

# THE Caregiver's HANDBOOK

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# Getting Started

*There were 36.3 million Americans over age 65 in 2000, and it is projected that there will be 86.7 million by 2050.*

2000 CENSUS, U.S. CENSUS BUREAU

*There were 33.9 million family caregivers of elders in 2004, and it is projected that there will be 81 million by 2050.*

CAREGIVING IN THE U.S., NATIONAL ALLIANCE FOR CAREGIVING AND AARP, 2004.

- *Do you want to find out basic information about elder care?*
- *Are you having difficulty finding an agency near you that has eldercare resources and services?*
- *Are you worried about financing eldercare needs for yourself in the future or for a family member now?*

Whether you are just starting to care for an elder\* or are an experienced caregiver, this *Handbook* will help you navigate the complexities of eldercare information and services, find national and local organizations, and help you choose the appropriate services and resources for your family. It has been designed for a wide variety of family caregivers, including:

- Those planning for the eventuality of caring for a spouse, parent, or other elderly relative
- Those currently caring for an elder with minimal or moderate needs for assistance
- Those caring for a chronically ill or critically ill elder with significant ongoing needs

The *Handbook* is also appropriate for those considering their own needs as they age.

This *Handbook* is designed to be a comprehensive guide to the issues you face as a caregiver. You can read (and download) the entire *Handbook*, or you can download sections of particular interest. The Glossary section at the end will help you understand unfamiliar terms. The **Handouts**, including helpful checklists, offer at-a-glance information. You may also be interested in creating a localized version of this *Handbook*. See **How to Create Your Own Caregiver Handbook**.

*\*Note: The term “elder” is used throughout the Handbook to refer to an older parent, relative, or friend in your care.*

## It Starts with a Conversation

- *Have you ever talked with the elder in your family about changes that are needed for him or her to live at home safely, now that his or her abilities are changing?*
- *Have you ever talked about bringing services and paid caregivers into the elder's home?*
- *Have you ever talked with the elder about assisted living or nursing homes?*
- *Have you ever asked the elder if he or she has a will or a health care proxy?*

Many people worry about raising these issues. They may mentally rehearse having “the conversation,” but are never able to actually do it. The following guidelines can help you to start the process—the first step in becoming a caregiver.

### Define the Need

Ideally these conversations should happen before there is a crisis. Usually they are prompted by a decrease in an elder's ability to do certain things she or he has always handled independently. Many elders also find it difficult to talk about these issues—but not always for the reasons you may think. In fact, they may be relieved to talk about their fears and concerns once the issues are raised. Don't assume that you are the only one who wants to talk.

You may want to start the conversation by telling the elder that you read an article, watched a film such as *Caring for Your Parents*, heard an expert on the topic, or spoke to a friend whose parents are in a similar situation. This helps remind the elder that he or she is not the only person whose life is changing—others are experiencing the same changes and confronting similar issues.

### Who Should Be There?

Consider how to make the conversation as caring and productive as possible. Although you don't want to bring too many people into the conversation—you don't want to overwhelm the elder—who is included in the conversation depends on family dynamics and the personality, marital status, gender, and health of the elder. If possible, talk together with your family *before* meeting with the elder in your care. Give everyone the chance to discuss their own needs and concerns, and what role they want to or are willing to play as part of a family caregiving team. Decide if:

- The elder's spouse should be present
- All, some, or one of the adult children should be present
- A favorite family member, such as a niece or nephew, should be included
- The elder's sibling(s) should be present
- A family doctor or other respected professional, such as an attorney, should help facilitate the conversation

## Where and When?

Assess what the best circumstances are for an elder to hear about your concerns and voice his or her own opinions. If the elder tires easily late in the day, you may want to meet in the morning. You may want to begin the conversation after a meal. Is there a favorite chair, room, backyard, or park where the elder feels especially safe and comfortable? The context for the conversation can have an impact on whether the elder can “hear” your concerns.

## Small Steps

You probably do not want to begin with the “big picture.” Start with small steps, small decisions, and small changes. It is important to be direct and specific about your concerns, next steps, or even proposed solutions.

Sometimes an assessment by an “outside expert” can be a good way to start. For instance, if the elder has stopped showering, you might suggest bringing in a social worker or occupational therapist to assess the elder’s ability to do daily tasks and make suggestions about how to make things easier and safer.

## What About Denial?

At first, the elder in your family may deny that there is a problem at all. This is very common. Concern about the elder’s ability to continue driving is a particularly sensitive topic. (See the Housing and Transportation section) However, a “successful” conversation does not mean that you both reach complete agreement. You have made progress simply by starting the conversation and beginning the process of change and planning for the future. Be prepared to have several talks over a period of time. Being supportive and sympathetic about the difficulty of change and the elder’s fears, as well as his or her loss of independence, will help ease the elder’s defensiveness and make him or her more receptive to what you are saying.

## Listen Carefully

Remember that the elder is still the expert on her or his situation. Listen thoughtfully to his or her ideas as you present your concerns and suggestions. Rather than telling the elder what he or she must do or change, ask the elder to help you assess the problem and welcome her or his input on possible solutions. The elder must ultimately “own” the solution. You may be surprised to discover that he or she is also worried or feels unsafe, and is comforted to learn that support is available.

For more tips, see **It Starts with a Conversation**. For concerns about driving, the *MIT Age Lab* and the *Hartford Insurance Company*, [www.thehartford.com/talkwitholderdrivers/driversatrisk.htm](http://www.thehartford.com/talkwitholderdrivers/driversatrisk.htm), have prepared a guide called “Having the Conversation” to help families discuss changing driving skills, risks, and alternatives. The site includes useful worksheets and links to other resources.

## Preparing for Caregiving

When people go through any major life change—graduation, marriage, parenthood—there is often a period of learning and preparation. However, we are rarely given the opportunity or skills to get ready to care for an elder. The following tips will help you prepare for your new role.

### Anticipating Care Needs

If you have an elderly parent or relative in your family, you may soon become a caregiver. Planning ahead is a luxury that many caregivers do not have, but most experienced caregivers say they wish they had started to prepare before facing a crisis. A few key questions to answer are:

- *Do I know what the elder's wishes would be if she or he were unable to make medical decisions?*
- *Do I know where important documents, such as insurance, wills, or financial statements are located?*
- *Do I have the authority to take over his or her finances if the elder in my care can no longer manage money?*
- *Has the elder set up legally binding documents stating his or her wishes about health care decisions?*

### Assessing Care Needs

It is common when first facing eldercare issues to feel overwhelmed and not know where to begin. The first step is to develop a care plan based on a careful assessment of current needs. The plan will depend in part on whether the elder has had a sudden health crisis, a medical condition that is progressive, such as dementia or vision deterioration, or has needs due to a normal and gradual process of aging. But a plan is only as good as the information it is based on. Ask yourself:

- *How do I assess what kind of care is needed?*
- *How can I get help in making this assessment?*
- *Once I understand the needs, what kind of services should be put in place?*
- *What services will be needed down the road?*

For more about assessment of needs, see the Home Care and Caring for the Caregiver sections.

## Assessing Your Needs

Many caregivers do not think about their own needs, but in order to manage caregiving over time—days, months, or years—you should think about your own needs, not just those of the elder you are caring for. Ask yourself:

- *Can I manage these services by myself?*
- *How can I get support or take a break?*
- *How do I take care of myself?*

For more about caregiver support, see the Caring for the Caregiver section.

## Finding Eldercare Services

If you are anxious about starting this process, you are not alone! Here are a few pointers to keep in mind as you begin to navigate the eldercare system:

- **Talk to a real person.** Many phone numbers you call will lead to voicemail. It's important to leave a message, but don't wait for a call back. Some services have backlogs of calls to return. Keep calling numbers until you connect with a human being who can help you.
- **Keep track of your conversations.** Write down names, phone numbers, and notes from each call, including customer service representatives.
- **No one person knows everything.** The person you finally get on the phone may be an expert in certain areas, but not in others. You will have to decide whether or not you will need to make additional calls.
- **All eldercare services are ultimately local.** Services can vary widely from state to state and region to region. If you are caring for an elder but not living nearby, make sure you look for resources in the state or neighborhood where the elder in your care lives.
- **Be persistent.** You may get frustrated trying to find the person and the information you need. You may be told that something cannot be done when in fact it can. Don't give up!
- **Ask for "Information and Referral."** I&R specialists are trained to answer a wide range of questions and connect you to services, so ask for that first.

## Using the Internet

The Internet has greatly expanded the information available about eldercare resources. In fact, there is so much information on the Web that it can actually be difficult to locate the precise information you want. (If you do not have Internet access, try your local public library.)

This *Handbook* provides Web site addresses (URLs) for reliable and up-to-date Web sites. However, URLs often change. If you find that a URL does not work, type the name of the organization into your search engine (Google, Yahoo!, etc.) to find the correct Web address.

## The Eldercare Locator

The **Eldercare Locator** at [www.eldercare.gov](http://www.eldercare.gov) is the “front door” to finding resources for eldercare services and caregiver support in any U.S. community. It is a free national service of the U.S. Administration on Aging, [www.aoa.gov/](http://www.aoa.gov/), and the National Association of Area Agencies on Aging, [www.n4a.org/](http://www.n4a.org/).

For information and referral to community-based services, visit the Web site or contact Eldercare Locator counselors at 800-677-1116 toll free\* (weekdays, 9:00 A.M. to 8:00 P.M., ET). Calls are answered by trained professionals, including Spanish-speaking specialists, and some questions are answered via a special line with 150 languages. TDD/TTY access is also available.

On the phone or online, be prepared to answer the following questions:

- 1 Are you seeking services for: Yourself? An elder? A client? (Choose one.)
- 2 Do you want to search for information by city, county, or Zip Code? (Choose one.)
- 3 What “aging” topic would you like to research? A menu will give you a list. “General Information & Assistance” is a good place to start, unless one of the topics is exactly what you want.

*\*Note: You will probably need to dial 1 before most of the phone numbers that are listed in this Handbook, including toll-free phone numbers that begin with 800 or 877.*

## How Eldercare Services Are Organized

Using the **Eldercare Locator**, you can access the “gateway organizations” that coordinate eldercare in all 50 states and the District of Columbia; Area Agencies on Aging, Councils on Aging, and State Units on Aging. These organizations are literally a gateway to a world of eldercare information, services, and resources that exist in your community—they are the link between you and a broad array of nonprofit and for-profit agencies.

## Area Agencies on Aging (AAAs)

There are 655 AAAs in the United States, and one nearby that serves you. They are known in the network of eldercare service providers as “Triple As.” Each AAA serves a group of cities and towns in a particular region of a state. AAAs coordinate services in three major areas:

- 1 Information and Referral (I&R):** AAAs provide free information about a wide range of eldercare services and resources through trained I&R specialists who will connect you to services. AAAs may also have trained volunteer counselors to provide Medicare and Medicaid information and can help with medical billing problems, reducing insurance costs, and completing public benefits applications.
- 2 Services for the Elderly:** AAAs coordinate services for elders who want to remain in their own home, but need assistance with their daily routines. Core services include in-home assessments by case managers, development of a care plan, and assistance arranging home care services delivered by the AAAs’ network of subcontracted provider agencies. AAAs also provide meals, transportation, and referrals to employment services, senior centers, and adult day care programs. (Note: Programs vary by area; not all services are offered by all AAAs.)
- 3 Support for Caregivers:** AAAs develop local programs as part of the National Family Caregiver Support Program, including information and referral, counseling, training, support groups, and access to respite care. Caregivers are eligible for this program if they are caring for an individual 60 years or older, regardless of the elder’s income.

## Councils on Aging (COAs)

Most cities, towns or municipalities have a Council on Aging or senior center. These agencies are part of local government and range in size from small, volunteer-run programs to large, multi-site eldercare service providers. They are the front line for many elder services in your community. Volunteers are critical to the operation of the COAs, regardless of their size or scope of services.

Most COAs offer information and referral, transportation, outreach, meals, health screening, and fitness and recreation programs. Some COAs also provide health insurance benefits counseling, food shopping assistance, telephone reassurance, friendly visiting and other in-home activities, peer support groups, supportive day care, pre-retirement programs, minor home repair, computer training, case management, intergenerational programs, and more.

## State Units on Aging (SUA)

Each state has an agency for elder affairs that coordinates services and funding, known as a State Unit on Aging (SUA). The agency may be located in your Department of Health and Human Services, or it may be in Social Services or Public Health departments. The names of the state agencies vary, as well as the titles of the senior officials, but generally the senior official reports to the governor or lieutenant governor's office. To locate this agency, search your phonebook's government listings or the Web. However, the best source for finding the agency nearest you is to use the **Eldercare Locator** at [www.eldercare.gov](http://www.eldercare.gov).

## Other Eldercare Resources

The “gateway organizations” are just some of the providers for eldercare. The overall system is a complex mix of nonprofit and for-profit agencies and organizations. Other resources to contact include:

- **Community agencies** that serve a particular ethnic group or faith tradition, but are usually open to others, and provide a range of services such as transportation assistance, home care, transportation, and meals
- **Outpatient centers** linked to HMOs and community health clinics
- **Rehabilitation facilities** with their own inpatient services and community-based follow-up programs
- **Hospitals** with their own geriatric medicine departments and geriatric community outreach programs
- **Housing authorities and housing facilities** such as continuing care retirement communities, assisted living residences, and nursing homes
- **Industry, trade, and professional associations** representing hospitals, extended care facilities, home care agencies, geriatric care managers, and others

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You may be worried about how to make the best eldercare decisions without compromising your family's overall economic security. The following questions may help you clarify your concerns:

- *What is the elder's financial picture?*
- *What eldercare services can the elder in my care afford?*
- *Does insurance cover any of these expenses?*
- *How can we find out if we are eligible for subsidized eldercare services?*
- *Is there any financial assistance for lower-income and middle-income families?*
- *Who in the family needs to be consulted about paying for eldercare services? Can other family members help pay for services?*

## Start Planning NOW

Making decisions about health care, home care, and housing needs can be not only overwhelming but also costly. If at all possible, start planning *now* for the future needs of elders. Since you may be approaching or past 60 yourself, you should try to do financial planning for your own future needs as well. Your ability to care for another person, and possibly provide financial assistance to him or her, may depend on making changes to your own financial plan.

A good financial plan—both for an elder and yourself—should include:

- A monthly budget with income and expenses
- A budget for large capital expenses over a three-to-five-year period
- A review of health insurance plan(s) for what is covered and what is not
- An overview of all assets and debts
- Choosing someone to handle finances and decision-making

## Professional Financial Planners

You might begin to think about these difficult financial and legal issues by talking with a professional financial planner, elder-law attorney, or geriatric care specialist. A good place to find such expertise is your local Area Agency on Aging (AAA), which can provide advice and also make referrals to fee-for-service financial planners.

For a checklist of questions to ask when interviewing a financial planner, call the **Financial Planning Association** at 800-322-4237 or visit its Web site at [www.fpanet.org](http://www.fpanet.org). The site provides a database of certified financial planners across the country and has useful information about retirement planning.

## Understanding Family Finances

To begin planning for yourself and the elder in your care, or to prepare for working with a financial planner, you will need to analyze two things:

- 1 **Cash flow**—determined by calculating current income and expenses including health insurance
- 2 **Net worth**—the current value of all assets (including the house or apartment) after you have subtracted all debts

Start by locating all important financial and legal records and documents. Use the [List of Important Documents](#) to help you. It is also important to review beneficiary designations on any life insurance policies, annuity contracts, and 401K/IRA accounts to make sure they are current. You should also be sure that you have a letter of permission from the elder in your care to contact and discuss his or her financial accounts and insurance policies. A good financial analysis should include the following:

### Current Income

- Personal income from pensions and other retirement benefit systems, such as 401ks, including their required minimum distributions
- Personal income from annuities and investments, such as mutual funds, stocks and bonds
- Rental income
- Income from public sources such as Social Security, SSI (Supplemental Security Income for aged, blind, and disabled people who have little or no income), and Veterans Benefits. (If you have questions about Social Security go to [www.ssa.gov/](http://www.ssa.gov/) or call or visit your local Social Security office. Call 800-772-1213 toll free, TTY 800-325-0778, to help locate an office near you.)

### Current Expenses

- Rent or mortgage payments
- Real estate taxes
- Utilities and telephone bills

- Bills for uninsured medical expenses, such as dental work or eyeglasses
- Insurance premiums
- Medications
- Food
- Clothing, toiletries, and other personal items
- Entertainment
- Gas, car maintenance, and other transportation expenses

### Insurance Coverage

- Health care
- Prescription drugs
- Long-term care
- Life insurance death benefits
- Medicare/Medicaid
- Veterans Benefits

### Assets

- Real estate
- Cash, CDs, stocks, bonds, mutual funds
- Deferred annuities
- Cash value of life insurance

### Debts

- Mortgages
- Credit card balances
- Car payments
- Outstanding bills/loans

## Eldercare Benefits

To quickly determine whether the elder is eligible for services that are free or for fees based on income, you may want to do a “benefits checkup.” The **National Council on Aging** Web site at [www.benefitscheckup.org/](http://www.benefitscheckup.org/) offers a free, confidential, and comprehensive online service that checks for federal, state, and some local private and public benefits for older adults (ages 55 and over). It provides a detailed description of available programs and also provides local contacts. Visit the Web site and click on “Find Benefits.”

Generally, eligibility criteria for elder services are based on a combination of the following factors:

- Age
- Assets
- Disability
- Employment status
- Expenses
- Health insurance
- Health status
- Household size
- Income
- Veteran status

Since there are so many factors in determining an individual’s eligibility, it’s essential to consult with a benefits counselor. Consult your local AAAs or COAs for referral to a benefits counselor.

## Long-term Care Costs

Most long-term care expenses are not covered by Medicare or other health care insurance plans, and the costs can be staggering when elders require round-the-clock care. Long-term care insurance, whether at home or in a long-term care facility, can help control long-term care costs and protect family assets. For more information see the Insurance section.

## Retirement Planning

While it may be too late for the elder in your care to plan his or her retirement, caregivers—particularly baby boomers—can get help now with the complex issues involved and make decisions for their own future needs. The **American Institute of Certified Public Accountants** at

[www.360financialliteracy.org/](http://www.360financialliteracy.org/) offers information for families who are balancing the financial needs of elders, children, and their own retirement. Visit its Web site and click on “Life Stages.”

## Reverse Mortgages

The costs of eldercare services can make it difficult for elders to continue living in their own homes. If the elder in your care wants to continue living at home but is having financial difficulties making ends meet, consider a reverse mortgage. This is a special type of home loan that lets a homeowner convert a portion of the equity in the home into cash. The equity built up over years of home mortgage payments can be paid out to the homeowner. But unlike a traditional home equity loan or second mortgage, no repayment is required until the borrower(s) no longer use the home as their principal residence, at which the point the home is usually sold to repay the mortgage.

- **AARP** at [www.aarp.org/money/revmort/](http://www.aarp.org/money/revmort/) offers information and resources about reverse mortgages. Visit the Web site or call 800-209-8085 toll free.
- **U.S. Department of Housing and Urban Development (HUD)** at [www.hud.gov](http://www.hud.gov) offers a safe, federally insured, private reverse mortgage that can give older Americans greater financial security. For information, call 800-569-4287 toll free or go to the Web site and enter “reverse mortgage” in the search box. Click on “Top 10 Things to Know If You Are Interested in a Reverse Mortgage.” In addition, HUD-approved housing counseling agencies are available for free, or at minimal cost, to provide information, counseling, and free referrals to a list of HUD-approved lenders.

## Pensions

If the elder in your care has not yet retired, she or he should discuss the payout options from her or his pension plan—lump sum versus lifetime payout—with a financial planner. In planning for long-term care, pension payout can be of vital importance, particularly if there is a family history of illness, or if the worker/retiree has been diagnosed with a health problem that may require long-term care. In retirement plans, once the decision has been made for an annuity payout that decision is irrevocable.

The **National Pension Lawyers’ Network** at [www.pensionaction.org/npln.htm](http://www.pensionaction.org/npln.htm), 617-287-7324, is a no-cost referral service that connects workers and retirees with attorneys who can help them understand and enforce their pension rights. Lawyers from around the country represent workers, retirees, and their families on a regular fee, reduced fee, or pro bono basis.

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Many important decisions concerning finances, health care, and end-of-life care require legal documents. Creating these documents in advance can save you time, money, and stress. Without them, you may need a court proceeding to establish guardianship or conservatorship when and if an elder loses his or her capacity to make financial or health care decisions.

It's never too early to start talking about health care decisions with the elder and others involved in the care of the elder. Good advance planning requires that you have an ongoing conversation with the elder about his or her beliefs and values about quality-of-life and end-of-life issues. You need to communicate *before* a crisis arises so that you can feel confident that you understand the wishes of the elder and can make decisions without arguing with him or her or other family members.

## Important Legal Documents

The following is a basic introduction to the important legal documents involved in caring for an elder, but it is NOT intended to substitute for professional legal advice.

### Durable Power of Attorney (DPOA)

DPOA is a document that grants a person or persons (“Attorney-in-fact”) the legal powers to perform on behalf of the elder (“Grantor”) certain acts and functions specifically outlined in the document. This power is effective immediately and continues even if the grantor becomes disabled or incompetent. The powers usually granted include real estate, banking and financial transactions, personal and family maintenance, government benefits, estate trust and beneficiary transactions.

The choice of the attorney-in-fact should be carefully considered because the responsibilities involved may require significant time and work. Professional advice should be used for the preparation of the DPOA, since the documents must meet certain legal requirements.

