

AGING **PARENTS** *The Family Survival Guide*™

Action Guide

An
AGING PARENTS.com
Production

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American Society on Aging



American Association of Homes
and Services for the Aging



National Council on the Aging, Inc.



American Health Care Association

AGING **PARENTS** *The Family Survival Guide*™

Action Guide

Eldercare needs and solutions will differ for each individual and family. The information in AGING PARENTS: The Family Survival Guide is intended to be used only as a guideline for families dealing with a crisis or planning for long-term caring. Determining how best to meet the needs of an aging parent involves the consideration of many complex issues relating to finance, insurance, legal, medical, psychological, cultural, ethnic, religious beliefs and practices, and more. As a result, consider consulting a professional in the appropriate field before making critical eldercare choices or decisions.

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Dear Friend:

The responsibilities of being an adult child of an aging parent can be overwhelming.

Some of us are confronted suddenly with helping our folks due to a medical emergency—others begin to help in less extreme situations. But no matter how you've come to be involved, you are on a journey that is filled with complexities, uncertainties, worry, and love.

Assuming more responsibility over your parents' needs may be new to you. However, the issues you are confronting have been daily concerns at The National Council on the Aging for nearly 50 years. We know how difficult and confusing this phase in your relationship with your parents can be. That is why we have taken the extraordinary step to endorse *AGING PARENTS: The Family Survival Guide*. We are confident that it will provide caregivers with the range of information they so desperately need.

This product is the first comprehensive resource to help families facing a parent care crisis and a powerful tool for long-term planning...and caring. As you use this DVD to help you make choices with your parents and for your family, you can feel confident that the information is clear, accurate and concise.

Remember that you're not alone in worrying about your parents—millions of people are caring for their parents every day...and are surviving! *AGING PARENTS* contains sound advice to help you steer clear of danger spots, tap into the wealth of services and resources in your community, and arrive at a strategy for helping you and your parents make the most of their later years.

Sincerely,



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The American Society on Aging is pleased to be joining our colleagues at the National Council on the Aging in endorsing and recommending to you *AGING PARENTS: The Family Survival Guide*. This is an outstanding resource which will prove to be extremely valuable to you and your family.

For adult children, our changing relationships with parents over the years is always a central concern. When the time comes that they need us as caregivers, much in the same ways we needed them as children, we may find ourselves without the information and resources we need to perform the necessary tasks to the best of our ability.

That is why the AGING PARENTS DVD is so important and why we are feel it should be in your hands.

Providing care for aging parents is often a difficult job, and is made even more complex because of the nature of parent-child relationships and because we are afraid of losing those we love most. We at ASA wish you well and hope that this resource will make the job somewhat easier.

Most sincerely,

Jennie Chin Hansen
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Introduction

Look around. Ask your friends. Are they one of the estimated 15 million Americans caring for an aging parent? You'll see that *you are not alone*. Americans are living longer than ever before so it's not surprising that experts in the field of aging confirm that a longer life expectancy is increasingly common as we approach the 21st century. Today more than 31 million Americans are over the age of 65 and their number is *growing at twice the rate* of the general population. With the *fastest growing* group comprised of those over the age of 85, for whom chronic illnesses and increased frailty are more evident, an increasing number of adult children find themselves suddenly thrust into the difficult role of care giver to one or both of their parents.

Caring for an aging parent is an enormous undertaking, even in the best of circumstances. Astonishingly, adult children often spend more years caring for a parent than they do raising their own children! Taking care of a frail parent can easily require more than 25 hours per week. The direct impact on a family's finances, lifestyle and jobs can be catastrophic, particularly if these responsibilities occur unexpectedly. This is often the case when a sudden illness or an accidental slip or fall occurs, creating a care giving crisis. Of course, advance planning can *greatly* ease the burden on the entire family, even in a crisis. Yet most families don't plan ahead and adult children often find themselves utterly unprepared to assume the responsibilities of care giving.

Then there is death. Most of us don't want to think about death or dying before the time comes. Denial is the most common human response to the reality and finality of the life cycle. It's not surprising then that through our denial of the inevitable, many of us require a crisis to motivate us to action. Sadly, when a crisis arises, it may be too late for us to prevent or control the possible financial and emotional damage the situation may cause.

A crisis that turns you into an instant care giver is only one scenario. There can be other and more subtle ways to conclude it's time for you to be there for your parent. Whether you are working through a crisis situation or are just beginning to learn about the care giving process, **AGING PARENTS: The Family Survival Guide** is a valuable resource for you and your family. This *Action Guide* and the accompanying video contain solid, reliable information you'll need to help you assist your parents...today as well as in the future.

Consider **AGING PARENTS** as your personal long-term resource, an informational support system to help alleviate the natural anxiety faced by both adult children and their parents during this difficult, yet potentially most meaningful, phase of a lifetime relationship.

How to Use **AGING PARENTS**

AGING PARENTS presents a broad range of care giving issues, each described from the perspective of the care giver and of subject experts. Some of the information in the video is repeated here in print. The chapters in the **AGING PARENTS** *Action Guide* run parallel to the video, so you may turn to a particular chapter as you view the video. Similarly, should you want to quickly reference the video while working in the book, we have included the running-clock time from the video next to the headings throughout this guide.

Our experts and care givers have provided lists of important questions for you when considering specific services. We've also included check lists to assist you in being more organized. Think of **AGING PARENTS** as a road map. It will take you through common byways and indicate where you might take detours for assistance appropriate to your particular situation. Together, the video and *Action Guide* will help you understand what to expect when caring for an aging parent or relative, giving you support and encouragement along the way.

While aging parents are obviously both men and women, for simplicity we have used the male pronoun throughout this *Action Guide*.

Records and Information

The *Records and Information* chapter can be used to record important addresses and phone numbers, financial, and legal information. While completing the records and forms can seem like a massive undertaking, you'll find that if you compile the data in small increments, or delegate some of the data collection tasks to your parents or other family members, the process will be much less intimidating. The sample documents in the *Action Guide* are designed to give you a realistic sense of what the actual documents look like and what information they should contain. As you meet with your parents and with members of your support network, you'll appreciate having the data well organized and stored in one place.

Glossary

As you begin to sort through the information you receive from professionals and organizations listed in this *Action Guide*, you may come across some unfamiliar terms. The **AGING PARENTS** *Glossary* gives you definitions of the terms used throughout the video and *Action Guide*.

Reference and Referral

A *Reference and Referral* section has been placed at the end of each chapter to guide you toward finding the best resources available to meet your needs. Listed alphabetically at the end of the *Action Guide* is an index reflecting the entries from each chapter listing. A *Reading List* is included to give you quick access to additional information.

By educating yourself, gathering the recommended information and discussing choices with your parent, you will save yourself hundreds of hours and perhaps thousands of dollars that care givers typically spend in their search for seemingly elusive information.

Information can open doors and empower you as a care giver; awareness is one of the keys to successful care giving.

When Crisis Hits

When a crisis hits, where do you start? You may still be in shock from the news and may not think clearly or have the objectivity you need. However, once you're over the initial shock of the situation, it's time to focus on gathering the documents you and your parent will need. Don't worry if you can't find some of them. Use the *Records and Information* section as a starting point and work through the steps as best you can. If the situation and time permit, we suggest that you also think about issues beyond the immediate crisis, such as preparing for legal and financial incapacity, income management, arranging long-term care (see *Housing Alternatives and Support Services*), division of responsibilities among family members, and community back-up services.

Although there is no single doorway into the vast number of national and local services for seniors, there are many ways to get help when a crisis hits—and beforehand. You may need information on organizing and developing a care plan, long distance care giving, family interactions, and emotional support for your other parent or family members. Other care givers may need information on legal issues, financial planning, and available housing options. There will likely be medical questions, and confusion over Medicare and what it covers. In some cases, you may need to know how to plan for death, and how to cope with grief.

In all cases, the single best starting point is your city or county's Area Agency on Aging (AAA). It might be called the Commission or Department on Aging. Check the local Yellow Pages. This federally funded service offers free information and referral to agencies and services for all elder care needs. You can also call the National ElderCare Locator at (800)677-1116 (9 a.m. to 11 p.m., Eastern time), for referrals to the local AAA anywhere in the United States. Refer to the *Reference and Referral* chapter for details on other specific agencies.

We suggest that your family has on hand at least four kinds of information about your parent:

- o Health data (see *Medical and Health Issues*).
- o Information that can help support your parent at home safely, such as community services (see *Housing Alternatives and Support Services*).
- o Facts on government programs that may supplement income or defray expenses (see *Government Programs*).
- o Financial and legal information (see *The Business Side of Care Giving: Finances and Insurance* and *Legal Issues: Protecting Your Parent's Wishes and Assets*).

In a crisis situation, we recommend that you focus your immediate attention on the following issues. A brief description is given here for each topic. Further detail can be found in the video and in the other chapters of the *Action Guide*.

Care giver burnout: Relief and guidance can come from support groups, family service agencies, professional geriatric care managers, hospital senior services, adult day care centers, volunteer agencies, transportation agencies, friendly visiting services, peer counselors respite programs, and mental health associations. (See *Reference and Referral.*)

Financial and legal planning: Your local Health Insurance Counseling and Advocacy Program (HICAP) office, an elder law attorney, Social Security and Medicare offices, Social Services departments, legal aid societies, the local bar association, and the Legal Counsel for the Elderly office can provide information and referrals to professionals. (See *The Business Side of Care Giving: Finances and Insurance and Legal Issues: Protecting Your Parents Wishes and Assets.*)

Home care: Home health care agencies, places of worship, senior centers, hospices, neighbors and friends, community college job boards, civic groups, and Family Service Agencies are all good resources. Check the Yellow Pages for other listings under Counseling Services, private geriatric care managers, the Red Cross, and the Department of Veterans Affairs. (See *Housing Alternatives and Support Services.*)

Hospice: Check the Yellow Pages under Hospice, Area Agency on Aging (AAA), hospitals and long-term care facilities. (See *Death and Dying.*)

Housing: Call the local Public Housing Authority for information about subsidized housing. Check the Yellow Pages for phone numbers for the County Social Services Department, ECHO housing, and/or Area Agency on Aging (AAA) for details on the availability of free or low-cost repair or modification services. Contact the Federal National Mortgage Association or the National Center for Home Equity Conversion for information about home equity conversion mortgages. Call city hall for information about social and rehabilitation services, independent living centers, geriatric care management professionals, and shared housing services. (See *Housing Alternatives and Support Services.*)

Medical care: Contact your parent's physician and other health professionals, mental health professionals, community mental health centers, hospital discharge planners or social workers, visiting nurse services, hospices, local and national medical associations, senior centers, family service agencies, adult protective services, and rehabilitation centers. (See *Medical and Health Issues.*)

Nursing homes/long-term care facilities: Resources include hospital discharge planners, doctors and nurses, family and friends, community social service agencies, local or state long-term care ombudsman programs, the Continuing Care Accreditation Commission, and care management professionals. (See *Housing Alternatives and Support Services.*)



Questions to Ask Yourself When a Crisis Strikes—Medical and Financial

The following questions can help you prioritize the steps you and your parent might need to take when working through the crisis.

- How might the crisis change your parent's life? How will it affect your life?
- Does or will your parent need to take many prescriptions? Will there be a need for physical or occupational therapy or psychotherapy? Is it likely your parent's condition may worsen? How soon?
- How soon and how often will your parent need some assistance at home? Will the needs be for homemaking, such as light housekeeping, laundry or preparing meals, or more extensive, such as personal assistance with dressing, toileting, bathing or feeding?
- Will your parent need long-term care or increasing levels of care? Will you need to discuss relocation to an assisted living setting or a skilled nursing facility? Does your parent have a long-term care insurance policy in place that covers some of the costs involved with home or skilled nursing facility care? (See *The Business Side of Care Giving: Finance and Insurance*.)
- Does your parent need to repair or adapt his home so he can return home after the emergency, sell it to finance a move, or rent it for income?
- Will your parent be able to use the resources of a local adult day services center? How will the adult day care expenses be paid? Does the center offer a sliding-fee scale where a person's fee is based on their level of income?
- Do you and your parent need the services of a professional care manager? Will a one-time assessment suffice or will ongoing monitoring and assessment be required?

RECAP

An unanticipated crisis can bring sudden and severe psychological and physical stress to the care giving situation. Because immediate actions and decisions are often required, you should try to first focus on gathering the documents necessary for immediate decision-making, and next determine what kinds of services and assistance your parent will need now and in the immediate future.

There are many resources available to care givers in a crisis. The National ElderCare Locator at (800) 677-1116 can direct you to local services; a hospital discharge planner or social worker can help you arrange for in-home care, renting medical equipment, physical therapy, or skilled nursing care. This chapter contains a check list of questions to help you and your parent focus on immediate care giving issues in a time of crisis.

WHEN CRISIS STRIKES

REFERENCE AND REFERRAL

ELDERCARE LOCATOR

(800) 677-1116

Free service will put you in touch with the network of organizations at the state and local levels that can help you with your elder care needs.

NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING

1112 16th St. NW, Suite 100

Washington, DC 20036

(202) 296-8130

Local referrals through Area Agencies on Aging across the country.

NATIONAL ASSOCIATION OF PROFESSIONAL GERIATRIC CARE MANAGERS

1604 N. Country Club Road

Tucson, AZ 85716

(520) 881-8008

Information and local referrals to care managers throughout the United States. Provides a listing of care managers in your area if you send a self-addressed, stamped envelope.

Getting Organized

KNOWING WHEN IT'S TIME TO ACT

When is it OK to step in and assist your parent? That's always a hard question, and one you'll have to judge the best you can. There's no single time or place. But there are some red flags to be on the lookout for, such as changes in diet and food habits. Chronic malnutrition affects nearly a quarter of Americans over age 70, including people who are well educated and financially solvent.

Bad teeth, loss of muscle tone in the digestive tract, loss of taste or smell, reduced finances, and loneliness or fear of going out into the neighborhood can all contribute to a poor nutritional diet. Check your parent's refrigerator and pantry—is there rotting food? Check the expiration dates on canned food. If you find evidence of these problems, try to bring in meals or have others visit with food, arrange for Meals on Wheels, and eat together as often as possible.

Other signs that may indicate your parent needs some assistance include: Putting on or losing weight, appearing unkempt, smelling unclean, wearing stained or dirty clothing, limping when walking, bumping into things, swelling feet or legs, speaking too loudly or softly, asking people to repeat things all the time, having difficulty getting in and out of chairs, missing doctor or dentist appointments, leaving the oven or burners on, not fixing or eating meals, not going grocery shopping, not using the entire home if it has more than one level, having unusual mood swings or abnormal skin color, having electricity or phone service shut off (indicating that they may be forgetting to pay bills), and not keeping the house or apartment in good repair.

It's hard to step in sometimes, especially if you feel you're humiliating your parent by noticing frailty or dependence. You may also have more than enough on your plate already, and don't want to think about what care giving might entail. If you and your parent live in different towns, states, or countries, long distance care giving can be particularly difficult (see *Care Giving From a Distance*).

Ask other people for their impressions of your parent, talk to your parent's doctor, clergy or close friends. Understand that there are many losses represented by aging, disease, or illness. Sometimes you have to give your parent the space and understanding needed before he is ready to open up. It can take time for him to adjust to serious changes, especially if your parent has become terribly frail, disabled, or has a terminal illness.

Once you've discovered that your parent needs your assistance, it's time to gather your energy and willpower and get all of the necessary documents together. Don't fret if you can't find some of them; just start where you can, and know that this step is a giant one. We suggest you start thinking about preparing for legal and financial incapacity, income management, arranging long-term care (see *Housing Alternatives*

and Support Services), division of responsibilities among family members, and community back-up services.

By getting organized, you can begin to get a handle on these matters. You can do it yourself, or you may want to do it through a geriatric assessment team, a care manager (see *Care Giving From a Distance*), or with friends and family.



Financial, Legal and Medical Issues to Consider *Before* a Crisis Strikes

- Don't be afraid to talk about "What If..." questions. It may not be easy, but listen and encourage expressions of feeling's.
- Find out who can assist your parent if you're unable to. Consider using an employer referral service, often referred to as an Employee Assistance Program (EAP), or a local Agency on Aging, private geriatric care manager, or clergy.
- Where are your parent's accounts and assets? Who are his advisors?
- Can you arrange to meet your parent's banker or broker? Consider an authorization (a joint signature card or bank's power of attorney) that allows the banker to talk to you about your parent's accounts. Ask the banker to alert you if there are any unusual changes in the accounts (large amounts withdrawn, many checks overdrawn). Try to arrange to review your parent's checkbook to catch any problematic patterns.
- Can you arrange automatic payment of as many recurring bills as possible (such as utility, telephone, health insurance)?
- Discuss using a Durable Power of Attorney (DPOA) with your parent. It allows one person (who must be mentally competent when the power is given) to give someone else specific authority to handle financial affairs (see *Legal Issues: Protecting Your Parent's Wishes and Assets*).
- Encourage direct deposit of Social Security and pension checks. If your parent invests, encourage him to consolidate multiple accounts at a brokerage firm to minimize potential for loss or theft, reduce paperwork, and time. This enables your parent to have one DPOA over the account, rather than a DPOA for multiple accounts. Consult a financial planner about tax consequences. (See *The Business Side of Care Giving: Finance and Insurance*.)
- Does your parent have legal documents, and where are they located?
- Let your parent's advisors know you want to assist, and give them your phone number(s).
- Consider creating a living will or other advance directives (see *Legal Issues: Protecting Your Parent's Wishes and Assets*).

- Develop a record of your parent's serious illnesses, operations, diseases, and chronic conditions.
- Make a list of your parent's allergies, medications, adverse reactions, and immunizations (such as tetanus, flu).

RECAP

It's difficult to know when to step in and assist a parent. Elders are proud and independent; they've lived full lives, and have well-established ways. You may suddenly realize that you really don't know your parent all that well, that he is a private person with an independent life. Whether you've been close or not, however, you will either sense or be told that there's a problem. That's the time to step in. You will need to talk to many people to get your arms around what's really going on, but it can be done. Recognizing that something needs to be done is sometimes the hardest step. Congratulations on taking it!

ASSESSING YOUR PARENT'S SITUATION

Are you finding that more and more of your time and energy is focused on your parent? Has there been a change in his health? Is he unable to do the things he used to do? Does he rely on you more? Is his present living arrangement becoming unsuitable?

Before you can be an effective care giver, you have to know what you're dealing with.

We suggest your family have on hand at least four kinds of information about your parent:

- Health data (see *Medical and Health Issues*).
- Information that can help support your parent at home safely, such as community services (see *Housing Alternatives and Support Services*).
- Facts on government programs that may supplement income or defray expenses (see *Government Programs*).
- Financial information (see *The Business Side of Care Giving: Finance and Insurance*).

Your role as care giver can range from assisting your parent with simpler tasks like balancing the checkbook, to more time-intensive jobs such as bathing, dressing, and feeding him at your home or his. Although the aging process is full of unknowns, there are some things you can do initially that will help you later, if and when a crisis hits. Once you sense that assistance may be needed--a relative or neigh-

bor has talked to you about changes, or you have noticed a difference yourself--you will need to talk to your parent. (See *Family Dynamics*.) That is usually the hardest step.

You'll also need to assess the situation, and that may take some time and research. The idea is to determine what's going on with your parent, stabilize the crisis, and create a game plan for immediate and long term caring.

For example, if your father falls and breaks a hip and he's in the hospital, you're going to have to deal with that immediately. But parallel to dealing with the crisis, you've got to anticipate the future. When he is discharged from the hospital, for example, how are you going to care for him? What sort of resources exist? What sort of complicating health issues accompany a broken hip? What about housekeeping? Who will perform in-home services such as housekeeping and home health care? Who supervises? Who hires? Who's responsible? There are many issues that must be considered. Therefore, in addition to managing an acute crisis situation, you must also think about long-term care.

Remember to put the desires of your parent first. If your parent has already done some planning for the future, find out what that is. Has he created a living will? Has he appointed someone to serve his interests through a Durable Power of Attorney? Created an Advance Directives for Health Care document? (See *Legal Issues: Protecting Your Parent's Wishes and Assets* for details.) Remember, this is the life of your parent, and you are working to maximize his independence and choice at whatever level is feasible.

An assessment is critically important to understanding your parent's current situation. It is also a benchmark for the future. With this information, you'll have a complete picture of your parent's physical and mental health capacities, the areas of life with which he may need assistance, and what changes may be required in his living situation.

Questions to Ask to Assess Your Parent's Needs

- Is this an acute illness, accident, or a worsening chronic condition?
- Is it really a crisis now, or just my first sense that my parent will need assistance soon?
- How quickly must I act? Do I need to move mountains today or do I have a few days, weeks, or months to gather my resources?
- What resources are available? Who can help me, and what information do I need?

The idea behind the assessment process is to determine the scope of the care



your parent needs and to determine your limits. What will this crisis mean in terms of your life, family, and job responsibilities? How much can you do alone? You may have to take some emergency steps to support your parent, but as you do so, consider your own life and that of your family. What are the consequences to your family and the impact on your job if you suddenly “disappear” while helping to get your parent’s situation stabilized or resolved?

Caring for an aging parent can mean coping with gradual changes over a long period of time. You will need to get a handle on your emotions, build strong networks, balance your needs with those of your parent, and be willing to let go and move on when necessary. Begin to consider the long-term consequences of your parent’s need for your assistance.

One of the first things you must do is find out if your parent’s affairs are in order, and if they are not, how to get them in order. He may not want to talk about such personal and sometimes frightening matters. And you may not want to either. It can mean addressing for the first time that your parent is getting old and will die some day. Look for natural opportunities to broach the subject. If he brings it up, let him talk. You can also ask a trusted friend or relative to talk to him, or act by example by putting your own affairs in order and letting him know what you’re doing. If you aren’t getting anywhere, let it go for now. There are still things you can do.

In assessing your parent’s health and capabilities, we suggest your first actions be to:

- Involve your parent and other family members for a discussion on as many decisions as possible, but be sure there is only one director.
- Call on people with appropriate areas of expertise, including neighbors and friends, as well as people from your parent’s religious and civic associations, doctors, and other health professionals. Move quickly, but not without thoughtfulness.
- Call on or create a support network as soon as possible.

Questions to Ask Your Parent’s Geriatric Specialist



- What is my parent’s current health status? Past health conditions?
- Is the condition acute or is it a worsening chronic condition?
- What are my parent’s medical and daily life needs? Are there limitations in activities of daily living, such as bathing, eating, and dressing?
- What immediate and midrange steps need to be taken?



Checklist for Choosing a Doctor to Care for Your Aging Parent

When you are dealing with doctors, you and your parent need to be comfortable, so keep these points in mind when selecting a primary care physician for this period of your parent's life, if your parent doesn't already have such a doctor in place. Ask your parent's current physician for recommendations to specialists that may be needed. (Put a check next to "yes" answers. You may want to add comments for discussion with other family members or care givers.)

- Can your parent openly discuss feelings and talk about personal concerns, such as sexual or emotional problems, with the doctor?
- Does the doctor rush through every appointment with little or no conversation?
- Do you believe the doctor will stand by you and your parent, no matter how difficult the problems become?
- Does the doctor listen and answer specific questions about cause and treatment? Is he or she vague and impatient?
- Is time available for follow-up questions?
- Does the doctor automatically prescribe drugs, or does he or she try to get to the root of the problem? Are the medications really necessary?
- Does the doctor simply attribute your parent's problems to "old age"?
- Does the doctor have an associate to whom you can turn should he or she retire or be unavailable?
- Does the doctor understand your parent's viewpoint on surgery, transfusions, and heroic measures such as life-support systems?
- Does the doctor treat you and your parent with respect?
- Did the doctor...
 - get a detailed history from your parent and interview you as well?
 - seem knowledgeable about the specific problems?
 - give a diagnosis or some explanation of the problems?
 - answer all of your questions and concerns?
 - ask you how you were coping with the stress of care giving?



Checklist of Medical Information to Obtain About Your Parent

- Your parent's Social Security number, Medicare ID number, insurance policies and numbers. (See the *Records and Information* chapter to keep track of this information.)
- Names, addresses and phone numbers of all doctors, specialists, and insurance companies.
- List all medications being taken by your parent (prescription and non prescription) and why they've been prescribed. List how, when and for how long each medication should be taken, the correct dosage, any possible side effects, and what might be done to prevent them. Also note any allergies, drug interactions, and what to do if your parent misses a dose or other special instructions. (A form for this information is in the *Records and Information* chapter of this *Action Guide*).
- Gather other health information, like family medical history, emotional stability (is your parent lonely or alone?), and sleeping patterns.
- Find out about health insurance coverage (Medicare, Medicaid, employer-sponsored health plans, private policies, and long-term care insurance). Are home care or prescription drugs covered?
- List if and how much your parent smokes and/or drinks caffeine and alcohol.



Questions to Ask When Meeting With the Medical Team

The field of medicine is filled with jargon and doctor's orders can be difficult for you and your parent to decipher. Ask the professionals you are working with to define terms in ways you can understand, and repeat the information back to them to be sure you are clear about what has been said.

- Ask what follow-up plans are preferable, how often you can consult with the medical team, and if there are any alternative treatments available.
- Ask if you should be doing specific tasks, like feeding or physical therapy exercises, or if you should hire someone. Also ask if the doctor can make referrals for home care and/or other needs.
- Ask for names of other community resources and referrals, such as medical supply houses.
- Ask what medical procedures are covered by insurance.

Don't leave your medical team meeting until your concerns have been addressed and answered. Ask specialists about books and other materials to help you

learn about particular problems or issues. Let the professionals know that you and your family are working together to deal with the problems.

Remember to make notes in a notebook about how to provide care, track your parent's schedule and habits, and jot down any problems that come up between doctor visits.

Care management, also known as case management (see *Care Giving From a Distance*), is increasingly becoming a part of the long-term care scenario. It's a consumer-oriented service that includes advocacy, assessment, advice, referral, and consultation.

Care managers (see *Care Giving From a Distance*) can help you develop, implement and coordinate a care plan, monitor services, reassess periodically, and discharge patients from institutional care when appropriate. To find a qualified care manager in your community, contact your county's Area Agency on Aging (AAA) or call The National Association of Professional Geriatric Care Managers at (520) 881-8008, or write to them at 1604 N. Country Club Road, Tucson, AZ 85716.

RECAP

Assess the situation. Stabilize the crisis. Create a game plan for immediate and long-term goals. Find out what your parent wants and allow his desires to take priority. Try to determine what advance planning your parent has already done, if any. Match your parent's wishes with his goals and the resources available.

Most of all, realize you are not alone. Most likely, the right resources for your situation are out there. It is never hopeless as long as you're taking steps each day. Find someone to listen.

You will go through many emotional stages, including guilt and denial, and that's normal. Allow yourself the full range of feelings, and don't be hard on yourself. There is no best way to do this; just do the best you can, and go on.

Assisting your aging parent doesn't have to mean giving up your own life. Here are some things to think about as you embark on this journey:

Admit your feelings. If you're tired, isolated, helpless, angry, resentful or feeling guilty, don't keep it bottled up inside. Talk to someone who understands care giving issues, or join a support group.

Set reasonable expectations for yourself. You can't be all things to all people all of the time. Take care of yourself physically. Eat right, get exercise, and use relaxation techniques.

Avoid destructive ways of coping such as abusing alcohol, overeating, or misusing drugs.

Seek assistance when you need it, from family and friends, professionals, and employers.

Maintain as many social activities and contacts as you can. Make personal time and plan occasions for your own pleasure and renewal.

Is your family close, or do you not talk with each other about personal issues or problems? Have you always kept in touch with your parent, or are you estranged? Depending on your situation, you may be able to start with a family conference right away, or you may need to build family support a step at a time.

A family meeting is the starting point for developing both short and long-term care plans. A family conference offers a place for opening communication among family members and a way to establish family member's positions in relation to the parent's care needs. Keep in mind that the family meeting isn't necessarily going to decide your parent's future! Involve your parent, siblings, spouses and other concerned relatives if possible—especially those who might be affected by actions under consideration. Include young children who might be affected by a grandparent's move into the home. Also, try to include any siblings who never visit or seem to care, to avoid future undermining of decisions. The goal here is to support and inform, not to control and blame.

Tips For Conducting a Smooth Family Meeting

If you anticipate friction or if there has been a history of family conflicts in the past, consider having the session led by a professional or third party (a friend, therapist, clergy), in order to keep the discussion focused and free from hostilities.

If war erupts, the group leader should call a time out. When the meeting reconvenes, restate the issue that started the conflict, summarize opposing arguments, and go for a compromise. Try to prevent harsh language and confrontations that open up old wounds or create new ones.

Consider involving only immediate family members in the first session, then hold a second family meeting to include extended family members, relatives, and close friends. Together these people will form a support network which you will need to put in place as soon as possible.

Prepare an agenda beforehand, and make sure everyone has a copy. Agenda items can include becoming familiar with the financial and legal ramifications of elder care, understanding your parent's medical condition, and a doctor's prognosis. Take notes during the meeting. Also, bring along a list of community resources and this *Action Guide* for quick reference.

During the meeting, respect differing opinions, and allow everyone a voice, especially your parent. Be aware of anxiety levels that no doubt are high on all sides. Be honest; voice your hopes and fears.

After the meeting, distribute a copy of the notes to all participants and present all options to your parent (if he is able to comprehend them). If all possible options are rejected, find out why and look for a compromise.

Keep in mind that a lot of old, unresolved issues and sibling rivalries can surface during this crisis period. You may need the assistance of a professional family

counselor to get you through. If your parent is suddenly acting hostile or combative, remember that this behavior may be caused by an illness, medication, or fear, so don't take it personally. Don't neglect what needs to be done now by getting sidetracked by the past. Step back, take a deep breath, and get control of the current issues. "Old stuff" can be dealt with later if you get organized and stay focused now. Elder care takes more self-control and patience than you may have ever had to apply before. Work toward a collective sense of responsibility, setting priorities and realistic goals, with an agreed-upon plan for reporting to everyone involved.

Accept the fact that family meetings do not always work. Some members may be too busy to attend and strong emotional patterns may prevail. In this case, seek outside help from a psychiatrist, psychologist, or social worker who has experience dealing with families. The objective is not to resolve long-standing conflicts, but to focus on the needs of the ailing parent.

Work toward a collective sense of responsibility, setting priorities and realistic goals, with an agreed-upon plan for reporting to everyone involved.

You will survive! Just remember to take reasonable steps—giant leaps are not always necessary.



Questions to Ask at the Family Meeting

- Do we need to or want to do this? To what extent and for how long? What are the limits of each family member?
- What are our parent's needs now, in the immediate future, and long-term?
- What are the best ways to provide our parent with needed assistance for independent living?
- What is the need for post-acute care recovery, nutrition, safety, and socialization? Who else can help, and how? For how long?
- How long will this situation and the care needs likely last?
- Who will be the primary and secondary care giver? What is their health like?
- What will be the responsibilities of each person? Can these responsibilities be divided fairly? For example, can one relative assist with finances while another provides hands-on help?
- What is the care giver's living situation? What is the strength of family relationships?
- What will the impact be on the care giver's current employment?
- What are our parent's options now, in the immediate future, and long term?
- How will we stay in touch and how will decisions be made—collectively or each with separate duties?

- Can we discuss institutionalization before it becomes necessary? What steps can be taken to prevent or delay institutionalization? Under what circumstances would it be a good idea? How would we find an acceptable facility?

RECAP

Working with your family to organize a plan, staying with it, and modifying it as needed is the best way to head off a crisis.

As much as possible, include your parent in all decision-making activities. Involving your parent in the planning process preserves his dignity and maximizes your parent's independence. "Taking over" all the decisions yourself promotes dependent, and helpless behavior from your parent, or an uncooperative attitude which defeats the purpose. Establish priorities. Getting the most important or most difficult things done first will have a domino effect, and will go a long way towards everyone's peace of mind.

DEVELOPING AN EXTENDED CARE PLAN

The following information is essential in planning for your parent's care and future. Ask your parent (if he is capable) to help you complete the checklist below. We suggest you note the location of important documents and/or how to gain access to them. A family member or friend should also know the location of this file and where to find all other important papers and documents. If your parent is unable to help you complete this task and you've looked in all of the obvious places and still cannot locate the information, try looking through his scrap books, attic, garage, file cabinets, basement, closets, desk drawers, safe deposit boxes, accountant's offices, lawyer's offices, or even under the bed.



Checklist for Your Parent's Personal Information

- Full legal name.
- Social Security card and number, and amount of monthly checks, if any.
- Medicare number.
- Date and place of birth and birth certificate.
- Names and addresses of spouse, former spouse, and children (or location of death certificates if any are deceased).

- Location of will or trust, Durable Power of Attorney, Advance Directives.
- Location of birth, marriage, divorce, citizenship certificates, and pre-nuptial agreements.
- List of employers and dates of employment.
- Education records.
- Religious affiliation, name of church, synagogue, or place of worship including names of clergy.
- Memberships in organizations and awards received.
- Names and addresses of close friends, relatives, doctors, lawyers.
- Requests, preferences, pre-arrangements for burial instructions, burial plot deed.
- Copy of military discharge papers, military record, military life and health benefits, and pension benefits.
- Inventory of valuable or unusual household items.
- Passport.
- Keys to the house, car, safe deposit box, boat, etc.



Checklist for Your Parent's Financial Records

- Sources of income (pension funds, interest income, savings bonds, etc.). Get phone numbers of all companies including a contact.
- Property deeds.
- Health and life insurance policies, names and numbers (including supplemental health and long-term care insurance).
- House, boat, auto insurance policies and titles.
- Names and phone numbers of investment policies, or accounts for stocks, bonds, money markets, property (investment income).
- Location of employer/retirement asset information such as profit-sharing, stock options, credit union, ESOP or TRASOP benefits, annuities, IRAs, 401ks, Keoghs, medical insurance for surviving spouse.
- Bank accounts (checking, savings, credit union), bank officer names, and phone numbers.
- Copy of the most recent income tax return and location of previous years' returns.
- Liabilities (what is owed to whom, when payments are due).

- Mortgages and debts (how and when paid).
- Credit card and charge account names and numbers.
- Property taxes: Receipts? Amounts? When Due?
- Inventory of all personal items such as jewelry, collectibles, family heirlooms, artwork, and other valuables.
- Names and telephone numbers of your parent's financial advisers, brokers, insurance agents, bank officers, and money management services.
- Estate documents including: wills, trusts, powers of attorney, living wills, health care proxies, names of relevant financial institutions, and attorneys.

NOTE: A lawyer and/or a qualified financial planner can advise you about which records to keep, and for how long. (See *The Business Side of Care Giving: Finance and Insurance*, *Legal Issues: Protecting Your Parent's Wishes and Assets* and *Reference and Referral* for more information.)

As you begin to put together a workable care plan, remember that it is important to take action now to compile a comprehensive list of your parent's personal and financial records. This will more easily solve problems that arise later. Stay flexible, open-minded, and informed.

As you work with your parent to put together a comprehensive care plan, you may find it reassuring to know that most communities have services for seniors. They may be provided by many different agencies, but they are there. A good place to begin gathering information or seeking referrals is the Area Agency on Aging (AAA) or your parent's State Department/Office on Aging. These offices are a good source for information about services funded with public dollars. Many also have information about private resources available through religious institutions, voluntary organizations, and professional for-profit agencies. Any or all of these services can play a role in your parent's care plan. Services available include: information and referral, home health care, home delivered meals, personal care, homemaker services, chore services, nutrition and meal providers, senior centers, adult day care, legal assistance, and employment counseling.



Questions to Ask When Developing a Care Plan for Your Parent

- What medical needs must be met now and in the future?
- How frail has your parent become?
- Do any regular tasks or activities present a danger or safety hazard to your parent or others? Which ones need to be monitored or curtailed? These tasks can include cooking, driving, using the stairs, equipment or machinery.

- Are there psychological or mental health factors that are preventing your parent from functioning effectively? For instance, is your parent lonely, depressed, dangerously forgetful or experiencing changes in sleep patterns?
- Is housekeeping or personal care assistance needed? Can your parent keep the house clean and cook meals? Does he need assistance with daily bathing and dressing?
- Are nutritious meals being prepared and eaten? Are there special diets or needs? Will those change?
- Is transportation a concern? When is transportation critical and who can help provide it?
- Does your parent have regular contact with others? Have friends or long-time neighbors died or moved away?
- Does your parent's housing situation need to change or should adaptations be made to the current living arrangement?
- What are other important needs? Make a list of everything you can think of, including health (home care, income management, homemaking chores), socialization (special events, religious services), protective systems (such as a home alarm or Medic Alert), transportation, reading material, and emotional support.

RECAP

Don't feel you must have all the answers right away, or that you must do all the work at once. You do need to make a plan and involve your entire family to determine what your parent needs now and in the future. If you get organized and outline a plan, the road will be smoother. Don't forget to discuss the emotional and psychological effects this plan will have on you and your loved ones. Don't worry about the problems you can't solve today; sometimes the answers are just a few steps away. Try to be both decisive and patient. Reach out to friends and family members for assistance and contact the range of services available in your parent's community (see *Care Giving From a Distance*). You will be rewarded with both peace of mind and a sensible, workable plan for taking care of your parent.

CARE COORDINATION: MAKING THE PIECES FIT

This section will help you coordinate your problem-solving efforts. If you feel overwhelmed, assigning specific tasks to specific people can help prevent duplication of efforts and can streamline the care plan. It's helpful to view the plan as a place to start, not as something inflexible or set in concrete. If something doesn't work, that's

OK. Your parent's care plan can be adjusted as needs and resources change. Identify the top two areas of concern. Ask a family or support group member to find solutions for each problem area. If a family member can't contribute the time to perform regular personal assistance or other priority tasks identified, there are other ways they can help, such as pitching in financially. He or she could also gather information or make phone calls. There is much that needs to be done and a coordinated care plan can facilitate the process, enabling each "player" to bring his or her own special strengths to the care giving process.

Write down the tasks your family and support network members (including paid professionals) have committed to do, and make sure everyone on the team has a copy. This will help you stay organized and on track. If you find that your family and support network can't meet all the needs, contact local senior centers or the Area Agency on Aging (AAA) for guidance, and/or hire a geriatric care manager to take over the coordination and/or maintenance of the plan.

MONITORING YOUR CARE GIVING PLAN

Once your parent's crisis has stabilized, you will need to monitor the care plan. Setting up a monitoring system can at first appear daunting, but you'll find that when you put the plan in writing it is easier to identify the resources and also the gaps. Keep a list of key contact people and times when they should be contacted. Key contact people are often the first to notice changes in your parent. They will be the first to notice something is wrong, so calling them directly (or having them call you) can save you time and effort. Key contact people might include a nurse, therapist, doctor, family member, close friend, neighbor, housekeeper, delivery person, or others who provide vital services or regularly visit your parent. Make notes as you talk to these key contacts and keep them updated. Stay in touch with your key contacts, and be sure to include your parent in as many discussions as possible.



Questions to Ask Your Parent's Key Contact People

- When was the last time they saw your parent?
- What were their impressions at the time?
- Do they have any concerns about your parent? Discuss any concerns that you or your parent may have.
- Do they have any suggestions to better assist your parent?
- Are they able to provide care? How do they feel about providing care?

