RESOURCES ON CALL

THE

ELDER CARE KIT

A comprehensive guide to finding, evaluating, and choosing programs for elders

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CARE MANAGEMENT WORKSHEET

The first step in determining what services and resources are needed for an elder relative is to talk about his/her needs and concerns. This "Care Management Worksheet," which was developed by the American Association of Retired Persons, describes some common situations, as well as some of the services and resources that may be helpful in providing appropriate care and support.

My Relative	Services Needed	Resources
really needs to get out and do something	socialization/volunteering	nutrition site, senior center, friendly visitors, day care, RSVP
can do light housework but needs help with heavy tasks	chore services	local agencies for the aging, area churches, youth groups
has some legal matters that need attention	legal services	bar association, legal council for the elderly, legal aid
is grieving over the loss of a loved one	bereavement support	AARP widowed persons service, local mental health and counseling centers
cannot drive or use public transportation	transportation services	private transportation companies, handicapped or elderly transportation, Red Cross
is unable to remain in his/her present housing	housing	retirement community, public housing, nursing home, group home, foster home
needs help with food preparation, cleaning or laundry	homemaker services	social service agencies, private homemakers, Red Cross, Visiting Nurse Association
needs assistance with personal care (dressing, bathing, etc.)	home health or personal care aide	Red Cross, Visiting Nurse Association, private home health agencies, public health nurses

doesn't eat right	nutrition	meals on wheels, nutrition sites, week-end meals programs
cannot be left alone during the day	friendly visitors or adult day care	adult day care, live-in attendant, social service agencies, foster homes
needs services for physical limitations and impairments	handicapped services	disease-specific organizations, local office of physical disabilities
cannot afford health care costs	health care cost containment	Medicare-Social Security office, Medicaid - Department of Human Services, insurance company
is depressed/suspicious/angry all the time, just sits	mental health	local mental health department, geriatric social workers, crisis intervention unit, psychiatric hospital, Alzheimer's Association
is acting strange	geriatric evaluation	complete medical and neurological evaluation, mental health evaluation
really needs 24 hour supervision	private nurse or nursing home	private nursing agencies, local office on aging, hospital social services, homes for the aged
has a terminal illness and wants to return home rather than dying in the hospital	hospice	Visiting Nurses Association, Cancer Society, Hospice Association, local church, hospital social services

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CAREGIVING FROM AFAR ISN'T EASY

For the last five years, Joyce Antler, a Brandeis University historian in her early 50s, has been living what she calls ' a terrible nightmare." Antler lives in Brookline and is trying to manage the care of her increasingly demented, 84-year-old mother, long distance.

At first, the solution seemed to be to have her mother move up from Florida to live with Antler and her family. But within a month, she says, her mother "found it impossible because we were so busy. She felt like a fifth wheel." So Antler's sister gave up her apartment in New York to move back to Florida with their mother. But this has proved only marginally better, Antler says, because her sister has serious medical problems of her own. The result is ever more frequent, not to mention expensive, plane trips to Florida, endless telephone calls to help her sister manage crises and 'semi-crises' and a lot of guilt.

Antler's dilemma is the tip of a huge iceberg that, some worry, could come close to sinking the Great Ship Baby Boomer. In fact, if you're among America's 76 million boomers, born between 1946 and 1964, and you thought finding child care was a colossal hassle, you are about to get smacked between the eyes with an even bigger problem, if you haven't been already. Call it the geographic crunch. Suitcase caregiving. Long-distance care management. By whatever name, managing the care of a frail or disabled parent, especially from far away, is, as Antler says, a true nightmare, and one that will almost certainly get worse as boomers and their parents age.

Many older people, of course, are willing to make a final move to assisted living or a nursing home when it looks as though they will no longer be able to manage things at home. But most want to live out their lives in their own homes with the right kind of help, nursing services, home health aides and someone to help with errands, housekeeping and yard work. The trouble with that, however, is that while services are available, especially for those who can pay for them, finding them usually means cutting through miles of red tape. "That is tough enough to do if your parents live next door, and it can be truly overwhelming if they don't," says Scott Bass, dean of the graduate school at the University of Maryland/Baltimore County.

Although most people over 65 live within an hour's drive of at least one child, an estimated 7 to 9 million aging parents do not, says gerontologist Merril Silverstein of the University of Southern California. And that gap could get worse. Currently, two million working Americans, most of them women, help older relatives with activities of daily life. But the greater geographic dispersion of families, smaller family sizes and the large percentage of women who work outside the home are straining the capacity of this care source," the government's General Accounting Office noted in 1994.

While hands on care - bathing, shopping, giving medications - is the most demanding help that children can provide to aging parents, the managerial stuff - the hours on the phone arranging or monitoring help given by others - is no small task. In fact, lining up care for aging parents is "much more complicated than setting up child care for kids," says Dorothy Howe, acting manager of health advocacy services for the American Association of Retired Persons in Washington. For one thing, "you're not dealing with a dependent," says gerontologist Bass. "You don't have the authority, necessarily, to intervene." Added to that is an often-complex family history, sibling disputes over who should help, and distance. "It adds up to a very stressful, difficult issue," says Bass. "This is probably the hardest thing a family can go through. It defies the complexity of what people experience with children."

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Even when a parent is able to find services on their own, it may still be worthwhile to do your own research to offer additional options, says Barbara Levitov, director of special events at WGBH-TV. "At the very least," says Levitov, having your own suggestions can help you start having a real conversation with your parent."

Whatever you do, be gentle as you plunge into this new role with your parent, say those who've been there. Managing a parent's housing, medical care and finances can be a burden, especially from afar, but it is also a chance to give back or smooth over decades of troubled history. And be persuasive, not coercive, even if your parent's pace toward solving a seemingly messy situation is slower than yours. In extreme cases, you can get legal guardianship of a parent - if, say, you need to sell property to pay for services. "But legal intervention may not get you what you want - what you probably need is some negotiating skills," says Nancy Coleman, director of the American Bar Association's commission on legal problems of the elderly.

And when the going gets tough - as it will - remember what John Paul Marosy, a specialist on elder care issues and president of a consulting business, HM Associates in Belmont, learned as a professional and as a son. "Think about this caregiving as an opportunity. It's almost a dress rehearsal for your own aging. In terms of emotional development, this is the entree to the second half of life. We can either ignore it or embrace it."

Helpful Tips To Remember

- Plan ahead. Don't wait for a crisis to get involved. As hospital stays get shorter, you may have only a few days to line up care before your parent is discharged.
- Get to know your parents' informal network - the names and phone numbers of their doctors, lawyer, minister, neighbors and friends who might help in a crunch
- Ask your parents to explain their health insurance, including long-term care.
- Ask if your parents would put you on their bank accounts and give you durable power of attorney so you can pay bills and contract for services if a crisis occurs.
- Ask your parents what care they want if they become disabled, especially where they want to live. Don't assume they should move in with you or that nursing homes and assisted living are the only options. Many people can get the care they need at home.
- Help them write a living will or health care.
- As you start to help them sort out options, don't try to settle everything at once. It usually takes many conversations, over many visits and phone calls.
- Know your limits. Be honest about what you can do and divide tasks as fairly as possible among siblings. At a minimum, keep other close family members informed.
- Respect your parents' autonomy and don't fall into the role reversal trap.
- If you get stuck trying to sort out options with your parents, bring in an outsider - a minister, doctor or family friend.
- Set up appointments with visiting nurses, nursing home administrators, home health aides, etc. by phone in advance to make the most of your time when you get there.
- If your parent has a specific disease, say Parkinson's, contact the local support group. Such groups can often make referrals to helpful doctors and other services.
- Keep a logbook or a computer notebook on your parent's status, including medical information, discussions with visiting nurses or home health aides about care at home.