### Advance Directives

Advance directives are written instructions regarding an individual’s medical care preferences. The forms vary from state to state, but in general, advance directives can include a Living Will, Health Care Power of Attorney or Health Care Proxy, and a Do Not Resuscitate or Do Not Intubate Order (DNR or DNI). You do not necessarily need a lawyer to create these.

*All* adults, young or old—and especially you and the elder in your care—should have advance directives to deal with an accident or illness that would make it impossible to communicate choices concerning treatment. Contact the following organizations for more information:

- The **American Bar Association Commission on Law and Aging** at [www.abanet.org/aging/publications/onlinepublicationsconsumers.shtml](http://www.abanet.org/aging/publications/onlinepublicationsconsumers.shtml), 202-662-8690, offers free online publications, including “Consumer’s Tool Kit for Health Care Advance Planning” and “Ten Legal Myths about Advance Directives.” Click on “Online Publications for Consumers” or order copies by phone.
- The **Medline Plus** Web site at [www.nlm.nih.gov/medlineplus/advancedirectives.html](http://www.nlm.nih.gov/medlineplus/advancedirectives.html), a service of the National Library of Medicine and the National Institutes of Health, offers various resources on creating advance directives.

## Living Will

A written advance directive, called a living will, is a valuable way to clarify an elder’s choices and wishes. It is used if an elder becomes terminally ill, incapacitated, or unable to communicate or make decisions. Some states do not recognize a living will as binding on medical personnel. However, documents used to prepare a living will provide information that can convey the individual’s intent, and help the health care agent carry out the elder’s wishes.

## Health Care Power of Attorney/Health Care Proxy

One of the most important steps in being able to implement an elder’s wishes is appointing a health care agent or proxy. To do this, you must draw up a Health Care Power of Attorney (POA) or a Health Care Proxy, a legal document that names a health care agent. The health care agent or proxy needs to be able to talk openly and often with the elder, so that he or she understands the elder’s wishes and values and can make treatment decisions (when the elder cannot) without having to argue with family members or medical staff. The agent should be someone the elder trusts and someone who can communicate easily with family, friends, and health care professionals. The health care agent will not only have decision-making powers, but also have full access to confidential medical records.

A health care agent does not have to be a family member. Any competent adult (18 or older) may serve as a health care agent, except someone who works at a facility where the elder is a patient at the time the agent is appointed. The health care agent can be different from the person who handles financial matters. Once a health care agent has been chosen, let your family and close friends of the elder know so that everyone is clear about who to contact in the case of emergency.

The health care proxy takes effect only if the family, hospital, or nursing home physician has determined in writing that the elder lacks the capacity to make or communicate health care decisions. The document should also contain specific language dealing with HIPAA (see [www.hhs.gov/ocr/hipaa/](http://www.hhs.gov/ocr/hipaa/)), the federal law that deals with patient privacy. You should know where this document is and bring it with you if the elder in your care is hospitalized or in the emergency room.

If the elder in your care has moved since documents were drawn up, travels frequently to, or lives full-time or part-time in another state, find out what that state requires to ensure that the documents you have are legally binding. If not, you may need additional legal documents.

### Do Not Resuscitate/Do Not Intubate (DNR/DNI) Order

If an elder does not want to have cardiopulmonary resuscitation (CPR) or have a breathing tube inserted, ask the doctor to prepare a “Comfort Care” or “Do Not Resuscitate Order” (DNR), and/or “Do Not Intubate Order” (DNI), sign it, and make it part of the elder’s medical record. It is also essential to keep a DNR Order visible and accessible at all times so that emergency medical personnel, such as EMTs and paramedics, can provide care and transport without defibrillation and/or intubation. Some families keep the document on the refrigerator door or in a clearly marked folder.

### Obtaining Legal Documents

You do not need a lawyer to complete an advance directive, living will, or health care proxy, although you may find an attorney’s advice helpful. (You *do* need a lawyer to complete the Durable Power of Attorney.) There are also free resources that can provide the legal templates you will need to fill out.

- **Caring Connections** at [www.caringinfo.org/stateaddownload](http://www.caringinfo.org/stateaddownload), a program of the National Hospice and Palliative Care Organization, is a national initiative to improve end-of-life care. It offers free advance directive packages (complete with instructions) for every state. Visit the Web site or call 800-658-8898 toll free to request a package.
- The **U.S. Living Will Registry** at [www.uslivingwillregistry.com/forms.shtm](http://www.uslivingwillregistry.com/forms.shtm), offers links to advance directive forms for each state. It also registers advance directives in a database and sends annual reminders to review and update your directives. Hospitals and health care providers check this registry. Visit the Web site or call 800-LIV-WILL (800-548-9455) toll free.

## Wills and Trusts

It is essential to have an up-to-date will and/or trust that designates financial, estate, and legal control and distribution. You and/or the elder may have few assets, but even with simple estates it is generally advisable to have an attorney create a document that will protect the elder’s wishes about her or his estate. For help in finding a lawyer to guide you through the process—sometimes at a reduced or sliding-scale fee—see the Legal Issues section. Union benefits may also include free or reduced-fee legal services.

## Guardianship

Guardianship (or conservatorship) is a legal process used when a person can no longer make sound decisions to protect his or her person or property, or when the court establishes that an elder has become susceptible to fraud or undue influence. Because establishing a guardianship removes considerable rights from the individual, it should only be used after other alternatives have been ineffective or are unavailable. The court decides who the guardian (sometimes called a conservator) will be: a family member, a friend, a professional certified guardian, a public guardian (such as a state agency), a bank, a volunteer or a nonprofit agency.

The court also decides how much authority to give to the guardian. A guardian might be appointed only to make decisions about living arrangements, personal needs, and medical care, or a guardian might be appointed only to make decisions about finances and property.

Setting up a guardianship can be expensive and emotionally difficult. If you think the elder in your care needs a guardian, first talk with a lawyer about the requirements in your state.

- **AARP** at [www.aarp.org/families/caregiving/caring\\_parents/a2003-11-07-Guardianship.html](http://www.aarp.org/families/caregiving/caring_parents/a2003-11-07-Guardianship.html), offers useful information on guardianships.
- The **National Guardianship Association, Inc.** (NGA) at [www.guardianship.org/index.htm](http://www.guardianship.org/index.htm), provides standards for guardians. Each standard is explained in detail and provides guidance to guardians in the private and public sectors.

## Finding Legal Services

Don't wait until a crisis to find a lawyer who specializes in legal planning for elders. Contacting one as you begin your role as a caretaker can help you avoid much aggravation and confusion. If an elder's income falls within certain guidelines, you may be able to receive help through the legal aid program from your local AAA or through volunteer lawyer programs of your local bar association. States offer legal assistance through the attorney general's office.

Other legal resources include the following:

- The **American Bar Association** at [www.abanet.org/legalservices/findlegalhelp/home.cfm](http://www.abanet.org/legalservices/findlegalhelp/home.cfm) offers a free resource guide by state on its Web site. It will direct you to local bar associations, legal aid providers, and other helpful organizations.
- The **American Bar Association Commission on Law and Aging** at [www.abanet.org/aging/resources/statemap.shtml](http://www.abanet.org/aging/resources/statemap.shtml) provides a free list of key legal service providers for elders in each state. Visit the Web site and click on your state to get a free report or call 202-662-8690.

- The **National Academy of Elder Law Attorneys (NAELA)** at [www.naela.org](http://www.naela.org) will help you locate an attorney. Visit its Web site and click on “Public,” then “Directory,” and enter your city or Zip Code. NAELA also offers a guide to help choose an attorney. Call 520-881-4005 or visit its Web site and click on “Public,” then “Questions and Answers When Looking for an Elder Law Attorney.”
- The **National Association of Social Security Claimants Representative** at [www.nosscr.org/refer.html](http://www.nosscr.org/refer.html), 800-431-2804 toll free, provides representation and advocacy for people who are having problems collecting Social Security and Supplemental Security Income.
- The **National Senior Citizens Law Center**, [www.nslc.org](http://www.nslc.org), 202-289-6976, focuses on the legal needs of poor and vulnerable elders and persons with disabilities.

## Protecting the Rights of Elders

Although many elders are quite savvy when it comes to being consumers and in standing up for their rights, others can be vulnerable because of diminished capabilities, lack of knowledge about financial matters, or trouble in navigating complex voicemail and/or online instructions.

### Consumer Protection

Today’s marketplace is complex, and, for many elders, it can be treacherous. Elders have often been the target of unethical business practices, such as abuse of guardianship and powers of attorney, lending scams, and Medicare fraud. The following organizations can help protect you as a caregiver and the elder in your care:

- **AARP** at [www.aarp.org](http://www.aarp.org) provides extensive information to help elders on a range of consumer issues, including scams, investment fraud, fixing homes, financing homes, utilities, and smart shopping. Visit the Web site and click on “Money and Work,” then “Be a Wise Consumer.”
- **Better Business Bureau, Inc. (BBB)** at <http://welcome.bbb.org/> answers questions about companies and can also assist in arbitration. To find the BBB near you, visit the Web site and enter your Zip Code.
- **Consumer Sentinel** at [www.consumer.gov/sentinel/](http://www.consumer.gov/sentinel/) is a secure online database used by the Federal Trade Commission to record Internet, telemarketing, identity theft, and other fraud-related complaints. Use this site to get the facts on consumer frauds such as Internet cons, prize promotions, work-at-home schemes, and telemarketing scams.

- The **National Consumer Law Center** (NCLC) at [www.consumerlaw.org/](http://www.consumerlaw.org/) is a consumer advocacy group that addresses problems such as challenges to sustaining home ownership, fraudulent and exploitive sales practices, debt management, and financial decision making. It also distributes a consumer education brochure on predatory lending (available in English, Spanish, and Chinese).
- The **U.S. Administration on Aging** (AoA), through the **Eldercare Locator** at [www.eldercare.gov/](http://www.eldercare.gov/), 800-677-1116 toll free, provides legal services and hotlines to assist in terminating exploitive contracts, guardianships, or powers of attorney and to help seek restitution. It also helps older persons understand their rights, and exercise choice through informed decision-making.
- **The U.S. Federal Trade Commission** (FTC) at [www.ftc.gov/bcp/consumer.shtm](http://www.ftc.gov/bcp/consumer.shtm), 877-382-4357 toll free (TTY 866-653-4261), works to prevent fraudulent, deceptive, and unfair business practices and to help consumers spot, stop, and avoid them. To find free information or file a complaint, visit the Web site or call.
- **USA.gov for Seniors** at [www.usa.gov/Topics/Seniors/Consumer.shtml](http://www.usa.gov/Topics/Seniors/Consumer.shtml) is a government Web site that provides links to information and assistance on all aspects of consumer and fraud protection. You can also sign up for e-mail updates.

### Protection from Elder Abuse

The frailty and dependence of elders can make them targets for abuse, even by family members. Signs to look for include poor hygiene, bedsores, marks or bruises, drowsiness from overmedication, and withdrawn or fearful behavior. Victims may be unwilling to seek assistance because they think no one will believe them, or they fear retaliation from their abusers, or they are too embarrassed. It may take the courage of a caring family member, friend, or caretaker to take action.

Adult Protective Services (APS) are provided in every state to ensure the safety and well-being of elders (and adults with disabilities) who are in danger of being mistreated or neglected, are unable to take care of themselves or protect themselves from harm, and have no one to assist them. APS receives reports of adult abuse, exploitation, or neglect; investigates these reports; and conducts case planning, monitoring, and evaluation. APS may also provide or arrange for the provision of medical, social, economic, legal, housing, law enforcement, or other protective, emergency, or supportive services.

Some state APS laws only apply to situations of domestic abuse, affecting people who live alone or with their families. Some states have laws against institutional abuse, protecting elders who live in nursing homes and other long-term care facilities. (For information on protective services for nursing home residents, see the Housing and Transportation section) Your state attorney general's office will have information as to where an elder can turn for protection and what organizations can help him or her, in addition to these:

- The **Eldercare Locator**, [www.eldercare.gov/Eldercare/Public/Home.asp](http://www.eldercare.gov/Eldercare/Public/Home.asp), provides information and referrals.
- The **National Center on Elder Abuse**, [www.ncea.aoa.gov/NCEAroot/Main\\_Site/Find\\_Help/State\\_Resources.aspx](http://www.ncea.aoa.gov/NCEAroot/Main_Site/Find_Help/State_Resources.aspx), provides information and assistance, including a state-by-state directory of hotlines and APS resources on its Web site. You can also call the NCEA Information Desk at 302-831-3525.

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Caregivers often feel that managing the health care of their elder is a part-time or even a full-time job in and of itself. Coping with chronic and acute illnesses, communicating with doctors, and understanding drug dosages and side effects are only a few of the issues elders and their caregivers face. Preparation and organization can go a long way in helping keep this task more manageable.

Caregivers become involved in a variety of health care issues when caring for elders. It is important to remember in all situations—whether accompanying the elder in your care to the doctor or the emergency room—to involve the elder as much as possible in health care decisions. Maintaining an elder’s dignity and independence is extremely important to his or her emotional and physical well-being.

## Geriatric Medical Care

A number of complex health conditions can affect elders. To become more familiar with the issues and help anticipate health problems, the **American Geriatrics Society** offers an online publication specifically designed for family caregivers called “Eldercare at Home: A Comprehensive Guide for Family Caregivers” at [www.healthinaging.org/public\\_education/eldercare/](http://www.healthinaging.org/public_education/eldercare/). The chapters are organized by symptoms and explain the possible health problems, as well as how to describe an elder’s health conditions, behavior, and symptoms to a physician. For access to the free online book or to purchase the book, go to the Web site and click on “View Table of Contents.” You can also purchase the book by calling 800-334-1429, ext. 2529.

## Record Keeping

Elders are likely to have multiple health conditions, more than one doctor or specialist, and a variety of medications. The sheer volume and complexity of medical information is very difficult to keep track of, yet it’s essential that you have accurate and up-to-date records that are easily accessible. You may want to create a notebook or folder containing names and phone numbers for all the health providers of the elder in your care, dates of major medical tests and/or surgeries, as well as a list of conditions, dietary restrictions, medications, and current dosages. It is also important to keep records of phone conversations with doctors and other providers or take notes when you visit.

The National Alliance for Caregiving has partnered with the National Family Caregivers Association to create a course called “Family Caregiving 101” at [www.familycaregiving101.org/](http://www.familycaregiving101.org/) to help caregivers communicate with health care providers and manage health care information. Visit the Web site and click on “How to Manage,” then “Navigating the Health Care Maze.”

*Eldercare at Home*, [www.healthinaging.org/public\\_education/eldercare/2.xml](http://www.healthinaging.org/public_education/eldercare/2.xml), published by the American Geriatrics Society, is written for family caregivers and explains how to communicate effectively with doctors and other professionals as part of a caregiving support team. For more information, see the Caring for the Caregiver section.

## Monitoring Chronic Health Issues

Chronic illnesses such as diabetes and heart disease may require daily care to monitor blood levels, dress wounds, or give injections. Family caregivers can get training and assistance in treating these conditions. Contact your local AAA or COA for help. Many chronic health conditions have their own national associations, such as the American Cancer Society or the American Diabetes Association. These organizations and their local chapters can provide training, caregiver support, and assistance. See also the Caring for the Caregiver section.

## Finding a Doctor

Not every doctor who practices primary care has special knowledge in geriatrics. When managing the health care needs of someone 60 or older, it is important to find a primary care physician (PCP) who:

- Has substantial experience with conditions that are common for elders, such as heart disease, high blood pressure, diabetes, stroke, osteoporosis, and depression
- Has a good reputation for prescribing appropriate medications and managing the interactive effects of medications on elders
- Is knowledgeable about home health services and when to use them
- Makes recommendations about regular screening tests such as mammograms, bone density tests, and stress tests
- Can work with you to coordinate all of your health care needs, particularly referrals to specialists and coordination among specialists

It is important to find a PCP who not only can help with illness and disease, but who can also make suggestions about staying healthy, such as modifications in diet (see the Home Care section) and an appropriate exercise routine (see the Staying Active section).

In larger metropolitan areas, you may be able to find a physician who specializes in geriatric medicine. However, fewer than 8,000 physicians are certified geriatricians. For help locating a qualified PCP for the elder in your care, contact your Area Agency on Aging (AAA) or your insurance provider. Other organizations that can help you find a doctor include the following:

- **The AGS Foundation for Health in Aging** at [www.healthinaging.org/public\\_education/physician\\_referral.php](http://www.healthinaging.org/public_education/physician_referral.php) offers a referral service to physicians who are members of the American Geriatrics Society and are board-certified in either family practice or internal medicine. If you submit an online request, the FHA will mail you a list of physicians in your area who are sensitive to the special health care needs of elders. Due to the high volume of requests, the response will take at least two to three weeks.
- The **American Board of Family Practice** at [www.theabfm.org/diplomate/index.aspx](http://www.theabfm.org/diplomate/index.aspx) offers an online search service for board-certified geriatricians. Visit the Web site and type in your city and state. Be sure to use the “Limit Your Search” box and select “Geriatric Medicine.”
- The **American Medical Association** at [webapps.ama-assn.org/doctorfinder/html/patient.html](http://webapps.ama-assn.org/doctorfinder/html/patient.html) offers an online search service by city and state or by specialty.

When interviewing primary care physicians on the phone or in person, it is useful to prepare written questions and take notes. Ask about:

- The location and hours of the practice
- Where tests, exams, and labs are performed
- The training and board certification qualifications of the physicians, nurses, and technicians in the practice
- The hospital(s) that the practice is affiliated with
- What insurance coverage is accepted
- Whether the practice accepts Medicare “assignment” (Medicare-allowable rates for services)

An elder’s PCP will help refer you to specialists; a PCP referral may be necessary if your elder is insured through a Medicare Advantage Plan. (For more information, see the Insurance section.)

## Visiting the Doctor

Today, the average doctor visit is measured in minutes, and it is important to make the most of it. You may also need to help elders understand that the doctor-patient relationship today has changed—patients must take more control of and responsibility for their own health care.

Before the appointment, write down questions or issues you both would like to discuss. You should also note any changes in an elder's health and abilities since the last visit, and take along a list of all medications and dosages (or the medications themselves). The PCP may not be fully aware of medications prescribed by other specialists, and vice versa. Drug interactions can cause many disturbing symptoms and even illness. Include natural and holistic remedies and over-the-counter drugs, since these can cause interactions as well. (For more tips, see [At the Doctor's](#).)

At the doctor's office, ask to be present during the initial consultation, the examination (if possible), and afterwards, when the doctor discusses findings and treatments. Both you and the elder should ask questions until you understand all the information the doctor is giving you. There is no such thing as a wrong or stupid question! Take careful notes, and ask who and when you can call if you have additional questions.

### Additional Resources

- The **Department of Health and Human Services'** Agency for Healthcare Research and Quality has prepared a list of questions, "Be Prepared for Medical Appointments" at [www.ahrq.gov/qual/beprepared.htm](http://www.ahrq.gov/qual/beprepared.htm) that you can print and take with you to the doctor. On the Web site, look for AHRQ Publication No. 07-0039-A, May 2007.
- **Medline Plus** at [www.nlm.nih.gov/medlineplus/talkingwithyourdoctor.html](http://www.nlm.nih.gov/medlineplus/talkingwithyourdoctor.html), a Web site of the National Library of Medicine and the National Institutes of Health, contains a section called "Talking with Your Doctor" and provides additional resources and links in both English and Spanish.
- The **Senior Health Web site** of the National Institute of Health has an excellent resource called "Talking with Your Doctor" at <http://nihseniorhealth.gov/talkingwithyourdoctor/toc.html> that explains how to prepare for a medical visit and how to understand the more technical parts, such as diagnoses and follow-up lab tests.

## Hospitalization and Discharge

Eventually, elders are likely to have a health crisis and need to enter a hospital or an “acute care facility.” You may think that a caregiver’s job starts only when the patient is discharged, but any caregiver who has lived through this will tell you otherwise. Caregivers play a critical role in all phases of hospitalization.

- **During admission:** describing symptoms or events precipitating the trip to the hospital (often the emergency room) and completing insurance forms and patient history.
- **During the stay:** monitoring the quality of health care, staff, medications, food, personal comfort and cleanliness, and being an advocate if the quality of any of these is low.
- **During discharge:** working with social workers to plan for discharge to an appropriate rehab facility or discharge to home with appropriate supports.

Hospitalizations are emotionally stressful not only for the elder but for caregivers too. One challenge that is often unanticipated is the absence of the elder’s regular physician. An elder may be cared for by a “hospitalist” (sometimes called an “inpatient specialist”), a doctor who is unfamiliar to you or the elder. Hospitalists, trained and board certified in internal medicine, specialize in the care of hospitalized patients. They serve as the “physicians of record” for inpatients during the hospital stay. The hospitalist coordinates care with specialists, such as an orthopedic surgeon. After being discharged from the hospital, patients return to their primary care physician.

There are advantages and disadvantages to this system. On the positive side, hospitalists can rapidly coordinate inpatient care and react in real time throughout the day to changes in a patient’s medical status. However, some elders and their families do not like having a new and unfamiliar doctor during an acutely stressful time. There may also be gaps in communication between inpatient physicians and the elder’s primary care physician during hospital admission and discharge. This can lead to additional stress for caregivers.

You can discuss beforehand with the elder’s PCP what would happen in a crisis in order to be better prepared for an elder’s hospital stay.