RECAP

Don't be discouraged if you can't get all the information you need right away, or don't have every step of your plan accomplished at the "designated" time. Care giving, and understanding who all the players are, takes time. You don't always have control over every situation, or have answers to all of your questions. Be sure, however, to give your parent the autonomy and respect he is entitled to; he needs to be able to make the decisions as much as possible. We suggest your goal be to keep things organized, keep the wishes of your parent at the forefront, and inform and support your care giving network.

Finally, realize that while you're dealing with one crisis, there may be another that arises. The good news is that after going through one, you are much better prepared to handle the next. Be alert and be ready to ask for help!

SURVIVING THE STRESSES OF PARENT CARE

Are there times when you're so overwhelmed, exhausted and confused that you worry more about whether you will survive than if your parent will? Take a deep breath; those feelings are normal and are part of the care giving roller coaster. There are ways to handle the stress that comes with caring for a parent.

Financial Considerations

Consider your financial situation. How much time away from work and how much of your resources can or are you willing to spend? Can you afford it? Review your phone bills, home care, grocery, travel, hired help, and supplies expenses. If you can't handle it all, see if other members of your family or support network are willing to donate time or cash.

Balancing Work and Family

Striking a healthy balance between work and family responsibilities is critical to your role as a care giver. If you're actively assisting your parent, or if you are actively worrying about him, you already know how caring for your parent can impact your life. It can also have a huge impact on your employer by affecting your ability to do your job.

Fortunately, employers today are becoming sensitive to the needs of their employees when it comes to elder care issues. Large and small employers are becoming aware that nearly 25 percent of the work force is dealing with elder care issues. If you work for one of the more enlightened employers, chances are you will have access to some type of elder care assistance. Congress recently mandated the Family and Medical Leave Act of 1993. This new employee benefit mandates that employers with more than 50 employees permit up to 12 weeks of unpaid leave to care for seriously ill family members. This could

play an important role in your care giving plan and provide some relief to working care givers.

To help you cope with the demands and stress of caring for your parent while performing your job to your fullest potential, find out what services are offered by your employer.

Employee Assistance Programs (EAPs), are generally offered through a company's human resources department. EAPs often have resource and referral hotlines employees can use to find local assistance and support services and to get information about elder care issues. If your company is large enough, it may contract out for these services with one of several national companies that provide referrals 24-hours-a-day. These services are typically free to employees and can be an effective tool in your efforts to assist your parent.

Some companies offer corporate or in-house elder care programs. Often they provide "brown bag lunch" seminars led by local elder care experts. Your employer may have an on-staff or on-call elder care consultant. Employers who provide these services do so because they recognize the impact that caring for an aging parent can have on their employees. Let's face it, employers realize the negative impact that a distracted employee can have on the company's bottom line.

For example, employees heavily involved in caring for their aging parents are often tardy, absent or have high levels of stress. The result could be frequent personal phone calls, an inability to work over-time, a decline in work quality, increased on-the-job accidents and health problems, a need to reduce hours, change jobs, relocate, or even quit. Employers have made big investments in their employees, so it's in their best interest to find ways to help employees manage the demands of work and dependent care, including parent care.

There are other ways employers may help you. Some provide flexible benefits that allow employees to tailor the benefits they need to their own situation. Tax benefit programs exist that allow employees to use pre-tax dollars to pay for elder care-related expenses if their parent lives with them. Some employers offer "dependent care subsidies" to help employees cover expenses, and a few offer long-term care insurance for an employee's parent through group insurance policies. Check with your human resources department to see what elder care assistance is available through your employer.

Working with your employer and identifying the demands you are facing might help you develop strategies to minimize the impact on the company, while allowing you to do the things you need to do for your parent. For example, by consulting or confiding in your boss, you may be able to arrange a temporary flexible schedule allowing you greater freedom to attend to parent care needs. You may be able to temporarily restructure your job to work part-time. Consider job sharing with another person in the company, or even telecommute—work from home using a telephone, computer and fax machine. If job restructuring is not possible, you might work with your boss to develop contingencies to handle emergencies when they come up. You might be able to arrange for stand-by help to allow you to stay on the job and use your personal days, a leave of absence, or even vaca-

tion time to stay employed while you care for your parent.

Finally, if your employer doesn't offer the options we've just discussed, they might be open to the possibility of your helping them develop an elder care program. Help develop an on-site lunch time support group and encourage your employer to provide "lunch and learn" seminars for care givers. An organization called Children of Aging Parents (see *Reference and Referral*) can help you start a work site support group. If you are a member of organized labor, check with your union to see what services are available through the Member Assistance Program, which is similar to an EAP.

Preventing Burnout

Don't neglect yourself by allowing yourself to become overly fatigued, malnourished, or burdened. Feelings of guilt, resentment, frustration, and worry are natural emotions that are raised in a care giver situation. If you are experiencing sleeplessness, stomach problems, heart palpitations, teeth-grinding, difficulty concentrating, headaches or changes in appetite, it's time to slow down and get help.

Coping with care giving is one of the hardest things you may ever have to do. It takes courage, time, energy, and determination. One of the best ways to "survive" care giving is to join a support group. Support groups differ widely in purpose, structure and effectiveness, but a good group can provide support, education, resources, perspective, coping skills, and the personal empowerment that comes from taking control and feeling that you're helping others by sharing your experiences.

You can find support groups through hospital senior services, religious affiliations such as the Jewish Family and Children's Services, Stroke Association, Alzheimer's Association, Catholic Charities, hospices, The United Way, local Area Agency on Aging offices or the State Department/Office on Aging. (See *Reference and Referral* for details.)

The major benefit people receive from support groups is the sharing of information and experiences. Many care givers who are not "joiners" have, out of desperation, gone to a support group at the behest of worried friends. They have walked into a room of strangers without any idea of what to expect, and have come away with coping skills, resources and helpful tips, and a sense of relief that they are sharing experiences they were afraid or ashamed to talk about with family, friends or co-workers.

Support groups aren't for everyone, but they can be a lifeline for those who have or make the time to do something for themselves. Care givers sometimes report what they have learned from these groups to their parent, who is relieved that his adult children are taking care of themselves.

Support groups are facilitated by a leader, who is typically a health care professional or seasoned care giver. Most are free or have a very low cost or membership fee, and meet regularly, sometimes even weekly. The groups are held in a confidential atmosphere, and can be composed of care givers, family members and friends. Support groups can help people feel more in control of life through education and sharing.



Checklist to Help You Cope With Care Giving

List your feelings. For example, are you feeling lonely, scared, embarrassed, useless, powerless, depressed, panic, self-pity, or anxious? Identify the situations that bring up these emotions. Then talk with someone (a friend, therapist, or support group) about them. Don't try to ignore the feelings. Rather, work them out. For example, develop an exercise routine, record your thoughts in a diary or journal, or treat yourself to a night out on the town.

- If you have never been close to your parent or if you grew up in an abusive environment, you have some choices to make. First, do you want to take care of your parent, and can you? Is it best to hire someone else to tackle the daily care, allowing you to monitor care from a distance?
- Take one day at a time, but prepare for the future. Recognize which problems you can do something about, and which are beyond anyone's control; focus on the former.
- Be realistic about your abilities and how much you can do right now. Don't try to do it all yourself, even if you think you're the best person for the job.
- Be realistic about your parent's abilities. Enjoy the memories but realize your parent's needs and relationships are changing. There are still many rewards and blessings to be had.
- Take time out. In care giving terminology, it's called respite, and every care giver needs more than they admit or realize. Ask family, friends or community agency workers or volunteers to come in while you go out. You may not be able to stop thinking about the situation, but at least you will have some time away from it. That can do wonders to keep you going.
- Set limits on what you are able to do for others.
- Be forgiving of your own limitations and mistakes. If you can't fulfill all your promises, do what you can, and recognize this is all you really can do. It is good enough!
- Keep a positive attitude and a sense of humor. Don't be afraid to share happy memories and special moments. Keep a journal. If you have children that will never know their elders, they might enjoy reading about these relatives when they get older. The journal may be helpful to you during times of frustration.
- Set aside time just for yourself, and make it stick. Make sure family and friends honor your request for personal time.
- Keep up your own interests and activities as much as possible. When you are no longer a care giver, you will still have your life to live.

RECAP

Family members — wives, husbands and adult children — do most of the care giving for aging parents. Caring for aging parents is a concern to millions of Americans. As you travel on this journey, remember to maximize the independence of your ailing parent, to let him do whatever possible. You need to take care of yourself, too. If you neglect your health or your life, you will become less effective as a care giver. Seek assistance when you need it. Care giving is a taxing business, and it doesn't mean you're weak or stupid if you ask for help. We ALL need help. There is no formal training program to prepare us for this part of life.

Your care giving experience may stretch you in more ways than you feel you can possibly manage—that's a normal feeling. You will survive, and you will probably become a much stronger and more focused person for having taken on these enormous responsibilities.

You will be in much better shape emotionally and psychologically if you have planned ahead, put together a support network and developed a care plan. You should, by now, have learned something about your parent's situation, mobilized some resources and probably have a good idea of what you need to do next.

Pat yourself on the back for the steps you have taken so far and realize you're on your way. Be good to yourself. Be proud of how far you've come, and applaud yourself for your courage. And ultimately, if you need to let go or say no, it's OK. Some situations do require outside intervention, and are more than you can realistically be expected to handle.

GETTING ORGANIZED

REFERENCE AND REFERRAL

AMERICAN ASSOCIATION OF RETIRED PERSONS (AARP)

601 E. St. NW
Washington, DC 20049
(202) 434-2277

Catalog of extensive free publications including: *Caregiver Resource Kit* (free kit available to anyone, ask for AARP Fulfillment, EE0926, and *National Continuing Care Directory*, by Anne Trueblood Raper, \$19.95 (Members \$14.50). Local chapters. On-line computer services available through America Online, CompuServe and Prodigy.

AMERICAN RED CROSS, NATIONAL OFFICE

430 17th Street, NW
Washington, DC 20006
(202) 737-8300

Local chapters and training on care giving.

AMERICAN SELF-HELP CLEARINGHOUSE

St. Clare's Riverside Medical Center
25 Pocono Road
Denville, NJ 07834
(201) 625-7101

Referrals to local support groups affiliated with a particular disease.

AMERICAN SOCIETY ON AGING

833 Market Street
San Francisco, CA 94103
(415) 974-9600

Publications on care giving are available. Call for a free publications list.

ASOCIACION NACIONAL PRO PERSONAL MAYORES (NATIONAL ASSOCIATION FOR HISPANIC ELDERLY)

3325 Wilshire Blvd., Suite 800
Los Angeles, CA 90010-1784
(213) 487-1922

Services and information available. Call for free publications catalogue.

CAREGIVERS PROGRAM

A.H. Wilder Foundation
919 Lafond Ave.
St. Paul, MN 55104
(612) 642-2055

Information on stress management, coping and self-care.

CATHOLIC CHARITIES USA

1731 King St.
Alexandria, VA 22314
(703) 549-1390

Network of multi-service agencies providing services and outreach to the elderly. Local chapters. Provides referrals for community services, including day care. Also operates some services.

CHILDREN OF AGING PARENTS

Woodbourne Office Campus
1609 Woodbourne Road, Suite 302A
Levittown, PA 19057
(215) 945-6900

National clearinghouse on care giver issues, resources, publications, local referrals to support groups and care managers. Publishes *Capsule*, a monthly newsletter.

ELDER SUPPORT NETWORK

(A service of the Association of Jewish Family and Children's Agencies)
P.O. Box 248
Kendall Park, NJ 08824-0248
(800) 634-7346

Information and referrals to local care giving resources in your community.

ELDERCARE LOCATOR

(800) 677-1116

Free service that will put you in touch with the network of organizations at state and local levels that can assist you with your elder care needs.

GETTING ORGANIZED

REFERENCE AND REFERRAL

FAMILY CAREGIVER ALLIANCE

425 Bush St., Suite 500
San Francisco, CA 94108
(800) 445-8106, (415) 434-3388

Clearinghouse for memory loss and brain injury. Extensive literature, publications list and services. Publishes the *Directory of California Support Groups for Caregivers of Brain-Impaired Adults*. Statewide clearinghouse information service, (800) 445-8106.

FAMILY CAREGIVER PROJECT UNIVERSITY OF NORTH CAROLINA, CHARLOTTE

Department of Psychology
Charlotte, NC 28223
(704) 547-4758

Caring Families series of manuals on care giving tips, managing finances, planning for the future and coping with particular illnesses.

FAMILY RESOURCE SERVICE

1400 Union Meeting Rd., Suite 102
Blue Bell, PA 19422
(800) 847-5437

InfoSheets on support groups, respite services, home health, care giving and community agencies.

NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING

1112 16th St. NW, Suite 100
Washington, DC 20036
(202) 296-8130

Local referrals through Area Agencies on Aging across the country.

NATIONAL ASSOCIATION OF PROFES- SIONAL GERIATRIC CARE MANAGERS

1604 N. Country Club Road
Tucson, AZ 85716
(520) 881-8008

Information and local referrals to care managers throughout the United States. Provides a listing of care managers in your area if you send a self-addressed, stamped envelope.

NATIONAL CAUCUS AND CENTER ON BLACK AGED

1424 K St. NW, Suite 500
Washington, DC 20005
(202) 637-8400

Referrals to community and local resources.

NATIONAL COUNCIL ON THE AGING, INC. (NCOA)

409 Third Street, SW, Second Floor
Washington, DC 20024
(202) 479-1200

National membership association serving professionals and volunteers who work on behalf of older adults and their families. Operates an information center to handle requests for information from the public including information on choosing a nursing home.

Publishes a variety of materials on a range of aging issues including: senior centers, adult day care services, family care giving, health promotion, and financial issues. A publications catalogue is free upon request.

NATIONAL COUNCIL OF SENIOR CITIZENS

1331 F St. NW, Suite 800
Washington, DC 20004-1171
(202) 624-9340

Nursing Home Information Center including a nursing home locator service. Publishes a nursing home residents *Bill of Rights*, and *Coping With Aging* series.

NATIONAL FAMILY CAREGIVERS ASSOCIATION

9223 Longbranch Parkway
Silver Spring, MD 20901-3642
(800) 896-3650

Membership organization serving family care givers. Publish *Take Care!*, a quarterly newsletter.

GETTING ORGANIZED

REFERENCE AND REFERRAL

NATIONAL HISPANIC COUNCIL ON AGING

2713 Ontario Road NW, Suite 200
Washington, DC 20009
(202) 265-1288

Information, advocacy, newsletter and other resources. Books available for purchase include: *Elderly Latinos: Issues and Solutions for the 21st Century* (\$20.45), *Empowering Hispanic Families: Critical Issues for the 90's* (\$20.45), and *The Hispanic Elderly: A Cultural Signature* (\$18). Prices include shipping.

NATIONAL INDIAN COUNCIL ON AGING

6400 Uptown Blvd. NE
City Center, Suite 510W
Albuquerque, NM 87110
(505) 888-3302

Referrals and information for Indians and Alaskan natives nationwide.

NATIONAL INSTITUTE ON AGING INFORMATION CENTER

P.O. Box 8057
Gaithersburg, MD 20898-8057
(800) 222-2225

Publishes a variety of useful booklets including: *Who? What? Where?: Resources for Women's Health and Aging* and *Resource Directory for Older People*. Distributes *Age Pages* series on a variety of health topics. Request a list of free publications.

NATIONAL INSTITUTES OF HEALTH

9000 Rockville Pike
Bethesda, MD 20892
(301) 496-4000

Many publications on aging, health and disease-related topics. Publish *Ages Pages* series distributed through the National Institute on Aging Information Center.

NATIONAL PACIFIC/ASIAN RESOURCE CENTER ON AGING

Melbourne Tower
1511 Third Ave., Suite 914
Seattle, WA 98101
(206) 624-1221

Concerned with improving services for Pacific and Asian elderly. Information, direct services and quarterly newsletter.

NATIONAL SAFETY COUNCIL

1121 Spring Lake Drive
Itasca, IL 60143
(800) 621-7619, (312) 527-4800,

Extensive information on safety and health topics.

NEW WAYS TO WORK

785 Market Street, Suite 950
San Francisco, CA 94103
(415) 995-9860

Provides information about how to restructure jobs for care givers who work full-time.

OLDER WOMEN'S LEAGUE

666 11th St. NW, Suite 700
Washington, DC 20001
(202) 783-6686

Publications include topics on elder women and poverty, care giving, pensions, legal, housing and long-term care.

SHEPHERD'S CENTERS OF AMERICA

6700 Troost, Suite 616
Kansas City, MO 64131
(816) 523-1080

Interfaith ministry programs and home services including hospice, handyman, shopping, transportation, respite, meals and telephone reassurance.

WIDOWED PERSONS SERVICE

601 E. Street, NW
Washington, DC 20049
(202) 434-2260

An American Association of Retired Persons (AARP) support service for widowed people.

Care Giving from a Distance

If you live hundreds or thousands of miles away from your parent, and you've noticed he doesn't call as often, isn't going out as much, and has more frequent health problems, what can you do? How can you possibly take care of a job and family and have a life of your own, when you may need to give hands-on care and emotional support to your parent from a distance? How will you find care giving assistance by phone? How many trips to your parent's home will you have to make? It's enough to overwhelm even the calmest person, especially if you suddenly feel guilty about not being a "good child" because you are not able or willing to move closer to your parent, or move him closer to you.

One of the ways to begin managing a long distance situation is to communicate with your parent as much as possible about what's going on, about his fears, your fears, his needs, and your needs; then you'll begin to focus on realistic expectations. If you work on honest communications, hopefully your parent will communicate more openly and make the tasks a lot easier. He may also be more willing to do his own research and gather documents for you.

How do you know when to step in and assist your parent? In the case of a medical crisis, it's obvious. But if you're observant, sometimes you will pick up signals that indicate intervention is needed sooner. Here are some clues to guide you:

- Changes in a parent's attitude or behavior.
- A parent asks questions about community services for "a friend" who needs assistance.
- Obvious signs of bruises.
- Impaired memory or mobility.

If your parent doesn't open up, you can contact an apartment manager, friends, neighbors, church and synagogue members, physicians, members of social clubs, and nearby relatives for assistance ask them to notify you when they notice your parent experiencing difficulty. You'll find that there's a lot you can do by phone, mail, fax, or e-mail.

PLANNING FOR THE "WHAT IF" QUESTIONS

If you are living a distance from your parent and he is not yet in a crisis, now is a good time to encourage some planning. Start a dialogue discussing a number of "what if" questions. Here are some sample questions you can ask your parent to identify the most urgent needs:

- What if there's a change in your health?
- What if your medical condition changes and you need some assistance with housework or shopping?
- What if you decide the house is too big to take care of?
- What if you become incapacitated and need intensive care?
- What if you need to move to another type of housing where others can assist with care?

WHO, IF ANYONE, RELOCATES?

One of the first reactions to long distance care giving is for people to want to minimize the distance between them and their parent, either by moving the parent to the child's area, or the child moving to the parent's area. Sometimes relocation is a viable option, but many times it is not. A parent is probably well established with friends, a home, and a way of life. The child has his independence as well, perhaps his own family, and may not fully realize the impact a move would have on his job, family, health, and finances—not to mention his relationship with his parent.

If during your conversations you discover that your parent wants to relocate, be sure to check on how medical insurance, retirement benefits, or income and estate tax structures might change. Call the local Area Agency on Aging or talk to financial counselors and elder law attorneys in both communities—the one your parent currently lives in and the one he may move to. Also find out what types of housing and skilled facilities are available in your area compared with what is available in your parent's area. Carefully review finances, expectations, and medical considerations with your parent before relocating anyone.

WHAT'S REALLY HAPPENING WITH YOUR PARENT

One problem you will face as a long-distance care giver is determining whether or not what your parent tells you is true. An aging parent may hide the truth about declining health and frailty because he may be too proud or embarrassed; he does not want to be a burden to his children. If you have a support network in place, you should be able to get a clearer picture of the real situation.

Don't forget to assess your own behavior patterns by reflecting on the following:

- Do you overreact? Do you tend to ignore the facts as presented?
- Be honest with yourself and with your parent; and remember that often a parent and child will perceive a situation differently.

- Understand that getting older means changes and limitations. Often a parent will adjust to these better than the child.
- An older person may be willing to put up with minor inconveniences in order to maintain his independence.

CREATING AND UTILIZING YOUR SUPPORT NETWORK

Care giving from a distance creates special challenges for you and your parent. (See *Getting Organized* for tips about how to set up and access your support network.) As you gather and organize the following information about your parent, check off each completed task and make a notation as to where you filed the information. When contacting members of your support network, some of these issues may arise. Planning ahead as much as possible will make your phone calls shorter and more productive.



Checklist for Care Giving From a Distance

- Learn more about your parent’s general living status from neighbors as well as from your parent. Often, a loving parent will keep the truth from a child in order to not be a burden. It’s helpful to have the point of view of a neutral and reliable third party.
- Collect information about your parent’s medical condition. Get the names, addresses and phone numbers of his health care providers, including pharmacists. List all medications taken and the pharmacies and assistive devices used by your parent.
- Get names, addresses, and phone numbers of all friends, relatives, neighbors and support people in your parent’s personal network. A support system is critical, whether it’s “informal” (consisting of neighbors, church, family, friends) or “formal” (the “aging network” of professionals and community services available in many areas).
- Plan your trips carefully. Be sure to schedule appointments ahead of time with everyone you need to see. Build in time to talk to your parent about your concerns, taking time to go over the information you’ve gathered.



Checklist of Things to do by Phone or When Visiting Your Parent

- Stay in contact with members of your parent's support network so you are clear about what they are willing or able to do for you and your parent.
- Ask one or more members of the support network to visit your parent at least once a week. Ask them to discreetly check around the house to observe your parent's appearance and behavior.
- Ask members of the group to share a meal with your parent or to see that he gets out of the house from time to time. Ask them to call you at the first sign of trouble.
- Keep a list of phone numbers for everyone assisting you in your parent's community and get a telephone book for your parent's area. (See *Records and Information*.)
- Call the State Office on Aging or the Area Agency on Aging serving your parent's county to start gathering community resources and programs that may serve his needs. If you can't find one listed through directory assistance, call the National ElderCare Locator, a federally funded information and referral service for this purpose at (800) 677-1116. (See *Reference and Referral*.)
- Get the names, addresses, and phone numbers of your parent's bankers, stock brokers, insurance agents, attorneys, and financial planners. List all legal and financial documents (wills, trusts, stocks, bank accounts, etc.; see *Legal Issues: Protecting Your Parent's Wishes and Assets* and *Business Side of Care Giving: Finance and Insurance* for details). Find out about your parent's assets and liabilities. Find out which bank has which account(s). If there's a safe deposit box, locate the key. Is there a Durable Power of Attorney for Legal and Financial, and is there one for Health Care? If so, where are these documents located? When you get a chance, make copies of all of these documents for yourself and keep them in a handy, safe place.
- If your parent lives in an unsafe neighborhood, call the local police department and ask if a police officer can cruise through your parent's neighborhood. If you have the means, hire a private security firm and arrange for guards to patrol the neighborhood. Ask the security firm to check door locks and windows. (Your parent should know ahead of time when the security firm is going to do this so as not to become alarmed.)
- Some care givers find it helpful to keep cash reserves for emergency travel and to reserve one credit card for travel use only.
- Be sure you have an extra set of your parent's house and car keys, and if possible, have a set made for a relative, trusted friend, or neighbor.
- Stay in touch with your parent. Call often, and visit whenever you can. Send your parent letters, photos, and articles of interest.

CARE MANAGERS: PROFESSIONAL SERVICES

If you find you just can't balance your needs with your parent's, and you have financial resources, consider hiring a professional geriatric care manager. One might be recommended by the local hospital discharge planner, the local health department or social service agency. For a list of local referrals, ask a home health agency, a hospice social worker, or call the local Area Agency on Aging or the National Association of Professional Geriatric Care Managers at (520) 881-8008 or write to them at 1604 N. Country Club Road, Tucson, AZ 85716.

Geriatric care (or case) managers are professionals who specialize in assisting older people and their families with long-term care arrangements. Look for a person with masters degrees in gerontology, social work, nursing, or counseling. For an hourly or flat fee, care managers can:

- Do assessments to identify problems, determine the need for services, and eligibility for assistance.
- Screen, arrange and monitor in-home services.
- Coordinate financial, legal, or medical issues, and offer referrals to specialists.
- Provide crisis intervention.
- Offer counseling and support.
- Find suitable institutional placement.
- Act as a liaison to families living at a distance.

Generally, geriatric care managers charge a flat fee (\$100 to \$250) for the initial family visit and evaluation, then a fee of \$75 to \$100 per hour when performing the services agreed upon in the care plan.

RURAL CARE GIVING

If your parent lives in a rural area, services may be more difficult to find. Check with the local Area Agency on Aging, volunteer fire department, mail carrier, transportation agencies, county health department, university extension service, and food delivery services to find out what arrangements can be made. Don't hesitate to call neighbors or friends to assist you and your parent. You may even consider paying them for their services, such as: hiring them to prepare and deliver daily meals, or to provide occasional transportation, housekeeping, and shopping.

TRAVEL: KNOWING WHEN TO GO

There are going to be times—too many you may sometimes feel—when you will have to make the trip yourself in order to assess your parent’s situation or take care of business or medical problems. A health professional may request your presence, a medical crisis may occur, family or friends may report a sharp decline in your parent’s physical or mental health, or perhaps no one has been able to successfully contact your parent. Traveling a far distance is expensive and time consuming, so when you feel a need to do so, be certain to make the best use of your time and financial resources. Try to step back from the situation and evaluate whether or not you really need to go, or if you can send someone in your place.



Questions to Ask Before You Travel

- Can someone take care of it locally?
- Can you afford the trip, with or without pay? Do you have leave time available?
- Do you need to find someone to work for you while you’re gone?
- Do you need to make arrangements for your children or spouse?
- Do you anticipate needing to visit your parent again in the near future?
- What are the consequences of not going right now?

RECAP

Long-distance care giving can be fraught with frustration and take an inordinate amount of time and energy to organize and plan. If you follow a few steps and keep the goals in focus, you can do a lot, even from far away, to provide a supportive environment for your parent.

If you must travel, plan ahead. Try to resolve one issue each day of your visit. Identify the most important tasks that you need to accomplish on each trip and schedule appointments with physicians and other professionals before you arrive. Schedule time to see your parent’s friends, family, and others in the support network and remember to stay focused on the main issues that caused you to travel in the first place. Always be sure to allow enough time to visit with your parent each time you travel.

Get a handle on your parent’s situation, and fill in the gaps whenever you can. Don’t get too frustrated if you can’t get everything done all at once. You may need to make many phone calls, and take a few travel days to get the situation organized, under control, and well maintained. If one isn’t in place already, be sure to set up a support network, monitor the situation, and remember that you’re not alone.

CARE GIVING FROM A DISTANCE

REFERENCE AND REFERRAL

AMERICAN ASSOCIATION OF RETIRED PERSONS (AARP) FULFILLMENT

601 E St. NW
Washington, DC 20049
(202) 434-2277

Publishes the booklet *Miles Away and Still Caring*.

AMERICAN SELF-HELP CLEARINGHOUSE

St. Clare's Riverside Medical Center
25 Pocono Road
Denville, NJ 07834
(201) 625-7101

Referrals to local support groups affiliated with a particular disease.

AMERICAN SOCIETY ON AGING

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San Francisco, CA 94103
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Alexandria, VA 22314
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Blue Bell, PA 19422
(800) 847-5437

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NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING

1112 16th St. NW, Suite 100
Washington, DC 20036
(202) 296-8130

Local referrals through Area Agencies on Aging across the country

NATIONAL ASSOCIATION OF PROFESSIONAL GERIATRIC CARE MANAGERS

1604 N. Country Club Road
Tucson, AZ 85716
(520) 881-8008

Information and local referrals to private care managers throughout the United States. Provides a listing of care managers in your area if you send a self-addressed, stamped envelope.

NATIONAL COUNCIL ON THE AGING, INC. (NCOA)

409 Third Street, SW, Second Floor
Washington, DC 20024
(202) 479-1200

National membership association serving professionals and volunteers who work on behalf of older adults and their families. Operates an information center to handle requests for information from the public including information on choosing a nursing home.

Publishes a variety of materials on a range of aging issues including: senior centers, adult day care services, family care giving, health promotion, and financial issues. A publications catalogue is free upon request.

Family Dynamics

One of the most complex, emotional aspects of care giving is the change in family relationships. Every family's dynamic is different: religious beliefs, educational backgrounds, and financial concerns all play a part. There may be sibling rivalries that have never been resolved. If you are an only child, chances are you may feel overwhelmed. If you have never been close to your parent, there are a host of other unresolved issues that can get in the way and come before actual care giving needs are met.

One of the most difficult issues, and one you and your parent may already be experiencing, is denial by the parent and child that a problem exists. Acknowledging that a problem exists, the immediate tasks necessary to resolve the crisis, and coming to terms with the fact that a parent is aging or may be dying is difficult for everyone. When a parent gets sick, it's tough to accept, especially at first.

Denial often works itself out as you make a care plan and start taking care of business. You may need professional assistance from a therapist, social worker, or support group to get beyond the barriers created by denial. There are a few signs of denial we suggest you be aware of, some of which are listed below.

Checklist for Symptoms of Denial



- Your attention span and ability to concentrate changes. You are easily distracted, unable to focus.
- Your work suffers. You just go through the motions at work and at home, and memory lapses are common.
- Your ability to think and process information changes. It's not uncommon to make mountains out of molehills and lose the ability to see what's important versus what isn't.
- Your emotions are in check. You don't feel much, you act mechanically.
- You feel aches and pains. Ailments like chest pains, irregular heartbeat, sweating, head-aches, skin rashes, and stomach problems begin bothering you.
- Your behavior changes as you obsess about your parent's situation. Or, you feel like running away. You avoid activities that bring you into contact with the reality you don't want to face.

ROLE REVERSAL

Reversing roles with your parent can mean that your parent is seeking your assistance for the first time, or more frequently than to what you're both accustomed. Although children never actually "parent" their parent the adult child does take on more adult responsibilities when they become a care giver for their parent. Role reversal can create a significant change in family dynamics. It's just something we don't think about as we're growing up, and don't want to think about when it happens. It's equally difficult for the parent and child.

It's important to never do for your parent what he can do for himself. Include your parent in all decisions whenever possible, and give him the freedom to choose. We suggest encouraging and supporting your parent's independence. You may gather and present information and alternatives to him, but again, to the extent possible, your parent needs to maintain decision-making authority, although there may come a time when you must make the decisions.

TALKING WITH YOUR PARENT

Talking to your parent may be difficult for many reasons. If you encounter resistance because of old patterns or his fear of dependence, explain to your parent that accepting assistance in one area of life may enable him to function more independently in another.

If the issue is public assistance or the use of government programs, explain that these services are often paid from your parent's lifetime contributions or tax dollars; they are not a handout. If your parent qualifies, as a U.S. citizen he has the right to use these services.

If the issue is cost, offer to give your parent any needed services as a gift or offer to assist him with budgeting the cost into his monthly expenses.

Tips on How to Talk With Your Parent

Try a "news hook" approach if you can't figure out how to approach the subject. For example, ask, "Did you see that story in the paper about long-term care insurance? Do you have anything like that?"

Think through your approach. If your parent is very ill, ask if he is up to discussing the matters at hand. If not, ask your parent for permission to gather information, develop a plan and make decisions on his behalf.

If your parent doesn't feel like talking about the issue, try again, later. Another tip (if you can't talk easily with your parent) is to consider writing a letter.

Remember to consider the *generation gap*. We often don't take into consideration the cultural context and life experience from which our parent has formed his values and opinions. Remember that different generations also use different terms for the same thing (i.e. "board and care" to a baby boomer could be translated as "flop house" by the parent).

Your attitude is crucial to a successful outcome. If you respect your parent's opinions, regardless of whether you agree, you'll find that communication is much smoother. There are many critical decisions to be made, but try not to overwhelm yourself or your parent. You need to approach care giving as a process, and not overstep your bounds or push for completion even if your parent appears to be procrastinating.

WORKING WITH YOUR SIBLINGS

Communicating with your siblings involves many of the same challenges faced when communicating with your parent. The key to establishing good communication involves respecting your siblings, listening to them, and expressing your own needs and feelings in a positive way. By working together as a team, sharing care giving tasks, and staying in close communication with one another, an elder care crisis may ultimately bring you and your siblings closer together.

RECAP

Accept your parent for who he is. Respect his cultural background and life history. Be willing to see him as a person, not just as your parent. Emphasize, every step of the way, that your parent is in control. Assure him that what you want to do is help him maximize his independence. Remember, communication skills can be learned by everyone.

FAMILY DYNAMICS

REFERENCE AND REFERRAL

CHILDREN OF AGING PARENTS

Woodbourne Office Campus
1609 Woodbourne Road, Suite 302A
Levittown, PA 19057
(215) 945-6900

National clearinghouse on care giver issues, resources, publications, local referrals to support groups and care managers. Publishes *Capsule*, a monthly newsletter.

NATIONAL ASSOCIATION OF PROFESSIONAL GERIATRIC CARE MANAGERS

1604 N. Country Club Road
Tucson, AZ 85716
(520) 881-8008

Information and local referrals to care managers throughout the United States. Provides a listing of care managers in your area if you send a self-addressed, stamped envelope.

NATIONAL COUNCIL ON THE AGING, INC. (NCOA)

409 Third Street, SW, Second Floor
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Publishes a variety of materials on a range of aging issues including: senior centers, adult day care services, family care giving, health promotion, and financial issues. A publications catalogue is free upon request.

SHEPHERD'S CENTERS OF AMERICA

6700 Troost, Suite 616
Kansas City, MO 64131
(816) 523-1080

Interfaith ministry programs and home services including hospice, handyman, shopping, transportation, respite, meals and telephone reassurance.

Housing Alternatives and Support Services

Where your parent lives as he ages depends on many factors. If he wishes to live independently, and is able to do so both physically and financially, we suggest you encourage him to do just that.

However, if your parent becomes more frail, living at home alone may not be in his best interest. But there is good news, as the percent of older adults in the U.S. population has increased, there has been a corresponding increase in the number of housing options available to older adults. These range from adaptive housing and home care services, to retirement communities that will provide care for people as they age, including skilled nursing care as needed.

Often, we assume that at a certain point, Mom or Dad will come live with us, or that they will have to live in a nursing home. For many reasons, these two choices may be inappropriate for your own family and the health and welfare of your parent and you. Keep in mind these are only two options in the continuum of housing and care possibilities.

Keep in mind that leaving home may be a very difficult decision for an older person to make. Leaving home has the potential to end or change familiar routines or patterns. But certain conditions may make it impossible for a parent to remain at home. These might include the death of a spouse, which may lead to the burden for the survivor to maintain a home, be left with inadequate finances, a sense of isolation or lack of safety, or increased difficulty in getting around or getting meals.

Housing alternatives for older adults vary, mainly based upon their changing needs. Your parent may initially live at home with no outside assistance, then live at home with some in-home care before leaving home if he or she requires 24-hour care in a skilled nursing facility.

LIVING INDEPENDENTLY AT HOME

In order to promote maximum independence and happiness, try to assist your parent so he can live at home as long as possible. Obtaining occasional outside assistance is a viable option for many older people. It's possible to arrange for a person or team of individuals to provide occasional homemaking and cooking services, for example, that can keep an older parent living at home instead of in an institution.

If you and your parent make the necessary arrangements, it may be possible for your parent to live at home, usually for far less money than it would cost him to live

in a facility. Sometimes home modification and weatherization or fuel bill assistance alone can make all the difference.

In some cases, a few home modifications are all it takes for a parent to remain living independently. In other cases, a move to a single-level home is needed. But with a little work, many older adults can stay put, and some remodeling could even improve the value of the home. Before starting any remodeling, however, check with an accountant for possible tax deductions that might apply, and for possible methods of financing. Also check with local authorities regarding building codes and permits for structural renovations.

There are many simple additions or adaptations that might enable your parent to remain home. Review the checklist below for items and suggestions that might work for your parent.



Checklist of Items to Assist Your Parent at Home

- Raised toilet seats to make it easier to sit and get up.
- Bath benches and hand-held shower heads.
- Intercoms.
- Handrails and/or grab bars in the bathroom near the toilet and in the shower/bath that are strong and stable.
- Furniture rearranged for easy passage. Widened hallways or steps covered with a ramp.
- A cordless phone.
- A device that turns on a lamp whenever the phone rings.
- Doorknobs replaced with lever-style handles.
- Light switches covered to make the lever longer and easier to reach or grab hold of.
- A security system, if it will make your parent feel safer.
- Doors and locks that are easy to use. Replace them if they are not. Entry doors should have dead bolts.

Adaptive equipment can make almost any task easier for older adults with disabilities. These items can include eyeglasses, hearing aids, canes, walkers, or even computers. Here are a few ideas for other items you can buy: clothes that open in the front (for example, bras), which make it easier for a person with limited mobility to dress himself or herself; button loops for one-handed buttoning; specially designed utensils (with foam attached at the handle, for example) for people with arthritis or diseases that affect motor skills.

Another prime consideration for a parent who wishes to remain living at home is accident prevention. How often have you heard of an older person who falls, breaks a hip (or worse), and is no longer able to function independently? Share the checklist below with your parent to help make his home a safe place and prevent accidents.



Checklist to Make Your Parent's Home Safe and Prevent Accidents

- Don't use high-gloss polish on uncarpeted floors.
- Use nonskid strips in tubs, showers, and on interior and exterior stairs.
- Repair or replace any worn or loose carpeting on stairs.
- Install smoke detectors and carbon monoxide detectors near the kitchen and all bedrooms, and check them regularly.
- Place a fire extinguisher in the kitchen and be sure your parent knows how to use it.
- Check electric cords and appliances to make sure they are in good working condition.
- Check furnace and exhaust systems regularly; replace filters when necessary.
- Place night lights in bedrooms, halls, and bathrooms. Be sure all areas of the home, inside and out, are well lit.
- Check stove and gas pipes for leaks. Repair any problems at once.
- Encourage your parent to enroll in an "elder fire awareness" program if a class is offered in his community.
- Discuss fire risks with your parent if he smokes.
- Encourage your parent to unplug small appliances when they're not in use.
- Set the hot water heater to 120 degrees. Higher temperatures can cause tap water scalds.
- Clearly and accurately mark and store all medicines in their proper containers.
- Plan an emergency escape route and be sure there are flashlights and batteries in strategic places. Select flashlights that are lightweight and easy to turn on and off.
- Sand and/or salt walkways in the winter to help prevent slip and fall accidents.

- Replace a spring-shower curtain rod with a screw-in model. If your parent starts to fall, the rod will offer more support.
- Consider an “emergency call button” for the bathroom and bedroom.
- Buy nonbreakable glasses and dishes.
- Rearrange kitchen cabinets and drawers so items are easy to reach.
- Keep a commode chair or bedpan in the bedroom for nighttime emergencies.
- Raise or lower the bed to make it easier to get in and out.