WHAT EXACTLY IS LONG-TERM CARE?

In addition to health services, long-term care includes a range of social and supports services. Long-term care services can be divided into three categories:

- In-home services
- Community-based services
- Institutional care

In-Home Services

Home Health Care brings care to the home to maintain or restore a person's health. These include medical services provided by professionals, such as nurses or physical therapists, or personal care services, provided by homemaker-home health aides.

Chore Services offer minor household repairs, cleaning, and yard work. Costs vary.

Home-Delivered Meals, or "Meals on Wheels," is a service provided by local government or volunteer organizations to deliver nutritious, hot meals daily.

Friendly Visitor Services where volunteers stop by regularly to write letters, run errands and shop, or simply to sit and talk with isolated older people. There is usually no charge for this service, which is typically provided through local religious or volunteer groups.

Emergency Response Systems provide reassurance by reliable contact, by telephone and electronic device, to police and rescue squads in the event of emergencies in the home.

Telephone Reassurance is usually offered by volunteers who make calls to or receive daily phone calls from the elderly living alone.

Community-Based Services

Community programs include a number of nutrition, social or health care services, and a range of alternative housing arrangements that make it possible for the person to remain at home and maintain independence. Some of these options are:

Senior Centers give older persons an opportunity to meet and socialize. They offer a variety of recreational, legal, financial, and counseling services. The centers, usually non-profit organizations, may be located in housing projects, churches, or synagogues.

Nutrition Sites offer inexpensive, nutritious meals in settings such as senior centers, housing projects, churches, synagogues, or schools. Transportation is sometimes provided.

Adult Day Care Centers provide comprehensive services ranging from health assessment and care to social programs for older persons who need some supervision. Transportation is sometimes provided. Hospitals, nursing homes, local governments, or religious, civic or other groups may operate the centers.

House Sharing is when two or more unrelated people live together in a combination of common space. Each has a private bedroom and all living areas are shared, as well as chores. Often expenses for food, utilities, housing costs, and transportation are shared.

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Board and Care Homes are privately operated facilities that provide room, meals, and personal care services such as help with bathing, dressing, getting in and out of bed, and 24-hour protective oversight. Most states do not license, inspect, or monitor these facilities.

Congregate Housing Facilities, operated by government agencies, nonprofit groups, private interests, offer independent living with central dining, transportation, and social and recreational programs. Sometimes the services of health and social service professionals and personal assistants also are provided.

Continuing Care Retirement Communities offer housing and a range of health care, social, and other services. They emphasize independent living in apartment rooms or individual cottages for as long as possible. All have a contract that guarantees residents access to care and services, including nursing home services for as long as they remain in the facility. Some communities provide home health care and onsite nursing home care without extra payments, while others charge additional daily fees.

Assisted Living provides housing and support services to residents who need assistance with the activities of daily living, but do not require daily skilled nursing care.

Respite Care offers from a few hours to several days of help to family members caring for a frail, ill or impaired person. Volunteers come to the home, an institution, or an adult day care center to provide the care. Churches and synagogues, nursing homes, home health agencies, or volunteer agencies organize this type of service.

Hospice Care provides counseling and other services to help patients and families cope with the dying process and handle the physical and emotional pain. Hospice workers support the patient and family with physical, psychological, social, and emotional care. Volunteers play an integral role in the provision of care. The care may be provided in a specialized hospice facility or, most frequently, care is provided in the patient's home.

Institutional Care

Nursing Home Care is for those who are chronically ill or recovering from an acute illness and who need extended care but not hospitalization. Nursing home residents may receive nursing services, room and board, supervision, therapeutic and rehabilitation services, and medication. They often have access to social and recreational. Generally, there are three levels of nursing home care:

> ***Skilled Nursing Care*** is for those who need intensive, 24-hour-a-day care and supervision by a registered nurse.
>
> ***Intermediate Nursing Care*** is for individuals who do not meet the medical criteria for skilled care. They require 24-hour supervision and nursing assistance.
>
> ***Custodial Care*** is for those who require room and board, and assistance with personal care, but don't necessarily need health care services.

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American Association of Retired Persons

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ELDERLY FIND COMFORT IN COMMUNAL HOUSING

When Gloria Saltzberg lived alone in her apartment she almost never ventured outside except to go grocery shopping. Gripped by depression, she decided she needed a change. A year later, she belongs to several discussion groups and looks forward to eating dinner in a communal dining room with her neighbors.

Saltzberg is one of many elderly people living in congregate housing, where residents depend on each other for support in ways not always available to people living alone. "I was afraid to come here because I was afraid I wouldn't enter into any groups and I might not like to have all those people around, and it hasn't turned out that way at all. I'm much more outgoing than I was," said Saltzberg, who's in her early 60s.

Memorial House, her new residence, offers a supportive environment similar to that of the more well known "assisted living" complexes springing up around the country. However, unlike assisted living units, congregate housing does not offer 24 hour medical services. There are about 30,000 to 40,000 assisted living facilities nationwide, serving about 1 million Americans, according to the American Association of Homes for the Aging.

The term "assisted living" is used by elder care providers to describe communal housing, both with and without full-time medical care. It's a gray area that makes congregate housing different from an assisted living facility," said Ted Bobrow, spokesman for the American Association of Retired Persons. Congregate housing is for people who don't need as much routine services, who are looking for companionship.

Residents in congregate housing have their own rooms or apartments within the overall complex. Some congregate housing complexes even have guestrooms for visitors. "It's often a very viable alternative for someone who doesn't want to remain in a house that's too big for him or her," said Jim Pfeiffer, an executive vice president of Presbyterian SeniorCare, based in Oakmont, Pa.

At the Bellmead congregate home in Washington, Pa., residents can pass the hours exercising, shopping at nearby stores or making ceramics. Bellmead residents can eat lunch and dinner in the dining room, but take their own breakfasts. The US Department of Housing and Urban Development sponsor the home. As they do at Memorial House, residents pay 30% of their income or rent. At both Bellmead and Memorial House, tenants' rent is partially subsidized by a state agency. Residents are responsible for the balance. A housekeeping service, which costs extra, is optional.

Marilyn Goldberg, coordinator of Memorial House, describes congregate housing as "an informal network among the neighbors where people help each other out." "Because health providers are not on staff 24 hours a day, applicants are carefully screened before they're accepted as residents," Goldberg said. "If the team feels the person is too frail or too mentally impaired then we would tend to reject that application," she said.

Saltzberg spends her time in her small apartment, which has a kitchenette with a refrigerator and a stovetop but no oven, watching television and knitting hats and booties for her grandchildren. "After you're here a while you get a little friendlier with some people and less with others. I seem to be more comfortable than I ever have been before "It's just a good, homey feeling. The most important thing is you take what you want and discard what you don't want," Saltzberg said. "This was a real challenge for me to do."