### Discharge to Rehabilitation Facilities

Many acute care hospital stays are shorter these days, and patients are often discharged to a rehabilitation facility (also called a skilled nursing care facility) for short-term follow-up care before returning home. The rehab environment provides medical monitoring, nursing, and personal care, as well as occupational, speech, and physical therapy treatments as needed. Patients are encouraged to regain strength and mobility in this supervised environment so that they can transition back to their normal life. Meals are served in dining rooms rather than in bed when patients are able, and patients are encouraged to dress in their own clothes.

Medicare covers these short-term rehabilitation stays, and hospital discharge staff will refer the elder to a certified nursing facility. (You may also choose another facility if you wish, but hospital staff will usually have a good sense of where the nearest certified facility with an available bed is when you need it.) See the Insurance section for more information.

Physicians and caseworkers will assess an elder's progress during rehabilitation and help families understand an elder's capacity to return home, including what home modifications might be needed, or if a more supervised environment might be required.

Like hospitalization, rehab stays can also be stressful for families. A stay in rehab is often the turning point in an elder's ability to live independently, especially after a stroke or surgery. It may be the first time you see the elder as frail or permanently impaired. Recovery can be slow, and there may be dramatic changes in an elder's abilities and emotions during rehabilitation.

Sometimes elder patients will need to transition back to the hospital because of a complication, only to return to the rehab facility, or a different rehab altogether, based on available beds. During these transitions, talk with the staff about issues that concern you. They are well trained to assess an elder's health conditions, but you are the one who knows the elder best, and your own assessment of his or her condition is very important. Don't be afraid to speak up to get the elder's needs met. Together, you and the rehab staff make a team that can help produce the best possible outcome for the elder in your care.

## Discharge to Home

For a caregiver, the discharge to home may be even more stressful—and sometimes more distressing—than the discharge to a rehab facility, because the transfer of responsibility for the elder then comes to rest solely on the caregiver. Keep in mind the following:

- **Timing:** Make sure that you and the elder in your care agree with the doctor's assessment that the elder is ready to go home. Caregivers may need to advocate for more time in rehab, and this may involve complex insurance issues about coverage that exceeds certain predetermined time limits.
- **Transportation:** Make sure that you have adequate support for getting the elder home safely. A car ride may be fine, but sometimes you may need a wheelchair van or another type of handicap-accessible vehicle. You should receive help from the hospital in making these arrangements.
- **Services:** Make sure that you have the skilled nursing care, physical therapy, or other personal care services that the elder needs in place before you go home. Sometimes discharge planners will simply hand a caregiver a folder of brochures and provide little guidance about which one is best or how to get things started in a timely way. Insist on more help. It is important that you are not put in a situation where you are expected to provide a kind of care you are not trained to do.

- **Follow-up/contact person:** Before you leave the hospital, make sure you understand what kind of follow-up will be needed. Are there doctor's appointments that have been made, or do you need to make them? Are there prescriptions that need to be filled by the hospital or home pharmacy? Who should you call if you are concerned about the elder's condition once you are home? It is important to know who you can call and reliably reach in case of an emergency or other concerns.

## End-of-Life Care

Whether in the midst of an acute, life-threatening crisis or during a terminal but ongoing illness, elders and their families must make many medical, legal, and practical decisions. These choices are difficult, intellectually and emotionally. Being informed can help ease some of the burden.

### Palliative Care

Palliative care is any form of treatment that focuses on reducing the severity of disease symptoms rather than providing a cure. The goal is to prevent and relieve suffering and to improve quality of life for people facing a serious illness. Palliative care is *not* only for end-of-life situations. In addition to pain management for the elder, palliative care may include supportive services for caregivers.

### Hospice Care

Hospice care is provided for people with a terminal illness when life expectancy is limited. Hospice care services may be chosen by an individual or a family, or recommended by a physician. In all cases, the elder's physician must be involved to verify that the patient has a terminal illness that cannot be cured.

There is no absolute rule linking admission to a hospice program to a specific number of days or months a terminally ill patient is expected to live. Many people (including some medical professionals) mistakenly think that to gain entrance to hospice, a person is expected to live less than six months. This is not true.

The "six-month rule" applies only to what is known about the *disease*, not the person suffering from the disease. In many instances, people can be reevaluated after the first six months and approved for continuing hospice care. In some cases, care can continue for 12 months or even longer. Periodic re-evaluations determine eligibility under federal Medicare guidelines.

Hospice professionals are skilled at making these decisions and explaining their work to elders and families. Although it may be difficult to even consider hospice care, you may find it helpful to meet with a representative who can discuss when the right time may be.

## Hospice Care Locations and Providers

Hospice care can be provided in the home or at an extended care facility, such as a nursing home or assisted living center. There are also freestanding hospice centers, sometimes called residential hospice centers. Some families prefer this kind of setting because it feels more like home and less like an institution. While these centers include medical staff, counselors also attend to the non-medical needs of patients and their families, such as providing emotional support and pastoral counseling. These services are often just as important as medical care.

Hospice services are available through private and nonprofit hospice agencies and programs, home health or visiting nurse associations, group medical practices, and hospitals and extended care facilities, such as nursing homes.

## Hospice Care Costs

Medicare, Medicaid, and private insurance plans cover the costs of hospice care:

- **Medicare:** Hospice care is a benefit under Medicare Hospital Insurance (Part A). This can be confusing because this care can be provided in the home and not a hospital. Once a patient is admitted to hospice it means they agree that they will only receive non-curative medical care and support services for their terminal illness. You will need the elder's doctor to certify that the elder is eligible for hospice.
- **Medicaid:** Hospice care is available to low-income, terminally ill adults without Medicare coverage through their state's Medicaid program and is similar to the Medicare hospice benefit.
- **Private insurance:** Most private insurance companies include hospice care as a benefit, but you should check the elder's policy carefully to see if benefits can add to what Medicare provides.
- **Private pay:** If the elder in your care is *not* eligible for Medicare or Medicaid, and has no health insurance, hospice services can be paid on a fee-for-service basis.

For more detailed information on insurance eligibility, services, and payment options, go to **Hospice Net** at [www.hospicenet.org/html/medicare.html](http://www.hospicenet.org/html/medicare.html), a nonprofit organization that provides information and support to patients and families facing life-threatening illnesses. See also the Insurance section for additional information.

## Hospice Care Resources

There are several organizations that provide in-depth information on hospice care and can help you locate a hospice facility in your state.

- **Center to Advance Palliative Care** at [www.getpalliativecare.org](http://www.getpalliativecare.org) is a national organization dedicated to increasing the availability of quality palliative care services. Visit its Web site to find out more about what palliative care is, how to know if it is right for you, and how to get it.

- **National Association for Home Care and Hospice** at [www.nahc.org/AgencyLocator/](http://www.nahc.org/AgencyLocator/) is a trade association that represents home care agencies, hospices, and home care aide organizations. It also offers a user-friendly tool on its Web site to locate agencies providing hospice when you enter your city, state, and Zip Code.
- **National Hospice and Palliative Care Organization** (NHPCO) at [www.nhpco.org](http://www.nhpco.org) is a nonprofit organization that promotes hospice and palliative care in each state, including education and advocacy, technical assistance, support, and information for professionals, families, and friends. To find hospice programs in your area, go to the Web site, click on “Find a Provider,” then enter your city or state. NHPCO also runs Caring Connections at [www.caringinfo.org/](http://www.caringinfo.org/), a program dedicated to building a national consumer initiative to improve care at the end of life.

### Additional End-of-Life Resources

- **Americans for Better Care of the Dying** at [www.abcd-caring.org/](http://www.abcd-caring.org/) is dedicated to ensuring good end-of-life care. The organization focuses on improved pain management, better financial reimbursement systems, enhanced continuity of care, support for family caregivers, and changes in public policy.
- The **American Psychological Association** at [www.apa.org/pi/eol](http://www.apa.org/pi/eol) has extensive information about psychosocial end-of-life concerns on their Web site.
- **Compassionate Care ALS** at [www.ccals.org/](http://www.ccals.org/) provides those affected by ALS (Lou Gehrig’s disease) with educational and legal resources, respite opportunities, subsidies for living aids and assistance, and chats with patients and their caregivers, families, and friends.
- **Growth House, Inc.** at [www.growthhouse.org](http://www.growthhouse.org) is a gateway to resources on life-threatening illness and end-of-life care issues. Its online “Handbook for Mortals” has good information for caregivers and elders.
- The **National Cancer Institute** (NCI) has a helpful fact sheet, “End of Life Questions and Answers,” on its Web site at [www.cancer.gov/cancertopics/factsheet/support/end-of-life-care](http://www.cancer.gov/cancertopics/factsheet/support/end-of-life-care).
- **Net of Care** at [www.netofcare.org/](http://www.netofcare.org/) is a program providing information and resources for caregivers taking care of family members who must cope with severe pain. Its integrative pain medicine Web site at [www.healingchronicpain.org/](http://www.healingchronicpain.org/) contains information on complementary treatments.

## Bereavement

For caregivers, end-of life issues do not stop when the person they are caring for dies. As the process of grieving begins, caregivers must also continue making practical decisions and arrangements, including getting a death certificate, finding a funeral home, and arranging for services.

### Practical Issues

The days, weeks, and months after a death can be overwhelming. Dealing with legal and financial issues in a timely fashion may seem too difficult, stressful, or even distasteful.

Two helpful resources are the following:

- **AARP** at [www.aarp.org](http://www.aarp.org) provides extensive information about end-of-life issues on its Web site, as well as links to resources about specific issues of law, grief, and loss. For a helpful checklist, click on “Family,” then “Life After Loss.”
- “Checklist Following Death” at [http://www.tennant-ewer.com/Article\\_Checklist\\_Following\\_Death.shtml](http://www.tennant-ewer.com/Article_Checklist_Following_Death.shtml) is another helpful list of tasks. It summarizes practical issues such as how to identify income and assets of the deceased, and how to minimize debts of the decedent.

### Bereavement Support

Life is unalterably changed after the loss of an elder. As our society continues to explore how to deal with death and dying, we are also learning and understanding more about grieving. You may want to check back with organizations and professionals you depended on as a caregiver, such as a resource specialist at your Area Agency on Aging (AAA), a staff member or volunteer at the local Council on Aging (COA), the elder’s primary care physician, or your own doctor.

Organizations that provide bereavement services and support groups include the following:

- **Bereavement Magazine** at [www.bereavementmag.com/](http://www.bereavementmag.com/) offers articles, stories, poems, and resources for the bereaved through its magazine *Living with Loss*. Obtaining copies of the magazine may be especially helpful for those who are less comfortable using the Web.
- **Griefnet** at [www.griefnet.org](http://www.griefnet.org) provides access to 50 e-mail support groups and Web sites. The support groups are organized by the relationship the caregiver had to the deceased, including a group for adult children of elderly parents. Go to the Web site. Under “Grief Support,” click on “Adult Support Groups,” then go to “Groups List.”
- **People Living With Cancer** at [www.plwc.org](http://www.plwc.org) provides a helpful overview about how to cope with change after a death. Click on “Coping,” then “Grief and Bereavement,” then “Coping after a Loss.” The information is not just for people who have lost an elder to cancer, but for anyone dealing with loss after a death.

## Looking Ahead

It is important for caregivers who have devoted months—often years—to the care of an elder to give themselves time to grieve. Not only have you lost a loved one, but you have also lost your role as caretaker. However stressful that way of life may have been, it has probably been the consuming focus of your life. Now more than ever, caregivers need support. Reaching out to family, friends, your doctor, your mental health provider, your clergy, and others can really help. Contact the **National Association of Social Workers** (NASW) at [www.HelpStartsHere.org](http://www.HelpStartsHere.org) for a directory of counselors and other advice.

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Today's health care system is very complex and often hard to understand by even the most sophisticated consumer. Keeping current on coverage limits and deductibles can be bewildering, the paperwork overwhelming, and finding answers on Web sites or by phone can be vexing. This section will help find your way through the maze of the insurance system.

## Understanding Health Care Insurance

These three organizations can help you locate the benefits that apply to the elder in your care. They will help you save valuable time in learning the health care insurance system.

- 1 **Medicare Rights Center** at [www.medicarerights.org/](http://www.medicarerights.org/) is an independent source of state-specific information on Medicare and other health care coverage issues. Its Web site offers an interactive search called "MI Counselor" that walks you through the qualification process. You can also call the consumer hotline at 800-333-4114 toll free. A Medicare counselor can answer your questions about health insurance choices, Medicare rights and protections, dealing with payment denials or appeals, complaints about care or treatment, and Medicare bills.
- 2 **The National Council on Aging** provides a "Benefits Checkup" at [www.benefitscheckup.org/](http://www.benefitscheckup.org/) on its Web site. It's a fast, free, and confidential screening tool to determine eligibility for nearly 1,000 unique state and federal programs, as well as detailed instruction on how to apply for these programs.
- 3 The **State Health Insurance Assistance Program (SHIP)** at [www.medicare.gov/contacts/static/allStateContacts.asp](http://www.medicare.gov/contacts/static/allStateContacts.asp) is a national program that offers one-on-one counseling and assistance. Every state provides free counseling and assistance by telephone or in person on a wide range of Medicare and Medicaid matters, including health plan options, long-term care insurance, claims and billing problem resolution, and information and referral on public benefit programs for those with limited income and assets. To locate the program in your state, go to the SHIP Web site or call 800-MEDICARE (800-633-4227) toll free and ask for health insurance counseling for your area.

## Medicare

Medicare is a federal health insurance program for people age 65 or over and is the major insurer of health care for elders and certain disabled people. It includes various programs with different requirements for different purposes and different groups of people.

Despite what many people believe, Medicare does *not* pay for long-term care in a nursing home or home care services. An elder is required to pay out-of-pocket for care until he or she has “spent down” to Medicaid eligibility.

For complete information about Medicare, go to the Web site at [www.medicare.gov/](http://www.medicare.gov/) or call 800-633-4227 toll free and request a copy of the publication, “Medicare and You” for your state. Here is a brief overview of Medicare’s major components.

### Original Medicare Plan

The Original Medicare Plan is a fee-for-service plan managed by the federal government that is used by the majority of elders. An individual is enrolled in the Original Plan by the Social Security Administration at the age of 65 unless he or she elects to enroll in another type of plan (see Part C). There are deductibles, co-payments, and health services, such as hearing aids and eyeglasses, that are not covered by the Original Medicare Plan, but supplemental insurance can provide coverage for these services.

**PART A: Hospital Insurance** helps pay for hospital care, some home health services, certain short-term stays in a skilled nursing facility (nursing home), and hospice care. There is no monthly premium charge for Part A coverage if the elder or spouse paid Medicare taxes while working. As of 2008, there was a \$1,000 deductible for hospital stays, co-pays for stays beyond 60 days in hospitals and 20 days in skilled nursing facilities, and limits on the number of days covered.

**PART B: Medical Insurance** helps pay for doctors, outpatient services, and supplies. Consumers pay a monthly premium for Part B (premiums vary by income, but an individual in 2008 would typically pay between \$97 and \$238 per month), plus a \$135 annual deductible. Some co-pay charges apply for equipment, therapies, and preventative services.

Home health services included in parts A and B are most frequently used to provide short-term follow-up care after discharge from a hospital or skilled nursing facility. Medicare covers expenses if four conditions are met:

- 1 The individual is confined to home
- 2 The individual needs intermittent skilled nursing care, physical, occupational or speech therapies

- 3 The individual is under the care of a physician who determines the need and establishes a home health care plan
- 4 The home health agency providing services is Medicare-certified

**PART C: Medicare Advantage Programs** are managed health care plans approved by Medicare and run by private companies to provide all of the medically necessary services provided in Parts A and B. Providers can charge different co-payments and deductibles and may require the use of providers in the plan. They can also offer additional services, such as prescription drug, vision, hearing, and dental coverage. There are five different types of Medicare Advantage Programs, and many different plans and providers. You can switch or join plans during defined periods of the year. Note that if an elder drops employer or union coverage or Medigap insurance by joining a Medicare Advantage Plan, he or she may not be able to get it back. The Medicare Web site at [www.medicare.gov](http://www.medicare.gov) provides a comparison of the plans, or you can call Medicare's consumer hotline at 800-633-4227 toll free.

**PART D: Prescription Drug Coverage** has been available since 2006. People in either the Original Medicare Plan or Medicare Advantage Programs can add drug coverage through Part D. Part D insurance plans, which include co-payments and deductibles, are run by private companies approved by Medicare. A number of plans are available, but they need to be assessed carefully. For help with this complex decision, call the Medicare hotline, the Medicare Rights Center, or your state's SHIP counselors.

### *Other Medicare Health Plans*

There are some types of Medicare Health Plans that aren't part of Medicare Advantage. When you are researching Medicare coverage in your area, ask the counselor for details on Medicare Cost Plans and Demonstration or Pilot Programs.

## Other Government Insurance Plans

Many people think that Medicare is the only government-funded program that provides health care insurance for people over 65. However, certain groups of elders have access to other government-funded insurance programs. The following information can help you decide if the elder in your care is eligible for one of these programs.

### **Government Employee Health Plans**

Retired federal, state, or local government employees (and their families) may have health care coverage that replaces Medicare or insurance that complements Medicare. Contact the employer's personnel or human resources department for details regarding the elder's health care benefits.

## Indian Health Plans

Native American elders who receive health care from the Indian Health Service, a Tribal Health Program, or Urban Indian Health Program should contact their provider to understand how Medicare benefits work with their coverage.

## Military Service Benefits

Some elders (and family members) may be eligible for health care coverage through the Veterans Administration (VA) or the Department of Defense (DoD) if they have served in the military or, in some cases, have been on active duty while in the National Guard. Coverage in either program may also require participation in Medicare Part A and Part B. There are two major programs:

**TRICARE:** The DoD provides coverage through TRICARE (formerly known as CHAMPUS) to active-duty and retired military persons and their dependents. Detailed information about eligibility and coverage is available on the Web site at [www.tricare.mil/](http://www.tricare.mil/) or by calling 877-TRICARE (877-874-2273). Not all VA Medical Centers participate in the TRICARE network. VA Medical Centers that participate in TRICARE will provide treatment for a non-service-related disability if space is available.

**CHAMPVA:** This VA health care coverage is provided to veterans and their dependents who meet one of the eight categories of eligibility. Detailed information is provided on the U.S. Department of Veterans Affairs Web site at [www1.va.gov/health/index.asp](http://www1.va.gov/health/index.asp) or by calling 877-222-8387 toll free. In many cases, home care services to manage daily living tasks are covered by the CHAMPVA.

Some veterans are eligible for health care coverage through either program. Choosing which program is best for the elder requires some research. Be warned that making a decision to change benefit coverage between these two programs within a specific episode of care may result in denial of payment from either program. For more information about how this works, contact the person who serves as the TRICARE “Beneficiary Point-of Contact” at your regional VA facility.

## Private Insurance Plans

While Medicare benefits provide an important component of health insurance for people 65 and over, it only provides the foundation of a comprehensive insurance coverage plan. It is advisable to investigate other kinds of private insurance plans that can provide coverage for services, medications, and equipment that are not provided by Medicare.

## Employer or Union Health Coverage

Elders (or family members) may have health coverage based on current or past employment that will help pay deductibles and other expenses not covered by Medicare. It is important to contact the benefits administrator of the union or employer to understand what the coverage includes and what it costs. The employer or union generally has the right to change benefits and premiums or stop offering coverage, so it is important to watch for notices regarding coverage and keep them on file. Prescription drug coverage, in particular, may change annually.

## Medigap

When an elder is not covered by an employer or union health care plan, it is possible to buy a supplemental policy to help bridge the gaps in the Original Medicare Plan. These policies are called Medigap insurance.

Medigap policies must follow federal and state laws and have certain standardized benefits so you can compare them. Costs do vary, and cost should be the only difference between standard Medigap policies. Standard policies cover co-payments for outpatient visits, deductibles for hospitalization, skilled nursing facilities, mental health benefits, and other specialized services. Medigap policies may also offer additional services for extra cost that may be helpful for the elder in your care, such as vision care.

Medicare does not pay for any of the costs of a Medigap policy. To buy a Medigap policy, you must be enrolled in Medicare Part A and Medicare Part B.

## Medicaid

Medicaid is a joint federal and state program that provides health insurance and long-term care to low-income children, parents, elders, and people with disabilities. While Congress and the Centers for Medicare and Medicaid Services (CMS) set out the main rules that govern Medicaid, each state runs its own program. As a result, the eligibility rules differ significantly from state to state, although all states must follow the same basic framework.

Elders with extremely limited income and assets often qualify for both Medicare and Medicaid, and they are referred to as “dual eligible.” Most of their health care and long-term care costs are covered.

Medicaid eligibility is extremely complicated. The types of programs, income limits, and definitions vary by state, and they are adjusted annually. State programs are also called by different names, such as “Medical Assistance,” “Medi-Cal,” or “MassHealth.” It is important to understand the impact of the Medicaid rules in your state on your personal situation.

Many states offer Medicaid managed care programs. Under managed care, Medicaid recipients are enrolled in a private health plan based on a fixed monthly premium paid by the state. Today, all but a few states use managed care to provide coverage for a significant proportion of poor children and parents, while the aged and disabled eligibility groups more often remain in traditional “fee for service” Medicaid. PACE (Program of All-inclusive Care for the Elderly) is a managed care model program that enables frail elders to remain independent in the community and in their own homes. It may be available in your area.