HOME CARE/ASSISTED LIVING

Recognizing the growing need for long-term care in an aging society, many social service agencies and other organizations now provide a variety of medical, nursing, and social services to help people stay out of institutions.

Home health care services include any combination of home health care, medical equipment, respite care, homemaker services, chore services (more heavy-duty than homemaker), home-delivered meals, companion services, telephone reassurance, and emergency response systems. Services can be hourly, weekly, monthly, or by any other arrangement.

Evaluate Your Parent’s Needs

Those who use home health care services include people:

- Who are discharged from a hospital or nursing home but are in need of additional care, either short- or long-term.
- Who are terminally ill who want to die in the comfort of their own home.
- With short-term health needs.
- Who need assistance to live independently at home due to frailty or chronic disability.

Your parent’s Activities of Daily Living (ADLs) include bathing, dressing, toileting, eating, and moving in and out of a bed or chair. Cleaning, cooking, laundry, and housekeeping are NOT considered ADLs. They are categorized as Instrumental Activities of Daily Living (IADLs). Your parent may need help with some or all of these activities, so consider them as you help your parent evaluate his needs.

Where Do Your Parent’s Needs Fit? Custodial and Supportive Services or Skilled Services?

Determine what services best meet your parent’s needs by reviewing the home health care services outlined below. These services are divided into custodial or supportive services, and skilled services.

Custodial and supportive services include:

- Hands-on care (bathing, shampooing, brushing teeth, toileting, dressing).
- Light housekeeping (personal laundry, meal preparation and planning, vacuuming, washing dishes).
- Non-medical supervision (preparing special meals, maintaining hygiene, monitoring health status, assisting with self-administered medications). Assisting with mobility (bed to wheelchair, bed to toilet).
- Companionship (reading, walks, conversation).
- Transporting and escorting (to doctor, market, bank, post office, etc.).

The supportive services listed above are NOT covered by Medicare or most health insurance plans except under very restrictive conditions. (See Government Programs.)

Skilled services prescribed by a physician and implemented by a home care agency staff may include:

- Physical therapy.
- Speech pathology.
- Occupational or intravenous therapy.
- Wound care and dressing.
- Catheterization and injections.
- Respite.

Medicare provides limited coverage for these skilled services. While home care coverage under Medicare Part B is limited (see Government Programs), in many cases, it's better than nothing at all. Under the Medicare hospice benefit, volunteers come in so you may take a break and go out (this is also known as respite).

Finding an Agency and Aide

You can find home care through referrals from friends and relatives, hospital personnel, physicians, nursing registries, and national organizations (especially if your parent's need is the result of a particular illness or disability).

Home care is provided by private agencies, hospitals, and public health departments. If you are referred to a home care agency, ask the following questions:



Questions to Ask When Choosing a Home Care Agency

- How long has the home care agency been in business? (Insist on getting some references from the agency.)
- How does the agency train, screen, and monitor its employees? How are substitutes arranged when needed?
- What are the qualifications and training of its employees? How does the agency insure against misconduct?
- Exactly how much will be charged?
- How much are the employees paid?
- Are the employees bonded and/or insured?
- Is the agency certified by both Medicaid and Medicare, the Joint Commission Accreditation of Health Care Organizations, or a state licensing board?
- What is the home care agency's reputation? What memberships do they hold?

Overseeing an Aide

Consider the following when overseeing an aide for your parent:

- Get the phone number, address, driver's license, and Social Security number (you may need it for tax purposes) of the prospective aide. Be sure to describe in writing what work you expect done.
- Have a trusted friend, relative, or neighbor make unscheduled visits to check on your parent's care, if you cannot.
- Beware of becoming overly dependent on the aide. Don't be afraid to fire someone who doesn't measure up. Immediately notify the overseeing agency of work not being done or suspicious activity.
- Beware of prospective aides that ask about your parent's finances. Be sure your parent's banker knows an aide has been hired and may be accompanying your parent to the bank.

Individual Providers

Realize that home care is also provided by individual providers such as students and young adults (especially in the fields of nursing, rehabilitation, and physical therapy), women with young children, and retirees.

To find a qualified home care worker without going through an agency, try some of the following:

- Recruit at public agencies, training programs, churches, schools, or cultural and civic groups.
- Advertise in the local paper, and use word of mouth.

- Call your county's Area Agency on Aging to tap into services such as: friendly visitor, telephone reassurance, and meal delivery programs.

Some disadvantages of hiring someone on your own include a lack of employee supervision, no back-up care system, and tax issues.

Tax Consequences of Hiring

Learn about the tax laws. If you are hiring a home health aide for a great deal of work, for tax purposes you must determine whether you are using an aide through an agency or an aide who is self-employed. Tax and employment practices will vary depending on which category you fall under, and may actually determine which way you go. If you hire an independent contractor, you can pay for services in lump sums and leave the tax issues to your aide. However, if your aide qualifies as your employee, call your income tax preparer, explain your situation and ask the questions listed below.



Questions to Ask the Internal Revenue Service (IRS) About Paid Care Givers and Taxes

- What federal, state, and local taxes are my parent responsible for?
- Does my parent need to get an employee identification number and file a form SS-4 with the IRS? If so, how?
- Does my parent have to pay Social Security tax?
- Does my parent have to pay unemployment tax?
- How does my parent confirm the employee is a legal immigrant?
- What does my parent include in the employee's W-2 form at the end of the year?

Community Services

While your parent is still living at home, there are many community services available to help keep him connected. Some of the following may meet your parent's needs:

- Postal alert and telephone reassurance programs.
- Personal emergency response systems.
- Friendly visitor, adopt-a-grandparent, and mobile library volunteers.
- Minor home modification, home delivered meals, respite, and adult day care services.

- Senior centers, transportation, peer counselors, and special medical equipment loan programs.

First check with your local Area Agency on Aging or the United Way. We suggest you ask the utility companies (telephone, gas, electric, oil) in your parent's town about discounts and payment programs. (Many utilities have programs where they will contact an adult child if the parent has missed several payments in a row.)

Listed below are several more examples of community services that may meet your parent's unique needs:

- Some Red Cross offices train adult volunteers to handle correspondence and bills for vision-impaired older adults.
- Public health departments often offer free flu shots to seniors, and some may have a nurse who makes house calls.
- Health fairs, often held in indoor shopping malls, offer free diagnostic screenings for diabetes, blood pressure, colon cancer, etc.

YOUR PARENT LIVES WITH YOU

At some point, you may decide that your parent should move in with you (or perhaps he is living with you now). You can remodel or add on to your own home, or perhaps you already have the room (see the discussion of Elder Cottage Housing Opportunity later in this chapter). If you choose to have your parent move in with you, be aware of the financial and emotional costs associated with this option. Privacy, interpersonal relationship strain, and reduced independence can make living with your parent difficult for both parties. Hold a family meeting, air views and concerns, and discuss how it might work. Make sure your parent, spouse, and children are willing to make this adaptation.

Or, you may decide your family should move in with your parent. You may be able to secure a home loan to remodel his home and take care of him in his place of residence.

Elder Cottage Housing Opportunity (ECHO) housing or accessory apartments work great for some families. ECHO housing is a small, self-contained unit in back or alongside a single-family dwelling. Accessory apartments are private units contained within the main house which typically have a separate entrance.

One of the fastest growing segments of services to the elderly is adult day care. Adult day care usually provides:

- A structured program with activities.
- Lunch.
- Health and rehabilitative services.
- Occasional outings.
- Family support and/or counseling.
- Transportation (sometimes included in the fee).

These community services benefit both the care giver and the older adult. Adult day care may be offered by hospitals, nursing homes, churches, mental health facilities, and stand-alone centers.

Before choosing an adult day care center, decide what level of activity and care your parent wants or needs. Then decide what you need (occasional free time, coverage while at your job, transportation, support, assistance with developing a care plan).

Locate an adult day care center to meet your needs by checking the Yellow Pages (look under Adult Day Care, Aging Services or Senior Citizens Services). Also contact the National Adult Day Services Association (NADSA) at the National Council on the Aging and your local Area Agency on Aging (AAA), or state unit on aging. To locate the AAA in your parent's area, call the ElderCare Locator at (800) 677-1116. Also, check with social service agencies such as Catholic Charities, Family Service Agency, and Jewish Family and Children's Services. If your parent is hospitalized, your parent's physician, the hospital social worker, or discharge planner might make a recommendation.

When you call adult day care centers, ask them to send you:

- A flier or brochure.
- Eligibility criteria.
- Costs and discounts.
- A monthly activities calendar.
- Sample menus for several weeks.
- Application procedures.

If the information is not provided in the flier, find out who the owner or sponsoring agency is, how long the center has been operational, the hours and days of operation, staff credentials, and ratio of staff to clients.

Discuss all aspects of adult day care with your parent. Often, initial reluctance vanishes within a short time after a parent starts attending the center and meets new people that accept him and value his talents and interests. For additional information about adult day care, write to the National Adult Day Services Association, The National Council on the Aging, Inc., 409 Third Street SW, Washington, DC 20024.

When visiting adult day care centers, we suggest you ask the following questions to guide you in choosing the center that best meets your parent's needs and your needs:



Questions to Ask About Adult Day Care Centers

- Are the staff and any volunteers well trained? Do they seem cheerful, helpful, and competent?
- Does the staff develop an individualized treatment plan for participants and regularly monitor their progress?
- Is the center certified by the state? Does it adhere to or exceed existing state and national standards and guidelines?
- Does the center assess individuals before admission to determine their range of abilities and needs?
- Is the center recommended by your parent's doctor, other professionals you trust, or the local Area Agency on Aging?
- Does the center provide referrals to other needed services in the community?
- Does the center provide an active program during the day which meets the social, recreational, and rehabilitative needs of the older person?
- Are the clients happy and enjoying themselves?
- Are transportation services (pick-up and drop-off) available? If so, is there a separate fee?
- Are there safety features such as handrails? Is the environment safe and secure?
- Is the center's entrance well lit and handicapped-accessible?
- Are there unpleasant noises or odors?
- What is the cost of each service? Are there discounts? Are there additional charges for late pick-up?

- Does the center offer refunds or credit if your parent can't attend due to illness?
- Are there any medical or therapy services?
- What is the procedure if your parent has an emergency while attending day care?
- Did you feel welcome? Did you get all the answers you were seeking?

OTHER ALTERNATIVES

As people age, their needs change. For many, the ability to independently care for themselves changes as well. Today there are many types of long-term care housing options that can help an elderly parent be cared for with dignity and varying degrees of independence. We will be reviewing these options in the remainder of this segment of the AGING PARENTS Action Guide.

But first, what is long-term care? It refers to a wide range of medical and non-medical services designed to assist those who find it difficult to function independently due to serious illness, injury, other health-related problems, or the gradual diminishing of capabilities. The “care” may be as simple as companionship or transportation, or as complex as bathing, dealing with incontinence, or giving injections or oxygen. In many cases, such care is already being given by a loved one, and all that's needed is occasional assistance or support.

Long-term care can be provided in a number of places, including:

- Your own home or apartment, or that of your parent.
- A retirement community.
- A special apartment with services.
- An assisted living facility.
- The home of a relative.
- A boarding home or congregate care.
- A nursing home, or skilled nursing facility.

Most care can be provided in any of these places, but costs and risks vary depending upon the situation. The type of long-term care needed depends on health care needs, assistance already available, what your parent can afford or is eligible for, and what is wanted.

Continuing Care Retirement Communities (CCRCs)

Continuing Care Retirement Communities (CCRCs), generally require that an individual be able to live independently upon admission. Then, as the resident becomes less independent, certain additional services become available. Most offer three levels of care: independent living, assisted living, and skilled nursing care. These communities offer residential, leisure, and nursing services in exchange for (usually) large entrance fees and a monthly payment. The purpose of CCRCs is to guarantee care across the continuum in one setting. Some offer medical care, others don't. Most elders finance this move by the sale of a home.

Tips for Choosing a CCRC

- Know the tax implications of selling your parent's home to move into a CCRC. Most home sellers can shelter up to \$125,000 of capital gain taxes on the sale of a primary residence if they are over age 55 and meet other eligibility requirements, but your parent may be responsible for paying a large amount of income tax if the house value is substantial. Consult a financial planner or tax preparer.
- Consider your parent's special needs. Your parent may want to be free of all household responsibilities. On the other hand, he may miss puttingter around in his home.
- Consult an attorney about the contract. Some life-care facilities offer questionable and impossible deals. Check the solvency of the project owner and management. Provisions for living quarters, medical care, recreational and educational activities, meals and special diets, personal assistance (assistance with bathing, dressing, etc.), emergency assistance, additional or customized services, and pets should be included in the contract.
- Learn and know about the varying levels of care. Know whether the facility offers fee for service or life care and measure the impact of the services on lump sum and monthly fees.
- Understand financial demands. Will your parent's finances last throughout the rest of his life? Discuss your concerns with residence managers.
- Talk to residents about what they like and don't like. Ask if the facility lives up to its promises. If there are guest facilities, arrange an overnight stay.
- Contact the Continuing Care Accreditation Commission (see Reference and Referral in this Action Guide) for additional guidelines.



Questions to Ask When Choosing a Continuing Care Retirement Community (CCRC)

- Name and location of the CCRC?
- What is the CCRC's mission, and how does it go about fulfilling it?
- Is there a waiting list? How long?
- What are the CCRC's health care obligations? Is it staffed to adequately meet them?
- Do residents participate in governance and policy making?
- Is the facility accredited? Contact the Continuing Care Accreditation Commission to find out (see Reference and Referral).
- What are the government standards and regulations for the CCRC? Are they being met at this facility?
- How are residents informed of the CCRC's financial status?
- Is the CCRC's fee reasonable, affordable?
- How large a deposit is required upon application? Is it refundable?
- What is the policy on entrance fee refunds?
- Are the health care services and fees charged for them, clearly specified in the contract?
- What is covered by the CCRC's monthly fee?

Age-segregated Apartments

Apartment living in age-segregated groups is often a welcome option for individuals seeking a housing environment of peers within the context of the larger local community. Usually the minimum age for entry is 55, and a resident generally has to be independent and ambulatory (able to walk about). HUD Section 202 housing provides age-segregated housing for individuals over 62 years old.

Check with the local Area Agency on Aging, Public Housing Authority, for senior housing, and the State Association of Homes for the Aging. Be aware that in many states, age-segregated apartments are illegal.

Board And Care Homes

Board and care homes may also be called adult care homes, adult foster care homes, residential care facilities, domiciliary care, and congregate care. With board

and care homes, as well as congregate care, the resident is responsible for coordination of his medical and dental care. Nomenclature varies from state to state so be sure to get written definitions when possible. Board and care homes are categorized in two types:

- Residential care for the elderly—generally for residents at least 60 years old.
- Adult residential facilities—for adults over 18 who often have physical or mental disabilities.

Typically, a board and care home is a large house where several elders who don't need medical care and are able to walk and take their own medicines with little or no assistance, have private bedrooms, and share a common living area. In some cases a private room costs more. There is usually live-in staff or a family that prepares meals and monitors (but does not administer) the taking of any medication. Laundry and cleaning may be included. Levels of activity and supervision differ, as do quality and price. In California, for example, board and care homes are licensed and inspected by the Community Care Licensing Division of the California Department of Social Services. However, not all states license board and care homes. Check with your local Area Agency on Aging to find out who regulates the homes in your community. Medicaid will pay for eligible residents.

A board and care home should be aware of changes in a resident's physical, mental, or emotional state. We suggest significant changes be reported to the resident's doctor and, if applicable, to a family member or friend. Most board and care homes do not have staff to perform assessments. If performed, we suggest that assessments be updated frequently, and the home makes sure each resident has access to necessary medical or dental services.

Before your parent considers moving into one of these facilities, we suggest you do as much of the following as possible. Use this checklist as a guide when visiting various board and care homes.



Questions for Choosing a Board and Care Home

- Is the facility licensed by the state? If it is, ask to see the license. (Most states do not license board and care or congregate care because they don't offer medical services.)
- Is the home located near family members and friends? (Try to find a home conveniently located for frequent visits.)
- Are the residents in the home active, groomed, and dressed? Is the general atmosphere warm and pleasant? Does the staff treat the residents respectfully? What is the staff to resident ratio? (Visit each prospective home. Look, listen, and smell.)

- Are residents assisted with meals if necessary? (Visit during meals to see if the food is hot, palatable, and nutritious.)
- Are resident's needs being met around the clock? (If possible, visit on a week-day, during a weekend, and at night to be sure needs are being met at all times.)
- What services are provided? Do lavish surroundings cover up a lack of staff or services?
- Are the home's inspection records available. (Examine each home's inspection records. If the facility is licensed, the inspection records are kept by a licensing division in your state).
- How much privacy do residents have? (Discuss with your parent whether he would share a bathroom or bedroom and how much privacy he desires.)
- Are pets allowed? How many personal belongings (furniture, mementos, etc.) may be brought in? Are there stairs? Does your parent have access to a telephone?
- How much will the rent cost, including add-ons?
- Does your parent qualify for Supplemental Security Income (SSI) if he has a low income? (Call the local Social Security Administration office to find out. Board and care services are not usually covered by Medicare or most insurance plans.)
- Do you suspect abuse? If so, there are several places to turn to for assistance. If there is an immediate threat to life or safety, call the police or fire department. Also call adult protective services, which under specific conditions can provide assistance. If the home is licensed, take your complaint to the licensing agency on the posted license. If the home is not licensed, call your county's long-term care ombudsman (a government official appointed to investigate complaints made by individuals against abuses or capricious acts of public officials), who is required to investigate complaints about long-term care facilities. You may also call your local Area Agency on Aging or Legal Services Corporation for assistance.
- Does the owner or administrator seem sincere? Informative? Available? Knowledgeable?
- Do the residents and administrator know each other? Do they seem to get along?
- Do the residents answer your questions, or do they seem afraid to talk to you?
- Do the residents get to go to places of worship, to the doctor or dentist, or shopping?
- Do the employees seem satisfied and involved?
- Is the home clean and odor free?

- Are there activities and reading materials available? Is there a schedule of events for your review?
- Does the facility have a current state license if they are granted in your parent's state?
- Is the contract clear and agreeable in all aspects?

Group Homes or Shared Living

If your parent doesn't want to live alone, or you and your family decide that your parent shouldn't live alone, there is the possibility of sharing a home.

Public or private community agencies may own or operate houses or large apartments that house several unrelated people who have separate sleeping quarters but share the rest of the rooms. The agency may provide cleaning, shopping, cooking, counseling, and other services.

Agencies recruit, match, and arrange for people to share a home, which can assist an older adult in remaining independent by sharing financial, social, and other needs. The rental arrangements vary. For example, two older people can share housing, a young couple and an older person, or a college student, etc. To find a match, call your county's local senior information and referral number, Area Agency on Aging, the Shared Housing Resource Center (see Reference and Referral), housing and social service agencies in your parent's community, a local university, or senior center.



Questions to Ask When Choosing to Share a Home

- How will household duties and finances be divided?
- How will differences be resolved?
- What will your parent's responsibility be if a house mate becomes ill?

If your parent does have to move, careful planning may help make a difficult time better. Be sensitive to his need to retain possessions and memories. Try to visit during and after the move, and help reinforce your parent's feelings that the new home is the right decision.

Congregate Housing With Services (Assisted Living)

Congregate housing with services is also referred to as assisted living, sheltered or enriched housing, or a retirement community. This housing alternative offers individuals the support services required to maintain an independent lifestyle. Residents typically rent their own apartment, including a kitchen. Meals are also available in a central dining facility. Other services might include housekeeping, personal care, transportation, recreation, and social activities.

Difference Between Congregate Housing With Services and Board and Care Homes

Congregate housing facilities generally provide more extensive professional services than board and care homes. These homes are often built with federal, state and/or local government financing, and most units are rentals (some rent subsidies may be available). They may range in size from 30 to 300 living units. You can find them under “Retirement Communities” in the local telephone book, or through the local housing authority.



Questions to Ask When Choosing Congregate Housing With Services

- Is there an agreement or contract that spells out the specific services provided to residents?
- What is included in the standard/flat fees? What is extra?
- Is transportation to stores, places of worship, and other services available?
- Can the facility accommodate special dietary needs?
- Is there access to a telephone? (Each unit should be equipped with a telephone jack.)
- Are there any restrictions on visitors?
- Is there adequate security for personal belongings?
- Are pets allowed?
- Are there limits on the level of a resident’s frailty?
- What service packages are offered? Do services like physical therapy cost extra?
- What in-house services are available—library, counseling, recreational and social activities, physical therapy, etc.?

Elder Cottage Housing Opportunity (ECHO)

Elder Cottage Housing Opportunity (ECHO) housing is a great option for some families. ECHO housing is defined as a small, self-contained unit in back or alongside a single-family dwelling. They are sometimes called in-law apartments. Contact your local Area Agency on Aging for more information about the ECHO program.



Questions to Ask When Considering ECHO Housing

- Do zoning laws restrict or allow an ECHO unit?
- Is parking adequate or needed?
- Will it increase or reduce the value of the property? How will that affect taxes?
- Are utility hookups available?
- What happens to the unit when it is no longer occupied?

HUD Subsidized Senior Housing

HUD, the U.S. Department of Housing and Urban Development, funds low-income residence hotels and apartment buildings in large cities and in rural areas. All HUD senior housing is for low-income elders. A select number of units are offered to low-income seniors at subsidized rates. Call your local Public Housing Authority to find out how to apply; waiting lists are often quite long (three years is not uncommon).

HUD Section 202 housing is housing with services for the elderly. This community housing option for low income older adults offers support to help residents maintain independence, privacy, and respect. All HUD Section 202 apartments must have kitchenettes, but they may also have central dining rooms where residents may eat together.

Maintenance of grounds and facilities are provided and there is often access to transportation and outside health services. Light housekeeping may be arranged, as well as assistance with bathing, dressing, medication supervision, and monitoring; however medications are not administered.

For more information about HUD subsidized senior housing, contact the local HUD office, the city hall, the local Social and Rehabilitation Services office, the

county health department, the senior information and referral office, or the local Area Agency on Aging.

NURSING HOMES

For many Americans, “nursing home” is the most dreaded phrase in the English language. It conjures up images of an unhappy parent placed in an institution by uncaring family members so they don’t have to deal with the parent while they wait for him to die. Not a pretty picture. Nor is it an accurate picture. Nursing homes are skilled nursing facilities (SNFs) that offer the highest level of medical care available, including nurse coverage 24-hours-a-day.

In fact, SNFs are for both young and old. They are places for people who will fully recover after a brief stay and go home, and they serve people who need long-term care and may never go home. Either way, the emphasis should be on living and the goal is to help the patient return home whenever possible.

There are different levels of care in SNFs, but all involve full-time residence and include room and board, monitoring, personal assistance, nursing, and other health services for people who are too frail to live independently.

It’s important to get the right referral for your parent’s current and long-term needs. You can find SNF referrals by contacting a hospital discharge planner, your doctor or your parent’s doctor, organizations that are disease-specific (cancer, heart, dementia), national long-term care organizations (see Reference and Referral), a long-term care ombudsman, government agencies including your county’s Area Agency on Aging, houses of worship, ethnic and fraternal organizations, relatives, friends, and neighbors.

There are hospital-based SNFs (also known as acute care), which are departments within hospitals. They are not permanent residences.

Non-hospital based SNFs provide a relatively high level of nursing and other medical care, and personal assistance. SNFs provide around-the-clock care with at least one supervising registered nurse on duty at all hours. The cost runs from about \$50 to \$250 a day; the cost varies state to state and even between counties. Medicare covers only up to certain limits (see Government Programs), and only if the care has been prescribed by a physician. Long-term care insurance may provide coverage—check your parent’s policy. For Medicare coverage, the SNF must be Medicare certified, and the coverage is only good while a resident’s condition is improving, or specifically, that the patient will ultimately return home. Private long-term care insurance can be used in facilities that are not certified by Medicare, or when the Medicare coverage ends.

Nursing Facility Costs

Fortunately there are ways to deal with the odds, and the prospect of a nursing facility stay. Private long-term care insurance is widely available. (See The Business Side of Care Giving: Finance and Insurance section for a complete discussion about long-term care insurance.) There are government programs that can be used, and there are “Medigap” policies and some private health insurance policies that pay a limited amount for SNF care. Medicare will pay for some intermediate care but will not pay for custodial care.

The average cost of nursing facility care can easily exceed \$3,000 per month to \$80,000 a year or higher. Costs are higher in urban and metropolitan areas. Therefore, it’s imperative that you determine with your parent and his physician if a SNF is really required for his care. After all, if your parent can get by with fewer services and still recover or move towards independence by using alternative services, why pay for the higher costs of a skilled nursing facility? And remember that some nursing facilities bill by the service so choose services based on actual need. (See The Business Side of Care Giving: Finance and Insurance and Government Programs sections of this Action Guide.)

Nursing facilities are a necessary part of the care giving continuum. If circumstances dictate that a nursing facility is a short term or long-term requirement, then it’s up to you, and if possible your parent, to explore the facilities available in your community.

There are many excellent reference books for your consideration. Particularly notable is the booklet from the American Health Care Association, *Thinking About A Nursing Home?: A Consumer’s Guide to Long-Term Care*; from the American Association of Retired Persons, *Before You Buy: A Guide to Long-Term Care Insurance*; from the American Society of Internal Medicine, *Medicare: What it Will and Will Not Pay For*; and from the Health Care Financing Administration, a booklet about Medicare and Medigap.

The subject of nursing homes can make a parent and his adult children very uncomfortable. Your parent may tell you he never wants to go to a nursing home. Indeed, a parent can be pretty adamant about the subject, pressuring you into agreeing that you will never “send” him to one. Listen to his concerns, but don’t humor or lie to him. Let him know that should his situation dictate that a nursing facility is the best or only alternative, he will be fully involved in the decision; it will not be a surprise and it will only happen if it is absolutely required.

When it’s the time to find a SNF, plan to visit several nursing facilities at different times of the day, both announced and unannounced. Start with any homes that friends or family have recommended and use these questions to guide you:



Questions to Consider When Choosing a Nursing Facility

- How will you meet the expenses? What are the base costs? What are add-on costs (i.e. laundry, bandages, beauty salon, etc.)?
- Is the facility Medicare and/or Medicaid certified?
- Is the home clean and odor free?
- Are the residents happy, alert, groomed, clean, well fed, and healthy? Or, are they restrained to wheelchairs or lethargic?
- What levels of care are available? Are they appropriate to your parent's needs?
- Is the staff respectful of the residents?
- What is the noise level?
- Is the home located conveniently nearby for frequent visiting?
- How involved will you (or can you) and family members become in monitoring your parent's care?
- How often can you visit? What are your parent's expectations regarding your visits?
- Is there an adequate staff-to-resident ratio?
- Is privacy respected?
- Is there a qualified social worker on staff?
- Are call bells accessible to residents?
- Are safety procedures adequate? Are stairways and exits clearly marked?
- How many residents share a bathroom? Do bathrooms have hand grips or rails near all toilets and bathing areas? Is there a call button?
- How often are meals offered? Are alternatives available, as required by law? Are there any ethnic-specific diets?
- Are meals served at appropriate temperatures and in a timely fashion?
- Who plans the meals? Is there a staff dietitian? How are special dietary needs met?
- Can residents bring their own furniture and personal effects to decorate the room? Is there a safe for valuables and money?
- Are there a variety of activities for the residents to participate in? Is there an activities coordinator?



- What arrangements are made for residents to honor their religious preferences?
- Is there a council for residents? When does it meet and who coordinates it? Is there a family council?
- Which hospital is used in emergencies? What is the emergency procedure? The evacuation procedure?
- What is the billing procedure? Will you be informed in writing of any changes?
- Is the telephone number for the ombudsman program listed?
- How is personal laundry handled? Will you need to do personal laundry for your parent?
- Is there a system to protect wanderers?

A Few Words of Caution

Today, nursing facilities are safer and better managed than they have ever been. This is due in part to increased regulation and inspections and the political activity of organizations that lobby for older Americans. But despite the improving picture of nursing facilities, there are still many that may not measure up to the legal standards set by a state, or that may not measure up to the standards of care and environment that many people consider minimal for an acceptable lifestyle. So choose carefully and monitor the facility continually.

MATCHING HOUSING OPTIONS WITH CARE GIVING NEEDS

If your parent needs long-term care, what is the best option for you and your parent? Moving your parent from a home of 25 years is more than just a residential decision. It's also a financial, emotional, real estate, tax, and health care decision. It's important to understand the complex nature and impact all of these decisions can have on your parent, and you as a care giver.

If your parent needs to relocate, be aware that his decision is difficult and emotionally a very stressful life event. A home has meant security, enjoyment and a sense of independence, and familiarity. You need to respect your parent's wishes to remain at home if at all possible. But if a physician or other health care professional recommends a change in the housing arrangement, if your parent needs health care or supervision 24-hours a day due to physical or mental limitations, if your parent's safety is at risk, or if the neighborhood has deteriorated, then make your plans and know you've done the right thing.

Questions to Consider When Matching Housing Options With Care Giving Needs

- If your parent needs long-term care, what's the best option?
- Is the building and neighborhood one in which you and your parent feel safe?
- Is the housing choice close to your parent's doctors and hospital? Is the living environment designed for elder access? Is assistance with medications and other medical needs available?
- How easy or difficult is the house or apartment to keep clean? Could your parent reside in just a few rooms of his or her current home? If you're considering some kind of advanced care facility, does it meet your standards for cleanliness?
- If independent living is no longer an option, does the alternative housing choice have a homey, caring atmosphere? Does the staff understand the cultural differences and needs of your parent? Would your parent be comfortable living there? Would you be comfortable living there?
- Stability and security are important considerations for everyone, especially the elderly. How long will your parent be able to stay in his current or new home? You'll want to work with your parent to minimize the number of future moves because moving is extremely stressful and costly. Yet multiple moves do happen, so don't rule anything out.
- Is the location of the prospective new home close to family, friends, and place of worship? Your parent's social life is critical to his mental health and ability to function independently. Is the location close to public transportation?
- Cost may be a key factor in choosing a housing option for your parent. What can your parent or your family afford? A financial planner or other advocate may be able to assist you and your parent with looking at the long range costs connected to any housing option.

HOUSING ALTERNATIVES AND SUPPORT SERVICES

REFERENCE AND REFERRAL

AMERICAN ASSOCIATION FOR CONTINUITY OF CARE

638 Prospect Ave.
Hartford, CT 06105-4298
(203) 586-7525

Promotes home care standards.

AMERICAN ASSOCIATION OF HOMES AND SERVICES FOR THE AGING

901 E St. NW, Suite 500
Washington, DC 20004-2037
(202) 783-2242

Represent non-profit housing providers. Free brochures on housing options, skilled nursing facilities and guide to long-term care. Call to request a publications catalog.

AMERICAN ASSOCIATION OF RETIRED PERSONS (AARP) - BOOKS

1865 Miner St.
Des Plaines, IL 60016

National Continuing Care Directory, by Anne Trueblood Raper, \$19.95 (Members, \$14.50).

AMERICAN HEALTH CARE ASSOCIATION

1201 L St. NW
Washington, DC 20005
(800) 321-0343 (Publications Department),
(202) 842-4444

Provides a *Here's Help* series of publications covering a wide range of elder care topics. Also a booklet *Thinking About A Nursing Home? A Consumers Guide to Long-Term Care* (single copies are free) and a video: *Helping Hands: The Right Way to Choose A Nursing Home* (\$25 + \$3 Shipping and Handling - Catalogue #K2551Z).

AMERICAN SOCIETY ON AGING

833 Market Street
San Francisco, CA 94103
(415) 974-9600

Publications on care giving are available. Call for a free publications list.

ASSISTED LIVING FACILITY ASSOCIATION OF AMERICA

9401 Lee Highway, Suite 402
Fairfax, VA 22031
(703) 691-8100

Consumer checklist for evaluating facilities.

CALIFORNIA ADVOCATES FOR NURSING HOME REFORM (CANHR)

1610 Bush St.
San Francisco, CA 94109
(415) 474-5171

Reports, advocacy. Publishes *So You Think You Need A Nursing Home* (\$15).

CALIFORNIA PARTNERSHIP FOR LONG-TERM CARE

714 P St., Room 616
Sacramento, CA 95814
(916) 657-0654

Four states, California, New York, Connecticut and Indiana, have special partnership arrangements whereby Medicaid (Medi-Cal in California) and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. Call for information concerning California residents.

CATHOLIC CHARITIES USA

1731 King St.
Alexandria, VA 22314
(703) 549-1390

Network of multi-service agencies providing services and outreach to the elderly. Local chapters. Provides referrals for community services, including day care. Also operates some services.

CONNECTICUT PARTNERSHIP FOR LONG-TERM CARE

Office of Policy & Management
450 Capital Avenue, MS# 52LTC
Hartford, CT 06134-1441
(203) 418-6318

Arrangement whereby Medicaid and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. Connecticut residents can call (800) 547-3443 to request information.

HOUSING ALTERNATIVES AND SUPPORT SERVICES

REFERENCE AND REFERRAL

CONTINUING CARE ACCREDITATION COMMISSION (CCAC)

901 E. St. NW, Suite 500
Washington, DC 20004-2037
(202) 783-2242

List of accredited Continuing Care Retirement Communities (CCRCs). Brochures about how to choose a CCRC.

FOUNDATION FOR HOSPICE AND HOMECARE

519 C St. NE
Washington, DC 20002-5809
(202) 547-6586

Extensive catalog of educational and training materials for consumers and caregivers. Free consumer guides, including *All About Hospice*.

INDIANA LONG-TERM CARE PROGRAM

Family & Social Services Administration
402 W. Washington Street, W353
Indianapolis, IN 46204
(317) 232-2187

Arrangement whereby Medicaid and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. Indiana residents may call toll-free, (800) 452-4800 for information.

NATIONAL ADULT DAY SERVICES ASSOCIATION

c/o National Council on the Aging, Inc. (NCOA)
409 Third St., SW, Suite 200
Washington, DC 20024
(202) 479-1200

Provides the following free information: *Adult Day Care Fact Sheet*, *Why Adult Day Care* and *Your Guide to Selecting an Adult Day Center* brochures, and the National Council on Aging (NCOA) Resources catalogue that describes the agency and its publications.

NATIONAL ASSOCIATION FOR HOME CARE

519 C St. NE
Washington, DC 20002
(202) 547-7424

Provides referrals to local home health agencies.

NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING

1112 16th St. NW, Suite 100
Washington, DC 20036
(202) 296-8130

Local referrals through Area Agencies on Aging across the country

NATIONAL ASSOCIATION OF PROFESSIONAL GERIATRIC CARE MANAGERS

1604 N. Country Club Road
Tucson, AZ 85716
(520) 881-8008

Information and local referrals to care managers throughout the United States. Provides a listing of care managers in your area if you send a self-addressed, stamped envelope.

NATIONAL CENTER FOR HOME EQUITY CONVERSION (NCHEC)

7373 147th St. West, Suite 115
Apple Valley, MN 55124
(612) 953-4474

Free information on reverse mortgages. They also publish: *Your New Retirement Nest Egg*, by Ken Scholen, NCHEC Press, 1995, \$24.95. 336 pages.

NATIONAL CITIZENS COALITION FOR NURSING HOME REFORM

1424 16th St. NW, Suite 202
Washington, DC 20036-2211
(202) 332-2275

Consumer advocacy organization connecting individuals to local aging resources. Publishes a catalogue listing consumer guides for sale.

NATIONAL COUNCIL OF SENIOR CITIZENS

1331 F St. NW, Suite 800
Washington, DC 20004-1171
(202) 624-9340

Nursing Home Information Center including a nursing home locator service. Publishes a nursing home residents *Bill of Rights* and *Coping With Aging* series.

HOUSING ALTERNATIVES AND SUPPORT SERVICES

REFERENCE AND REFERRAL

NATIONAL COUNCIL ON THE AGING, INC. (NCOA)

409 Third Street, SW, Second Floor
Washington, DC 20024
(202) 479-1200

National membership association serving professional and volunteers who work on behalf of older adults and their families. Operates an information center to handle requests for information from the public including information on choosing a nursing home.

Publishes a variety of materials on a range of aging issues including: senior centers, adult day care services, family care giving, health promotion, and financial issues. A publications catalogue is free upon request.

NATIONAL ELDERCARE INSTITUTE ON HOUSING

Andrus Gerontology Center
University of Southern California
Los Angeles, CA 90089-0191
(213) 740-1364

Information on senior housing alternatives.

NATIONAL SAFETY COUNCIL

1121 Spring Lake Drive
Itasca, IL 60143
(800) 621-7619, (312) 527-4800

Extensive information on safety and health topics.

NATIONAL SHARED HOUSING RESOURCE CENTER

321 E. 25th St.
Baltimore, MD 21218
(410) 235-4454

Local referrals.

NEW YORK STATE PARTNERSHIP FOR LONG-TERM CARE

NYS DSS
40 North Pearl Street
Albany, NY 12243
(518) 473-7705

Arrangement whereby Medicaid and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. New York residents can call for information.

666 11th St. NW, Suite 700
Washington, DC 20001
(202) 783-6686

Publications include topics on elder women and poverty, care giving, pensions, legal, housing and long-term care.

SHEPHERD'S CENTERS OF AMERICA

6700 Troost, Suite 616
Kansas City, MO 64131
(816) 523-1080

Interfaith ministry programs and home services including hospice, handyman, shopping, transportation, respite, meals and telephone reassurance.

VOLUNTEERS OF AMERICA INC.

110 South Union Street, 2nd Floor
Alexandria, VA 22314
(800) 899-0089
(703) 548-2288

A national organization with programs for elderly, including affordable housing, assisted living centers and home improvements. Call for more information.

SOCIAL SECURITY, MEDICARE, MEDICAID, IRS, HEALTH CARE, ELDERCARE LOCATOR

ELDER CARE LOCATOR: A starting point when searching for home health care or nursing home facilities.

www.ageinfo.org/elderloc/elderdb.html

HEALTHFINDER: Government site for publications, databases, self-help & support groups, government agencies, and not-for-profit groups.

www.healthfinder.gov/

INTERNAL REVENUE SERVICE: Income tax forms, instructions, regulations and publications are all available on-line.

www.irs.ustreas.gov/prod/cover.html

MEDICARE ON LINE: The "official" government site for Medicare and Medicaid. Look here for the most current information on benefits, eligibility requirements and other vital assistance.

www.hcfa.gov/

HOUSING ALTERNATIVES AND SUPPORT SERVICES

REFERENCE AND REFERRAL

SOCIAL SECURITY ON LINE: Social Security information including current benefits, eligibility requirements. Includes PEBS (personal earnings and benefits statement) section to determine your parent's (or your own), benefits.

www.ssa.gov/

Medical and Health Issues

CRITICALLY NEEDED DOCUMENTS

Whether you anticipate a medical crisis or not, it's a good idea to do advance legal planning for medical issues, especially if your parent has a chronic illness or there is a family history of ailments such as heart disease, diabetes, or cancer.

