
AGING PARENTS AND COMMON SENSE

*A PRACTICAL GUIDE
FOR YOU AND YOUR PARENTS*

THIRD EDITION

LONG-DISTANCE
CARE

YOUR

PARENTS'

FINANCIAL

AFFAIRS

BEING THERE
WHEN YOU'RE NEEDED

GATHERING

INFORMATION

ADVANCE MEDICAL DIRECTIVES

OPENING THE
DIALOGUE

YOUR

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WHERE WILL

THEY BE
LIVING

THE NEED
FOR PLANNING

YOUR

PARENTS'

LEGAL

AFFAIRS

THEIR
HEALTH

HOW TO FIND

LOCAL

SERVICES



AXA FOUNDATION

Sponsored by AXA Foundation and Children of Aging Parents (CAPS)

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This guide is intended to raise important issues and provide the reader with some background information on the topics it covers. It must not be construed as providing legal, financial, medical, or other advice. In addition, some of the topics in this guide could be impacted by changes in legislation or the introduction of new products and services. Before making decisions, readers are urged to consult with their professional advisors, who can counsel them on their own specific situation.

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TALK MUCH WHEN I WAS
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WITH. AND WE’VE STARTED
TALKING ABOUT THE
IMPORTANT THINGS.”*

SARA, AGE 49
ARIZONA

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A MESSAGE FROM THE AXA FOUNDATION

As our society ages, and people are living longer and more productive lives, eldercare has become a growing issue affecting families across our country. To address this issue, AXA Financial, through its philanthropic arm, the AXA Foundation, is pleased to publish *Aging Parents and Common Sense – A Practical Guide for You and Your Parents*.

Support for this publication is part of the AXA Foundation's ongoing commitment to address social issues affecting clients, investors, employees, and financial professionals within the AXA Financial organization, as well as the general public. As a provider of financial planning products and services, AXA helps people and businesses plan for the future, maximize the quality of life, and manage their responsibilities toward those who depend on them. AXA Financial is a member of the global AXA Group.

We would like to thank our nonprofit partners who assisted us in developing this publication:

Children of Aging Parents (CAPS) is a national organization providing information and resources on caregiving issues. The AXA Foundation provides funding to support the *CAPS toll-free eldercare help line: 800-227-7294*.

The National Alliance for Caregiving (NAC) is an umbrella organization of 25 national aging groups whose mission is to conduct research, develop national programs and increase public awareness of the issues of family caregivers. The AXA Foundation sponsors the *AXA Foundation Family Care Resource Connection*, an Internet clearinghouse listing professionally rated resources for caregivers which is hosted on the NAC Web site: www.caregiving.org.

For additional information on AXA Financial and the AXA Foundation, please visit our Web site: www.axa-financial.com. We hope you find this publication useful and will share it with those in need.

Sincerely,



Kathleen A. Carlson
President
AXA Foundation

INTRODUCTION

“WHEN DID MY PARENTS GET OLD? IT SEEMS IT WAS ONLY A COUPLE OF YEARS AGO THAT SOMEONE THOUGHT MY MOTHER WAS MY SISTER. SHE WAS DELIGHTED, AND GAVE AN EMBARRASSED LAUGH. MY PARENTS WERE STRONG, VIBRANT. GETTING OLD WAS SOMEWHERE . . . WAY OUT THERE. BUT SUDDENLY, OR SO IT SEEMS, MOM AND DAD ARE OLD. AND VULNERABLE. I WANT TO HELP, BUT HOW DO I BEGIN?”

DANIEL, AGE 44
MISSOURI

A DREAM COME TRUE

In 1900, only one out of four Americans lived beyond the age of 65. Today, the number is three out of four. This increased life expectancy has brought joy to many families, as grandparents — or even great-grandparents — now see the youngest members of their families grow to adulthood. It’s a dream come true.

Some aspects of living longer, however, may not be quite as we imagined. Today’s adults in their 40’s and 50’s represent the first generation who will be likely to spend more years helping their parents than taking care of their children. In nearly one in four U.S. households, there is someone caring for an elderly relative or friend. Generally this involves helping the older person with a host of questions and choices ranging from medical care to living arrangements, to finances, and to judgments about whether we may need to intervene in our parents’ lives.

The financial costs and the responsibility for physical care of a frail parent are not the only demands family members must face. Old issues of parent-child relationships may be rekindled, or dormant sibling rivalries may resurface. These emotional aspects of family relationships — and simply talking about the future — are often the most difficult hurdles to overcome.

Most people feel ill-informed about the problems of aging, unequipped to help, and unaware of resources that are available to assist them. Our mobile society, with children often living far away from their parents, makes these issues even more complex and difficult.

This guide is designed to offer suggestions and ideas for adults who are — or expect to be — providing support and care to their aging parents or other relatives. The details will be different for each family, but many of the experiences will be shared. We have put together a set of practical steps you can take to help assure (now and for the long term) that the dream of enjoying a long life is preserved, as much as possible, for everyone involved.

BEING THERE WHEN YOU'RE NEEDED

COMMUNICATION — ITS IMPORTANCE

Many families find it difficult to talk about issues involved with aging. Discussing personal family business, such as one's financial situation, plans for living arrangements, or health care, can be uncomfortable for parent and child alike. You may be concerned that your parents will think you are prying and greedy when you ask them to discuss their finances. They may fear they'll eventually become dependent upon you. It's painful to think about losing your parents to debilitating diseases which might deprive them of the ability to function independently or cause a lengthy illness.

Yet learning about your parents' legal and financial affairs can help prevent serious problems later. Should terminal illness or incapacitation strike them, you'll need to know where their important documents are located. You'll also want to know, and fully understand, their desires and concerns. Talking with your parents now, and putting a plan in place that addresses these issues head-on, can make everyone involved feel more comfortable.

IT MIGHT BE EASIER THAN YOU THINK

Listen carefully to your parents. Perhaps they have already mentioned some of the aging issues they are thinking about, but you may have chosen to brush aside the discussion or reassure them that "they'll live forever." This might make you feel more comfortable, but you are missing an important opening for discussion. You could be surprised to find that your parents have already given their future plenty of thought.

OPENING THE DIALOGUE

There are many ways for you to start the discussion. Think about the issues you want to talk over, then add your own creativity to opening a dialogue. The following suggestions may guide your thinking before you initiate a conversation with your parents.

"MOM AND DAD HAVE BEEN FAILING LATELY, AND I DIDN'T KNOW HOW TO BRING UP MY CONCERNS TO THEM. I WAS OVER FOR DINNER AND DECIDED TO JUST START TALKING ABOUT MY FEARS. THEY'VE ACCEPTED THE IDEA OF A HOUSEKEEPER TO DO A FEW THINGS, BUT ANY TALK ABOUT THEIR FINANCES IS STILL OUT OF THE QUESTION. I'M GOING TO ASK THEIR BANKER TO TALK WITH THEM."

ANN, AGE 53
CALIFORNIA

PRACTICAL HINT

Give your parents a gift of your time. Rather than “things,” consider giving your Dad an afternoon of golf for the two of you, and your Mom a weekend for both of you at a spa. Or spend time working together on projects of any type, for instance, helping with financial paperwork or painting the backyard fence. There doesn’t need to be an agenda; just enjoy your time together.

PRACTICAL HINT

The illness or death of a friend or relative may be the catalyst for a conversation with your parents about whether their personal affairs are in order.

- Ask for their advice. Say, “I’m putting my will together. How did you go about doing this?” Or, “I’ve been thinking about my retirement plan. What do you suggest I do?”
- Listen. Ask questions. Express your concerns in ways that emphasize your respect and affection for your parents. Tell them, “I want to be sure we know what you want done.”
- Be specific rather than general and use statements that are not judgmental to help keep the discussion going. Tell your mother, “I’m worried about your driving late at night,” rather than, “You are not a good driver anymore.”
- Bring their professional advisors into the discussion. Say, “Based on what the doctor says about your eyesight, what is your plan, Dad? Would you like me to get some information on options to provide some help around the house?”
- Use your own concerns as a way to begin. Start with, “I’m worried about your losing so much weight. You may not think it’s important, but this is not normal and your doctor would want to know.”
- Respect their decisions. If you don’t agree, don’t get into an argument. Instead, ask questions that help them to decide if their decision is best, such as, “If your plan doesn’t work out the way you’d like, what else might you do?”

Regardless of the issue or your way of broaching the subject, your first attempt may not be successful. If this happens, you may want to step back and approach the subject in another way, at a later date. Allowing your parents time to react and adjust to the seriousness of your concerns is important. Major issues are seldom resolved in a single discussion.

If there are some subjects you and your parents simply cannot discuss, suggest they talk with someone who has fewer emotional ties, for instance, another family member or friend, their lawyer, accountant, financial planner or physician.

GATHERING INFORMATION

One of the most important elements in helping you and your parents plan for the future is accumulating and organizing information that pertains to their personal and financial affairs. Accurate and readily accessible data will help you understand the issues and be prepared to resolve a crisis, should one occur. In addition, the task of collecting and reviewing information often is a catalyst for discussing issues, as well as for identifying actions that need to be taken or plans that need to be updated. The following list is designed to suggest types of information that should be maintained in a safe but accessible place, and reviewed periodically (perhaps at tax time) to be sure it is current.

When recording information, be sure to include account numbers, telephone numbers, addresses, and the location of all key documents.

INFORMATION AND KEY DOCUMENT LIST

PERSONAL AND FAMILY

- Birth certificates
- Marriage certificate
- Citizenship papers
- Divorce/separation papers
- Adoption papers
- Social Security numbers/cards
- Passports (numbers, expiration dates)
- Driver's licenses (numbers, expiration dates)
- Military records

MEDICAL

- Health care professionals (names, address/telephone)
 - physicians
 - dentists
 - pharmacists
 - other professionals
- Health care proxies/living wills
- Medications (dosages, purpose, name of prescribing physicians, pharmacy, address/telephone)
- Hospitals of choice (address/telephone)
- Medicare numbers
- Medicaid numbers (caseworker numbers, address/telephone)
- Social worker or caseworker names (address/telephone)

FINANCIAL

- Income sources (retirement and/or disability benefits, Social Security, etc.)
- Financial assets (institution names, account numbers, address/telephone, form of ownership, current value)
 - cash
 - bank accounts
 - stocks
 - bonds
 - mutual funds
 - money market funds
 - retirement and pension plans
 - IRAs
 - annuities
 - life insurance
- Real estate (property addresses, location of deeds, form of ownership, insurance, current value)
 - primary home
 - vacation home
 - investment property
- Other assets (location of items/titles/documents, form of ownership, insurance, current value)
 - automobiles
 - boats
 - inheritances
 - precious gems, jewelry
 - collectibles
 - interests in businesses
 - hidden valuables/items in storage
 - loans to family members/friends
- Liabilities (creditor institutions, address/telephone, approximate debt)
 - mortgages
 - personal loans
 - credit cards
 - notes
 - IOUs
 - other

PRACTICAL HINT

Many people find it useful to collect all personal and financial information in one master binder or file. The binder or file can be divided into the categories suggested in this list, or others if more suitable. It can include copies of important papers that are kept elsewhere, or any other materials that are useful to have at hand. This method is flexible and easy to update, and serves as a convenient summary of your parents' personal, financial, and legal affairs.

THEIR HEALTH AND WELL-BEING

WHAT CONSTITUTES NORMAL AGING?

As your parents grow older, it will be important for you to distinguish between the normal signs of aging and those that indicate possible illness. While it is common to experience physical changes in later life, illness, confusion, or depression is not a “normal” part of aging.

“Normal” physical changes of aging are, for the most part, visible changes such as gray hair, drying and wrinkling of the skin and some sensory changes. While all older persons do not experience diminished sensory capacity, many do experience vision problems, hearing problems, and a reduction in the sense of touch and taste. And, energy levels and strength and agility are often affected by age.

Changes in sleep patterns, pain, and unexplained weight loss or gain are not normal parts of the aging process and signal problems that should be discussed with a health care professional.

HEALTH ISSUES THAT MAY NEED TO BE ADDRESSED

A number of diseases and conditions that frequently occur among the elderly may be mistakenly identified as part of the aging process, and thought therefore to be untreatable. The fact is, these diseases and conditions very often are treatable and should be addressed by a physician. A few of these include:

Adult onset diabetes	Glaucoma
Alzheimer’s disease	Heart disease
Arthritis	Lung disease
Cancer	Kidney and bladder problems
Cataracts	Macular degeneration
Dementia	Osteoporosis
Depression	Parkinson’s disease
Enlarged prostate	Vascular disease

“DAD WAS ABOUT TO BE RELEASED FROM THE HOSPITAL. MOM CALLED, SOBBING. SHE WAS SURE SHE WOULD MAKE THINGS WORSE BY NOT KNOWING HOW TO TAKE CARE OF HIM. I IMMEDIATELY ARRANGED FOR HOME NURSING CARE. MOM HAS NOW LEARNED HOW TO DO MUCH OF WHAT NEEDS TO BE DONE AND A NURSE COMES EVERY NIGHT. SO THEY’RE ABLE TO STAY IN THEIR HOME.”

KAY, AGE 51
MINNESOTA

PRACTICAL HINT

To help you understand the various drugs your parent is taking, ask the pharmacist for a printout listing all prescriptions, including possible interactions and side effects.

If your parents are diagnosed with these or other illnesses, you will want to learn more about what can be done. In addition to your parents' or your own physician, there are many sources of information. The Directory of Resources on pages 40-60 lists organizations that provide information and services specific to various illnesses.

STAYING INFORMED ABOUT THEIR MEDICAL CONDITION

Try to become informed about the medical conditions of your parents. Most older people have one or more chronic conditions such as arthritis or high blood pressure which they are managing in partnership with their physician. The successful management of chronic illness is a key to continued good health. Make sure you ask questions and show your support of their efforts to remain healthy.

Ask your parents for the names of their physicians, a listing of all of the drugs they take — both prescription and over-the-counter — and the name of their pharmacist and drug store. This basic information can be vital if a parent is in an accident or unable to communicate with health care professionals. You can overcome any resistance on their part to provide this information by giving them your own vital health information in case something happens to you and suggest that it's a good idea for family members to share this information in case of emergencies.

If your parent is unsure of the reasons for taking certain medication that has been prescribed by their physician, offer to accompany them to their next appointment to help them discuss their medical condition with their physician. And, if your parent has been told that a condition that bothers them is a "normal" part of aging, suggest to them that a second opinion would be a good idea. Remind them that it is not "normal" to be sick.

OVERMEDICATION: RECOGNIZE IT . . . PREVENT IT

Overmedication and adverse interaction of drugs are a common problem for older people. Changes in the aging body sometimes result in an "overmedication" problem even when taking the same dosage of a drug that has been taken for many years. Also, many drugs have noticeable adverse interactions with food or other drugs in older people that would not occur in younger persons. And, prescription drugs can interact with over-the-counter medications to create a serious health problem.

Problems with medication can occur because the patient lacks adequate information to make informed choices about their schedule for taking prescription drugs, or over-the-counter medications. Physicians do not always provide adequate information to patients about drug interactions and patients often do not ask enough questions about side effects or interactions which may occur. Overmedication can occur when several physicians prescribe drugs for a patient, and are unaware of other medications the patient is taking. However, even if an older person sees only one physician, there are risks associated with medications related to drug interactions with over-the-counter drugs, food, alcohol, and changes in

health status. Problems can also arise when there is no system in place to ensure that medications are taken as prescribed.

If you notice confusion, personality changes, or changes in the overall well-being of your parent, you may want to suggest that they schedule an appointment with their doctor. In order for this appointment to be successful, your parent should take with them a list of all drugs — prescribed and over-the-counter — they are currently taking.

The pharmacist is also an excellent source of information about drugs and should be consulted as well as the physician. A pharmacist can discuss not only possible interactions and problems with a medication, but suggest strategies for managing medication as well. Your pharmacist can advise you and your parent if a visit to the physician and a review of medication is needed.

ADDITIONAL THINGS YOU CAN DO:

1. Help your parent make a list of prescriptions and over-the-counter medications they are currently taking. Go through their medicine cabinet and kitchen shelves with your parents and throw out all out-dated prescriptions and medications.
2. Make sure that they are only getting their prescriptions filled at one pharmacy or, if they are using a mail-away service, that anyone filling their prescriptions has the complete list of medications in their file.
3. Remind them to discuss any new prescriptions with their pharmacist to make sure they understand the possible side effects, possible interactions, and that the pharmacist has added it to their file.

YOUR PARENTS' WELL-BEING

Adults of all ages benefit from feelings of independence and autonomy. In later life, concerns about a loss of autonomy and independence can be barriers to asking for help or seeking assistance from family members and friends. One of the most common forms of help that adult children can provide for their parents is information about resources that are available to enhance their independence. Finding out about these resources is one of the most important gifts you can give to your parents.

Today there are many resources available to make the home safer and reduce the risk of accidents. There are also resources which increase the feeling of security and safety within the home. And, finally, there are many community services to help an older person by providing information or by providing a needed service.

The key to well-being in later life is the maintenance of a lifestyle that suits the individual. Helping your parent maintain their lifestyle and independence is sometimes a challenge, but with information about resources and services that fit their needs, you will have the satisfaction of knowing that you are doing everything you can to be supportive of their needs and wishes. Remember, your parents have been making their own decisions all of their adult lives and will want to continue this practice as long as they are able.

