescription and over-the-counter, and include 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, do not answer for your parent unless you have been asked to do so. Always talk to the doctor and to your parent.
- Respect your parent's privacy, and leave the room when necessary.
- Ask the doctor if she or he can recommend community resources that might be helpful.
- Larger medical practices and hospitals may have a social worker on staff. Ask to speak with the social worker. She or he may have valuable information about community resources.

NIA has a free booklet called *Talking with Your Doctor: A Guide for Older People* that provides helpful information about doctor/patient communication. It includes hints on getting ready for a doctor's appointment, making health care decisions, and talking about sensitive subjects. The Resources section of this booklet has information on getting a copy of this guide. 





How on earth can my parents afford everything they need? They saved money for retirement, but the cost of their health care is really high.


You are not alone in worrying about how much everything costs. Health care expenses can be crushing, even for middle-class families who thought they had saved enough. Your parents may be eligible for some health care benefits. People on fixed incomes who have limited resources may qualify for Medicaid, a program of the Centers for Medicare and Medicaid Services (CMS), a Federal agency. CMS covers the costs of health care for people of all ages who meet income requirements and who are disabled. Because the guidelines change often, you should check with CMS regularly.

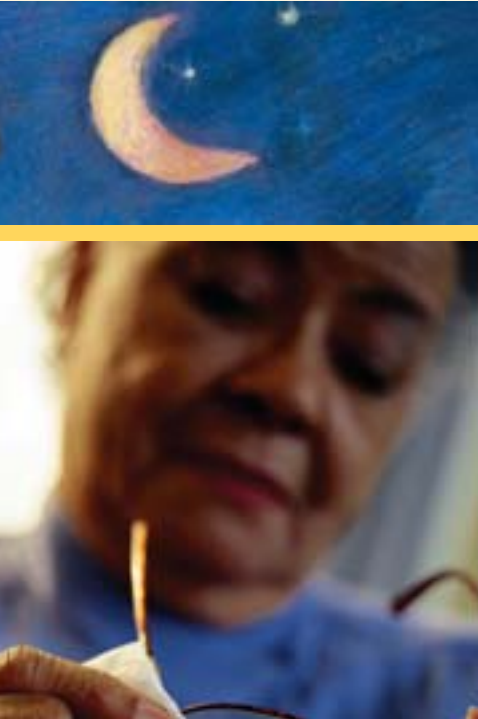
Medicare offers insurance for prescription drugs. For information about this coverage, visit www.medicare.gov or call 1-800-MEDICARE (1-800-633-4227).



The State Health Insurance Assistance Program (SHIP) is a national program offering one-on-one counseling and assistance to people and their families on Medicare. SHIPs provide free counseling and assistance to Medicare beneficiaries on a wide range of Medicare, Medicaid, and Medigap matters. To find your State program, visit www.shipusa.org.

If prescription medications cost too much, talk to the doctor about the possibility of prescribing a less expensive medication. The Partnership for Prescription Assistance can provide a list of patient assistance programs supported by pharmaceutical companies.

The Resources section of this booklet has information on how to contact these organizations. 



10

What kinds of documents do we need? It sounds like caregiving requires a lot of paperwork.

Effective caregiving depends on keeping a great deal of information in order and up-to-date. Often, long-distance caregivers will need to have information about 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. Gathering and organizing this information from far away can seem even more challenging. Maintaining up-to-date 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 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.

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 they (and you) will need in the event of an emergency. Assure them that you will respect their privacy and 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. 🧘





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. Sometimes a geriatric care manager or other professional is the first to notice changes. For families dealing with Alzheimer's disease and other dementias, 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 Alzheimer's disease.

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 concerned. Listen to what the primary caregiver says about the situation, and whether he or she feels there are problems.

Continues



Discuss what you think needs to be done: *“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 up 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. ✨

12

How can we make the house safer for my mother who has Alzheimer's disease? I'm worried about her safety.

You can take many precautions that will make the house safer, more accessible, and comfortable. Because you are not present, you may want to evaluate the safety of your mother's home during one of your visits (with the understanding that you must quickly correct any real dangers). On future visits, you should be alert for hazards and aware of things you can do to make the house safer.