Discuss "Advance Directives" with your parent. You'll find a detailed discussion of these in the Legal Issues: Protecting Your Parent's Wishes and Assets section of this Action Guide. Advance Directives are legal documents that enable your parent to give instructions about his legal and medical care in the event that he becomes ill or incapacitated and can no longer give instructions about how to manage his financial, legal or health matters. Copies of Advance Directives, Living Wills, and Durable Powers of Attorney should be given to each doctor attending to your parent. Be sure copies are also given to the hospital, your parent and yourself (or the primary care giver) because documents often get lost or overlooked.

HOSPITALS AND THE HEALTH CARE SYSTEM

When dealing with medical professionals, remember they don't know all the answers. Never be afraid to get a second opinion. If a particular doctor doesn't seem right for you and your parent, choose another.

Due to changes and cost cutting measures in today's health care system, your parent might be discharged more quickly than he expected to be. Sometimes, before he has fully recuperated. This means your parent may need some assistance at home for a while, or need to spend time in a skilled or semi-skilled nursing facility. The discharge planner at the hospital can help you make arrangements and find services for your parent's continuing care needs.

Medical issues are different for every aging person. Talking openly to your parent and staying in touch with his medical team and pharmacist are important elements in your parent's recovery and continued well-being.

MENTAL AND PHYSICAL WELLNESS

While old age can bring its share of problems, perhaps the biggest problem with aging is how we think about it. Aging represents the decline of physical powers, and for some of us, a decline in mental functions. Physical and mental changes differ greatly among individuals. In fact, men and women age differently, too. The good news is that not everyone will become disabled or frail, but if that happens, there are options and ways to deal with it.

We're all getting older. The aging process and our role in supporting our parents is continually changing. It's a continuum requiring us to remain sensitive to what's happening now, while being aware of what may be needed in the future.

As we age, we experience changes in organs, skin, memory and bone mass. Our youth-oriented Western society dreads these things, but if you can accept them as a normal part of life, you're on your way to overcoming a major attitude obstacle. Real aging is different from popular notions. For example, most people never end up in nursing homes, and more old people live without chronic disabilities than with them.

If you've been thrust into the role of care giver because of a sudden medical crisis with your parent, remember it's a common entry into the world of elder care, and not the most pleasant. Take heart. There are guide posts such as this Action Guide to help you recognize and take advantage of the resources available to you and your parent. (See When Crisis Hits.)

A normal part of the aging process is sensory change. Most older people in their late 70s and early 80s discover that their vision, hearing or senses of taste and smell are not what they used to be. For many people, the sense of touch diminishes only slightly with age. Even though some of our senses often lose their sharpness, life need not lose its quality.

We can assist the elderly by adapting living, working and recreational space to accommodate the sensory changes that result from aging. We can also learn to be more patient with the sometimes slower and seemingly uncertain responses of older adults if we gain a better understanding of the aging process.

There are certain universal characteristics of aging, and there are also several misconceptions. The aging process is one of continual change. Some of the key ingredients to successful aging include:

- A positive mental attitude. If you asked a panel of specialists to tell you the most important thing you could do to promote healthy aging, one might say diet, another would say exercise and nutrition. They would all agree, however, that self-image, mental wellness, and how you perceive yourself are the keys to successful aging.

- Proper nutrition and exercise. Sometimes signs of memory loss or depression can be the result of poor hydration or unbalanced meals. Many health problems can be helped with medication, diet, and exercise. Mental acuity can be stimulated, encouraged, and even exercised.
- Social interaction. Isolation breeds depression, which can cause a host of ailments that are preventable if caught in time.
- Regular medical check-ups. Deterioration or frailty can overtake an elder suddenly or over time. If your parent has a chronic condition, your family should be aware of it. Regular visits to the doctor's office could prolong his life.

AGE-RELATED AILMENTS AND DISEASES

It's true that older people have more medical problems than younger people. Thanks to the advances in medical care and technology, people are aging better and living longer. This often means there will be an increased chance of disability and chronic illness as we enter old age.

Let's review some of the changes that come with aging. The biggest change occurs in our sensitivity to sensory stimulation—our ability to hear, see, smell, taste, and feel. These changes can, over time, begin to affect the Activities of Daily Living (ADLs)—our ability to do the tasks of life such as bathing, cooking, cleaning, and getting out of bed.

We may begin to notice changes in sensory perceptions in our middle years. For example, in our 40s many of us begin to notice that our eyes are changing. We need stronger eyeglasses or even bifocals. Serious sensory changes become more noticeable when people enter their 70s. In general, older people need higher light levels to function effectively. Another impact on vision is difficulty adjusting to the change between dim and bright light. As we age, we simply don't see as clearly once our eyes do adjust to the dark. These are all normal changes we can adjust to, but one can see how these changes might affect our ability to perform Activities of Daily Living (ADLs).

Hearing is another sense that can change with age and have an important impact on the quality of our life and of those around us. Prolonged exposure to loud sounds may cause hearing loss. When we start to experience diminished hearing capacity, it can impact others, such as when the TV volume is turned up. Hearing loss can cause physiological problems, too. Someone with hearing problems may become withdrawn, feel isolated and distrustful. Depression may also result from hearing loss. Hearing loss may be compensated by the use of a hearing aid and other assistive devices.

It is also important to understand how our psychological and mental processes are affected as we get older. There is a misconception that as we age, we become less mentally acute. In fact, there are many brain-related diseases such as Alzheimer's and other forms of dementia about which we have much to learn. It is not true everyone will experience some form of dementia as they age. Many people have fully functioning, active, healthy minds during old age. It's also not unusual to find frail bodies with vibrant minds.

Dementia is the loss of intellectual functions such as thinking, reasoning and remembering to a degree that is severe enough to interfere with a person's daily functioning. Symptoms of dementia may include changes in personality, mood, and behavior. There are more than 100 other symptoms that mimic dementia. As a care giver you need to be mindful of these symptoms because they can be due to poor nutrition, medication interaction, omission or overdose, and lack of exercise.

Some of the more well-known diseases that produce dementia include Alzheimer's, Parkinson's, Huntington's, Lou Gehrig's, multiple sclerosis, and multi-infarct dementia.

The most common mental affliction older people experience is depression. Often mislabeled as senility, depression can become a dysfunctional problem. Depression can be treated. Relief of anxiety, stress, or depression can improve an older person's ability to recognize where they are and what they are doing. It's true some people are naturally depressed, particularly if they have lived long enough to lose many friends and family members. For these people, active socialization may help diminish the impact of their losses. While it's probably true that a lifelong hermit won't be much of a socialite in later years, a person who has always thrived on the interaction of others will continue to need that interaction as they get older. Do whatever you can do to encourage continued social interaction for your aging parent.

Regardless of a person's state of mental health, aging can complicate lifelong personality traits or behaviors. Don't expect significant changes in the way a person relates to you or others as they age. An easy-going individual is likely to remain so as he ages, and a difficult personality may not get easier to deal with later on.

Physical limitations can be relieved through the use of assistive devices such as walkers or wheelchairs that can aid a person with mobility. Loneliness can be mitigated by active caring from family, friends, and professionals. The deaths of others, especially peers, contribute to loneliness. Here too, active physical care, coupled with loving assurance and relief of pain when needed, can have a very positive influence on your parent's emotional state.

The good news about aging—for all of us—is that regular exercise and proper eating habits can improve many parts of our lives. Healthy living habits can begin anytime, and the results will be improved cardiovascular endurance, strengthened muscles, improved flexibility, increased sexual appetite, better sleeping, relief of daily tensions, and improved overall psychological functioning. If your parent is experiencing problems with any of these areas, talk to him about the benefits of healthy living.

There are many community resources available to help you locate fun senior exercise programs. Adult day care centers often provide an exercise program. You and your parent may also find programs at the YMCA, YWCA or Jewish Community Center. Of course, exercise programs should begin only under medical supervision. If you'd like to take a look at a good resource, consider reading *Pep Up Your Life: A Fitness Book for Seniors*, published by the American Association of Retired Persons, #D549, 1909 K St. N.W., Washington, DC 20049.

The basic guidelines for nutrition for seniors are the same for most healthy adults. Pay attention to the quality of foods, and be certain your parent is eating a well balanced diet that includes selections from a variety of food groups. Remember that changes in an older person's body and a decrease in physical activity usually mean a need for fewer calories.

Excess weight is a factor in some age-related disorders such as diabetes, heart disease and high blood pressure. Limiting fat in a diet may help prevent weight gain and may prove beneficial to reducing the likelihood of some forms of cancer. The key to good nutrition is common sense, variety, and moderation. Your parent should always follow his physician's advice about diet, foods and exercise, especially if an illness is involved (see the Reference and Referral and Reading List chapters for more ideas).

MEDICATIONS

According to a study published in the *Journal of the American Medical Association*, 23 percent of Americans 65 and older are taking medications that are notorious for triggering insomnia, fainting spells or amnesia. Some drugs considered safe for the elderly (whose metabolism will not process chemicals as quickly as a young person's) may become dangerous if used at high doses or for long periods. Mixing prescription drugs, or taking dosages excessive for an older person can produce symptoms that mimic diseases or mental disorders such as Alzheimer's (see Reference and Referral for more details).

Medical interaction problems may also be caused by a drug's interaction with food or alcohol, not just with another medicine. It's a good idea to keep track of all your parent's medications, both over-the-counter and prescription, and learn as much as you can about what he is taking.



Questions to Ask Your Parent's Doctors About Prescription Drugs

- Name of drug?
- What is it supposed to do? How long should it be taken for beneficial effect?
- How and when should it be taken?
- How does it interact with over-the-counter medicines?
- What should be done if a dose is missed?
- Should the drug be taken before, during or after meals?
- What is the correct amount of time between doses?
- What does the doctor mean when a drug is prescribed "as needed"?
- What foods, drinks, other drugs or activities should be avoided while taking this specific drug?
- What side effects might occur?

Your parent's pharmacist is a great resource for learning about the medications your parent is taking, and about potential problem drug and food interactions. Most pharmacists provide other valuable services. For example, pharmacists:

- Track medicines on a computer to help alert people of possible harmful interactions.
- Provide medicine delivery service to homes.
- Dispense medications in easy-to-open containers.
- Supply written information about each prescription.

Health Care Professionals

The health care system is a complex mix of many disciplines. It is a highly specialized network of hospitals, clinics, and private offices. Adding to the confusion are the various titles of health professionals and settings in which health care is provided. Listed below are the types of health care professionals you and your parent may encounter and the treatments in which they specialize.

Physicians, including specialists:

- Allergist - allergies
- Cardiologist - heart problems
- Dermatologist - skin disorders
- Endocrinologist - glandular system disorders
- Gastroenterologist - digestive system diseases and disorders

- Geriatrician - elder health care specialist
- Gynecologist - female reproductive system
- Hematologist - blood disorders
- Immunologist - immune problems
- Internist - internal medicine specialist
- Nephrologist - kidneys
- Neurologist - nervous system disorders
- Oncologist - tumors and cancers
- Ophthalmologist - eye diseases and prescribe eyeglasses
- Orthopedist - bone, joint, muscle, ligament, and tendon
- Otorhinolaryngologist - ears, nose and throat
- Plastic & Reconstructive - plastic and reconstructive surgery
- Podiatrist - foot injuries and diseases
- Proctologist - colon and rectal
- Psychiatrist - emotional and mental difficulties
- Radiologist - X-ray
- Rheumatologist - arthritis and other rheumatic diseases
- Urologist - urinary system problems

Physician assistants and nurse practitioners perform medical exams, take medical histories, conduct diagnostic tests and assist doctors in developing and carrying out treatment plans under supervision of a Medical Doctor (MD).

Other Health Care Professionals:

- Nurses provide direct patient care under the guidance of MDs.
- Physical therapists work with patients to help them regain mobility after disease or injury.
- Occupational therapists help people with disabilities function more independently in their home environment.
- Speech therapists help restore or improve communication skills of people with language and/or speech impairments.
- Audiologists test hearing functions, recommend and sometimes dispense hearing aid devices.
- Optometrists conduct eye exams for prescription lenses.
- Opticians fit and supply eyeglasses and contact lenses prescribed by an ophthalmologist or optometrist.

- Psychologists counsel people with mental and emotional problems.
- Licensed clinical social workers provide counseling to help both patients and family handle problems related to illness or disabilities.
- Discharge planners are social workers and nurses who help make plans for continuing care after a hospital stay.

Dentists - including specialists:

- Oral surgeons - tooth removals and jaw surgery
- Endodontists - root canals
- Periodontists - gum disease
- Dental assistants - help dentists take x-rays and do lab work
- Dental hygienists - preventive dental care and education

Dietitians plan special diets and provide nutrition education.

Alternative health care includes:

- Acupuncturists
- Chiropractors
- Homeopathy
- Holistic medicine

RECAP

A parent's medical crisis is usually an adult child's first entry into the world of aging and long-term care. It can be a shocking and terrifying experience, full of unknowns and worries. Your best defense is preparation. Learn to differentiate the myths from the realities of aging. Get to know your parent's specific medical history and situation. Health and medical care planning, as with all other aspects of elder care, can alleviate a lot of stress and confusion when a crisis hits.

Medical emergencies do happen. They're part of aging, part of life. Just because people age, though, doesn't mean they can't maintain a sense of dignity, wellness, and good health.

MEDICAL AND HEALTH ISSUES

REFERENCE AND REFERRAL

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.

919 N. Michigan Ave., Suite 1000
Chicago, IL 60611-1676
(800) 272-3900, (312) 335-8700

Literature and resources including brochures, newsletter, information, local referrals, respite care and care giver support groups.

AMERICAN ASSOCIATION FOR CONTINUITY OF CARE

638 Prospect Ave.
Hartford, CT 06105-4298
(203) 586-7525

Promotes home care standards.

AMERICAN COUNCIL OF THE BLIND

1155 15th St. NW, Suite 720
Washington, DC 20005
(800) 424-8666, (202) 467-5081

Free educational materials, local referrals and funding sources.

AMERICAN DIABETES ASSOCIATION

1660 Duke St.
Alexandria, VA 22314
(800) 868-7888

Management, local referrals and literature.

AMERICAN HEART ASSOCIATION NATIONAL CENTER AND STROKE CONNECTION

7272 Greenville Ave.
Dallas, TX 75231-4596
(800) 242-8721, (800) 553-6321 (Stroke Connection),
(214) 373-6300

Free publications on heart disease and prevention.

AMERICAN MEDICAL ASSOCIATION

515 N. State St.
Chicago, IL 60610
(312) 464-5000

Referrals for all fields of practice, including psychiatry.

AMERICAN SELF-HELP CLEARINGHOUSE

St. Clare's Riverside Medical Center
25 Pocono Road
Denville, NJ 07834
(201) 625-7101

Referrals to local support groups affiliated with a particular disease.

AMERICAN PSYCHIATRIC ASSOCIATION

1400 K St. NW
Washington, DC 20005
(202) 682-6000

Free pamphlets on mental disorders seen in the elderly.

AMYOTROPHIC LATERAL SCLEROSIS ASSOCIATION (LOU GEHRIG'S DISEASE)

21021 Ventura Blvd., Suite 321
Woodland Hills, CA 91364
(800) 782-4747

Low-cost manuals, support groups and referrals.

ARTHRITIS FOUNDATION

1314 Spring St. NW
Atlanta, GA 30309
(800) 283-7800 (information line), (404) 872-7100

Brochures, local referrals.

CANCER INFORMATION SERVICE

Office of Cancer Communications
(800) 4-CANCER
Hotline of National Cancer Institute.

CATHOLIC CHARITIES USA

1731 King St.
Alexandria, VA 22314
(703) 549-1390

Network of multi-service agencies providing services and outreach to the elderly. Local chapters. Provides referrals for community services, including day care. Also operates some services.

MEDICAL AND HEALTH ISSUES

REFERENCE AND REFERRAL

COUNCIL ON FAMILY HEALTH

225 Park Ave. South, Suite 1700
New York, NY 10003
(212) 598-3617

Publishes free booklets and brochures including *Medicines and You: A Guide for Older Americans* and *How to Prevent Drug Interactions*.

COURAGE STROKE NETWORK

Courage Center
3915 Golden Valley Rd.
Golden Valley, MN 55422
(800) 553-6321, (612) 588-0811

Information and catalog of products.

DIRECT LINK FOR THE DISABLED HOTLINE

(805) 688-1603

Extensive database of 12,000 local organizations that provide various services for the disabled.

FAMILY CAREGIVER PROJECT

University of North Carolina, Charlotte
Department of Psychology
Charlotte, NC 28223
(704) 547-4758

Caring Families series of manuals on care giving tips, managing finances, planning for the future and coping with particular illnesses.

HELP FOR INCONTINENT PEOPLE

P.O. Box 8310
Spartanburg, SC 29305
(800) 252-3337, (803) 579-7900

Low-cost educational leaflets, books and audiovisuals. *Resource Guide* of products and services. Referrals to local support groups.

HUNTINGTON'S DISEASE SOCIETY OF AMERICA

140 W. 22nd St., Sixth Floor
New York, NY 10011-2420
(800) 345-HDSA, (212) 242-1968

Pamphlets, audio-visuals, nationwide chapters and support groups.

NATIONAL ALLIANCE FOR THE MENTALLY ILL

200 N. Glene Road, Suite 1015
Arlington, VA 22203-3754
(800) 950-6264, (703) 524-7600

Medical information series, support groups and local chapters.

NATIONAL COUNCIL ON THE AGING, INC. (NCOA)

409 Third Street, SW, Second Floor
Washington, DC 20024
(202) 479-1200

National membership association serving professionals and volunteers who work on behalf of older adults and their families. Operates an information center to handle requests for information from the public including information on choosing a nursing home.

Publishes a variety of materials on a range of aging issues including: senior centers, adult day care services, family care giving, health promotion, and financial issues. A publications catalogue is free upon request.

NATIONAL HEALTH INFORMATION CENTER

U.S. Department of Health and Human Services
P.O. Box 1133
Washington, DC 20013-1133
(800) 336-4797

Toll-free health lines on particular diseases, publications and referrals.

NATIONAL HISPANIC COUNCIL ON AGING

2713 Ontario Road NW, Suite 200
Washington, DC 20009
(202) 265-1288

Information, advocacy, newsletter and other resources. Books available for purchase include: *Elderly Latinos: Issues and Solutions for the 21st Century* (\$20.45), *Empowering Hispanic Families: Critical Issues for the 90's* (\$20.45), and *The Hispanic Elderly: A Cultural Signature* (\$18). Prices include shipping.

MEDICAL AND HEALTH ISSUES

REFERENCE AND REFERRAL

NATIONAL INSTITUTE ON AGING INFORMATION CENTER

P.O. Box 8057
Gaithersburg, MD 20898-8057
(800) 222-2225

Publishes a variety of useful booklets including: *Who? What? Where?: Resources for Women's Health and Aging* and *Resource Directory for Older People*. Also publishes a series of *Age Pages* on a variety of health topics. Request a listing of their free publications.

NATIONAL INSTITUTE ON DRUG ABUSE

U.S. Department of Health and Human Services
(800) 729-6686 to order (from the National Clearinghouse for Alcohol & Drug Information) publication No. PHD 500, *Using Your Medicines Wisely: A Guide for the Elderly*.

NATIONAL MEALS ON WHEELS FOUNDATION

2675 44th St. SW, Suite 305
Grand Rapids, MI 49509
(616) 531-9909

Hotline for service and volunteer referrals.

NATIONAL PACIFIC/ASIAN RESOURCE CENTER ON AGING

Melbourne Tower
1511 Third Ave., Suite 914
Seattle, WA 98101
(206) 624-1221

Concerned with improving services for Pacific and Asian elderly. Information, direct services and quarterly newsletter.

OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION

U.S. Department of Health and Human Services
Information Center
(800) 336-4797

Information and referral for health questions. Spanish-speaking staff available.

PARKINSON'S DISEASE FOUNDATION

William Black Medical Research Building
Columbia Presbyterian Medical Center
650 W. 168th St., New York, NY 10032
(800) 457-6676

Information about support groups by zip code.

PARSONS TECHNOLOGY

One Parsons Drive, P.O. Box 100
Hiawatha, IA 52233-0100
(800) 223-6925

Publishes a variety of software programs useful for families involved in parent care. Affordable titles include: *Medical Drug Reference*, *Quicken Family Lawyer*, *Personal Advocate*, *Quicken* (financial record-keeping), *Personal Home Inventory*, *Family Origins* (family tree), and others. Call for a free catalogue.

SHEPHERD'S CENTERS OF AMERICA

6700 Troost, Suite 616
Kansas City, MO 64131
(816) 523-1080

Interfaith ministry programs and home services including hospice, handyman, shopping, transportation, respite, meals and telephone reassurance.

SIMON FOUNDATION FOR CONTINENCE

P.O. Box 815
Wilmette, IL 60091
(708) 864-3913

(800) 23-SIMON: 24-hour hotline for free information packets.

WORLD WIDE WEB

SOCIAL SECURITY, MEDICARE, MEDICAID, IRS, HEALTH CARE, ELDERCARE LOCATOR

ELDER CARE LOCATOR: A starting point when searching for home health care or nursing home facilities.

www.ageinfo.org/elderloc/elderdb.html

HEALTHFINDER: Government site for publications, databases, self-help & support groups, government agencies, and not-for-profit groups.

www.healthfinder.gov/

MEDICAL AND HEALTH ISSUES

REFERENCE AND REFERRAL

INTERNAL REVENUE SERVICE: Income tax forms, instructions, regulations and publications are all available on-line.

www.irs.ustreas.gov/prod/cover.html

MEDICARE ON LINE: The “official” government site for Medicare and Medicaid. Look here for the most current information on benefits, eligibility requirements and other vital assistance.

www.hcfa.gov/

SOCIAL SECURITY ON LINE: Social Security information including current benefits, eligibility requirements. Includes PEBS (personal earnings and benefits statement) section to determine your parent’s (or your own), benefits.

www.ssa.gov/

Legal Issues: Protecting Your Parent's Wishes and Assets

Before we begin our discussion of legal issues, it's important to understand that each state has its own laws and legal terminology. In this section we've used broadly defined terms to describe a range of documents and legal procedures. But clearly, your parent needs to seek out an attorney who is familiar with the specific terminology and laws in his state.

THE NECESSITY OF LEGAL DOCUMENTS

Planning for life encompass the tools or legal instruments your parent needs to ensure his wishes concerning assets and health care are carried out in the event he becomes incapacitated and is unable to act on his own behalf. This series of tools will prepare a parent and child to deal with incapacity or incompetence. Definitions or terminology may vary between states, so consult an attorney and get definitions in writing to minimize confusion.

Incapacity is the inability to care for oneself, and usually means a person is unable to make decisions due to illness. Incompetence is when a person can no longer understand the consequences of their actions. Incapacity and incompetence can happen anytime, to anyone, so it's wise to be prepared.

Incapacity—inability to make a decision due to illness.

Incompetence—inability to understand the consequences of your actions.

DOCUMENTS FOR LIFE

- Durable Power of Attorney for Property and Financial Matters.
- Durable Power of Attorney for Health Care.
- Advance Directives and Living Wills.

We can't emphasize enough the importance of obtaining legal documents to prevent heartache and financial catastrophe.

Durable Powers Of Attorney (DPOA)

A Power of Attorney (POA) assigns authority for decision making to another person. There are several types of POAs, but generally you want to be sure your parent has a Durable Power of Attorney (DPOA). “Durable” means that the document stays legally binding through incapacity to death (not after death). There are Durable Powers of Attorney (DPOAs) for Property and Financial and/or Health Care.

These are important legal documents that are good to have in your possession, before they are needed, because once you’re declared incompetent you cannot sign POAs or DPOAs and have them be legal.

Durable Power of Attorney for Property and Financial Issues

In planning for the possibility of incapacity and incompetence, we suggest your parent choose another person, usually a spouse or adult child, to serve his best interests when he is no longer able to do so. We also suggest legal documentation stipulate a specific person or persons to make decisions and manage the affairs of someone deemed to be incapacitated or incompetent. In general, a Power of Attorney (POA) is a document authorizing someone to serve as the “attorney in fact” or “agent,” granting him or her the power to act in any way, (or in any specified way) for someone else as long as that power is given in the document. The designee can sign checks, sign a deed, make gifts, or do just about anything that a person can do for himself. You’ll want to discuss these issues with your parent and his attorney.

Your parent will have the final say in deciding who will ultimately act for him. You can assist by encouraging your parent to be certain he trusts and feels comfortable with the appointed person. This is a critical decision that deserves careful thought. The appointed person must willingly accept the role and have full knowledge of what is expected.

There are both “limited” and “general” POAs. The former allows another to act on one’s behalf only in certain areas; the latter permits the “attorney-in-fact” or “agent” to do any act that the signator could do.

A POA that is NOT durable gives the agent authority to act on the parent’s behalf any time BEFORE the parent becomes incapacitated, but not AFTER. Also, most experts agree that it’s a good idea to have a DPOA for property and financial issues, and a separate DPOA for Health Care. Obviously, there is an important difference.

Many people feel uncomfortable giving someone the immediate ability to act for them. For this reason, a “springing” power of attorney is used. The “springing DPOA” becomes effective only when the parent actually becomes incapacitated. This assures your parent that he will have complete control of his affairs until or if incapacity or incompetence occurs. Most banks and brokerage firms have their own “specific power of attorney” form. If your parent uses this form, we suggest he file a POA form for each account and safe deposit box. In most cases, it is wise to have these specific POAs in addition to, and not in place of, a general DPOA.

It's never too early to establish a DPOA. It's one of those things, like having a will, that helps your loved ones help or honor you. It is a very important legal document because anyone can be thrust into a care giver role in an instant.

What may be less clear is exactly when you know it's time for the appointed care giver to truly "take over." Elsewhere (see Medical and Health Issues), we talk about Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). You can use these as a guide to help assess the need an aging parent may have for some simple assistance or complete care, with all the responsibilities it entails. In addition, it is helpful to have an objective set of criteria to use in determining when to step in as POA for your parent. If you and your parent have not previously discussed the kinds and circumstances in which he would like the POA to be used, an objective opinion from one or two doctors saying that your parent is no longer able to manage his affairs could be used.

If there is no DPOA, in the event of incapacity and incompetence, the court can step in and appoint a Guardian or a Conservator (see later in this chapter) to handle your parent's affairs. The Guardian or Conservator, through the Court, will direct the management of your parent's assets, make medical decisions on his behalf, and make all decisions on behalf of your parent. The Guardian or Conservator may or may not be someone related to your parent.

Durable Power of Attorney for Health Care

The DPOA for Health Care, referred to as a "health care proxy" in some states, is particularly important if your parent is chronically or terminally ill, or otherwise facing serious medical treatment. Again, it is the planning before incapacity that makes these documents valid. The DPOA for Health Care enables your parent to appoint another person to make health care decisions if and when he cannot do so. It also allows the agent to make life or death decisions. If your parent is concerned about how his personal affairs are conducted, how personal care is arranged, how medical decisions are made should he become incapacitated, this "health care proxy" is a must.



Checklist for Setting Up a DPOA for Health Care Document

- Be specific about when the document can be used. It can be designed to go into effect immediately or only when, or if, the parent becomes incapacitated or unable to make such decisions for himself. Decide who will determine "incapacitation." Once again, a certificate by a doctor is a good, objective test.
- Be sure the DPOA for Health Care document is drawn up by an attorney licensed to practice in the state where your parent lives. This also applies to the DPOA for Property and Financial matters. Also, if your parent spends a significant amount of time in another state (winter or summer home), it

would be wise for them to prepare a Living Will or Advance Directives for Health Care document effective in that state.

- Be sure your parent's attorney and doctor understand your parent's viewpoint on surgery, transfusions, and any heroic medical measures such as the use of life support systems.

Advance Directives for Care and Living Wills

Two other important legal documents that are becoming increasingly popular are called Advance Directives for Care and Living Wills. Advance Directives for Care specify desired treatments and medical procedures. Living Wills specify preference about medical care in the event of a terminal illness. These documents allow your parent to put into writing his wishes about medical treatment at the end of his life, especially if he is unable to communicate. A Living Will is one type of Advance Directive. However, an Advance Directive may not necessarily be a Living Will.

Different states have different terms for the Advance Directives for Care document, such as "directive to physicians" or "medical directive." They can be treated differently from state to state. But always, its purpose is to guide family and doctors in deciding how aggressively to use medical treatment to delay death. In many states, the wishes expressed in an Advance Directive for Care are to be followed explicitly, while in some states the document is considered advisory.

There is an important distinction between a DPOA for Health Care, which was discussed earlier, and Advance Directives for Care and Living Wills. The DPOA is entirely different because it assigns authority to another person to help with those decisions should the elder become incompetent. The Advance Directives and Living Will act as a "road map" for the health care attorney to follow when exercising his or her powers. Advance Directives essentially outlines a person's wishes regarding limits of treatment.

Advance Directive - specifies desired treatments.

Power of Attorney - assigns authority for decision making.

For example, if a person can no longer eat or take fluids, do they want an intravenous line to be established for sustenance? If a person can no longer breathe, do they want to be on a respirator? If these situations occur, and there are Advance Directives for Care in place, guidelines will already be established and the parties involved will know what to do.

We suggest you keep a copy of the Advance Directives for Care and Living Will and also give a copy to your parent's doctor, health care provider, agent for the DPOA

for Health Care, nursing home or institution, and to a family member or trusted friend.

It's important for your parent to seek out local counsel to discuss these issues in greater depth. Your parent may be able to get information about these documents from his doctor, local Area Agency on Aging, hospital, Health Maintenance Organization (HMO), or attorney. We suggest he talk to his doctor about this, and possibly even to his religious or spiritual advisor.

Free samples of state-specific documents for both the Advance Directives for Care and Living Wills, are available from Choice in Dying, 200 Varick St., 10th Floor, New York, NY 10014-0148 at (800) 989-WILL.

RECAP

Talking to your parent about his wishes for care is imperative. You may be surprised by what you learn about his choices for medical intervention, and you may not agree with his wishes. But it is your parent's life, and the Advance Directives for Care or Living Will is an important document to help him maintain his independence and integrity of thought, even if he is no longer able to express himself because of accident or illness.

DOCUMENTS FOR DEATH

Wills

A will is one method of providing your parent with control over who gets his possessions. Dying without a will, or "intestate," can create legal headaches and potential conflicts among surviving relatives. If there is no will (or other provision), the state intestacy law will decide how assets are distributed. If there are no blood relatives, the state will take the entire estate. The existence of a will is especially important in a second or subsequent marriage situation.

Both husbands and wives need wills. We suggest these be reviewed and updated every three to five years, or when there is a major change in circumstances (divorce, marriage, changes in the law, death of beneficiaries, move to another state or severe illness, for example).

The main purposes of a will are: 1) To indicate the beneficiaries, exactly what the parent wants; 2) estate tax planning; and 3) to appoint the executor (or executrix) who will administer the estate. Wills need not be complicated documents. There are many commercial forms your parent can buy and fill out. Your parent should be very careful that his state's legal requirements for wills are met when using these commercial forms. Otherwise, despite the fact that it's in writing, the "will" may not be legally effective.

A will is not the only way to control the distribution of possessions. Some people try to avoid probate proceedings by doing other planning, such as (1) gifting, (2) setting up joint ownership of assets, and (3) living trusts (which will be discussed below). The first two methods are easy and inexpensive methods of estate planning and ultimately avoid probate. However, there can be unexpected problems associated with them including: loss of control of the assets, gift taxes, and capital gains taxes. Care should be used when doing this type of planning.

Be certain the original will is maintained in a secure and accessible place other than a safe deposit box. Under certain circumstances, upon death of the owner, safe deposit boxes are temporarily closed by courts and become inaccessible.



Questions to Ask When Writing a Will

- Who are the beneficiaries?
- What assets will be left to each beneficiary? (Exact dollar figures aren't necessary; they usually can't be known at the time the will is drawn up.)
- Will there be a bequest or legacy (eg: a gift of personal or real property)?
- Are there any special assets such as art or jewelry that your parent wants to give to someone in particular?
- Does your parent have any charitable interests?

Trusts

There are several Living Trusts that are available to your parents. The basic nature of these Living Trusts is that they are inter-vivos (made during one's lifetime) and they are "revocable" (it has the ability to be changed or canceled) or "irrevocable" (it does not have the ability to be changed or canceled). The value of any trust differs from situation to situation and should be looked at closely. Your parents should know that a trust is an important document that empowers the Trustee with broad powers to handle the trust. Those powers include the right to sell or otherwise dispose of the trust property without the consent of anyone else.

Key Terms

Like in many legal situations, there are some terms that one must become acquainted with to avoid confusion. The "corpus" or "remainder" refers to the property that is held in the trust account. The "grantor", "settlor" is the person making the trust. One should also know that the "Trustee" is the individual who looks after the management of the assets and the administration of the trust. The "grantee" or "beneficiary" are the individuals who take some benefit from the assets placed in the trust. Trusts often have "successors" names placed in the document. If one of the

named parties dies, becomes incapacitated, or resigns, then the successor takes over for that person.

How A Trust Is Created

When your parent does decide to set-up a trust, he will have to be prepared to transfer the title (ownership) to their property. The new title will read the trust's name and will now be managed by the trustee. In many cases, your parent will choose himself as trustee and income beneficiary under the trust. The corpus of the trust is generally held for a third party's benefit. It is important to note that if the grantor, trustee, and beneficiary are all one person, the trust "merges" and becomes the sole property of the person holding all three interests.

Trusts are created for various reasons including the avoidance of probate, the creation of property management tools, to help care for a disabled child, and to aid in estate and tax planning. There are several types of trusts that are available and each should be entered into very carefully after consultation with a qualified professional.

In summary, we suggest your parent ask questions and consider the same things about a trust as he does about a will. In addition, he should consider the timing of distributions. This can be especially important if there is a disabled or spend-thrift child involved. Living trusts offer your parent the following benefits:

- Prevent court control of assets at incapacity.
- Multiple probates can be avoided if property is owned in more than one state.
- They provide maximum privacy. (A will is open to public record.)
- They prevent unintentional disinheritance and other problems of joint ownership.
- Revocable Trusts can be changed or canceled at any time.
- They are difficult to contest.

Living trusts sometimes require an annual maintenance fee; they do not eliminate obligations to creditors or the Internal Revenue Service (IRS).

Guardians and Conservators

When a person is unable to make health care or financial decisions, someone else needs to assume responsibility for making these decisions for him. And it is determined that if no plans have been made prior to incapacity, such as the creation of a DPOA, then the Court has to step in. When this occurs, the Court may appoint guardians (for health care) and conservators (for financial matters). If no one has this legal authority prior to the incapacity, then the Court must be asked to appoint someone to intervene and assist. The same person may serve as your parent's guardian and conservator.

A guardian is appointed by a court to make health care and personal decisions for a person who is incapacitated through physical or mental disability. Guardians

have the same rights, powers and duties over their “wards” as parents over children, except the guardians do not use their own money. A guardian also determines where the ward will live, the medical treatment he will receive, and with whom the ward may associate or marry.

A conservator is appointed by a court to handle the financial affairs of a person unable to do so for himself. The conservator takes possession and control of all of the “protected person’s” assets and must protect, invest and use them only for the protected person’s welfare. In other words, conservators take control of all of the protected person’s assets. The protected person may not sell his own assets or determine how they will be invested without the consent of the conservator. This includes spending money.

Most specialists in elder law agree that guardianships and or conservatorships are something to be avoided if possible. The major disadvantages are:

- All rights of the protected person are completely eliminated.
- The process is expensive and complex because of court involvement.
- The process is a lengthy public proceeding, so the conservatee’s (protected person’s) assets, income, and expenses become a matter of public record.

While there may be times when court supervision of a person’s affairs is warranted, we suggest viewing such intervention as a last resort. However, when properly used, the appointment of a guardian or conservator can be a good way to provide continuing care and management for people who need such help. Procedures to follow are in place to ensure a person’s rights are protected, so these appointments are not made lightly by courts. Consult an elder law attorney or legal aid society in your parent’s community for details about guardianship or conservatorship proceedings.

Finding an Elder Law Attorney

Your parent may already have a lawyer, however, when it comes to dealing with the complexities that make up what has become known as “elder law,” the best professional for the job is one with experience in the field. Elder law attorneys are defined by the clients they serve and the type of law they practice (such as estate planning and Medicaid planning), not by technical legal restrictions. In other words, attorneys practicing elder law may handle a range of legal issues, but they serve a specific type of client – seniors and their families.

Some of the issues an elder law attorney deals with are:

- Preservation and transfer of assets.
- Medicaid law and its rules and regulations.
- Medicare claims and appeals.
- Social Security.
- Medicare supplemental and long-term care insurance.
- Disability planning.

- Estate planning.
- Conservatorships and guardianships.
- Management of estates and trusts.
- Nursing home and life care community placements.
- Elder abuse and elder fraud.
- Retirement questions, including distributions from retirement plans.
- Wills and Advance Directives.
- Health and mental health law.

When your parent first makes contact with an elder law attorney, (for, in fact, it is his attorney, not yours) there are a number of questions he can ask to determine if that person has the experience to be an effective advocate for him. Prior to an initial consultation, ask on the phone what an initial consultation will cost (for example: gratis or free first half hour), and how long it will be. Are the charges paid up front or at the end of the interview or planning process? Watch out for anyone who wants to charge an hourly rate for services to prepare specific legal documents.



Questions to Ask a Prospective Elder Law Attorney

- How long have they been in practice? If they are just starting their career, you might want to look elsewhere.
- Do they emphasize a particular area of law? If the answer is other than elder law, we suggest you probably keep looking.
- What percentage of their practice is devoted to elder law?
- How many Living Trusts and Durable Powers of Attorney have they prepared? How recently were they prepared?
- What kind of experience with estate planning and living trusts do they have?
- What is their fee for specific legal documents?
- How many Medicaid plans have they done?
- How much experience with hearings and/or appeals related to Medicaid and Medicare do they have?

Ask for references and check them. For example, ask for the names of clients who have had similar services performed to those you are seeking.

These questions will assist your parent in getting a solid foundation for the selection of an elder law expert to represent his interests. Naturally, there are other criteria as well, such as personal referrals you trust, and the degree of trust your parent has for the attorney.

You might find a good elder law attorney by asking:

- Friends and associates.
- Accountants and insurance professionals.
- State and local bar associations.
- Advocacy and support groups.
- Your community's senior information and referral service.

You can also find a local elder law attorney through the National Academy of Elder Law Attorneys (NAELA), the professional organization responsible for bringing elder law professionals into the American Bar Association as a recognized sub-specialty of law. You can contact them at (520) 881-4005, 1604 N. Country Club Road, Tucson, AZ 85716. The ElderCare Locator at (800) 677-1116 may also be used (see Reference and Referral).

If your family can't afford an attorney, contact the local legal aid society, Legal Services for the Elderly office, local law schools (some schools have legal clinics serviced by law students), and human resource agencies. The American Bar Association's Senior Lawyers do pro bono (free) work. Also, investigate the availability of legal help through groups that help protect the rights of older people, women, and minority groups.

RECAP

No law requires the care giver to become proficient in all matters of elder law, so don't take on this behemoth if you don't want to or have to! You can get started by becoming informed about the types of help your parent may need, putting a legal team together, and preparing all the advance paperwork you can before a crisis strikes. It's time consuming, but it will definitely pay off later.