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ASSISTED-LIVING COMMUNITIES

Assisted living residences are changing the face of elder care.

Not all elderly people need the full medical services of a skilled care nursing home. There are many who are basically in good health but who cannot live at home or even in boarding houses for the elderly. So-called assisted living facilities allow such people to continue to live on their own, but in a safer setting than their own house or apartment. Licensed facilities provide 24-hour supervision but not medical care. According to the American Health Care Association, the typical assisted living resident is an 86-year-old ambulatory woman able to perform most of the activities of daily living on her own.

"It is housing, first, with medical services, not medical services with housing thrown in," says Franklin P. Ollivierre, Massachusetts Secretary of the Executive Office of Elder Affairs.

The concept of assisted living comes from Scandinavia and was introduced in this country in the mid 1980s. The goal is to allow people to continue to live as independently as possible while providing supervision, assistance and limited health services. Personal care services are provided on a graduated basis, according to need. Residents of assisted living facilities are offered help with meals, shopping, housekeeping and laundry, as well as bathing, dressing, using the toilet and taking medications. An assisted living facility may be a freestanding institution, part of a retirement community or even part of a nursing home.

Residents commonly share at least one meal per day, socialize in common areas and participate in activities such as games, crafts, cooking, trips and discussions.

Advocates for the elderly say other concerns include the stress of leaving a long established home and moving to new, usually smaller quarters, often in a new town. At the same time, the facilities are widely praised.

"We think assisted living is a wonderful way to grow old, because it emphasizes independence and dignity," said Ellen Philbin, a health education advocate for the Boston office of the American Association of Retired Persons. "It allows people to remain in a situation where they can receive services, but are still in control."

State official Ollivierre said assisted living "has filled a niche that was missing between the completely independent, which includes 80% of our seniors, and the completely dependent, which would be those in need of a nursing home or chronic-care facility."

Chris Delaney of Holliston, formerly a psychotherapist with the MetroWest Mental Health Association in Framingham, noted that risk of depression is high in older age groups. He has seen how assisted living can help lift the depression.

"It takes them out of the isolation that many find themselves in, and gets them involved in socializing activities," Delaney said. "They are no longer burdened by survival, by the most basic chores of housekeeping."

Excerpted with permission from "Assisted Living Units Growing In Popularity," y Richard Higgins, The Boston Globe

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initiative in making needed changes. They'll end up with a safer home, an easier daily routine, and a well-earned, renewed sense of independence.

Home Adaptations

There are four types of adaptations.

- **Mobility Into And Through The Home**

There is a strong possibility that someone in the home will eventually use a wheelchair or walker for periods of time. At the very least, as one gets older, it is more difficult to get around and steps will become a significant barrier. Even those who never need to use a wheelchair may wish to make use of grocery bag carts, strollers wheeled trashcans, wheeled luggage, and a variety of other conveniences. All these devices are stopped cold by steps and, like wheelchairs are difficult to maneuver in tight spaces once inside the home. So there are two things to aim for: eliminating steps and creating room to maneuver.

One of the easiest ways to make a home easier to live in is to make at least one entrance to the main living level accessible without going up or down steps. This may mean rerouting or regrading the front walk and porch. If this rerouting or regrading is done when the walk is being replaced anyway, there will be little additional cost.

Inside the home, there usually aren't many steps that can be easily eliminated. If an addition is added, make sure it isn't necessary to use steps to get into it! Another approach that works well is to prepare for single-level living. As changes are made over the years, seek the option of living entirely on one level, even if only temporarily. Make sure there are a full bath, a kitchen, and a bedroom all on one level. Having laundry facilities on the same level is a big plus.

Maneuverability is most critical in the kitchen and the bathroom. Use floor surfaces that don't become slippery when wet. Open up spaces and doorways. Whenever possible, design doorways that are 36 inches wide and eliminate thresholds over ½ inch high. Make sure the thresholds, the wooden, metal, or stone bumps on the floor of outside doorways and bathroom doorways, have beveled (sloped) edges. Thresholds represent real obstacles to wheelchairs and other wheeled devices. These changes will not only make a home wheelchair friendly but will also give it a more open, spacious feel.

- **Handholds**

The next issue to focus on is a handhold. Keep in mind that many serious falls are caused by inadequate railings and grips. This is especially true in the bathroom. Ensure that there is plenty of support around the toilet and the tub or shower.

Check the stairs. Does every step have an adequate railing? Many original stair banisters are good for little more than show - an adult's body weight can easily tear them from the wall. These banisters need to be checked and should be reinforced if necessary.

- **Hand-Friendly Handles And Control Knobs**

Getting around in a home doesn't do much good if one can't open the doors or use the appliances! A room-by-room review of handles and knobs will yield a substantial list of inadequacies. Hand-friendly door levers, window handles and controls are available. Bathroom faucets are another problem area.

The kitchen may be the most critical room for checking hand-friendly handles and controls. Can stove control knobs be reached without risking a burn? Will they be easy to turn, as hands become less nimble? How about the sink faucet? What about all those cabinets and drawer handles?

Other Safety Issues

Finally, there are some other issues to consider. Are there bright, automatic, external lights? What about internal lighting? As people get older, it takes more light to see the same things. Reading lights need to be brighter. Well lit stairs become ever more important.

Are there adequate home security measures? An intercom can provide added safety and a convenient way to communicate with others when it's difficult to get around. Something as simple as a peephole in the front door can be very helpful.

Burns are one of the most common injuries for older people. Often, one can eliminate entirely the use of the stove for heating water - its most common use. There are hot water dispensers that are set up like another faucet at the sink and eliminate the need for heavy pots and the risk of spilling scalding water.

Scalding water also causes many injuries in the bathroom. It is not at all unusual for someone to fall in the shower or tub, hitting the faucet on the way. If the water temperature is suddenly increased and one can't get to the controls, even moderately hot water will cause burns if allowed to flow for several minutes. 'This is another hazard that can be eliminated. A number of manufacturers make faucets that have a built-in scald-prevention mechanism, which automatically cuts off water flow if the temperature exceeds a preset maximum. Such devices can also eliminate the scalding that can occur in the shower when someone else is flushing a toilet or otherwise lowering the cold water pressure.

Conclusion

Maintaining independence takes more than words and will: it takes actions. Adaptations can maximize the years a person can operate independently in his/her own space.

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THE INDEPENDENCE OF AGING IN PLACE

Velma Glynn is a seventy-five year old collector of china and antiques. She lives alone in her Charlestown apartment, despite knee joints that are degenerating, a chronic sciatic nerve problem that shoots pain down from her lower back to her legs and despite the need to be tethered to an oxygen tank around the clock. Glynn lives alone and insists she wouldn't have it any other way. "I can have my own things to look at and enjoy," says Glynn, who keeps herself busy by helping older friends and volunteering.