If you are worried about your parent's safety, don't wait until the next visit. If you feel that your parent is unsafe alone, make note of which behaviors have become most worrisome and discuss these with the primary caregiver and the doctor. Behavior that is unsafe or unhealthy may have become familiar to the primary caregiver. The kitchen in particular presents many opportunities for accidents, especially when a parent misuses appliances or forgets that something is cooking. Discuss your concerns and offer to help adapt the environment to meet your parent's changing safety needs.

If you are concerned about home safety for a parent who has Alzheimer's disease, NIA's free pamphlet, *Home Safety for People with Alzheimer's Disease* has plenty of helpful suggestions. The Resources section of this booklet has information on getting a copy of this publication.

Continues



Consider these principles about home safety for older people:

Think prevention. It is hard to predict or anticipate every problem, but you can go through the house room-by-room and evaluate safety problems. Checking the safety of your parent's home may prevent a hazardous situation. Some easy steps to take:

- Remind the primary caregiver to lock all doors and windows on the inside and outside to prevent wandering.
- Make 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.
- Use child-resistant caps on medicine bottles and child-proof door latches on storage units as well.

Adapt the environment. Because it is easier to change a place than to change a person, consider the following:

- Install at least one stairway handrail that extends beyond the first and last steps.
- Place carpet or safety grip strips on stairs.
- Avoid clutter, which can cause disorientation and confusion.
- Keep all walk areas free of furniture, and extension and electrical cords.
- Cover unused outlets with childproof plugs.
- Make sure all rooms have adequate lighting. 🦯

13

How can I help 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. True, caregiving can be satisfying, but it also can be very hard work. Offer to help arrange for respite care.

Respite care will give your mother a break from her caregiving responsibilities. Respite care can be for 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 to 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. The Resources section of this booklet has information on how to contact these organizations.

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 help is invaluable. If your mother is reluctant, point out that with in-home help she may have more energy to devote to your father's care and some time for herself.

Over time, your father may need to move to assisted living or a nursing home. If that happens, try to support your mother. 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. 🧶



14

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. Should I suggest that they move to my home? Move to assisted living? 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 no longer need so much space or cannot 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.

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. In some cases, an adult child moves 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.

Older adults and their families have some choices when it comes to deciding where to live, but these choices can be limited by factors such as illness, 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:

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

Experts advise families to think carefully before moving an aging adult into an adult child's home. In its fact sheet *Home Away From Home*, the Family Caregiver Alliance suggests considering the following issues before deciding whether or not to move your parent to your home:

- Evaluate whether your parent needs constant supervision or assistance throughout the day, and consider how this will be provided.
- Identify which activities of daily living (eating, bathing, toileting) your parent can perform independently.
- Determine your comfort level for providing personal care such as bathing or changing an adult diaper.
- Take an honest look at your health and physical abilities, and decide if you are able to provide care for your parent.
- Expect changes in your parent's medical or cognitive condition.
- Explore the availability of services such as a friendly visitor, in-home care, or adult day services.
- Investigate back-up options if living with your parent does not work or is not your choice.
- Consider the type of medical care your parent needs and find out if appropriate doctors and services are available in your community. 🧵

15

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. "Promise you'll never send me to a nursing home," your mother says. This request 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 really do want their adult children to make a promise. Think carefully before doing so. According to the Centers for Medicare and 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. Many people discover too late that the 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 may need to revisit your agreement. Your father’s situation might change. Your situation might change. You truly do not know what will happen in the future—disease and illness can lead to enormous changes. And, of course, it’s not only your parent’s health that changes—your own health may alter over time, too.

If you’ve already made a promise to a parent, remember you can bring the subject up again; you can change 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. 🌀

16

How is it that long-distance caregiving makes me feel so guilty all the time? I thought being so far away would be easier than this.

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 that this is not so. Although you may not feel as physically exhausted and drained as the primary, hands-on caregiver, you may still feel worried and anxious. Many long-distance caregivers describe feeling terribly guilty about not being there, about not being able to do enough or spend enough time with the parent. Remind yourself that you are doing the best you can given the circumstances, and you can only do what you can do.

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.