To learn more about an elder’s eligibility for Medicaid, visit the Web site of the **National Association of State Medicaid Directors** at [www.nasmd.org/links/state\\_medicaid\\_links.asp](http://www.nasmd.org/links/state_medicaid_links.asp) which offers links to each state agency or call 800-Medicare (800-633-4227) toll free and ask for Medicaid counseling for your area. The **Eldercare Locator** at [www.eldercare.gov/eldercare/Public/Home.asp](http://www.eldercare.gov/eldercare/Public/Home.asp) can also connect you with Medicaid counseling. Visit the Web site or call 800-677-1116 toll free.

## Long-term Care Insurance

Medicare and other health care policies do *not* cover long-term care. According to the American Health Care Association, costs of services provided by a nursing facility can exceed \$50,000 a year. Financial planners advise retirees and other individuals who may face high costs for nursing home or in-home long-term care to adopt strategies that will protect their financial assets. Long-term care insurance is becoming increasingly popular as the baby boomer population ages and elders realize the potentially devastating effect of long-term care expenses. (To estimate an individual’s long-term care costs, see the Planning Tool offered on the Medicare Web site at [www.medicare.gov/LTCPlanning/Home.asp](http://www.medicare.gov/LTCPlanning/Home.asp).)

Long-term care policies can vary greatly from one insurer to the next. Policies may include benefits for care in a nursing home, in an assisted living facility, in your home, or in an adult day care center. Some policies may pay for family benefits, such as caregiver training, but do not pay for services provided by family members.

It is important to determine what types of care are covered by a long-term care policy. Policies that limit coverage to care provided in a nursing home will not generally pay for services you receive at home. More flexible policies are available which allow you to use benefits to cover any necessary long-term care in any setting, but these policies usually are more expensive. If you are thinking of buying a policy, ask an experienced eldercare lawyer or financial planner to review the policy with you before you sign. (See the Finances section for information on finding a financial planner and the Legal Issues section for information on locating a lawyer.)

To evaluate the pros and cons of long-term care insurance, visit these Web sites:

- **AARP** at [www.aarp.org/families/caregiving/guide\\_to\\_longterm\\_care.html](http://www.aarp.org/families/caregiving/guide_to_longterm_care.html) provides resources on long-term care and planning
- **The Department of Health and Human Services Medicare** Web site at [medicare.gov/LongTermCare/Static/StepsOverview.asp](http://medicare.gov/LongTermCare/Static/StepsOverview.asp) offers useful information on planning for long-term care, including links to information on long-term care insurance
- **The National Clearinghouse for Long-Term Care Information** at [www.longtermcare.gov/LTC/Main\\_Site/index.aspx](http://www.longtermcare.gov/LTC/Main_Site/index.aspx) is managed by the Administration on Aging (AoA) to provide information on services and financing options that can be helpful to all individuals planning for long-term care

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Many situations can prompt the need for home care services for an elder in your family:

- **Medical emergency:** *My mother fell and broke her hip. She was in the hospital and in a rehab center. Now it's time for her to come home, but she can't manage by herself and still needs physical therapy. What should I do?*
- **Changes in a chronic illness:** *My dad has Parkinson's. He gets easily confused, can no longer drive, and has a hard time cooking for himself. I'm increasingly afraid to leave him alone while I'm at work during the day. What should I do?*
- **Natural aging process:** *My parents are lucky to be healthy and fairly active, but they are both in their early 80s, and it's getting harder and harder for them to get groceries and keep up their house and yard. They want to remain in their home. What should I do?*

The goal of home care services is to allow elders to remain at home and to maximize their ability to be independent without jeopardizing their safety. The term “aging in place” has become a catchphrase for describing this goal, and there is increasing support among health care professionals and policy makers for keeping elders in their communities with appropriate services.

Many elders need only a small number of services to function independently at home, such as help with home repair, cleaning, and cooking. However, with hospitals and rehab centers shortening the length of patient stays, some elders need a fairly high level of home health care services, either for a limited period of time following an illness or accident, or as ongoing care to manage decreased abilities or a chronic health condition.

## What Is Home Care?

Home care services fall into five general categories, although some home care agencies may offer multiple services and have more than one service provided by the same person from their agency.

- 1 **Homemaker Services** provide home management assistance, such as grocery shopping, light housekeeping, laundry, and changing beds.
- 2 **Personal Care Services** provide assistance with daily routines, such as bathing, dressing, grooming, eating, using the bathroom, and getting around.
- 3 **Meal Services** provide meals to seniors either in their own homes (“Meals on Wheels”) or in senior centers, churches, synagogues, schools, and other community locations (“Congregate Meal Programs”).

- 4 **Home Health Care Services** assist people with health and medical conditions that are being treated at home. Home health aides will assist with basic health care such as taking vital signs (temperature and pulse), changing bandages and dressings, and assisting with medications.
- 5 **Skilled Health Care Services** provide registered nurses, licensed practical nurses, and physical, occupational, and speech therapists who give skilled nursing care and rehabilitative therapies at home. Medicare will pay for short-term home care when skilled services are needed, usually following surgery or acute care stay in a hospital. For more information, see the Health Care and Insurance sections.

## When Is Home Care Needed?

Getting a “care assessment” is the best way to determine when an elder needs home care services. Caregivers can do it by themselves or get help with the process by calling their Area Agency on Aging (AAA) or a geriatric care manager.

### Activities of Daily Living (ADL)

An assessment is based on different kinds of information, starting with your elder’s ability to manage ADLs. These are the basic tasks involved in personal care and household work. See the [Checklist of Activities of Daily Living \(ADL\)](#) to help you determine what assistance is needed. The checklist can help you answer questions about physical limitations and memory problems affecting an elder’s ability to:

- Do housework, laundry, shopping, and cooking
- Maintain personal care, such as bathing, dressing, and using the bathroom
- Manage medical appointments and medications
- Handle personal finances and legal issues

Filling in the checklist before calling your AAA or a home care agency will make the conversation more useful and productive, so that you can move ahead with home care decisions.

### Physical Health Considerations

Planning for home care also involves an assessment of health issues affecting both physical and mental health. Caregivers may want to consult with the elder’s primary care physician (PCP) or a geriatric specialist to evaluate an elder’s physical capacities. Issues to consider include:

- **Mobility:** The ability to safely move around one’s own home and neighborhood is often compromised with advancing age. For a professional assessment, ask the elder’s doctor or get a referral to an occupational therapist. To make your own assessment, you can use a tool

developed by the Society of Hospital Medicine at [www.hospitalmedicine.org/geriresource/toolbox/mobility\\_assessment\\_tools.htm](http://www.hospitalmedicine.org/geriresource/toolbox/mobility_assessment_tools.htm).

- **Vision:** Vision impairment is common among the elderly and often leads to reduced social interaction and quality of life, depression, and injuries from falls. But since elders often do not report their vision problems to their health care providers, vision screening is recommended. Treatment for many vision problems common in older adults, such as cataracts and refractive errors, is available and can greatly improve quality of life.
- **Hearing:** Hearing deficits are also common among older adults and can affect quality of life. Assistive technology, such as hearing aids and cochlear implants, can be used to help basic hearing loss, while more serious conditions may require specialized medical attention.

### Mental Health Considerations

Assessing the mental health of the elder in your care can be challenging. The line between memory problems that naturally occur with aging and memory problems that occur in the early stages of dementia and/or Alzheimer's can sometimes be hard to distinguish. If an elder seems more confused than usual, has trouble completing daily routines, or has difficulty keeping track of daily medications, house keys, and other personal items, these may be signs that some level of cognitive impairment has occurred.

The signs of depression are also difficult to sort out; low energy, loss of appetite, and lack of interest in others can have a variety of sources. Getting a geriatric mental health assessment can help you get a clearer picture of what is going on and whether home care is advisable for this reason. For advice on how to get this kind of assessment done, ask your PCP, your local Area Agency on Aging (AAA) or Council on Aging (COA).

### Nutrition Considerations

Nutrition can be a major issue for elders remaining at home. Caregivers need to consider several questions about the elder in their care:

- Is the elder getting the right kinds and amount of food to meet daily health requirements?
- Is the elder capable of shopping for the right foods and preparing them?
- Is the elder eating the food he or she prepares or that is prepared for him or her?

Healthy eating is a challenge for all of us, and elders may have additional issues that make healthy eating even harder: poor health, difficulty shopping or cooking, food insecurity (hoarding), loneliness, or depression. Malnutrition is one of the primary reasons that many elders can no longer live on their own. If the elder in your care is having difficulty managing proper nutrition, there are meal services available.

The Elderly Nutrition Program is a federal- and state-funded program which allows local elder agencies to provide meals, nutrition screening, assessment, health education, and counseling. People age 60 or older and their spouses are eligible. There is no income requirement. A small voluntary donation is requested for those who can afford to pay. Your local senior center or Area Agency on Aging (AAA) can help you locate the appropriate type of meal program. There are two types:

- 1 The “Congregate Meal Program” provides at least one meal per day at senior centers, churches, schools, and other locations. The group setting offers many elders an important opportunity for socialization and companionship. Transportation is often available for those who have trouble getting around on their own. Some programs also offer meals on weekends.
- 2 “Meals on Wheels” are home-delivered meals of nourishing food for elders who are homebound and not able to prepare their own food. This subsidized home delivery program can also be supplemented with meals purchased through private services.

### Putting It All Together

Combining information on these five elements—ADLs, mobility, vision, hearing, and nutrition—can help you make your own assessment about the need for home care services.

A useful assessment tool can be found in the *Caregiver’s Handbook: A Guide to Caring for the Ill, Elderly, Disabled...and Yourself* at [www.health.harvard.edu/special\\_health\\_reports/Caregivers\\_Handbook.htm](http://www.health.harvard.edu/special_health_reports/Caregivers_Handbook.htm), produced by Harvard Health Publications. It includes a four-page questionnaire to determine needs.

## Who Provides Home Care?

There are different types of home care service providers. Each provider offers a different level and/or kinds of care, may vary in price, and may require more or less of your caregiving time.

- **Certified Home Care Agencies and Hospice Agencies** provide both medical and nonmedical services and have met strict federal requirements for patient care and management. In some cases they can provide home health services covered by Medicare and Medicaid. These agencies take care of all benefits and tax requirements for their employees.
- **Non-certified Agencies** also provide medical and nonmedical home services, but are not licensed.
- **Placement services** provide medical and nonmedical services. The providers are self-employed independent contractors, not employees.
- **Independent Workers** are employees hired directly by the elder or family caregiver, who is then legally responsible to pay state payroll taxes and worker’s compensation. There is no oversight or licensing for these services, and no source of coverage to pay for them.

## Finding Home Care

Caregivers can find services in several ways:

- Contact your local Area Agency on Aging (AAA) or Council on Aging (COA). These groups keep information on home care agencies in your community. They may also be able to provide a free initial assessment.
- Go directly to a private home health care agency. Begin your research with your local phonebook and the Internet.
- Ask your primary care physician or geriatric specialist to recommend agencies. They may have firsthand, recent information based on the experiences of other elders they treat.
- Ask other family members, friends, and co-workers.
- Check with your employer or insurance company to see if they offer referral services.

## Paying for Home Care

Paying for home care services is one of the most challenging issues for caregivers because most elders and families must pay for services out-of-pocket. This is a harsh reality for many working- and middle-class families, yet home care services may be the only way to keep an elder out of a nursing home. Since home care can become a major expense, it is a key issue to consider while doing long-term financial planning. (See also the Finances section.)

Some health maintenance organizations (HMOs) and some health and long-term care insurance plans provide coverage for home health care, so be sure to check benefits statements and policies carefully. You may want to contact the insurance providers to clarify what is covered by the elder's plan. The provider may require the elder's written or verbal permission in order for you to be able to discuss his or her insurance, so be sure to find out from the provider what is required so that you can gather information.

### Subsidized Home Care Services

Some or all of the cost for home health care services may be covered in these situations:

- **Follow-up care for elders who are homebound due to medical reasons.** Elders who need short-term skilled nursing care and physical or other therapy in response to an acute care stay in a hospital or rehab facility will receive Medicare coverage, regardless of their income level. (See the Insurance section for more information.)
- **Low-income elders.** Medicaid programs in most states support home care services as an alternative to nursing homes. (See the Insurance section for more information.)

- **Veterans of the U.S. military and their families.** Medically indicated home care services are available to eligible active-duty or retired veterans and their spouses, widows, and dependents through the CHAMPVA program. Call 877-222-8387 toll free to determine eligibility for these services. (See the Insurance section for more information.)

Your local AAA can help explain which services are subsidized on a no-fee or sliding scale basis in your community for the elder in your care. If you would like additional information about eligibility for state and federal subsidies, see the Benefits Checkup at <http://www.benefitscheckup.org/> from the National Council on Aging, or contact your State Unit on Aging.

### Home Care Rates

For families who are paying out-of-pocket for home care services, it is wise to get information on cost from several different agencies. You will probably be faced with some difficult choices between quality and affordability, but you should not be paying less than the average hourly rate in your area.

The hourly rate for a home health aide varies by state, and sometimes by whether the agency is an urban area or not. To get information on the range of hourly wages in various states, go to the Web site of the **Bureau of Labor Statistics** at [www.bls.gov/oes/current/oes311011.htm](http://www.bls.gov/oes/current/oes311011.htm) and click on “State Profile” for the occupation. According to the American Association of Homes and Services for the Aging, the national average hourly rate in 2008 for a certified home health aide was \$32. The average hourly rate for non-certified workers was \$19.

### Paying Families for Home Care

The issue of paying family caregivers to provide home-based care is an ongoing debate among eldercare professionals and public policy makers. There is currently no federal policy in place, but there are a small number of state-level demonstration projects designed to test the costs and benefits of such an approach. These demonstration projects all require the elder to be Medicaid eligible.

- 1 **Cash and Counseling Programs:** These programs are based on a “consumer-directed care” model. They give an elder a cash allowance for her or his home care needs. The cash may be spent to hire a relative or friend who can provide personal and household care, purchase assistive devices, and/or pay for home modifications.
- 2 **Caregiver Homes:** These programs allow a family member, friend, or other unrelated party to be paid by Medicaid to provide home care for an elder. Caregivers are paid from \$10,000-18,000 a year and are given training for their job.

To find out if there is a demonstration project in your state, call your state Medicaid office. The **Eldercare Locator** at [www.eldercare.gov/eldercare/Public/Home.asp](http://www.eldercare.gov/eldercare/Public/Home.asp) can connect you with Medicaid counseling. Visit the Web site or call 800-677-1116 toll free.

## Choosing a Home Care Agency

Once you have determined what home care services are needed, how to pay for them, and where to find them, you are ready to compare the quality and cost of the services offered by different agencies. There are essentially three stages to this process: screening, evaluating, and monitoring.

### Screening Home Care Agencies

Before you take an in-depth look at a particular agency, you may want to screen a few agencies with these preliminary questions:

- Is the agency Medicare or Medicaid certified?
- Does the agency offer the specific care we need (e.g., skilled nursing care vs. personal care and meals)?
- Is the agency recommended by a hospital/rehab discharge planner, social worker, or doctor?
- Does the agency have staff who can communicate effectively in a language other than English, if needed?
- Does the agency do background checks on all staff?

### Evaluating Home Care Agencies

When you have found several agencies that meet all these criteria, you may want to choose one or two for an in-depth evaluation. The following questions can guide you:

- **How will the agency assess needs?** Most agencies begin by sending someone to make an initial assessment of needs. Although you may have performed a needs assessment for the elder in your care, you should ask the agency how it determines the appropriate level of services. The elder's needs may increase or decrease over time, and the agency should have a process to assess any change in the services needed.
- **What is the training and experience of the caregivers?** Ask what training the agency provides to its caregivers, and if the home care aides are certified by the agency. Does the agency require that its caregivers participate in a continuing education program? Ask if the caregivers are trained to identify and report changes in service needs and health conditions.

- **What specific caregivers will be assigned to your elder?** Do the caregivers have experience or receive special training in the type of care that is needed, such as Alzheimer's care? Do they have training with a particular type of assistive technology, such as a hooyer lift? How long have they been working in the home care field?
- **What services are provided?** Sometimes an aide who helps with bathing and dressing can't cook meals, or someone who cleans and does shopping isn't licensed to drive with the elder in the car. Aides also may not be able to administer medications.
- **How does the agency develop the elder's care plan and supervise the caregiver?** Does a medical professional or experienced supervisor evaluate and supervise the caregiver in the elder's home and get input from the elder? How much control and personal independence does an agency provide to its clients? How does an agency involve the elder and family members in the process of assigning and supervising caregivers? Does the agency seek input from the elder on his or her care plans?
- **How does the agency assure continuity of care?** Having your elder cared for by a limited number of people (and the same people if possible) is less confusing and more comforting for the elder. Can the agency reasonably ensure that the same caregiver(s) will provide the home care services each week? How long do caregivers stay with the agency? What is the turnover rate? If a substitute caregiver is sent, when does the agency provide notice to the client? Ask how the agency assures that the substitute caregiver will be familiar with the care plan and individual needs of the client and the family.
- **What special or support services are provided?** For instance, does the agency provide a 24-hour phone line?
- **How can the agency be paid?** If you will be paying for service, compare the billing process and payment plans offered by different agencies. Compare how often you will be billed and whether you will be required to pay in advance. Ask if there are additional costs, such as fees or deposits, not included in the price quoted. Will you have to pay extra for holidays and weekends? If the elder needs special equipment, will it be covered by the elder's insurance or will the agency pay for it?
- **How much will the caregiver be paid?** Does the caregiver earn enough to be dependable? Paying a decent wage, although costly for you, will minimize turnover. (Note: If you are paying for services directly, pay by check or get receipts for all cash payments.)

*\*These evaluation guidelines were adapted from the Home Care Alliance of Massachusetts' "How to Choose a Home Care Agency" guide ©2005.*

## Monitoring Home Care Agencies

Once you choose an agency, your job as a caregiver is only half done. Now you must change hats from an evaluator to a monitor—an ongoing job as long as you are using home care services. The Center for Medicare and Medicaid Services (CMS) offers a useful publication, “Medicare and Home Health Care,” on the Medicare.gov Web site at [www.medicare.gov/HHCompare/Home.asp?dest=NAV|Home|Resources#TabTop](http://www.medicare.gov/HHCompare/Home.asp?dest=NAV|Home|Resources#TabTop). The publication, which includes a checklist to evaluate staff once they start caring for an elder, can be downloaded for free or obtained by calling 800-MEDICARE (800-633-4227 toll free) for a free copy.

Don’t forget that the most important source of information on the quality of the home care service you have chosen is the quality of the relationship between the elder and the home health care provider. Check in with both the provider and the elder in your care on a regular basis. (See also the Legal Issues section.)

## Geriatric Care Management

While family caregivers possess a great deal of knowledge about what their elder needs, sometimes making decisions about services *and* coordinating them over time can be overwhelming. Additional professional advice and expertise can be very helpful, especially when you are a first-time caregiver. You do *not* need to do this alone!

Geriatric Care Managers (“GCMs”) are nurses, social workers, counselors, or gerontologists. You can find one by calling your local Area Agency on Aging (AAA), hospital, rehab center, community service center, or multi-service private home care agency.

GCMs are experienced in working with families, evaluating needs, and dealing with complicated family dynamics. They will make home visits and assist in determining eligibility for resources. If you live in a different state from the elder you care for, a GCM can be very helpful in overseeing your elder’s care. GCMs can:

- Make an assessment about the need for home care services
- Develop a care plan about the specific services needed
- Coordinate home and medical care and hire home care workers, either through contracts with designated service providers or through workers of their own agency
- Monitor home care services, reassess them periodically and make needed adjustments
- Secure respite care for family caregivers, adult day programs, long-term care, and senior housing

- Provide assistance to families in addressing legal and financial issues
- Assist in dealing with complicated government benefits
- Assist with medical service and equipment providers

If you work with a geriatric care manager through a publicly subsidized program, the services will be free of charge or provided on a sliding scale. If you are paying for a geriatric care manager privately, the average hourly rate varies by location and experience, but in 2008 expect to pay from \$90–\$200 an hour out-of-pocket for assessments and care management.

A national organization of private geriatric care managers provides names and background information about care managers in every state. For more information visit the Web site of the **National Association of Geriatric Care Managers** at [www.caremanager.org/](http://www.caremanager.org/) and click on “Find a Care Manager.”

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WITH THIS PROGRAM.





# Housing and Transportation

- *My husband is having trouble going up and down stairs....Do we need to move?*
- *How do I get safety modifications for my mother's bathroom?*
- *We are considering moving to a retirement community, but how can we find something that is affordable?*
- *Is there such a thing as a "good" nursing home if my father needs that level of care?*
- *When should I ask my mother to stop driving?*

## Remaining at Home

A sense of place—a home—is essential to our health and well-being. But many families find that home is not a safe environment for elders. Home modifications, assistive technologies, and home care supports can help solve problems for many elders, but some may need to move into more specialized environments.

You may have heard an 80-year-old person complain that he or she doesn't want to move to an assisted living community. "That's for OLD people," he or she may protest. The loss of independence, community, and the stigma of old age in our society makes it difficult to consider such a profound change.

Some elders make a transition when they retire and move to be closer to children and grandchildren, or to a warmer climate, or to a planned retirement community. Most elders, however, continue to live in the same house or apartment where they have lived for many years. They want to remain in a community where they have friends, familiar stores and streets, and a lifetime of memories.