She could never continue her independent lifestyle without help from an agency that brings services to her home: a house cleaner, a health aide to help her bathe, groceries delivered every two weeks, a taxi ride for medical appointments and visits by a nurse. The in-home services have helped Glynn do what she and millions of elders like her say they want as they age: to remain at home as long as possible. The concept is called "aging in place." Health care experts who support it say it is also a low-cost alternative to the highly touted but expensive assisted living centers and nursing homes.

"The trend is there. There's no doubt the aging-in-place phenomenon is a reality," says Leon Harper, senior housing specialist at the American Association of Retired Persons. "People want to age in place. They want to remain independent." An AARP survey published last year found that 85% of the 1,507 respondents age 55 and older want to remain in their homes. More elders are living longer in their current homes and 28% said they lived in their current homes for more than 30 years compared to 24% in 1989. 62% own their homes outright, 21% are paying a mortgage and 15% rent.

"Older people's first choice is always to stay in their own homes because they develop close ties to the place where they have been living for many years. What has changed is that people are living much longer," says Joan Hyde, senior policy analyst at The Gerontology Institute at the University of Massachusetts at Boston. "In the good old days, people rarely lived past sixty-five. If you're going to live ten years longer, you can expect to live with more disabilities and need more help."

An array of services targeted for stay-at-home seniors has sprouted, both government funded agencies that contract with other businesses and private enterprises which recognize a money-making niche. Services may include homemaking and personal care, nutrition such as delivered hot meals, transportation, money management programs, home safety assessments, and programs that will repair, maintain or adapt houses for elders.

Carmen D'Addario of Waltham, a 73 year old former meat cutter, says that after his wife of the same age suffered a stroke last year, he used an agency to install safety bars around the tub and railings along the basement steps. The contractor also lowered their bed by two inches and added railings so D'Addario's wife could get up alone. "It's important that I can stay in my house. I'm comfortable," says D'Addario, who has lived in his three-bedroom house since 1957.

Specialists predict the move to independent living will continue to grow. "It's important because the elderly have made it important," says Al Norman, executive director of Mass Home Care, a nonprofit consumer rights group for the elderly. "At the top of the list of what they want is convenience of lifestyle and independence," he said. "We're trying to make the environment that older adults face much more supportive of their independence."

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HOSPICE CARE

Dame Cicely Saunders, the founder of the modern hospice movement in Great Britain, started the first American hospice in New Haven, Conn., in 1974, after a lecture at Yale University. Hospices are designed to manage pain and allow terminally ill people to die with dignity, providing for their emotional and spiritual needs along with their medical treatment. The hospice philosophy, as Saunders describes it, is that "you matter to the last moment of your life, and we will do all we can, not only to help you die peacefully but to live until you die."

In England, hospices are inpatient facilities, but in the U.S. 90% of hospice services are delivered to patients at home; the other 10% of services are given to patients in nursing homes or hospice centers. Patients go into the hospice facility only when they need evaluation or pain management, when their disease requires more intense, round-the-clock monitoring, or when their families need a break.

There are more than 2,200 hospices in the U.S. and more than 1 million people have been hospice patients. Hospice patients sign consent and insurance forms that say they understand their care is aimed at controlling pain and symptoms, not at a cure. The majority of hospice patients have cancer; most of the rest have AIDS or heart disease.

Hospice care does nothing to speed up or slow down the dying process, but if patients show improvement or go into remission, they can leave the hospice to resume an independent lifestyle and or seek aggressive therapy for their illness. The hospice team consists of doctors, nurses, social workers, counselors, home health aides, therapists, clergy and volunteers. Hospices provide medication, supplies, equipment and additional help at home as needed. Some also have staff to help patients put their financial affairs in order. Volunteers provide personal services such as helping with household chores, bringing in food and just being there to listen.

If a patient is eligible for Medicare and accepted by a Medicare-approved hospice, almost the entire cost of care will be covered, including physicians, nurses, medical appliances and supplies, medication and homemaking services. To qualify for Medicare payment of hospice services, a patient must have two physicians certify that he has six months or less to live. Patients who live beyond the six-month period must be recertified. Most private health insurance policies also pay for hospice care, and many employers cover it under their health plans.

CHOOSING A NURSING HOME

No one wants to go into a nursing home. "Most Americans view entering a nursing home as a death sentence," says Dr. Marc Cantillon, a geriatric psychiatrist at Georgetown University. "For one thing, you have to live by an institution's rules, which include when to get up, when to eat and when to go to bed. And people don't like to admit they're dependent and in need." Add to this the widespread image of nursing homes as malodorous human warehouses, where people are strapped in wheel chairs with nothing to do all day long. It's no surprise that most of us put off thinking about choosing one until a time of crisis, such as when a family member is about to leave the hospital, or after an operation or accident. The chance of finding the best care for a loved one can be compromised by haste.

Despite our reticence, nursing homes are a booming industry. According to the Department of Health and Human Services, there are now approximately 16,000 licensed nursing homes caring for about 1.5 million elderly people in this country. And the need for such institutions is growing as our population ages. In 1990, the over-65 population was 31.6 million. By the year 2000 it's expected to be 35 million. Moreover, the fastest-growing segment of the elderly population is the group 85 and older.

In 1990 there were 3.3 million Americans over 85; by the year 2000 there will be approximately 4.4 million. The Health Care Financing Administration (part of the HHS) estimates that 40% to 45% of people who turned 85 in 1990 will stay in a nursing home at least once in their lifetime. Despite the common fear that once you're admitted to a nursing home you're there for life, 30% of all residents eventually go home or to other types of facilities.

To qualify for a nursing home, a person must require 24-hour care and supervision or be chronically ill, but not so sick as to require intensive hospital care. Residents remain under the care of their personal physicians, usually the same doctor who referred them to the home, who sets up and monitors an overall treatment program, with day-to-day care provided by the nursing home's medical staff. By law, all nursing procedures must be performed by registered or licensed practical nurses, who assess residents, conduct treatments and coordinate care with other members of the staff.

In addition, nursing homes provide personal care, residential services and rehabilitation following a stroke, a heart attack or an orthopedic problem. Residents are given physical, occupational and speech therapy, dietary consultations and medication. Dental care, laboratory and x-ray services may be provided at the home or elsewhere. The staff also helps residents with such tasks as dressing, eating, bathing, getting in and out of bed and using the toilet. Some nursing homes offer religious services and counseling programs.

Virtually everyone who gets admitted to a nursing home comes directly from a hospital. But unlike hospitals, nursing homes have much less restricted visiting hours and most residents eat in communal dining rooms. Married couples can enter nursing homes together and share rooms (this is in fact mandated for any facility receiving Medicare and Medicaid funding). Staff members are trained to give residents privacy and to knock on doors before entering.

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Though the activities of nursing home residents are usually limited, in a good home people don't merely sit around all day. "In a hospital, a person is confined to a bed and 'deconditions' he loses muscle function," says Steve Katz, vice president for corporate programs of Beth Abraham Hospital in New York City. "A good nursing home offers many therapeutic and leisure activities. At the Beth Abraham nursing home, for instance, residents do art therapy, have physical therapy, watch movies and play various games." Dr. Oliver Sacks, the neurologist and author who was portrayed in the film *Awakenings,* is doing research on music therapy for patients with dementia or who are recovering from strokes at Beth Abraham.

