

HANDBOOK FOR LONG-DISTANCE CAREGIVERS

AN ESSENTIAL GUIDE FOR FAMILIES AND FRIENDS
CARING FOR ILL OR ELDERLY LOVED ONES



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National Center on Caregiving

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FAMILY CAREGIVER ALLIANCE®
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Welcome to Caregiving at a Distance

The Journey Begins...

It is the long-dreaded phone call. Your mother lives 1,000 miles away, and her neighbor calls you late at night, speaking in anxious tones to deliver a troubling message.

Your mom hasn't picked up the mail for three days. When the neighbor knocked on the door, your mother opened it and began talking in a confused manner. Her hair was disheveled, her housecoat wrinkled and dirty. On the kitchen table was a bowl of cereal, smelling of sour milk. The neighbor says she insisted your mother come spend the night at her house.

You say, "Thanks, I'll be there as soon as I can book a flight." You start calling the airlines.

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Suddenly, you're playing a new role. No longer just a devoted son or daughter, you're now what the professionals in the aging field call a "long-distance caregiver."

This guide is for people like you, thrust into a new world of intricate responsibility. This booklet offers many useful tips, whether you live an hour away or across the country. But we suggest you read it a little at a time and give yourself the opportunity to absorb the information.

When you first enter the unfamiliar world of long-distance caregiving, you may not see the personal rewards ahead. But they're there, along with very real challenges. You may be the main person who oversees your loved one's care (the "primary caregiver"), even though you live far away, or you may be a "secondary caregiver"—a mainstay for someone else, perhaps a

sibling. Either way, you'll play a key role on a caregiving team that supports your loved one in being as independent as possible.

You can expect your caregiving role to include two key functions: **information gatherer** (using websites and other resources) and **coordinator of services**. Many community agencies exist to help you and your family handle the challenges you may face. Your job is to find out about these resources and use your knowledge to put the pieces together in a way that's most effective for your family.

The Rules of the Road

There's no one right way to be a caregiver; there are many possibilities. The best way for you will evolve as you go along. Think of it as a journey:

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- You'll take it step by step.
- Navigation is generally more important than speed—spending time at the beginning to understand your situation and your options will serve you better than rushing into action without a plan.
- Finding your way is a bit of a treasure hunt and a mental puzzle.
- A team approach is key to success.
- Conditions change along the way and your strategies will shift accordingly.

Most of all, you will need to stay in good condition yourself for the long run. If there are any rules to keep in mind, they are these:

- **Take care of yourself.** This rule is the most important—yet family caregivers so often forget it. We suggest that you take a look, very soon, at

Family Caregiver Alliance's Fact Sheet *Taking Care of YOU: Self-Care for Family Caregivers*. This publication offers suggestions about managing stress, setting goals, seeking solutions, communicating constructively and asking for and accepting help. (Note: all Family Caregiver Alliance publications are available at www.caregiver.org. See the References section at the end of this guide for more information.)

- **Knowledge and confidence will come a little at a time.** Sometimes you have to take a step sideways, or even step backward, before you make progress. But bit by bit, you will sort out the challenges and find the solutions.
- **Get the support you need.** Support comes in many forms and from lots of places. What you find supportive is individual to you—the main thing is to not expect to “go it alone.”

Perhaps it goes without saying, but it is so important we'll say it: As much as possible, involve the one who needs care in the decision-making process. Respect his or her expressed values and preferences, even when these differ from yours.

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Preventive Steps

It will help you immeasurably if, before there is a crisis, your parent provides you with information to locate his or her records, important telephone contacts and other essential items.

Where to Find My Important Papers is a one-page document available on the FCA website. It will help you collect information which will simplify communication with government agencies such as Social Security or the Veterans Administration; help with banking

and other financial transactions; and make speaking with your parent's attorney or physician easier.