## To Move or Not to Move

There are a number of housing-related issues that families must consider when helping an elder decide whether he or she can remain at home. Here are some resources that can help:

- The **Family Caregiver Alliance** at [www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=849](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=849) offers a publication entitled "Home Away from Home: Relocating Your Parents," which discusses the issues related to changing needs in the home and making modifications and transitions, if necessary.
- The **U.S. Department of Housing and Urban Development** (HUD) at [www.hud.gov/offices/hsg/sfh/hecm/topten.cfm](http://www.hud.gov/offices/hsg/sfh/hecm/topten.cfm) has many resources to help elders remain at home. To access local resources, visit its Web site and click on "Information by State," then click on your state or the elder's state.

## Home Modification and Repair

There are adaptations to homes that can make them easier and safer for activities such as bathing, cooking, and climbing stairs, as well as alterations to the physical structure of the home to improve its overall safety and condition.

To help you determine what modifications may be helpful, check out the useful home safety checklist at Careguide@Home at [www.eldercare.com](http://www.eldercare.com). Click on “Home,” then “Home Safety for Your Aging Parent.”

For elders with limited resources, paying for home modifications can be a challenge. Some help is available for low- and moderate-income elders who are homeowners. There are no-interest or low-interest loans available through HUD for home modification and repair. To find out how the program works in your state, contact your Area Agency on Aging (AAA) or your Council on Aging (COA).

If an elder does not qualify for assistance loans, and lacks the funds for needed home improvements or repairs, he or she may want to consider a *reverse mortgage*. A reverse mortgage is a special type of home loan that lets the homeowner convert a portion of the equity in his or her home into cash. (For more information, see the Finances section)

### Assistive Technology

Assistive technology refers to equipment and other services that enhance the mobility and independence of people with disabilities. Ranging from simple devices, such as amplified telephones and handheld showers to high-tech medication monitoring equipment, assistive technology has great potential for helping an elder remain at home.

Assistive technology is also important for caregivers. Caring for an elder often involves physical demands that can jeopardize a caregiver’s own health. Home modifications, such as portable ramps, roll-in showers, widened doorways, and assistive devices can provide immediate relief while helping caregivers deliver care more safely. **Caregiver Adaptations to Reduce Environmental Stress** (CARES) at <http://homemods.org/folders/cares-project/library.shtml#centerpub>, funded by the U.S. Administration on Aging, is one of the best resources for current information. You can access a free PDF in six languages on the Web site, or call 213-740-1364, or e-mail [cares@csu.edu](mailto:cares@csu.edu).

### Energy Assistance

As energy costs continue to rise, heating and air conditioning bills may become a factor in an elder’s ability to stay in his or her current home. Most states have energy assistance programs, as well as laws that prevent utility companies from shutting off service to elder households that are experiencing a financial hardship. Contact your local utility companies to see if they offer reduced rates for elders.

## New Models for Remaining at Home

The conventional approach to “aging in place” is to deliver home care services to each person separately, based on an individual assessment and development of an individual care plan. (See the Home Care section for more information on care plans.)

New models are being created that emphasize building (or rebuilding) social connections among elders while meeting individual service needs. Three such models, described below, share common features:

- The strong preference of many elders to remain in a neighborhood and in daily contact with people of all generations
- The value of community for elders who may be living alone or are socially isolated for other reasons
- The need to improve the affordability and accessibility of support services, such as home care, home repair, grocery shopping, transportation, and assistance with other daily activities

### NORCs

A “Naturally Occurring Retirement Community” (NORC) refers to a geographic area or building with a multigenerational population but a significant number of residents that are 60 and over. Some eldercare agencies have created community-based interventions that build on this “natural” concentration of elders called NORC-Supportive Service Programs (SSPs). These organizations connect elders to a variety of health care and home care services that allow them to remain healthy and independent. By serving a large number of elders in a small area, this model benefits from economies of scale in the organization and delivery of services, and creates related cost savings. There are now more than 80 NORCs nationwide. For more information on NORCs, visit the Web site at [www.norcs.com](http://www.norcs.com).

### It Takes a Village

Another model for aging in place has been pioneered by Beacon Hill Village (BHV), a grassroots membership organization that connects people age 50 and older who live in downtown Boston with supportive services. By negotiating and partnering with service providers, BHV offers its dues-paying members access to social and cultural activities, health and fitness programs, household and home maintenance services, and medical care. The goal of the “village” is to offer the benefits of assisted living without requiring members to move from their homes.

There are now five “villages” in different parts of the country, and ten more to open in 2008. Caregivers and elders interested in learning how to start an organization similar to Beacon Hill Village in their own neighborhood can order a copy of “The Village Concept: A Founder’s Manual” at [www.beaconhillvillage.org/](http://www.beaconhillvillage.org/) or call 617-723-9713.

## Elder Housing Options

Even if an elder is able to remain in his or her home now, you should begin your exploration of other housing options as soon as possible. Many communities and facilities have waiting lists. You may want to gather brochures and visit locations ahead of time, so you'll know what the local options are.

Your local Area Agency on Aging (AAA) or public housing agency has information about the options best suited for the elder in your care. For a more in-depth discussion of each housing option, see the "National Care Planning Council's Guide to Retirement Care Communities" at [www.longtermcarelink.net/eldercare/retirement\\_care\\_communities.htm#putting](http://www.longtermcarelink.net/eldercare/retirement_care_communities.htm#putting).

### Independent Living

These facilities are designed for elders who are able to live on their own, but want the security and conveniences of community living. Some facilities offer organized social and recreational programs as a part of everyday activities (Congregate Living or Retirement Communities), while others provide housing with only a minimal amount of amenities or services (Senior Apartments).

Independent living facilities may offer housekeeping services, laundry facilities, linen service, meals or access to meals, local transportation, and planned social activities. Some facilities offer recreational activities, exercise facilities, community lounges, and reading rooms. Health care is not provided, but many facilities allow a home health aide or nurse to come in to assist with medicines and personal care. Because these facilities are not licensed by local, state, or federal agencies, there are no formal regulations.

There are now independent living options for seniors and others on the campuses of more than 60 colleges and universities, usually referred to as "campus-based" or "university-affiliated" residences. Although the residents may be largely age 65 and older, they have chosen to live there because of the proximity to an age-integrated neighborhood, rich with educational and cultural opportunities. Their focus is on lifelong learning, and residents have access to college classes, cultural programs, and recreational facilities while enjoying ongoing contact with students and faculty. Some of these communities are financed and facilitated by universities, while others have been launched by real estate developers and other commercial interests. For a partial list of communities, visit the **AARP** Web site at [www.aarp.org/bulletin/yourlife/campus\\_retirement.html](http://www.aarp.org/bulletin/yourlife/campus_retirement.html).

**Financial Considerations:** Private funds are most often used to pay for independent living, although some apartments are subsidized and accept state and/or federal funding to cover a portion of the payment for low-income individuals. Medicare and Medicaid do *not* cover independent living since no health care is provided.

## Assisted Living

Assisted living offers a combination of residential housing, meals, and personalized support services, but it does not provide skilled nursing care. Assisted living is designed for adults who may need help with activities of daily living such as housecleaning, bathing, dressing, and/or medication reminders, and want the security of having assistance available on a 24-hour basis in a residential environment. All meals are provided, and often there are transportation services and cultural programs. The underlying goal of assisted living is to support the autonomy, privacy, and individuality of the residents.

Assisted living residences are regulated at the state level, and the definition of assisted living varies by state. Assisted living can also be called by different names, such as residential care, supportive housing, or congregate care. Your local Area Agency on Aging (AAA) can provide information on assisted living options in your area.

**Financial Considerations:** The cost of assisted living varies according to location, size of the unit, services included, and whether the unit is owned or rented. In 2008, the monthly fee was typically \$2,700 or more per month (\$32,000 or more per year). Most assisted living residents pay privately, but there are a few ways for qualified low-income elders to access subsidies through either HUD vouchers and/or Medicaid waivers. (See the Insurance section for information on Medicaid eligibility.)

## Alzheimer's or Specialized Care Facility

An increasing number of assisted living facilities and nursing homes offer specialized care to people with Alzheimer's disease and related memory disorders or dementia. These facilities offer higher staffing levels and care that supports individual skills and interests, in an environment designed to minimize confusion and agitation.

Similar to assisted living communities, specialized care facilities provide assistance with dressing, grooming, bathing, and other daily activities. Meals, laundry, and housekeeping are usually provided within private and semiprivate rooms in a residential-type setting. Your local Area Agency on Aging (AAA) can help you identify facilities in your area that offer these services.

**Financial Considerations:** Somewhat higher costs and similar opportunities for third-party assistance (Medicare, private insurance, Medicaid) apply for these facilities as for other assisted living facilities and nursing homes.

## Continuing Care Retirement Community (CCRC)

CCRCs provide the services necessary for residents who wish to remain in the same retirement community as their personal and health care needs change. CCRCs typically combine three housing options on one campus:

- Townhouses, apartments, or cottages for independent living
- Assisted living apartments for elders who need meals and some personal care assistance
- Nursing home accommodations for elders who require more comprehensive skilled nursing care

CCRC units follow the same licensing and regulation rules as freestanding facilities. Independent living units are not licensed; the assisted living units are regulated by the state; and the nursing facilities are licensed and regulated by both the state and the federal government.

**Financial Considerations:** Most CCRCs require a sizable entrance fee. In 2008 these ranged from less than \$100,000 to more than \$300,000, with monthly fees from \$700 to more than \$3,000. The composition of service packages, especially the health care component, varies greatly. It is important to be clear about which services are included in the monthly fee and which services are additional. Units in a CCRC may be rented or owned, but almost all are paid for privately.

Some CCRCs have had significant financial problems that have created hardship among their residents. Your state's attorney general's office or your local Better Business Bureau may be able to tell you if any complaints have been filed against a CCRC that you are considering. (See also the Legal Issues section.)

## Nursing Homes and Long-term Care

Nursing homes are licensed, regulated, and individually certified by the state for Medicare and Medicaid and provide 24-hour care. They offer a staff of licensed and/or registered nurses, nursing aides, and administrators as required by licensing standards. The health care is supervised and authorized by a physician. You can look at a facility's recent evaluation on the **Medicare** Web site at [www.medicare.gov](http://www.medicare.gov). Click on "Compare Nursing Homes" and search for a nursing home by name or location. The Web site also offers a useful 64-page "Guide to Choosing a Nursing Home" at [www.medicare.gov/Library/PDFNavigation/PDFInterim.asp?Language=English&Type=Pub&PubID=02174](http://www.medicare.gov/Library/PDFNavigation/PDFInterim.asp?Language=English&Type=Pub&PubID=02174).

There are three types of facilities offering different levels of care, but they are all referred to as nursing homes. If a resident expects to access third-party payment, a determination of need for long-term care in a nursing home must be documented by the elder's primary care physician and your local Area Agency on Aging (AAA) Coordination of Care Unit.

- 1 A **Residential Care Facility** or Rest Home provides 24-hour supervision and supportive services for individuals who do not routinely need nursing or medical care.
- 2 A **Nursing Facility** is a residential facility that provides 24-hour nursing care, rehabilitation services, and support for activities of daily living for the chronically ill who require nursing care.
- 3 A **Skilled Nursing Facility** provides 24-hour skilled nursing care and extensive rehabilitative care and services to the chronically ill; short-term care for individuals who have been hospitalized and need rehabilitation before returning home; and specialty care for individuals with physical and neurological disabilities. These facilities provide room and board, personal care, protection, supervision, and may offer other types of therapy.

**Financial Considerations:** Nursing homes charge a basic daily or monthly fee. In 2008 the average cost of a semiprivate room in a nursing home was \$5,448 per month (\$65,385 a year). Some families purchase long-term care insurance in anticipation of the cost, while most depend on other forms of financing. Nursing homes accept third-party payment from a variety of sources, including Medicare, Medicaid, and private insurance. Medicaid currently pays for 60 percent of nursing home care, typically covering costs after the resident has exhausted his or her private resources. Medicare also pays for short-term nursing care within 30 days of a hospitalization of three or more days and is medically certified. For more information, see also the Insurance section.

### Protective Services for Nursing Home Residents

Adults residing in long-term care facilities can be victimized by abuse, neglect, and exploitation. There are ways to monitor the care elders receive, such as participating in the home's Resident Council, reviewing an elder's care plan with the staff on a regular basis, and asking family members to visit throughout the day and week. Nursing homes should offer a family reevaluation meeting with all the staff who care for the elder (nurses, aides, recreation directors, etc.) at least once per year.

If you suspect that an elder is not receiving care and you are not able to work with the staff to resolve care issues, you can report it. The *National Long Term Care Ombudsman Resource Center* at [www.ltombudsman.org/](http://www.ltombudsman.org/) can help you resolve problems between residents and nursing homes or assisted living facilities. To locate the ombudsman for your region, visit the Web site or call 202-332-2275. The *National Citizens' Coalition for Nursing Home Reform* at [www.nccnhr.org/default.cfm](http://www.nccnhr.org/default.cfm) was formed because of public concern about substandard care in nursing homes. It offers fact sheets about nursing homes and other resources. (See also the Legal Issues section.)

## Veterans' Housing

Soldiers' Homes provide health care services to honorably discharged wartime veterans with non-service connected health problems. Soldiers' Homes are state-funded, accredited health care facilities that offer veterans hospital care, skilled nursing and long-term care, full-time residential accommodations, and a multi-service outpatient department. To find veteran housing options in your state, contact your AAA or your veteran's health care provider. (See also the Insurance section.)

**Financial Considerations:** Veterans' housing is subsidized for eligible veterans who meet income requirements. In 2008, charges applied for those with a gross monthly income over \$300.

## Elder Housing Resources

For more information on finding elder housing, use these resources:

- The **American Association of Homes and Services for the Aging** (AAHSA) represents nonprofit organizations providing health care, housing, and services. Its Consumer Information Web site at [www.aahsa.org/consumer\\_info/default.asp?](http://www.aahsa.org/consumer_info/default.asp?) offers useful information and a directory of nonprofit providers. Click on the "Homes and Services" directory and enter your city and/or state to find housing options near you.
- The **Centers for Medicare and Medicaid Services** (CMS) provides listings of licensed nursing homes, including the results of recent inspections at those nursing homes on its Compare Nursing Home site at [www.medicare.gov](http://www.medicare.gov). Click on "Compare Nursing Homes in Your Area."
- The **National Care Planning Council** at [www.longtermcarelink.net/](http://www.longtermcarelink.net/) offers clear, in-depth explanations of housing options and other long-term care planning information, including veterans' benefits and financing information.
- The **National Center for Assisted Living** (NCAL) at [www.ncal.org](http://www.ncal.org), 800-321-0343, offers consumer and long-term care information.
- The **National Family Caregiver Support Program** publication "Because We Care" at [www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking\\_care\\_of\\_others/wecare/housing-options.asp](http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_others/wecare/housing-options.asp) has recommendations on choosing housing and other living arrangements.
- The **National Long Term Care Ombudsman Resource Center** at [www.ltombudsman.org/](http://www.ltombudsman.org/), 202-332-2275, is an independent advocate that works to solve problems between residents and nursing homes or assisted living facilities. An ombudsman can also give you information about how to find a facility and get quality care.

- **Senior Housing Net** at [www.seniorhousingnet.com/seniors/](http://www.seniorhousingnet.com/seniors/) is part of a free realtor search engine tool called “move.com.” Although it is a commercial site, it provides helpful checklists and information about types of housing and financing.
- The **U.S. Administration on Aging** (AoA) offers a directory of senior housing options and resources at [www.aoa.gov/prof/notes/Docs/Housing\\_Options\\_Directories.doc](http://www.aoa.gov/prof/notes/Docs/Housing_Options_Directories.doc).
- The **U.S. Department of Housing and Urban Development** (HUD) at [www.hud.gov/groups/seniors.cfm](http://www.hud.gov/groups/seniors.cfm) provides a number of resources on its Web site for elders. Click on the “Information by State” link to find HUD counseling in your area.

## To Drive or Not to Drive?

- *How do I know when it's time for my father to stop driving?*
- *I can't leave work in the middle of the day—how can I get my mother to her doctors' appointments?*
- *How do I get my husband to his Alzheimer's day program when he is too heavy for me to move in and out of our car?*

Being able to get out and about—going shopping, seeing friends, visiting the doctor, taking classes—is vital to maintaining an elder's sense of independence and can contribute to an elder's physical, mental, and emotional well-being. Transportation is one of the key things that elders who want to “age in place” need. But problems with transportation—whether it's the elder's driving ability or the need to find safe and reliable transportation for the elder—is one of the most troublesome issues for caregivers.

Most elders prefer driving their own car. According to the American Automobile Association, drivers age 65 and older take more than 80 percent of trips in their own vehicles. However, the American Medical Association reports that motor vehicle injuries are the leading cause of injury-related deaths among 64-to-75-year olds and the second leading cause (after falls) among 77-to-84-year olds.

For general public safety, we need to help elders recognize their changing abilities and adapt their driving practices accordingly. We must identify impaired drivers and remove their licenses, while supporting competent elders with on-going monitoring.

For the caregiver, the conversation about whether an elder can continue to drive is often one of the most difficult ones. Information and assessment resources can be found at the following Web sites:

- **AAA Foundation for Traffic Safety's** Senior Driver Web site at [www.seniordrivers.org/home/](http://www.seniordrivers.org/home/) provides helpful tools to assess and improve driving skills, as well as how to prepare to stop driving and find alternative transportation solutions.

- **AARP** at [www.aarp.org/families/driver\\_safety/driver\\_ed/](http://www.aarp.org/families/driver_safety/driver_ed/) offers driver safety courses and information.
- The **MIT Age Lab** and the **Hartford Insurance Company** at [www.thehartford.com/talkwitholderdrivers/driversatrisk.htm](http://www.thehartford.com/talkwitholderdrivers/driversatrisk.htm) have prepared a guide called “Having the Conversation” to help families discuss changing driving skills, risks, and alternatives. Their site includes useful worksheets and links to other resources.

See also [It Starts with a Conversation](#).

## Transportation Services

Your local Area Agency on Aging (AAA), Council on Aging (COA), or senior center will probably be the best source of information about transportation services in the area. They can help you identify the best transportation option for the elder in your care. The **Eldercare Locator** at [www.eldercare.gov/Eldercare/Public/Home.asp](http://www.eldercare.gov/Eldercare/Public/Home.asp) can provide contact information for these services and programs. Other resources include the following:

- **INTAmerica** at [www.itnamerica.org](http://www.itnamerica.org) has created a model of transportation services for elders through a combination of fares and volunteer drivers. Started in Maine, the organization also has programs in California, Connecticut, Florida, Illinois, Kentucky, and South Carolina.
- **National Center on Senior Transportation** (NCST) at [http://seniortransportation.easterseals.com/site/PageServer?pagename=NCST2\\_older\\_directory](http://seniortransportation.easterseals.com/site/PageServer?pagename=NCST2_older_directory) offers links to transit agencies and providers of community transportation.
- **U.S. Department of Transportation** (DOT) offers an Americans with Disabilities Act (ADA) Assistance Line for questions regarding public transportation for persons with disabilities. Contact the Federal Transit Administration (FTA) Office of Civil Rights at 888-446-4511 toll free or by e-mail at [FTA.ADAAssistance@dot.gov](mailto:FTA.ADAAssistance@dot.gov).

## Public Transportation Systems

Many local and regional public transit systems are inexpensive and offer services tailored to the needs of elders. In most states, public transportation for elders is offered through a mix of contracted vendors, volunteers, and not-for-profit organizations, including local AAAs, COAs, and senior centers. However, the availability of transportation services varies greatly from community to community. If you are not familiar with your local public transportation provider, you can call your state’s Department of Transportation or go to the Web site of the American Public Transportation Association (APTA) at [www.apta.com/links/state\\_local/](http://www.apta.com/links/state_local/) that links to public transportation agencies in all states.

## Other Transportation Services

If your elder cannot walk, drive, or use public transportation, the burden usually falls on you. More than 8 out of 10 caregivers provide transportation assistance, either directly or through arranging for services. However, nonprofit organizations offer transportation through vanpools, taxi voucher programs, volunteer driver and escort programs, and other services. Talk to your local AAA to see what is available in your community, such as:

- **Fixed Route Services:** Reduced fares for seniors and/or people with disabilities who can use regular public transportation routes.
- **Paratransit Services** or **“On Demand”** services: Accessible transportation for people whose physical condition restricts the use of public transportation. These demand-responsive services use accessible vans, mini-buses, or taxis. They do not follow fixed routes or schedules—pick-ups and drop-offs are arranged for each trip. These services may be provided by your local transit authority, social service agency, or volunteers (or by a combination of all of the above). Some private taxi services offer senior discount coupons.
- **Chair Service:** Local ambulance companies can also provide wheelchairs to transport elders for medical appointments. See local listings in the telephone yellow pages or contact your local city or town hall for ambulance services in your area.
- **Shuttles:** Some cities and towns provide scheduled, point-to-point senior shuttles for services, such as weekly bus trips to supermarkets from senior housing facilities. Some health care providers provide transportation services between their community-based clinics and hospitals. Regional transportation authorities may provide scheduled transportation service to medical facilities.



Being eligible for Social Security and Medicare at age 65 are the milestones that many people think mark the end of “middle age” and the beginning of “old age.” But as we live longer and healthier lives, and as the baby boomer generation begins to age, the way we view and live past age 65—the very notion of old age—is being challenged. Many elders want to stay involved in activities and work into their 70s, 80s, and even 90s.