Still, even the most progressive nursing homes can be difficult environments to adjust to. Many residents are incontinent. In any facility there will be some residents who act confused as a result of illness or the natural aging processes. Some have Alzheimer's disease, which causes them to behave strangely, forget things, wander and express feelings of paranoia. Some older people who were "confused" before entering such institutions improve because of better nutrition and increased social contact.

There's a common perception of nursing home residents as dazed or drugged, but antidepressants, tranquilizers and sleeping pills should be used only to help resident function better, not to keep troublesome ones quiet. Physical restraints are used only when a physician orders them for the residents' safety or to support people paralyzed by strokes, who may need help sitting up in a chair.

The best way to make sure a nursing home is a good one is to visit it yourself. Speak to the staff and the residents. Get to know the administrators. Go at night when the staff turns over, and see if the atmosphere is different. Trust your instincts: generally they'll tell you if anything is wrong. And don't forget to speak with your family physician. According to Dr. Charles P. Duvall, past president of the American Society of Internal Medicine, "Doctors know local nursing homes very well and can tell you which ones are better in terms of medical care and staff."

The American Association of Homes and Services for the Aging recommends making sure that the nursing home and its administrator have a current operating license. Nursing homes are more highly regulated than any industry in this country except the nuclear power industry. The home should be approved for Medicare and Medicaid programs. *If any of these requirements aren't met, look elsewhere*.

In Addition, You Should:

- Make sure the home is in a location that suits the patient and is convenient for family and friends.
- Check that the interior and grounds of the home are clean and well maintained. Make sure the home doesn't have a bad odor.
- See that exits are clearly marked and unobstructed in case of a fire.
- Look for wheelchair ramps and hallways wide enough for two wheelchairs to pass with ease. Also, check the hallway for handrails and the bathrooms for grab bars.
- Check that the bedrooms open onto a corridor and have windows, as required by law.
- Observe and talk with the residents. Do they appear clean and comfortable? Are they dressed appropriately?

- See that there are areas set aside for walking or sitting in nice weather and that these activities are encouraged.
- Look at the dining and activity rooms. Is there adequate staff around? Are people who need help getting it? Are the communal living areas busy and full?
- Make sure there's a physician available for emergencies and observe whether the staff seems caring.
- Ask whether there's a resident council program that meets regularly and allows residents to recommend changes.

The American Health Care Association, a nonprofit federation of state associations that represent more than 11,000 long-term-care facilities nationwide, recommends that you inquire about quality-assurance programs. Ask if the home participates in the Long Term Care Accreditation Program of the Joint Commission on Accreditation of Healthcare Organizations, which surveys nursing homes to make sure they meet certain standards. Many nursing homes also take part in the AHCA's Quest for Quality program, which evaluates the home's departments and surveys patients, family members and staff.

Remember, a beautiful facility doesn't mean everything, Beth Abraham Hospital's Katz says. "The trick is to get past the physical appearance and look at the relationships between staff and residents. Our facilities at Beth Abraham are older. But we take great care to treat everyone with dignity and we try to provide a homelike atmosphere. For example, we have a canteen designed to look like a candy store from years past. The most important thing a nursing home can do for its residents is to give them a good quality of life."

Paying For Nursing Homes

The average cost of nursing home care in the U S is about $36,000 per year, with most residents depending on Medicare or Medicaid to pick up at least part of the tab. Coverage for nursing home care under Medicare, a health insurance for people 65 and older and certain disabled people, is very limited: It pays in full for care in a skilled nursing facility for the first 20 days only. For the next 80 days, the patient must share part of the burden.

Medicaid is a federal-state program designed to help people with low income. In order to qualify for Medicaid, you must meet your state' s "poverty level." Medicaid is the chief payer for nursing home services. Fully 68% of people in nursing homes receive Medicaid, 5.6% receive Medicare and 25.6% pay the bulk of their bill privately or through insurance. Each state administers Medicaid individually and sets its own reimbursement rates. Medicaid pays only for certified nursing homes.

Private insurance policies can also help pay for nursing home services. Policies are available through the American Association of Retired Persons, some employers and private insurers.

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HOW TO FIND HOME HELP

Deciding To Find Home Help

- Is your older relative having trouble managing at home?
- Do you find it difficult to help him or her dress, use the bathroom, or bathe?
- Do you have problems juggling caregiving, family duties, work and free time?

If the answer to any of these questions is yes, perhaps you should consider using home help. A variety of services exist in most communities. These include:

- ***Homemaker Services*** - help with shopping, laundry, meal preparation, cleaning
- ***Chore Services*** - household repairs, errands, lawn care
- ***Home-Delivered Meals*** - afternoon meals delivered to the home
- ***Personal Care*** - help with bathing, dressing, feeding
- ***Companion Services*** - social contact and supervision

Home help can allow your family member to remain in familiar surroundings, while easing the demands on your time and energy.

Starting Your Search For Home Help

Before seeking home help, figure out what kinds of services would be most useful. If you can, talk it over with your older relative and his or her physician. Consider:

- What can the person do? What help does he or she need?
- What help can you and other family members provide?
- What other assistance is required?

Obstacles To Hiring Home Help

Some people hesitate to have someone come into their home. Here are several reasons:

- Inability to admit they need assistance.
- Fear that contacts with relatives will decrease because others are doing chores.
- Prejudice toward people of different racial, religious or ethnic groups.
- The expense of such services.

You Can Respond To These Issues By:

- Involving your relative to whatever extent possible m providing help or in the process of choosing home help.
- Reassuring your family member by your words and actions, making him or her feel a part of family events and activities.
- Exploring government programs and other sources of financial assistance.

You too may have mixed feelings about your family member's using home help. Talk openly with other relatives about reasons for using home help. Realize that with more free time, you can care give your relative the kind of emotional support needed.

How To Pay For Home Help

The cost of home care varies from service to service and area. Medicare and Medigap insurance generally do not pay for this help. Check insurance policies, veterans' benefits, and specific agencies for coverage. If your relative has a limited income, the department of social services can help with application for certain federal and state programs.

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How To Find Home Care Services

- Turn to **Resources On Call** for agency referrals.
- Ask friends, family, clergy, and other caregivers for individuals or agencies.

You may decide to use an agency that will send a person to your relative's home or you may hire directly. Much depends on you and your relative's needs and the resources.

Choosing An Agency

How do you find a good agency? **Resources On Call** refers you to agencies that meet your requirements. Consult your relative's doctor, hospital discharge planners, the Better Business Bureau, and fellow caregivers about the agencies you are considering. Review the contents of any service contract. Consider these questions.

- How long has the agency provided home help services?
- Does the agency have a written statement of fees, eligibility, and payment policies?
- Is the agency currently licensed and bonded?
- Can the agency provide references from people who have used its services?
- Does the agency provide a written plan of care that explains the service to be performed, days, hours, and fees? Is the plan reassessed periodically?
- Are there extra charges for travel, meals, supervision, holidays, or agency fees?
- Must we accept a minimum number of hours or days of service?
- Is help available evenings and weekends?
- Is there someone to contact after hours?
- How are emergencies handled?
- How does the agency recruit, screen, and train its workers?
- Will the agency send the same worker(s) regularly?
- How does the agency respond when a worker calls in sick?
- Who supervises the worker(s)? Will the supervisor observe the employee/
- If we are dissatisfied with the employee, will the agency send someone else?