PRACTICAL HINT

Personal Emergency Response

Systems (PERS) are a great gift idea. Suppliers may be found in your local yellow pages under Medical Alarms or Systems and Monitoring. Your parents' local hospital may also be able to direct you to PERS suppliers.

PRACTICAL HINT

Many newspaper, magazine, and book publishers offer large-print editions for individuals with vision problems. Consider giving these as gifts. A large-print lending library is also available at the National Association for the Visually Handicapped (see the Directory of Resources, page 53). Books on tape are another alternative for parents who miss being able to read.

When dementia or Alzheimer's Disease interferes with decision making ability, it is sometimes necessary for an adult child to help with decisions (see p. 27, Powers of Attorney). However, if both parents are living and one has some cognitive impairment, the most appropriate role for the adult child is to support the healthy parent and their needs and wishes — both for themselves and their spouse.

DAILY LIVES MADE EASIER

As our aging population increases in number, manufacturers are making many specialized products to help individuals remain comfortable in their homes. So-called "aids for daily living" are useful and generally inexpensive items that can make daily activities easier to perform for those with physical restrictions. Some of these devices are:

- Kitchen implements that make opening cans and bottles, peeling potatoes, and cutting and dicing vegetables easier
- "Reachers," pincer-like devices for people who have a weak grasp or limited mobility, to eliminate bending over or having to reach for objects
- Levers instead of door knobs, to eliminate a twisting wrist motion
- Bathing benches and hand-held showers for bathing with greater safety
- Pill crushers, for those who have difficulty swallowing medication
- Talking clocks, wristwatches, and calculators, for people with poor vision
- Automatic lifts, for beds and chairs
- Button loopers and zipper pulls, for easier dressing
- Specialized dinnerware, to enable eating with one hand
- Single lever faucets for kitchen and bath
- Touch-tone telephones with large numbers, speaker or hands-free telephones and TDD (Telecommunications Device for the Deaf)

Many pharmacies and the new superstores devote a section to products that serve the elderly, as do medical equipment dealers and local telephone companies. Home health catalogs, featuring many of these devices, are advertised in consumer health magazines.

Some examples of products and modifications that can make the home safer or more comfortable are:

- Bathtubs with doors for easy access
- Elevator-chairs that glide up and down stairways
- Handrails to aid rising and sitting
- Ramps, enlarged doorways, and lower kitchen and bathroom cabinets for wheelchair accessibility

PERSONAL EMERGENCY RESPONSE SYSTEMS

Installing a personal emergency response system (PERS) in your parents' home can relieve anxiety when your parents are alone. A PERS is a small device worn around the neck or on the wrist that allows the wearer to signal for help by pressing a button. The button activates a communicator located in the home that sends an emergency signal over a telephone line to a 24-hour monitoring center. The center attempts to determine the nature of the emergency and calls a relative, neighbor, ambulance, or the police. Studies show that users of these types of systems report heightened feelings of independence, security, and peace of mind.

FINDING LOCAL SERVICES

Most communities have human services agencies that may be able to assist you. To find out what your parents' community has to offer, contact the Eldercare Locator, 800-677-1116, sponsored by the National Association of Area Agencies on Aging. Another source is your parents' state Department of Aging or county Area Agency on Aging. These government-funded agencies will know what services are available in their area. See *Where You Can Turn for Help*, pages 33-35, and the *Directory of Resources*, pages 40-60, for more information on organizations that can assist you. There are also Web sites available that provide information about local services and quality care. See the *Directory of Resources* section for tips on using the Internet to help you locate services.

Many local resources are also listed in the telephone book. Yellow pages list businesses and nonprofit organizations under many categories, such as:

FACILITIES

Adult Day Care
Assisted Living
Hospices
Hospitals
Nursing Homes
Rehabilitation Centers
Retirement Communities
Senior Citizen Centers

HOME CARE

Home Health Services
Homes-Residential Care
Nurses
Visiting Nurses

PROFESSIONALS

Geriatric Care Managers
Geriatricians
Gerontologists
Nurses
Nutritionists
Social Workers

SERVICES

Elder Services
Geriatric Evaluation Centers
Human Services
Medical Claims Services

Resources may include independent services, and some hospitals, that have outreach programs to go into private residences to help with daily activities such as cooking, cleaning, personal hygiene, bill paying, and other paperwork. In some communities, volunteers, such as students and members of religious organizations, perform these kinds of services. Organizations such as Meals-on-Wheels also can help you care for your parents in their home. The blue pages, available in some telephone books, list federal, state, and city government offices which may also provide information.

PRACTICAL HINT

Keep in mind that the types, caliber, and accuracy of information provided by the Eldercare Locator (800-677-1116) or your parents' state Department of Aging and county Area Agency on Aging, can vary widely from area to area.

PRACTICAL HINT

Your older relative may be able to live at home much longer if their home is made safer and more accessible by assistive devices and home modifications. Examples include entrance ramps, grab bars, bathing benches in the bathroom, and personal emergency response systems.

WHERE WILL THEY LIVE?

“MOM MOVED INTO A HIGH-RISE APARTMENT BUILDING FOR THE ELDERLY AFTER DAD DIED. MY SISTER, BROTHER, AND I HAVE DINNER AT HER APARTMENT ONCE A WEEK. WE BRING THE FOOD. IT MAKES HER FEEL LIKE SHE’S STILL THE HUB OF THE FAMILY. MY BROTHER HANDLES ALL MEDICAL APPOINTMENTS AND PRESCRIPTIONS, MY SISTER ALL THE FINANCIAL AFFAIRS, AND I DRIVE MOM ANYWHERE SHE WANTS TO GO. WE’RE A CLOSE FAMILY AND WE’RE ALL HELPING.”

ROGER, AGE 42
MASSACHUSETTS

THE MEANING OF HOME

As you talk about their plans, it’s important to understand what your parents’ home means to them. For some, home represents the familiar comforts they’ve created over the years. It can mean self-sufficiency and privacy, or neighborhood and friends. For others, home is wherever their family is. Or it may simply be anywhere they live. This understanding of what home means to your parents, and a good look at their present housing, financial resources, and health, should shed some light on what direction their plans may take.

Your parents may want to remain in their current home. As long as they can physically and financially care for themselves and their home, this may be the best option. For some parents, moving to a smaller, simpler house or apartment in the same community, a retirement community, or elsewhere may be ideal.

SHOULD YOUR PARENTS MOVE INTO YOUR HOME?

There are many reasons why you might consider having your parents move in with you. It may be a matter of convenience; or the least expensive alternative, especially if costly overnight help is required to keep parents in their own home. This decision is frequently made on short notice, responding to a discharge from the hospital or following a bereavement. Even when there is little time to decide, it’s important to weigh the advantages of a shared household along with the drawbacks. Remember that most parents do not want to live with their children but would rather live independently.

Start by listing the pros and cons and then discuss them with your parents, spouse, and children. Give serious thought to your, and your family’s, ability to live together comfortably with your parents. Think about how well you get along, and whether there is enough space to ensure everyone’s privacy. Also, consider what physical modifications, if any, might be required to make your home more accessible, and what local services are available in your community should you require help.

HOUSING OPTIONS

PARENTS WHO ARE HEALTHY AND NEARLY INDEPENDENT

SENIOR APARTMENTS

also called Congregate Residences or Senior Retirement Apartments

DESCRIPTION

- Apartment for individual/couple
- No entrance fee
- Provide meals, housekeeping, and a variety of social, recreational, and cultural programs
- Dispense medications (in some cases)
- No hospital or 24-hour care facilities on premises

REQUIREMENTS

- Individuals or couples must be mobile and capable of caring for themselves
- Monthly fee covers rent (meals and other services are extra)
- Age requirement may vary by facility

RETIREMENT HOTELS

DESCRIPTION

- Room with private or shared bath
- May or may not be furnished
- Maid and linen service available
- Meals available
- Dispensing medications and other medical services vary by facility

REQUIREMENTS

- Weekly or monthly fee covers rent (meals and other services are extra)
- Residents must be able to care for themselves
- Age requirement may vary by facility

SUBSIDIZED CONGREGATE HOUSING

also called Public Housing or Section 202 Housing

DESCRIPTION

- Apartment for individual/couple
- State or federally subsidized low-income housing
- Provide 1-3 meals a day, housekeeping, and some social, recreational and cultural programs
- No hospital or 24-hour care facilities on premises

REQUIREMENTS

- Must be 62 or older
- Specified income guidelines
- Residents must be able to care for themselves
- Monthly fee covers rent, meals, and programs

Parents who cannot, or do not wish to, remain in their present home have a number of options to consider. The terms used to describe these housing options can vary from region to region. The following glossary describes the types of facilities and may help in choosing the appropriate option for your parents. Housing experts also note that “naturally occurring retirement communities” or “NORCS” are emerging in many cities and towns where a majority of the residents in the apartment building or neighborhood are older. These communities are a result of the residents’ decision to stay in their own homes as they age and, in many areas, special services are now available to those living in independent housing.

CONSIDERATIONS

- Prolonged illness or inability to care for themselves requires moving to another facility
- Quality of facility and types of services vary

CONSIDERATIONS

- Few, if any, social programs
- Prolonged illness or inability to care for themselves requires moving to another facility

CONSIDERATIONS

- Long waiting lists
- No medical care

PRACTICAL HINT

Help your parents collect information on the housing options available in their local area or in other communities they may be considering. Even if they decide to remain in their own home for now, the exploration process will have been helpful if they decide or need to make a move at some later date.

PRACTICAL HINT

Develop a worksheet for evaluating each residence and use it to compare facilities your parents are considering. Some things to look for include: the facility license or accreditation and financial condition; qualifications of the administrator; 24-hour nursing care availability, emergency policies and services; transfer arrangements with hospitals; accommodations for special diets; recreational services and social events; the general atmosphere; and safety policies and procedures. Ask to talk with others whose parents live at the residences you are considering.

HOUSING OPTIONS *(CONTINUED)*

SHARED HOUSING

also called Small Group-Shared or Supportive Housing

DESCRIPTION

- Shared home for 5 to 20 residents
- Residents do all cooking and housekeeping chores
- Some have full-time, live-in housekeeping managers
- Sponsored by churches, synagogues, or advocacy groups

REQUIREMENTS

- Monthly rent, plus shared expenses
- Residents must be mobile and capable of handling some household chores

MATCHED HOUSING

DESCRIPTION

- Parents stay in own home
- Rent room to someone in need of housing in exchange for household help

REQUIREMENTS

- Private arrangement (some local social services provide potential renter candidates)

PARENTS WHO WANT FLEXIBLE/PROGRESSIVE CARE IN A SINGLE FACILITY

CONTINUING-CARE RETIREMENT COMMUNITIES

also called Life-Care Communities

DESCRIPTION

- Rental or condominium apartment for individual or couple
- Residents remain in community for the remainder of their lives
- Hospital and nursing home facilities on premises (in most cases)
- 24-hour care (as needed)
- All meals, housekeeping, social, recreational, and cultural programs available (as needed)

REQUIREMENTS

- Good health when entering
- High entrance fee as well as monthly maintenance
- Age requirement may vary by facility

CONSIDERATIONS

- Home-like environment
- Living closely with strangers may be difficult for some
- Residents tend to take care of each other once they get to know one another
- Prolonged illness or inability to care for themselves requires moving to another facility
- Quality of facility varies widely

CONSIDERATIONS

- Locating and trusting an individual to share your parents' home may be difficult

CONSIDERATIONS

- Very expensive
- Most flexible alternative
- Over time, as parents' needs change, all levels of care are available
- If one parent becomes ill, other can remain in their nearby apartment
- Facilities available in most parts of the country
- Features, services, and quality of care can vary widely

PRACTICAL HINT

Spend plenty of time with your parents at each of the residences you are considering, especially during activities and at mealtime. Is there good interaction between the residents and the staff? Make return visits to the residences that look most promising. If your parents have been unable to accompany you on earlier visits, ask them to come along on these return visits.

PRACTICAL HINT

Keep in mind that home health care is an option that can help your parents to continue living in their own home as long as possible. Private and nonprofit professional services, available in most communities, range from providing help with medications to 24-hour skilled nursing. See page 34 for more discussion on home health care.

HOUSING OPTIONS *(CONTINUED)*

PARENTS WHO REQUIRE HELP WITH DAILY LIVING

ASSISTED-LIVING FACILITIES

also called: Semi-Dependent, Board-and-Care, Institutional Living, or Personal Care Facilities

DESCRIPTION

- Licensed facilities that range from a large private home, to converted hotels with apartments, a shared dining room, and nurses
- Room with private or shared bath
- Provide all meals, housekeeping, and social programs
- Services include bathing, dressing, and other routine functions as required
- Medical services will vary by facility

REQUIREMENTS

- Monthly fee
- Resident does not require skilled nursing or 24-hour care

PARENTS WHO NEED 24-HOUR CARE

NURSING HOMES

also called Convalescent, Rest, Intermediate or Extended Care, or Skilled Nursing Facilities

DESCRIPTION

- Licensed facilities
- Private or semi-private room with bath
- Skilled nursing care 24 hours a day
- Physical and mental rehabilitative services
- Provide all meals, and social and cultural programs
- Help with eating, bathing, and grooming
- Dispense medications

REQUIREMENTS

- Daily fee (billed monthly)
- Resident must need 24-hour skilled nursing care and/or rehabilitative services

CONSIDERATIONS

- If need for personal assistance increases, help is available
- Prolonged illness requires moving to nursing home
- Medicare does not cover this type of care
- Medicaid may be available for a few facilities in some states
- Cost and quality of care can vary
- Some long-term care insurance plans cover part of the costs of assisted living facilities.

CONSIDERATIONS

- Expensive
- Medicaid generally takes over payment once the individual qualifies financially
- Quality of care can vary by facility

PRACTICAL HINT

If you are looking for an assisted-living facility or a nursing home, make sure you ask to see each facility's state inspection report (also called the state survey). If you get the runaround or if the report contains any unexplained health, safety, or quality of life deficiencies, drop that facility from your consideration.

PRACTICAL HINT

During this evaluation process, it's important that you and your parents get answers to whatever questions you have, that you not feel intimidated, and that you have a tour of the entire facility. Only with thorough research will you and your parents begin to feel comfortable with their move to a new residence.

YOUR PARENTS' FINANCIAL AFFAIRS

THE IMPORTANCE OF PLANNING

There's a reason for everyone to spend time thinking about their financial future. Many people assume that "financial planning" applies only during their working years, when they are accumulating assets and preparing for their retirement. They often overlook the importance of continuing the financial planning process after retirement, while the assets are being used.

Post-retirement financial planning includes developing strategies to maintain purchasing power in the face of inflation, preparing for emergencies and major events in the future, determining how to use savings and other assets to supplement income, and – for many people – making major investment decisions, for example, as a result of the sale of a house. Another part of planning for older people, if they have not already done so, is beginning to think about the eventual disposition of their assets.

If your parents haven't taken stock of their financial future, you may be able to make a big contribution to their peace of mind (as well as your own) with some encouragement and coaching.

Ideally, financial planning should be done by your parents in partnership with trusted advisors who fully understand their financial situation and with whom they feel comfortable, for example, their accountant, insurance agent, broker, attorney, banker, or other professionals. Several resources for finding professionals who have expertise in financial and investment issues facing the elderly are listed on pages 57-59 in the Directory of Resources.

GETTING THE MOST FROM INVESTMENTS

Most retired people supplement their pension and Social Security income with some combination of earnings and principal from personal investments and/or employer-sponsored retirement and savings plans. Your parents' financial advisors can help determine in what order various categories of assets should be used, advise on legal and tax issues (for example, there are specific

"WHEN MY PARENTS RETIRED AND MOVED TO A SMALLER TOWN, THE OBJECT WAS TO SIMPLIFY THEIR LIVES A LITTLE. BUT WITH DAD'S PROFIT-SHARING DISTRIBUTION, MOM'S LUMP-SUM PENSION, AND THE PROCEEDS FROM SELLING THE HOUSE, THEY SUDDENLY HAD MORE MONEY TO MANAGE AND MORE FINANCIAL DECISIONS TO MAKE THAN THEY'D EVER HAD IN THEIR LIVES!"

MARTHA, AGE 46
NEW JERSEY

PRACTICAL HINT

If you have questions concerning your parents' current Medicare coverage, eligibility, or enrollment requirements, visit the Medicare Web site at www.medicare.gov and the Social Security Web site at www.ssa.gov, or your local office of either of these agencies.

requirements as to when they should begin drawing on any IRA accounts), and recommend financial products and investments to meet their needs.

If your parents are relatively young and in good health at retirement, they need to be aware of the potentially devastating effect on fixed incomes of even a moderate level of inflation over a long period of time. Many parents of today's baby boomers grew up during the Depression and are deeply distrustful of investments they consider "risky." But being overly conservative in their choice of investments may in fact be a high-risk strategy that exposes them to the danger of losing purchasing power. The fear of outliving one's assets during a long retirement can lead older people to deny themselves the enjoyment they could have with a little more to spend, or even to scrimp on the necessities of life. There are creative solutions to convert a portion of their assets into a dependable lifetime income, thus allowing other funds to be used, free of worry. Your parents' financial advisors should be able to describe investment programs and annuity-type products that address this concern.