## Exercise and Fitness

Many people assume that it’s normal for elders to slow down and become less active, but being inactive can cause elders to lose ground in four areas that are important for staying healthy and independent: strength, balance, flexibility, and endurance. Exercise and physical activity can help elders maintain or even partly restore function in these four areas. Some exercise is possible no matter how old or frail an elder becomes, and it can be just as important as medication in the treatment of certain chronic diseases, such as diabetes.

Fitness programs also offer a chance for elders to socialize. This may help some elders overcome their resistance to exercising. The elder's doctor may know of programs at local medical centers. YMCAs, local churches, and senior centers may offer programs specifically designed for elders.

Keep in mind that it is important for you or the elder in your care to talk with the elder's doctor before starting a new exercise routine. For more information, contact the following:

- The **National Institute on Aging** at [www.nia.nih.gov/HealthInformation/Publications/](http://www.nia.nih.gov/HealthInformation/Publications/) offers free online publications and an exercise video. Visit its Web site or call 800-222-2225 toll free.
- **NIH SeniorHealth** at <http://nihseniorhealth.gov/> is an elder-friendly Web site from the National Institute on Aging and the National Library of Medicine. This site features information on popular health topics, and it has both a large-type and a “talking” feature that reads text aloud.

## Employment or Retirement?

What does it mean to retire? There is increasing evidence that the full-start/full-stop model of paid work is no longer feasible. Many people are not financially prepared to stop working at 65, and even those who are may miss the intellectual stimulation and social benefits of working. In addition, some companies are beginning to experience a shortage of talent for skilled jobs, just as experienced workers are beginning to retire. To help address these changing forces, both workers and employers are experimenting with new models of work.

- **Phased Retirement:** A transition from full-time work to full-time retirement by decreasing workload and/or responsibilities over time. Phased retirement is prevalent in fields such as education, where teacher shortages have spurred some school systems to create incentives to keep experienced teachers in the classroom.
- **Bridge Jobs/Careers:** Jobs that facilitate moving from one field of work to another, including a significant or modified career change.
- **Flexible Work Arrangements:** Jobs that allow for adjusting the start and end times of the workday, part-time work, telecommuting, job sharing, and other arrangements that make the hours and location of working more amenable to the worker.

Not only is the way people work after 65 under scrutiny, so is the purpose of working in later years. Many elders want to use this time of life to become more involved in their communities. Their experience can be especially beneficial to organizations that are already facing labor shortages such as education, health care, and social services.

**Civic Ventures** at [www.civicventures.org](http://www.civicventures.org) is a nonprofit organization that explores new ways for people over 65 to continue to make a contribution. For information on how retirees can find public service jobs, see its online pamphlet, “The Boomers’ Guide to Good Work.” Click on “Publications,” then “Booklets.”

## Volunteer Opportunities

About 45 million Americans volunteer each year, and elders make up about one-third of those volunteers. Elders contribute many valuable services, from work that relates to their prior work experiences or hobbies to jobs that offer a chance to try something new, or simply to help someone in need. The following organizations provide a variety of opportunities for elders:

- The **Experience Corps** at [www.experiencecorps.org](http://www.experiencecorps.org) invites people over 55 to volunteer in public schools and youth-focused organizations. The volunteers work one-on-one with young children, create before- and after-school programs, get parents more fully involved in schools, and serve as advocates for children and their needs.

- **Family Friends** at [www.family-friends.org/](http://www.family-friends.org/) organizes elders over 55 who are interested in working as advocates for children with special needs. There are no income guidelines for either volunteers or families, and volunteers receive extensive training.
- **Points of Light Foundation** and **Hands On Network** at [www.pointsoflight.org/programs/50plus/](http://www.pointsoflight.org/programs/50plus/) have partnered to form an organization that helps connect people and resources for creative solutions to community problems, including a network for older adults called the “50+ Volunteering Initiative.”
- **Senior Corps** at [www.seniorcorps.org](http://www.seniorcorps.org), 800-424-8867 toll free or 202-606-5000 (select Senior Corps), runs three programs that rely on elder volunteers. For two of the programs—*Foster Grandparents* and *Senior Companions*—the elder must be age 60 or older and be able to serve between 15 and 40 hours a week. In return, elders receive training, transportation, some meals, a free physical, and insurance protection while on assignment. Income-eligible volunteers also receive a modest weekly stipend.
  - 1 *Foster Grandparents* help disadvantaged or disabled youth. They offer emotional support, tutor children with low literacy skills, mentor troubled teenagers and young mothers, and care for premature infants and children with physical disabilities and severe illnesses.
  - 2 *Senior Companions* provide assistance to disabled adults who wish to continue to live independently at home.
  - 3 *The Retired and Senior Volunteers* (RSVP) program places adults age 55 and over in nonprofit organizations and faith-based institutions to provide a variety of services, from leading local museum tours to teaching adult education computer classes. RSVP volunteers serve without compensation, but may be reimbursed for expenses such as transportation.
- **The Senior Environment Corps** at [www.easi.org](http://www.easi.org) of the Environmental Alliance for Senior Involvement (EASI), is a national, nonprofit coalition whose mission is to increase opportunities for elders to play an active, visible role in protecting and improving the environment in their communities.
- **Senior Medicare Patrols** (SMP) at [www.aoa.gov/smp](http://www.aoa.gov/smp) programs teach retired professionals, such as doctors, nurses, accountants, investigators, law enforcement personnel, attorneys, and teachers, to help Medicare and Medicaid beneficiaries become better health care consumers. It focuses on issues such as identifying billing errors and preventing potential Medicare fraud.
- **Service Corps of Retired Executives** (SCORE) at [www.score.org/index.html](http://www.score.org/index.html) 800-634-0245 toll free, is an association made up of retired executives and small-business owners. Sponsored by the Small Business Administration (SBA), it coordinates volunteer counselors to assist first-time entrepreneurs and small-business owners in the areas of planning and management.

## Additional Volunteer Resources

Although the following organizations are not specifically geared towards elders, they are additional resources for volunteering.

- **The Peace Corps** at [www.peacecorps.gov](http://www.peacecorps.gov), 800-424-8580 toll free, provides 27 months of training and service for elders interested in volunteering in another country in business development, education, youth and community development, agriculture and the environment, and health. The Peace Corps prepares volunteers with extensive language, technical, and cross-cultural awareness training, and covers the cost of transportation and medical care during the volunteer period.
- **Volunteers in Parks (VIP)** at [www.nps.gov/](http://www.nps.gov/) provides those with an interest in history and the outdoors volunteer opportunities with the National Park Service, the federal agency entrusted with preserving more than 360 national parks in the United States.

Additional resources can be found on the Web site of the **Administration on Aging** at [www.AoA.gov](http://www.AoA.gov). Click on “Elders and Families,” then “Volunteer Opportunities.” You may also find volunteer opportunities at your Area Agency on Aging (AAA), senior center, or faith-based organization.

## Lifelong Learning

The benefits of remaining intellectually engaged as people grow older is an area of active investigation by neuroscientists and physicians. “Engagement” is defined as a behavior that involves a high level of both intellectual and social function, and there is growing evidence based on longitudinal studies that leading an intellectually stimulating life seems to foster cognitive vitality. It is also well established that lifelong learning has a protective effect with respect to dementia.

## Colleges, Universities, and Libraries

A good place to start looking for courses and adult education classes is your local college, university, or public library.

- The **National Center for Education Statistics (NCES)** at <http://nces.ed.gov/>, a division of the U.S. Department of Education, helps locate the lifelong learning resources nearest you. At the bottom of the home page, click on “School/Library Search,” then enter your city or town and state. The search will generate a list with addresses and telephone numbers. You can also search by type of institution (public and private higher education institutions and libraries) or look up all institutions within 50 miles of your Zip Code.

- **The Osher Lifelong Learning Institutes (OLLI)** at [www.usm.maine.edu/olli/national](http://www.usm.maine.edu/olli/national) is a network of 101 university and college programs that are designed for older students. Each institute reflects the culture of its own university and its learning community. To see if there is one in your community, visit the Web site. Click on “Find an OLLI Near You,” then click on your state.

## Travel and Other Learning Communities

- **The Elderhostel Institute Network (EIN)** at [www.elderhostel.org/](http://www.elderhostel.org/), 800-454-5768 toll free or 877-426-8506 toll free, coordinates more than 400 programs in the U.S. and Canada. This includes short-term educational travel opportunities for adults 55 and over. To receive a free catalog, call or visit the Web site.
- **Senior Net** at [www.seniornet.org](http://www.seniornet.org) is a national, nonprofit organization that offers older adults both local classes and online, self-paced instruction in computers and the Internet. In many states, on-site courses for elders 50 and older provide a low-cost, friendly introduction to computers as well as topics such as genealogy, graphics, personal financial management, and tax preparation. Senior Net sites offer open lab time, user groups, workshops, and social activities. To learn more, visit the Web site and click on “Learning Centers,” then “Courses.”

## Other Learning Opportunities

To learn about other opportunities for lifelong learning, check with your local Council on Aging (COA) or senior center. Some offer their own classes; others partner with local schools and colleges. Some faith-based institutions offer adult education programs, tours, and day trips. Many museums offer free tours and lecture programs, as well as discounted admission for seniors. For a complete list of museums, go to the Web site of **Museumlink** at [www.museumlink.com/](http://www.museumlink.com/) and click on “U.S. Museums by State.”

## Caregiver and Elder Advocacy

With the aging of the population and life expectancy increasing, elder issues have become increasingly important in public discussions and public policy. There are several national organizations that promote legislation, influence public policy, conduct research, and provide public education on a wide range of issues of concern to elders and caregivers. As a caregiver—or a future caregiver—you may want to become involved in one of the following organizations:

- **AARP** at [www.aarp.org/issues](http://www.aarp.org/issues), 888-OUR-AARP (888-687-2277), is the largest organization of seniors in the United States. Its “Grassroots America” initiative is designed to mobilize AARP’s 35 million members to impact the outcome of legislative debates and elections on both the state and national levels.

- **National Alliance for Caregiving** at [www.caregiving.org/](http://www.caregiving.org/) is a nonprofit coalition that provides support and education to family caregivers and eldercare professionals. It conducts research and policy analysis, develops national programs, and increases public awareness of family caregiving issues. It also provides ongoing support, resources, and Webcasts to more than 20 local caregiving coalitions.
- The **National Center on Caregiving** (NCC) at <http://caregiver.org/caregiver/jsp/home.jsp> 800-445-8106 toll free, is a program of the Family Caregiver Alliance. NCC is a central source of information and technical assistance on caregiving and long-term care for policy makers, health and service providers, media, program developers, funders, and families. Visit its Web site and click on “Public Policy and Research.”
- **National Council on Aging** at [www.ncoa.org/](http://www.ncoa.org/), 202-479-1200, works to improve health, find employment, and improve access to government and private benefits for older Americans. It is a leading advocate on national issues affecting elders and has shaped programs such as Meals on Wheels and Foster Grandparents. It also leads a nationwide network of organizations to advocate for and provide ways to improve the quality of life for elders.
- **National Family Caregivers Association** (NFCA) at [www.nfcacares.org](http://www.nfcacares.org), 800-896-3650 toll free, supports, educates, and advocates for more than 50 million people caring for an aged, chronically ill, or disabled loved one. Its Web site has information about eligible tax deductions for caregiving.
- **National Senior Citizens’ Law Center** at [www.nsclc.org](http://www.nsclc.org), 202-289-6976, advocates for the independence and well-being of low-income elders and people with disabilities through litigation, legislation, and assistance to attorneys and paralegals.

In addition to these organizations, many organizations linked to a specific disease (e.g., cancer, heart disease), have significant advocacy and legislative initiatives that benefit elders and their caregivers. (See also the Caring for the Caregiver section.)

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WITH THIS PROGRAM.





# Caring for the Caregiver

*Caregiving is hard work...It is important that we listen to caregivers in order to know what their needs are and then address the specific needs they identify.*

FORMER FIRST LADY ROSALYNN CARTER, FOUNDER OF THE ROSALYNN CARTER INSTITUTE FOR CAREGIVING

You may be asking:

- *How long can I keep this up? (Ten weeks...ten months...ten years?)*
- *How do I know when my own health is being compromised?*
- *How can I overcome the daily isolation I feel?*
- *What should I do when I feel I can't keep going?*

The information in this section is useful for *all* caregivers—those currently providing care and those who want to plan for providing care in the future. In fact, many current caregivers say that they wish someone had told them to start preparing for eldercare *before* there was a crisis. You are a caregiver if you are a close family member (spouse, domestic partner, child, sibling, or relative), friend, or neighbor, and:

- You manage a variety of tasks, from personal care and managing the checkbook to taking blood pressure and giving medication
- You care for healthy elders or elders who are chronically or acutely ill
- You provide direct service and/or organize and monitor the care others provide
- You provide care in the home, hospital, rehab center, retirement community, nursing home, or other setting
- You provide help intermittently, regularly, and/or on a 24/7 basis
- You live with or near, or far away from the elder you care for

## Why Caregivers Need Care

Some people who provide care for an elder do not realize that everything they do is part of caregiving. They may say, “This is just what families do for each other,” or “This is what friends are for.” However true these statements are, they tend to mask the value of the care (for the elder and the community at large) and the significant toll that this work can take.

For many caregivers, the errands, tasks, and daily care they provide are rewarding and based on feelings of love and attachment to the person they are caring for. For most elders, the care they receive enhances their health and well-being and brings comfort, companionship, practical help, and safety. [The Joys of Caregiving](#) outlines some of the benefits caregivers experience.

However, caring for elders can be very stressful, physically and psychologically. Taking on the responsibility for someone else’s affairs, dealing with doctors and insurance companies, finding appropriate and affordable resources, and attending to daily meals, dressing, bathing, or even just providing company can be time-consuming, exhausting, and challenging. Elders may make your job as a caregiver more difficult by being uncooperative, demanding, or bad-tempered. Their frustration, sadness, and fears about being ill, dependent on you for care, or otherwise impaired, may be expressed as anger, irritability, or anxiety.

Caregiving can involve considerable sacrifice on the part of caregivers. Some have to take a leave from work. Some retire early. Others feel constant conflicts between job responsibilities and the demands of caring for family at home. Many baby boomers are now part of the “sandwich” generation—caught between caring for young children and aging parents—and find the demands of both overwhelming.

Caring for an elder can be a very isolating experience, especially for those who have limited help or are the sole caregiver for an elder who cannot be left alone for long periods of time. But you are not alone. There *are* support systems to help you meet the challenges of providing eldercare—short-term or long-term.

## Learning Caregiving Skills

Once you learn about your role as a caregiver, you will be better equipped to face the current and future needs of caring for the elder in your life. Two helpful publications are the following:

- **Because We Care** at [www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking\\_care\\_of\\_others/wecare/wecare.asp](http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_others/wecare/wecare.asp) from the U.S. Administration on Aging, introduces families to their new role as caregivers.
- **Eldercare at Home** at [www.healthinaging.org/public\\_education/eldercare/2.xml](http://www.healthinaging.org/public_education/eldercare/2.xml), published by the American Geriatrics Society, is written for family caregivers and explains how to communicate effectively with doctors and other professionals as part of a caregiving support team, as well as how to care for yourself. (See also the Health Care section.)

## New Skills

Caregivers need more than information. You may need to learn new healthcare-related skills. As hospitals and rehab facilities shorten the length of patient stays, families are asked to provide more direct care for elders. Families may be expected to keep wounds clean, give medications, administer CPR, or monitor heart and blood sugar levels, but often they are not given the training they need to provide this care effectively.

These two organizations provide training and courses for caregivers:

- The **American Red Cross** at [www.redcross.org/](http://www.redcross.org/) has courses in first aid that give hands-on training on how to recognize and respond to emergencies, how to perform CPR, and how to use automated external defibrillators (AEDs) to save victims of sudden cardiac arrest. Visit the Web site and enter your Zip Code to find classes near you.
- **Visiting Nurse Association of America** (VNA) at [www.vnaa.org/vnaa/gen/html~home.aspx](http://www.vnaa.org/vnaa/gen/html~home.aspx) provides in-home training for caregivers about wound care, nutrition, diabetes, asthma, and other topics by registered nurses. To find a VNA near you, visit the Web site and enter your city, state, or Zip Code.

Many organizations related to specific diseases (cancer, diabetes, Alzheimer's, etc.) provide education and training on various aspects of caring for elders with those conditions.

## Collecting and Organizing Information

Caregivers need to know how to collect and organize many details about their elder's health care, home care, medications, safety equipment, and so on. These records are vital but difficult to keep track of. "The Caregiver's Organizer" at [www.seniorconnection.org/caregiversupport.htm](http://www.seniorconnection.org/caregiversupport.htm), developed by the Central Massachusetts Family Caregiver Support Program, can be downloaded from its Web site in ten different languages. Click on "Services and Resources Provided," then "The Caregiver's Organizer." See also the Finances and Health Care sections.

## Support Groups and Services

The challenges of caring for elders can result in caregivers ignoring their own physical and emotional health. Caregivers often don't recognize the symptoms of stress that they are experiencing. For a simple self-test, see the American Medical Association's **Caregiver Self-assessment Questionnaire**. If you take the test and find you do have a number of symptoms associated with high levels of physical and emotional stress, contact your primary care doctor for an appointment, take the questionnaire with you, and discuss next steps, such as finding a therapist or support group, or taking medication.

You may also want to talk with your clergyperson, a trusted friend, or a close family member. Securing support from other family members, friends, and community groups is essential. It may be hard to ask for and/or accept help, but you cannot do it all alone. Think in terms of concrete actions that can help. Could a friend pick up groceries for you or the elder? Could a neighbor do yard work for you or give you a lift to the doctor's? Could a friend or relative keep the elder company so that you can take a break—go to a movie, the gym, take a walk or a drive, or do some shopping for yourself? Perhaps you could set up a regular visit from a friend (yours or the elder's) so that you don't feel so isolated or overloaded. You may not be able to reciprocate, but don't worry. The people who care about you want to help, and you may be able to return the help at a later time.

You may feel that you are the only one dealing with an elder who is demanding, difficult, or belligerent. You may feel sad that your elder is in need and confused about your new role as caregiver. You may also be dealing with siblings or other family members who criticize you or do not share in caring for the elder. Some caregivers find support groups helpful. They allow caregivers to share their experiences, exchange information, and point each other toward organizations that have been particularly helpful. Some support groups may be linked to stress management or exercise classes.

Support groups also encourage caregivers to care for themselves and help remind you that it is not selfish for caregivers to attend to their own needs. Many support groups are run by professionals, such as social workers, and can help caregivers devise productive strategies for dealing with intra-family conflicts or tensions that may arise around difficult caregiving decisions.

There are many organizations to help you find a support group suited to your needs. Some are organized around a particular city or region, while others are focused on the kind of illness an elder may have. Support groups can be in person or they can be online. There are also some health care providers that provide caregiver support groups. Call your doctor or your health insurance provider to get referrals to groups covered under your health plan.

One of the best ways to find support groups in your area is through the Family Caregiver Support Program in your state. Contact your local Area Agency on Aging (AAA) through the **Eldercare Locator** at [www.eldercare.gov/Eldercare/Public/Home.asp](http://www.eldercare.gov/Eldercare/Public/Home.asp), 800-677-1116 toll free.

### **The National Family Caregiver Support Program (NFCSP)**

The NFCSP is administered through the U.S. Administration on Aging (AoA) and its nationwide “aging network” made up of 56 state government agencies and 655 Area Agencies on Aging (AAAs), with more than 25,000 local community programs, such as senior centers and Councils on Aging (COAs).

The program targets two groups: adults who are caring for elders and the disabled, and grandparents who are caring for grandchildren. The information below focuses on eldercare services.

NFCSP primarily serves family caregivers of adults 60 years of age and older, and people of any age with a diagnosis of Alzheimer's. There are no income eligibility requirements for information or services. The overall goal of the program is to enhance the caregiver's ability to keep elders at home and in their communities, in a safe and supportive environment. Each program works to provide support in five key areas:

- 1 **Information** about available services, community resources, and local programs
- 2 **Assessment of needs and access to services** through one-on-one assistance to identify options and gain access to community-based services
- 3 **Training, support, and counseling**, such as caregiver support groups and training classes to assist caregivers in making decisions, solving problems, and managing stress
- 4 **Respite programs** to provide temporary relief through in-home care, or adult day care or emergency respite (see the Caring for the Caregiver section.)
- 5 **Supplemental services**, on a limited basis, for home modifications and repair, transportation, and other things it may be difficult for the caregiver to do

Within these five broad areas, each state program designs its own programs, publications, and resources. The NFCSP has made it a priority to provide caregiver support services and resources that are culturally and linguistically sensitive. AAAs and COAs have developed partnerships with organizations linked to specific ethnic and cultural groups. These partnerships make it possible to get publications translated into languages other than English and/or to have bilingual staff available to answer questions on the phone and link caregivers from diverse communities to the broad array of elder services and resources.

The NFCSP program gives priority to caregivers with the greatest social and economic need, but it is also open to middle-income families. There are no income-related eligibility criteria for adult day care and respite programs, although there are limited slots available in these programs. There are no eligibility criteria for case management services that are provided free for the first six months. Eldercare advisers offer an initial needs assessment free of charge. (Additional services may require a nominal fee.)