LEGAL ISSUES: PROTECTING YOUR PARENT'S WISHES and ASSETS

REFERENCE AND REFERRAL

AMERICAN ASSOCIATION OF RETIRED PERSONS (AARP) LEGAL COUNSEL FOR THE ELDERLY

Order Fulfillment
P.O. Box 96474
Washington, DC 20090-6474
(202) 434-2174

Publishes: *Organizing Your Future: A Guide to Decision Making In Your Later Years*, 1993, order #D13877, \$5.00 (98 pages) and *Finding Legal Help*, order #D15579, \$2.00. Make checks payable to: Legal Counsel for the Elderly.

AMERICAN BAR ASSOCIATION

Order Fulfillment Department
750 N. Lake Shore Drive
Chicago, IL 60611
(800) 621-6159

Publishes: *Planning for Life and Death* (#PC: 543-0040-01) and *Wills: Why You Should Have One* (#PC: 543-0039-01). Single copies available at no charge.

BET TZEDEK LEGAL SERVICES

145 S. Fairfax Ave., Suite 200
Los Angeles, CA 90036
(213) 939-0506

Guides in English, Spanish and Russian include: *Nursing Home Companion*, *How to Get Care From a Board and Care*. Call for free publications catalogue.

CHOICE IN DYING

200 Varick St., 10th Floor
New York, NY 10014-4810
(800) 989-WILL, (212) 366-5540

Free publication of state-specific *Living Will* and *Durable Power of Attorney* forms.

NATIONAL ACADEMY OF ELDER LAW ATTORNEYS, INC.

1604 N. Country Club Road
Tucson, AZ 85716
(520) 881-4005

List of local referrals sent out for a fee. Free booklet, *Questions & Answers When Looking for an Elder Law Attorney*.

NATIONAL CENTER ON ELDER ABUSE

810 First St. NE, Suite 500
Washington, DC 20002-4257
(202) 682-2470

Offers a free information packet that includes articles, statistics and a publications catalogue. Can also refer you to state adult protective services agencies.

NATIONAL CLEARINGHOUSE FOR LEGAL SERVICES, INC.

205 W. Monroe St., Second Floor
Chicago, IL 60606-5013
(312) 263-3830

Catalog of publications on housing, senior citizens and health.

NATIONAL COUNCIL ON THE AGING, INC. (NCOA)

409 Third Street, SW, Second Floor
Washington, DC 20024
(202) 479-1200

National membership association serving professionals and volunteers who work on behalf of older adults and their families. Operates an information center to handle requests for information from the public including information on choosing a nursing home.

Publishes a variety of materials on a range of aging issues including: senior centers, adult day care services, family care giving, health promotion, and financial issues. A publications catalogue is free upon request.

NATIONAL SENIOR CITIZENS LAW CENTER

1815 H Street, N.W., Suite 700
Washington, DC 20006
(202) 887-5280

Call to request a free publications catalogue.

NOLO PRESS

950 Parker St.
Berkeley, CA 94710-9867
(800) 992-6656

Publishes books and software on estate planning, long-term care insurance, wills, conservatorships and nursing homes. Prices vary; call for a free publications catalogue.

LEGAL ISSUES: PROTECTING YOUR PARENT'S WISHES and



OLDER WOMEN'S LEAGUE

666 11th St. NW, Suite 700
Washington, DC 20001
(202) 783-6686

Publications include topics on elder women and poverty, care giving, pensions, legal, housing and long-term care.

The Business Side of Care Giving: Finance and Insurance

Editor's Note: Government programs such as Social Security, Medicare, and Medicaid are routinely amended by Congress. Follow news reports to stay abreast of the current status of these programs and IRS rules. The most current information about benefits, eligibility requirements, and other critical subjects are available on the World Wide Web, so check the Web sites listed in *Reference and Referral*. We also strongly suggest that you consult with a qualified elder law attorney, long-term care insurance specialist, or financial planner to determine how the current status of government programs might impact your care giving plans.

One of the scariest issues we must deal with when assisting our aging parent is the question of how to pay for his care. Most Americans are living longer, and with increased longevity comes the very real possibility that some kind of long-term care will be needed for our parent.

FINANCE

Talking About Financial Matters

If a parent outlives his finances, he may wind up in a position of asking his grown children for assistance. For this reason, there is no substitute for having a full understanding of your parent's financial picture. To focus that picture, you will need to talk to him in detail about his finances. You can start this discussion by the direct approach, or by informally asking about a news story you've recently seen on TV, or a situation that you know of where a friend has been assisting his parent make a lifestyle change. You can say, "Mom and Dad, did you see that news story on TV the other night about long-term care insurance? Do you have anything like that?" Whichever approach you take, be certain you discuss the full range of finances. You'll find additional ideas for helping you have an effective conversation with your parent in the Family Dynamics section of the video and Action Guide.

When dealing with money issues, it is imperative that your parent trusts you and your ability to assist him with making wise financial decisions. In families with more than one adult child, there often is one sibling or spouse that has a better understanding of finances than another, so it may be that your parent will feel more comfortable working on these issues with that child. What's important is that the adult children work with their parent early to uncover the financial picture.

The first step in solving the puzzle of paying for long-term care is finding out exactly what planning, if any, your parent has already done. You may be surprised by how much planning your parent has already done for himself. However, you may find he has not thought much about the future, and will require your activation or encouragement to get going.

Estate and Tax Planning

Discussions about finances can be time consuming. It might take many hours to help your parent organize his records and compile information about bank accounts, insurance policies, and assets. These are extremely important things to learn about. If your parent has a financial planner, ask to have him or her work with you and your parent to answer all of your questions. If your parent does not have a financial planner, you might want to identify a professional to assist him. This is particularly true even if your parent is not wealthy. Many middle income families can have a complicated financial picture. If your parent's situation is not complex, you can help him develop a cash-flow statement and balance sheet yourself.

If your parent accepts your assistance, the first step is to find out everything about his current financial status. In a nutshell, you'll need to know what your parent's income and expenses are. In order to do this, you can help your parent put together a cash flow statement, which lists all the money that comes in and goes out each month, quarterly, or annually. This statement not only gives your parent a financial planning picture, it also helps determine your parent's eligibility for various government programs (see Government Programs), and his need for long-term care insurance (see below). It can also make clear what funds are available for out-of-pocket expenses and home care. A cash-flow statement lists all income and expenses, and when completed tells your parent how much cash is available.

The balance sheet lists all assets and liabilities. In other words, all that is owned and all that is owed. In a sense, when developing a balance sheet you're assisting your parent with tax planning; it's linked to estate planning late in life. The estate consists of all of your parent's assets, small or large. Estate planning can include deciding who will get property after death, setting up procedures to avoid probate, and reducing taxes if the estate is large. It can mean that now is the time to begin making gifts to children and grandchildren (up to \$10,000 a year from each parent, to each person), that can reduce the size of the estate and thus reduce the amount of estate tax. Involved in such planning are wills, trusts, joint tenancy, life insurance, pension plans, and retirement accounts (see Legal Issues: Protecting Your Parent's Wishes and Assets for more details). For specific information, consult a financial planner or elder law attorney.

General Questions to Ask About Finances for Estate and Tax Planning Purposes

- **Bank accounts:** Where are your parent's bank accounts? You'll want your parent to list the bank names, account numbers, locations of safe deposit box(es) and key(s).
- **Life insurance policies:** What insurance policies does your parent have, what is the current face and cash value of each, and where is each kept? Who are



the named beneficiaries and contingent beneficiaries? Who is the insurance agent and what is his or her phone number?

- **Taxes:** Who is your parent's accountant? Where are your parent's tax returns? What does his current IRS picture look like? For example, has he taken deductions for medical expenses or gifts to qualified charities? What about taxability of non-qualified plans? Has any preparation been done regarding estate taxes? (See Legal Issues: Protecting Your Parent's Wishes and Assets).

Checklist for Learning About Your Parent's Finances



Assets:

- Cash on hand.
- Checking accounts.
- Savings accounts.
- Certificates of Deposit.
- Stocks, and bonds
- Mutual funds.
- Money market accounts.
- Brokerage accounts.
- Annuities (surrender value).
- Loans receivable (IOUs due to your parent).
- Business and partnership equity.
- Precious metals and collectibles.
- Real Estate.
- Vested pension plans, Individual Retirement Accounts (IRAs), and tax sheltered annuities.

Liabilities:

- Taxes due.
- Credit cards and balances due.
- Car loans.
- Mortgages.

Other:

- Safe Deposit Box(es).
- Will(s) and Trust(s).
- Cemetery Plot(s) and Deed(s).
- Insurance policies (life, health, home, automobile).

Not only is it important to know if the above documents exist, but it's even more important to know where they're located. (Use the Records and Information chapter for worksheets to record you parent's information.)

Financial Planners

Financial planning can be described as a coordinated, continuous process of working with a client to set and achieve goals that are subject to review and modification as personal and professional objectives, family and business circumstances, and economic conditions change. We suggest financial planning be viewed as a coordinated, integrated, ongoing process of managing an individual's financial concerns. Financial planning includes the interdisciplinary areas of risk management (insurance), income tax, estate planning, retirement plans, and investments to meet a client's needs.

A financial planner can be a valuable asset to your parent's care giving team because he or she can assist in developing a written financial plan. A financial planner can show your parent options and help you and your parent plan for long-term care, and estate and tax matters. It's important to remember that the financial planner is working for your parent. Your parent is in the driver's seat when it comes to making financial decisions.

Depending upon their level of experience, financial planners may have different designations. A "Certified Financial Planner" (CFP) is a financial planner that has earned a license by demonstrating his or her competence in analyzing and developing personal and business financial plans through the successful completion of a series of rigorous financial planning examinations. A "Chartered Financial Consultant" (ChFC) is a financial planner whose knowledge spans the spectrum of personal financial management. To attain the ChFC designation, a candidate must complete a series of ten college level courses and must have a minimum of three years experience in the financial services industry. (See Business Side of Care Giving Reference and Referral Section for a description of financial planning associations.)

When your parent works with a financial planner, the financial planner will walk your parent through these six steps. He or she will:

- Gather the relevant information about your parent.
- Analyze your parent's present financial position.

- Develop a plan for achieving your parent's objective(s).
- Obtain your parent's approval of the plan.
- Implement the plan.
- Review the performance of the plan periodically and revise the plan as needed.

Interview several financial planners. Find out the financial planners' qualifications, professional designations, background, education, how they are compensated and how long they've been in the business. Ask if they've worked with older clients. Get references if possible, and check them out. For a referral to Certified Financial Planners in your parent's area, contact the Institute of Certified Financial Planners; for a referral to fee-only financial planners, contact the National Association of Personal Financial Advisors (see Reference and Referral). If your parent is considering investing through a stock broker, call the National Association of Securities Dealers (NASD) at (800) 289-9999 to check the record of any stock brokers you are considering working with. The NASD keeps records of any complaints or lawsuits filed against any licensed stock broker. Don't feel pressured, and don't settle for anyone you and your parent aren't comfortable with.

RECAP

By working with your parent to determine his financial situation, you are being a responsible adult child and are helping to plan for your parent's future. Developing sound financial strategies as early as possible is critical to protecting your parent's financial future, and quite possibly, your own.

Paying for Long-Term Care

One of the major expenses you and your parent might have to confront is that of paying for nursing home or other long-term health care expenses. What are the odds of spending some time in a nursing facility? The probability that a woman will enter a nursing facility at some point in her life is 50%, for men it's 33%. Many people require only a few weeks of care in a nursing facility, usually to recover from a stay in a hospital. But the odds for a longer stay, a year or more, is 1 in 3 for women and 1 in 7 for men. Although 74% of facility stays are less than one year, a prolonged stay can be financially disastrous. The charges can be staggering, even beyond \$50,000 a year, depending upon which state your parent resides in and the level of care required. A long stay, without comprehensive planning done in advance, can bankrupt a family.

Funding long-term care is a difficult and complicated subject. If you believe that government programs such as Medicare or Medicaid will cover long-term care, you are not alone, but you are mistaken. In fact, Medicare provides very limited payments

for nursing home or long-term care (see Government Programs), and Medicaid won't pay for nursing home care until a person's funds are nearly gone.

Nursing facilities are an important part of the continuum of long-term care, and one of the most expensive. Long-term care is different from acute care. Acute care is provided in a hospital and is usually short-term. Long-term care is needed by people with chronic, degenerative illness (such as Multiple Sclerosis) or disability who require continued support of one form or another.

With proper planning, your parent can protect himself and his heirs against financial disaster. A conversation with a qualified financial planner will uncover many strategies. An elder law attorney is another good referral. (See *Legal Issues: Protecting Your Parent's Wishes and Assets* for more information.) These professionals will help your parent develop an effective estate and tax plan to maximize and protect his assets, they will also explore the advantages and disadvantages of various financial options for paying for long-term care.

One technique for generating cash flow to pay for long-term care in the home, is a reverse mortgage (also called reverse annuity mortgage, or RAM) or a home equity loan. This is a loan against the home equity (or value) that gives your parent cash and requires no monthly re-payments. It's a way to turn a home into cash. Since many older adults have been paying for their homes for decades (or own them outright by now – find out if your parent does), and real estate values have vastly increased in many areas of the country, this is sometimes a good way for older adults to cash in on the home without leaving it. RAMs will not pay for nursing home care, however, because most RAMs have a residency requirement. They might be a good option, though, for home care. Another option to generate income is through the use of annuities. Annuities offer seniors a way to invest money, at competitive interest rates, for tax-deferred growth and/or income. Annuities require that your parent deposit a sum of money and then he realizes a stream of payments, usually a fixed amount monthly. There are two types of annuities, immediate or deferred. And an annuity can either be fixed or variable. A fixed annuity is similar to a CD wherein the rate of return is stipulated and earned for a set period of time. A variable annuity is more like a mutual fund because the buyer can choose where the annuity money will be invested.

Consult an elder law attorney or certified financial planner to determine if reverse mortgages or annuities are viable options for covering the costs of long-term care for your parent.

INSURANCE

Policies and Their Intent

Finances are one side of the personal business coin. The other side is insurance. Like finances, there are many aspects of insurance. The first step you can take is to find out what types of insurance your parent has in place. Check his life, home,

fire, auto, health, disability, Medigap, long-term care or specific disease insurance policies. Find out what the original intent was and how old the policy is. For example, if a policy was purchased when your parent was age 25 or 30, the reasons for purchasing the policy may have changed or become obsolete. It probably needs some review! Give serious thought before canceling any policies. If one is uninsurable and cancels a policy, they won't be able to obtain new coverage. Talk to a financial planner or a community counselor, through your local Area Agency on Aging (AAA) or Health Insurance Counseling and Advocacy Program (HICAP) office, for any questions about how to update your parent's insurance coverage to reflect current needs. Once you've gathered the information, log it in the Records and Information section of your Action Guide.

Medigap Insurance (also called Medicare Supplemental Insurance)

It's important to understand the coverage and limitations of Medigap policies. Medigap policies are specifically designed to supplement Medicare's benefits and must be clearly identified as Medicare Supplement insurance. Documents such as hospital indemnities and specific disease plans are NOT Medicare Supplemental insurance. Neither Medicare Supplemental nor hospital indemnity and special disease plans pay for long term care.

If your parent has any type of a Medicare Supplemental insurance policy called Medigap it's unlikely he will need any additional disease-specific or hospital indemnity insurance. Medicare supplemental insurance usually doesn't cover long-term care, though. There are some policies that cover co-payments for skilled nursing home care for some duration, but usually Medicare Supplemental plans only pay toward hospital deductibles and co-payments, and physician co-payments.

There are ten standard Medicare Supplemental insurance (Medigap) plans available with variations on basic benefits and optional services, such as hospital deductibles, skilled nursing home co-insurance, at-home recovery, excess doctor charges, preventive screening, and outpatient prescription drugs. For more information about these plans and the benefits, check with a financial planner, insurance specialist, your local Social Security office, or write to the U.S. Department of Health and Human Services, Health Care Financing Administration (HCFA), at 6325 Security Blvd., Baltimore, MD 21207 for a copy of the Guide to Health Insurance for People With Medicare, published annually.

Long-Term Care Insurance

The rationale for long-term care insurance is that a) people are living longer, so b) their chances of winding up frail or chronically disabled and in need of care in a nursing home, assisted living facility or at home are greater, and c) there may not be enough personal assets to cover the costs. Long-term care insurance is a relatively new planning tool. It can provide money to provide for long-term care in a facility or at

home for either a limited or an unlimited amount of time. Some states (California, New York, Connecticut, and Indiana) have special “partnership” programs which marry the public and private methods of financing long-term care by providing Medicaid back-up after a limited private insurance policy is used up. Detailed information on these special partnership programs can be obtained from their offices. (See Reference and Referral for the addresses of these four partnerships).

The purpose of long-term care insurance is to cover some of the long-term care expenses whether your parent is in a facility or requires care in the home. Needing assistance with the basic Activities of Daily Living (ADL’s), or cognitive impairment, such as Alzheimer’s Disease, are conditions that “trigger” insurance policies to pay benefits. Long-term care insurance helps pay for care in facilities such as a nursing home or an assisted living residence. It may also pay for community-based services, such as home care, chore service, personal care and adult day care.

Annual long-term care insurance premiums vary from a few hundred dollars to several thousand dollars. Premiums are based on two “given” variables – age at application and state of health at application. These factors one cannot change. The variables determining premium which can be changed are the maximum daily benefit, the length of the benefit, the elimination period (deductible) and the type of inflation protection chosen. If one is dealing with a limited amount of money that can be spent on insurance premiums, it is better to build a “shorter, fatter policy” rather than a long, thin one (e.g. insure for 3 years with inflation protection with a generous amount of daily benefit rather than buying a lifetime, unlimited length policy with no inflation protection.) Paying premiums for long-term care insurance should not impact significantly on your parent’s lifestyle or take food out of your parent’s mouth. If the premium for good coverage is unaffordable for your parents, you can do one of two things – 1) you, their child, could help them pay for premiums or 2) they could elect not to take the coverages. They should not take coverage for a relatively insignificant amount of benefits, because they do not want to pay any higher premium, assuming it is better than nothing. If the benefits provided are very low the eventual help that the policy provides could, indeed, be next to useless. In that case all the premiums paid would have been for naught.

On the other hand, it is not necessary to insure for the full cost of care. In order to keep premiums down, they could make a decision to self-insure some of the costs themselves or with help from the adult child(ren). The difference here is that the decision to lower the policy daily maximum is done consciously. Structure the policy to provide good coverage, then look at the premium, make some adjustments (keeping in mind their total financial ability to self-insure some of the cost of care), and decide to pay the premium or not.

If your parent’s assets are either very low or very high, long-term care insurance may not be an appropriate option. Those with very high net worth could afford to self-insure (pay for their care, if needed, out of pocket). On the other hand, these fortunate folks would also look at the cost of the insurance as minimal. Those people with few assets might qualify for Medicaid (welfare program) very quickly because the

cost of their care would wipe out the little they have and put them in the position of being able to receive assistance from the government. It is the folks in the middle range of assets and income who would benefit most from a program of private long-term care insurance.

The Kennedy-Kassebaum bill of 1996, provided some tax advantages for those who purchase long-term care insurance. Plans that had been approved by the state insurance departments as long-term care insurance and put into effect by December 31, 1996, are "grand-fathered" and considered tax-qualified. Now, your parents will have to purchase specific "tax-qualified" plans in order to benefit from the provisions of the law. Premiums for "qualified" long-term care insurance will be deductible as a medical expense for those who itemize, subject to limitations. The limitation to the amount of premiums eligible for tax deductibility are based on the current age of the person filing the tax return.

Having a tax-qualified plan will also assure your parents of receiving these benefits tax-free. (There are limitations for some plans which are not reimbursement plans, but which pay a flat amount per day regardless of the cost of care. Be sure to consult with your accountant, financial planner, or tax advisor to determine what will work best for your own family's situation.)

The concept of asset transfers (also called "spending down") as a way to qualify for government program coverage through Medicaid has been a widely used method to pay for long-term care in nursing homes. Be advised that the same law which provides for some tax advantages to those who purchase long-term care insurance also has a dramatic impact with respect to the spending down strategy. In fact, section 217 of the Kennedy-Kassebaum bill provides for "CRIMINAL PENALTIES FOR FRAUDULENT DISPOSITION OF ASSETS IN ORDER TO OBTAIN MEDICAID BENEFITS." Consequently, we strongly recommend you seek advice from a qualified elder law attorney regarding how this provision of the law might impact your situation and the planning you are doing. Consult a financial planner who specializes in long-term care insurance, or your county's Legal Services for the Elderly program, Area Agency on Aging (AAA) or Health Insurance Counseling and Advocacy Program (HICAP).

Before we go into the questions your parent needs to answer to determine whether long-term care insurance is a good idea for his situation, it's important to note that evaluating the company offering long-term care insurance is as important as evaluating what type of policies they offer. For example, how long has the company been providing this type of insurance? What is their financial strength? You want to know that the insurance carrier will be there when your parent needs to file a claim. You can get information about the financial strength of the prospective insurance providers from the State Insurance Commissioner's office (who will tell you which companies are licensed to sell in that state), or an insurance rating bureau such as A.M. Best, Moody's or Standard & Poors. As a general rule, don't consider any company with an A.M. Best rating lower than A, or a comparable rating from the other two rating bureaus. Each bureau has their own rating systems.

Just because your parent has decided long-term care insurance might be a good idea, don't be surprised to find that not everyone can qualify for it. Insurance companies have a range of restrictions that might include the age of the potential buyer, their current health status and other factors such as state-specific benefit availability in the state your parent resides or plans to retire or relocate to.



Questions to Ask When Choosing Private Long-Term Care Insurance

- How would your parent pay for long-term care?
- What about informal resources your parent might tap into for assistance in paying for nursing home care, such as family, friends, civic, social, religious, or other organizations that might have assistance plans?
- Do heirs have a vital need for money the estate can provide?
- Are skilled, intermediate, and custodial care provided? What's covered? Be certain the policy is clear about the types of services covered, i.e. nursing home, home health care, adult day health care, assisted living facilities, registered nurse care, licensed nurse practitioner care, physical therapy, geriatric care coordination, etc. Read the policy to see if it covers custodial care and does not duplicate any other insurance coverage your parents may have.
- How does the policy handle pre- and post-claim underwriting?
- What is the financial rating status of the insurance carrier (A or A+ by A.M. Best Rating Service)?
- Are “organically-based mental conditions” covered? (Alzheimer's, dementia, and others may be covered, or they may be excluded. Find out about limits.)
- Is coverage limited to Medicare “certified” facilities?
- Is a hospital stay prior to entering a nursing home required for benefits?
- Has your parent suffered a stroke or other long-term debilitating illness (genetic indicator towards pre-disposition or probable need)?
- What happens if your parent has a pre-existing condition?
- Are there any restrictions, such as the age and health status of the buyer?
- How does the policy determine eligibility? Physical impairment, cognitive impairment, or medical necessity?
- When do the benefits begin? How long is the waiting period?

- What is the maximum benefit period? Long-term care policies are sold on the basis of the number of days or years of coverage provided before the benefits run out. Be certain you understand the benefit period.
- What is the policy daily benefit? Compare this rate to the actual charges in your parent's town, or the town where they will be living.
- Are the premiums competitive? Do rates go up as you age? (Rates cannot be increased solely on the basis of age.)
- Can your parent, or you, afford the premium payments?
- Will premiums amount to no more than 5% of your parent's income?
- Is there an inflation protection clause? Does the premium stay level or increase as the daily benefit rises over time? Is there a daily benefit cap by percent of increase or age limitation?
- What happens if premium payments are missed?
- Does the policy waive the premium when on-claim for facility and/or home care?
- What is the deductible? Does the deductible or elimination period apply to every health care occurrence or "claim"?
- Is the policy renewable for life?

In general, you must be in good health to buy long-term care insurance. Shop around carefully and be certain you and your parent understand the limits and exclusions of any policy. Consider buying a policy to cover both nursing home and at-home care. Find out exactly what the policy covers, in detail. The United Senior's Health Cooperative's Dollars and Cents Guide is an excellent publication for helping people determine if long-term care insurance is appropriate. (See Reference and Referral for the address.)

Let the following precautions guide you if your parent is seriously considering an investment in long-term care insurance:

- Realize that the younger your parent is when he buys long-term care insurance, in general, the lower the premiums. Conversely, premiums will be paid for a longer period.
- Many policies permanently exclude coverage for some mental and nervous disorders, alcohol dependence, and drug abuse.
- Realize that brochures and advertisements can be misleading and incomplete. Don't buy insurance based solely on what you read in the marketing literature.
- Beware of mail-order and limited-offer policies.
- Check the company's financial rating.

- Don't be misled by agents who say your medical history is not important.
- Don't buy multiple policies.
- Find out what conditions must be met in order to collect benefits.
- Read the fine print!

As with all insurance, when considering long-term care insurance you and your parent must weigh the financial costs against feelings of security. Remember, the large print giveth and the small print taketh away. Be sure to read all of the fine print!

For more information, write to the American Association of Retired Persons (AARP), 601 E St. NW, Washington, DC 20049 for a copy of *Before You Buy: A Guide to Long-term Care Insurance* (D12893).

RECAP

The business side of care giving cannot be ignored. The decisions you and your parent make, or the decisions you avoid, will have a real impact on the quality of your parent's life, your life and that of your family. For more information on financial planning, retirement options, long-term care insurance and other resources, turn to the Reference and Referral section of your **AGING PARENTS** *Action Guide*.

THE BUSINESS SIDE OF CARE GIVING

REFERENCE AND REFERRAL

AMERICAN ASSOCIATION OF RETIRED PERSONS (AARP) FULFILLMENT

601 E St. NW
Washington, DC 20049
(202) 434-2277

Booklets on long-term care insurance, planning for retirement, etc. Request a publications catalogue.

AMERICAN SOCIETY OF CLU AND CHFC

270 Bryn Mawr Ave.
Bryn Mawr, PA 19010
(610) 526-2500

The American Society of CLU and ChFC, a national organization of insurance and financial services professionals, is dedicated to enhancing the ability of its members to provide services and solutions that meet the financial needs of individuals, families and companies through a commitment to continuing professional education and ethical practices.

Members earn the designations CLU (Chartered Life Underwriter) and/or ChFC (Chartered Financial Consultant) through The American College, Bryn Mawr, PA.

AMERICAN SOCIETY ON AGING

833 Market Street
San Francisco, CA 94103
(415) 974-9600

Publications on care giving are available. Call for a free publications list.

CALIFORNIA PARTNERSHIP FOR LONG-TERM CARE

714 P St., Room 616
Sacramento, CA 95814
(916) 657-0654

Four states, California, New York, Connecticut and Indiana, have special partnership arrangements whereby Medicaid (Medi-Cal in California) and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. Call for information concerning California residents.

CONNECTICUT PARTNERSHIP FOR LONG-TERM CARE

Office of Policy & Management
450 Capital Avenue, MS# 52LTC
Hartford, CT 06134-1441
(203) 418-6318

Arrangement whereby Medicaid and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. Connecticut residents can call (800) 547-3443 to request information.

COUNCIL OF BETTER BUSINESS BUREAUS, INC.

Publications Department
4200 Wilson Blvd., Suite 800
Arlington, VA 22203
(703) 276-0100

Publishes several low-cost booklets: *Medicare and Medicaid*, *Long-Term Nursing Home Care*, *Continuing Care Retirement Homes*, and *How to Select a Financial Planner*. Request a free publications listing which includes ordering instructions and fees.

DEPARTMENT OF DEFENSE

National Personnel Record Center
9700 Page Blvd.
St. Louis, MO 63132
(314) 263-3901

If you cannot find the certificate of discharge from the armed forces, send the branch of service, dates and service serial number to receive a copy of the certificate.

FEDERAL NATIONAL MORTGAGE ASSOCIATION (FANNIEMAE)

Public Information Office
3900 Wisconsin Ave. NW
Washington, D.C. 20016
(800) 732-6643

Information on reverse mortgages. Publishes free brochures on the subject including: *HomeKeeper Mortgages*, *Home Equity Conversion Mortgages*, and *Money From Home*.

THE BUSINESS SIDE OF CARE GIVING

REFERENCE AND REFERRAL

HEALTH INSURANCE ASSOCIATION OF AMERICA

Consumer Information Service
555 13th St. NW, Suite 600 East
Washington, DC 20004-1109
(800) 635-1271

Publishes a free *Guide to Long-Term Care Insurance*. Also publishes at no charge a list of companies that offer long-term care insurance policies.

HEALTH INSURANCE COUNSELING AND ADVOCACY PROGRAM (HICAP)

Check "Government Listings" in phone book under "State", to obtain the phone numbers for either the State Insurance Division - Consumer Affairs, or the State Office on Aging for a referral to the state's HICAP counselor(s).

INDIANA LONG-TERM CARE PROGRAM

Family & Social Services Administration
402 W. Washington Street, W353
Indianapolis, IN 46204
(317) 232-2187

Arrangement whereby Medicaid and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. Indiana residents may call toll-free (800) 452-4800 for information.

INSTITUTE OF CERTIFIED FINANCIAL PLANNERS

3801 E. Florida Ave., Suite 708
Denver, CO 80210
(800) 282-7526, (303) 751-7600

Will send a list of Certified Financial Planners who practice in your zip code area. Publishes a free brochure *Selecting a Qualified Financial Planning Professional: Twelve Questions to Consider*.

INTERNATIONAL ASSOCIATION FOR FINANCIAL PLANNING

5775 Glenridge Dr. NE, Suite B-300
Atlanta, GA 30328-5364
(800) 945-IAFP

Publishes a free brochure, *Consumer Guide to Comprehensive Financial Planning*, and will provide a list of qualified advisors in your area.

NATIONAL ASSOCIATION OF INSURANCE COMMISSIONERS

120 W. 12th St., Suite 1100
Kansas City, MO 64105
(816) 842-3600

Publishes a free brochure, *A Shopper's Guide to Long-term Care Insurance*.

NATIONAL ASSOCIATION OF PERSONAL FINANCIAL ADVISORS

1130 West Lake Cook Road, Suite 150
Buffalo Grove, IL 60089
(800) 366-2732, (708) 557-7722

Professional group of fee-only planners. Publishes a free brochure about "fee-only planning" and will send it along with names of fee-only financial planners in a given area.

NATIONAL CENTER FOR HOME EQUITY CONVERSION (NCHEC)

7373 147th St. West, Suite 115
Apple Valley, MN 55124
(612) 953-4474

Free information on reverse mortgages. They also publish: *Your New Retirement Nest Egg*, by Ken Scholen, NCHEC Press, 1995, \$24.95. 336 pages.

NATIONAL COUNCIL ON THE AGING, INC. (NCOA)

409 Third Street, SW, Second Floor
Washington, DC 20024
(202) 479-1200

National membership association serving professionals and volunteers who work on behalf of older adults and their families. Operates an information center to handle requests for information from the public including information on choosing a nursing home.

Publishes a variety of materials on a range of aging issues including: senior centers, adult day care services, family care giving, health promotion, and financial issues. A publications catalogue is free upon request.

THE BUSINESS SIDE OF CARE GIVING

REFERENCE AND REFERRAL

NATIONAL ENDOWMENT FOR FINANCIAL EDUCATION

4695 S. Monaco Street, Department 022
Denver, CO 80237-3403
(303) 220-1200

Offers a free *Wealth Care Kit* that walks consumers through the processes involved in planning their financial future. For a free kit write to the address above.

NATIONAL INSURANCE CONSUMERS HELPLINE

1001 Pennsylvania Avenue, NW
Washington, DC 20004
(800) 942-4242

Information and referrals on the following insurance types: life, health (including long-term care, Medicare), home, business and auto. An insurance industry service which does not promote specific companies. Referrals to elder care agencies as needed or requested.

NEW YORK STATE PARTNERSHIP FOR LONG-TERM CARE

NYS DSS
40 North Pearl Street
Albany, NY 12243
(518) 473-7705

Arrangement whereby Medicaid and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. New York residents may call for information.

NOLO PRESS

950 Parker St.
Berkeley, CA 94710-9867
(800) 992-6656

Publishes books and software on estate planning, long-term care insurance, wills, conservatorships and nursing homes. Prices vary; call for a free publications catalogue.

PARSONS TECHNOLOGY

One Parsons Drive, P.O. Box 100
Hiawatha, IA 52233-0100
(800) 223-6925

Publishes a variety of software programs useful for families involved in parent care. Affordable titles include: *Medical Drug Reference*, *Quicken Family Lawyer*, *Personal Advocate*, *Quicken* (financial record-keeping), *Personal Home Inventory*, *Family Origins* (family tree), and others. Call for a free catalogue.

OLDER WOMEN'S LEAGUE

666 11th St. NW, Suite 700
Washington, DC 20001
(202) 783-6686

Publications include topics on elder women and poverty, care giving, pensions, legal, housing and long-term care.

UNITED SENIORS HEALTH COOPERATIVE

1331 H St. NW, Suite 500
Washington, DC 20005-4706
(202) 393-6222

Publications catalogue lists many helpful books. Counselors use benefit outreach and screening software to provide assistance in determining eligibility for public programs and assistance. Will provide referrals to counselors or similar services throughout the country.

WORLD WIDE WEB

SOCIAL SECURITY, MEDICARE, MEDICAID, IRS, HEALTH CARE, ELDERCARE LOCATOR

ELDER CARE LOCATOR: A starting point when searching for home health care or nursing home facilities.

www.ageinfo.org/elderloc/elderdb.html

HEALTHFINDER: Government site for publications, databases, self-help & support groups, government agencies, and not-for-profit groups.

www.healthfinder.gov/

THE BUSINESS SIDE OF CARE GIVING

REFERENCE AND REFERRAL

INTERNAL REVENUE SERVICE: Income tax forms, instructions, regulations and publications are all available on-line.

www.irs.ustreas.gov/prod/cover.html

MEDICARE ON LINE: The “official” government site for Medicare and Medicaid. Look here for the most current information on benefits, eligibility requirements and other vital assistance.

www.hcfa.gov/

SOCIAL SECURITY ON LINE: Social Security information including current benefits, eligibility requirements. Includes PEBS (personal earnings and benefits statement) section to determine your parent’s (or your own), benefits.

www.ssa.gov/

Government Programs

Editor's Note: Government programs such as Social Security, Medicare, and Medicaid are routinely amended by Congress. Follow news reports to stay abreast of the current status of these programs and IRS rules. The most current information about benefits, eligibility requirements, and other critical subjects are available on the World Wide Web, so check the Web sites listed in *Reference and Referral*. We also strongly suggest that you consult with a qualified elder law attorney, long-term care insurance specialist, or financial planner to determine how the current status of government programs might impact your care giving plans.

The federal government offers many programs designed to assist older Americans. These programs include Social Security, Supplemental Security Income (SSI), Medicare, Medicaid, and the Older Americans Act.

SOCIAL SECURITY PROGRAMS

Social Security programs include the retirement program, disability insurance for people under 65 who are unable to work, family benefits, survivor benefits, and Medicare.

Retirement and Survivor Benefits

Full Social Security retirement benefits are payable at age 65 (with reduced benefits available as early as age 62) to anyone with enough Social Security credits. If your parent continues to work after he begins to receive Social Security benefits, his benefits may be reduced due to the Earnings Limitation or Retirement Test.

If your parent is eligible for Social Security retirement or disability benefits, other family members might be eligible to receive benefits too. Check with your Social Security Administration (SSA) office for details.

When your parent dies, certain members of your family may be eligible for survivor benefits if your parent earned enough Social Security credits while working. Eligible family members include the widow(er) age 60 or older (50 years old or older if disabled) and dependent or minor children. A special one-time payment may be made to the surviving spouse or minor child when your parent dies. If your parent is divorced, the ex-spouse could be eligible for a widow(er)'s or retired person's benefit on the deceased's record. Again, call the SSA for details.

To apply for Social Security, your parent should contact the local SSA at least three months before the date he wants retirement benefits to begin. Documents to have on hand include your parent's Social Security card and number, proof of date of birth such as a birth certificate, a marriage certificate, divorce decrees (especially if the divorce occurred after 10 years of marriage), and a spouse's death certificate (if applicable). Remember, there is a delay between the time a person applies for Social Security and the time they receive their first check. This delay can be a month and a half to three months, so plan accordingly.

Supplemental Security Income

Your parent may be eligible for Supplemental Security Income (SSI) benefits if he is 65 or older and has little or no income, and if the value of his assets is less than \$2,000 (single) or \$3,000 (married). The value of the home is not counted, nor are certain other possessions. With SSI benefits, your parent usually gets medical assistance automatically. (For Medicaid/Medi-Cal information contact the county welfare office.) In some states, Food Stamps are also automatically given with SSI. The federal government pays a basic or minimum benefit amount, but states add money to that amount. SSI benefits are not contingent upon past earnings. They are financed by general tax revenues and are based on the present needs of the recipient.

MEDICARE

Medicare is a government funded program, financed by American taxpayers and enrollee premiums, to provide medical care for the elderly. Medicare Part A is financed by payroll taxes. One-fourth of Medicare Part B is financed by monthly premiums paid by enrollees and three-fourths paid by general revenues of the federal government. The government contracts with private insurance companies to review hospital and medical services and pay benefits claims based on established guidelines.

Medicare becomes available at the beginning of the month in which your parent turns 65, whether your parent is retired or still working. It also becomes available after your parent has been entitled to Social Security disability benefits for two years or if your parent has end-stage renal disease. To apply for benefits, your parent must sign up with the local Social Security office, or he can call the SSA toll-free at (800) 772-1213 to have the forms mailed directly to him. You can also get forms from the Web (www.ssa.gov). When your parent signs up for Medicare Part A, he automatically signs up for Medicare Part B coverage unless he tells the SSA that he doesn't want Part B. (See Part B below.) Note: If your parent refuses Part B coverage, have him check the rules for declining carefully. Your parent's ability to change his mind is limited and becomes more costly as time goes on.

There are two parts to Medicare, Part A and Part B. Part A is Hospital Insurance. Part B is Supplementary Medical Insurance.

Part A of Medicare pays some of the costs of hospitalization, certain related inpatient care and home health services. Part B primarily covers doctor's fees, most outpatient hospital services and certain related services.

Medicare covers only services that are medically necessary and charges that are considered reasonable. Medicare does NOT cover all health care expenses. A telephone call to the carrier that handles your Medicare claim is the best way to get answers to your questions about your parent's specific case. Some people carry additional private insurance—Medicare supplement policies—to cover some or all of the costs Medicare doesn't cover. (See *The Business Side of Care Giving: Finance and Insurance* for more information.)

Medicare Part A (Medicare Hospital Insurance Benefits)

Part A covers hospital charges, and expenses. Medicare Part A pays about 40% of the total hospital/facility bills (there is NO coverage for routine medical visits, hearing aids, glasses, foot care, vaccinations, or prescriptions). Part A helps pay certain (BUT NOT ALL) charges for doctor-prescribed inpatient hospital care, skilled nursing care, and rehabilitative services that are medically reasonable and necessary (i.e., not cosmetic or elective surgery), in a Medicare-approved facility. A set deductible is required as a co-payment for these services.