Legal documents, such as **Durable Powers of Attorney** and **Advance Directives**, can and should be prepared before a medical condition makes it impossible to do so. See the FCA Fact Sheet *Legal Issues in Planning for Incapacity* for more information, or contact an **elderlaw attorney**.

Sometimes, as you travel this road, you might think you need the skills and knowledge of a lawyer, accountant, doctor and social worker to make sense of things. Don't get discouraged! No one can master everything, not even the people who work full-time in the field. The solution lies in putting together a team and using each team member's strengths—including yours.

4 Getting the Lay of the Land

The sudden realization of your new role as a caregiver is likely to be stressful. You may feel overwhelmed and quite alone. In reality, you have lots of company. An estimated seven million Americans—including more than three million baby boomers—provide or manage care for a relative or friend over the age of 55 who lives at least an hour away. And more are joining us every day, for our society is both mobile and aging.

The good news is with so many of us involved in care at a distance, there's lots of information to help. For example, a search on the Internet using the words "long-distance caregiving" yields quite a list. That list likely includes **Family Caregiver Alliance's** website, www.caregiver.org; the **American Association of Retired Persons (AARP)** website (most specifically its

longdistance caregiver section) at www.aarp.org/life/caregiving/articles/a2003-10-27-caregiving-longdistance.html; and the caregiver section of the federal **Administration on Aging's** site, which has many useful links, at www.aoa.dhhs.gov. You'll find additional resource information throughout this guide.

To keep things in order, some long-distance caregivers suggest creating a **Care Notebook**—a handy three-ring binder in which you keep all the information you assemble.

What's Needed?

Before you get too deep into exploring what help is available to you, you'll want to assess your loved one's situation. As you get more details about the condition, whether by going to visit right away or by talking with your relative and others over the telephone, an initial plan will take shape. You'll gain clarity on who else is involved now in your loved one's care, and who also could be involved later. In short, your team will emerge.

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Let's next take a look at what your parent might need, then at who might be part of your caregiving team.

Has your parent suffered a sudden crisis, such as a stroke or a serious fall? Or has the situation emerged gradually over years, as with arthritis or Alzheimer's disease? Is the impairment physical, or are there memory problems as well? In answering these questions, you've already begun to assess what, exactly, is going on with your relative and what kind of help is needed.

The assessment process will go on for a while. In fact, there may not be a completion point for assessment because needs change over time.

So think of this assessment as *gathering information as a basis for making care decisions*. You will do the best you can, based on what you know at the time. Depending upon how things go, and what else you learn, you may change your decisions. And you may in fact discover that despite your best efforts, your parent may not be able to live independently. You and your loved one, perhaps in discussion with others close to you, will decide what is needed.

First and foremost, getting a complete and accurate medical diagnosis for physical or cognitive problems is very important. You'll want to find out what your relative can do independently—without any support—what can be done with a little help, and what your loved one cannot do at all right now. Then the two of you, and others on your caregiving team, will be in a better position to plan care.

- 6 Use the checklist on the following page to start reviewing your relative's needs.

Checklist of Care Needs

- Help with chores, laundry, yardwork and household maintenance.
- Help with grocery shopping.
- Meals delivered at home or fixed and served there, clean-up included.
- Personal care, such as help dressing or bathing.
- Transportation to places important to your relative, such as church or social gatherings.
- Transportation to the pharmacy and doctors' appointments.
- Assistance at medical appointments, and/or consultation with doctors and other health professionals.
- Assistance with paying the bills, banking, budgeting or other money matters.
- Financial assistance to make ends meet.
- Referral to an attorney experienced in elder-law issues; for example, to establish Durable Powers of Attorney or to address estate planning concerns.
- Dispensing of medications and ensuring they are taken on time. (One of the most important items in your Care Notebook should be a list of medications your parent takes.)
- A safety inspection of the house (e.g., smoke alarms, uneven flooring, loose rugs, lighting).
- Installation of grab bars or a ramp to make the home safer and easier to navigate (called "home modification").
- Trips out of the house, perhaps to an adult day care or senior center.
- Visitors who make sure all is well on a weekly (or twice weekly or even a daily) basis.
- Additional social visits from friends, family and other volunteers.
- Emotional support, reassurance and someone to talk to.

