



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/. 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/ 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, 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 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 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 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 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, 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, 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 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/ 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.nhpc.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/, 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/ 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 has extensive information about psychosocial end-of-life concerns on their Web site.
- **Compassionate Care ALS** at 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 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.
- **Net of Care** at 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/ 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 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 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/ 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 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 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 for a directory of counselors and other advice.

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