Each state has its own version of NFCSP. To see the profile of the Family Caregiver Support program in your state, go to the *National Conference of State Legislatures* Web site at [www.ncsl.org](http://www.ncsl.org). Click on "Bookstore," then "Browse," then "Family Caregiver Support" or call 202-619-0724. For a publication called "Family Caregiver Support: State Facts at a Glance," go to [www.aoa.gov/PROF/aoaprogram/caregiver/careprof/resources/fcs.pdf](http://www.aoa.gov/PROF/aoaprogram/caregiver/careprof/resources/fcs.pdf). (Note: This URL links to a large PDF file.) You can also contact your local Area Agency on Aging (AAA) through the **Eldercare Locator** at [www.eldercare.gov/Eldercare/Public/Home.asp](http://www.eldercare.gov/Eldercare/Public/Home.asp), 800-677-1116 toll free.

## Respite Services

Respite means “time off.” *Every* caregiver needs time off. Respite through substitute care can be provided on a regular basis, such as three days a week, or can be scheduled in advance when needed for vacations or special occasions.

### In-home Care

In-home care is provided by a companion who comes to the house. Usually this is done one or two times a week for four hours or less to provide companionship and supervision, but no personal care or household services. In-home care allows caregivers, especially full-time caregivers, to do errands, attend to personal business, socialize, and exercise. It can be arranged through your local AAA or from private service providers. Sometimes volunteers are available through a “Friendly Visitor Program” or local faith-based organizations.

### Out-of-home Care

Out-of-home programs offer a secure, friendly environment for elders and provide caregivers with respite. These services can be arranged through your local AAA or COA. There are several types of out-of-home care programs:

- **Social Day Care Groups** provide daytime supervision outside the home, usually with snacks or meals, along with recreational and social activities.
- **Adult Day Care Centers** provide recreational programs and meals for elders who need closer supervision, usually due to dementia or Alzheimer’s.
- **Adult Day Health Care** provides an organized program of health care, supervision, and social activities for elders who have health conditions that need to be monitored.
- **Emergency Relief Respite Programs** are available to caregivers who have a personal or medical emergency, such as a sudden illness or a funeral out-of-town. These programs usually utilize a room in a long-term care facility or rehabilitation center, and the elder is taken care of as if she or he were a resident in that facility.

Paying for respite services can be challenging. There is some funding for low-income caregivers available through Medicaid, and states are increasingly finding additional revenue sources to support moderate-income families. For information on services nationwide, visit the *National Respite Locator Service* at <http://chtop.org/ARCH/ARCH-National-Respite-Locator.html>, a free service that connects caregivers and respite programs in their own community or the community where the elder in their care resides.

## Combining Work and Caregiving

Combining a full-time job and eldercare creates special challenges. Check with your employer's Human Resources Department, if available, for information about employee assistance resources. Workplace support programs can assist you with local and long-distance caregiving in the following ways:

- **Information and referral services.** These I&R services can help caregivers with locating home care services, housing options, and long-term care facilities.
- **Flexible work arrangements.** You may be able to leave early or come in late, so that you can give an elder her or his medication, take her or him to doctor's appointments, and so on.
- **Short-term and long-term leaves.** You may be able to take a leave with job protection and continuation of benefits. Employed caregivers may be entitled to 12 weeks of leave to care for an elderly spouse or parent through the Family and Medical Leave Act (FMLA). Although this law only covers 55 percent of the workforce, FMLA provides unpaid leaves that are job-protected and ensure continuation of health benefits for those who are already covered.

For more detailed information on flexible work arrangements and your rights under the FMLA, and to find out if you have additional benefits under state law for family leave, contact the following organizations:

- **The Center for Aging and Work** at Boston College at [http://agingandwork.bc.edu/template\\_index](http://agingandwork.bc.edu/template_index) has resources and information on flexible work options that can help employees and employers address the issues created by caring for elders while working.
- **Labor Project for Working Families** at [www.working-families.org/](http://www.working-families.org/), 510-643-7088, is a national, nonprofit advocacy and policy organization providing technical assistance, resources, and education to unions and union members on family issues in the workplace.
- **U.S. Department of Labor, Wage and Hour Division** at [www.dol.gov/esa/whd](http://www.dol.gov/esa/whd), 866-487-9243 toll free, regulates the FMLA and advises employees on their rights under the law.

## More Caregiver Resources

There are many other resources for information, support, and more. The following organizations will help you cope with your role as a caregiver.

### National Organizations

- **AARP** at [www.aarp.org/learntech/family\\_care/](http://www.aarp.org/learntech/family_care/) has free online seminars for caregivers, such as "Managing Caregiving Details: The Basics" and "Planning for the Care of Aging Parents." Click on "Learning and Technology," then "Family Caregivers." For help with conversations with an elder who is too sick or frail to live independently, check out "Providing the Care."

- **Caring from a Distance** at [www.cfad.org](http://www.cfad.org) is a nonprofit organization geared specifically to the particular challenges faced by caregivers who live far away from the elder. It offers information, support, and helpful links.
- **Children of Aging Parents (CAPS)** at [www.caps4caregivers.org](http://www.caps4caregivers.org), 800-227-7294 toll free, offers caregiver support programs in 13 states for adult children caring for elderly parents.
- **Family Caregiver Alliance** at [www.caregiver.org/caregiver/jsp/home.jsp](http://www.caregiver.org/caregiver/jsp/home.jsp), 800-445-8106 toll free, is a national network that addresses the needs of families and friends providing long-term care at home. The Web site includes information, free publications, and an online caregiver support discussion group.
- **National Alliance for Caregiving** at [www.familycaregiving101.org/](http://www.familycaregiving101.org/) provides information for caregivers on how to take care of themselves while providing care. Click on “Family Caregiving 101.”
- **National Family Caregiver Support Program, U.S. Administration on Aging Resource Page** [www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp](http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp) provides links to government, nonprofit, and commercial caregiver Web sites. It also includes information and articles on a variety of topics. Call 202-619-0724 for a caregiver support program near you.
- **National Family Caregivers Association** at [www.thefamilycaregiver.org/](http://www.thefamilycaregiver.org/) provides useful tips and guides for all aspects of family caregiving.
- **Rosalynn Carter Institute for Caregiving** at [www.rosalynncarter.org](http://www.rosalynncarter.org) works to establish local, state, and national partnerships committed to building quality long-term care systems and providing greater recognition and support for caregivers. Visit the Web site for publications, workshops, and conferences.
- **Well Spouse Foundation** (also known as the Well Spouse Association) at [www.wellspouse.org/index.php?option=com\\_contxtd&Itemid=50](http://www.wellspouse.org/index.php?option=com_contxtd&Itemid=50), 800-838-0879, is a nonprofit organization providing support and other resources to husbands, wives, and partners of chronically ill or disabled individuals. Click on “About Us,” then “Join a Support Group,” and select your state to find a support group nearby.
- **Women’s Health Information Center** at [www.4woman.gov/faq/caregiver.htm](http://www.4woman.gov/faq/caregiver.htm), 800-994-9662 toll free, offers useful resources on topics that affect women caregivers. The Web site is part of the U.S. Department of Health and Human Services’ Office of Women’s Health.

### Faith-based Organizations

Faith-based organizations have a long tradition of providing assistance to those in need, whether they are members of that faith or not. Faith-based organizations coordinate volunteers to help and visit with the elderly and sponsor meal programs and other direct services at places

of worship. Many faith-based organizations run their own retirement communities and/or nursing homes. The following organizations are just a few examples of the kinds of services provided by faith-based organizations. Check with your clergy or religious affiliation for additional resources.

- **Association of Jewish Family and Children’s Agencies (AJFCA)** at [www.ajfca.org/elder.html](http://www.ajfca.org/elder.html), 800-634-7346 toll free, links concerned family members of frail elders living in distant cities, with Jewish Family Services Agencies in that community through its Elder Support Network.
- **Catholic Charities**, [www.catholiccharitiesusa.org/NetCommunity/Page.aspx?pid=292&srcid=777](http://www.catholiccharitiesusa.org/NetCommunity/Page.aspx?pid=292&srcid=777), 703-549-1390, provides social service programs that may include home visiting programs, adult day health, visiting nurse services, a foster grandparents program, caregiver support programs, and basic needs services (food, fuel, utility, and rental assistance). To find a chapter near you, visit the Web site and enter your state into the search box.
- **Faith in Action** at [www.fiavolunteers.org/](http://www.fiavolunteers.org/), 877-324-8411 toll free, provides volunteers who can give caregivers non-medical assistance, such as picking up groceries or running errands, friendly visiting, reading, or helping to pay bills.
- **Lutheran Services in America** at [www.lutheranservices.org](http://www.lutheranservices.org) has more than 300 health and human service organizations that provide care, ranging from health care to disaster response. Visit its Web site and click on “Find Services Near You,” then “Search by Service” (or Location or Organization name), and then “Aging Services,” to find 24 different services to help elders and their caregivers.

### Disease-specific Organizations

Sometimes the information caregivers need is specific to a particular disease or condition.

- **Alzheimer’s Association** at [www.alz.org/](http://www.alz.org/) has extensive information about Alzheimer’s disease, updates on research and treatments, training for caregivers and for people with dementia, and short-term counseling. Contact its 24/7 Helpline at 800-272-3900 for information, referral, and support.
- **American Cancer Society (ACS)** at [www.cancer.org/docroot/home/index.asp](http://www.cancer.org/docroot/home/index.asp) provides health information, support groups, and other resources for caregivers, including a caregiver discussion board. For your nearest ACS chapter, visit the Web site and click on “Find ACS in your Community,” then enter your Zip Code.
- **American Diabetes Association** at [www.diabetes.org/home.jsp](http://www.diabetes.org/home.jsp) provides diabetes research, information, and advocacy. For information about caregiver support groups and other resources in your area, visit the Web site and click on “In Your Area,” then enter your Zip Code, then “Find a Recognized Education Program.”

- The **American Heart Association** at [www.americanheart.org/](http://www.americanheart.org/) provides information and resources for consumers, as well as information specifically designed for caregivers at [www.americanheart.org](http://www.americanheart.org). Click on “Diseases and Conditions,” and then on “Caregivers.”
- **The American Stroke Association** at [www.strokeassociation.org/presenter.jhtml?identifier=1200037](http://www.strokeassociation.org/presenter.jhtml?identifier=1200037) provides outreach to stroke survivors and their caregivers through a national call center, 888-4-STROKE (888-478-7653) toll free. To reach the support group registry, visit the Web site and click on “Life after Stroke,” then “For Family Caregivers,” then “Getting Support,” then “Support Groups,” then “More.” The locator will help you find the chapter nearest you.
- The **Arthritis Foundation** at [www.arthritis.org/](http://www.arthritis.org/), 800-283-7800 toll free, offers resources in English and Spanish, including detailed information about arthritis, drug treatments and pain management, as well as help lines and message boards.
- **Compassionate Care ALS** at [www.ccals.org](http://www.ccals.org) provides educational and legal resources, respite opportunities, instruction and guidance, subsidies for assistance, and conversations with ALS patients and their caregivers, families, and friends.
- **COPD-Support, Inc.** at [www.copd-support.com/](http://www.copd-support.com/) provides information on organizations, support groups, and online meeting places for patients with emphysema, chronic bronchitis, and chronic asthma, and their caregivers.
- **The Leukemia and Lymphoma Society** at [www.leukemia-lymphoma.org/hm\\_lls](http://www.leukemia-lymphoma.org/hm_lls), 800-955-4572 toll free, provides information on the diseases and both online and in-person group support for caregivers. Visit its Web site and click on “Chapter Finder,” then enter your Zip Code.
- The **National Multiple Sclerosis Society** at [www.nationalmssociety.org/site/PageServer?pagename=hom\\_gen\\_homepage](http://www.nationalmssociety.org/site/PageServer?pagename=hom_gen_homepage), 800-344-4867 toll free, has a useful Web site that includes publications for caregivers.
- **National Parkinson Foundation** at [www.parkinson.org/NETCOMMUNITY/Page.aspx?pid=214&srcid=201](http://www.parkinson.org/NETCOMMUNITY/Page.aspx?pid=214&srcid=201) supports related research, patient care, education, training, and outreach. Support groups are listed on its Web site.
- **The Wellness Community** at [www.thewellnesscommunity.org/support/](http://www.thewellnesscommunity.org/support/), 888-793-WELL (888-793-9355) toll free, provides support for cancer patients and their caregivers, and has online and in-person support groups in Spanish and English.



**Activities of Daily Living (ADL)**—The self-care tasks, which are used to measure the Functional Impairment Level of an applicant or a client for home care services, include the ability to bathe, dress and undress, eat, toilet, transfer in and out of a bed or chair, get around inside one's own home, and maintain continence. Also see Instrumental Activities of Daily Living. (IADL).

**Administration on Aging (AoA)**—The principal federal agency responsible for administering the provisions of the Older Americans Act, except Title V. It advocates for the needs, concerns, and interests of elders, nationwide, and is housed within the Department of Health and Human Services (DHHS).

**Adult Day Care**—A community-based group program designed to meet the needs of functionally impaired elders and other adults who can benefit from participating in group settings. Most programs include an individualized plan of care, group exercise, adult education classes and recreation, nutritious meals, and social work services. In addition, these programs make respite for caregivers possible and provide support groups for participants and caregivers.

**Adult Day Health Care**—A community-based program similar to adult day care but designed for elders and persons with disabilities who need a higher level of care, but can still benefit from receiving services in a group setting. In addition to the services of an Adult Day Care program, other services include physical, occupational, and speech therapies; nursing supervision; monitoring of vital signs, blood glucose, blood pressure, and medications; assistance with bathroom visits; dietary counseling and supervision; psychological counseling; and an Individualized Plan of Care. All services are supervised by trained geriatric specialists.

**Adult Foster Care**—See Group Adult Foster Care (GAFC).

**Adult Protective Services (APS)**—A federal program provided in every state to ensure the safety and well-being of elders (and adults with disabilities) who are in danger of being mistreated or neglected, are unable to take care of themselves or protect themselves from harm, and have no one to assist them.

**Advance Directive**—A document, such as a health care proxy or living will, which allows an individual to convey his or her wishes about end-of-life care ahead of time. Advance directives are not legally binding unless they comply with state law. For legal documents, also see Health Care Agent and Health Care Power of Attorney, or Proxy.

**AMI** —See Area Mean Income.

**Appeal**—A special kind of complaint made if you disagree with a Medicare coverage decision, including: a denial for a request for health care services, a billing for services you already received, or a dispute with a decision to stop services that you are receiving. There is a specific process used by your Medicare health plan for an appeal.

**Area Agency on Aging (AAA)**—Agencies established under federal law, the Older Americans Act (OAA), to respond to the needs of Americans age 60 and over in every local community, with the goal of keeping seniors living independently in their own homes. AAAs plan and provide social services and nutrition services for elders and support for caregivers.

**Area Mean Income (AMI)**—A statistical table of income levels by states, metropolitan areas and counties published by the Department of Housing and Urban Development (HUD) to determine eligibility for loans and housing support.

**Assignment**—A system under Medicare in which doctors and health care equipment and supplies companies agree to accept the Medicare-approved payment amount. When doctors and suppliers agree, they accept assignment. A patient’s co-payment still applies.

**Assisted Living Facility (ALF) or Assisted Living Residence (ALR)**—A facility that combines housing and supportive services for elders. Services include assistance with personal care, such as medication management, bathing, dressing, and ambulating, and may include laundry, housekeeping, transportation, and social activities.

**Assistive Technology**—Products, devices, or equipment used by individuals with disabilities to maintain, increase, or improve their functional capabilities. Assistive technology can include mobility devices such as walkers and wheelchairs, as well as hardware, software, and peripherals that assist people with disabilities in accessing computers or other information technologies.

**Caregiver**—A person who helps care for someone who is ill, disabled, or aged. Caregivers can be paid or unpaid. See also Family Caregiver.

**Care Plan**—A “road map” to guide the team of professionals involved in a person’s care. Care plans start with an assessment, outline treatments or services needed, and list the expected outcomes or goals. Social workers develop care plans for home care services; nursing staff also develop care plans for patients in hospitals or skilled nursing facilities. See also Geriatric Care Manager.

**CARF Accredited**—A rehabilitation facility that has been chosen to be reviewed by the Commission on the Accreditation of Rehabilitation Facilities (CARF), an independent accreditation agency, and has been found to be in compliance with CARF quality standards.

**Case Management**—See Geriatric Care Manager.

**Certified Home Health Agency (CHHA)**—A home health agency that meets Medicaid and Medicare requirements and standards for the provision of nursing care, rehabilitation therapies, and the service of home health aides.

**Certified Nursing Assistant (CNA)**—A professional who is trained and certified to help nurses by providing nonmedical assistance to patients, such as help with bathing, dressing, and using the bathroom.

**CHAMPUS** (Civilian Health and Medical Program of the Uniformed Services)—Auxiliary medical services for active military/veterans and their dependents.

**Chore Services**—A type of home care service to assist frail elders, including vacuuming, washing floors and walls, defrosting freezers, cleaning ovens, cleaning attics and basements, and removing fire and health hazards.

**COBRA** (Consolidated Omnibus Budget Reconciliation Act)—A federal law requiring employers to offer time-limited cash-premium health insurance to employees who will lose their insurance because of termination. If you were an active participant in your employer's health plan prior to your departure date, you can continue the health insurance that you and your family received for up to 18 months.

**Comfort Care Order**—See DNR/DNI Order.

**Companions**—People provided by home care agencies who regularly visit frail elders and provide socialization, medical escort, errand service, light meal preparation, as well as respite or temporary relief to family caregivers.

**Congregate Housing**—A shared living arrangement that allows elders to maintain their privacy and independence in a homelike setting with supportive services.

**Congregate Living Facility**—A noninstitutional, independent group living environment that integrates shelter and service needs of functionally impaired and/or socially isolated elders who do not need institutional supervision and/or intensive health care.

**Congregate Meals**—A program, funded under Title 111-C of the Older Americans Act, providing one meal a day (usually lunch) at senior centers, churches, and other community sites.

**Conservatorship**—Legal process in which a probate court appoints one or more persons to handle the financial affairs of a person the court determines to be incompetent or otherwise unable to handle her or his own finances.

**Continuing Care Retirement Communities (CCRCs)**—An alternative housing option designed to accommodate the needs of elders. CCRCs offer a full continuum of care, ranging from fully independent units to assistance with personal care in assisted living apartments to long-term care in a skilled nursing facility.

**Co-payment**—In some health care plans, the amount you pay for each medical service, like a doctor’s visit or a prescription. A co-payment is usually a set amount, such as \$10 or \$20. Co-payments are also used for some hospital outpatient services in the Original Medicare Plan.

**Council on Aging (COA)**—A municipally appointed agency that provides services to elders, families, and caregivers. While each is unique to its community, most COAs offer information and referral, transportation, outreach, meals (congregate and home delivered), health screening, and fitness and recreation programs.

**Custodial Care**—Nonskilled, personal care, such as help with activities of daily living like bathing, dressing, eating, getting in and out of bed, moving around, and using the bathroom. It may also include care that people do themselves, such as using eyedrops. Medicare does not pay for custodial care.

**Dementia**—A progressive decline of cognitive function, such as memory, concentration, and judgment, due to damage or disease of the brain beyond the natural process of aging. It is sometimes accompanied by emotional disturbance and personality changes.

**DNR/DNI Order** (Do Not Resuscitate/Do Not Intubate Order, also known as a “Comfort Care Order”)—An individual’s instructions that he or she does not wish cardiopulmonary resuscitation or a tube to provide mechanical breathing assistance. A DNR or DNI informs medical personnel, including EMTs and paramedics, to provide care without artificial means to maintain heart function and breathing.

**Durable Medical Equipment (DME)**—Medical equipment that is ordered by a doctor for use in the home. These items must be reusable, such as walkers, wheelchairs, or hospital beds. DME is paid for either under Medicare Part A or Part B for home health services.

**Durable Power of Attorney**—A document that grants a person(s) the legal powers to perform on behalf of the grantor certain specified acts and functions, related to real estate, banking and financial transactions, personal and family maintenance, and government benefits, among others. This power is effective immediately and continues to be effective once the grantor becomes disabled or incompetent.

**Elder Abuse Prevention Programs**—Programs, such as adult protection and guardianship/conservatorship, designed to alleviate situations of abuse, neglect, or self-neglect.

**Emergency Response Systems**—See Personal Emergency Response Systems.

**End-stage Renal Disease (ESRD)**—Permanent kidney failure that requires a regular course of dialysis or a kidney transplant.

**Enrollment Period**—A certain period of time when you can join a Medicare health plan, if it is open and accepting new Medicare members. There are four periods during which you can enroll in Medicare Part A: Initial Enrollment Period (IEP), which starts three months before you are age 65 and seven months afterward; General Enrollment Period (GEP), which is the first three months of each year; Special Enrollment Period (SEP) for people who did not sign up when they were 65; and Transfer Enrollment Period (TEP) for those who only have Part B and enrolled in a Medicare managed care plan.

**Escort Services (Escorted Transportation)**—A service that provides either group transportation or individual escorts to take seniors to medical appointments, shopping, errands, banks, government offices, hospitals to visit friends and family, and on recreational or cultural outings.

**Executor**—A person appointed in a will to handle the probate of a deceased person's estate and the instructions stated in the will.

**Family Caregiver**—A relative or a friend who helps care directly for someone who is ill, disabled, or aged, or organizes and monitors the care others provide in the home or in institutions, such as hospitals or nursing homes. Family caregivers may live with or near the elder they are caring for, or live far away, and provide help intermittently, regularly, and/or on a 24/7 basis. Some family caregivers are compensated for their work; most are not.

**Family Caregiver Support Program**—A national program created by a 2000 amendment of the Older Americans Act. It provides information and referrals, training, counseling, support groups, respite care options, and other services to family caregivers.