Many of these needs may be met by service organizations within the community. You will want to be on the scene yourself for a time to establish services, and later to observe how things are going, what assistance is most effective and what might need to be changed.

To use your time most efficiently, start your research by computer and phone *before* the visit to find out what resources and services are available. This will allow you to make appointments to meet providers during your visit. Introduce yourself to your family member's doctor and any others engaged in providing care if you have not already met.

Care Managers

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In more and more communities, specialists in planning care for older persons are available. Sometimes called **geriatric care managers**, these professionals are often trained as gerontologists, social workers or nurses. They focus on assessing needs and arranging for services required by an older person with health problems. Care managers can be helpful for long-distance caregivers by being able to update you on your loved one's situation, options and needs.

Care managers may be in private practice and charge a fee for their services, or be employed by a local nonprofit organization or government agency (generally at lower cost). Whether you will have to pay a fee for their assistance, and how much that fee will be, will depend upon the particular circumstances.

Always check references and credentials before you engage help—personal recommendations from acquaintances are especially helpful. Another source for

locating a private care manager is The National Association of Professional Geriatric Care Managers, www.caremanager.org.

A local caregiving or seniors agency may be of great help in locating a care manager and other assistance. Keep in mind that services vary from state to state, so what is available in one community may not be available in another.

Who's on Your Team?

You live far away. Others residing nearer your loved one, such as the neighbor who called, are possible team candidates. These individuals will help you make the most of your visits, plus ease your mind in between times by pitching in on various tasks.

Ask yourself, "Who is in regular contact with my loved one?" Possibilities include:

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- Nearby siblings, other family members and close friends
- Neighbors who know your relative well
- People your loved one sees frequently, such as clergy or a housekeeper who comes often
- Professionals with longstanding relationships.

In your Care Notebook, compile a list of the names, telephone numbers and e-mail addresses for these people. Now leave spaces for care managers, social workers or other professionals who can help you navigate the care system, and for in-home aides and others who may help provide care. You'll fill in those names—if needed—as you go.

Who Can Do What?

Here's where your creativity and perseverance count. As you see the kind of help your relative needs today—what he or she can, or cannot do independently—you'll be in a better position to understand how the local community can support the two of you. Remember, whenever possible, to make these decisions in agreement with your loved one.

Most of us are not schooled in health care delivery or social services programs, so don't be surprised if you find things confusing at first. Each community has its own group of agencies and providers ("formal system"), as well as informal supports you can use (friends, neighbors, and volunteers). Services in your relative's community may include:

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- meal delivery
- adult day care
- in-home aides
- transportation
- help with Medicare claims
- volunteers and "friendly visitors"
- support groups
- telephone check-ins
- financial assistance.

Learning about the formal system in the local community, especially if you are doing this on your own without the aid of a professional care manager, will take some effort. There are good tools available to help you.

Places to Start

- The Administration on Aging's **Eldercare Locator** is useful in finding aging services in your

loved one's community. You may reach the Eldercare Locator via telephone at (800) 677-1116, or visit www.eldercare.gov.

The Eldercare Locator provides contact information for every **Area Agency on Aging** in the country. The federal government established Area Agencies on Aging, also called AAAs, in every state to provide a range of programs and services for the elderly. Most, but not all, of these agencies are associated with county or city government. Information and referral to other community agencies is one of their functions. A call to the agency serving your relative's community should answer many of your questions about local services.

- **Family Caregiver Alliance's** website offers a state-by-state searchable database to help you locate publicly funded programs. See www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1274.

You may also contact us at info@caregiver.org or call (800) 445-8106 to reach an Information Specialist who can offer advice on local services.

The FCA Fact Sheet on **Community Care Options** also provides more detail on the types of resources that may be available in your area.