MANAGING THEIR DAY-TO-DAY AFFAIRS

What if your parents reach the point where – because of physical impairments or failing memory – they have difficulty keeping track of their financial situation and performing routine tasks like balancing the checkbook and paying bills on time? One solution is for you to take over some or all of these responsibilities. You may wish to check with utility companies, landlord or mortgagee, and others to arrange for bills to come directly to you, or alternatively for you to be notified if bills aren't paid on time. Consider providing your parents with a checkbook with NCR (No Carbon Required) paper, so there is a record of each check exactly as it's written. Other approaches include getting a durable power of attorney (see p. 27) which survives disability or, for smaller amounts of money, you can set up a joint checking account with your parents.

Additionally, entrepreneurial businesses have started up to help elderly people with their routine financial, legal, and medical paperwork. Social workers, geriatric care managers, accountants, or bookkeepers are good sources of references for this type of service. Be sure to interview the service provider, compare prices, and check with other clients before making your decision. "Treating" your parents to this type of service might be a much-appreciated gift.

PLANNING FOR FINANCIAL EMERGENCIES

The potentially devastating impact of a catastrophic or long-term illness is a great concern for most older people. Medicare, the federal health insurance program for the elderly and disabled, covers many basic medical expenses for people over age 65. Medicare Part A covers hospital costs, and Part B covers doctor bills and other medical costs. In 2000, this included hospital stays of up to 60 days, after a \$766 deductible per stay, and 80% of Medicare-approved doctor bills, after an annual \$100 deductible. After the first 60 days in a Medicare-certified hospital and continuing through the

90th day of hospitalization, the beneficiary must pay a coinsurance of \$194 per day in 2000.

Health insurance from a private company (commonly called “Medigap” or supplemental insurance) can be added to fill in the holes in Medicare coverage. Policies can be purchased that cover your parents’ Medicare deductibles, longer hospital stays, co-payments for doctors’ services, and a portion of their prescription drugs. Medigap coverage is an important way to protect against catastrophic medical expenses should your parents become ill. All Medigap policies issued since 1992 must match one of ten standard benefit plans, regardless of the insurance company (except in Wisconsin, Minnesota, and Massachusetts). Your parents will want to understand their Medicare coverage and the benefits provided by the ten Medigap insurance plans before making a purchase.

Consumer interest in insurance to cover long-term health care has risen in recent years primarily because the rates charged for nursing home care can range from about \$150 to over \$300 per day. Medicare and Medigap coverage for skilled nursing home care is extremely limited, and Medicaid generally doesn’t cover full-time long-term care until your parents’ net worth dwindles to a few thousand dollars. Long-term care insurance to cover these costs can be expensive, but it can also protect your parents’ assets if they act early. Your parents should be aware that even if they can afford a long-term care policy, they may not qualify if they are already in poor health, and that coverage is more expensive and harder to qualify for as they get older. They should compare several different policies and insurance companies to determine which policy best fits their needs and budget.

Also, some employers offer long-term care insurance that employees can purchase on behalf of their parents, paying the premium for them. This can provide coverage for the older person’s long-term care needs while retaining their assets. Your parents may also have some health care protection available from previous employers. It is important to stay abreast of the available benefits, and to be sure not to duplicate coverage they already have.

As people grow older, their needs for life insurance may change and should be reviewed with a professional, keeping in mind that advancing age and poor health may make it very expensive – or impossible – to buy a new policy. Any decision to exchange a life insurance policy or to allow it to lapse should be made with this in mind.

SOME POSSIBLE RESOURCES IF MORE MONEY IS NEEDED

Emergencies or opportunities may arise which will require large amounts of cash. Before considering the liquidation of income-generating assets, the following options may offer a solution:

- Life insurance as a cash resource. If your parents have a whole-, universal-, or variable-life policy, it may be possible to borrow against the cash value. The loan, plus interest, is simply deducted from the death benefit when the insured dies. A “living benefit” enhancement is also available on many life insurance policies. If the insured person is

PRACTICAL HINT

For help in understanding the ten standard Medigap insurance plans, contact the United Seniors Health Council, listed on page 59 in the Directory of Resources. Ask for a copy of the annual Special Report Medicare Health Plan Choices: Consumer Update.

PRACTICAL HINT

If you are in a position to help your parents financially, there are a variety of ways to do so, for example – taking over some of their ongoing expenses, purchasing a home in which they live rent free, giving them an annuity that will augment their income, buying them a long-term health care policy, or giving a simple cash gift. You and your spouse may each currently give up to \$10,000 annually to each parent without creating any tax consequences for them or yourselves. This \$10,000 annual gift tax exclusion will be adjusted for future inflation. Check with your tax advisor.

diagnosed with a condition limiting life expectancy to, for example, six months or less, the policyholder may be able to receive, in advance, a substantial portion of the benefit that would ordinarily be payable at death. Your parents should contact their life insurance agent for more information.

- Utilizing home equity. If your parents own their home, there are potential “real estate paybacks” that can convert their home into cash. Some of them are:

REVERSE ANNUITY MORTGAGE

This home equity loan has several different plans whereby a bank creates monthly income by extending a loan based on the existing equity and the owner’s life expectancy. Your parents would retain the right to remain in the home until they choose to sell it, or until they die, at which time the loan is paid off to the lender, or the lender receives the home.

DEFERRED PAYMENT LOAN

With this type of home equity loan your parents use their home’s equity as a line of credit that allows them to draw cash as needed. The interest on a deferred loan accrues and is added to the principal when the loan is repaid. The loan is payable upon the sale of the property or your parents’ death.

SALE LEASEBACK

Your parents sell their home to someone who will allow them to live in it at a specified rent for a specified time – usually for as long as they live. This is sometimes called a “life rights” lease.

FINANCIAL ASSISTANCE PROGRAMS

If your parents’ resources have become depleted, and family members are unable to provide direct financial support, there are various local, state, and federal programs to help with basic living expenses such as medical care, food, and housing. Older people are frequently reluctant to accept governmental financial aid and social services. Having paid their own way for most of their lives, they may be uncomfortable to admit that they now need financial help. If your parents feel that way, you might remind them that they have worked hard and paid taxes to support these social programs, so they are entitled to use them.

Once you and your parents have determined that they indeed require assistance, contact the Social Security Administration office and the Area Agency on Aging (AAA) in their community. A social worker can tell you which government programs and community services could help your parents, and whether they meet the eligibility requirements, which can include age and state of health, as well as level of income.

Visit the Web sites hosted by Medicare and the Social Security Administration to check out their consumer information. See page 53 and 58, respectively of the Directory of Resources section.

EXAMPLES OF ASSISTANCE AVAILABLE TO ELIGIBLE SENIORS ARE:

- Rent subsidies
- Utility company discounts
- Municipal programs established for low-income elderly
- Health fairs that provide free diagnostic screening
- Physicians who accept Medicare and Medicaid assignments
- Nonprofit and governmental health care providers who offer health services on a sliding-fee basis
- The Veterans' Administration's Non-Service-Connected Pension with Aide and Attendance Program for honorably discharged veterans who meet criteria for disability and financial need
- Supplemental Security Income (SSI) paid by the Social Security Administration to seniors living below the poverty level (SSI provides additional monthly income and Medicaid coverage for many medical expenses not covered by Medicare)
- Supplemental aid programs provided by state agencies in consultation with the Social Security Administration
- Food stamps, housekeeping services, home-delivered meals, home health care, and transportation

ESTATE PLANNING

The section on Your Parents' Legal Affairs on pages 25-28 of this guide discusses the importance of having an up-to-date will and other legal instruments to be sure your parents' wishes are carried out in the event of disability or death. There are many financial issues to be taken into consideration when planning for the ultimate disposition of assets following the death of a parent. Key estate planning issues to consider include:

- Determining the benefits payable from all life insurance and employee benefit plans in the event of death
- Reviewing major financial arrangements that would need to be taken care of (pay off a mortgage, transfer ownership of a business, etc.) and working with your parents' advisors to make sure the structure of the transactions is clear and the funding is in place to accomplish them as desired
- Reviewing the way in which property is owned (joint ownership, tenancy-in-common) in light of laws that would govern disposition of these assets and could supersede the wishes expressed in the will
- Estimating the size of the estate for estate or inheritance tax purposes, and being sure there are adequate provisions for funds to meet any tax requirements
- Reviewing strategies to limit estate tax liability (for example, affluent elders can reduce the size of their estates by giving gifts of cash or other assets to family members rather than waiting to pass along all their assets after death)

These estate planning issues are best addressed with the help of a professional who understands your parents' financial situation and personal philosophy as well as the legal and tax framework that will apply.

PRACTICAL HINT

Current Federal law allows the first \$675,000 of an individual's estate to be passed on – free of estate taxes – to any beneficiaries, in 2001. This amount will gradually increase to \$1,000,000 per individual in 2006 and thereafter. Many people don't realize that if they own an insurance policy on their own life, the proceeds of this policy will be included in the estate and could well put the total amount over the 2001 \$675,000 limit, thereby needlessly incurring estate taxes. This problem can usually be avoided by transferring ownership of the life insurance policy to an irrevocable trust or to another member of the family at least three years prior to death.

YOUR PARENTS' LEGAL AFFAIRS

“MY BROTHER RAY AND I DIDN’T KNOW IF DAD HAD DONE ANY PLANNING. WHAT DID HE WANT TO HAVE HAPPEN? WAS ONE OF US SUPPOSED TO HANDLE THINGS? WE WEREN’T SURE HE EVEN HAD A WILL. NOW HE WAS IN THE HOSPITAL. IT WAS ONLY A SCARE, BUT IT REALLY MADE US THINK. WE HELPED DAD FIND AN ATTORNEY. HE’S UPDATED HIS WILL (THERE WAS ONE) AND EVEN SIGNED A HEALTH CARE PROXY. I WISH WE HAD DONE ALL THIS EARLIER.”

JUDY, AGE 54
SOUTH CAROLINA

DO YOUR PARENTS HAVE AN ATTORNEY?

It would be ideal, of course, if your parents’ legal affairs were handled by an attorney who is expert in wills, estates, and similar matters and who is familiar with your parents and their lifestyle. If they do not have an attorney, a good way to find one is through referrals from trusted friends or relatives who have used the same type of legal and planning services and are satisfied. If they know an attorney who practices in a different field of law, they could ask that attorney for a referral. They could also contact the local bar association for referrals.

DO YOUR PARENTS NEED AN ELDER LAW ATTORNEY?

The legal problems affecting the elderly have become increasingly complicated in recent years and, as a result, family attorneys are not always qualified to advise about specific issues concerning this population. In specialized areas such as the preservation/transfer of assets to avoid spousal impoverishment when one spouse enters a nursing home, and Medicaid, Medicare, Social Security, and disability claims and appeals, you may wish to consult with an attorney who practices the relatively new specialty of “elder law.” Working together, the family attorney and an elder law attorney can help your parents address the legal concerns and issues facing them or help you to help them.

As with other professional advisors, the best way to find help is generally through referrals. You might ask for referrals from social workers, doctors, or nurses who work with seniors; or your local bar association may have an elder law referral service. The National Academy of Elder Law Attorneys (NAELA) is a professional organization that publishes an “Experience Registry” of members who specialize in various aspects of elder law. See the Directory of Resources, page 60, for information on ordering a copy of the Registry. There is a charge for the Registry, so you will want to ask whether it includes attorneys practicing where your parents reside before ordering.

ESTATE PLANNING

The main objective of estate planning is to preserve assets and protect loved ones. How do your parents want their assets to be distributed? How can they minimize federal and state estate and inheritance taxes? What should be done if they become unable to manage their affairs? Are your parents beneficiaries or grantors of any trusts? Some of the tools used in estate planning are legal instruments such as wills and trust agreements. The Financial Affairs section of this guide includes additional information about the financial aspects of estate planning.

WRITING AND UPDATING WILLS

In almost every situation it's important to have a will. If your parents do not have valid wills, they should consult a skilled lawyer. Your parents' attorney, working with their professional financial advisor, is best able to ensure that all concerns, including tax issues, are taken into consideration and to draw up wills, trusts, or other instruments needed to assure their objectives are met. Before this process begins, your parents need to review their assets and create an organized, up-to-date list for use by their attorney and financial advisor.

Your parents should discuss with their attorney whether to have separate wills rather than a joint will. They should consider who would be an appropriate party to serve as the executor. In addition to immediate family and relatives, there may be friends or charitable organizations that your parents want to include as beneficiaries. If either parent is a grantor or beneficiary of a trust, they should discuss what their rights and obligations are under those agreements and what will happen under the agreements upon the death or incompetence of the individual. If your parents have definite preferences regarding burial or other funeral arrangements, they should discuss these with their attorney and executor, and put their wishes in their will.

If your parents already have wills, they should review them at least once a year, preferably with an attorney, to update their wishes. The existing wills should be reviewed for:

- changes in beneficiaries resulting from births, deaths, marriages, and divorces
- changes in circumstances such as illness, increases or decreases in assets, and/or age of children
- changes in tax, probate, or property law
- changes in executor, trustee, and guardians
- major sale or purchase of property or other assets

Absolutely no changes should be made, however, without consulting an attorney.

PRACTICAL HINT

The American Bar Association Commission on Legal Problems of the Elderly, listed on page 59 of this guide, can be a source for finding help. You should also be aware that many states have programs for the elderly who cannot afford a private attorney. Contact your parents' county Area Agency on Aging (AAA) for more information on what options may be available.

PRACTICAL HINT

If your parents decide to execute a durable power of attorney, one individual should be named, with a second person as successor in case the first person is unable to serve.

PRACTICAL HINT

It is generally useful to execute more than one copy of a power of attorney and provide these certified copies to key people, such as the individual having the power of attorney and your parents' physicians, bankers, or attorneys.

POWERS OF ATTORNEY

There is a difference between a power of attorney your parents may have arranged for a specific purpose and a durable power of attorney.

A power of attorney is a legal document in which an individual gives another person the authority to act on his or her behalf in specified types of transactions. It terminates if the individual dies or becomes incapacitated or incompetent.

A durable power of attorney remains valid and enforceable despite the incompetency or incapacity of the principal. It terminates upon death of the principal. Powers may include financial decisions such as purchasing and selling properties, making gifts, managing bank accounts, and insurance and medical decisions such as whether or not to use heroic medical treatments.

GUARDIANSHIPS AND CONSERVATORSHIPS

If one or both of your parents can no longer make their own decisions, and a durable power of attorney or other arrangements are not in place, a court will determine your parents' competence and then appoint a guardian if necessary. The guardian can be authorized to make decisions about living arrangements, financial matters, medical care, and related matters. The guardian appointed by the court may be a relative, friend, hired professional, or even a court, state, or county agency. There are several types of guardianship – voluntary, involuntary, permanent, temporary, limited, and total – and all are regulated by the laws of the state in which your parents reside. The actions of a guardian are subject to review by the court and in some circumstances, where wrongdoing or negligence can be shown, a guardian may be removed by the court. If one or both of your parents need a guardian, you should consult with an attorney on how to have one appointed or how you can be appointed yourself as guardian for your parents.

Conservatorship is different from guardianship in that a conservator is responsible only for an individual's financial affairs. Again, state laws govern establishing a conservatorship.

ADVANCE MEDICAL DIRECTIVES

Advance medical directives are legal documents that put in writing an individual's instructions about his or her future medical care. They are designed to help guide medical professionals, family members, and friends should the individual no longer be able to make medical decisions. Laws regulating medical directives vary by state, so it's important to contact an attorney familiar with the requirements of the state in which your parents reside, or their county Area Agency on Aging, for help in putting their wishes in writing. Three types of advance medical directives available in most states are:

DURABLE MEDICAL POWER OF ATTORNEY

This document allows your parents to designate someone they trust to make medical decisions on their behalf, should they become incapacitated. Because the durable medical power of attorney eliminates the need for your parents to know in advance all the decisions that may arise, it is important that they discuss their feelings and intentions regarding medical decisions with the persons they designate. An attorney should be consulted for help in drawing up a durable medical power of attorney.

HEALTH CARE PROXY

A health care proxy has the same effect as a durable power of attorney with one difference: a lawyer is not usually required to complete the simple preprinted form. If the state in which your parents reside has a health care proxy law, you can usually get the appropriate form from hospitals or other medical facilities or from the county Area Agency on Aging. Again, the individual your parents designate to make decisions should have a clear understanding of their wishes regarding medical treatment.

LIVING WILL

This legal document differs from the above in that instead of naming another person to make decisions, it specifically authorizes doctors to discontinue medical care under certain circumstances. For example, it may direct a doctor to cease life-prolonging medical treatment when the patient is unable to participate in the decision and is terminally ill, permanently unconscious, or severely brain damaged. If your parents have a durable medical power of attorney or a health care proxy, but also have a living will, the living will provides written instructions for the individual they have designated to make decisions. An attorney can assist in preparing a living will.

PRACTICAL HINT

Keep in mind that if your parents relocate to another state, their existing wills may not be valid in the new state of residence. Thus, new wills drafted by an attorney in that state would be appropriate.