**Family Medical Leave Act (FMLA)**—A federal law that provides caregivers up to 12 weeks of job-protected leave to care for a seriously ill parent, child, or spouse (also covers leave for one's own serious illness, a birth, or an adoption). Workers are eligible if they work for firms with 50 or more employees, have at least one year of continuous employment, and have worked at least 1,250 hours in the 12 months prior to leave. There is no wage replacement available with this leave.

**Friendly Visitor**—A volunteer who visits isolated elders in their homes up to one or two hours per week, usually arranged by a home care agency.

**Gateway Organization**—An agency or organization that provides eldercare information and programs and is a key way for elders and caregivers to access additional elder care resources and service providers. As used in this Handbook, key gateway organizations include the U.S. Agencies on Aging (AAAs), the State Units on Aging (SUAs), and local Councils on Aging (COAs).

**Geriatric Care Manager**—A professional case manager, usually a licensed social worker, who assesses an elder’s ability to live independently in a home environment, develops an appropriate care plan for services and equipment, and organizes needed home care services. This person may monitor and augment services on an ongoing basis, or troubleshoot as particular problems arise.

**Geriatric Medicine**—A subspecialty of internal medicine or family medicine focused on the clinical care of elders.

**Gerontologist**—A health care professional who specializes in eldercare, with a degree in nursing, psychology, sociology, or other social-related professions. An applied gerontologist works directly with elders, evaluating and assisting individuals, families, and groups. A research gerontologist is a scientist who conducts research on the biological, psychological, and sociological phenomena associated with old age and aging.

**Group Adult Foster Care (GAFC)**—A Medicaid waiver program adopted in several states that pays for personal care services for eligible seniors and adults with disabilities who live in GAFC-approved housing. Housing may be an assisted living residence or specially designated public or subsidized housing.

**Guardianship**—A legal process by which a probate court appoints one or more individuals to handle the personal and financial affairs of a minor or person of any age the court determines to be mentally incompetent.

**HCBS Waivers (Home and Community-based Services)**—Medicaid services offered by a state plan to support a person so that he or she can live independently at home, rather than in a nursing home. Sometimes called 1915(c) waivers.

**Health Care Agent or Proxy**—A person designated in a legal document to act in your place should you become unable to make or communicate decisions regarding health care treatment.

**Health Care Power of Attorney or Proxy**—A document legally authorized by a competent person designating another person to act as his or her health care agent with the authority to make all health care decisions (unless specifically limited) for the grantor should he or she become unable to make or communicate those decisions.

**Health Maintenance Organization (HMO)**—A group health insurance plan that entitles members to services of participating physicians, hospitals, and clinics. Coverage for services must be cleared by the HMO, and a primary care physician (PCP) within the HMO handles referrals. Members of the HMO pay a fee for coverage as well as small additional co-payments for outpatient visits and prescription drugs. There are HMO programs for Medicare-eligible patients. (See Medicare.)

**HIPAA (Health Insurance Portability and Accountability Act)**—A federal law that ensures privacy provisions for health information and sets rules and limits on who can see an individual's health information. The law must be followed by health care providers and institutions, and certain government programs that pay for health care, such as Medicare and Medicaid. Medical records, insurance records, and billing records are protected.

**Home Health Agency (HHA)**—A public or private agency that specializes in providing skilled nursing services, home health aides, and other therapeutic services, such as physical therapy, in the home.

**Home Health Care**—Health care services provided in the home on a part-time basis for the treatment of an illness or injury, and covered by Medicare only if skilled care is needed and required on an intermittent or part-time basis.

**Home Monitoring System**—An electronic system designed to alert a caregiver when an elder, wearing a transmitting device, enters the zone near a monitored door or goes beyond a designated footage outside the home. These systems can be rented or purchased and are useful for conditions, such as Alzheimer's disease, that cause disorientation or restlessness.

**Homemaker Services**—Assistance in home management, including light housekeeping, laundry, grocery shopping, and meal preparation, provided by trained personnel working under home care agency supervision.

**Hospice**—A public or private organization that provides pain relief, symptom management, and supportive services to terminally ill people and their families in the home or in a separate hospice facility.

**Hospitalist**—Physicians trained and board certified in internal medicine who specialize in the care of hospitalized patients. Hospitalists serve as the “physicians of record” for patients while they are being treated in the hospital. The hospitalist returns the patient to the care of his or her primary care physician at the time of hospital discharge.

**Independent Living Units**—Housing units that include some basic services such as meals and housekeeping, usually for a fee. These units may exist in a Continuous Care Retirement Community (CCRC) that also has assisted living units and a skilled nursing facility.

**In-home Services**—Services provided under the federal Older Americans Act by all Area Agencies on Aging (AAA). They include homemaker and home health aide services, in-person and telephone reassurance, chore maintenance, in-home respite care (including adult day care) and minor home modifications.

**Initial Enrollment Period**—See Enrollment Periods.

**Instrumental Activities of Daily Living (IADL)**—The six daily tasks (light housework, preparing meals, taking medications, shopping for groceries or clothes, using the telephone, and managing money) that enable the patient to live independently in the community. (See also ADL, Activities of Daily Living.)

**Intermediate Care Facility (ICF)**—A nursing home which provides health-related services to individuals who do not require the degree of care or treatment given in a hospital or skilled nursing facility, but who (because of their mental or physical condition) require care and services which are greater than custodial care and can only be provided in an institutional setting.

**JCAHO Accreditation**—Indicates that a facility, like a hospital, has voluntarily chosen to be reviewed by the Joint Commission on the Accreditation of Health Care Organizations (JCAHO), a private accreditation agency, and has been found to be in compliance with JCAHO quality standards.

**Legal Services Programs for the Elderly**—Programs providing free legal assistance, counseling, and representation in civil matters by an attorney, or other person under the supervision of an attorney, to people age 60 and older, prioritizing those elders in the greatest economic and social need.

**Levels of Care in Nursing Facilities**—Although the federal government has eliminated all references to and makes no distinction regarding levels of care, some states still utilize level of care classifications for the sole purpose of licensing long-term care facilities. Multilevel facilities may maintain graduated levels-of-care up to or including skilled nursing services.

Level I and Level II, financed by Medicaid or private payment, provide 24-hour skilled nursing services as well as restorative and other therapeutic services. Many specialize in areas such as rehabilitation.

Levels III and IV include nursing homes and retirement homes. Services range from routine nursing care to assistance with activities of daily living or supervised care for persons who do not require nursing or medical services. Most retirement homes (Level IV) provide residential rather than nursing care.

**Life Line**—A personal emergency alert system or alarm; also a trademarked name for the company that provides them.

**Limited Medication Administration**—An optional service in assisted living residences that allows a family member or licensed practitioner to administer medication to a resident.

**Living Will**—A set of instructions documenting a person’s wishes about medical care intended to sustain life. It is used if a patient becomes terminally ill, incapacitated, or unable to communicate or make decisions. Some states do not recognize a Living Will as binding on medical personnel. However, documents used to prepare a living will provide information that can convey the individual’s intent, and facilitate instructions to the designated agent in a health care agent or proxy. (See Health Care Agent.)

**Local Match**—The funds that a program must raise in order to qualify for and receive funding from various federal or state programs.

**Long-term Care Insurance**—An insurance policy designed to alleviate some of the costs associated with nursing home and/or home health care for persons who become unable to care for themselves independently. Most policies provide coverage for a specified number of years or may offer lifetime coverage. The cost of policies varies in relation to the age of the individuals at purchase, the conditions and services covered, and the amount and length of coverage.

**Long-term Care Ombudsman**—An independent advocate (supporter) for residents of nursing homes and assisted living facilities who works to solve problems between residents and management regarding health, safety, welfare, and human rights. They may also be able to provide information about home health agencies in their area.

**Meals on Wheels (MOW)**—A service that provides home-delivered meals to elder and disabled citizens without regard to income. It is funded through a combination of federal funds through Title III C of the Older Americans Act and state funds. There are also private-pay programs that deliver meals at home to offer more variety or meals on days not covered by benefit programs, such as weekends, in some cases.

**Medicaid**—The government health insurance program for low-income people of all ages. It is financed by the federal and state governments and is the primary means of payment for nursing home services in the United States and, increasingly, in-home care services.

**Medicare**—Title XVIII of the Social Security Act provides for a federal health insurance program for people 65 years of age or older, certain younger people with disabilities, and people with End-Stage Renal Disease (permanent kidney failure with dialysis or a transplant).

**Medicare Advantage Plan**—A Medicare program that gives you more choices among health plans. With few exceptions, everyone with Medicare Plans A and B is eligible. Medicare Advantage Plans used to be called Medicare + Choice Plans. They include Medicare Managed Care Plans, Medicare Preferred Provider Organizations, and Medicare Private Fee-for-Service Plans.

**Medicare-approved Amount**—The fee Medicare sets for a covered medical service. This is the amount a doctor or supplier is paid by you and Medicare for a service or supply. It may be less than the actual amount charged by a doctor or supplier. The approved amount is sometimes called the “Approved Charge.”

**Medicare Health Plan**—A Medicare Advantage Plan (such as an HMO, PPO, or private fee-for-service plan) or other plan such as a Medicare Cost Plan. Everyone who has Medicare Part A and Part B is eligible for a plan in their area, except those who have end-stage renal disease (unless certain exceptions apply).

**Medicare Managed Care Plan**—These are health care choices in some areas of the country. In most plans, you can only go to doctors, specialists, or hospitals on the plan’s list. Plans must cover all Medicare Part A and Part B health care. Some plans cover extras, like prescription drugs. Your costs may be lower than in the Original Medicare Plan.

**Medicare Part A**—Hospital insurance for those 65 and older, primarily provides coverage for inpatient hospital care, skilled nursing home, home health, and hospice care.

**Medicare Part B**—Medical insurance for those 65 and older, provides limited coverage for outpatient physician services, ambulance use, durable medical equipment, and home health care services.

**Medicare Part C**—See Medicare Advantage Plan.

**Medicare Part D**—See Medicare Prescription Advantage Program.

**Medicare Preferred Provider Organization (PPO)**—A type of Medicare Advantage Plan in which you use doctors, hospitals, and providers that belong to the plan’s list (network). You can use doctors, hospitals, and providers outside of the network for additional cost.

**Medicare Prescription Advantage Program**—Coverage available to people with Medicare that began January 1, 2006. Medicare provides prescription drug coverage through insurance companies and other private companies who offer different plans, with different covered prescriptions and co-payments. Medicare prescription drug plans require you to pay a regular monthly premium, a yearly deductible, and a share of the cost of your prescriptions.

**Medicare Private Fee-for-Service Plan**—A private insurance plan that accepts people with Medicare. You may go to any Medicare-approved doctor or hospital that accepts the plan's payment. The insurance plan, rather than the Medicare program, decides how much it will pay for the services you get. You may pay more for Medicare-covered benefits, or you may have extra benefits the Original Medicare Plan doesn't cover.

**Medigap**—A type of health insurance elders can purchase to supplement their health benefits under Medicare and bridge the gap between what Medicare pays and what clinical care and prescription drugs actually cost.

**NORC (Naturally Occurring Retirement Communities)**—A building, group of buildings, or geographic area where there is a high concentration of people 65 and over because the residents have remained in their homes over multiple decades. Also refers to an initiative for connecting elders who are clustered together to community-based eldercare services and health programs while remaining in their own homes.

**Nursing Facility**—A Medicaid-certified nursing facility.

**Nursing Home**—A term used to cover a wide range of institutions providing 24/7 personal care and skilled nursing care, also called Skilled Nursing Facilities, Intermediate Care Facilities and Custodial Care Facilities. Not all nursing homes are Medicare- approved/certified facilities.

**Nursing Home Screening**—A procedure to determine if a person entering a Skilled Nursing Facility or participating in an Adult Day Health Program meets Medicaid guidelines.

**Occupational Therapy**—A form of therapy that helps people improve basic motor functions and reasoning and their ability to perform tasks in their daily living and working environments. Services are often given to help people return to usual activities (such as bathing, preparing meals, and housekeeping) after illness.

**Ombudsman (ombudsperson)**—A person who advocates on behalf of others. In this context, a long-term care ombudsman advocates for residents in an assisted living facility or health care institution. This person receives, investigates, and resolves complaints against the residential facility or health care institution involving the safety, health, welfare, and rights of the elderly residents and patients.

**Original Medicare Plan**—A fee-for-service health plan that lets you go to any doctor, hospital, or other health care provider who accepts Medicare. You must pay the deductible. Medicare pays its share of the Medicare-approved amount, and you pay your share (co-insurance). The Original Medicare Plan has two parts: Part A (hospital insurance) and Part B (medical insurance).

**PACE** (Program of All-inclusive Care for the Elderly)—A program that provides low-income frail elders with all of their health, medical, rehabilitation, social, and support services and health insurance for one monthly fee. It enables them to remain independent in their community and in their own homes. PACE programs are available in some, but not all, states.

**Palliative Care**—Any form of medical care or treatment that concentrates on reducing pain and/or the severity of the symptoms of a disease, or slowing the disease’s progress, rather than providing a cure.

**Paratransit**—A type of transportation for people whose physical condition restricts their use of regular public transit systems. Services are provided by lift-equipped vans and shuttles that can be scheduled as needed for pick-ups and drop-offs. This is also known as “demand responsive transportation.”

**PDF** (Portable Document Format)—A file format used to create copies of documents that can be read, copied, or printed by any computer with Adobe Reader software installed (available free on the Internet.) PDFs allow you to share and/or download pages containing text, graphics, and photos, but the document cannot be modified.

**Primary Care Physician** (PCP)—A doctor who provides continuing care of varied medical conditions, not limited by cause, organ system, or diagnosis. A PCP generally does not specialize in the treatment of specific organ systems, such as cardiology, nor perform surgery. The term is often used by Health Maintenance Organizations (HMOs) to describe the physician who manages treatment for HMO members and provides referrals to specialized care and services.

**Personal Care Attendant** (PCA)—A person trained to provide assistance with the personal care activities of daily living, such as bathing, shampooing, personal hygiene, and medication reminders, usually arranged by a home care agency and paid by the hour.

**Personal Care Services**—Services that provide assistance with one or more activities of daily living either through physical support or supervision. These services are not routinely paid for by either Medicare or Medicaid.

**Personal Emergency Response Systems** (PERS)—A medical communications alerting system that allows an elder experiencing a medical emergency at home to access medical service via an electronic transmitter to a central monitoring station.

**Physical Therapy**—A form of therapy that helps restore function, improve mobility, relieve pain, and prevent or limit permanent physical disabilities of patients suffering from injuries or disease. Treatments of the patient’s illness or injury are made using mechanical means, such as heat, light, exercise, and massage.

**Prescription Advantage**—A Medicare program that provides insurance to cover prescription costs. Premiums, deductibles, and co-payments are required and vary by income and marital status.

**Probate**—A legal proceeding defined by state law in which the court determines the validity of a decedent’s will and the correctness with which the provisions of the will are carried out.

**Provider**—A health care professional or health care facility that provides care to patients, including those in hospitals, rehabilitation facilities, and outpatient settings

**Qualified Medicare Beneficiary Program (QMBs)**—A federally required medical assistance program administered by Medicaid which pays the Medicare premiums, deductibles, and co-payments for certain Medicare recipients whose assets are limited and whose income falls at or below the federal poverty level.

**Quality Improvement Organization**—Groups of practicing doctors and other health care experts that are paid by the federal government to check and improve the care given to Medicare patients. They must review complaints about the quality of care given by inpatient hospitals, hospital outpatient departments, hospital emergency rooms, skilled nursing facilities, home health agencies, private fee-for-service plans, and ambulatory surgical centers.

**Rehabilitation**—Services and therapies needed by people who have sustained severe injury, often as a result of trauma, stroke, infection, tumor, surgery, or a progressive disease.

**Regional Home Health Intermediary**—A private company that Medicare contracts to review the billing, pay providers, and check on the quality of home health care.

**Respite Care**—Temporary care service to relieve an in-home caregiver of responsibility for an individual with long-term care needs. Relief care can be provided in the home, in day programs, nursing facilities, rest homes, or an Adult Foster Care program.

**Rest Home**—A facility providing custodial care. Services provided in these facilities are more residential than medically oriented. They include protective supervision for the residents, as well as room, board, social activities and limited social services.

**Restraints**—Restraints can be physical or chemical. Physical restraints are any manual method, device, material, or equipment attached to or adjacent to an individual which restricts freedom of movement or normal access to one’s body, and can’t be easily removed. Chemical restraints are any drugs used for discipline or convenience and not required to treat medical symptoms. A term used in elder abuse cases.

**Reverse Mortgage**—A special type of home loan that allows homeowners to convert a portion of their home equity into cash. The U.S. Department of Housing and Urban Development (HUD) offers a federally insured reverse mortgage loan plan that enhances financial security and allows elders to stay in their own homes and pay for needed home modifications and/or home care services.

**Section 8 Housing**—An affordable housing assistance program offered by the U.S. Department of Housing and Urban Development (HUD), either as rental vouchers or as a “project-based Section 8,” which pertains to a specific building. In some cases, vouchers may apply to assisted living facilities.

**Self-administered Medication Management**—A program in certified assisted living residences that enables frail elders to take their own medications. Trained practitioners remind patients to take medication, check the medication package, verify the resident’s name on the package, observe the resident while they take the medication, and document their observations.

**Senior Companions**—Senior Corps volunteers who are assigned to provide company and supervision to handicapped or socially isolated elder people, and to provide relief to family members with dependent elders. Senior Corps is a division of the Corporation for National and Community Service.

**Skilled Nursing Care**—Services that can only be performed safely and correctly by a licensed nurse (either a registered nurse or a licensed practical nurse). Examples of skilled nursing facility care include intravenous injections and physical therapy. The need for custodial care does not, in itself, qualify for Medicare. If you qualify for coverage based on a need for skilled nursing, however, Medicare will cover short-term skilled nursing care, including personal care assistance with activities of daily living.

**Skilled Nursing Facility (SNF)**—A nursing facility with the staff and equipment to give skilled nursing care and/or skilled rehabilitation services and other related health services. SNFs are often used in short-term rehabilitation after hospital discharge, which is covered by Medicare. Long-term care in an SNF must be covered by private payment or Medicaid, if the elder meets eligibility requirements.

**Sliding Fee**—A fee that fluctuates according to the income of the person receiving the service. This term is applied to certain home care services and may be applied to other eldercare services.

**Social Day Care (SDC)**—See Adult Day Care.

**Social Security Disability Income** (SSDI or SSI, Supplemental Security Income)—A monetary benefit paid through Social Security to persons under age 65 with disabilities. SSI provides funds for eligible residents to help pay for certified assisted living. It can be combined with Medicaid subsidy for those financially and clinically eligible.

**Special Care**—A unit on a special floor or wing of a long-term care facility designed for those with Alzheimer’s disease, dementia, and other related brain disorders.

**Speech-Language Therapy**—Treatment to regain and strengthen speech skills from stroke, dementia, Parkinson’s disease or multiple sclerosis; cognitive and memory problems with speaking and listening, voice disorders, speech disorders, and swallowing disorders (dysphasia).

**Spousal Impoverishment Law**—A federal law providing that if one member of a married couple becomes a nursing home resident, the property and assets of the married couple will be combined, regardless of who owns the asset, and divided in half, according to Health Care Financing Administration (HCFA) standards. This process protects the spouse who still lives in the community from becoming impoverished. The spouse who still lives in the community can appeal the division of marital assets under certain conditions.

**SSI**—See Social Security Disability Income.

**State Health Insurance Assistance Program** (SHIP)—A state program that gets money from the federal government to give free health insurance counseling to people with Medicare. SHIPs provide free counseling and assistance via telephone and face-to-face interactive sessions. Information is provided about Medicare, Medigap insurance, Medicaid, HMOs, public benefits, retiree health plans, individual insurance, prescription drug charge coverage, health insurance counseling, and other health insurance options.

**State Medical Assistance Office**—A state agency that is in charge of the state’s Medicaid program and can give information about programs to help pay medical bills for people with low incomes.

**State Survey Agency**—A state agency that oversees health care providers that participate in the Medicare and/or Medicaid programs. The State Survey Agency inspects health care providers and investigates complaints to ensure that health and safety standards are met.

**Supplemental Security Income**—See Social Security Disability Income.

**Supportive Housing**—An “assisted living-like” environment in state-funded, public elderly/disabled housing. Services are provided on an as-needed basis 24 hours a day.

**Telephone Reassurance**—Regular, pre-scheduled calls to homebound older adults to reduce isolation and provide a routine safety check.

**Third-party Liability**—A party other than a beneficiary who is responsible for payment of part or all of a specific Medicare claim. Medicare supplemental insurance (Medigap) coverage is one example.

**TTY** (Text Telephone) or **TTD** (Telecommunication Device for the Deaf)—Special telephones and telephone numbers for the deaf and those who are hard of hearing or speech impaired that allow people to communicate by typing messages back and forth rather than talking and listening.

**Veterans' Benefits**—Medical services and other benefits provided by the Veterans' Administration to honorably discharged ex-service members and sometimes to their dependents. For those without service-connected disabilities, income and asset restrictions may apply.

**Visiting Nurses** (Visiting Nurse Association/VNA)—Registered nurses who provide skilled nursing, rehabilitation, and hospice services at home. The VNA is a membership association of home health care providers in the region, connected by a network of partnerships with regional insurers, hospitals and clinics, and health care providers.

**Wander Locator**—tracking equipment used for wander prevention and location for those who are prone to wander, such as Alzheimer's patients.



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