Part A benefits for a skilled or rehabilitation facility require a doctor-certified need for daily skilled nursing care or rehabilitative services. The required services must be the result of an acute, medical incident. To qualify for Medicare covered skilled nursing facility benefits, an older adult must:

- Require daily skilled care, which as a practical matter, can only be provided in a Skilled Nursing Facility (SNF) on an in-patient basis.
- Be in the hospital at least three consecutive days (not counting the day of discharge), before entering a SNF that is certified by Medicare.
- Be admitted to the SNF for the same condition that was being treated in the hospital.
- Generally, be admitted to the SNF within 30 days of discharge from the hospital.
- Be certified by a medical professional as needing skilled nursing or skilled rehabilitation services on a daily inpatient basis.

It's important to note that Medicare draws a distinction between SNFs and nursing homes. Medicare will not cover a stay in a SNF or nursing home if the services received are primarily personal care or custodial services.

Part A pays 100% of medically necessary home health care if all of the following apply:

- The provider/agency is Medicare approved.
- The patient is homebound.
- The patient requires skilled nursing care, physical therapy, or speech therapy.*
- The doctor coordinates the care plan.

*If the patient is receiving skilled nursing care, physical therapy or speech therapy, Medicare Part A will pay for limited occupational therapy, medical equipment and part-time home health aides. Medicare Part A will also pay 80% of the approved cost for wheelchairs, hospital beds, and other durable medical equipment supplied under the home health benefit.

Medicare Part A pays for the first 20 days of approved skilled care coverage in a Medicare-certified facility. After that, it pays only a portion of costs through day 100, and nothing after that. Medicare Part A will also cover hospice charges. For Part A, there are further limits as to length of coverage, and there is a deductible for each benefit period.

The amount your parent pays for the Medicare premium changes each year, depending upon increases in hospital costs. Check the "official" government web site for Medicare and Medicaid (www.hcfa.gov/) for the most current information on benefits, eligibility requirements and other vital assistance.

When admitted to a hospital, your parent must pay an initial deductible but no more than the actual charges. Your parent's benefit period ends 60 days after discharge from the hospital or SNF. If another hospital admission occurs after that, your parent will have to pay another deductible, as well as the other cost-sharing amounts.

Part A will NOT pay for institutional or home health care when those services are considered custodial care for comfort, such as assistance with bathing, dressing, grooming, and transporting.

Medicare Part B (Medicare Medical Insurance Benefits)

Part B covers physician's charges and supplies. To receive Medicare Part B coverage, your parent must pay a monthly premium. The premium is subject to change by Congress. These premiums are ordinarily deducted from your parent's Social Security benefits, if he gets them. If your parent enrolls late, or if he drops out and enrolls again, he may have to pay a higher premium.

Part B pays for a wide range of medical services and supplies, but the most significant coverage is for doctor bills. Medically necessary physician services are covered, regardless of where such service is performed—at home, in the doctor's office, at a clinic, a nursing home, or a hospital.

Part B pays 80% of Medicare "approved charges" for doctor's fees, ambulance, lab tests, outpatient hospital and clinic charges, some home health care, PAP smears, outpatient physical and speech therapy, and other medical services, and supplies. Medicare Part B has an annual \$100 deductible and co-payments of 20 percent for all physician's bills.

Part B does NOT generally pay for outpatient prescription drugs; however, it does cover some oral anti-cancer drugs, certain drugs for hospice enrollees, and non-self administrable drugs provided as part of a physician's services.

There are other ways your parent can receive Medicare insurance, even if he has not paid into the system through payroll taxes. To find out more information, Consumer Reports publishes an easy to follow book entitled, *Medicare/Medigap: How to Cut Through Red Tape and Get Complete Medical Coverage* by Carl Oshire and Harry Snyder. Or, consult with your local Social Security office.

Nearly three-quarters of people over age 65 have private health insurance policies that supplement their Medicare coverage. These are “Medigap” policies, which can be purchased from insurance agents, through groups or directly from an insurance company by mail. Some policies have provisions for skilled nursing or home health care coverage, but rarely go beyond Medicare’s coverage; they primarily cover deductibles and co-payments. These policies must meet certain minimum standards set by federal law and are enforced by each state through its Department of Insurance. (See *The Business Side of Care Giving: Finance and Insurance* chapter for more information.)

To guide your parent through the maze of Medicare, consult the Social Security Administration (SSA), insurance agents, insurance brokers (they can recommend the most appropriate coverage and find an insurer), independent insurance consultants, Health Insurance Counseling and Advocacy Program (HICAP) counselors, and the state insurance commissioner or other responsible state agency.

MEDICAID

Medicaid (Medi-Cal in California) is a federal and state health insurance program that pays the medical expenses, including nursing home care, for low-income people, senior citizens and disabled Americans. Coverage can include prescription drugs, doctor visits, hospital care, dental care, nursing home and mental health care, lab and X-ray charges, home health, and hospice care.

Any aged or disabled person receiving Supplemental Security Income (SSI) cash payments is eligible for Medicaid. Eligibility requirements vary from state to state. (See *Legal Issues: Protecting Your Parents Wishes and Assets and Reference and Referral* for additional information.)

If your parents have a low income and few resources, your state may pay their Medicare premiums and, in some cases, other “out-of-pocket” Medicare expenses such as deductibles and co-insurance. The rules vary from state to state. There is also a special rule in which your state may pay Medicare Part B premiums to assist people whose income is slightly above the poverty level.



Checklist for Medicaid Qualification

Help your parent divide his assets into irrevocable, countable and non-countable lists. Figure out what counts for Medicaid eligibility or probate. Medicaid limits allow:

- No more than \$2,000 in savings or other liquid assets such as stocks or Certificates of Deposit (state limits vary slightly).
- A car worth up to \$4,500.
- One wedding and engagement ring of any value.
- A home under limited circumstances.
- Household and personal items up to about \$2,000.
- A burial plot and up to \$1,500 in a burial fund.
- A life insurance policy with a face value of no more than \$1,500.
- Property essential to self-support (up to \$6,000).

For information about Medicaid, call your State Medicaid Office. They will refer you to proper professionals to help you and your parent determine what benefits might be forthcoming and what programs are available. Also, check with the National Academy of Elder Law Attorneys (NAELA) for assistance with Medicaid planning. Contact your local legal aid society, the American Association of Retired Persons (AARP), and the United Seniors Health Cooperative (see Reference and Referral) for more information.

OLDER AMERICANS ACT

Congress established the Older Americans Act of 1965 to ensure that older Americans have access to in-home and community-based services, transportation to medical care, nutritious meals in a congregate or home-delivered setting, access to legal assistance, opportunities for employment, access to those supports needed to live independently as long as possible. The Act also created a federal agency called the Administration on Aging (AOA), which is part of the U.S. Department of Health and Human Services. The AOA funds community-based support services, trains professionals, and gives technical assistance and grants to state and local agencies.

Funding for Older Americans Act programs are the subject of frequent debates in Congress. Check with your Area Agency on Aging or State Unit on Aging to see what funding and programs are available.

RECAP

The federal government offers many programs designed to assist older Americans. These programs include Social Security, Supplemental Security Income (SSI), Medicare, Medicaid, and the Older Americans Act.

Social Security programs include a retirement program, disability insurance for people under 65 who are unable to work, family benefits, survivor benefits, and Medicare.

Supplemental Security Income (SSI) benefits may apply to your parent if he is 65 or older, has little or no income, and the value of his assets is less than \$2,000 (single) or \$3,000 (married). With SSI benefits, your parent usually gets medical assistance automatically.

Medicare is a federal program designed to help cover the costs of health care for older Americans. There are two parts to Medicare, Part A and Part B. Part A is hospital insurance and pays some of the costs of hospitalization, certain related inpatient care and home health services. Part B is supplementary medical insurance and primarily covers doctor's fees, most outpatient hospital services, and certain related services.

Medicaid is a federal and state health insurance program that pays the medical expenses, including nursing home care, for low-income people, senior citizens, and disabled Americans.

The Older Americans Act of 1965 created a federal agency called the Administration on Aging (AOA), which is part of the U.S. Department of Health and Human Services. The AOA provides oversight and funding for programs targeted to older Americans.

If the complexity of Social Security, Medicare and Medicaid give you high anxiety, be aware that the same is true for most of the U.S. population! That's why there are experts available to assist you and your parent. There are many resources to help you determine which benefits your parent may be eligible for. Don't feel like you have to figure it all out by yourself. You don't.

GOVERNMENT PROGRAMS

REFERENCE AND REFERRAL

AMERICAN ASSOCIATION OF RETIRED PERSONS (AARP) FULFILLMENT

601 E St. NW
Washington, DC 20049
(202) 434-2277

Booklets on long-term care insurance, planning for retirement, etc. Request a publications catalogue.

AMERICAN SOCIETY OF CLU AND CHFC (9, 10)

270 Bryn Mawr Ave.
Bryn Mawr, PA 19010
(610) 526-2500

The American Society of CLU and ChFC, a national organization of insurance and financial services professionals, is dedicated to enhancing the ability of its members to provide services and solutions that meet the financial needs of individuals, families and companies through a commitment to continuing professional education and ethical practices.

Members earn the designations CLU (Chartered Life Underwriter) and/or ChFC (Chartered Financial Consultant) through The American College, Bryn Mawr, PA.

AMERICAN SOCIETY ON AGING

833 Market Street
San Francisco, CA 94103
(415) 974-9600

Publications on care giving are available. Call for a free publications list.

CALIFORNIA PARTNERSHIP FOR LONG-TERM CARE

714 P St., Room 616
Sacramento, CA 95814
(916) 657-0654

Four states, California, New York, Connecticut and Indiana, have special partnership arrangements whereby Medicaid (Medi-Cal in California) and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. Call for information concerning California residents.

CONNECTICUT PARTNERSHIP FOR LONG-TERM CARE

Office of Policy & Management
80 Washington Street
Hartford, CT 06106-4459
(203) 418-6318

Arrangement whereby Medicaid and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. Connecticut residents can call (800) 547-3443 to request information.

COUNCIL OF BETTER BUSINESS BUREAUS, INC.

Publications Department
4200 Wilson Blvd., Suite 800
Arlington, VA 22203
(703) 276-0100

Publishes several low-cost booklets: *Medicare and Medigap*, *Long-Term Nursing Home Care*, *Continuing Care Retirement Homes*, and *How to Select a Financial Planner*. Request a free publications listing which includes ordering instructions and fees.

DEPARTMENT OF DEFENSE

National Personnel Record Center
9700 Page Blvd.
St. Louis, MO 63132
(314) 263-3901

If you cannot find the certificate of discharge from the armed forces, send the branch of service, dates and service serial number to receive a copy of the certificate.

FEDERAL NATIONAL MORTGAGE ASSOCIATION (FANNIEMAE)

Public Information Office
3900 Wisconsin Ave. NW
Washington, D.C. 20016
(800) 732-6643

Information on reverse mortgages. Publishes free brochures on the subject including: *HomeKeeper Mortgages*, *Home Equity Conversion Mortgages*, and *Money From Home*.

GOVERNMENT PROGRAMS

REFERENCE AND REFERRAL

HEALTH INSURANCE ASSOCIATION OF AMERICA

Consumer Information Service
555 13th St. NW, Suite 600 East
Washington, DC 20004-1109
(800) 635-1271

Publishes a free *Guide to Long-Term Care Insurance*. Also publishes at no charge a list of companies that offer long-term care insurance policies.

HEALTH INSURANCE COUNSELING AND ADVOCACY PROGRAM (HICAP)

Check "Government Listings" in phone book under "State", to obtain the phone numbers for either the State Insurance Division - Consumer Affairs, or the State Office on Aging for a referral to the state's HICAP counselor(s).

INDIANA LONG-TERM CARE PROGRAM

Family & Social Services Administration
402 W. Washington Street, W353
Indianapolis, IN 46204
(317) 232-2187

Arrangement whereby Medicaid and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. Indiana residents may call toll-free (800) 452-4800 for information.

INSTITUTE OF CERTIFIED FINANCIAL PLANNERS

3801 E. Florida Ave., Suite 708
Denver, CO 80210
(800) 282-7526, (303) 751-7600

Will send a list of Certified Financial Planners who practice in your zip code area. Publishes a free brochure *Selecting a Qualified Financial Planning Professional: Twelve Questions to Consider*.

INTERNATIONAL ASSOCIATION FOR FINANCIAL PLANNING

5775 Glenridge Dr. NE, Suite B-300
Atlanta, GA 30328-5364
(800) 945-IAFP

Publishes a free brochure, *Consumer Guide to Comprehensive Financial Planning*, and will provide a list of qualified advisors in your area.

GOVERNMENT PROGRAMS

REFERENCE AND REFERRAL

NATIONAL ASSOCIATION OF INSURANCE COMMISSIONERS

120 W. 12th St., Suite 1100
Kansas City, MO 64105
(816) 842-3600

Publishes a free brochure, *A Shopper's Guide to Long-term Care Insurance*. The National Association of Insurance Commissioners also offers *The Guide to Health Insurance for People with Medicare* (covers Medigap and includes a matrix of the 10 Medigap policies) published in conjunction with the U.S. Department of Health and Human Services.

NATIONAL ASSOCIATION OF PERSONAL FINANCIAL ADVISORS

355 W. Dundee Road, #107
Buffalo Grove, IL 60089-3500
(800) 366-2732, (708) 557-7722

Professional group of fee-only planners. Publishes a free brochure about "fee-only planning" and will send it along with names of fee-only financial planners in a given area.

NATIONAL ASSOCIATION OF PROFESSIONAL GERIATRIC CARE MANAGERS

1604 N. Country Club Road
Tucson, AZ 85716
(520) 881-8008

Information and local referrals to care managers throughout the United States. Provides a listing of care managers in your area if you send a self-addressed, stamped envelope.

NATIONAL CENTER FOR HOME EQUITY CONVERSION (NCHEC)

7373 147th St. West, Suite 115
Apple Valley, MN 55124
(612) 953-4474

Free information on reverse mortgages. They also publish: *Your New Retirement Nest Egg*, by Ken Scholen, NCHEC Press, 1995, \$24.95. 336 pages.

NATIONAL COUNCIL ON THE AGING, INC. (NCOA)

409 Third Street, SW, Second Floor
Washington, DC 20024
(202) 479-1200

National membership association serving professionals and volunteers who work on behalf of older adults and their families. Operates an information center to handle requests for information from the public including information on choosing a nursing home.

Publishes a variety of materials on a range of aging issues including: senior centers, adult day care services, family care giving, health promotion, and financial issues. A publications catalogue is free upon request.

NATIONAL ENDOWMENT FOR FINANCIAL EDUCATION

4695 S. Monaco Street, Department 022
Denver, CO 80237-3403
(303) 220-1200

Offers a free *Wealth Care Kit* that walks consumers through the processes involved in planning their financial future. For a free kit write to the address above.

NATIONAL INSURANCE CONSUMERS HELPLINE

555 13th St. NW
Washington, DC 20004-1109
(800) 942-4242

Information and referrals on the following insurance types: life, health (including long-term care, Medicare), home, business and auto. An insurance industry service which does not promote specific companies. Referrals to elder care agencies as needed or requested.

NEW YORK STATE PARTNERSHIP FOR LONG-TERM CARE

NYS DSS
40 North Pearl Street
Albany, NY 12243
(518) 473-7705

Arrangement whereby Medicaid and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. New York residents may call for information.

GOVERNMENT PROGRAMS

REFERENCE AND REFERRAL

NOLO PRESS

950 Parker St.
Berkeley, CA 94710-9867
(800) 992-6656

Publishes books and software on estate planning, long-term care insurance, wills, conservatorships and nursing homes. Prices vary; call for a free publications catalogue.

OLDER WOMEN'S LEAGUE

666 11th St. NW, Suite 700
Washington, DC 20001
(202) 783-6686

Publications include topics on elder women and poverty, care giving, pensions, legal, housing and long-term care.

SOCIAL SECURITY ADMINISTRATION

6401 Security Blvd., Room 4J5
West High Rise, Baltimore, MD 21235
(800) 772-1213

Free publications include: *Understanding Social Security, Medicare and Coordinated Care Plans*, and *Hospice Benefits*. Telephone counselors will answer questions and set-up appointments.

UNITED SENIORS HEALTH COOPERATIVE

1331 H St. NW, Suite 500
Washington, DC 20005-4706
(202) 393-6222

Publications catalogue lists many helpful books. Counselors use benefit outreach and screening software to provide assistance in determining eligibility for public programs and assistance. Will provide referrals to counselors or similar services throughout the country.

WORLD WIDE WEB

SOCIAL SECURITY, MEDICARE, MEDICAID, IRS, HEALTH CARE, ELDERCARE LOCATOR

ELDER CARE LOCATOR: A starting point when searching for home health care or nursing home facilities.

www.ageinfo.org/elderloc/elderdb.html

HEALTHFINDER: Government site for publications, databases, self-help & support groups, government agencies, and not-for-profit groups.

www.healthfinder.gov/

INTERNAL REVENUE SERVICE: Income tax forms, instructions, regulations and publications are all available on-line.

www.irs.ustreas.gov/prod/cover.html

Death and Dying

PREPARING FOR DEATH

The death of a loved one is probably the most emotionally charged, difficult and draining experience for a human being. It can bring out the worst and best in individuals, families and communities. Emotions range from guilt over not having said or done everything you think you should have, to gratitude for the mercy that a loved one's pain has ended.

Times are changing, and the information presented here will help you come to terms gently, but realistically, with what lies ahead. The work you will do in this section involves emotional planning, and learning about the options and resources available to you.

Before your parent dies, try to make a list of lawyers, banks, creditors, insurance companies, employers, retirement and membership affiliations, and subscriptions to periodicals your parent receives to make things easier at the end (see Getting Organized).

MAKING FUNERAL ARRANGEMENTS

It's not easy to discuss funeral planning and wills with anyone, let alone your mother or father. However, someone needs to know what your parent would like done for him before and after he dies. If you need the assistance of a family or grief counselor, clergy, or social worker to discuss the subject, don't be afraid to ask for assistance.

Pre-planning funerals is more common today. Try to determine what your parent would like. Here are some of the funeral options available:

- A traditional funeral with or without viewing.
- A formal religious or non-religious service.
- Graveside rites.
- A memorial service.
- Immediate burial without a service.
- Cremation with or without a service.

Keep in mind the ritual of a funeral is one way to say good-bye to a loved one, so we suggest the service be thought of in terms of the living as well as the deceased.

It's an opportunity to acknowledge love shared, to let go of what binds and finish business, so to speak.

The Funeral Home

How do you find a good funeral home if you don't know of any? You will probably feel rushed and bewildered if you haven't planned ahead at all. Word-of-mouth recommendations from friends or your religious group are best. Medical personnel, a hospital administrator, or a hospice social worker can sometimes recommend a compassionate place. If there is a memorial society in your town or your parent's town, they can be very helpful.

With proper planning you will have everything you need in place. Planning may also help you avoid complications and unnecessary expenses. You don't necessarily need a "pre-need" contract from a funeral home that pays for funeral arrangements in advance. The funeral home could go out of business, your parent could move, etc. Some experts recommend instead establishing a bank account, buying additional life insurance (burial insurance), or investing funds to cover costs. If for everyone's peace of mind you, or your parent decide to pay in advance, obtain a statement outlining all costs before signing anything. Make sure there will be no surprises when you are least able to deal with them.

Funeral homes prepare the deceased for burial, but they also serve the family in other ways. Funeral homes provide the following services:

- Prepare and transport the body.
- Fill out the death certificate and send it to the proper authorities. They also provide numerous copies to the survivors so copies may be presented to the Social Security Administration (SSA), the airlines to verify bereavement fares, banks and other institutions for closing accounts, and other agencies.
- Work out logistics of the service (arranging flowers or donations, music, notifying pallbearers, seating, etc.).
- Write and send an obituary to the local newspaper.
- Prepare memorial folders and tribute cards.
- Make arrangements with the cemetery for burial or cremation.
- Some funeral homes assist the survivors with applications for benefits and file claims with the Veterans Administration (VA) or Social Security Administration (SSA), usually for an additional fee.

The Veterans Administration (VA) offers certain death benefits. These may include a cash or burial allowance; free burial in a national cemetery for most veterans, their spouses and minor children; a grave marker, flag, and perpetual grave site care. Check with the local VA office.

The Social Security Administration (SSA) gives a one-time death benefit of about \$255 to the surviving spouse or survivors under certain conditions. This death benefit must be applied for. Inquire at the local SSA office.

Figures vary, but in general cremations are the least expensive form of burial, around \$1,000. Traditional funerals include a coffin or burial vault, a headstone or monument, opening and closing space fees, and perpetual care for an average cost of \$5,000. A mausoleum is the most expensive form of burial, with fees up to \$500,000.

TALKING ABOUT DEATH

Those who are dying may have difficulty talking about what they're experiencing, even if they would like to. It's likely that your parent shares your concerns about the quality of life at the end, tying up loose ends regarding relationships with close friends and family, getting finances in order, taking care of unfinished business, and questioning the afterlife and spirituality. Everyone has a different idea of what death should be. Remember that for now, the impending death is your parent's, and you need to let it be as it needs to be, for him, whether or not you like the way it's being handled. You can't put yourself in your parent's place, or understand what it's like.

HOSPICE CARE

In Medieval times, a "hospice" was a way station for weary pilgrims. Today a hospice serves a similar function of providing supportive, quality care for people at the end of their life.

Most people do not want to die alone, in a sterile environment, surrounded by tubes and tanks instead of family and friends. Nor do they wish to die in pain. When you and your support team have truly done all you can, and you know that you've reached the end of what you can do, you may still need to face the inevitable: your parent is dying.

In this case, you might want to consider hospice care. This is a service that provides palliative (comfort without curing) care and pain relief for people who are judged terminally. (Usually, they have six months or less to live.) Hospice services can be delivered at home or in an institutional setting (and can move from home to nursing home if needed). If provided through a hospice agency approved by Medicare, the benefits may include nursing care, counseling, medical equipment and supplies, and respite for the care giver and family.

Hospice care consists of an interdisciplinary team of physicians, nurses, aides, volunteers, social workers, and clergy who put together and monitor an intense care plan. Nurses are on-call 24-hours-a-day, and all personnel work closely with your family to involve you in many aspects of your parent's care. The hospice team can train family members to do certain low-tech medical procedures such as injections and they are often there with all of you at the bedside when death occurs.

Hospice social workers and trained volunteers help you make decisions and face the inevitable losses. They can also assist you with questions about insurance, funeral plans, death certificates, who should be informed, and other details about the death of a loved one.

Hospices provide bereavement counseling, support groups and follow-up calls or letters for a year. In some cities, religious organizations have their own hospices. Hospice philosophy is dedicated to caring for the patient and family's emotional and spiritual needs.

Some of the most commonly asked questions and answers about hospice, according to the National Hospice Organization, are listed below:

Q: When should a decision about entering a hospice program be made, and who should make it?

A: At any time during a life-limiting illness the family or patient should broach the subject with a physician, clergy or friends. More hospices are adding an early admission program that starts services at the time of diagnosis, which can give you a year of treatment and planning ahead of time.

Q: How do I find a hospice?

A: Most physicians know about hospice. You can call the National Hospice Helpline, (800) 658-8898, medical societies, state hospice organizations, or the American Cancer Society, American Association of Retired Persons (AARP) and Social Security Administration (SSA).

Q: What is the hospice admission process?

A: A physician or hospice medical staff member agree that hospice care is warranted, and discusses hospice with the patient. After a consultation with a hospice team, the patient signs insurance and consent forms for palliative care (aimed at symptom control and pain relief), not curative care. The forms outline services and Medicare benefits.

Q: How difficult is caring for a dying loved one at home?

A: It's never easy. It can be quite difficult. Hospices have staff available around the clock to consult with the family and make night visits if necessary. The rewards can be immeasurable.

Q: Does hospice do anything to hasten death?

A: No. Hospice provides support and expertise in the dying process.

Q: What does the Medicare hospice benefit cover?


A: Physician services, nursing care, medical appliances and supplies, drugs for symptom management and pain relief, short-term in-patient and respite care, homemaker services and home health aid, physical and other therapy, and coun-

seling. In some cases a small (\$4 or \$5) co-payment is required.


PRACTICAL CONSIDERATION AFTER DEATH

Even during this tumultuous time, there are still many details that need to be attended to. There is new business to do despite the grief you are feeling. If you can benefit from this section, it will help you and your parent gain an awareness of everything that must be done (whether you go ahead and do it now or not). Take care of as much of it as you can before your parent dies, because time taken now will give you relief later, when you'll need it the most.

Checklist for Final Funeral Arrangements

- 
- If you are more comfortable, take along a friend or relative to assist with making the funeral arrangements.
 - Bring the full name of the deceased, last current address, birth certificate, Social Security card, and date of death.
 - Know what your financial resources are before entering a funeral home.
 - Bring along a full set of clothing and a recent photograph of the deceased.
 - Begin claims, benefits, and other legal procedures.

Checklist of Information Executor Needs to Finalize Your Parent's Estate

- 
- Full name of deceased, last current address, birth date and place, and date of death for the death certificate.
 - A complete list of property, including real estate, stocks, bonds, savings accounts, land titles, stock certificates, and other financial papers.
 - Copies of all insurance policies.
 - Social Security card.
 - Name, address, and phone number of your parent's employer. If retired, also include the retirement date, pensions, and other retirement benefits.
 - A copy of the will.
 - Spouse and children's names, addresses and dates of birth.

For veterans, branch of service, dates and service serial number. (If you cannot find the certificate of discharge, write to The Department of Defense, National Personnel

Record Center, 9700 Page Blvd., St. Louis, MO 63132.)

Federal and state income taxes of the deceased are due for the year of death, on the normal filing date unless an extension is procured. Contact your local Internal Revenue Service office for details.

State laws vary, but generally any estate that pays a federal estate tax must also file a state estate tax return, paid to the state in which the deceased lived. For information, contact the state tax or revenue department, or an estate or elder law attorney.

State inheritance taxes vary too. Some states don't charge any inheritance tax, while others levy one percent or more. Contact the applicable state tax departments.

DEALING WITH GRIEF

There is no way to measure the impact the death of a parent has on a child.

Experts agree that if you don't address your grief, it will find a way to express itself. And you and your loved ones may not like the result. It's important to understand that there is no time frame, there are no rules, for the grieving process to flow and for you to find peace. For some people it may seem brief; for others it may seem to take forever. We don't know what another person is feeling, or hiding. You must accept that it's your grief. You have to handle it your way, even if at first that means denial, anger, crying, fear, depression or guilt. These are all parts of the process. **YOU ARE NOT GOING CRAZY.**

What keeps people from grieving fully is the intensity of being overwhelmed, the fear that if you start crying or let go, you won't be able to pull yourself back together. It takes time, and the degree to which you are willing to grieve, and investigate the grief process, is a decision only you can make. The reward may be a transformation in your life that gives you greater resilience and authenticity as a person. It may mean you have found a way to enjoy life in all its aspects, setting priorities based not on fear and self-interest but on an understanding of how we all suffer loss in our lives, or how at the heart, we are all really created equal.

Death and the grief that follows is a major life passage. Grief therapist Alexandra Kennedy, whose own loss of her father a few years ago began her investigation of what it means to lose a parent, recommends the tips listed below to help the grief process.

Tips for Dealing With Grief

Take time each day to check in with your grief, even if it's only for five minutes. Observe your feelings, without judgment as much as possible. Face your grief 100 percent. Be honest with yourself about how you are feeling today.

Network with people who have shared these experiences, who can support you and validate your feelings, no matter how horrible or embarrassing or childish they

might seem. You could also see a grief counselor or join a support group.

Understand that your relationship with your parent hasn't ended with his death. You can still inwardly connect, in memories, dreams, and the imagination. For example, dreams can indicate unfinished business; that something still needs to be worked out, completed. Pay attention to everything you're experiencing.

Losing a parent brings up overwhelming feelings about the magnitude of it all. You don't know when these feelings are going to erupt, when they will subside. You may feel out of control when you're grieving. That's normal.

When a parent dies, in a sense our whole world comes apart, and we may want to question our priorities and the meaning of our life. We may also want to ask questions we have not thought about before, such as what is the meaning of life, what is death, and what's important.

Educate yourself about what is involved with grief so you can know that all ranges of reactions are OK, and that it's a very wise process if you trust it.

When grieving, changes in your relationship with your job, spouse and relatives are not uncommon. There is often pressure on the primary care giver and on families, so expect some things just won't be the same.

RECAP

Dealing with the death of a loved one is probably the most difficult thing you will ever have to go through. There are many coping strategies you may use, but ultimately you will have to live through the experience. If you have done some careful planning for all the peripheral matters, you will be able to focus on the real issues at hand: grief, loss and moving on. Give yourself time, feel your feelings, and take care of yourself. Don't set a schedule for the grieving process; it's a slippery thing with unpredictable ups and downs. Give yourself breathing room, don't be judgmental about your reactions or feelings. Just as there's no right way to be a care giver, there's no right way to grieve.

DEATH AND DYING

REFERENCE AND REFERRAL

AMERICAN CANCER SOCIETY HOTLINE

235 Montgomery St., Suite 320
San Francisco, CA 94104
(800) ACS-2345 or (415) 394-7100

Information, referral to support groups, sources of financial assistance and treatment-related needs.

AMERICAN SAFE DEPOSIT ASSOCIATION

330 West Main Street
Greenwood, IN 46142
(317) 888-1118

For a \$75 fee, this group will help find out if a deceased family member had a safe deposit box. Call for further instructions and procedures.

AMERICAN SOCIETY ON AGING

833 Market Street
San Francisco, CA 94103
(415) 974-9600

Publications on care giving are available. Call for a free publications list.

CEMETERY CONSUMER SERVICE COUNCIL

P.O. Box 2028
Reston, VA 22090
(703) 391-8407

For assistance with issues related to maintenance, marker or financial difficulties. Publishes two free brochures: *Having A Problem With A Cemetery?* and *Cemetery and Memorial Parks: Questions and Answers.*

CENTER FOR LOSS AND LIFE TRANSITION

3735 Broken Bow Road
Fort Collins, CO 80526
(970) 226-6050

Education, publications and videos on bereavement, support.

CHOICE IN DYING

200 Varick St., Suite 1001
New York, NY 10014-4810
(800) 989-WILL, (212) 366-5540

Free publication of state-specific *Living Will* and *Durable Power of Attorney* forms.

COMPASSIONATE FRIENDS HOTLINE

P.O. Box 3696
Oakbrook, IL 60522-3696
(708) 990-0010

National self-help support group for bereaved parents and siblings. Referral to local chapters.

FOUNDATION FOR HOSPICE AND HOMECARE

519 C St. NE
Washington, DC 20002-5809
(202) 547-6586

Extensive catalog of educational and training materials for consumers and care givers. Free consumer guides, including *All About Hospice.*

GRIEF RECOVERY INSTITUTE

8306 Wilshire Blvd., Suite 21A
Beverly Hills, CA 90211
(213) 650-1234

Extensive bereavement and support programs.

HOSPICE ASSOCIATION OF AMERICA

519 C St. NE
Washington, DC 20002
(202) 546-4759

Publishes booklets and brochures about hospice services. Call to request a catalogue.

HOSPICE EDUCATION INSTITUTE

Hospice Link
190 W. Brook Rd.
Essex, CT 06426
(800) 331-1620

Information and local referrals.

NATIONAL CATHOLIC MINISTRY TO THE BEREAVED

9412 Heath Ave.
Cleveland, OH 44102
(216) 441-2125

Support and referral services for Catholic families.

DEATH AND DYING

REFERENCE AND REFERRAL

NATIONAL COUNCIL ON THE AGING, INC. (NCOA)

409 Third Street, SW, Second Floor
Washington, D.C. 20024
(202) 479-1200

National membership association serving professionals and volunteers who work on behalf of older adults and their families. Operates an information center to handle requests for information from the public including information on choosing a nursing home.

Publishes a variety of materials on a range of aging issues including: senior centers, adult day care services, family care giving, health promotion, and financial issues. A publications catalogue is free upon request.

NATIONAL FUNERAL DIRECTORS' FUNERAL SERVICE CONSUMER ARBITRATION PROGRAM

P.O. Box 27641
Milwaukee, WI 53227-0641
(414) 541-2500

Help with resolving a problem with a funeral director via arbitration.

NATIONAL HOSPICE ORGANIZATION

1901 N. Moore St., Suite 901
Arlington, VA 22209
800-658-8898 for helpline, (703) 243-5900

Information, literature and resources.

SHEPHERD'S CENTERS OF AMERICA

6700 Troost, Suite 616
Kansas City, MO 64131
(816) 523-1080

Interfaith ministry programs and home services including hospice, handyman, shopping, transportation, respite, meals and telephone reassurance.

WORLD WIDE WEB

SOCIAL SECURITY, MEDICARE, MEDICAID, IRS, HEALTH CARE, ELDERCARE LOCATOR

ELDER CARE LOCATOR: A starting point when searching for home health care or nursing home facilities.

www.ageinfo.org/elderloc/elderdb.html

HEALTHFINDER: Government site for publications, databases, self-help & support groups, government agencies, and not-for-profit groups.

www.healthfinder.gov/

INTERNAL REVENUE SERVICE: Income tax forms, instructions, regulations and publications are all available on-line.

www.irs.ustreas.gov/prod/cover.html

MEDICARE ON LINE: The "official" government site for Medicare and Medicaid. Look here for the most current information on benefits, eligibility requirements and other vital assistance.

www.hcfa.gov/

SOCIAL SECURITY ON LINE: Social Security information including current benefits, eligibility requirements. Includes PEBS (personal earnings and benefits statement) section to determine your parent's (or your own), benefits.

www.ssa.gov/

Glossary

Accessory Apartments: Self-contained “in-law” units within a house.

Acute Care: Medical care needed for an illness or injury requiring short-term intense care, and usually hospitalization.

Activities of Daily Living (ADLs): ADLs include bathing, dressing, toileting, eating, and moving in and out of a bed or chair. Cleaning, cooking, laundry, and housekeeping are NOT considered ADLs. They are categorized as Instrumental Activities of Daily Living (IADLs).

Adult Day Care Center: A structured program, usually weekdays, featuring activities, lunch, health, and rehabilitative services for elderly people who need a protective environment. Meals and snacks, programming, outings, support, and counseling may be provided. Transportation is sometimes included in the fee.

Aging Network: A system of federal, state, regional, and local agencies providing services to the elderly.

Annuity: A monthly payment for life.

Area Agency on Aging (AAA; also known as the County Office on Aging): Created in 1973 under the Older Americans Act to address the needs of Americans over 60. Provides services, directly and indirectly, for free or minimal cost. In-home services may include home-delivered meals, homemaker and chore services, personal care, telephone reassurance, respite for care givers, home maintenance repairs, and weatherization. Community services may include multi-

purpose senior centers, adult day care, adult protective services, legal aid and tax assistance, recreation, and employment services. Access services may include transportation to nutrition and meal sites, case management, assistance with how to find housing, and outreach for needy seniors. Services for people in long-term care facilities may include individual counseling, case work, visitation, escorts to outside activities, and ombudsman services.

Assisted Living: A professionally managed residential facility that provides room and board, and some assistance with activities of daily living, supervision, and activities. Health care (wellness), but not medical care, is provided.

Beneficiary: The person designated to receive the income of a trust estate. Also, the person named (as in an insurance policy) to receive proceeds or benefits.

Board and Care: Independent rental living for those needing daytime assistance with non-medical personal care. Provides some protective supervision. Usually not paid for by Medicare or Medicaid. Also called foster homes, shared housing, community residential facilities, and congregate housing.

Care Giver: Anyone who helps a spouse, parent, relative, or friend with daily living.

Care Manager (Case Manager): A social worker or health care professional who evaluates, plans, locates, coordinates, and monitors services with an older person and the family.

Chore/housekeeping Services: Assistance with cleaning, meal preparation, laundry, escort, and shopping. No personal care is provided. Worker may be certified by an accredited program.

Chronic Illness: An illness marked by long duration, such as arthritis or disability resulting from a stroke.

Common Property: An asset of a marital relationship. Not all states have common property laws.

Companion: A minimally trained worker who provides assistance with shopping, laundry, cleaning, meal preparation, escort, and personal care services such as bathing, grooming, and dressing. No nursing responsibilities are assumed. The worker may or may not receive agency supervision.

Congregate Housing: Individual apartments in a multi-unit rental housing unit for older people. Shared common areas. Supportive services can include meals, housekeeping, transportation, and recreation. Professional staff can include social workers, counselors, and nutritionists. Also called sheltered or enriched housing, or a retirement community.

Conservator: Person appointed by the court in a formal proceeding to act as the legal representative of a person who is mentally or physically incapable of managing his or her own affairs.

Continuing Care (or Life Care) Retirement Communities (CCRC): Privately owned and operated retirement living with a variety of housing alternatives on one campus ranging from separate (detached) cottages, to individual apartments, to a skilled nursing facility. Entrance fee can be steep; monthly fee required.

Custodial Care: Board, room, and other

personal assistance services are generally provided on a long-term basis and don't include a medical component. Usually not covered under public or private health insurance except as incidental to medical care.

Discharge Planner: A member of the professional staff of a hospital or nursing home who develops a plan of future care for a patient prior to discharge.

Dread-disease Insurance: Pays you only if you need treatment for a particular disease, such as cancer. Policy doesn't pay if you need treatment for any other reason, or if you have been diagnosed already with the disease they cover.

Durable Power of Attorney: A Power of Attorney that stays in effect even after the maker of the power becomes incompetent.

ECHO Housing: Also called "granny flats". These are small, free-standing, removable housing modules placed on the same lot as a single-family dwelling.

Emergency Response System: Includes equipment hooked to the telephone line and a wireless signal button worn by the older adult. Trained responders are available 24-hours-a-day to provide assistance in the event of a medical emergency in the home, such as a fall.

Equity: The value of a home minus any debt against it.

Estate: Assets and liabilities, real and personal property, left by a decedent.

Estate Planning: Actions you can take while living to determine what happens to your property when you die.

Estate Tax: Tax imposed by the government on the estate of a person who has died.

Executor/Executrix (or Administrator): Fiduciaries who act on behalf of deceased people, either appointed in a will or by a court order if there is no will. Executrix is the term for a female administrator.

Fiduciary: A legal representative, which includes anyone who acts on your behalf (alive or after death), to do the things you would have done if available or capable. Executors, administrators, conservators, trustees, attorneys-in-fact, and guardians are all fiduciaries.

Financial Planning: A coordinated, integrated, ongoing process of managing an individual's financial concerns.

Friendly Visitor: A volunteer who regularly visits an older person and provides companionship. Volunteers receive training and orientation to the needs of older people.

Geriatric Assessment: Provides a comprehensive evaluation of a person's physical, psychological, and social condition by a physician, nurse, social worker, and other medical staff as needed. Offered by hospitals and social service agencies.

Grantor/Settlor: Person who creates a trust.

Guardianship: An extreme measure that severely restricts the legal rights of an elder based on a court's finding of legal incompetence. Can be appointed by the court to protect an elder's property, conduct daily financial affairs, or arrange for services.

Health Care Power of Attorney: Allows the holder to decide on the health care of an incompetent person.

Health Care Proxy: Same as a Health Care Power of Attorney. Usually relates only to life support care.