PRACTICAL HINT

Check out the following Web sites for end of life legal issues:
www.agingwithdignity.org
www.lastacts.org

SOME OF THE TOUGHEST ISSUES

“THE BIG ISSUE IS WHETHER DAD, 93, AND MOM, 83, CAN CONTINUE TO LIVE IN THEIR HOME. THEY’RE IN A SMALL TOWN IN SOUTH DAKOTA. MOM HAD A STROKE TWO YEARS AGO, AND DAD HAS BEEN TAKING CARE OF HER. EVEN THOUGH MY BROTHER LIVES IN THE SAME TOWN AND MY SISTER IS IN IOWA, I’M A NURSE, AND THEY THINK I KNOW MORE. IT’S ALSO THAT I’M THE ELDEST DAUGHTER. THEY TURN TO ME FOR EVERYTHING.”

RUTH, AGE 57
NEW YORK

LONG-DISTANCE CARE: GETTING INVOLVED WHEN YOU’RE NOT NEARBY

There are currently 7 million Americans who are providing assistance for an elder who lives at a distance. Managing this situation for most of these long-distance caregivers is possible because they have family or friends who live near the elder who help out and keep the long-distance caregiver informed about their parent.

When your parents live far away, the issues that arise may not be all that different from the ones you would experience if they were next door. What is different is that you may have to work harder to get the same results.

The key to long-distance care is planning ahead and communicating regularly with your parents, other family members, your parents’ friends and neighbors, doctors, bankers, lawyers, and other members of the network you develop to assist you in helping your parents remain independent.

Here are some suggestions you may find helpful, should you need to provide long-distance care. With your parents’ knowledge, select two or three key people (e.g., friends, neighbors, or clergy) who care about your parents’ welfare. Meet with them and discuss the situation. If they agree to help, give them your home and work telephone numbers, or even a telephone credit card, so they can easily contact you. From time to time, tell them how much you appreciate their efforts, and perhaps send them a note or gift.

Spend some time with your parents so you become familiar with the challenges they may be facing and the resources available in the area that you or they may need to contact. Subscribing to your parents’ local newspaper can keep you abreast of the services offered in their community. See *Finding Local Services*, page 12, and *Where You Can Turn for Help*, pages 33-35, for the types of services that might be helpful now or later when your parents’ needs change. The Directory of Resources (page 40) will also assist you in finding the help you may require. The book, *Long Distance Caregiving: A Survival Guide for Far Away Caregiving*, listed in Additional Source Material, page 63, has many suggestions that you may find helpful.

WHEN YOUR PARENTS WON'T GO TO THE DOCTOR

This is a decision your parents make for themselves. Unless they are judged mentally incompetent, they are legally responsible for their own actions. Parents' refusal to see their physicians can be very upsetting. Reasons may include lack of money, exhaustion, or fear. Talking with their doctor or a hospital social worker, preferably one who specializes in geriatrics, can help you look at options to help resolve this dilemma. You may also offer to go with your parents – for some older people the idea of going to the doctor alone is a barrier.

WHEN YOUR PARENTS SHOULDN'T DRIVE

There may come a time when it is clear to you that your parents should no longer drive. Giving up driving may be one of the most divisive issues you and your parents must face. The fact that they can't get into their car and go where they please is a defining limit to their independence.

There is no right or wrong way to discuss this issue. If you are lucky, they will have come to the same conclusion. If not, you will have to try to override their objections. Before taking any action, however, do some research to locate alternatives to driving that are available in their community. These can include shuttle buses that provide door-to-door service; home delivery services from various stores, and local transportation services for the elderly. Contact a local senior citizen center for additional suggestions.

If your parents refuse to discuss the matter and won't agree to stop driving, yet it is clear that safety is an issue, you may want to consider talking with their doctor about your concerns.

RECOGNIZING ELDER ABUSE

Elder abuse is defined as the mistreatment of an elderly person. It may include assault, threats of assault, verbal abuse, financial exploitation, physical and/or emotional neglect, or sexual abuse.

Elder abuse is one of the most under-reported problems in the country because victims may be ashamed, unable to report it, or fearful of reprisals if they speak up. Abuse is more likely when the stress level of the individual providing the care is heightened as an older person's condition worsens.

The following indicators are listed by The National Center on Elder Abuse as important clues to, but not necessarily signifying, possible abuse:

- Bruises, burns, or cuts
- Dehydrated or malnourished appearance
- Anxiety, confusion, or withdrawal
- Expressions of shame, embarrassment, and fear
- Poor personal hygiene
- Overmedication or oversedation
- Sudden bank account withdrawals or closings

PRACTICAL HINT

Give your parents a telephone answering and/or fax machine as a gift. There are many relatively inexpensive models that combine these functions in a single unit and hook up to existing telephone lines. Look for ones with large, easy to read numbers. You may find this gift an invaluable tool for communicating and sending notes, articles, and bills. If your parents are not comfortable with this technology, an answering service may be more to their liking. Also consider giving them a computer to communicate with you by e-mail.

PRACTICAL HINT

Alcoholics Anonymous (AA) can be a source of information on alcoholism, and it has been singularly successful in long-term recovery through its shared-support program. Al-Anon, an offshoot of AA, can help you and your family deal with the issues of relating to an alcoholic parent. See your local telephone book (white or yellow pages) to contact AA or Al-Anon. Or talk with a friend, neighbor, or anyone who has successfully used these programs.

PRACTICAL HINT

If you suspect elder abuse, additional sources of help listed in the Directory of Resources include the National Committee for the Prevention of Elder Abuse, page 44, and the American Bar Association Commission on Legal Problems of the Elderly, page 59.

In most jurisdictions, either Adult Protective Services (APS), the Area Agency on Aging (AAA), or the county Department of Social Services is designated as the agency to investigate allegations of elder abuse. If the investigators find abuse, they make arrangements for services to help protect the victim. Call the National Eldercare Locator at 800-677-1116 and ask for the county Area Agency on Aging telephone number.

ALCOHOLISM IN OLD AGE

Alcohol abuse among the elderly is no longer a hidden or ignored problem. But, as with alcoholism among the general population, it thrives on denial, neglect, and secrecy, and it often goes undetected. The alcoholic and the family may deny its existence, and the health care provider may misdiagnose the disease because many of the symptoms of alcoholism imitate those of other pathologies often described as “old age complaints.” These include: tremors, confusion, hypertension, and depression. Some additional indicators of possible alcohol abuse are:

- Burns on hands and other extremities from cooking, bathing, or smoking
- Evidence of repeated falls
- Other unexplained “accidents”
- Fear or avoidance of doctors and dentists
- Paranoid behavior
- Mood swings
- Malnutrition
- Preference for isolation, secretiveness
- Inability to remember particular periods of time (blackouts)

The Center for Substance Abuse Prevention offers the following cautions regarding the potential for alcohol abuse in older people:

- Age-related stresses, such as loss of employment, loss of spouse or friends, or a move to an unfamiliar environment, are among the factors which may put a person at risk for increased alcohol consumption. Also, the changing metabolism that comes with aging can make older people more susceptible to the effects of alcohol.
- As with any other drug, problems can occur in the interaction between alcohol and other medications, both prescription and over-the-counter. Here is a clear case of the importance of asking questions of the doctor and pharmacist, and being very sure of the instructions regarding interaction and side effects of every medication your parents are taking.
- To help lessen the loneliness, isolation, and depression which can lead to and be made worse by alcohol abuse, your parent should be encouraged to stay as actively involved in family and community affairs as possible. Offering needed skills and experience to volunteer programs can also enhance your parent’s self-esteem and sense of self-worth.

Alcoholism is a progressive disease, and while not curable it can be successfully arrested with proper treatment. If you suspect an alcohol

problem with a parent, first contact your parent's doctor or other competent medical person to discuss where to find help. Confrontation is rarely successful without professional guidance. There are many facilities and programs for detoxification, evaluation, and rehabilitative treatment.

DEPRESSION AND THE ELDERLY

Depression is a common illness, yet few sufferers are properly diagnosed. This is especially true for the depressed elderly. Everyone experiences variations in mood, ranging from minor frustrations to the grief that accompanies a major loss. But a clinically diagnosed depression that interferes with the ability to function, feel pleasure, or maintain interest is not a simple case of the "blues." It is an illness that doctors, psychiatrists, psychologists, and other mental health professionals have made great progress in understanding and treating.

Aging itself does not cause depression, but many conditions that occur among the elderly can contribute to its onset. Among these are:

- Diseases that produce chronic pain, disability, dependence, isolation, and fear
- Some medications, such as steroids and those for the treatment of hypertension, heart disease, and diabetes
- The loss of peers and loved ones, which may create a continual mourning process contributing to feelings of loneliness and isolation
- Keeping fears and negative feelings "bottled up," due to the fact that many parents grew up in an era when expressing these feelings was not acceptable

Depression is usually a treatable illness. Talk with your parent's or your own physician about your concerns. They can suggest an appropriate professional for diagnosis. Treatment may include counseling sessions, medication, and a supportive family.

THE HOSPICE OPTION: WHEN YOUR PARENT IS TERMINALLY ILL

The hospice concept, developed in the 1960's in England, enables an individual diagnosed with a terminal illness to die a dignified death in a caring environment. Hospice services emphasize comfort measures rather than aggressive treatment, and they provide a coordinated program of professional services, including pain control and counseling for the patient, as well as counseling and support for family members and friends, including bereavement services.

Hospice services are available in a variety of environments. Some families and patients prefer to have care given in their home. Others prefer a hospital or nursing home environment that is comfortable and home-like. The hospice services may also consist of a combination of both home and hospital care.

PRACTICAL HINT

Approximately 3,100 national hospice programs offer services to 700,000 terminally ill patients and their families annually in the U.S. For more information on hospice services, see the National Hospice and Palliative Care Organization listing in the Directory of Resources, page 54.

PRACTICAL HINT

For information about hospice programs and the hospice philosophy as well as other useful end-of-life resource information, visit www.hospicefoundation.org.

YOUR WELL-BEING

“MOM JUST TURNED 79. SHE’S DETERMINED TO STAY IN HER OWN HOME BUT WANTS ME ON CALL TO HELP WITH EVERYTHING. I’M DOING THE BEST I CAN BECAUSE I’M ALL SHE HAS. BUT MY JOB, MY FAMILY, AND EVERYTHING ELSE ARE SUFFERING. SHE REFUSES TO DO LAUNDRY AND GO GROCERY SHOPPING. I’M AT MY WITS’ END.”

ELEANOR, AGE 48
ILLINOIS

HELPING YOURSELF IS AS IMPORTANT AS HELPING YOUR PARENTS

Most adult children find that when their parents occasionally need help, they can drop everything and do what’s necessary. Many start running into trouble, however, when assistance is needed on an ongoing basis. The daily demands of caring for an elderly parent can be overwhelming, even in the best of circumstances.

Whether you are in the early stages of helping your parents plan their future or in the midst of singlehandedly trying to manage everything for them, it’s important for you to find out what resources are available to help your parents. It is equally important for you to locate and tap into resources to help yourself. After all, if you are exhausted, depressed, or ill as a result of trying to “do it all,” you’re in no shape to help anyone.

WHERE YOU CAN TURN FOR HELP

In addition to the many national organizations listed in this guide’s Directory of Resources, pages 40-60, and the local businesses and nonprofit groups (see *Finding Local Services*, page 12) that can assist you, there are several other resources to investigate for both periodic and ongoing help for your parents as well as for yourself. These resources include:

YOUR FAMILY AND YOUR PARENTS’ CLOSE FRIENDS

Brothers, sisters, or other relatives are the logical people for you to call on for help. Even if siblings cannot always be available physically, their willingness to be involved is a big advantage. If your siblings don’t offer their help, ask them for it. Be honest about your own needs as well as those of your parents. Divide up the ongoing duties such as grocery shopping, driving to appointments, bill paying, and daily telephone calls to chat and confirm that everything is all right. If you are an only child, ask a relative or friend to help by giving you regularly scheduled breaks each week or month.

ADULT DAYCARE

Adult daycare centers specialize in providing care for the frail elderly, adults who are physically impaired, and/or those with dementia, confusion problems, and Alzheimer's Disease. Adult daycare centers offer health-related and rehabilitative services, social interaction, and a variety of activities. If your parent cannot be at home alone during the day and/or requires frequent health-related and rehabilitative services, an adult daycare center may be the answer. Such centers also offer the frail older person a chance to socialize with others.

HOME HEALTH CARE

These services are helpful if your parent needs various levels of nursing care or other professional health services in their home or yours. Home health care services include registered nurses, licensed practical nurses, home health aides, and companions, as well as occupational therapists, physical therapists, speech therapists, and social workers. Your local hospitals, Visiting Nurse Associations (VNA), and Area Agency on Aging (AAA) can help you in obtaining the assistance your parents may require. Medicare and health insurance may cover some of these services.

GERIATRIC CARE MANAGERS

If you feel your parents need more care than you are able to give, a private geriatric care manager may be the answer. Geriatric care managers are especially helpful if you live a long distance from your parents. These professionals can assess your parents' needs and home situation, then coordinate and monitor the necessary care and services. They work closely with all family members and may be helpful in keeping lines of communication open. Contact the social worker at a hospital near your parents for names of geriatric care managers or call the National Association of Professional Geriatric Care Managers (see the Directory of Resources, p. 44).

TEMPORARY CARE FROM HOSPITALS, NURSING HOMES AND PERSONAL CARE FACILITIES

If you are managing everything for your parents and need some time off or a vacation with your own family, a "respite" care program may be the answer. Respite care programs, developed by hospitals and nursing homes in many communities, are designed to provide temporary 24-hour care for an elderly individual at a special facility or in their own home. The purpose of the care is to allow the primary caregiver some short-term relief from day-to-day responsibilities. If possible, compare several respite programs and rates. You'll also want to check whether your parents' health or long-term care insurance will cover periodic respite care.

SENIOR CENTERS

These neighborhood centers offer a variety of programs and services for the well elderly. The center's offerings will vary, but can include inexpensive meals, exercise classes, trips to local museums and events, and many other health, nutritional, educational, and recreational activities. Visit a local center, meet with the Director, and ask for a copy of the weekly or monthly schedule of programs and events so you can help your parents plan which activities they may want to attend.

PRACTICAL HINT

*Read through the list of books
and video tapes listed in*

*Additional Source Material,
pages 61-63. You may find
particularly insightful Claire*

Berman's book, Caring for

Yourself While Caring for

Your Aging Parents: How to

Help, How to Survive.

PRACTICAL HINT

If you are planning a leave of absence under the Family and Medical Leave Act, both you and your employer have the option to substitute certain types of paid leave (e.g., vacation time) for the unpaid leave. You should discuss this option with your company's human resources department.

These senior centers can also be a valuable source of information on other services for the elderly that may be available locally.

YOUR PLACE OF WORSHIP

Local religious organizations often provide dependable volunteers who make home visits. If they can't help, they may be able to recommend someone who can.

SUPPORT GROUPS

You need not feel alone as you go through the caregiving experience with your family. Many adult children become isolated by their inability to communicate the difficulties they are going through. You should be able to find a support group in your community that includes other caregivers with whom you can share your experiences. You will also learn coping skills and find out about other resources and services available to you and your parents. Check with your Area Agency on Aging for support group information.

YOUR EMPLOYER

Many employers have become aware of the growing number of employees who are providing care for an elder and have developed programs to assist these working caregivers. Check with your company's human resources department or Employee Assistance Program to find out what you are eligible for and what support is available through your place of employment.

THE FAMILY AND MEDICAL LEAVE ACT

Enacted in August, 1993, this federal law entitles an eligible worker to unpaid leave for up to 12 weeks a year, either at one time or intermittently, to care for the employee's seriously ill parent, without loss of job security or health benefits. To be eligible, companies may require medical certification from a doctor to support your claim that your parent is seriously ill and in need of your care. Family leave regulations generally apply to those individuals who have worked for the company for at least a year, put in at least 1,250 hours of work during the previous 12 months, and are employed by companies with a minimum number of employees within certain geographic distances. Reinstatement may not be required for those individuals who are classified by their employers as key employees, e.g., individuals who are among the highest-paid ten percent of its workers. For more information, ask your employer for a copy of your rights under the Family and Medical Leave Act, or contact the Wage and Hour Division of your regional Department of Labor.

GLOSSARY OF MOST COMMONLY USED TERMS

A glossary has been included to help you further understand not only specific words and terminology used in this guide's text, but also terms currently used, across the country, in the discussion of aging and related issues.

Accessory apartment: A separate, self-contained living unit created within, or attached to, an existing single-family home.

Activities of daily living (ADLs): Tasks necessary for daily life, including bathing, dressing, grooming, eating, toileting, walking, taking medications, and other personal care activities.

Acute illness: A serious illness such as a heart attack or stroke that develops rapidly with pronounced symptoms. The illness can be of short duration such as influenza.

Adult daycare: A daycare center that offers health-related and rehabilitative services, social involvement, and activities to meet the needs of the physically and/or mentally impaired elderly on a daily, weekly, or part-time basis.

