



A Guide for Caregivers

It's a big, complicated job, and somebody's got to do it. What you need to know to provide for your loved one.

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June 18, 2007 issue - Some 20 million boomers are caring for their families while trying to provide care for aging parents. Few know what they are getting into, says Donna Schempp, program director of the Family Caregiver Alliance, a San Francisco advocacy group. "Caregiving simply happens," says Schempp. "No one really chooses their caregiver. It's almost always a default decision based on who is available." Taking care of a parent can be tough. But there are some extraordinary resources available. The smartest approach is to plan ahead, recognizing that someday you will be a caregiver or someone will be caring for you. Here are some tips to help lighten the load.

Medical Issues

There will come a time when an adult child must make decisions regarding a parent's health care. To ease the way, there are two legal documents that experts say are vital. The first is a health-care proxy. This document, also called a health-care power of attorney, appoints a specific person to make all decisions regarding health care and end-of-life care, including refusal of treatment. The health-care proxy goes into effect when the attending physician determines that an individual is no longer able to make decisions on his or her own.

The second critical document is an advance directive, also known as a living will, which allows the person to state what kind of medical care he wants and which life-support procedures he doesn't want. "One of the greatest gifts an adult child can give to parents is to speak for them when they can't speak for themselves," says Kathy Brandt, vice president of the National Hospice and Palliative Care Organization. According to Brandt, advance directives can be powerful tools alone, but generally carry the most weight when combined with a health-care proxy. "It's kind of an insurance policy that your wishes will be carried out," she says.

It's very important for parents to talk about their spiritual beliefs and values, which may shape their decisions about the procedures they may or may not want at the end of life, says Brandt. One caveat: the laws governing advance directives vary from state to state, so it is important that they make sure their advance directives are state-specific.

Another type of advance directive is the Do Not Resuscitate order, or the DNR. Unlike the living will or health-care proxy documents, the patient does not prepare this document. The DNR is a request not to have cardiopulmonary resuscitation if the heart or breathing stops. Though it may be requested by a patient or by a health-care proxy, it is valid only if it is signed by a doctor. A DNR order will then be put into your medical chart. DNRs are accepted in all states.

Finances

Talking to parents about their finances can be extraordinarily difficult, but not talking about finances can be worse, especially if a parent's health starts to decline rapidly. In the past, estate planning involved little more than a will. Now, due to better medical care, people are living longer. That's why estate planning must cover long-term incapacity, including out-of-pocket expenses for assisted living, nursing homes (which, contrary to popular belief, Medicare does not cover long term), in-home care and other expenses related to aging. Long-term-care insurance is an option for some, but it is not a panacea, especially if people cannot keep up with rising premiums. Even if you are already a caregiver and your parents don't have an estate or financial plan in place, it is not too late. There are many strategies, such as reverse mortgages, living trusts and other options that may offer a solution to their long-term needs. A number of professionals can help form a plan, including attorneys, accountants, estate specialists and others.

Legal Issues

At a minimum, a caregiver should have a document called durable power of attorney, which gives you authority to make legal decisions when your parent becomes incapacitated or incompetent. These legal decisions can involve bank accounts, real estate and other personal matters. The durable power of attorney is extremely important for both the parent and adult child, explains Mark Shalloway, president of the National Academy of Elder Law Attorneys. "Financial, legal and other everyday routine decisions need to be made even if a parent suffers a catastrophic event or becomes impaired," says Shalloway. "This is a simple document that reduces hassles with banks, doctors, anyone the parent did business with." Though there are no hearings necessary to set up the durable power of attorney, the person granted the power has a fiduciary duty not to take advantage of the situation. "By law, people must act in good faith," says Shalloway. "There can be some very real legal consequences if someone sells off assets for their own use." If you don't have a durable power of attorney, and if your parent becomes

incompetent, you'll need to be appointed guardian by the court, which is "expensive and time-consuming," and removes all legal rights of an older person, says Shalloway.

Also, make sure your parents have wills. This simple document names a person who will manage the estate upon your parents' deaths and the beneficiaries of the estate. If a person dies without a will in place, state "intestacy" statutes will determine who gets the property. Keep all legal documents, including the deed to the house, life-insurance policies and other important papers, in one place, such as a safe-deposit box. If your parents have a safe-deposit box, make sure that you are a signer.