Home Equity Conversion: Turning home equity into cash without having to leave one's home or make regular loan repayments.

Home Health Agency: Medical care in the home, ordered by a physician. Services can include nursing, occupational, speech or physical therapy, social work, or a home health aide. Medicare usually only covers this care during an acute period of illness.

Home Health Aide: Provides personal care and some household services. A Certified Nurse Assistant (CNA) provides care under the direction of a nurse from a home health agency.

Home Health Care: Services rendered in the home to a disabled, sick or convalescent person who doesn't need institutional care. The services may be provided by a visiting nurse association, home health agency, hospital, or organized community group, and may include nursing service, speech or other therapy, social, and homemaker services.

Homemaker Services: Aides assist with light housework, laundry, ironing, and cooking.

Home Sharing: Two or more unrelated people living together, sharing tasks, and expenses. Organized programs include screening, matching, monitoring, and helping negotiate house rules.

Hospice: Specialized care for the terminally ill, focusing on comfort care and pain control, not cure. Multidisciplinary team includes clergy, social worker, family, and medical staff. Services include medical, home care, social services, and bereavement counseling to the terminally ill and their families.

Incapacity: Can be mental or physical, temporary or permanent. A person can be incapacitated without being incompetent, but a test must be met.

Incompetence: The state of being declared legally incapable of handling assets and exercising certain legal rights.

Informal Network: Families, friends, and neighbors who provide unpaid assistance to older people.

Information and Referral: Service that provides information about aging services and refers inquirers to programs that will meet their needs.

In-home Care: Assistance with the tasks of daily living. May include chores, housekeeping, home health care, homemaker services, companionship, counseling, meals, respite, emergency response system, and telephone reassurance services.

Intermediate Nursing Care: One of the two main levels of licensure for a nursing home. Less intensive than skilled nursing care, but still providing 24-hour nursing care, with focus on personal care, and social work. For those with long-term disability of stabilized illness, rehabilitative services may be included. Medicaid reimbursement for such services can be provided to qualified patients.

Intestate: Dying without a will.

Irrevocable Trust: A legal arrangement in which an interest is given to another, and in which the settlor retains no rights of ownership or control. (Also see Trust).

Joint Tenancy Ownership: Usually held between two people and allows the survivor to claim sole ownership in the event of the death of the other owner. Property held in joint tenancy does not have to pass through a will or probate.

Letters Testamentary: Letters issued by a court empowering an executor of a will to act.

Licensed Practical Nurse (LPN): In charge of nursing in the absence of a registered nurse (RN). LPNs often give medications and perform treatments, and are licensed by the state.

Living Trust: Names a person or institution as a trustee to meet an elder's needs and obligations. After the death of the elder, the trust often serves as a will, directing how the balance of the trust assets will be distributed. Can be revocable or irrevocable. (Also see Trust).

Living Will: A document that makes a person's wishes regarding medical treatments at the end of life known.

Long-term Care: Health and personal care services required by the chronically ill, aged, disabled, or retarded in an institution or at home, on a long-term basis.

Long-term Care Facilities: A range of institutions that provide various levels of care (maintenance, personal, nursing) to people who are unable to care for themselves and who may have health problems ranging from minimal to very serious.

Medicaid: A federal and state government program in which the states provide health care for low-income people, regardless of age. Each state operates its own Medicaid program under general rules established by the federal government. (Medi-Cal in California.)

Medicare: Federal program providing health care coverage/insurance for people over 65 and some disabled. Part A covers in-patient hospital care, skilled nursing facility, hospice and short-term health care. Part B covers doctors' services, outpatient hospital care, lab, X-ray, and durable medical equipment. It does not provide for long-term care of the elderly except under limited conditions.

Nursing Home Care: For people who are chronically ill or recovering from an acute illness but do not need hospital care. Homes can be licensed for intermediate or skilled care, as well as other levels of care. Care can be for short, or long-term.

Nutrition Sites: Noon meals offered in a central location such as a senior center, church, synagogue, community center, or housing project.

Occupational Therapist: Helps a person re-learn the activities of daily living and makes adaptations in the home to enable the person to remain independent.

Ombudsman: A trained person who investigates consumer complaints against a nursing home or community resident facility.

Personal Emergency Response System (PERS): Allows older people to transmit a distress signal to an emergency telephone number. Can be worn on the person or set-up in a bathroom or bedroom.

Physical Therapist: Works with a person through an exercise program to improve physical mobility.

Power of Attorney: A legal document allowing one person to act in legal matters on another's behalf. Powers may be limited or unlimited, general or specific. They may include money management and health care.

Pre-existing Condition: A medical condition that was known before the effective date of an insurance policy.

Probate: Court process by which a will is proven to be valid and the estate is administered.

Pro bono: Services provided free of charge.

Protective Services: Support for severely disabled elders who may be abused, neglected, or exploited. Available from family service agencies or social service agencies.

Registered Nurse (RN): Graduate nurse who has completed at least two years at an accredited nursing school. Trained in providing skilled nursing care, including administration of medications, and treatment. Licensed by the state.

Respite: Provides temporary relief to family or friends from the tasks of care giving. May last for a few hours or days. May include in-home care with services from a companion, home health aide or homemaker, or out-of-home care in a short-term nursing home or hospital respite program. Adult day care also provides respite for the care giver.

Retirement Community: For active elders who want a recreational and social lifestyle with peers. Elders are usually responsible for their own needs.

Reverse Mortgage: A loan against home equity providing loan advances to a borrower and requiring no repayment until a future time.

Senior Centers: Places where older people go to participate in health, nutrition, and recreational programs.

Senior Housing: Housing usually subsidized by the local, state, or federal government. Rents are usually based on 30 percent of income.

Settlor/Grantor: Person who creates a trust.

Shared Housing: Several people together in a house or apartment with shared common areas. (Also see Congregate Housing).

Sheltered Care: A residential facility that provides assistance with the Activities of Daily Living (ADLs), meals, supervision, and activity programs. Usually offered in a retirement home setting where residents have rooms rather than apartments.

Skilled Nursing Facility: One of the two main levels of licensure for a nursing home. Medical nursing care is provided around-the-clock by registered nurses, licensed practical nurses, and nurses aides as prescribed by a physician. Restorative, physical, and other therapies are available.

Social Worker: A person who can help coordinate care with other programs and services not provided by the agency involved, and can help with financial and insurance planning and paperwork.

Supplemental Security Income (SSI): A federal government program for elders 65 or older with little or no income. Any aged or disabled person receiving SSI cash payments is eligible for Medicaid.

Support Group: A group of people that meets regularly and consists of those who share a common life situation, such as caring for a dying spouse or a parent with Alzheimer's or cancer. Groups are usually led by a professional. Sometimes a nominal fee is charged; many are free.

Telephone Reassurance: A volunteer service that provides daily telephone calls to elderly people living alone.

Tenancy In Common (TIC): An arrangement by which a person owns an asset along with any number of other people. The portion each owns is part of that person's estate and may be passed/willed to another person.

Transfers: The process of depleting (spending down) one's assets and income until eligible for Medicaid. It is a controversial strategy because it shifts the burden of paying for care from family funds to the U.S. taxpayer.

Trust: A written document designed to put your money in the hands of a third party, so that the third party can use it ONLY for the benefit of your designated loved ones.

Trustee: Person or entity/institution appointed in a trust document to administer money according to specific instructions in the document.

Will: Document whereby one makes a disposition of property, to take effect after death.

Records and Information

Feel free to copy these forms as needed to assist your parents.

GETTING ORGANIZED

Personal Information

FATHER

MOTHER

Name

Address

Phone

Social Security #

Medicare #

Medicaid #

Military ID #

Drivers License #

CONTACTS - IN CASE OF EMERGENCY:

Family

Doctor

Neighbors

Clergy

Friends

Important Documents and Records

	FATHER	MOTHER
BANK RELATED		
Safety deposit box and key(s)	_____	_____
Check register and savings passbook	_____	_____
Other	_____ _____	_____ _____
LEGAL DOCUMENTS		
Will	_____	_____
Advance Directives	_____	_____
Living Will	_____	_____
Durable Power of Attorney for Property and Finance	_____	_____
Durable Power of Attorney for Health Care	_____	_____
OTHER MISCELLANEOUS DOCUMENTS		
Divorce Records	_____	_____
Contracts	_____	_____
Partnership Agreements	_____	_____
Other	_____ _____ _____	_____ _____ _____

NOTES: _____

GETTING ORGANIZED

Checklist of your parent's assets: what they have, don't have:

	DOLLAR AMOUNT	ACCOUNT NUMBER	HAS	DOESN'T HAVE	LOCATION
CASH ASSETS					
Stock money funds	_____	_____	_____	_____	_____
Checking accounts	_____	_____	_____	_____	_____
Savings accounts	_____	_____	_____	_____	_____
Stocks	_____	_____	_____	_____	_____
Bonds	_____	_____	_____	_____	_____
Collateralized mortgage obligations	_____	_____	_____	_____	_____
Treasury bills	_____	_____	_____	_____	_____
Bonds and notes	_____	_____	_____	_____	_____
Municipal bonds	_____	_____	_____	_____	_____
Anticipation notes	_____	_____	_____	_____	_____
Mutual funds	_____	_____	_____	_____	_____
Unit trusts	_____	_____	_____	_____	_____
Residential real estate	_____	_____	_____	_____	_____
Commercial real estate	_____	_____	_____	_____	_____
Public limited partnerships	_____	_____	_____	_____	_____
Private limited partnerships	_____	_____	_____	_____	_____
Art	_____	_____	_____	_____	_____
Antiques	_____	_____	_____	_____	_____
Jewelry	_____	_____	_____	_____	_____
Collectibles	_____	_____	_____	_____	_____
Family business evaluations	_____	_____	_____	_____	_____
Homeowners insurance	_____	_____	_____	_____	_____
Car insurance	_____	_____	_____	_____	_____
Tenants insurance	_____	_____	_____	_____	_____
Life with cash value insurance	_____	_____	_____	_____	_____
Life term only insurance	_____	_____	_____	_____	_____
Mortgages held	_____	_____	_____	_____	_____
Notes held	_____	_____	_____	_____	_____
LIABILITIES					
Mortgages	_____	_____	_____	_____	_____
Personal loans	_____	_____	_____	_____	_____
Credit cards	_____	_____	_____	_____	_____
Car loans	_____	_____	_____	_____	_____
Boat loans	_____	_____	_____	_____	_____
Business loans	_____	_____	_____	_____	_____
Moral obligations	_____	_____	_____	_____	_____
Pledges to charity	_____	_____	_____	_____	_____

GETTING ORGANIZED

Personal Care Plan

Use this form to help yourself and others in your parent's support group.

	MONTHLY	WEEKLY	DAILY	AS NEEDED
Meal Schedule	_____	_____	_____	_____
Preparation of Meals	_____	_____	_____	_____
Grocery Shopping	_____	_____	_____	_____
Bathing Assistance	_____	_____	_____	_____
Wash Hair	_____	_____	_____	_____
Comb Hair	_____	_____	_____	_____
Shave	_____	_____	_____	_____
Dental	_____	_____	_____	_____
Dressing	_____	_____	_____	_____
Help To/In Bathroom	_____	_____	_____	_____
Toileting	_____	_____	_____	_____
Transferring	_____	_____	_____	_____
Exercise	_____	_____	_____	_____
Laundry	_____	_____	_____	_____
Visiting	_____	_____	_____	_____
Transportation	_____	_____	_____	_____
Medical Appointment	_____	_____	_____	_____
Housecleaning	_____	_____	_____	_____
Correspondence	_____	_____	_____	_____

NOTES

RECORDS AND
INFORMATION

HOUSING ALTERNATIVES AND SUPPORT SERVICES

Questions to Ask Before Choosing Home Care Services

(From the Joint Commission on Accreditation of Healthcare Organizations)

	(CIRCLE ONE)
Is the agency certified by Medicare?	YES NO
Does the agency have a written description of its services and fees?	YES NO
What financial aid resources does the agency provide? _____ _____ _____	
Does the agency train, supervise and monitor its care givers?	YES NO
Does the agency create a plan of care for each new patient? (Include details about the services to be provided, frequency of care, and the period of time over which care will be provided.)	YES NO
Does a nurse or therapist conduct a preliminary evaluation of the types of services needed in the patient's home?	YES NO
Are family members, physicians or other health professionals involved in the evaluation?	YES NO
Does the organization teach the family how to use any high-tech equipment in the home? (If not, is someone else available who will? i.e. manufactures rep., etc.)	YES NO
Does the agency have a 24-hour telephone number for questions or complaints?	YES NO
Does the agency explain the patient's rights and responsibilities? (Ask to see a copy.)	
Is the agency accredited by a nationally recognized accrediting body? (This can indicate that the organization meets health and safety standards and is committed to quality care.)	YES NO
Do staff members identify themselves at the door?	YES NO
Does the bill for services accurately state the cost of services provided?	YES NO
Are questions about your bill answered satisfactorily, with adequate and accurate information?	YES NO

MEDICAL AND HEALTH ISSUES

Health Care Providers

FOR: _____

PRIMARY CARE PHYSICIAN: _____

Address: _____

Phone/FAX: _____ Alt. Phone: _____

PHYSICIAN SPECIALIST: _____

Address: _____

Phone/FAX: _____ Alt. Phone: _____

PHYSICIAN SPECIALIST: _____

Address: _____

Phone/FAX: _____ Alt. Phone: _____

PHYSICIAN SPECIALIST: _____

Address: _____

Phone/FAX: _____ Alt. Phone: _____

PHYSICIAN SPECIALIST: _____

Address: _____

Phone/FAX: _____ Alt. Phone: _____

HOSPITAL: _____

Address: _____

Phone/FAX: _____ Alt. Phone: _____

PHARMACIST: _____

Address: _____

Phone/FAX: _____ Alt. Phone: _____

PERSONAL CARE ATTENDANT: _____

Address: _____

Phone/FAX: _____ Alt. Phone: _____

MEDICAL AND HEALTH ISSUES

Medication Record

Drug: Brand name/generic name: _____ Refill Number: _____

Prescribing doctor and phone number: _____

Pharmacy name and phone number: _____

Dosage: _____ No. of times a day: _____

Food (circle one): With Without

Reason for drug: _____ Parent's reaction: _____

Side effects possible: _____

Emergency numbers: _____

Drug: Brand name/generic name: _____ Refill Number: _____

Prescribing doctor and phone number: _____

Pharmacy name and phone number: _____

Dosage: _____ No. of times a day: _____

Food (circle one): With Without

Reason for drug: _____ Parent's reaction: _____

Side effects possible: _____

Emergency numbers: _____

Drug: Brand name/generic name: _____ Refill Number: _____

Prescribing doctor and phone number: _____

Pharmacy name and phone number: _____

Dosage: _____ No. of times a day: _____

Food (circle one): With Without

Reason for drug: _____ Parent's reaction: _____

Side effects possible: _____

Emergency numbers: _____

Drug: Brand name/generic name: _____ Refill Number: _____

Prescribing doctor and phone number: _____

Pharmacy name and phone number: _____

Dosage: _____ No. of times a day: _____

Food (circle one): With Without

Reason for drug: _____ Parent's reaction: _____

Side effects possible: _____

Emergency numbers: _____

LEGAL ISSUES: PROTECTING YOUR PARENT'S WISHES AND

Legal Documents

	HAVE	LOCATION	NEED TO GET
BIRTH CERTIFICATE	_____	_____	_____
MARRIAGE CERTIFICATE	_____	_____	_____
DEED TO HOUSE	_____	_____	_____
WILL	_____	_____	_____
LIFE INSURANCE	_____	_____	_____
HEALTH INSURANCE POLICIES	_____	_____	_____
TAX RECORDS	_____	_____	_____
ADVANCE DIRECTIVES	_____	_____	_____
LIVING WILL	_____	_____	_____
POWER OF ATTORNEY FOR HEALTH CARE	_____	_____	_____
POWER OF ATTORNEY FOR PROPERTY AND FINANCIAL ISSUES	_____	_____	_____
FUNERAL INSURANCE POLICY	_____	_____	_____
MORTGAGE PAPERS	_____	_____	_____
APARTMENT LEASE	_____	_____	_____
AUTOMOBILE TITLE	_____	_____	_____
BOAT TITLE	_____	_____	_____
AUTOMOBILE INSURANCE POLICY	_____	_____	_____
BOAT INSURANCE POLICY	_____	_____	_____
APPRAISALS/JEWELRY	_____	_____	_____
OTHER	_____	_____	_____
	_____	_____	_____
	_____	_____	_____
	_____	_____	_____
	_____	_____	_____

RECORDS AND INFORMATION

LEGAL ISSUES: PROTECTING YOUR PARENT'S WISHES AND

The following Durable Power of Attorney form is designed for use in California; however, most states have similar standards for these documents.

California Durable Power of Attorney for Health Care

1. Designation of Health Care Agent. I, _____
NAME

SS _____
ADDRESS

do hereby designate and appoint _____
NAME OF AGENT

ADDRESS AND TELEPHONE NUMBER OF AGENT

as my attorney in fact (agent) to make health care decisions for me as authorized in this document. For the purposes of this document, "health care decision" means consent, refusal of consent, or withdrawal of consent to any care, treatment, service, or procedure to maintain, diagnose, or treat an individual's physical or mental condition.

2. Creation of Durable Power of Attorney for Health Care

3. General Statement of Authority Granted Subject to any limitations in this document, I hereby grant to my agent full power and authority to make health care decisions for me to the same extent that I could make decisions for myself if I had the capacity to do so. In exercising this authority, my agent shall make health care decisions that are consistent with my desires as stated in this document or otherwise made known to my agent, including but not limited to my desires concerning obtaining or refusing or withdrawing life-prolonging care, treatment, services, and procedures.

4. Statement of Desires, Special Provisions, and Limitations. In exercising the authority under this Durable Power of Attorney for Health Care, my agent shall act consistently with my desires as stated below and is subject to the special provisions and limitations stated below:

- (a) Statement of desires concerning life-prolonging care, treatment, services and procedures:
- (b) Additional statement of desires, special provisions, limitations:

5. Inspection and Disclosure of Information Relating to My Physical or Mental Health. Subject to any limitations in this document, my agent has the power and authority to do all of the following:

- (a) Request, review and receive any information, verbal or written, regarding my physical or mental health, including but not limited to medical and hospital.
- (b) Execute on my behalf any releases or other documents that may be required in order to obtain this information.
- (c) Consent to the disclosure of this information.

6. Signing Documents, Waivers, and Releases. Where necessary to implement the health care decisions that my agent is authorized by this document to make, my agent has the power and authority to execute on my behalf all of the following:

- (a) Documents titled or purporting to be a "Refusal to Permit Treatment" and "Leaving Hospital Against Medical Advice".
- (b) Any necessary waiver or release from liability required by a hospital or physician.

7. Duration. This Durable Power of Attorney for Health Care expires on _____
FILL IN ONLY IF YOU WANT TO LIMIT THE DURATION

8. Designation of Alternate Agents. If the person designated as my agent in paragraph 1 is not available or becomes ineligible to act as my agent to make a health care decision for me or loses the mental capacity to make health care decisions for me, or if I revoke that person's appointment or authority to act as my agent to make health care decisions for me, then I designate and appoint the following persons to serve as my agent to make health care decisions for me as authorized in this document, such persons to serve in the order listed:

LEGAL ISSUES: PROTECTING YOUR PARENT'S WISHES AND

California Durable Power of Attorney for Health Care Continued

A. First Alternate Agent (Name, address and telephone): _____

B. Second Alternate Agent (Name, address and telephone): _____

9. Prior Designation Revoked. I revoke any prior durable power of attorney for health care. DATE AND SIGNATURE OF PRINCIPAL I sign my name to this Durable Power of Attorney for Health Care on _____ DATE at _____ CITY STATE

(PRINCIPAL SIGNS HERE)

(THIS POWER OF ATTORNEY WILL NOT BE VALID UNLESS IT IS SIGNED BY EITHER A NOTARY PUBLIC OR TWO QUALIFIED WITNESSES WHO ARE PRESENT WHEN YOU SIGN OR ACKNOWLEDGE YOUR SIGNATURE. IF YOU HAVE ATTACHED ANY ADDITIONAL PAGES TO THIS FORM, YOU MUST DATE AND SIGN EACH OF THEM AT THE SAME TIME YOU DATE AND SIGN THIS POWER OF ATTORNEY.) I declare under penalty of perjury under the laws of California that the person who signed or acknowledged this document is personally known to me (or proved to me on the basis of convincing evidence) to be the principal, that the principal signed or acknowledged this durable power of attorney in my presence, that the principal appears to be of sound mind and under no duress, fraud, or undue influence, that I am not the person appointed as attorney in fact by this document, and that I am not a health care provider, an employee of a health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, or an employee of an operator of a residential care facility for the elderly.

Witness #1 Signature _____ Date _____
Print Name _____
Residence Address _____

I declare under penalty of perjury under the laws of California that the person who signed or acknowledged this document is personally known to me (or proved to me on the basis of convincing evidence) to be the principal, that the principal signed or acknowledged this durable power of attorney in my presence, that the principal appears to be of sound mind and under no duress, fraud, or undue influence, that I am not the person appointed as attorney in fact by this document, and that I am not a health care provider, an employee of a health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, or an employee of an operator of a residential care facility for the elderly.

Witness #2 Signature _____ Date _____
Print Name _____
Residence Address _____

(At least one witness must read and sign the following statement):

I further declare under penalty of perjury under the laws of California that I am not related to the principal by blood, marriage, or adoption, and to the best of my knowledge, I am not entitled to any part of the estate of the principal upon the death of the principal under a will now existing or by operation of law.

SIGNATURE _____

SIGNATURE _____

STATEMENT OF PATIENT ADVOCATE OR OMBUDSMAN

(If you are a patient in a nursing home.)

I further declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and that I am serving as a witness as required by subdivision (f) of Section 2432 of the Civil Code.

SIGNATURE _____

LEGAL ISSUES: PROTECTING YOUR PARENT'S WISHES AND

The following Living Will form is designed for use in California; however, most states have similar standards for these documents.

The Living Will

If I should have an incurable and irreversible condition that has been diagnosed by two physicians and that will result in my death within a relatively short time without the administration of life-sustaining treatment or has produced an irreversible coma or persistent vegetative state, and I am no longer able to make decisions regarding my medical treatment, I direct my attending physician, pursuant to the Natural Death Act of California, to withhold or withdraw treatment, including artificially administered nutrition and hydration, that only prolongs the process of dying or the irreversible coma or persistent vegetative state and is not necessary for my comfort or to alleviate pain. If I have been diagnosed as pregnant and that diagnosis is known to my physician, this declaration shall have no force or effect during my pregnancy. Other instructions: (add any) _____

Signed this _____ day of _____, 19 _____

Signature _____

Address _____

The declarant voluntarily signed this writing in my presence. I am not a health care provider, an employee of a health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, or an employee of an operator of a residential care facility for the elderly.

Witness #1 _____ Date _____

Address _____

The declarant voluntarily signed this writing in my presence. I am not a health care provider, an employee of a health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, or an employee of an operator of a residential care facility for the elderly.

Witness #2 _____ Date _____

Address _____

STATEMENT OF PATIENT ADVOCATE OR OMBUDSMAN

(For use if you are a patient in a nursing home.)

I further declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and that I am serving as a witness as required by Section 7178 of the Health and Safety Code.

SIGNATURE _____

A Living Trust (joint or not) is an important part of estate planning. This sample form, courtesy of Parsons Technology, is one of the documents in Quicken Family Lawyer. Your parent's elder-law attorney or financial planner should be consulted to determine the suitability of trusts for their situation.

Joint Living Trust

This Joint Living Trust Agreement (this "Agreement") is made this ____ day of _____, ____ between _____ and _____ (the "Grantors or Beneficiaries") of _____, _____ and _____, of _____, _____ (the "Trustee").

In consideration of the mutual covenants and promises set forth in this Agreement, the Grantor and the Trustee agree as follows:

I. PURPOSE. The purpose of this Agreement is to establish a Trust to receive and manage assets for the benefit of the Grantors during the Grantors' lives, and to further manage and distribute the assets of the Trust upon the death of the surviving Grantor.

II. FUNDING OF TRUST. This Trust shall be funded with assets transferred to this Trust by either or both of the Grantors at the time of creating this Trust, or at any later time. Any community property transferred to this Trust shall remain community property until the death of either Grantor. This Trust may also receive property from any person or entity who is acting under the authority granted to that person or entity by the Grantors. It is also expected that this Trust may receive assets pursuant to the terms of either of the Grantors' Last Will and Testament.

III. MANAGEMENT OF TRUST ASSETS. The Trustee shall manage and distribute the trust assets for the benefit of the Beneficiaries in accordance with the terms of this Agreement.

IV. DISTRIBUTIONS DURING THE LIVES OF THE GRANTORS. During the joint or survivor lives of the Grantor(s), the Trustee shall distribute to or for the benefit of the Grantor(s), or as the Grantor(s) may designate, as much of the net income and/or principal as the Trustee (in the Trustee's sole discretion) may determine is necessary for the health, support, education, maintenance, and comfort of the Grantor(s). Such distributions shall be made at least _____. The Grantor(s) may change the amount of distribution at any time by providing notice to the Trustee. Any excess income shall be retained in the Trust and added to its principal at the discretion of the Trustee.

A. *Payments During a "Disability" of a Grantor.* During any period that a Grantor has a "disability", the Trustee may pay to or for the benefit of such Grantor such amounts of income and principal as the Trustee believes in the Trustee's sole discretion to be required for (i) such Grantor's support, comfort and welfare, (ii) such Grantor's accustomed manner of living, or (iii) any purpose that the Trustee believes to be in the best interest of such Grantor.

B. *Disability Defined.* For the purposes of this Trust, "disability" shall mean a legal disability or the inability to provide prompt and intelligent consideration to financial matters by reason of illness or mental or physical disability. The determination of whether a Grantor has a disability shall be made by such Grantor's most recent attending physician. The Trustee shall be entitled to rely on written notice of that determination.

V. DEATH OF A GRANTOR. Upon the death of the first of the Grantors to die (the "Decedent"), this trust shall continue for the benefit of the surviving Grantor (the "Surviving Grantor"), subject to distributions (if any) that may be required (i) by this Agreement, or (ii) to pay the just debts, funeral expenses, and expenses of last illness of the Decedent.

VI. DISTRIBUTION OF RESIDUARY TRUST ASSETS UPON THE SURVIVING GRANTOR'S DEATH. Upon the death of the second of the Grantors to die (the "Surviving Grantor"), the residuary assets of this Trust shall be distributed to the Grantors' child(ren) in equal shares.

If a child does not survive the Grantors, such deceased child's share shall be distributed in equal shares to the children of such deceased child who survive the Grantors, by right of representation. If a child does not

LEGAL ISSUES: PROTECTING YOUR PARENT'S WISHES AND

Joint Living Trust Continued...

survive the Grantors and has no children who survive the Grantors, such deceased child's share shall be distributed in equal shares to the Grantors' other children, if any, or to their respective children by right of representation. If no child of the Grantors survives the Grantors, and if none of the Grantors' deceased children are survived by children, the residuary assets of this Trust shall be distributed to _____, _____, _____.

If such beneficiary does not survive the Grantors, the residuary assets shall be divided into two equal shares, with one share distributed to the heirs-at-law of one Grantor, and the other share distributed to the heirs-at-law of the other Grantor, their identities and respective shares to be determined under the laws of the State of _____ then in effect relating to the succession of separate property that is not attributable to a decedent's predeceased spouse.

VII. TRUSTEE POWERS. The Trustee, in addition to other powers and authority granted by law or necessary or appropriate for proper administration of the Trust, shall have the following rights, powers, and authority without order of court and without notice to anyone.

- A. *Receive Assets.* To receive, hold, maintain, administer, collect, invest and reinvest the trust assets, and collect and apply the income, profits, and principal of the Trust in accordance with the terms of this instrument.
- B. *Receive Additional Assets.* To receive additional assets from other sources, including assets received by bequest.
- C. *Standard of Care.* To acquire, invest, reinvest, exchange, retain, sell, and manage estate and trust assets, exercising the judgment and care, under the circumstances then prevailing, that persons of prudence, discretion and intelligence exercise in the management of their own affairs, not in regard to speculation but in regard to the permanent disposition of their funds, considering the probable income as well as the probable safety of their capital. Within the limitations of that standard, the Trustee is authorized to acquire and retain every kind of property, real, personal or mixed, and every kind of investment, specifically including, but not by way of limitation, bonds, debentures and other corporate obligations, and stocks, preferred or common, that persons of prudence, discretion, and intelligence acquire or retain for their own account, even though not otherwise a legal investment for trust funds under the laws and statutes of the United States or the state under which this instrument is administered.
- D. *Retain Assets.* To retain any asset, including uninvested cash or original investments, regardless of whether it is of the kind authorized by this instrument for investment and whether it leaves a disproportionately large part of the estate or trust invested in one type of property, for as long as the Trustee deems advisable.
- E. *Dispose of or Encumber Assets.* To sell, option, mortgage, pledge, lease, or convey real or personal property, publicly or privately, upon such terms and conditions as may appear to be proper, and to execute all instruments necessary to effect such authority.
- F. *Settle Claims.* To compromise, settle, or abandon claims in favor of or against the Trust.
- G. *Manage Property.* To manage real estate and personal property, borrow money, exercise options, buy insurance, and register securities as may appear to be proper.
- H. *Allocate Between Principal and Income.* To make allocations of charges and credits as between principal and income as in the sole discretion of the Trustee may appear to be proper.
- I. *Employ Professional Assistance.* To employ and compensate counsel and other persons deemed necessary for proper administration and to delegate authority when such delegation is advantageous to the Trust.
- J. *Distribute Property.* To make division or distribution in money or kind, or partly in either, at values to be determined by the Trustee, and the Trustee's judgment shall be binding upon all interested parties.
- K. *Enter Contracts.* To bind the Trust by contracts or agreements without assuming individual liability for such contracts.
- L. *Exercise Stock Ownership Rights.* To vote, execute proxies to vote, join in or oppose any plans for reorganization, and exercise any other rights incident to the ownership of any stocks, bonds, or other properties of the Trust.
- M. *Duration of Powers.* To continue to exercise the powers provided in this Agreement after the termination of the Trust until all the assets of the Trust have been distributed.

LEGAL ISSUES: PROTECTING YOUR PARENT'S WISHES AND

Joint Living Trust Continued...

VIII. ADDITIONAL TRUSTEE PROVISIONS.

These additional provisions shall apply regarding the Trustee.

- A. *Grantor(s) as Trustee.* If at any time either or both Grantors are "Trustee", a successor trustee may be designated by such Grantor Trustee(s), if such designation is made in writing. Such designee shall become the Successor Trustee upon acceptance of the terms and conditions of this Agreement.
- B. *Death or Disability of a Grantor as Trustee.* If at any time no Grantor is able to serve as Trustee because of a disability (as previously defined) or death, _____, of _____, _____, is designated as the Successor Trustee.
- C. *Resignation of Trustee.* The Trustee, or any successor may resign at any time by giving _____ days' written notice to a Grantor. If both Grantors are deceased, such notice shall be given to all adult beneficiaries, and to a parent or guardian, if any, of each minor beneficiary.
- D. *Successor Trustee.* The beneficiaries to whom such notice of resignation is given shall designate a Successor Trustee by written notice to the resigning Trustee within _____ days after receipt of the notice of resignation. If a Successor Trustee is not so designated, the resigning Trustee shall have the right to secure the appointment of a Successor Trustee by a court of competent jurisdiction, at the expense of the Trust. If a Successor Trustee is appointed, such Trustee shall be bound by, and subject to, the provisions of this Trust.
- E. *Accounting.* The Trustee shall provide an accounting to the Beneficiary (or beneficiaries) on at least a _____ basis. If a beneficiary has a "disability", the Trustee shall provide the accounting to a guardian or conservator, if any.
- F. *Bond.* No bond shall be required of any Trustee.

IX. REVOCATION OR AMENDMENT. Either Grantor may revoke at any time and/or the Grantors may jointly amend, this Agreement by delivering to the Trustee an appropriate written revocation or amendment, signed by the Grantor(s). If the Trustee consents, the powers of revocation, but not the power of amendment, may be exercised by a duly appointed and acting attorney-in-fact for the Grantors, or either of them, for the purpose of withdrawing assets from the Trust.

X. GOVERNING LAW. This Agreement shall be construed in accordance with the laws of the State of _____.

XI. PERPETUITIES SAVINGS CLAUSE. Despite any other provision of this Agreement to the contrary, the Trust created by this Agreement shall terminate no later than 21 years after the death of the last to die of a class of persons to include the Grantors and any other beneficiary of this Agreement who is living on the date that this Agreement is signed.

XII. SEVERABILITY. If any portion of this Agreement shall be held to be invalid or unenforceable for any reason, the remaining provisions shall continue to be valid and enforceable. If a court finds that any provision of this Agreement is invalid or unenforceable, but that by limiting such provision it would become valid and enforceable, then such provision shall be deemed to be written, construed, and enforced as so limited.

XIII. MISCELLANEOUS PROVISIONS.

- A. *Paragraph Titles and Gender.* The titles given to the paragraphs of this Trust are inserted for reference purposes only and are not to be considered as forming a part of this Trust in interpreting its provisions. All words used in this Trust in any gender shall extend to and include all genders and in numbers when the context or facts so require, and any pronouns shall be taken to refer to the person or persons intended regardless of gender or number.

GRANTOR 1 Signature _____

GRANTOR 2 Signature _____

TRUSTEE Signature _____

State/Commonwealth of _____ County/City of _____

LEGAL ISSUES: PROTECTING YOUR PARENT’S WISHES AND

Joint Living Trust Continued...

This Trust instrument was acknowledged before me on this _____ day of _____, 19____, by _____ and _____, as Grantors.

_____, My commission expires _____
NOTARY PUBLIC _____, TITLE (AND RANK) _____
State/Commonwealth of _____ County/City of _____

This Trust instrument was acknowledged before me on this _____ day of _____, 19____, by _____ and _____, as Grantors.

_____, My commission expires _____
NOTARY PUBLIC _____, TITLE (AND RANK) _____
State/Commonwealth of _____ County/City of _____

LEGAL ISSUES: PROTECTING YOUR PARENT'S WISHES AND

This sample Will is courtesy of Parsons Technology. It is one of the documents in Quicken Family Lawyer. Consult with a qualified elderlaw attorney to determine if or how this document is suitable for your parent's situation.

Last Will and Testament of _____

I, _____, of _____, _____, revoke my former Wills and Codicils and declare this to be my Last Will and Testament.

ARTICLE I—PAYMENT OF DEBTS AND EXPENSES

I direct that my just debts, funeral expenses and expenses of last illness be first paid from my estate.

ARTICLE II—DISPOSITION OF PROPERTY

A. *Residuary Estate.* I direct that my residuary estate be distributed to my spouse, _____. If my spouse does not survive me, my residuary estate shall be distributed to my child(ren) in equal shares. If a child of mine does not survive me, such deceased child's share shall be distributed in equal shares to the children of such deceased child who survive me, by right of representation. If a child of mine does not survive me and has no children who survive me, such deceased child's share shall be distributed in equal shares to my other child(ren), if any, or to their respective children by right of representation. If no child of mine survives me, and if none of my deceased child(ren) are survived by child(ren), my residuary estate shall be distributed to _____, _____. If such beneficiary does not survive me, my residuary estate shall be distributed to my heirs-at-law, their identities and respective shares to be determined under the laws of the State of _____ then in effect relating to the succession of separate property that is not attributable to a predeceased spouse.

ARTICLE III—NOMINATION OF EXECUTOR

I nominate _____, of _____ as the Executor, with bond.

ARTICLE IV—EXECUTOR POWERS

My Executor, in addition to other powers and authority granted by law or necessary or appropriate for proper administration, shall have the right and power to lease, sell, mortgage, or otherwise encumber any real or personal property that may be included in my estate, without order of court and without notice to anyone.

ARTICLE V—MISCELLANEOUS PROVISIONS

A. *Paragraph Titles and Gender.* The titles given to the paragraphs of this Will are inserted for reference purposes only and are not to be considered as forming a part of this Will in interpreting its provisions. All words used in this Will in any gender shall extend to and include all genders and in numbers when the context or facts so require, and any pronouns shall be taken to refer to the person or persons intended regardless of gender or number.

IN WITNESS WHEREOF, I have subscribed my name below, this ____ day of _____, 19____.

We, the undersigned, hereby certify that the above instrument, which consists of ____ pages, including the page(s) which contain the witness signatures, was signed in our sight and presence by _____ (the "Testator"), who declared this instrument to be his/her Last Will and Testament and we, at the Testator's request and in the Testator's sight and presence, and in the sight and presence of each other, do hereby subscribe our names and addresses as witnesses on the date shown above.

Witness Signature: _____ Witness Name: _____

Witness Address: _____

Witness Signature: _____ Witness Name: _____

Witness Address: _____

LEGAL ISSUES: PROTECTING YOUR PARENT'S WISHES AND

Last Will and Testament Continued...

AFFIDAVIT

STATE OF _____, COUNTY OF _____

Before me, the undersigned, on this day personally appeared _____, _____ and _____, known to me to be the Testator and the witnesses, respectively, whose names are signed to the foregoing instrument. All of these persons were first duly sworn by me. _____, the Testator, declared to me and to the witnesses, in my presence, that the foregoing instrument is the Testator's Will and that the Testator willingly signed and executed such instrument (or expressly directed another person to sign the instrument for the Testator in the Testator's presence) in the presence of the witnesses, as the Testator's free and voluntary act for the purposes expressed in the instrument. Each of the witnesses declared in the presence and hearing of the Testator that the foregoing instrument was executed and acknowledged by the Testator as the Testator's Will in their presence and that they, in the Testator's presence, hearing and sight and at the Testator's request, and in the presence of each other, did subscribe their names to the instrument as attesting witnesses on the date of the instrument. The Testator, at the time of the execution of such instrument, was of full age, of sound mind, and the witnesses were sixteen years of age or older and otherwise competent to be witnesses.

_____, Testator

_____, Witness

_____, Witness

Subscribed, sworn to and acknowledged before me by _____, the Testator; and subscribed and sworn before me by _____, and _____, witnesses, this ____ day of _____, 19____.

Notary Public, or other officer authorized to take and certify acknowledgements and administer oaths.