Adult home: *See personal care home.*

Advance medical directive: *See medical directive.*

Aids for daily living: Simple and generally inexpensive items designed to help maintain independence and to make daily living easier. *See page 11.*

Area Agency on Aging (AAA or Triple A): Also known as County Office on Aging, usually a nonprofit agency or unit of local government with the responsibility for planning and coordinating services for people over age 60 in a designated geographical area.

Assisted living facility: *See personal care home.*

Board-and-care home: *See personal care home.*

Caregiver support group: Group led by a professional and/or volunteer that allows family caregivers to meet in a supportive atmosphere to express their feelings, share coping skills, and learn about aging issues and resources for help.

Care (case) management: Assessing, arranging, and overseeing an individual's health care routine by a trained professional.

Chore service: Help with repairs and chores inside or outside a house or apartment, provided through the local Area Agency on Aging, volunteer programs, or youth groups to help older people live safely and comfortably in their own homes.

Chronic illness: A physical or mental disability that continues or

recurs frequently over a long period of time.

Congregate housing: Apartments or rooms in a multi-unit building or garden complex, planned and designed for the elderly.

Continuing care retirement community (CCRC): Also known as a CCC, continuing care community or life-care community. Residences that offer care to individuals and couples for the remainder of their lives. Most require an entrance fee plus a monthly maintenance charge. *See pages 16-17.*

Custodial care: Help and supervision with daily living activities – dressing, eating, personal hygiene, and similar functions.

Dementia: A clinical term used to describe a group of brain disorders that disrupt and impair cognitive functions (thinking, memory, judgment, personality, mood, and social functioning).

Dependent care tax credit: Federal income tax credits for certain home care services and adult daycare services for adults who are dependent upon you. Check with your local IRS office or a tax advisor for details.

Diagnostic related groups (DRGs): A method of grouping illnesses that is used to calculate Medicare Part A reimbursements to hospitals and nursing homes. DRGs are based on the patient's

diagnosis rather than on the actual length of the hospital stay.

Discharge planner: The professional staff member of a hospital or nursing home who develops a plan for the future care of a patient prior to discharge. *See social worker.*

Domiciliary home care: A living arrangement for ambulatory and independent adults who require minimum supervision. *See personal care home and foster home.*

Durable power of attorney: A power of attorney that remains valid and enforceable despite the incompetency or incapacity of the principal. *See page 27.*

Durable medical power of attorney: A legal document which names a person who will make health care decisions for the principal if that individual becomes incompetent or unable to express wishes for himself or herself. *See page 28.*

Elder law attorney: An attorney who specializes in the laws that deal with the rights and issues of the health, finances, and well-being of the elderly and the power of other individuals and the government to control them. *See page 25.*

Estate: The term used to represent all of an individual or couple's personal assets.

Estate planning: A plan for what will happen to an individual or couple's assets and liabilities after death. *See page 26.*

Executor: The person named in a will to carry out the distribution of an estate.

Geriatric assessment: An evaluation of an older person's physical,

psychological, and social condition by a professional team of specialists. This team makes recommendations to the older person, family, and primary care doctor. Geriatric assessments are offered in geriatric evaluation centers and are generally associated with hospitals.

Geriatric Psychologist: A psychologist who specializes in the mental and behavioral characteristics of aging.

Geriatric social worker: A licensed professional who assists the elderly and their families in understanding and coping with the social, emotional, and psychological aspects of aging. The social worker coordinates, directs, and instructs in the accessing of services.

Geriatrician: A medical doctor with special education and training in the diagnosis, treatment, and prevention of disabilities in older people.

Gerontologist: A professional with special expertise and training in the study of human aging. This term is used by a variety of professionals including those in social work, human services, mental health, and psychology.

Guardian: An individual appointed by a court of law to manage a person's financial and/or personal affairs because the court has found that the person is not competent to manage his or her own affairs. A conservator is similarly appointed, but only for financial affairs. *See page 27.*

Health care power of attorney: *See durable medical power of attorney.*

Home-health agency: A public or private organization with a staff of skilled nurses, home makers, home-

health aides, and therapists that provide nursing, rehabilitative, and homemaking services to homebound patients with chronic or temporarily debilitating conditions or to individuals recovering from major medical treatment.

Home health care service: Service performed in the home for an elderly person by someone who has special medical training.

Homemaker service: Service providing trained person for household cleaning, cooking, grocery shopping, laundry, transportation, and personal care for an elderly person. Does not include nursing care.

Hospice: Usually a combination of at-home and hospital care of the terminally ill that combines medical and social services. It is designed to help both the patient and the family. Hospice care emphasizes pain control, symptom management, and emotional support rather than life-sustaining equipment. *See page 32.*

Incontinence: The loss of voluntary control over bladder or bowel functions.

Instrumental Activities of Daily Living (IADLs): Tasks over and above ADLs necessary for everyday living, such as grocery shopping, bill paying, transportation to doctors' appointments, etc.

Intermediate care facility (ICF): A nursing facility that provides help with personal or social care and a minimum of medical supervision. Often a section of a nursing home or personal care home.

Life-care community: *See continuing care retirement community.*

Living trust: A trust created during the life of the grantor. An irrev-

ocable living trust is often used in estate and tax planning. All assets become the property of the trust and, generally, the trust is liable for income tax payable on amounts earned by those assets, but may result in removing assets from the estate and, therefore, reducing possible estate tax liability. It should be noted, however, that the transfer of assets to the trust may result in gift tax liabilities.

Living will: A legal expression of an individual's wishes about future medical treatment, at a time when they have become incompetent or cannot communicate due to illness. *See page 28.*

Long-term care: A general term that describes a range of medical, nursing, custodial, social, and community services designed to help people with chronic health impairments or forms of dementia.

Long-term care insurance: Insurance policies issued by private companies to defray the costs of long-term care in nursing facilities as well as home care services. *See page 22.*

Matched housing: A private arrangement in which an individual or couple remains in their own home and rents a room to a capable person in exchange for help. *See pages 16-17.*

Meals-on-wheels: Meals delivered on a regular schedule to housebound elderly or elderly people unable to cope with meal preparation, for little or no cost.

Medicaid: The health insurance program financed by the federal and state governments for eligible low-income people 65 and older. Needy older people can have their Medicare deductibles and co-payments paid

by Medicaid. Nursing home care may also be paid for by Medicaid if the individual's income and assets are within certain limits. *See pages 21-22.*

Medical directive: Also called a living will, advance medical directive, and health care proxy. This legal document enables an individual to give instructions about future medical care, in the event they have become incompetent or are unable to speak for themselves due to illness. *See pages 27-28.*

Medicare: The national health insurance program for eligible people 65 and older and some disabled individuals. Part A covers hospital costs. Part B covers doctor bills and other medical costs. Patients must pay deductibles and co-payments, and make up any expenses not covered by Medicare. *See pages 21-22.*

Medigap insurance: Private health insurance policies intended to cover medical costs not fully covered by Medicare. Also known as supplemental insurance. *See pages 21-22.*

Nursing home: A licensed nursing facility that provides a full range of care and medical services to those recovering from hospitalization or suffering from chronic illness, dementia, or other factors that make it impossible for them to live at home. *See intermediate care facility (ICF) and skilled nursing facility (SNF).*

Occupational therapist (OT): A licensed professional therapist who helps a person relearn activities of daily living (ADLs) through rehabilitation and modifications and devices for the home environment to help the person function more independently.

Ombudsman services: Programs

that advocate and protect the rights of residents in long-term care facilities by investigating complaints, mediating and resolving disputes, and initiating corrective actions.

Patient bill of rights: A list of policies and procedures to be followed to ensure that patients receiving health care services will be treated with dignity and will participate fully in decisions relevant to their health care.

Personal care facilities: Residential facilities for those who need help with activities of daily living (see ADLs) within an environment that helps the person remain as independent as possible. Usually does not include any level of nursing care. *See pages 18-19.*

Personal emergency response system (PERS): Equipment that monitors the safety of older people in their homes through signals electronically transmitted over the telephone and received at an emergency monitoring center. *See page 12.*

Physical therapist (PT): A licensed professional who treats impaired motion or disease through exercise, massage, hydrotherapy, or mechanical devices to improve physical mobility.

Power of attorney: A legal document in which an individual gives another person the authority to act on his or her behalf. *See durable power of attorney.*

Primary caregiver: The individual who has the main responsibility for helping an older person. The individual usually is the one who makes decisions and organizes care and services.

Primary care physician: The doctor who is consulted first when a

health problem occurs and on whom the patient relies for advice, referrals, and ongoing care.

Qualified medicare beneficiary (QMB) program: Program for eligible individuals who cannot afford a Medigap (supplemental) insurance policy. Contact the local Medicaid office for more information.

Respite care: A service that provides temporary care for an older person. The purpose of the care is to allow the family caregiver some short-term relief from their day-to-day responsibilities. Respite care may be provided in or out of the home. *See page 34.*

Senility: A term used to refer to the mental and physical deterioration of old age. Not a medical term. *See dementia.*

Senior centers: Neighborhood or community centers that offer a range of services and social, health, nutritional, educational, and recreational activities. Senior centers are for the healthy elderly. *See page 34.*

Shared housing: A program available in some communities that matches individuals for the purpose of living together in one house. One of the individuals may be the owner of the house. *See pages 16-17.*

Skilled nursing facility (SNF): A licensed facility that provides 24-hour medical services by registered nurses, licensed practical nurses, and nurses aides for seriously ill or severely disturbed people who do not require hospitalization. *See pages 18-19.*

Supplemental insurance: *See Medigap insurance.*

Telephone reassurance program: A program, available in some com-

munities, in which frail, ill, or housebound people are called on a regular basis to check on their safety and to provide personal contact.

Visiting nurse: A trained professional nurse who visits patients in their homes to monitor vital signs and physical condition and carry out a physician's treatment orders.

Will: A legal document that sets forth a person's wishes for disposing of assets after death. *See page 26.*

DIRECTORY OF RESOURCES

There are many agencies and organizations located throughout the country that can provide information and support to help you and your parents cope with the problems of aging. A number of these are listed in this Directory of Resources. Each listing includes the organization's name, address, telephone and fax numbers, Web site, a brief description of the organization, and the services and publications that are available.* These resources are alphabetized within the following categories:

- General
- Health
- Housing
- Financial
- Legal

Many of the listings are for national associations with local affiliates. They will be able to refer you to services in your community. When contacting any of these groups, you may want to ask for suggestions for additional local or national resources to help with your specific problem or question.

Web-based resources for caregivers are expanding rapidly with new Web sites coming online frequently. For caregivers with access to the Internet, the Web-based resources can save a lot of time and provide valuable information. Not all sites, however, contain quality information. Since new sites are emerging rapidly, check every week or so to make sure you haven't missed a Web site that meets your informational needs. Here are a few tips for finding good information and quality sites:

1. Remember that Web site addresses that end with ".com" are for-profit organizations. These sites often are established to sell a product or service and because of this commercial aspect, may not be the most reliable source of information. However, there are a number of high quality ".com" Web sites with good services and good information. Investigate the Web site thoroughly before you make a judgment. Sites ending with ".edu" are hosted by educational organizations, and those ending with ".org" are generally non-profit organizations. For objective information about benefits and entitlements, look for the ".gov" Web site indicating that it is government-related.

2. When using a search engine, some key words to enter to locate caregiving Web sites include:

- caregiving
- eldercare
- elders
- health
- seniors

If you are seeking information about a specific disease, enter that disease name into the search engine to find disease-specific information. Often there is a non-profit association that provides information about the disease and services available to those who have that disease or who are caregiving for someone who does. These Web sites may also provide up-to-date information about new and emerging treatment therapies.

3. Many Web sites request that you register in order to gain access to information they have available and most provide free registration. Before registering, it is a good idea to view their privacy policy in order to limit the amount of "junk" e-mail you receive as a result of registering.

* All information is accurate as of December, 2000. Check with each organization regarding membership fees and prices and availability of publications.

KEY TO RESOURCE LISTING

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<i>Name, Address, Telephone, Hours: (T)= Telephone, (F)=Fax, (TDD)= Telecommunications Device for the Deaf, (800 or 888)= Toll-free service. Hours are ET (Eastern), CT (Central), MT (Mountain), or PT (Pacific), Web site</i>		

GENERAL INFORMATION RESOURCES

AARP 601 E Street NW Washington, DC 20049 (T) 202-434-2277 <i>24-hour Member Assistance Hotline:</i> (800) 424-3410 www.aarp.org	Non-profit membership organization dedicated to the needs of people age 50 and older. Membership fee.	Services include free publications, mail order pharmacy, group health insurance, reports on legislative developments, and investment programs. Bimonthly magazine, <i>Modern Maturity</i> . Publications cover a wide range of topics on aging and related subjects. Ask for Caregiver Resources. The Web site has a caregiving section and offers information on consumer issues, and local AARP chapter services.
ADMINISTRATION ON AGING, INTERNET AND E-MAIL RESOURCES 330 Independence Avenue SW Washington, DC 20201 (T) 202-619-7501 <i>(National Aging Information Center)</i> (F) 202-260-1012 www.aoa.gov	This Web site lists numerous sites concerned with aging and related topics.	<i>Because We Care: A Guide for People Who Care</i> is an online resource guide for caregivers, and provides information and suggestions to make caregiving easier.
ADULT DAYCARE CENTERS <i>Check with County Office on Aging or Area Agency on Aging for centers in your area.</i>	Daycare centers with daily, weekly, or part-time schedules planned to fit the needs of the frail elderly, adults who are physically impaired, and/or those with dementia, confusion problems, and Alzheimer's disease.	Provide socialization, activities, and a variety of health, rehabilitative, and social services in a protective group setting. Adult daycare centers are offered in a variety of settings.