- **National Council on Aging Benefits Check Up** at www.benefitscheckup.org will help you find out whether your relative qualifies for state and federal assistance programs.

- The **Alzheimer’s Association** at *www.alz.org* and other “disease-specific” organizations offer support services.
- Religious organizations such as **Catholic Charities** or **Jewish Family Services** may offer services.
- **Faith in Action** can help you locate volunteers in your relative’s area.

When you investigate local resources, whether by phone, online or in person, prepare to be patient and persistent. Have as much information on hand about your relative’s situation as you can. It’s a good idea to write down whom you spoke to, the dates, and any follow-up needed. Be ready to take notes on topics such as:

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- Services an agency offers
- How to apply (including documents needed)
- Whether there is a waiting list
- Fees, if any, for their services.

The next steps are to figure out:

- How to link up these resources to take care of your relative’s needs
- How to bridge the gaps that remain
- How to pay for these services.

What Are Your Caregiving Strengths and Limits?

Now it’s time to step back, take a deep breath and make an honest assessment of your own strengths and limits. Remember that your relative’s care is a team effort.

You may, or may not, be the team leader. Either way, you need to be realistic as to how much you can do.

As for your *strengths*, what are you particularly good at doing?

- Are you best on the phone, finding out information, keeping people up to date on changing conditions and offering cheer?
- Are you good at supervising employees?
- Are you comfortable speaking with medical staff?
- Is your strongest suit doing the numbers—paying bills, keeping track of bank statements, reviewing insurance policies and reimbursement reports?

In working with your team it will help if you can make known how your skills complement theirs. Ideally, each of you will be able to take on what is easiest and most rewarding for each individual.

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In 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?
- Can you be both patient and assertive enough when communicating from a distance?
- How will your decision to take on care responsibilities affect the rest of your family and your work?

Balancing Work and Eldercare

In thinking about work issues, you might find it useful to look at the *Work and Eldercare* section of Family

Caregiver Alliance's website at www.caregiver.org/care-giver/jsp/content_node.jsp?nodeid=795.

A very important development for caregivers is the **Family and Medical Leave Act** (“FMLA”) of 1993. This federal law requires covered employers to provide up to 12 weeks of unpaid leave to eligible employees for certain family and medical reasons. The U.S. Department of Labor FLMA web site, www.dol.gov/esa/whd/fmla, provides details on this law. Many states have enacted similar laws, extending coverage to more employers and employees. Some states are considering legislation that would continue partial pay for some employees during an authorized leave. In 2004, most California employees became eligible to take partially paid leave to care for an ill family member. During this leave, you can organize services for your parent, provide care yourself, or be with them during a medical emergency.

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If you work in a large corporation, your **Human Resources** or **Employee Assistance department** may have information or services that can help. It might also be useful to look into the possibility of working flexible hours to allow you to spend time on the phone setting up services or speaking with your care team.

With a deepening understanding of your personal capacity, you can move on to teamwork—exploring how to link care resources and bridge gaps by sorting out who will do what. A method to keep your team on track is the family meeting.

The Family Meeting

A family meeting brings together the core team involved in decisions about care for your family member. Whether or not team members are actual relatives,

they make up the “family” for this meeting. (See Family Caregiver Alliance’s Fact Sheet *Holding a Family Meeting* for more information.)

The earlier the first family meeting can occur, the better. Each person involved in your loved one’s care will benefit by having a common understanding of goals and tasks. Don’t delay setting up a meeting simply because you can’t get everyone that you think should be included to participate. Do what you can as soon as you can, making sure that the family member needing care participates as much as possible in all decision-making.

The point of the first family meeting is to clarify goals and responsibilities, as well as air feelings and ask for support. Your family meeting can take place in person, by e-mail, in a private web chat room, through a telephone conference call or with a combination of these.