Choosing To Hire A Worker Directly

- Be selective. When interviewing a candidate, think about whether you and your relative will feel at ease working with that person. Ask questions about the individual's work history, what he or she wants out of a job and his or her experience with older people. Find out if he or she has habits that might be disturbing - for instance, if the person likes to watch soap operas while working. Consider whether he or she was polite and on time.
- Tell the applicant about your relative's condition. How does the person respond? How does he or she handle such situations? Do not hide problems. You will not get and retain the kind of person you need if you fail to be open.
- Ask the candidate for at least three references, and check them.
- Draft a contract that states the conditions of employment, specific duties, and termination procedures. These actions provide you legal protection.
- Having confidence in the worker will start your working relationship off well. Discuss how things are going and make adjustments, if necessary.

Finding home help takes time. But the practical support you and your relative derive from using home care services will be worth your efforts.

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PARENTAL GUIDANCE

We spend billions each year to insure ourselves against catastrophes, from fires to floods. But we rarely prepare for the one crisis that is all but inevitable: that our parents will need our help in their old age. More than seven million Americans - 55% of them in the work force - now look after an aging parent or other elderly relative. Nearly two-thirds of those employees are women, and 38% care for children, too. The professional, financial and emotional toll is enormous. Nine out 10 employed caregivers acknowledge that their responsibilities adversely affect their work, and 55% report increased financial strain; they are also nearly three times as likely as their colleagues to suffer from depression. There is no magic formula to ease the psychological pain of a parent-child role reversal. But if you are caring for an elderly parent, or believe you will be one day, there are programs, services and personal strategies that can help you better balance your competing responsibilities to your parents, your employer, your spouse, your children and, most important, yourself.

When To Talk About Money

Your parents' old age could wreck their financial plans - and yours. Here's what to do now, and how to talk to them about it.

Back when you were a kid, your parents paid the bills, and you always figured you'd do the same for your children. It probably never occurred to you that you might end up helping to support your parents as well. Are you ready to take on that burden? You'd better be. If current demographic trends continue, your parents are likely to live considerably longer than their parents did - perhaps long enough to outlive their assets.

And what if they don't? 40% of people over 65 will require nursing-home or other long-term care at some point, but fewer than a third have planned financially or that possibility, according to a 1992 Gallup Poll sponsored by the insurance company Unum. That lack of planning may help explain these numbers: half of all unmarried nursing-home residents become impoverished within 13 weeks of signing in and 80% of married residents lose all their assets within a year.

That means *you* may become your parent's financial safety net - if you aren't already. "Very often it is the daughters who are left to care for the elderly parents," says Karen Altfest, a New York financial planner. "These women are often working, putting kids through school and trying to save for their own retirement. Their parents' care can add tremendously to their financial burden."

By careful planning, however, you can lighten the load. The task will be far easier if you consider your options now. Some of the lowest-cost strategies will disappear if you delay. "Advance planning is the single most important factor in caring for aging parents," says Mirca Liberti, co-founder and director of development of Children of Aging Parents, a national clearinghouse in Levittown, Penn. "Think ahead for your parents' sake and your own."

Get The Facts Early

To be of real assistance to your parents, you have to be familiar with their financial situation, which may be much better, or worse, than you think. Ideally, you should get the information when both parents are still in good health and without apparent money problems. "You could cost your parents or yourself thousands of dollars by not preparing for the worst," says Liberti. "And when a crisis occurs, it might also be

too late to find out their wishes." Approach the subject of money diplomatically, especially if you think the news will be bad. Discussing the issue with your siblings beforehand can be helpful, but nominate one child to talk to your parents so they won t feel overwhelmed. If they object strongly to sharing their financial details, have Plan B in reserve. "Your parents may find it easier to talk to a professional," says Jan Walsh, a certified financial planner with the National Endowment for Financial Education. Come armed with the names of some trustworthy financial planners to recommend."

If you end up being the emissary, and your parents are willing to discuss their finances with you, make sure you get a complete list of their assets, income and debts, as well as descriptions of their medical coverage and current physical condition. Find out the names and phone numbers of their banks, brokerage and mutual fund companies, as well as those of their lawyer, accountant and other trusted advisers.

Designate a family member to act on your parents' financial behalf in case of an emergency. While you're at it you might gently suggest that your parents make you or one of your siblings an alternate signatory on their checking and savings accounts. That way you'll be able to help them with mortgage, insurance and other payments if they become temporarily disabled, and you will have easy access to funds in an emergency. Better yet, ask them to have their lawyer draw up papers granting one child a durable power of attorney. In addition to simply signing checks, the child will be able to make financial decisions on the parents' behalf if they become incapacitated. Choose the family member who would likely be the caregiver in an emergency.

That done, you and your siblings can work together with your parents to plan a secure future for them. The job will be easier if your parents are still relatively young, in good health and affluent than if they are old, sick or financially pinched. Either way, however, you and your parents face decisions in several major areas.

Plan For Living Expenses

Your paramount concern must be whether your parent, income and assets will be sufficient to meet their basic living expenses over time. Even if they appear financially fit now, the slow creep of inflation could decimate their buying power in 10 or 20 years. But if you catch the problem early, there may be a simple solution: "Your parents may not need your money," says Eileen Sharkey, a certified financial planner in Denver. "They might need to allocate their assets to growth investments, such as stocks or mutual funds.

Investigate Strategies That Use Your Parents' Home To Solve Existing Money Problems

Parents in a cash crunch may be able to boost their income by tapping other assets. If they own their own home, that's likely to he their biggest resource. One option is for your parents to trade down to a smaller house or apartment. The move will reduce their housing costs and free up some equity to invest toward future living expenses.

If your parents are reluctant to leave their home, a reverse mortgage might be a better solution. Under its terms, your parents will receive a loan in the form of a line of credit or a monthly stipend. If they choose to receive payments based on their life expectancy, the loan doesn't fall due until they move or both die. At that point, the bank sells the house to pay the debt. "A reverse mortgage is a great option for retirees with tight finances who put a high priority on remaining in their home," says Curtiss. "It might mean $1,000 or more a month in extra income."

Look Into A Loan Against Cash Value Life Insurance

Another possible source of additional funds is a cash-value life-insurance policy that is, a whole, universal or variable-life policy that directs a portion of the premiums paid into an investment account. If your parents own such a policy, they might borrow against the cash value they've built up in their account. When the policyholder dies, the loan, plus interest, is simply deducted from the death benefit the beneficiaries receive. A widowed parent, who no longer has to worry about protecting a surviving spouse, might consider cashing in the policy and investing the proceeds.

Protect Against Catastrophic Illness

If your parents are 65 or older, Medicare, the federal heath insurance program for the elderly and disabled, will cover many of their basic medical expenses, including hospital stays of up to 60 days and 80% of most of their doctor bills - no matter what their means. About two-thirds of the nation's elderly buy additional private insurance to fill the holes in Medicare coverage. Known as Medigap insurance, these policies typically cover longer hospital stays, the co-payments required for doctors' services, a portion of deductibles and, sometimes, prescription drugs.