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>ALLIANCE FOR CHILDREN AND FAMILIES 11700 West Lake Park Drive Milwaukee, WI 53224 (T) 414-359-1040 (F) 414-359-1074 (800) 221-2681 <i>Also check local listings.</i> www.alliance1.org</p>	<p>National organization of non-profit service agencies offering assistance to individuals and families.</p>	<p>National toll-free service provides referrals to local Family Service Associations offering counseling, support groups, and assessments to individuals and families.</p>
<p>AMERICAN SELF-HELP CLEARINGHOUSE 100 East Hanover Avenue Cedar Knolls, NJ 07927 (T) 973-326-8853 (800) 367-6274 www.selfhelpgroups.org</p>	<p>Lists national and local self-help support groups for any type of illness, disability, bereavement, or other stressful conditions.</p>	<p>Will advise on local groups nearest to you. Can direct you to your state or county self-help clearinghouse, if available.</p>
<p>AMERICAN SOCIETY ON AGING 833 Market Street Suite 511 San Francisco, CA 94103-1824 (T) 415-974-9600 (F) 415-974-0300 (800) 537-9728 8:30 a.m.-5:00 p.m. PT, M-F www.asaging.org</p>	<p>Professional membership association of individuals and organizations working with and on behalf of older people. Membership fee.</p>	<p>Provides education and training events for professionals in aging. Publications for members and subscribers include <i>Aging Today</i>, <i>Generations</i>, and special interest newsletters. The Web site is linked to the National Alliance for Caregiving Web site and the <i>AXA Foundation Family Care Resource Connection</i>.</p>
<p>CATHOLIC CHARITIES, U.S.A. 1731 King Street Suite 200 Alexandria, VA 22314 (T) 703-549-1390 <i>Check local listings.</i> www.catholiccharitiesusa.org</p>	<p>Social service organization offering assistance to people of all ages with a broad range of social problems and needs.</p>	<p>Extensive services offered for older people include counseling, home-maker services, home health care, health clinics, emergency assistance, and shelter.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>CHILDREN OF AGING PARENTS (CAPS) 1609 Woodbourne Rd Suite 302A Levittown, PA 19057-1511 (T) 215-945-6900 (F) 215-945-8720 (800) 227-7294 www.careguide.net/careguide.cgi/caps/capshome.html</p>	<p>Assistance to caregivers of the elderly with reliable information and referrals, a network of support groups, and publications and programs that promote public awareness of the value and the needs of caregivers. Membership fee.</p>	<p>Extensive national information resource files. Publications on a variety of caregiver issues. <i>The Capsule</i>, bi-monthly newsletter for members. Telephone counseling.</p>
<p>ELDERCARE LOCATOR SERVICE 927 15th Street NW 6th Floor Washington, DC 20005 <i>Nationwide assistance directory:</i> (800) 677-1116 9:00 a.m.–8:00 p.m., ET, M-F</p>	<p>National guide to finding community assistance for seniors. Sponsored by the National Association of Area Agencies on Aging.</p>	<p>May be helpful, particularly for long-distance care. Referrals are made to local organizations offering services for the elderly. Give county, city, or ZIP code to help identify the nearest resource. (Caliber and accuracy of information can vary from area to area.)</p>
<p>EPISCOPAL SOCIETY FOR MINISTRY ON AGING PO Box 3065 Meridian, MS 39303 (T) 601-485-0311 www.esmanet.com</p>	<p>Agency of the Episcopal Church responsible for developing and supporting programs with and for older adults.</p>	<p>Services designed to meet the spiritual, physical, and mental needs of the elderly include a program to involve the homebound in community activities.</p>
<p>FAMILY CAREGIVER ALLIANCE 690 Market Street, Suite 600 San Francisco, CA 94104 (T) 415-434-3388 (F) 415-434-3508 www.caregiver.org</p>	<p>This organization helps families and caregivers of adults with brain disorders and diseases.</p>	<p>Many of the services described are California specific, but the publication section has excellent caregiver fact sheets. The Web site links to other useful Web sites.</p>
<p>JEWISH FAMILY AND CHILDREN'S SERVICES (JFCS) <i>No national office. Check local listings for JFCS offices in all major urban and suburban areas.</i> (T) 415-449-1244 www.jfcs.org</p>	<p>Comprehensive social service organizations that provide a full range of affordable services to people of all ages.</p>	<p>Many offices have Services for Older Persons (SFOP) offering the elderly and their families individual and family counseling, visitors, volunteer grandparent program, and professional care managers.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>NATIONAL ALLIANCE FOR CAREGIVING 4720 Montgomery Lane Suite 642 Bethesda, MD 20814 (T) 301-718-8444 www.caregiving.org</p>	<p>A national resource center on family caregiving.</p>	<p>Research, national programs to support family caregivers and increase public awareness of caregiver issues. <i>AXA Foundation Family Care Resource Connection</i> listing professionally rated resources for caregiver.</p>
<p>NATIONAL ASSOCIATION FOR HOME CARE 228 7th Street SE Washington, DC 20003 (T) 202-547-7424 (F) 202-547-3540 www.nahc.org</p>	<p>National organization representing home care agencies and aide organizations and hospice providers who provide in-home health and supportive services.</p>	<p>Offers consumer's guide to choosing home care provider. Also hospice and home care agency national locator.</p>
<p>NATIONAL ASSOCIATION OF PROFESSIONAL GERIATRIC CARE MANAGERS 1604 North Country Club Road Tucson, AZ 85716 (T) 520-881-8008 (F) 520-325-7925 8:00 a.m.-5:00 p.m., MT, M-F www.caremanager.org</p>	<p>Association of private practitioners who arrange and oversee health and social services for elderly and disabled clients. Publishes a directory of care managers, available for a fee.</p>	<p>Directory of care managers is available for a fee.</p>
<p>NATIONAL COMMITTEE FOR THE PREVENTION OF ELDER ABUSE 119 Belmont Street Worcester, MA 01605 (T) 508-793-6166 (F) 508-793-6906 www.preventelderabuse.org</p>	<p>Non-profit organization promoting understanding of the problem and the development of services to protect older people and disabled adults from abuse and neglect through outreach, research, advocacy, and training.</p>	<p>Publishes the <i>Journal of Elder Abuse and Neglect</i>, assists in forming affiliate groups and developing elder abuse prevention programs, and provides information to the public and referrals to local groups.</p>
<p>NATIONAL CONSUMER LEAGUE 1701 K Street NW Suite 1200 Washington, DC 20006 (T) 202-835-3323 (F) 202-835-0747 <i>National Fraud Information Center:</i> (800) 876-7060 www.NCLnet.org</p>	<p>Private non-profit group that promotes consumer education and government and industry awareness of consumer issues.</p>	<p>Offers publications on subjects such as energy, food and drug safety, cost of medical care, and consumer and telecommunications fraud. Ask for publication list, with prices and ordering information.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>NATIONAL COUNCIL OF SENIOR CITIZENS 8403 Colesville Road, Suite 1200 Silver Spring, MD 20910-3314 (T) 301-578-8800 (F) 301-578-8999 www.ncscinc.org</p>	<p>Educational and action organization of senior citizens' groups. Supports the preservation of Medicare and Social Security and a national health plan that includes long-term care. Membership fee.</p>	<p>Sponsors rallies, workshops, and leader training; provides speakers; maintains library of materials on senior issues. Monthly <i>Retirement Newsletter</i> and <i>Senior Citizens News</i> are free to members.</p>
<p>NATIONAL COUNCIL ON THE AGING, INC. 409 Third Street SW, Suite 200 Washington, DC 20024 (T) 202-479-1200 (F) 202-479-0735 (800) 424-9046 9:00 a.m.-5:00 p.m., ET, M-F www.ncoa.org</p>	<p>A private, non-profit organization made up of professionals, volunteers, and organizations that work to make life better for older Americans and their families. The mission is to enhance opportunities for older persons and their families.</p>	<p>The Council's affiliate, The National Institute of Senior Centers and National Adult Day Services Association, has information about senior centers and adult day-care programs on a national basis. A list of publications and resources on health, caregiving, employment and aging is available.</p>
<p>NATIONAL FAMILY CAREGIVERS ASSOCIATION 10400 Connecticut Avenue Suite 500 Kensington, MD 20895-3944 (800) 896-3650 www.NFCACARES.org</p>	<p>A national organization that provides information, education, and advocacy for the caregiver community. Membership fee for organizations. No fee for family caregivers.</p>	<p>Offers a toll-free caregiver Helpline and quarterly membership newsletter</p>
<p>OLDER WOMEN'S LEAGUE (OWL) 666 11th Street NW, Suite 700 Washington, DC 20001 (T) 202-783-6686 (800) 825-3695 www.owl-national.org</p>	<p>Advocacy and educational association of individuals and organizations focusing on issues of concern to midlife and older women, including health care, social security, violence, and housing. Membership fee.</p>	<p>Provides legislative advocacy, model state bills, research and reports, publications, and tapes on older women's issues, and a quarterly newsletter, <i>The OWL Observer</i>. Publication list available.</p>
<p>SENIOR CENTERS <i>County Office on Aging or Area Agency on Aging can provide a list of senior centers in your area.</i></p>	<p>Neighborhood centers that offer a variety of services and programs. Senior centers are for the healthy elderly.</p>	<p>Offers companionship, recreational, and educational activities. Some offer a hot lunch, social services, and other activities and services.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>STATE DEPARTMENT OF AGING <i>Located in each state capital. Listed in the telephone book in Human Services section under Social Services or County Services. The social service department of a local hospital may also have the telephone number.</i></p>	<p>Offers information on state and county services as well as state entitlements for the elderly.</p>	<p>Area Agency on Aging or County Office on Aging Services (name varies by county) administer all government services for the elderly including case management, counseling, chore services, transportation, and referrals to meals-on-wheels, telephone reassurance.</p>
<p>U.S. DEPARTMENT OF VETERANS' AFFAIRS (VETERANS' ADMINISTRATION, VA) <i>Check local listings, VA office.</i> (TDD) (800) 829-4833, for hearing impaired, based in the Chicago VA Regional Office, available 8:00 a.m.-4:00 p.m., CT, M-F (800) 827-1000 www.va.gov</p>	<p>The VA has a comprehensive system of veterans' assistance and care. It provides benefits through three VA departments: Veterans Benefits, Memorial Affairs, and Medicine and Surgery.</p>	<p>Benefits for eligible veterans include nursing home care; outpatient services such as dental, prosthetic appliances and eyeglasses, and alcohol and drug dependency treatment; burial and death benefits; disability benefits; and pensions. VA hospitals offer extensive care and treatment, pharmacies, and social services.</p>
<p>VISITING NURSE ASSOCIATION OF AMERICA (VNA) 11 Beacon Street, Suite 910 Boston, MA 02108 (888) 866-8773 (F) 617-227-4843 8:00 a.m. to 5:00 p.m. ET www.vnaa.org</p>	<p>The national organization of local VNAs, community-based non-profit home health care providers.</p>	<p>National Toll-free referral line provides callers with information about the nearest Visiting Nurse agency in their area. VNA services include nursing, physical, occupational and speech therapy, medical social services, high-tech home interventions, case management, personal care, adult day care, respite care, hospice, nutritional counseling and meals on wheels.</p>
<p><i>In addition to the organizations listed above, the following general caregiving resources are available solely on the Internet.</i></p>		
<p>WWW.CAREGIVER.ORG</p>	<p>This Web site is sponsored by the Family Caregiver Alliance.</p>	<p>Contains general caregiving information and specific information important to families and caregivers of adults with Alzheimer's Disease and other brain disorders.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>CAREGIVER SURVIVAL RESOURCES www.caregiver911.com</p>	<p>A resource center for caregivers developed by Jim and Merlene Sherman, who have worked for many years with caregivers and professionals serving the elderly.</p>	<p>The Web site links with numerous useful caregiving resources on the Internet; lists resources for finding help locally, regionally, and nationally; provides responses to frequently asked questions; lists recommended reading including books by Jim Sherman in The Caregiver Survival Series.</p>
<p>WWW.CAREGUIDE.COM</p>	<p>Careguide offers an Elder Care Resource Center to assist caregivers with decision-making.</p>	<p>Visitors will find a directory of resources as well as an online bookstore.</p>
<p>WWW.CARESCOUT.COM</p>	<p>Designed specifically for those seeking information about available services and long-term care.</p>	<p>There is a data base of services that have been reviewed for quality. Information on quality ratings and vacancies in nursing homes is available on this Web site. Includes an assessment inventory to help identify the needs of an elder.</p>
<p>WWW.CARETHERE.COM</p>	<p>This Web site is up-dated daily with news and events.</p>	<p>Features online record-keeping tools, a “mall” with gift selections, and a system of communication for family members involved in caregiving.</p>
<p>WWW.ELDERWEB.COM</p>	<p>Through a well-organized directory, this Web site provides access to a large variety of eldercare resources available on the Web.</p>	<p>Although this Web site contains a good deal of information about caregiving, it has a special niche in the area of financial planning and financing care as well as a range of practical information helpful to caregivers and elders themselves.</p>
<p>EMOTIONAL SUPPORT GUIDE www.frii.com/geomanda/endo/ supportguide.html</p>	<p>This guide to “Internet Resources for Physical Loss, Chronic Illness, and Bereavement” includes caregiver information.</p>	<p>The chronic illness resources section describes supportive Internet resources about Alzheimer’s disease, arthritis, cancer, diabetes, Parkinson’s disease, and stroke.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
WWW.EXTENDED CARE.COM	This Web site contains an archive of data about aging, health and wellness, (Senior Health Library and Informed Living) and an opportunity to e-mail questions to a geriatric physician.	Visitors can also take a “virtual” tour of facilities and search for providers of services online.
WWW.LIVING STRATEGIES.COM	The Living Strategies Web site provides an opportunity for enhanced online case management services.	Provides a network of geriatric case management professionals for a fee.
WWW.SENIOR-DIRECTIONS.COM	A Web site with links to information about housing, homecare, financing long-term care, retirement planning, professional resources and assessing needs.	Specific questions about caregiving will be answered by e-mail.
WWW.THIRD AGE.COM	This is an award-winning Web site that is designed to serve seniors and those who care about them.	The caregiving section includes guides for making decisions, fact sheets on services, eldercare resources and helpful links.
WWW.WEBOFCARE.COM	On this Web site, visitors can gain access to a library of caregiving skills and get information about different caregiving situations.	The Web site also includes links, news and resources.