You may find some consolation or comfort in knowing that you are not alone. Many people find that support groups are a great resource and a way to learn caregiving tips and techniques that work—even from a distance. Others find the camaraderie and companionship helpful. Some enjoy meeting monthly or weekly, while others find what they need in online support groups. The Eldercare Locator may be able to help you find a local group. The Resources section of this booklet has details on how to contact organizations that may have helpful information. 🧘



17

How can I be sure that my father's caregiver isn't mistreating him? Everything has been fine so far, but I'm worried that as his mental status deteriorates, something harmful 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. Sometimes a geriatric care manager can help. You can stay in touch by phone and take note of any concerns that might indicate neglect or mistreatment. These can happen in any setting, at any socioeconomic level. They can take many forms, including domestic violence, emotional abuse, financial abuse, and basic neglect.

The stress that may happen when adult children care for their aging parents 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 mid-to-late stages of Alzheimer's disease, the older adult may become physically aggressive and difficult to manage. This might cause a caregiver to respond angrily. But no matter what the cause or who is the perpetrator, 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.

Continues





Elder Mistreatment

Elder mistreatment is the intentional or unintentional hurting, either physical or emotional, of an older person. Some signs to watch for:

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

If your parent is in a long-term care facility, the facility must take steps to prevent (and report) abuse. Nursing homes, like hospitals, are subject to strict State licensing requirements and Federal regulations. Even so, neglect and abuse can occur. For more information, contact the National Center on Elder Abuse. The Resources section of this booklet has details on how to contact the Center.



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 self-neglect and a person's right to independence can be hard. Here are some signs that may mean it's time to intervene:

- 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

18

How can I help my parents think about their future health care preferences? Since my mother was diagnosed with cancer, we've heard a lot about the importance of advance care planning. How do we do that?

Making advance care plans is a key step for your parent to take to be sure that his or her health care preferences are known. Health care providers can only respect those wishes that have been made known and are documented in the medical record. Advance care planning can help your family avoid some of the conflicts that can occur when family members disagree over treatment decisions.

It may be easier to make certain decisions after discussing them with family, clergy members, or health care providers. Decisions about forgoing treatment, for instance, or ending life support, involve complex emotional issues and are hard for many people to make alone. Try to make peace with yourself and your family, whatever the decision. As one caregiver put it, *“So much of the task is wading through your own feelings—and the rest is just figuring out what to do.”*

When thinking about the future consider:

- Naming a surrogate decision maker (a surrogate has the authority to make decisions on behalf of someone who is too ill to do so),
- Stating which treatment results are desirable and which ones are unacceptable,
- Discussing what to do in an emergency,
- Noting preferences regarding any possible treatments, and whether or not a time-limited trial would be acceptable (for instance, 5 days on a ventilator to recover some strength; a week with a feeding tube, and so on),
- Talking to the doctor and surrogate about preferences and including written instructions in the medical record.



Advance care planning is an ongoing process. As an illness progresses and circumstances change, your parent may want to revisit his or her preferences. If so, be sure to update all written instructions and share the changes with health care providers and anyone who assists with care.

Try to approach decision-making tasks by recognizing that you are working with a parent, not for a parent (unless you are healthcare proxy or agent, in which case, you will be implementing a family member's decisions). How will you know when the advance care plans are complete and that you have covered all the bases? A complete plan will:

- Be very specific and detailed and cover what is to be done in a variety of medical situations,
- Name a healthcare proxy,
- Be recorded in the medical record,
- Be readily available to any caregiver in the home, nursing home, or hospital. 📄

19

What is the difference between an advance directive and a living will? The terms are confusing. Since my father is still relatively healthy, what kinds of instructions should I help him think about now?

Advance directives are oral and written instructions about future medical care should your parent become unable to make decisions (for example, unconscious or too ill to communicate). Each State regulates the use of advance directives differently. A **living will** is one type of advance directive. It takes effect when the patient is terminally ill.

Advance directives are not set in stone. A patient can revise and update the contents as often as he or she wishes. Patients and caregivers should discuss these decisions—and any changes in them—and keep the health care team informed.


Everyone involved should be aware of your parents' treatment preferences. Because State laws vary, check with your Area Agency on Aging, a lawyer, or financial planner. They may have information on wills, trusts, estates, inheritance taxes, insurance, Medicare, and Medicaid.