Consider Long-Term-Care Insurance, Particularly If Your Parents Are Relatively Young

Even the most deluxe Medigap policy won't cover long-term nursing - home care, which can cost $150 or more a day. Medicare pays only for nursing-home stays that last less than 100 days and at-home care that's needed for less than 35 hours a week. And Medicaid, the federal and state health-insurance program for the poor, won't kick in for full-time long-term care unless your parents' savings dwindle to very low levels.

The government does offer some financial protection to the spouse who doesn't require care: He or she can retain a main residence, a car, personal belongings and half of the couples financial assets up to a limit set by each state.

You may be able to protect your parents' assets if you act early. One option is to buy long-term-care insurance for them. Unfortunately, it's expensive: Your parents can reduce the premium by as much as two-thirds by purchasing coverage before age 65.

Helping From Your Pocket

There may come a time when your parents need more than advice. At that point, you might have to start digging deep into your own savings. You can minimize the pain and expenses by taking advantage of strategies that provide tax breaks and reduce the potential for family conflicts. "There are a number of way s to reduce the burden," says Joan Gruber, a certified financial planner in Dallas. "Unfortunately, many people don't know that those strategies exist."

Take Advantage Of Tax Breaks That Help Reduce The Net Costs

By law, you can give as much as $10,000 to an individual ($20,000 if you and your spouse make the gift jointly) without triggering a tax bill. If you provide more than half of a parent's income, you can claim the parent as a dependent and get a tax exemption. Likewise, if you pay more than half of your parents' support, you may be able to deduct the medical expenses you pay on their behalf.

You may also look for help from your siblings, though that can lead to disputes about who can afford to contribute the most. If you are paying the lion's share, consider making your parents a loan rather than a gift. That way, the money can be repaid tax-free

from their estate if it includes sizable assets, such as a house. "Using a loan instead of a gift can also help maintain their dignity," adds Gruber.

If there isn't enough money in the family to maintain a separate household for your parents, you may decide to bring them into your home. The federal government will give you a tax credit when you hire at-home caretakers to look after a parent in your home while you work. Some employers offer dependent-care accounts that let you use pre-tax dollars to care for a live-in parent.

Consider The Services Of A Geriatric-Care Manager

Of course, your parents would probably prefer to live at home as long as they can. Hiring a geriatric care manager can help you create and implement a care plan to assist your parents with their personal and financial needs at a reasonable cost. The services of such a manager - who does everything from recommending local services for the elderly to personally providing assistance - come at a stiff price, however, so it definitely pays to shop around.

Before you hire a care manager, interview several and ask what the charge for different services. More important, find out if they will help you find low-cost providers for some jobs, such as driving your parents to the doctor or grocery store and assisting with their home-health care needs. And check with your local area agency on aging, which may have information on inexpensive services that can save you money.

Faced with the problem of two sick, elderly parents living on a limited budget 1,600 miles away in Denver, Marlene Darby of Washington, D.C., hired the services of Louise Brunk, a local geriatric care manager, as a Christmas present to her parents in 1993. Brunk helped find workers to handle her parents' checking account and look after her housebound father when her mother went shopping or visited friends.

When Darby's father died last January at 91, Brunk was on hand to comfort his widow and handle the arrangements until Darby arrived. "Having Louise makes life easier for Mom," she says. "And I don't know what I would do without her help."

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PLANNING FOR LONG TERM CARE

How can we pay for long term care?

To plan effectively for the future, you need to find out what financial resources your elderly relative has or can access what services are available, and how to pay for the services. Payments for long-term services are now the largest out-of-pocket health care for older persons. So, as you plan, it's important to understand the financing mechanisms that exist for payment:

Medicare: a federal health insurance program providing health care benefits to all Americans age 65 and over. Medicare Part A covers hospital care and Medicare Part B covers physician and other outpatient care. Insurance protection intended to cover major hospital care is provided without regard to income, but only restricted benefits are allowed for nursing home care or home care.

Medicaid**:** established more than 25 years ago to pay for medical care for low-income Americans. Payments are made to providers of services on behalf of eligible persons. Today, thousands of older people who have exhausted their personal financial resources rely on Medicaid to pay long-term care costs not covered by Medicare or private insurance. In 1990, Medicaid paid 45 percent of all nursing home costs.

Approximately 61 percent of all nursing home patients receive Medicaid payments. Medicaid also covers home health care services, medical supplies, and equipment for eligible persons. Medicaid is a joint federal - state program. Persons who are eligible for state public assistance (DFDC) or for Supplemental Security Income (SSI), the Federal program for the aged, blind or disabled poor, automatically are eligible for Medicaid. Other eligibility requirements and benefits are based upon personal income and assets, but they vary significantly from state to state.

Medicare Supplemental Insurance (Medigap): is a private health insurance option, which, if purchased, supplements Medicare coverage. It generally pays for the non-covered costs of Medicare covered services only, e.g., hospital deductibles and physician copayments, and does not pay for long-term care services.

Private Long-Term Care Insurance*:* Is Another Option For Financing Long-Term Care services. Until recently, most private insurance companies had largely ignored the elder's long-term care needs. Some health insurance companies are now offering long-term care policies, which pay for some long-term care services, such as nursing home and home health care. Although these policies are becoming more popular and more widely available, in 1990 they represented about one percent of the nationwide expenditures for long-term care services.

Services covered under long-term care private insurance policies vary greatly. Each policy has its own eligibility requirements, restrictions, costs, and benefits. The cost of the policy usually depends on the options chosen.

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Therefore, if you are considering purchasing a long term care insurance policy, it s crucial to read the fine print before purchasing. Find out what conditions must be met in order to collect benefits. For example, some policies require prior hospitalization before coverage for long-term care services. Other questions to consider:

- Does it pay for any nursing home costs or just skilled nursing home costs?
- Under what conditions will it pay for custodial home care or hospice care?
- Are there built in benefit increases to allow for inflation?
- Are there provisions that would provide some coverage if policy should lapse?

It's also important to research the background of the company providing the policy. Find out how long they've been in business and check with the Better Business Bureau for any complaints, which may have been registered.

The Older Americans Act*:* provides funding for programs available to everyone age 60 and older. Services available may include: congregate nutrition services, home-delivered meals, case management and assessment, chore services, adult day care, home health care, homemaker services, senior centers, transportation, friendly visiting, and telephone reassurance.

Social Services Block Grants: provide similar programs for low-income persons. Individual states determine income criteria, the populations to be served, and how the federal government funds will be allocated. Services available may include case management and assessment, chore services, companion services, congregate meals, home-delivered meals, homemaker services, and transportation.

How Do I Go About Planning?

As you can see, you must consider many options before you can make a wise decision about financing long-term care services. That's why it's important to plan ahead for the possibility of long-term care, before there is a crisis.

First, assess current and potential needs. Consider if it s important for your family member to stay in his/her community and find out what long-term care services are available. Determine current eligibility requirements and costs of services. Estimate the potential cost increases over the years ahead. Remember that:

- Long-term care includes a wide range of health, social, and personal care services, many of which may be appropriate alternatives to nursing home care. Some are available at little or no cost to the consumer.
- Not all long-term care services are available in all communities.
- Medicare provides very limited coverage for long-term care. Medicare home health benefit covers only part-time skilled care.
- Patients must show they are either financially or medically needy, according to state criteria, to establish eligibility for Medicaid assistance.
- Private insurance policies vary greatly in costs, eligibility criteria, coverage, benefits, and duration of coverage.

