



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, 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 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/, and the National Association of Area Agencies on Aging, 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.

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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