The person who has the authority to make medical decisions on another person's behalf is called a **healthcare proxy**. The terms "healthcare proxy" and "healthcare agent" or "surrogate" are used interchangeably. These responsibilities are called "durable" (for example, you may hear the phrase "durable power of attorney") because they remain in effect even if your parent is unable to make decisions. Most people appoint a close friend or family member. Some people turn to a trusted member of the clergy or a lawyer. The designated person should be able to understand the treatment choices. Know your parents' values, and support their decisions.



The decision to name a healthcare proxy is extremely important. A written document, kept in the medical record and identifying the designated proxy, should always be up-to-date.

Durable medical power of attorney forms do not give explicit guidance to the proxy about what decisions to make. Many States have developed forms that combine the intent of the durable power of attorney (to have an advocate) and the intent of the living will (to state choices for treatment at the end of life). These combination forms may be more effective than either of the two used individually. Each State regulates advance directives differently, so you will need to consult with the physician, nurse, social worker, or family lawyer to know what is required. It's also a good idea to check to make sure that all financial matters, including wills and life insurance policies, are in order. 📖



What other information should I 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
- Social Security number
- 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 and charge account names and numbers

20

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.

When Ellen's father, Sam, 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 Ellen, 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. Sam was happy. He enjoyed playing bridge, dining in the common room, and taking walks through his hometown. Over time, Ellen did her best to visit her father. With two young children, she couldn't get there regularly, but she made a point of calling Sam twice a week. Eventually it became harder for Sam to catch his breath and on some days he was too tired to get out of bed. Sam died quietly one night in his sleep. Ellen said she had no regrets: She had done everything she needed to do in her relationship with her father. Knowing this comforted her.

The news that a family member is dying is difficult to bear—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. Try to locate 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. Just about everyone has experienced the serious illness and death of a beloved friend or family member. Exchanging stories can

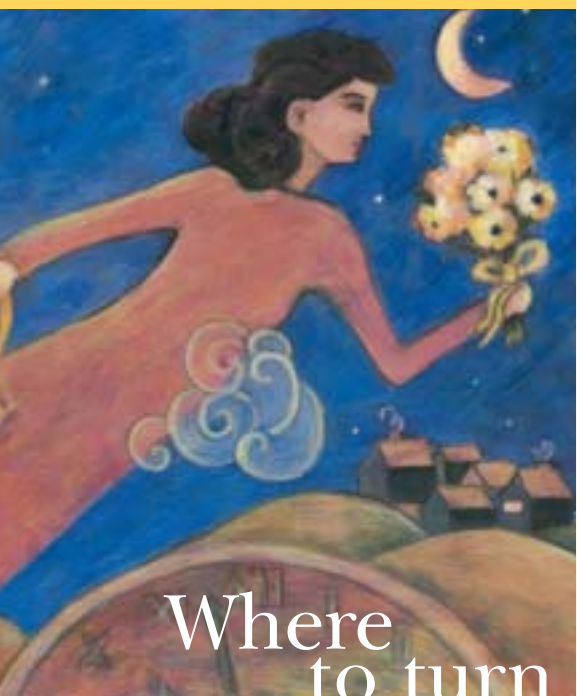


help you as you cope with your own loss and with trying to decide what you can do.

Contact your parent's doctor and talk to your own doctor 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.

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. ❧

Resources



Where
to turn
for **Help**

National Institute on Aging (NIA)

NIA offers free information on a wide variety of subjects, in English and Spanish, including doctor/patient communication, end-of-life care, the biology of aging, and Alzheimer's disease. NIA also publishes over 40 different *Age Pages* and, in conjunction with the National Library of Medicine, produces *www.NIHSeniorHealth.gov*, an easy-to-use website designed especially for older people.

National Institute on Aging Information Center

P.O. Box 8057

Gaithersburg, MD 20898-8057

Phone: 1-800-222-2225 (toll-free)

TTY: 1-800-222-4225 (toll-free)

Website: *www.nia.nih.gov*

To order publications (in English or Spanish) online or sign up for email alerts, visit: *www.nia.nih.gov/HealthInformation*

Alzheimer's Disease Education and Referral Center (ADEAR)

A service of NIA, the ADEAR Center offers free publications and information on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to Alzheimer's disease.

P.O. Box 8250

Silver Spring, MD 20907-8250

Phone: 1-800-438-4380 (toll-free)

Website: *www.alzheimers.org*

Administration on Aging (AoA)

AoA provides funds and community-based services for programs that serve older adults.