Housing

Ask any older person where he or she wants to live and chances are good they'll say they want to stay in their own homes. But where Mom and Dad eventually live will more than likely be determined by their health, available resources and caregiver's needs. If a parent is healthy and mobile, one option is to make an existing home safer by reducing fall risks. Simple improvements can include adding grab bars in the shower and getting rid of throw rugs. Adult children can also help their parents by arranging for someone to prepare meals and do light housekeeping or to assist with more-personal tasks, such as dressing and bathing. Your local Area Agency on Aging, a governmental program that provides a network of elder services throughout the United States, can help you find a qualified home health-care outfit or individual, as well as provide tips and services on making homes more senior-friendly. But no matter what you do, it's important that your parent be comfortable with the person or persons providing care. So a meet-and-greet between your parents and their aides is essential. And, of course, get references.

When a parent wants to leave a home and is still healthy, there are many options available, including independent senior communities, continuing-care retirement communities and assisted-living facilities. Independent senior communities usually feature private apartments with senior-friendly designs. Some may offer 24-hour emergency-call services, group outings, social activities and other amenities.

The continuing-care retirement model offers numerous services that allows people to stay in place, even if their needs change. Generally, these facilities provide services that include housekeeping, emergency help, personal care and social activities. According to the American Association of Homes and Services for the Aging (AAHSA), these continuing-care communities differ from other senior-housing options in that they agree under contract to provide residents with housing and services for life. They do require a one-time entrance fee and monthly

payments that vary by region and by the type of housing and services needed. And some groups do operate on a rental basis.

For folks who need daily help with bathing or dressing, assisted-living residences are another option. These facilities can be part of a retirement community or nursing home. Most offer single rooms, but some offer suites or apartments, according to the AAHSA.

When someone is too sick to live on his own and requires round-the-clock care or is recovering from an illness or operation, a nursing home is generally the best choice. These facilities are state licensed, providing nursing and personal care and needed medical services. Like other facilities, nursing homes do offer social activities to residents.

Assisted-living facilities cost on average about \$32,000 per year; a semiprivate room in a nursing home runs about \$65,000 per year. While Medicare will pay for nursing-home services for a specified period of time for people recovering from surgery or in need of rehabilitation, it does not cover long-term-care expenses. Nor does Medicare pay for assisted living or any of the other senior housing options. "People will say to me, 'What do you mean, Medicare doesn't pay for assisted living or nursing homes?' " says Larry Minnix, AAHSA president. "People are in a world of hurt when they do the math." Your best bet, again, is to plan ahead.

Sometimes a move to an assisted-living facility can help elders socialize. "The decision to move from an existing home is really tough," says Minnix. "Within reason, the wishes of the parent should come first. If a parent wants to stay in the home, do all you can to help them stay there." Internet resources provide a wealth of information on how to choose the best facility or how to help parents make a decision to stay or leave their homes. To help assess your parents' needs, your first stop should be your local Area Agency on Aging.

Family Dynamics

Providing care for an aging parent can create friction among family members. Some siblings may be in denial about a parent's condition; others may not want to be involved in caregiving. "There is no easy way to straighten out years of problems among siblings," says the Family Caregiver Alliance's Schempp.

"Sometimes when a parent requires care it can bring out the best in people. Sometimes it can bring out the worst." If you're having trouble in the sibling-rivalry department, try a family meeting with an outside facilitator, such as a close family friend, attorney, social worker or clergy member. This mediator can make sure that all siblings get their say.

One of the most undervalued roles that siblings can play is providing respite care to the primary caregiver, helping with shopping, transportation, doctor's visits and other tasks. According to the Family Caregiver Alliance, baby boomers caring for aging parents while juggling work and their own family responsibilities are at increased risk for depression and chronic illness and an overall decline in quality of life. Ask for help from siblings or local resources, such as senior centers and the local Area Agency on Aging. Support groups can help, too.

Resources

There is a wealth of resources to help caregivers with information on legal, medical, financial and support issues. Here are a few good places to start:

Administration on Aging (**aoa.gov**): Provides caregivers and their parents information on various services including elder rights.

Area Agency on Aging: This government program provides a national network of social services. See **n4a.org** (National Association of Area Agencies on Aging) or call 800-677-1116 for your local agency.

Family Caregiver Alliance (**caregiver.org**): Offers programs at national, state and local levels to support caregivers.

AARP (**aarp.org**): Membership organization for people age 50 and older; provides numerous benefits to members.

Eldercare Locator (**eldercare.gov**): A service of the U.S. Administration on Aging; links caregivers with senior services.

National Academy of Elder Law Attorneys (**naela.org**): Provides searchable database to assist in finding an elder-law attorney.

Medicare Rights (**medicare rights.org**): Independent source of health-care information and assistance for people with Medicare.

National Hospice and Palliative Care Organization (**nhpco.org**): Offers information on end-of-life issues and state-specific advance directives.

Nursing Homes (**medicare.gov/nhcompare**): Provides detailed information on the past performance of every Medicare- and Medicaid-certified nursing home in the country.