Virginia Morris, a journalist who cared for her own father through a terminal illness, shares guidelines for holding family meetings in her book, *How to Care for Aging Parents*. We’ve added to her ideas to create this set of tips:

- Agree to rules in advance. For example, set a time limit for the meeting and for each person to talk (so no one dominates the meeting), and establish who will act as moderator.
- Avoid attacks, accusations and blaming. If the meeting is likely to be difficult, consider inviting a facilitator such as a social worker, therapist, religious leader or another trusted professional.
- Focus the discussion on care issues, not matters between siblings or others.
- Let everyone’s views be aired.

- Make a detailed list of the tasks (refer to the checklist on page 6). It's helpful to circulate a tentative list before the meeting to refine during the meeting. Try to think of everything needed, such as researching resources, shopping for groceries, interviewing home care aides, accompanying your relative to doctor's appointments, coordinating care, organizing important documents and talking with financial and legal professionals.
- Appoint one person to be the family's voice when talking with health care professionals. This individual may or may not be the primary caregiver.
- Divide the duties. Start by having team members volunteer.
- Decide when you want to meet again and how often you want to have meetings.

16 It will help keep everyone on track if, right after the meeting, one participant distributes notes summarizing the decisions made.

A central issue—how you will pay for services—will shape some of the decisions you make. While a detailed discussion of this complex topic is not covered here, we can suggest some resources.

Paying for Care

Earlier in this guide we mentioned a website where you could check eligibility for government programs (www.benefitscheckup.org). This is a beginning.

New caregivers sometimes assume that **Medicare** will pay for most, or all, of the services needed by their parents or other loved ones. Unfortunately, that's not true. The reality is that Medicare is an important health insurance program with complicated rules, and it focuses on acute medical care or hospital and skilled

nursing care rather than the kinds of long-term care your relative might need. For information on recent changes in Medicare, see www.medicare.gov.

Often, when individuals have exhausted (or spent down) their financial resources, they become eligible for **Medicaid**. This government insurance program may pay for certain long-term care costs, including nursing homes (although not usually assisted living facilities). Medicaid is administered through the states and provides assistance to individuals and families with low incomes. Medicaid varies from state to state, so it is important to determine the regulations in your loved one's area. For more information, visit the Medicaid Home Page at www.cms.hhs.gov/medicaid/consumer.asp. You may also need to contact the Medicaid office in your family member's state.

If you must pay out-of-pocket, a **reverse mortgage** may be an option. For information, visit www.reverse.org.

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As with the other pieces of caregiving, you soon will have a handle on costs and payment sources, which in turn will help you and your relative make the best choices for your situation.

An elderlaw attorney or financial planner can be a useful part of the team to determine how to pay for care. To find an elderlaw attorney, you can use the Eldercare Locator (see page 11) or contact the **National Academy of Elder Law Attorneys** at www.naela.org or call (520) 881-4005.

Practical Tips and Resources for a Distant Caregiver

We've already touched on many of the things you can do from a distance and through occasional short visits.

Here's a quick summary, with some additions inspired by AARP's "Caregiving from Afar—Your Guide to Long Distance Caregiving" (www.aarp.org/life/caregiving/articles/a2003-10-27-caregiving-longdistance.html):

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- Information gathering by telephone or the web —on medical conditions, medications, local community resources, support groups, government programs. This will all go into your Care Notebook.
- Emotional support to your loved one and to others on your caregiving team, through regularly scheduled phone calls or e-mails. Letters every week about the goings-on in your life can also include friendly reminders to purchase medication or remember doctor's appointments.
- Banking and bill paying, using online services, direct deposit or traditional mail. Many public utilities now will notify a caregiver, even one at a distance, if the loved one's account becomes past due or if service is in danger of being disconnected.
- Arranging and monitoring hands-on services to help your relative. After the initial arrangements, much can be handled through telephone calls and occasional short visits.
- Providing a break, when you visit, for the on-the-scene members of your team if they are involved in direct care or supervision.
- Acting as the primary contact for physicians, care providers or others.
- Remembering to obtain emotional support for yourself. It may be helpful to talk to friends, colleagues at work or find an in-person or online support group where you can talk about your caregiving challenges. Discussing your situation, letting your feelings out and listening to other points of view can provide some relief and help you to refuel.