Second, review projected financial resources to find out what can be done now to provide for future needs. Learn what specific coverage can be expected, if any, from Medicare or private insurance. You may benefit from professional assistance in planning.

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A CAREGIVER'S BILL OF RIGHTS

I Have The Right:

- To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my relative.
- To seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person and I have the right to do some things just for myself.
- To get angry, be depressed, and express other difficult feelings occasionally.
- To reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger, or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do from my loved one for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.
- Add your own statements of rights to this list. Read the list to yourself everyday.

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ADAPTATIONS FOR INDEPENDENCE

Most homes and condominiums today are designed for young adults. They simply do not have the features and conveniences that would make them appropriate and safe for older people. The ability to function well in one's home is one of the most important factors determining how long an individual can maintain comfortable independence. A well-adapted home will make many day-to-day living tasks both easier and safer and can prevent the most common accidents that may ultimately rob elders of their independence.

Start Early

Preparing a home for the senior years is a long-term project that should be started as early as possible - preferably well before there is an urgent need. Whenever possible, adaptations should be made during the natural course of home improvement and maintenance. This will often require little, if any extra cost. This is because most adaptations are simply a matter of appropriate design. For example, it costs no more to build a wide hallway than it does to build a narrow one, yet the wide one will make life much easier for anyone dealing with a wheel chair or walker. Another advantage is that solutions can be designed right into the project. For example, if levered door handles are installed instead of knobs, an add-on gadget to help turn doorknobs won't be needed later.

Making home adaptations over time makes it easier to keep control over the process. Decisions can be thought through carefully. All too often nothing gets done until there is a crisis or immediate need. Ultimately, the price of putting off adaptations can increase the chance of an accident, wasted money, lost independence, and a home that looks like it was designed by a committee!

For seniors and just about everyone else, independence is a central element of a fulfilling lifestyle. There is no greater symbol of independence than living in one's own home. More experts are discovering that extending the time that seniors can manage in their own home is important in terms of both mental and physical health.

Advice For Caregivers

Concerned caregivers often are preoccupied with the risks their loved ones take by living independently. This preoccupation can put caregivers in the position of trying to impose a long list of home adaptations in a misguided effort to make the home accident proof. When imposing solutions, however, caregivers lose sight of the key element in the equation: independence.

Most people are such fierce protectors of their independence that they will reject out-of-hand a plan of action that usurps their independence - even if the plan of action has many merits. In other words, any approach that tramples on someone's sense of independence is doomed.

Understanding the need for independence leads to the most important element of adapting a home to better suit the needs and desires of seniors: *the seniors whose needs are to be met must be in the driver's seat.* It is their home; it is their turf. Once this issue of whose home it is has been resolved, most people become open to making changes. If the adaptations are being forced from the outside, most people will resist heartily.

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There is a flip side to the independence equation. Seniors who want to prevent actions imposed by concerned family, friends, and social workers should take the initiative in making needed changes. They'll end up with a safer home, an easier daily routine, and a well-earned, renewed sense of independence.

Home Adaptations

There are four types of adaptations.

- **Mobility Into And Through The Home**

There is a strong possibility that someone in the home will eventually use a wheelchair or walker for periods of time. At the very least, as one gets older, it is more difficult to get around and steps will become a significant barrier. Even those who never need to use a wheelchair may wish to make use of grocery bag carts, strollers wheeled trashcans, wheeled luggage, and a variety of other conveniences. All these devices are stopped cold by steps and, like wheelchairs are difficult to maneuver in tight spaces once inside the home. So there are two things to aim for: eliminating steps and creating room to maneuver.

One of the easiest ways to make a home easier to live in is to make at least one entrance to the main living level accessible without going up or down steps. This may mean rerouting or regrading the front walk and porch. If this rerouting or regrading is done when the walk is being replaced anyway, there will be little additional cost.

Inside the home, there usually aren't many steps that can be easily eliminated. If an addition is added, make sure it isn't necessary to use steps to get into it! Another approach that works well is to prepare for single-level living. As changes are made over the years, seek the option of living entirely on one level, even if only temporarily. Make sure there are a full bath, a kitchen, and a bedroom all on one level. Having laundry facilities on the same level is a big plus.

Maneuverability is most critical in the kitchen and the bathroom. Use floor surfaces that don't become slippery when wet. Open up spaces and doorways. Whenever possible, design doorways that are 36 inches wide and eliminate thresholds over ½ inch high. Make sure the thresholds, the wooden, metal, or stone bumps on the floor of outside doorways and bathroom doorways, have beveled (sloped) edges. Thresholds represent real obstacles to wheelchairs and other wheeled devices. These changes will not only make a home wheelchair friendly but will also give it a more open, spacious feel.

- **Handholds**

The next issue to focus on is a handhold. Keep in mind that many serious falls are caused by inadequate railings and grips. This is especially true in the bathroom. Ensure that there is plenty of support around the toilet and the tub or shower.

Check the stairs. Does every step have an adequate railing? Many original stair banisters are good for little more than show - an adult's body weight can easily tear them from the wall. These banisters need to be checked and should be reinforced if necessary.

- **Hand-Friendly Handles And Control Knobs**

Getting around in a home doesn't do much good if one can't open the doors or use

the appliances! A room-by-room review of handles and knobs will yield a substantial list of inadequacies. Hand-friendly door levers, window handles and controls are available. Bathroom faucets are another problem area.

The kitchen may be the most critical room for checking hand-friendly handles and controls. Can stove control knobs be reached without risking a burn? Will they be easy to turn, as hands become less nimble? How about the sink faucet? What about all those cabinets and drawer handles?

- **Other Safety Issues**

Finally, there are some other issues to consider. Are there bright, automatic, external lights? What about internal lighting? As people get older, it takes more light to see the same things. Reading lights need to be brighter. Well lit stairs become ever more important.

Are there adequate home security measures? An intercom can provide added safety and a convenient way to communicate with others when it's difficult to get around. Something as simple as a peephole in the front door can be very helpful.

Burns are one of the most common injuries for older people. Often, one can eliminate entirely the use of the stove for heating water - its most common use. There are hot water dispensers that are set up like another faucet at the sink and eliminate the need for heavy pots and the risk of spilling scalding water.

Scalding water also causes many injuries in the bathroom. It is not at all unusual for someone to fall in the shower or tub, hitting the faucet on the way. If the water temperature is suddenly increased and one can't get to the controls, even moderately hot water will cause burns if allowed to flow for several minutes. 'This is another hazard that can be eliminated. A number of manufacturers make faucets that have a built-in scald-prevention mechanism, which automatically cuts off water flow if the temperature exceeds a preset maximum. Such devices can also eliminate the scalding that can occur in the shower when someone else is flushing a toilet or otherwise lowering the cold water pressure.

Conclusion

Maintaining independence takes more than words and will: it takes actions. Adaptations can maximize the years a person can operate independently in his/her own space.

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