Phone: 202-619-0724

Website: www.aoa.gov

Alzheimer's Association

A national voluntary health organization supporting Alzheimer's research and care, the Association offers information and support to patients and families.

225 North Michigan Avenue, Suite 1700

Chicago, IL 60601-7633

Phone: 1-800-272-3900 (toll-free)

Website: www.alz.org

American Association of Homes and Services for the Aging

This trade association for non-for-profit nursing homes, continuing care retirement communities, assisted living, senior housing facilities, and community service organizations offers information for consumers and families.

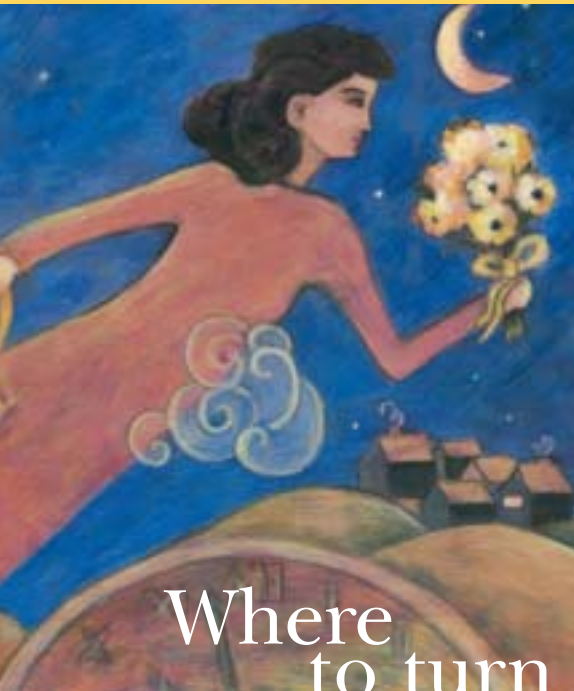
2519 Connecticut Avenue, NW

Washington, DC 20008-1520

Phone: 202-783-2242

Website: www.aahsa.org

Resources



Where
to turn
for **Help**

ARCH National Respite Network and Resource Center

This national resource center provides resources and information, including a respite locator program, technical assistance to State organizations, and an information clearinghouse.

800 Eastowne Drive, Suite 105

Chapel Hill, NC 27514

Phone: 1-800-473-1727, ext. 222 (toll-free)

Website: www.archrespite.org

BenefitsCheckUp

An online service provided by the National Council on Aging, this program allows people to find programs that can help them meet health care costs.

Website: www.benefitscheckup.org

Caregiver Resource Directory

Offered by Beth Israel Medical Center, this guide offers resources, facts, and advice about caring for a family member, as well as the caregiver.

Website: www.stoppain.org/caregivers/resource_form.html

Centers for Medicare and Medicaid Services (CMS)

CMS is a Federal agency that administers the Medicare program and works in partnership with the States to administer Medicaid.

7400 Security Boulevard
Baltimore, MD 21244-1850
Phone: 1-877-267-2323 (toll-free)
TTY: 1-866-226-1919 (toll-free)
Website: *www.cms.hhs.gov*

Children of Aging Parents

This organization provides information, referral services, and educational outreach.

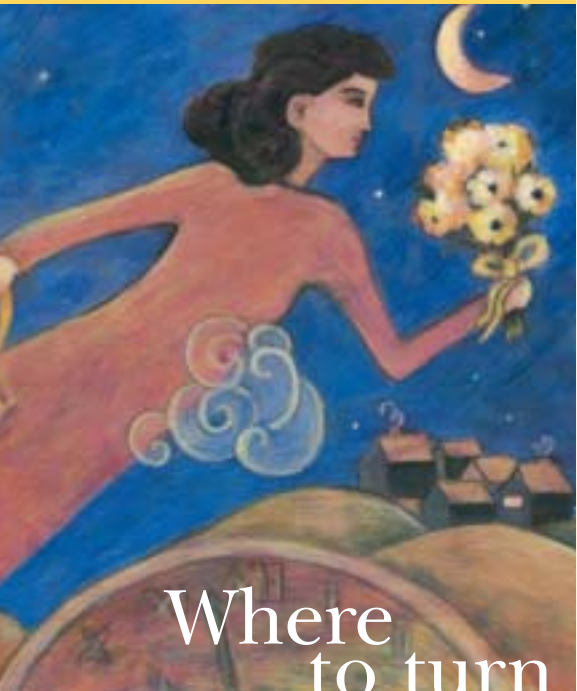
1609 Woodbourne Road, Suite 302A
Levittown, PA 19057
Phone: 1-800-227-7294 (toll-free)
Website: *www.caps4caregivers.org*

Eldercare Locator

This nationwide service helps identify local resources for seniors.