Where Do You Go from Here?

In this guide we've focused on the beginning of your journey as a long-distance caregiver, and we've offered a lot of information. But each family is different, and each care situation is different, so we encourage you to pick and choose resources appropriate for *your* situation. As you become more expert you will develop the skills and resources you need to provide good care. Just remember to take care of yourself, too, and to seek professional assistance if you become overwhelmed.

You may also run into resistance to your offers of help, which may be misinterpreted as needless interference or an attempt to limit your relative's independence. You might explain that, in fact, their accepting outside help will make you feel better—this is something they can do for you. It also might help to have a doctor or another respected person make the suggestion to your parent to accept assistance.

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Both you and your loved one will need to adapt to new situations as they arise. There are some things you can control, and some you can't—it might help to step back and be sure you're not spending energy trying to fix something that really is not fixable.

In closing, we want to offer you encouragement in your new role, along with a few more tools for use in the future and contact information for several government agencies and organizations other caregivers have found helpful.

Some Tools for the Future

Hiring In-Home Help is a Family Caregiver Alliance Fact Sheet that covers the responsibilities of caregivers as employers, and provides information on assessing your home care needs. It also has tips on writing a job

description, developing a job contract and finding the right worker.

Driving and Dementia. Driving is an important symbol of independence—and many older people are reluctant to give it up, no matter how incapacitated they may appear. This FCA Fact Sheet outlines steps needed to handle this dilemma.

Home Away from Home: Relocating Your Parents, an FCA Fact Sheet that takes you through the issues involved when you are considering a residence change for a relative who is no longer able to live independently. It covers topics such as family dynamics, various types of housing, and moving your relative into your own home.

CarePlanner, sponsored by the Centers for Medicare and Medicaid Services, is a website that acts as a “decision support tool.” It allows you to explore options for care based on your loved one’s particular values and needs and provides information on a range of options. Find it at www.careplanner.org.

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Helpful Agencies and Organizations

Family Caregiver Alliance and its **National Center on Caregiving** can be reached at (800) 445-8106 (M-F, 9-5 PST), info@caregiver.org, or at www.caregiver.org.

FCA operates programs at national, state and local levels to support the important work of families and friends caring for adults with disabling health conditions. You’ll find free online support groups and publications on its comprehensive website. There is no charge to receive information about care resources in your area.

Administration on Aging (AoA) is the home of the **Eldercare Locator**, (800) 677-1116 (M-F, 9-6, EST) or www.eldercare.gov, and the oversight agency for the National Family Caregiver Support Program. AoA's Home Page is www.aoa.gov.

Medicare has a HOTLINE: (800) MEDICARE, or (800) 633-4227, as well as www.medicare.gov. Included are ratings for home health agencies across the country.

Social Security Administration website offers links to many government services for seniors, including Veterans benefits: www.seniors.gov.

National Council on Aging Benefits Check-Up checks eligibility to receive benefits at www.benefitscheckup.org.

Children of Aging Parents offers assistance for caregivers of the elderly or chronically ill. Visit www.caps4caregivers.org or call (800) 227-7294.

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National Family Caregivers Association is a support organization for caregivers. Find them online at www.nfcacares.org.

Faith in Action is an interfaith volunteer organization providing help for those with long-term health needs. Visit www.fiavolunteers.org/programs/index.cfm or call (877) 324-8411.

AARP's website has a long-distance caregiver page with many useful links: www.aarp.org/life/caregiving/articles/a2003-10-27-caregiving-longdistance.html.

References

All Family Caregiver Alliance Fact Sheets mentioned in this guide are available free online. Printed versions are \$1 for each title—send your request to *FCA Publications*, 180 Montgomery St., Ste. 1100, San Francisco, CA 94104.

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