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>ALZHEIMER'S ASSOCIATION 919 North Michigan Avenue Suite 1100 Chicago, IL 60611-1676 (T) 312-335-8700 (F) 312-335-1110 (TDD) 312-335-8882 <i>Information Helpline:</i> (800) 272-3900 8:30 a.m.-5:00 p.m., CT, M-F www.alz.org</p>	<p>Voluntary organization offering supportive services to patients and families who are coping with Alzheimer's Disease (AD) or related disorders.</p>	<p>24-hour toll-free hotline for information on local support groups, community resources, and practical suggestions. Educational materials on patient care, research updates, diagnosis, and social services. Ask for brochure, <i>Just the Facts</i>. The Web site includes a listing of local chapters, and online versions of brochures.</p>
<p>AMERICAN ACADEMY OF OPHTHALMOLOGY, NATIONAL EYE CARE PROJECT P.O. Box 7424 San Francisco, CA 94120 (T) 415-561-8500 <i>National Eye Care Project Helpline:</i> (800) 222-3937 8:00 a.m.-5:00 p.m., PT, M-F www.eyenet.org</p>	<p>Professional organization supporting research on diseases of the eye. Offers continuing education programs for its members and information to the general public on the prevention and treatment of eye problems.</p>	<p>Project offers referrals (by mail) for medical eye care from a practicing ophthalmologist at no cost to U.S. citizens and legal residents, 65 or older, who have no access to a personal eye doctor, are on fixed incomes, and have difficulty paying for eye care. (Program does not pay for glasses.)</p>
<p>AMERICAN CANCER SOCIETY (ACS) 1599 Clifton Road NE Atlanta, GA 30329 (T) 404-320-3333 <i>Information Service:</i> (800) 227-2345 24 hours/7 days a week www.cancer.org</p>	<p>National voluntary health organization. Local ACS units sponsor a wide range of services for patients and their families.</p>	<p>Offers referrals to state and local groups for information on self-help groups, transportation programs, and limited financial aid. Programs for specific cancers offer help such as a registry of professionals, educational materials, and rehabilitation services. Free publications and general information about cancer.</p>
<p>AMERICAN DENTAL ASSOCIATION (DIVISION OF COMMUNICATIONS) 211 East Chicago Ave. Chicago, IL 60611 (T) 312-440-2593 (F) 312-440-2800 www.ada.org</p>	<p>Professional organization that works to improve the dental health of the public. Its members are encouraged to participate in community outreach programs.</p>	<p>Gives referrals to state dental associations and dental schools which offer a number of free or low-cost services for older people who meet economic criteria. Free publications on tooth decay, dentures, smoking, diet, and mouth care.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>AMERICAN DIABETES ASSOCIATION (ADA) 1701 Beauregard Street Alexandria, VA 22311 (T) 703-549-1500 <i>Patient Information Line:</i> (800) 232-3472 8:30 a.m.-5:00 p.m., ET, M-F www.diabetes.org</p>	<p>Voluntary organization established to prevent and cure diabetes and improve the lives of all people effected with diabetes.</p>	<p>Toll-free service offers information on diabetes. Local ADA chapters sponsor screening programs and offer information, support, and referral to community agencies. Monthly publication, <i>Diabetes Forecasts</i> to members free of charge. Request the <i>Healthy Living Catalog</i>. (Membership - \$28.00 per year)</p>
<p>AMERICAN FOUNDATION FOR FOR THE BLIND 11 Penn Plaza, Suite 300 New York, NY 10001 (T) 212-502-7600 <i>Information Hotline:</i> (800) 232-5463 10:00 a.m.-12:00 p.m., 2:00- 4:00 p.m., ET, M-F www.afb.org</p>	<p>National non-profit organization that advocates, develops, and provides programs and services to help people who are blind or visually impaired achieve independence.</p>	<p>Toll-free hotline offers information on visual impairment and blindness and answers questions about the services of the Foundation. Publications available for a charge.</p>
<p>AMERICAN HEART ASSOCIATION 7272 Greenville Avenue Dallas, TX 75231-4596 <i>24-hour Information Service:</i> (800) AHA-USA1 www.americanheart.org</p>	<p>National voluntary health organization dedicated to reduction of disability and death due to cardiovascular disease and stroke. State and local affiliates in the U.S. and Puerto Rico.</p>	<p>Public education programs teach about the risk of heart disease and stroke. Toll-free service connects caller with state affiliate for local information and to order educational materials.</p>
<p>AMERICAN STROKE ASSOCIATION 7272 Greenville Avenue Dallas, TX 75231-4596 (T) 214-706-5231 <i>24-hour Information Service:</i> (888) 4-STROKE www.strokeassociation.org</p>	<p>Links stroke survivors, their families, and the professionals who serve them by providing a forum for sharing knowledge and experiences related to living with a stroke.</p>	<p>Provides information on strokes, referrals to stroke support groups, and assistance to those who wish to start one. Publishes the <i>Stroke Connection</i> magazine (subscription is \$12.00 per year). Information service staffed by stroke survivors.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>AMERICAN PARKINSON DISEASE ASSOCIATION, INC. 1250 Hylan Boulevard Suite 4B Staten Island, NY 10305 (T) 718-981-8001 (F) 718-981-4399 <i>Information Hotline:</i> (800) 223-2732 9:00 a.m.-5:00 p.m., ET, M-F www.apdaparkinson.org</p>	<p>Voluntary organization that funds research, educates the public, and offers assistance to patients and their families.</p>	<p>Toll-free number refers people to local chapters around the country that provide information about community services, doctors experienced in treating Parkinson's disease, and up-to-date treatment methods. Request a list of their publications.</p>
<p>AMERICAN PODIATRIC MEDICAL ASSOCIATION 9312 Old Georgetown Road Bethesda, MD 20814-1698 (T) 301-581-9200 <i>24-hour Information Service:</i> (800) 366-8227 www.apma.org</p>	<p>Professional society of podiatrists that offers continuing education to its members and works to create a greater public awareness of the benefits of good foot care.</p>	<p>Toll-free service offers information on foot care and catalog of publications. Single brochure copies free to individuals.</p>
<p>AMERICAN PSYCHIATRIC ASSOCIATION 1400 K Street NW Washington, DC 20005 (T) 202-682-6000 (F) 202-682-6850 (888) 357-7924 www.psych.org</p>	<p>A professional society of psychiatrists that supports research to improve the diagnosis, treatment, and rehabilitation of people with mental or emotional illness, and offers continuing education programs for psychiatrists.</p>	<p>The Association's Council on Aging evaluates psychiatric care for older patients and offers training programs in geriatric psychiatry. Individuals may contact the association to locate a district office in proximity to caller who can make local referrals.</p>
<p>ARTHRITIS FOUNDATION 1330 West Peach Tree Street Atlanta, GA 30309 <i>24-hour Information Service:</i> (800) 283-7800 www.arthritis.org</p>	<p>Nationwide non-profit, voluntary organization whose mission is to prevent, control and cure arthritis.</p>	<p>Toll-free service offers referrals to local chapters, which provide general information and referral services for help, programs, and support groups. More than 100 brochures and other resources are available free or at minimal cost. The Arthritis Answers Line promotes events and training.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>BETTER HEARING INSTITUTE 515 King Street, Suite 420 Alexandria, VA 22314 (T) 703-684-3391 (TDD) 703-684-3391 <i>Hearing Helpline:</i> (800) 327-9355 9:00 a.m.-5:00 p.m., ET, M-F www.betterhearing.org</p>	<p>Non-profit educational organization that provides the public with information on hearing loss and encourages the use of available resources and assistance.</p>	<p>Toll-free helpline provides information on hearing loss and hearing help. Offers national public educational programs on hearing loss and available medical, surgical, hearing aid, and rehabilitative assistance.</p>
<p>CANCER CARE, INC. National Office 275 7th Avenue New York, NY 10001 (T) 212-302-2400 (800) 813-HOPE (4673) www.cancercare.org</p>	<p>Non-profit organization provides free professional help to people with all cancers through counseling, education, information and referral, and direct financial assistance</p>	<p>Online services include <i>The Helping Hand: A Resource Guide for People with Cancer</i> as well as online support groups and a referral service to find resources in your community.</p>
<p>LIGHTHOUSE INTERNATIONAL 111 East 59th Street New York, NY 10022-1202 (T) 212-821-9200 (800) 829-0500 (TDD) 212-821-9713 www.lighthouse.org</p>	<p>A leading resource worldwide on vision impairment and vision rehabilitation.</p>	<p>Programs for the visually impaired. Newsletter available on Web site.</p>
<p>MATURE SMART 1050 Crown Pointe Parkway Suite 1700 Atlanta, GA 30338 (800) 720-6278 www.maturesmart.com</p>	<p>This is the Web site of a mail order company, offering products and aids for daily living.</p>	<p>This Web site offers self-help devices for older people. Catalogue available.</p>
<p>MEDIC ALERT FOUNDATION P.O. Box 1009 Turlock, CA 95381-1009 (T) 209-669-2403 (F) 209-669-2450 (888) 633-4298 <i>24-hour Information Service:</i> (800) 432-5378 www.medicalert.org</p>	<p>Worldwide non-profit organization dedicated to providing personal medical information to protect and save lives.</p>	<p>Provides information and publications about this emergency medical identification (ID) system for persons with medical problems not readily apparent, such as allergies, diabetes, or epilepsy. Provides ID bracelet or necklace, wallet card, and a 24-hour collect answering service (to be called only by emergency personnel).</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>MEDICARE <i>Offices located nationwide. Check white or blue pages of local telephone directory. Automated Information Service:</i> (800) 638-6833 (800) MEDICARE 7:30 a.m.-4:30 p.m., ET, M-F www.medicare.gov</p>	<p>This agency, under the Health Care Financing Administration of the United States Department of Health and Human Services, operates the national health care system for older and disabled citizens.</p>	<p>Information service provides general information, answers to questions on eligibility and enrollment, and referrals to local offices. (<i>See also, Social Security Administration.</i>)</p>
<p>MEDICARE RIGHTS CENTER 1460 Broadway New York, NY 10036 (T) 212-869-3850 <i>National Medicare HMO Appeals Hotline</i> (888) HMO-9050 M-TH 12:00 p.m. - 2:00 p.m. ET www.medicarerights.org</p>	<p>Helps caregivers understand health-care coverage and options.</p>	<p>Numerous publications available for a fee include <i>Medicare Basics</i>.</p>
<p>NATIONAL ASSOCIATION FOR CONTINENCE (NAFC) P.O. Box 8310 Spartanburg, SC 29305 (F) 864-579-7902 <i>Information Service:</i> (800) 252-3337 8:00 a.m.-5:00 p.m., ET, M-F www.nafc.org</p>	<p>A patient advocacy group that works to educate the public and health professionals about the prevalence, diagnosis, and treatment of urinary incontinence.</p>	<p>Clearinghouse for information and resources for people with bladder and bowel control problems. Provides listings of specialized physicians, makes referrals to other sources of information, and distributes publications. List of information available. List of health professionals by state available.</p>
<p>NATIONAL ASSOCIATION FOR THE VISUALLY HANDICAPPED 22 West 21st Street 6th Floor New York, NY 10010 (T) 212-889-3141 (F) 212-727-2931 www.navh.org</p>	<p>Non-profit membership organization serving the partially-seeing population.</p>	<p>Publishes a visual aids catalog. Offers a by-mail, large-print lending library of 7,000 titles, free to members, suggested charge for non-members.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION (NHPCO) 1700 Diagonal Road, Suite 300 Alexandria, VA 22314 (T) 703-516-4928 (F) 703-525-5762 <i>Quick-Referral Resource Helpline:</i> (800) 658-8898 8:30 a.m.-5:30 p.m., ET, M-F www.hospiceinfo.org www.nhpco.org</p>	<p>Promotes quality care for terminally ill patients and provides information about hospice services available in the United States.</p>	<p>Individuals can contact NHPCO to learn about hospice services in their area and the different types of hospice programs that are available. List of publications includes: <i>Hospice Care: A Consumer's Guide to Selecting a Hospice</i>, <i>Communicating Your End of Life Wishes</i>, and <i>Hospice Care and the Medicare Hospice Benefit</i>.</p>
<p>NATIONAL REGISTER OF HEALTH SERVICE PROVIDERS IN PSYCHOLOGY 1120 G Street NW, Suite 330 Washington, DC 20005 (T) 202-783-7663 (F) 202-347-0550 www.nationalregister.org</p>	<p>Maintains listings of psychologists. The register is recommended by the American Psychological Association.</p>	<p>Provides listings of psychologists by geographic area and by specific services required.</p>
<p>NATIONAL STROKE ASSOCIATION 9707 East Easter Lane Englewood, CO 80112-3747 (T) 303-649-9299 (F) 303-649-1328 <i>Information Service:</i> (800) 787-6537 (24-hour voice-mail) staffed 8:00 a.m.-4:30 p.m. (M-Th), 8:00 a.m.-4:00 p.m. (F), MT. www.stroke.org</p>	<p>Provides information to the public and health professionals and offers supportive services to stroke survivors and their families.</p>	<p>Materials on the prevention, detection, and treatment of strokes and information about aftercare centers and rehabilitation. Self-help services for recovering stroke survivors and guidance for starting support groups. List of publications includes items on prevention, acute care, survivor/caregiver resources, <i>Be Stroke Smart</i> Series, and professional educational materials. Charge for some publications.</p>
<p>ONCOLINK, THE UNIVERSITY OF PENNSYLVANIA CANCER CENTER RESOURCE www.oncolink.upenn.edu</p>	<p>This Web site has several sections with many items of general caregiving interest.</p>	<p>Section for psychosocial support and personal experiences with a number of resources for caregivers, including a caregiver education course and pointers for caring for the caregiver.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>PARKINSON'S DISEASE FOUNDATION William Black Medical Building Columbia-Presbyterian Medical Center 710 West 168th Street New York, NY 10032-9982 (T) 212-923-4700 <i>Information Service:</i> (800) 457-6676 9:00 a.m.-5:00 p.m., ET, M-F www.pdf.org</p>	<p>Non-profit organization with the goal of seeking the cause of and cure for Parkinson's disease and related disorders through research.</p>	<p>Offers information on the disease and how to live with it through publications, counseling, advocacy, and referrals to physicians and support groups. Educational materials provided without charge.</p>
<p>PREVENT BLINDNESS AMERICA 500 East Remington Road Suite 200 Schaumburg, IL 60173 (T) 847-843-2020 <i>Information Service:</i> (800) 331-2020 8:30 a.m.-5:00 p.m., CT, M-F www.preventblindness.org</p>	<p>Works to preserve sight and prevent blindness by sponsoring community services, public and professional education programs, and research.</p>	<p>Free information on eye health and safety topics, and referral to state affiliates offering community services such as eye exams, screening for glaucoma and cataracts, and self-help groups. Available publications catalog includes the brochure <i>Growing Older with Good Vision</i>.</p>
<p>SELF-HELP FOR HARD OF HEARING PEOPLE, INC. (SHHH) 7910 Woodmont Avenue, Ste 1200 Bethesda, MD 20814 (T) 301-657-2248 (F) 301-913-9413 (TDD) 301-657-2249 www.shhh.org</p>	<p>Non-profit educational organization concerned with the welfare and interests of people with hearing impairments. Membership fee.</p>	<p>Local chapters offer hearing impaired people support, encouragement, and information about community resources. Special programs for older people offer information about coping with hearing problems, hearing aids, and ways to communicate effectively. Publication list available. Fees for non-members.</p>
<p>SIMON FOUNDATION FOR CONTINENCE Box 835-F Wilmette, IL 60091 (T) 847-864-3913 (F) 847-864-9758 <i>Information Service:</i> (800) 237-4666 9:00 a.m.-5:00 p.m., CT, M-F www.simonfoundation.org</p>	<p>A non-profit educational organization that fosters awareness, research, and education on urinary and bowel incontinence among health professionals and provides information to the general public. Membership fee.</p>	<p>Distributes information and offers assistance and support to people suffering from incontinence. Helps organize self-help groups. Publications include quarterly newsletter, <i>The Informer</i>; the book, <i>Managing Incontinence: A Guide to Living With the Loss of Bladder Control</i>, and videos. Charge for publications.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>WELL SPOUSE FOUNDATION 30 East 40th Street, PH New York, NY 10016 (T) 212-685-8815 (F) 212-685-8676 (800) 838-0879 www.wellspouse.org</p>	<p>Non-profit organization providing support and information to well partners of the chronically ill and/or disabled and educating professionals and the public about the needs of spousal caregivers. Membership fee.</p>	<p>Provides networking, local self-help support groups, bi-monthly newsletter, and round-robin letters.</p>

HOUSING INFORMATION RESOURCES

<p>AMERICAN ASSOCIATION OF HOMES AND SERVICES FOR THE AGING 901 E Street NW, Suite 500 Washington, DC 20004-2037 (T) 202-783-2242 www.aahsa.org</p>	<p>National association of over 5,000 non-profit homes, housing, health-related facilities, and community service organizations providing services primarily to the elderly.</p>	<p>Publishes free brochures on how to choose a nursing home or assisted-living facility, a directory of continuing-care retirement communities, and information on long-term care insurance. Offers a facilities accreditation service (<i>see following entry</i>).</p>
<p>CONTINUING CARE ACCREDITATION COMMISSION (CCAC) 901 E Street NW, Suite 500 Washington, DC 20004 (T) 202-783-7286 (F) 202-783-2255 www.ccaonline.org</p>	<p>A service of the American Association of Homes and Services for the Aging established in 1985, it is the nation's only accrediting commission for non-profit and for-profit continuing-care retirement communities.</p>	<p>Provides lists of accredited housing by area. You may also confirm whether a community you are considering is accredited. Ask for the brochure, <i>Selecting a Continuing Care Retirement Community</i>.</p>
<p>HEMOCARE ON-LINE 228 Seventh Street SE Washington, DC 20003 (T) 202-547-7424 (F) 202-547-3540 www.nahc.org</p>	<p>Web site of the National Association for Home Care (NAHC) provides information on home and hospice care.</p>	<p>Provides information from their consumer guide, <i>How to Choose a Home Care Provider: A Consumer's Guide</i>. Includes a Home and Hospice care agency locator.</p>
<p>NATIONAL CITIZENS' COALITION FOR NURSING HOME REFORM 1424 16th Street NW, Suite 202 Washington, DC 20036 (T) 202-332-2275 (F) 202-332-2949 www.nccnhr.org</p>	<p>National organization monitoring long-term care facilities and promoting "positive care planning" approaches.</p>	<p>National clearinghouse for information on choosing a nursing home. Provides referral to the Ombudsman's office in your parents' state (to deal with unresolved complaints about long-term care facilities).</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>NATIONAL COUNCIL OF SENIOR CITIZENS 8403 Colesville Road Suite 1200 Silver Spring, MD 20910 (T) 301-578-8800 (F) 301-578-8999 www.ncscinc.org</p>	<p>Information and referral center for consumers of long-term care services. The National Council of Senior Citizens sponsors or co-sponsors senior housing in 11 states.</p>	<p>Offers information on nursing homes, alternative community services, and how to select a nursing home.</p>
<p>SENIOR SITES www.seniorsites.com</p>	<p>This Web site provides a listing of non-profit senior housing, assisted living facilities, and retirement communities that are members of the American Association of Homes and Services for the Aging.</p>	<p>Housing options and levels of care are described, and the directory for over 5,000 communities is searchable by state and by county.</p>

FINANCIAL INFORMATION RESOURCES

<p>THE AMERICAN COUNCIL OF LIFE INSURERS (ACLI) 1001 Pennsylvania Avenue NW Washington, DC 20004 (T) 202-624-2000 www.acli.com</p>	<p>A national organization of life insurance companies.</p>	<p><i>Long-Term Care Insurance: A Choice You Can Afford, and What You Should Know About Buying Life Insurance</i> available on Web site or send a self-addressed, stamped envelope for brochure.</p>
<p>HEALTH CARE FINANCING ADMINISTRATION (HCFA) www.hcfa.gov</p>	<p>This is a government agency Web site.</p>	<p>This Web site provides benefit information about Medicare and Medicaid programs, access to consumer publications and forms, e-mail access to customer service, and local contacts.</p>
<p>HEALTH INSURANCE ASSOCIATION OF AMERICA 1201 F Street NW, 5th Floor Washington, DC 20004 (T) 202-824-1849 www.hiaa.org</p>	<p>Offers information on all aspects of health and disability insurance.</p>	<p>Provides information about health insurance issues including continuation of group medical benefits, major medical, Medicare supplements, and long-term care insurance. Publications available on the Web site or by mail include <i>A Consumer's Guide to Long-Term Care Insurance</i>.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>FINANCIAL PLANNING ASSOCIATION 3801 East Florida Avenue Suite 708 Denver, CO 80210 <i>Consumer Line:</i> (800) 282-7526 8:00 a.m.-5:00 p.m., MT, M-F www.fpanet.org</p>	<p>National association of certified financial planning professionals.</p>	<p>PlannerSearch, an online consumer service program, helps individuals find Certified Financial Planners in their area. Ask for a copy of their brochure <i>How a Financial Planner Can Help You and How to Choose the Right One</i>.</p>
<p>NATIONAL ASSOCIATION OF PERSONAL FINANCIAL ADVISORS 355 West Dundee Road Buffalo Grove, IL 60089 (T) 847-537-7722 (F) 847-537-7740 (888) FEE-ONLY www.napfa.org</p>	<p>Non-profit association of professionals who provide financial planning services on a fee-for-service basis, and do not receive commissions or other compensation from the implementation of their investment recommendations to clients.</p>	<p>Consumers receive a list of fee-only planners in their area plus <i>Financial Planner Interview: How to Choose a Financial Planner and Tough Questions to Ask</i>.</p>
<p>NATIONAL INSURANCE CONSUMER HELPLINE (NICH) (800) 942-4242 8:00 a.m.-8:00 p.m., ET, M-F</p>	<p>A toll-free consumer information telephone service sponsored by major insurance industry trade associations representing life, health, and home and auto (property-casualty) insurance companies.</p>	<p>Answers a wide range of questions about insurance matters, refers complaints to appropriate sources, and sends consumer brochures. Topics include how to choose an agent or broker, how to select an insurance company, and the various kinds of coverage available.</p>
<p>SOCIAL SECURITY ADMINISTRATION (SSA) Office of Public Inquiries 6401 Security Blvd. Baltimore, MD 21235 (T) 410-965-1234 8:00 a.m.-5:00 p.m., ET, M-F <i>24-hour automated service:</i> (800) 772-1213 www.ssa.gov</p>	<p>The federal agency that operates the national retirement system provides information on Social Security coverage, earnings records, claims eligibility and adjustments, and Medicare and Medicaid.</p>	<p>Provides an estimate of benefits upon request. The SSI (Supplemental Security Income) program provides additional payments to older persons already receiving public assistance. Web site has an index to benefit information, an online edition of the U.S. Social Security Handbook on Benefits and Policies, reports to Congress, statistics, legislation and some online SSA documents.</p>

RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>SOCIETY OF FINANCIAL SERVICE PROFESSIONALS 270 S. Bryn Mawr Avenue Bryn Mawr, PA 19010 DC 20004 <i>Consumer Referral Service</i> (888) ChFC-CLU (888) 243-2258 www.financialpro.org</p>	<p>A national organization of insurance and financial service professionals.</p>	<p>Offers free brochure <i>Take the Mystery Out of Financial Planning</i>. For a copy write to: "Financial Consultant Brochure" (see address) or call Consumer Referral Service.</p>
<p>U.S. INTERNAL REVENUE SERVICE (IRS) (800) 829-3676 <i>Call for local addresses and other information, also check local listings.</i> www.irs.ustreas.gov</p>	<p>The agency that collects federal taxes.</p>	<p>Ask for a free copy of <i>Older Americans Tax Guide</i> (publication 554).</p>
<p>UNITED SENIORS HEALTH COUNCIL 409 Third Street SW, Suite 200 Washington, DC 20024 (T) 202-479-6973 (F) 202-479-6660 www.unitedseniorshealth.org</p>	<p>Non-profit educational organization of consumers, advocates, and elder-care professionals. Provides research and publications on consumer issues relating to home and long-term care and managing health care finances and insurance.</p>	<p>Offers consumer reports, books on home and long-term care, insurance, and financing. <i>United Seniors' Health Report</i> (fees).</p>

LEGAL INFORMATION RESOURCES

<p>AMERICAN BAR ASSOCIATION (ABA) COMMISSION ON LEGAL PROBLEMS OF THE ELDERLY 740 15th Street NW, 8th Floor Washington, DC 20005 (T) 202-662-8690 (800) 285-2221 www.abanet.org/elderly</p>	<p>Commission established by the ABA in 1979 to address the legal issues affecting older persons through public policy, education, and technical assistance to the legal profession and agencies on aging in the delivery of legal services.</p>	<p>Information addressing the legal aspects of planning for incapacity and introducing durable and medical powers of attorney, living wills, and trusts, and booklets on Medigap insurance, advance medical directives, and housing rights of older persons.</p>
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RESOURCE	DESCRIPTION	WHAT HELP IS AVAILABLE
<p>NATIONAL ACADEMY OF ELDER LAW ATTORNEYS (NAELA) 1604 North Country Club Road Tucson, AZ 85716 (T) 520-881-4005 (F) 520-325-7925 8:00 a.m.-5:00 p.m., MT, M-F www.naela.org</p>	<p>Professional association of attorneys concerned with improving the availability and delivery of legal services to the elderly.</p>	<p>Maintains a national registry of attorneys who specialize in Elder Law. Check Web site or write for lists by state. Publishes brochures on legal issues that affect the elderly. NAELA does not make referrals to individual attorneys.</p>
<p>NATIONAL SENIOR CITIZENS LAW CENTER (NSCLC) 1101 14th Street NW, Suite 400 Washington, DC 20005 (T) 202-289-6976 9:00 a.m.-5:00 p.m., ET, M-F www.nsclc.org/consumers</p>	<p>A public interest law firm specializing in the legal problems of older people. NSCLC serves Legal Aid Offices and private lawyers who offer legal assistance to low-income older people. It does not accept individual clients.</p>	<p>Clearinghouse for information on legal problems of the elderly including Social Security, age discrimination, pension plans, Medicaid, Medicare, nursing homes, and consumer products. Free services include consulting and referrals to other sources. A variety of documents are available at nominal cost.</p>
<p>PARTNERSHIP FOR CARING: AMERICA'S VOICE FOR THE DYING 1620 I Street NW, Suite 202 Washington, DC 20006 (T) 202-338-9790 (800) 989-9455 www.partnershipforcaring.org</p>	<p>Non-profit organization dedicated to protecting the rights and serving the needs of dying patients and their families.</p>	<p>Provides state specific advance directives and publications on medical treatments. Publications are available on Web site.</p>

ADDITIONAL SOURCE MATERIAL

Publications and video tapes are available that can help you and your parents with the specific problems they may face. Many of these items may be available in the public library or a local book store.

GENERAL INFORMATION

AGE AWARE: HOW TO HELP AND BETTER UNDERSTAND YOUR PARENTS, RELATIVES, AND OTHER OLDER ADULTS
Gayle Yelenik
Kansas City, MO: Home Is Better, 1999. \$29.95

AGING PARENTS: THE FAMILY SURVIVAL GUIDE (BOOK/VIDEO)
Gary Weinstein
Carlsbad, CA: Lifetapes Communications, 1997. \$99.00

BY YOUR SIDE (VIDEO)
Washington, DC: State of the Art, Inc., 1998. \$12.95

CAREGIVERS: THE HEART OF HOME CARE (VIDEO)
Washington, DC: State of the Art, Inc., 1998. \$12.95

CAREGIVING: THE SPIRITUAL JOURNEY OF LOVE, LOSS, AND RENEWAL
Beth Witrogen McLeod
New York: Wiley & Sons, 1999. \$22.95

CARING FOR YOUR AGING PARENTS: A PLANNING AND ACTION GUIDE
Donna Cohen, PhD., and Carl Eisdorfer, PhD., M.D.
New York, NY: G.P. Putnam's Sons, 1993. 304 pages. \$21.95

CARING FOR YOUR AGING PARENTS: A SOURCEBOOK OF TIMESAVING TECHNIQUES AND TIPS
Kerry S. Smith.
San Luis Obispo, CA: Impact Publishers, American Source Books, 1992. 120 pages. \$9.95

CARING FOR YOURSELF WHILE CARING FOR YOUR AGING PARENTS: HOW TO HELP, HOW TO SURVIVE
Claire Berman
New York, NY: Henry Holt & Co.: 1996. 272 pages. \$22.50

THE COMPLETE BEDSIDE COMPANION: NO-NONSENSE ADVICE ON CARING FOR THE SERIOUSLY ILL
Rodger McFarlane and Philip Bashe
New York, NY: Simon & Schuster, 1998. \$21.60

THE COMPLETE ELDER CARE PLANNER
Joy Loverde
New York, NY: Hyperion, 1997. \$14.95

COPING WITH YOUR DIFFICULT OLDER PARENT: A GUIDE FOR STRESSED-OUT CHILDREN
Grace LeBow and Barbara Kane
New York, NY: Avon Books, 1999. \$12.00

ELDER CARE FOR THE MILLENNIUM
*Dr. Lisa Mienville,
Dr. Bonnie L. Robeson*
Columbia, MD: Graphix III Productions, 1999. \$22.95

ELDERCARE: THE BEST RESOURCES TO HELP YOU HELP YOUR AGING RELATIVES
Marty Richards, Editor
Issaquah, WA: Resource Pathways, Inc., 1999. 288 pages. \$19.96

GOOD DAUGHTERS: LOVING OUR MOTHERS AS THEY AGE
Patricia Beard
New York, NY: Warner Books, 1999. \$23.00

HANDBOOK FOR MORTALS: GUIDANCE FOR PEOPLE FACING SERIOUS ILLNESS
Joanne Lynn and Joan Harrold
New York, NY: Oxford University Press, 1999. \$20.00

HARD QUESTIONS, SIMPLE ANSWERS: A WORKBOOK TO TAKE THE CRISIS OUT OF CAREGIVING
Elana Peters, M.A.
Irvine, CA: Caregiving Solutions, 1999. \$24.95

HE USED TO BE SOMEBODY, A JOURNEY INTO ALZHEIMER'S DISEASE THROUGH THE EYE OF A CAREGIVER.
Beverly Bigtree Murphy.
Boulder, CO: Gibbs Association, 1995. 331 pages. \$16.95

**HELPING YOURSELF HELP OTHERS:
A BOOK FOR CAREGIVERS**
Rosalynn Carter, with Susan K. Golant
New York, NY: Random House,
1995. \$14.00

**HOME NURSING CARE: A PRACTICAL
GUIDE FOR FAMILY CAREGIVERS**
Genevieve Timpane and Margaret Wholey
Arlington, VA: AYA, Inc., 1998.
\$29.95

**HOW TO CARE FOR AGING PARENTS:
A COMPLETE GUIDE**
Virginia Morris
New York, NY: Workman
Publishing Company, Inc., 1996.
544 pages. \$12.76

**HOW TO CARE FOR YOUR
PARENTS: A PRACTICAL GUIDE
TO ELDERCARE**
Nora Jean Levin
New York, NY: W.W. Norton and
Company, 1997. 192 pages. \$9.60

**HOW TO GO ON LIVING WHEN
SOMEONE YOU LOVE DIES**
Therese A. Rando, PhD
New York, NY: Bantam Books,
1991. \$11.96

**LONG DISTANCE CAREGIVING:
A SURVIVAL GUIDE FOR FAR AWAY
CAREGIVING**
Angela Heath
San Luis Obispo, CA: Impact
Publishers, American Source Books,
1993. 122 pages. \$12.95

**LOSING A PARENT: PASSAGE TO A
NEW WAY OF LIVING/A GUIDE TO
FACING DEATH AND DYING**
Alexandra Kennedy
New York, NY: HarperCollins
Publishers, 1991. \$12.00

THE RESOURCEFUL CAREGIVER
National Family Caregivers Association
St. Louis, MO: Mosby Lifeline, 1996.
145 pages. \$12.95

**SEVEN STEPS TO EFFECTIVE PARENT
CARE: A PLANNING AND ACTION
GUIDE FOR ADULT CHILDREN WITH
AGING PARENTS**
*Donna Cohen, Ph.D., and Carl
Eisdorfer, Ph.D., M.D.*
Los Angeles, CA: Jeremy P. Tarcher,
Inc., 1993.
*To obtain this resource, write to Jeremy P.
Tarcher, Inc., 5858 Wilshire Blvd., Suite
200, Los Angeles, CA 90036.*

**TAKING CARE OF AGING FAMILY
MEMBERS: A PRACTICAL GUIDE**
*Wendy Lustbader,
Nancy R. Hooyman*
New York, NY: Macmillan, Inc.,
1994. 356 pages. \$17.95

HEALTH INFORMATION

**THE 36-HOUR DAY: A FAMILY
GUIDE TO CARING FOR PERSONS
WITH ALZHEIMER'S DISEASE,
RELATED DEMENTING ILLNESSES,
AND MEMORY LOSS IN LATER LIFE**
*Nancy L. Mace and
Peter V. Robins, M.D.*
Baltimore, MD: Johns Hopkins
University Press, 1999. 339 pages.
\$11.16

**CAREGIVER'S HANDBOOK:
A COMPLETE GUIDE TO HOME
HEALTH CARE**
Visiting Nurse Associations of America
Boston, MA: DK Publishing, Inc.,
1998. 192 pages. \$11.96

**COMPLETE GUIDE TO AGING
AND HEALTH**
Mark E. Williams, M.D.
American Geriatric Society.
New York, NY: Harmony Books,
1995. 500 pages. \$32.00

**HEALTHWISE FOR LIFE:
MEDICAL SELF-CARE FOR PEOPLE
AGE 50 AND BETTER**
Donald W. Kemper and Healthwise Staff
Boise, ID: Healthwise, 1998. \$9.95

**LEBOEUF'S HOME HEALTHCARE
HANDBOOK**
LeBoeuf & Associates, Inc.
Great Falls, VA: Noel Press, Inc.,
1996. 532 pages. \$24.95

**LIVING WITH ALS: A SERIES OF SIX
MANUALS**
ALS Association, 1999.
*To obtain this resource, write to ALS,
27001 Agoura, Ste. 150, Calabasas
Hills, CA 91301*

**MEDICAL CRISIS COUNSELING:
SHORT-TERM THERAPY FOR LONG-
TERM ILLNESS**
Irene Pollin with Susan Baird Kanaan
New York, NY: Norton, 1995.
\$30.00

TAKING CHARGE OF YOUR HEALTH
Alice Hodge and Mary Lonergan
San Francisco, CA: BookPartners,
1999. 179 pages. \$14.95

**WHEN SOMEONE YOU LOVE
HAS A STROKE**
Marilynn Larkin
New York, NY: Dell, Lynn Sonberg
Book Associates, 1995. \$5.39

HOUSING INFORMATION

**CARING FOR SOMEONE
IN YOUR HOME**
*K.N. Tigges, W.M. Marcil,
and C.J. Alterio*
Baltimore, MD: Johns Hopkins
University Press, 1993. \$11.95

**THE COMPLETE GUIDE TO
ALZHEIMER'S PROOFING YOUR HOME
(REVISED EDITION)**
Mark L. Warner
Purdue University Press, 2000.
368 pages. \$19.96

THE COMFORT OF HOME:
*AN ILLUSTRATED STEP-BY-STEP
GUIDE FOR CAREGIVERS*
Maria M. Meyer with Paula Derr, RN
Portland, OR: CareTrust
Publications, 1998. \$23.00

**CONTEMPORARY ENVIRONMENTS
FOR PEOPLE WITH DEMENTIA**
Uriel Cohen and Kristen Day
Baltimore, MD: Johns Hopkins
University Press, 1993. \$47.00

ELDERDESIGN
Rosemary Bakker.
New York, NY: Penguin, 1997.
228 pages. \$14.95

HIRING HOME CAREGIVERS:
*THE FAMILY GUIDE TO IN-HOME
ELDERCARE*
D. Helen Susik, M.A.
San Luis Obispo, CA: Impact
Publishers Inc. \$11.95

**HOME PLANNING FOR YOUR
LATER YEARS.**
William Wasch.
St. Louis, MO: Beverly Cram
Publishers, 1996. 181 pages. \$19.95

**HOME SWEET HOME: HOW TO HELP
OLDER ADULTS LIVE INDEPENDENTLY**
Aid Association for Lutherans, 1996.
*To obtain this resource write to Aid
Association for Lutherans, 4321 N.
Ballard Road, Appleton, WI 54919-0001*

MAKING LIFE MORE LIVABLE:
*A PRACTICAL GUIDE TO OVER 1,000
PRODUCTS AND RESOURCES FOR
LIVING WELL IN THE MATURE YEARS*
Ellen Lederman
New York, NY: Fireside, 1994.
\$20.50

MOVING MOM & DAD:
**WHY, WHERE, HOW, AND WHEN TO
HELP YOUR PARENTS RELOCATE**
(LANIER GUIDES SERIES)
Sarah Morse, Donna Quinn Robbins
Petaluma, CA: Lanier Publishing,
1998. \$19.95

FINANCIAL INFORMATION

BEAT THE NURSING HOME TRAP:
*CHOOSING AND FINANCING
LONG-TERM CARE*
Joseph Matthews
Berkeley, CA: Nolo Press, 1993. \$18.95

CAREGIVING:
A MONEY MANAGEMENT WORKBOOK
Washington, DC: AARP, 1992.
*Available from AARP Consumer Affairs
Section, 610 E Street NW, Washington,
DC 20049*

THE COST OF CARING:
MONEY SKILLS FOR CAREGIVERS
Anne M. Johnson, Ruth Rejnis
New York, NY: John Wiley & Sons,
1998. 250 pages. \$14.95

A GUIDE FOR ELDER:
*PLANNING THAT PROTECTS YOU
AND YOUR ASSETS*
Gerontology Institute and Center,
University of Massachusetts, Boston.
*To obtain this resource, write to Gerontology
Institute and Center, University of
Massachusetts, Boston, 100 Morrissey
Blvd., Boston, MA 02125-3393*

LONG-TERM CARE PLANNING:
A DOLLAR & SENSE GUIDE.
Washington, DC: United Seniors
Health Council, 1997. 100 pages.
\$19.50
*Available from the United Seniors Health
Council, 409 Third St., SW, Suite 200,
Washington, DC 20024-3212*

**PROTECT YOUR PARENTS AND THEIR
FINANCIAL HEALTH: TALK WITH
THEM BEFORE IT'S TOO LATE**
Susan C. Richards, CFP
Chicago, IL: Dearborn Financial
Publishing, Inc., 1999. 272 pages.
\$15.96

**A SHOPPER'S GUIDE TO
LONG-TERM CARE INSURANCE**
Kansas City, MO: National
Association of Insurance
Commissioners, 1999.
*Available from the National Association
of Insurance Commissioners, 120 W. 12th
St., Suite 1100, Kansas City, MO
64105-1925*

LEGAL INFORMATION

**THE AMERICAN BAR ASSOCIATION
LEGAL GUIDE FOR OLDER AMERICANS:**
*THE LAW EVERY AMERICAN OVER
FIFTY NEEDS TO KNOW*
*Charles P. Sabatino, American Bar
Association, Nancy Coleman*
New York, NY: Times Books, 1998.
272 pages. \$10.40

**THE FINANCIAL POWER OF
ATTORNEY WORKBOOK:**
*MAKE YOUR OWN DURABLE
& CONVENTIONAL POWERS
OF ATTORNEY*
Shae Irving
Berkeley, CA: Nolo Press, 1997.
\$24.95

A GUIDE FOR ELDER:
*PLANNING THAT PROTECTS
YOU AND YOUR ASSETS*
Boston, MA: Gerontology Institute
and Center, University of
Massachusetts, 1995.

HOW TO SETTLE AN ESTATE:
*A MANUAL FOR EXECUTORS
AND TRUSTEES*
*Charles K. Plotnick,
Stephan R. Leimberg*
New York, NY: Penguin, 1998. 336
pages. \$11.96

THE OTHER MID-LIFE CRISIS:
*EVERYTHING YOU NEED TO KNOW
ABOUT WILLS, HOSPITALS, LIFE-AND-
DEATH DECISIONS AND FINAL
MATTERS (BUT WERE NEVER TAUGHT)*
Adeline Rosemire
San Jose, CA: Meridian, 1994.
\$14.95

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