Phone: 1-800-677-1116 (toll-free)
Website: *www.eldercare.gov*

Resources



Where
to turn
for **Help**

Family Caregiver Alliance

The Alliance provides information, education, services, research, and advocacy for caregivers.

690 Market Street, Suite 600

San Francisco, CA 94104

Phone: 1-800-445-8106 (toll-free)

Website: www.caregiver.org

National Alliance for Caregiving

The Alliance supports family caregivers and the professionals who help them and works to increase public awareness of issues facing family caregivers. The website features peer-reviewed links to other resources for family caregivers.

4720 Montgomery Lane, Suite 642

Bethesda, MD 20814

Website: www.caregiving.org

National Association of Professional Geriatric Care Managers

The Association offers information and referral services.

1604 North Country Club Road

Tucson, AZ 85716-3102

Phone: 520-881-8008

Website: www.caremanager.org

National Center on Elder Abuse

The Center promotes understanding and action on elder abuse, neglect, and exploitation.

1201 15th Street, Suite 350

Washington, DC 20005-2800

Phone: 202-898-2586

Website: www.elderabusecenter.org

National Family Caregivers Association

This group supports family caregivers and offers education, information, and referrals.

10400 Connecticut Avenue, Suite 500

Kensington, MD 20895-3944

Phone: 1-800-896-3650 (toll-free)

Website: www.nfcacares.org

National Hospice Foundation

The Foundation promotes hospice care and educates professionals and families about issues related to caregiving, terminal illness, loss, and bereavement.

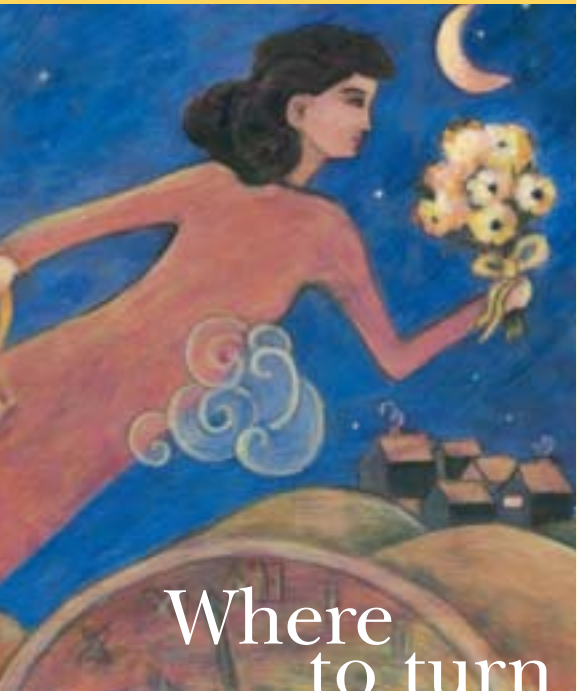
2001 S Street NW, Suite 300

Washington DC 20009

Phone: 1-800-854-3402 (toll-free)

Website: www.hospicefoundation.org

Resources



Where
to turn
for **Help**

National Hospice and Palliative Care Organization

This professional association for hospices has resources and information for the public.

1700 Diagonal Road, Suite 625
Alexandria, VA 22314

Phone: 1-800-658-8898 (toll-free)

Website: www.nhpco.org

Partnership for Prescription Assistance

This program helps qualified people who lack prescription coverage to get needed medicines.

Phone: 1-888-477-2669 (toll-free)

Website: www.pparx.org

Well Spouse Association

The Association is a national, nonprofit membership organization providing support to wives, husbands, and partners of chronically ill and/or disabled people.

63 West Main Street, Suite H
Freehold, NJ 07728

Phone: 1-800-838-0879 (toll-free)

Website: www.wellspouse.org

Please send comments, suggestions, or ideas to:
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