Legal and Financial Advisors

NOTES

ATTORNEY NAME: _____

Address: _____

Phone/FAX: _____

ACCOUNTANT _____

Name: _____

Address: _____

Phone/FAX: _____

FINANCIAL ADVISOR _____

Name: _____

Address: _____

Phone/FAX: _____

Banking Information

CHECKING Account Number: _____

Bank/Branch Location: _____

SAVINGS Account Number: _____

Bank/Branch Location: _____

INVESTMENT Account Number(s): _____

Bank/Branch Location: _____

INVESTMENT Account Number(s): _____

Bank/Branch Location: _____

INVESTMENT Account Number(s): _____

Bank/Branch Location: _____

Household Income and Expenses

INCOME	ANNUAL AMOUNT		
	19____	19____	19____
Wages/salary	_____	_____	_____
Retirement Benefits	_____	_____	_____
IRAs	_____	_____	_____
Keogh	_____	_____	_____
Profit Sharing	_____	_____	_____
Deferred Compensation Plan	_____	_____	_____
Social Security	_____	_____	_____
Investment Income	_____	_____	_____
Interest & Dividends – taxable	_____	_____	_____
	_____	_____	_____
Interest – non-taxable	_____	_____	_____
	_____	_____	_____
Rental Income	_____	_____	_____
	_____	_____	_____
Additional income sources	_____	_____	_____
TOTAL INCOME	\$ _____	\$ _____	\$ _____
EXPENSES	ANNUAL AMOUNT		
	19____	19____	19____
Housing: Rent or Mortgage	_____	_____	_____
Insurance	_____	_____	_____
Taxes	_____	_____	_____
Utilities	_____	_____	_____
Maintenance/Repairs	_____	_____	_____
Food	_____	_____	_____
Clothing	_____	_____	_____
Car or other transportation	_____	_____	_____
Repairs	_____	_____	_____
Medical and Dental	_____	_____	_____
Other Insurance	_____	_____	_____
Additional Taxes	_____	_____	_____
Travel & Entertainment	_____	_____	_____
Donations/Contributions	_____	_____	_____
Other Expenses	_____	_____	_____
	_____	_____	_____
TOTAL INCOME	\$ _____	\$ _____	\$ _____
Subtract TOTAL EXPENSES	< _____ >	< _____ >	< _____ >
NET INCOME	\$ _____	\$ _____	\$ _____

Location of Financial Records

FATHER

MOTHER

Tax returns for 19 _____

Prior years _____

Current year's taxes _____

Promissory Notes _____

IRA, pension records _____

Other deferred
compensation records _____

Real estate documents _____

Health care records _____

Funeral and burial
plan documents _____

Insurance premium
payment records _____

NOTES _____

Insurance Information

FATHER

MOTHER

PRIMARY HEALTH INSURANCE

Policy Name and Number _____

MEDICARE SUPPLEMENTAL INSURANCE

Policy Name and Number _____

LONG-TERM CARE INSURANCE

Policy Name and Number _____

AUTO INSURANCE

Policy Name and Number _____

HOMEOWNER'S INSURANCE

Policy Name and Number _____

LIFE INSURANCE

Policy Name and Number _____

NOTES:

Private Insurance Check List

(For convenient comparison shopping three columns are provided).

LONG-TERM CARE INSURANCE

Company #1: _____ Agent _____ Phone _____

Company #2: _____ Agent _____ Phone _____

Company #3: _____ Agent _____ Phone _____

	Company 1	Company 2	Company 3
I. RANGE OF COVERAGE			
• Home Care Services	_____	_____	_____
• Case Management Services	_____	_____	_____
• Skilled Nursing Facility	_____	_____	_____
• Intermediate Care Nursing Home Facility	_____	_____	_____
• Custodial Care Facility	_____	_____	_____
• Other Care Services	_____	_____	_____
Comments:	_____	_____	_____
II. COVERAGE LIMITS			
• Maximum duration of home care services	_____	_____	_____
• Maximum life-time benefit for home health care services	_____	_____	_____
• Maximum duration of stay in nursing home	_____	_____	_____
• Maximum life-time benefit for nursing home	_____	_____	_____
• Waiting period for pre-existing conditions	_____	_____	_____
• Alzheimer's Disease coverage	_____	_____	_____
• Waiting period before benefits start	_____	_____	_____
III. COST OF COVERAGE			
• Monthly	_____	_____	_____
• Quarterly	_____	_____	_____
• Semi-annually	_____	_____	_____
• Annually	_____	_____	_____
• Deductible	_____	_____	_____
IV. NEEDED BEFORE COVERAGE BEGINS			
• Physician certification of need	_____	_____	_____
• Other	_____	_____	_____
V. ADDITIONAL COVERAGE			
Does policy allow for additional coverage to offset inflation?	_____	_____	_____
• Other	_____	_____	_____

Before canceling existing insurance coverage consider:

1. What, if any, are the drawbacks to giving up existing insurance coverage?
2. Are there new limits for pre-existing conditions?
3. What are the limits on renewability?
4. Will a new annual deductible need to be paid?

Additional Notes: _____

Policy Selected: _____

Comparing Medicare Supplemental (Medigap) Insurance Coverage

Because Medigap insurers are required to use the same format, language and definitions in describing the benefits of each of the Medigap plans they offer, when comparing Medigap plans, it is helpful to keep in mind that insurance companies are competing on service, reliability and price. Compare premiums and benefits of the specific Medigap plan (for example Plan C or Plan H) you are considering, and be satisfied that the insurer is reputable before buying.

Company #1: _____ Agent _____ Phone _____
 Company #2: _____ Agent _____ Phone _____

MEDIGAP PLAN__ MEDIGAP PLAN__ MEDIGAP PLAN__

1. Will the policy pay some or all of the annual Medicare Part A deductible for hospitalization? Will the policy pay some or all of Medicare Part B deductible? Copayment for Part B services? What if any are the limitations? _____
2. Will the policy provide benefits for psychiatric hospitalization beyond Medicare's limit of 190 days? If so, how much? _____
3. Will the policy cover part (or all) of the co-payment charges for days 21-100 of skilled nursing care in a Medicare certified facility? _____
4. Will the policy cover excess charges beyond what is approved by Medicare for physicians, nursing facility care, and other health care providers? _____
5. Will outpatient prescription drugs be covered? If so, under what circumstances? What pay-out limits are there? What deductibles are you responsible for each calendar year? Is there an extended prescription drug benefit? _____
6. Will the policy extend coverage for outpatient physical therapy after the annual Medicare allowance is depleted? What percentage of the allowable expenses will your policy cover and what amounts are you responsible for? _____

Price Comparison
 Company #1 _____
 Company #2 _____

Parents, or caregivers arranging for services for parents, should have a signed agreement when contracting for services. This form, courtesy of Parsons Technology, is one of the documents in Quicken Family Lawyer.

Work for Hire Agreement

This Work for Hire Agreement (this "Agreement") is made effective as of _____, 199_, by and between _____, of _____, and _____, of _____. In this Agreement, the party who is contracting to receive the services shall be referred to as "_____", and the party who will be providing the services shall be referred to as "_____".

1. DESCRIPTION OF SERVICES.

Beginning on _____, 199_, _____, will provide the following services, (collectively, the "Services"):

2. PAYMENT FOR SERVICES. _____, will pay compensation to _____ for the Services in the amount of \$ _____. This compensation shall be payable in a lump sum upon completion of the Services.

3. ENTIRE AGREEMENT. This Agreement contains the entire agreement of the parties, and there are no other promises or conditions in any other agreement whether oral or written.

4. SEVERABILITY. If any provision of this Agreement shall be held to be invalid or unenforceable for any reason, the remaining provisions shall continue to be valid and enforceable. If a court finds that any provision of this Agreement is invalid or unenforceable, but that by limiting such provision it would become valid and enforceable, then such provision shall be deemed to be written, construed, and enforced as so limited.

Party contracting services:

By: _____

Service Provider:

By: _____

DEATH AND DYING

It is important to list names, addresses and phone numbers of people to be contacted immediately in the event of death (clergy, lawyer, employer, immediate family and funeral director).

Decisions should be put in writing and left where the document can be accessed by family, friends, and lawyer (NOT in a safe deposit box or in a will). It is also important to include the location of any safe deposit box or vault (state number) and key(s). The following form can supply this information:

Important Information on the Event of My Death

I am _____
FIRST MIDDLE LAST

When I die contact: _____
NAME TELEPHONE RELATIONSHIP

My important papers are located at _____

Information for Death Certificate and Filing for Benefits

My street address _____ City _____

County _____ State _____ Zip code _____

Citizen of _____ Race _____ Birthplace _____ Social Security number _____

Occupation/Type of Business _____

If veteran: Rank _____ Branch of service _____ Serial number _____

Date and place entered service _____ Date discharged _____

I have: never married married been widowed separated divorced remarried

Spouse's full (maiden) name _____

Name of next of kin (other than spouse) _____ Relationship _____

Address _____

Father's full name and birthplace _____

Mother's full name and birthplace _____

PLEASE NOTE:

I want to donate these organs: _____

That my body be: donated (arrangements made on date ____ with _____ (medical school)

I want: simple arrangements no embalming no public viewing

the least expensive burial or cremation container immediate disposition a nice funeral

cremated and the ashes: scattered _____ or, buried in _____

or disposed of as follows _____

The following services: memorial (after disposition) funeral (before disposition)

graveside omit flowers

Services to be held at: my house of worship mortuary other

Memorial gifts to: _____

I have made pre-arrangements with (mortuary) _____

SIGNATURE

DATE

DEATH AND DYING

This sample form, courtesy of Parsons Technology, is one of the documents in Quicken Family Lawyer. Use this as a starting point for memorial service and/or funeral planning.

Declaration Regarding Final Arrangements of _____

I wish to describe my desires and to facilitate the making of arrangements at the time of my death. My family will be in the best position depending upon the circumstances to do what is right. To assist them in that process I am providing the following information:

I have given careful thought and consideration to these instructions. I understand that this declaration is not legally binding, and that the ultimate decision will be made by my family and other appropriate person(s) based on the circumstances at the time of my death. I hope that my desires will be fulfilled, to the extent possible.

Dated this _____ day of _____, 19__.

Name: _____

Address: _____

The following form, provided courtesy of Parsons Technology, is one of the documents in Quicken Family Lawyer.

Organ Donation Form

I, _____, of _____, _____, give my organs, tissues, or parts as directed below. This Anatomical Gift will take effect upon my death.

I give: (initial one of the three options)

_____ any needed organs, tissues, or parts.

_____ any needed organs, tissues, or parts except: _____.

_____ the following organs, tissues, or parts only: _____.

I give my organs, tissues, or parts indicated above to be used for: (initial one of the two options)

_____ any purpose authorized by law.

_____ the following purposes only: (initial all that apply)

_____ transplantation

_____ research

_____ therapy

_____ education

Limitations or special wishes, if any: _____

If any provision in this document is held to be invalid, such invalidity shall not affect the other provisions which can be given effect without the invalid provision, and to this end the directions in this document are severable.

DATE

DONOR SIGNATURE

DONOR'S DATE OF BIRTH

I witnessed that this document was signed in my presence by the Donor. I am signing in the presence of and at the direction of the Donor and in the presence of the other witness:

DATE

WITNESS SIGNATURE

DATE

WITNESS SIGNATURE

Reference and Referral

The following organizations are excellent resources for information and problem solving. In addition, many offer free or low-cost books and pamphlets that may address your specific needs.

The numbers after the name of each organization listed reference the *Table of Contents Code* for the chapters in the *Action Guide*.

Table of Contents Code

- | | |
|--|-------------------------------------|
| 1. How to Use Aging Parents | 7. Medical and Health Issues |
| 2. When Crisis Hits | 8. Legal Issues |
| 3. Getting Organized | 9. The Business Side of Care Giving |
| 4. Care Giving from a Distance | 10. Government Programs |
| 5. Family Dynamics | 11. Death and Dying |
| 6. Housing Alternatives and Support Services | |

Editors Note: Addresses and phone numbers subject to change.

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC. (7)

919 N. Michigan Ave., Suite 1000
Chicago, IL 60611-1676
(800) 272-3900, (312) 335-8700

Literature and resources including brochures, newsletter, information, local referrals, respite care and care giver support groups.

AMERICAN ASSOCIATION FOR CONTINUITY OF CARE (6, 7)

638 Prospect Ave.
Hartford, CT 06105-4298
(203) 586-7525

Promotes home care standards.

AMERICAN ASSOCIATION OF HOMES AND SERVICES FOR THE AGING (6)

901 E St. NW, Suite 500
Washington, DC 20004-2037
(202) 783-2242

Represent non-profit housing providers. Free brochures on housing options, skilled nursing facilities and guide to long-term care. Call to request a publications catalogue.

AMERICAN ASSOCIATION OF RETIRED PERSONS (AARP) (3, 4, 6, 8, 9, 10)

601 E. St. NW
Washington, DC 20049
(202) 434-2277

Catalog of extensive free publications including: *Caregiver Resource Kit* (free kit available to anyone, ask for AARP Fulfillment, EE0926) and, *National Continuing Care Directory*, by Anne Trueblood Raper, \$19.95 (Members, \$14.50). Local chapters. On-line computer services available through America Online, CompuServe and Prodigy.

AMERICAN ASSOCIATION OF RETIRED PERSONS (AARP) - LEGAL COUNSEL FOR THE ELDERLY (8)

Order Fulfillment
P.O. Box 96474
Washington, DC 20090-6474
(202) 434-2174

Publishes: *Organizing Your Future: A Guide to Decision-Making In Your Later Years*, 1993, order #D13877, \$5.00 (98 pages) and *Finding Legal Help*, order #D15579, \$2.00. Make checks payable to: Legal Counsel for the Elderly, .

AMERICAN BAR ASSOCIATION (8)

Order Fulfillment Department
750 N. Lake Shore Drive
Chicago, IL 60611
(800) 621-6159

Publishes: *Planning for Life and Death* (#PC: 543-0040-01) and *Wills: Why You Should Have One* (#PC: 543-0039-01). Single copies available at no charge.

AMERICAN CANCER SOCIETY HOTLINE (11)

235 Montgomery St., Suite 320
 San Francisco, CA 94104
 (800) ACS-2345, (415) 394-7100

Information, referral to support groups, sources of financial assistance and treatment-related needs.

AMERICAN COUNCIL OF THE BLIND (7)

1155 15th St. NW, Suite 720
 Washington, DC 20005
 (800) 424-8666, (202) 467-5081

Free educational materials, local referrals and funding sources.

AMERICAN DIABETES ASSOCIATION (7)

1660 Duke St.
 Alexandria, VA 22314
 (800) 868-7888

Management, local referrals and literature.

AMERICAN HEALTH CARE ASSOCIATION**(6)**

1201 L St. NW
 Washington, DC 20005
 (800) 321-0343 (Publications Department), (202) 842-4444

Provides a *Here's Help* series of publications covering a wide range of elder care topics. Also a booklet *Thinking About A Nursing Home? A Consumers Guide to Long-Term Care* (single copies are free) and a video: *Helping Hands: The Right Way to Choose A Nursing Home* (\$25 + \$3 Shipping and Handling - Catalogue #K2551Z).

**AMERICAN HEART ASSOCIATION
 NATIONAL CENTER AND STROKE
 CONNECTION (7)**

7272 Greenville Ave.
 Dallas, TX 75231-4596
 (800) 242-8721, (800) 553-6321 (Stroke Connection),
 (214) 373-6300

Free publications on heart disease and prevention.

AMERICAN MEDICAL ASSOCIATION (7)

515 N. State St.
 Chicago, IL 60610
 (312) 464-5000

Referrals for all fields of practice, including psychiatry.

AMERICAN PSYCHIATRIC ASSOCIATION (7)

1400 K St. NW
 Washington, DC 20005
 (202) 682-6000

Free pamphlets on mental disorders seen in the elderly.

**AMERICAN RED CROSS, NATIONAL OFFICE
 (3)**

430 17th Street, NW

Washington, DC 20006
 (202) 737-8300

Local chapters and training on care giving.

**AMERICAN SAFE DEPOSIT ASSOCIATION
 (11)**

330 West Main Street
 Greenwood, IN 46142
 (317) 888-1118

For a \$75 fee, this group will help find out if a deceased family member had a safe deposit box. Call for further instructions and procedures.

**AMERICAN SELF-HELP CLEARINGHOUSE
 (3,4,7)**

St. Clare's Riverside Medical Center
 25 Pocono Road
 Denville, NJ 07834
 (201) 625-7101

Referrals to local support groups affiliated with a particular disease.

**AMERICAN SOCIETY OF CLU AND CHFC (9,
 10)**

270 Bryn Mawr Ave.
 Bryn Mawr, PA 19010
 (610) 526-2500

The American Society of CLU and ChFC, a national organization of insurance and financial services professionals, is dedicated to enhancing the ability of its members to provide services and solutions that meet the financial needs of individuals, families and companies through a commitment to continuing professional education and ethical practices.

Members earn the designations CLU (Chartered Life Underwriter) and/or ChFC (Chartered Financial Consultant) through The American College, Bryn Mawr, PA.

**AMERICAN SOCIETY ON AGING (3, 4, 6, 9, 10,
 11)**

833 Market Street
 San Francisco, CA 94103
 (415) 974-9600

Publications on care giving are available. Call for a free publications list.

**AMYOTROPHIC LATERAL SCLEROSIS
 ASSOCIATION (LOU GEHRIG'S DISEASE) (7)**

21021 Ventura Blvd., Suite 321
 Woodland Hills, CA 91364
 (800) 782-4747

Low-cost manuals, support groups and referrals.

ARTHRITIS FOUNDATION (7)

1314 Spring St. NW
 Atlanta, GA 30309
 (800) 283-7800 (information line), (404) 872-7100

Brochures, local referrals.

ASOCIACION NACIONAL PRO PERSONAL MAYORES (NATIONAL ASSOCIATION FOR HISPANIC ELDERLY) (3,4)

3325 Wilshire Blvd., Suite 800
Los Angeles, CA 90010-1784
(213) 487-1922

Services and information available. Call for free publications catalogue.

ASSISTED LIVING FACILITY ASSOCIATION OF AMERICA (6)

10300 Eaton Place, Suite 400
Fairfax, VA 22030
(703) 691-8100

Consumer checklist for evaluating facilities.

BET TZEDEK LEGAL SERVICES (8)

145 S. Fairfax Ave., Suite 200
Los Angeles, CA 90036
(213) 939-0506

Guides in English, Spanish and Russian include: *Nursing Home Companion*, *How to Get Care From a Board and Care*. Call for free publications catalogue.

CALIFORNIA ADVOCATES FOR NURSING HOME REFORM (CANHR) (6)

1610 Bush St.
San Francisco, CA 94109
(415) 474-5171

Reports, advocacy. Publishes *So You Think You Need A Nursing Home* (\$15).

CALIFORNIA PARTNERSHIP FOR LONG-TERM CARE (6, 9)

714 P St., Room 616
Sacramento, CA 95814
(916) 657-0654

Four states, California, New York, Connecticut and Indiana, have special partnership arrangements whereby Medicaid (Medi-Cal in California) and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. Call for information concerning California residents.

CANCER INFORMATION SERVICE (7)

Office of Cancer Communications
(800) 4-CANCER

Hotline of National Cancer Institute.

CAREGIVERS PROGRAM (3, 4)

A.H. Wilder Foundation
919 Lafond Ave.
St. Paul, MN 55104
(612) 642-2055

Information on stress management, coping and self-care.

CATHOLIC CHARITIES USA (3,4,6,7)

1731 King St.
 Alexandria, VA 22314
 (703) 549-1390

Network of multi-service agencies providing services and outreach to the elderly. Local chapters. Provides referrals for community services, including day care. Also operates some services.

CEMETERY CONSUMER SERVICE COUNCIL (11)

P.O. Box 2028
 Reston, VA 22090
 (703) 391-8407

For assistance with issues related to maintenance, marker or financial difficulties. Publishes two free brochures: *Having A Problem With A Cemetery?* and *Cemetery and Memorial Parks: Questions and Answers*.

CENTER FOR LOSS AND LIFE TRANSITION (11)

3735 Broken Bow Road
 Fort Collins, CO 80526
 (970) 226-6050

Education, publications and videos on bereavement, support.

CHILDREN OF AGING PARENTS (3, 4, 5)

Woodbourne Office Campus
 1609 Woodbourne Road, Suite 302A
 Levittown, PA 19057
 (215) 945-6900

National clearinghouse on care giver issues, resources, publications, local referrals to support groups and care managers. Publishes *Capsule*, a monthly newsletter.

CHOICE IN DYING (8, 11)

200 Varick St., 10th Floor
 New York, NY 10014-4810
 (800) 989-WILL, (212) 366-5540

Free publication of state-specific Living Will and Durable Power of Attorney forms.

COMPASSIONATE FRIENDS HOTLINE (11)

P.O. Box 3696
 Oakbrook, IL 60522-3696
 (708) 990-0010

National self-help support group for bereaved parents and siblings. Referral to local chapters.

CONNECTICUT PARTNERSHIP FOR LONG-TERM CARE (6,9)

Office of Policy & Management
 450 Capital Avenue, MS# 52LTC
 Hartford, CT 06134-1441
 (203) 418-6318

Arrangement whereby Medicaid and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. Connecticut residents can call (800) 547-3443 to request information.

CONTINUING CARE ACCREDITATION COMMISSION (CCAC) (6)

901 E. St. NW, Suite 500
 Washington, DC 20004-2037
 (202) 783-2242

List of accredited Continuing Care Retirement Communities (CCRCs). Brochures about how to choose a CCRC.

COUNCIL OF BETTER BUSINESS BUREAUS, INC. (9)

Publications Department
 4200 Wilson Blvd., Suite 800
 Arlington, VA 22203
 (703) 276-0100

Publishes several low-cost booklets: *Medicare and Medigap*, *Long-Term Nursing Home Care*, *Continuing Care Retirement Homes*, and *How to Select a Financial Planner*. Request a free publications listing which includes ordering instructions and fees.

COUNCIL ON FAMILY HEALTH (7)

225 Park Ave. South, Suite 1700
 New York, NY 10003
 (212) 598-3617

Publishes free booklets and brochures including *Medicines and You: A Guide for Older Americans* and *How to Prevent Drug Interactions*.

COURAGE STROKE NETWORK (7)

Courage Center
 3915 Golden Valley Rd.
 Golden Valley, MN 55422
 (800) 553-6321, (612) 588-0811

Information and catalog of products.

DEPARTMENT OF DEFENSE (9)

National Personnel Record Center
 9700 Page Blvd.
 St. Louis, MO 63132
 (314) 263-3901

If you cannot find the certificate of discharge from the armed forces, send the branch of service, dates and service serial number to receive a copy of the certificate.

DIRECT LINK FOR THE DISABLED HOTLINE

(7)

(805) 688-1603

Extensive database of 12,000 local organizations that provide various services for the disabled.

ELDER SUPPORT NETWORK (3, 4)

(A service of the Association of Jewish Family and Children's Agencies)

P.O. Box 248

Kendall Park, NJ 08824-0248

(800) 634-7346

Information and referrals to local care giving resources in your community.

ELDERCARE LOCATOR (2, 3, 4)

(800) 677-1116

Free service will put you in touch with the network of organizations at the state and local levels that can help you with your elder care needs.

FAMILY CAREGIVER ALLIANCE (3, 4)

425 Bush St., Suite 500

San Francisco, CA 94018

(800) 445-8106, (415) 434-3388

Clearinghouse for memory loss and brain injury. Extensive literature, publications list, and services. Publishes the *Directory of California Support Groups for Caregivers of Brain-impaired Adults*. Statewide clearinghouse information service, (800) 445-8106.

FAMILY CAREGIVER PROJECT (3, 7)

University of North Carolina, Charlotte

Department of Psychology

Charlotte, NC 28223

(704) 547-4758

Publishes *Caring Families* a series of manuals on care giving tips, managing finances, planning for the future and coping with particular illnesses.

FAMILY RESOURCE SERVICE (3, 4)

1400 Union Meeting Rd., Suite 102

Blue Bell, PA 19422

(800) 847-5437

InfoSheets on support groups, respite services, home health, care giving and community agencies.

FEDERAL NATIONAL MORTGAGE ASSOCIATION (FANNIEMAE) (9)

Public Information Office

3900 Wisconsin Ave. NW

Washington, D.C. 20016

(800) 732-6643

Information on reverse mortgages. Publishes free brochures on the subject including: *HomeKeeper Mortgages*, *Home Equity Conversion Mortgages*, and *Money From Home*.

**FOUNDATION FOR HOSPICE AND
HOMECARE (6, 11)**

519 C St. NE
Washington, DC 20002-5809
(202) 547-6586

Extensive catalog of educational and training materials for consumers and care givers. Free consumer guides, including *All About Hospice*.

GRIEF RECOVERY INSTITUTE (11)

8306 Wilshire Blvd., Suite 21A
Beverly Hills, CA 90211
(213) 650-1234

Extensive bereavement and support programs.

**HEALTH CARE FINANCING
ADMINISTRATION (10)**

U. S. Department of Health and Human Services
200 Independence Ave., SW
Washington, DC 20201
(800) 772-1213, (202) 619-0100

Free publications include: *Medicare Handbook 1996, Guide to Health Insurance for People With Medicare*, and *Medicare and Advance Directives*.

**HEALTH INSURANCE ASSOCIATION OF
AMERICA (9)**

Consumer Information Service
555 13th St. NW, Suite 600 East
Washington, DC 20004-1109
(800) 635-1271

Publishes a free *Guide to Long-Term Care Insurance*. Also publishes at no charge a list of companies that offer long-term care insurance policies.

**HEALTH INSURANCE COUNSELING AND
ADVOCACY PROGRAM (HICAP) (9)**

Check "Government Listings" in phone book under "State", to obtain the phone numbers for either the State Insurance Division - Consumer Affairs, or the State Office on Aging for a referral to the state's HICAP counselor(s).

HELP FOR INCONTINENT PEOPLE (7)

P.O. Box 8310
Spartanburg, SC 29305
(800) 252-3337, (803) 579-7900

Low-cost educational leaflets, books and audio-visu-als. *Resource Guide* of products and services. Referrals to local support groups.

HOSPICE ASSOCIATION OF AMERICA (11)

519 C St. NE
Washington, DC 20002
(202) 546-4759

Publishes booklets and brochures about hospice services. Call to request a catalogue.

HOSPICE EDUCATION INSTITUTE (11)

Hospice Link
190 W. Brook Rd.
Essex, CT 06426
(800) 331-1620

Information and local referrals.

**HUNTINGTON'S DISEASE SOCIETY OF
AMERICA (7)**

140 W. 22nd St., Sixth Floor
New York, NY 10011-2420
(800) 345-HDSA, (212) 242-1968

Pamphlets, audio-visu-als, nationwide chapters and support groups.

**INDIANA LONG-TERM CARE PROGRAM (6,
9)**

Family & Social Services Administration
402 W. Washington Street, W353
Indianapolis, IN 46204
(317) 232-2187

Arrangement whereby Medicaid and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. Indiana residents may call toll-free, (800) 452-4800 for information.

**INSTITUTE OF CERTIFIED FINANCIAL
PLANNERS (9)**

3801 E. Florida Ave., Suite 708
Denver, CO 80210
(800) 282-7526, (303) 751-7600

Will send a list of Certified Financial Planners who practice in your zip code area. Publishes a free brochure *Selecting a Qualified Financial Planning Professional: Twelve Questions to Consider*.

**INTERNATIONAL ASSOCIATION FOR
FINANCIAL PLANNING (9)**

5775 Glenridge Drive, NE, Suite B-300
Atlanta, GA 30328-5364
(800) 945-IAFP

Publishes a free brochure, *Consumer Guide to Comprehensive Financial Planning*, and will provide a list of qualified advisors in your area.

MEDICARE INSURANCE HELP LINE (10)

(800) SSA-1213

Social Security Administration service for answering questions about Medicare.

**NATIONAL ACADEMY OF ELDER LAW
ATTORNEYS, INC. (8)**

1604 N. Country Club Road
Tucson, AZ 85716
(520) 881-4005

List of local referrals sent out for a fee. Free booklet, *Questions & Answers When Looking for an Elder Law Attorney*.

NATIONAL ADULT DAY SERVICES ASSOCIATION (6)

c/o National Council on the Aging, Inc. (NCOA)
409 3rd St., SW, Suite 200
Washington, DC 20024
(202) 479-1200

Provides the following free information: *Adult Day Care Fact Sheet*, *Why Adult Day Care* and *Your Guide to Selecting an Adult Day Center* brochures, and the National Council on Aging (NCOA) *Resources* catalogue that describes the agency and its publications.

NATIONAL ALLIANCE FOR THE MENTALLY ILL (7)

200 N. Glene Road, Suite 1015
Arlington, VA 22203-3754
(703) 524-7600, (800) 950-6264

Medical information series, support groups and local chapters.

NATIONAL ASSOCIATION FOR HOME CARE (6)

519 C St. NE
Washington, DC 20002
(202) 547-7424

Provides referrals to local home health agencies. Publishes a free brochure, *What Is Home Care?*

NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING (2, 3, 4, 6)

1112 16th St. NW, Suite 100
Washington, DC 20036
(202) 296-8130

Local referrals through Area Agencies on Aging across the country.

NATIONAL ASSOCIATION OF PROFESSIONAL GERIATRIC CARE MANAGERS (2, 3, 4, 5)

1604 N. Country Club Road
Tucson, AZ 85716
(520) 881-8008

Information and local referrals to care managers throughout the United States. Provides a listing of care managers in your area if you send a self-addressed, stamped envelope.

NATIONAL ASSOCIATION OF INSURANCE COMMISSIONERS (9)

120 W. 12th St., Suite 1100
Kansas City, MO 64105
(816) 842-3600

Publishes a free brochure, *A Shopper's Guide to Long-term Care Insurance*.

NATIONAL ASSOCIATION OF PERSONAL FINANCIAL ADVISORS (9)

355 W. Dundee Road, Suite 107
Buffalo Grove, IL 60089-3500
(800) 366-2732, (708) 557-7722

Professional group of fee-only planners. Publishes a free brochure about "fee-only planning" and will send it along with names of fee-only financial planners in a given area.

NATIONAL CATHOLIC MINISTRY TO THE BEREAVED (11)

9412 Heath Ave.
Cleveland, OH 44102
(216) 441-2125

Support and referral services for Catholic families.

NATIONAL CAUCUS AND CENTER ON BLACK AGED (3)

1424 K St. NW, Suite 500
Washington, DC 20005
(202) 637-8400

Referrals to community and local resources.

NATIONAL CENTER FOR HOME EQUITY CONVERSION (NCHEC) (6, 9)

7373 147th St. West, Suite 115
Apple Valley, MN 55124
(612) 953-4474

Free information on reverse mortgages. They also publish: *Your New Retirement Nest Egg*, by Ken Scholen, NCHEC Press, 1995, \$24.95. 336 pages.

NATIONAL CENTER ON ELDER ABUSE (8)

810 First St. NE, Suite 500
Washington, DC 20002-4257
(202) 682-2470

Offers a free information packet that includes articles, statistics and a publications catalogue. Can also refer you to state adult protective services agencies.

NATIONAL CITIZENS COALITION FOR NURSING HOME REFORM (6)

1424 16th St. NW, Suite 202
Washington, DC 20036-2211
(202) 332-2275

Consumer advocacy organization connecting individuals to local aging resources. Publishes a catalogue listing consumer guides for sale.

NATIONAL CLEARINGHOUSE FOR LEGAL SERVICES, INC. (8)

205 W. Monroe St., Second Floor
Chicago, IL 60606-5013
(312) 263-3830

Catalog of publications on housing, senior citizens and health.

NATIONAL COUNCIL OF SENIOR

CITIZENS (3, 6)

1331 F St. NW, Suite 800
 Washington, DC 20004-1171
 (202) 624-9340

Nursing Home Information Center including a nursing home locator service. Publishes a nursing home residents *Bill of Rights* and *Coping With Aging* series.

NATIONAL COUNCIL ON THE AGING, INC. (NCOA) (3, 4, 5, 6, 7, 8, 9, 11)

409 Third Street, SW, Second Floor
 Washington, DC 20024
 (202) 479-1200

National membership association serving professionals and volunteers who work on behalf of older adults and their families. Operates an information center to handle requests for information from the public including information on choosing a nursing home.

Publishes a variety of materials on a range of aging issues including: senior centers, adult day care services, family care giving, health promotion, and financial issues. A publications catalogue is free upon request.

NATIONAL ELDERCARE INSTITUTE ON HOUSING (6)

Andrus Gerontology Center
 University of Southern California
 Los Angeles, CA 90089-0191
 (213) 740-1364

Information on senior housing alternatives.

NATIONAL ENDOWMENT FOR FINANCIAL EDUCATION (9)

4695 S. Monaco Street, Department 022
 Denver, CO 80237-3403
 (303) 220-1200

Offers a free *Wealth Care Kit* that walks consumers through the processes involved in planning their financial future. For a free kit write to the address above.

NATIONAL FAMILY CAREGIVERS ASSOCIATION (3)

9223 Longbranch Parkway
 Silver Spring, MD 20901-3642
 (800) 896-3650

Membership organization serving family care givers. Publish *Take Care!*, a quarterly newsletter.

NATIONAL FUNERAL DIRECTORS' FUNERAL SERVICE CONSUMER ARBITRATION PROGRAM (11)

P.O. Box 27641
 Milwaukee, WI 53227-0641
 (414) 541-2500

Help with resolving a problem with a funeral director via arbitration.

NATIONAL HEALTH INFORMATION CENTER (7)

U.S. Department of Health and Human Services
 P.O. Box 1133
 Washington, DC 20013-1133
 (800) 336-4797

Toll-free health lines on particular diseases, publications and referrals.

NATIONAL HISPANIC COUNCIL ON AGING (3, 7)

2713 Ontario Road NW, Suite 200
 Washington, DC 20009
 (202) 265-1288

Information, advocacy, newsletter and other resources. Books available for purchase include: *Elderly Latinos: Issues and Solutions for the 21st Century* (\$20.45), *Empowering Hispanic Families: Critical Issues for the 90's* (\$20.45), and *The Hispanic Elderly: A Cultural Signature* (\$18). Prices include shipping.

NATIONAL HOSPICE ORGANIZATION (6, 11)

1901 N. Moore St., Suite 901
 Arlington, VA 22209
 (800) 658-8898 for helpline, (703) 243-5900

Information, literature and resources.

NATIONAL INDIAN COUNCIL ON AGING (3)

6400 Uptown Blvd. NE
 City Center, Suite 510W
 Albuquerque, NM 87110
 (505) 888-3302

Referrals and information for Indians and Alaskan natives nationwide.

NATIONAL INSTITUTE ON AGING INFORMATION CENTER (3, 7)

P.O. Box 8057
 Gaithersburg, MD 20898-8057
 (800) 222-2225

Publishes a variety of useful booklets including: *Who? What? Where?: Resources for Women's Health and Aging and Resource Directory for Older People*. Distributes *Ages Pages* series on a variety of health topics. Request a list of free publications.

NATIONAL INSTITUTE ON DRUG ABUSE (7)

U.S. Department of Health and Human Services
 (800) 729-6686 to order (from the National Clearinghouse for Alcohol & Drug Information) publication No. PHD 500, *Using Your Medicines Wisely: A Guide for the Elderly*.

NATIONAL INSTITUTES OF HEALTH (3)

9000 Rockville Pike
 Bethesda, MD 20892
 (301) 496-4000

Many publications on aging, health and disease-related topics. Publishes *Ages Pages* series distributed through the

**NATIONAL INSURANCE CONSUMERS
HELPLINE (9)**

1001 Pennsylvania Avenue, NW
Washington, DC 20004
(800) 942-4242

Information and referrals on the following insurance types: life, health (including long-term care, Medicare), home, business and auto. An insurance industry service which does not promote specific companies. Referrals to elder care agencies as needed or requested.

**NATIONAL MEALS ON WHEELS FOUNDATION
(7)**

2675 44th St. SW, Suite 305
Grand Rapids, MI 49509
(616) 531-9909

Hotline for service and volunteer referrals.

**NATIONAL PACIFIC/ASIAN RESOURCE
CENTER ON AGING (3,7)**

Melbourne Tower
1511 Third Ave., Suite 914
Seattle, WA 98101
(206) 624-1221

Concerned with improving services for Pacific and Asian elderly. Information, direct services and quarterly newsletter.

**NATIONAL RURAL HEALTH ASSOCIATION
(4)**

1 W. Armour Blvd., Suite 301
Kansas City, MO 64111
(816) 756-3140

Publications, resources, products and newsletter.

NATIONAL SAFETY COUNCIL (3, 6)

1121 Spring Lake Drive
Itasca, IL 60143
(312) 527-4800, 1-800-621-7619

Extensive information on safety and health topics.

**NATIONAL SENIOR CITIZENS LAW CENTER
(8)**

1815 H St., N.W., Suite 700
Washington, DC 20006
(202) 887-5280

Call to request a free publications catalogue.

**NATIONAL SHARED HOUSING RESOURCE
CENTER (6)**

321 E. 25th Street
Baltimore, MD 21218
(410) 235-4454

Local referrals.

NEW WAYS TO WORK (3, 4)

785 Market Street, Suite 950
 San Francisco, CA 94103
 (415) 995-9860

Provides information about how to restructure jobs for care givers who work full-time.

NEW YORK STATE PARTNERSHIP FOR LONG-TERM CARE (6, 9)

NYS DSS
 40 North Pearl Street
 Albany, NY 12243
 (518) 473-7705

Arrangement whereby Medicaid and private insurance companies offer policies with greater asset protection than usual with long-term care insurance policies. New York residents can call for information.

NOLO PRESS (8, 9)

950 Parker St.
 Berkeley, CA 94710-9867
 (800) 992-6656

Publishes books and software on estate planning, long-term care insurance, wills, conservatorships and nursing homes. Prices vary; call for a free publications catalogue.

OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION (7)

U.S. Department of Health and Human Services Information Center
 (800) 336-4797

Information and referral for health questions. Spanish-speaking staff available.

OLDER WOMEN'S LEAGUE (3, 6, 8, 9)

666 11th St. NW, Suite 700
 Washington, DC 20001
 (202) 783-6686

Publications include topics on elder women and poverty, care giving, pensions, legal, housing and long-term care.

PARKINSON'S DISEASE FOUNDATION (7)

William Black Medical Research Building
 Columbia Presbyterian Medical Center
 650 W. 168th St., New York, NY 10032
 (800) 457-6676

Information about support groups by zip code.

SHEPHERD'S CENTERS OF AMERICA (3, 5, 6, 7, 11)

6700 Troost, Suite 616
 Kansas City, MO 64131
 (816) 523-1080

Interfaith ministry programs and home services including hospice, handyman, shopping, transportation, respite, meals and telephone reassurance.

SIMON FOUNDATION FOR CONTINENCE (7)

P.O. Box 815
 Wilmette, IL 60091
 (708) 864-3913

(800) 23-SIMON: 24-hour hotline for free information packets.

SOCIAL SECURITY ADMINISTRATION (10)

6401 Security Blvd., Room 4J5
 West High Rise, Baltimore, MD 21235
 (800) 772-1213

Free publications include: *Understanding Social Security, Medicare and Coordinated Care Plans*, and *Hospice Benefits*. Telephone counselors will answer questions and set-up appointments.

UNITED SENIORS HEALTH COOPERATIVE (9, 10)

1331 H St. NW, Suite 500
 Washington, DC 20005-4706
 (202) 393-6222

Publications catalogue lists mae following sites through the AGING PARENTS web site (www.agingparents.com) or go to them directly.

VOLUNTEERS OF AMERICA INC.

110 South Union Street, 2nd Floor
 Alexandria, VA 22314
 (800) 899-0089

(703) 548-2288

A national organization with programs for elderly, including affordable housing, assisted living centers and home improvements. Call for more information.

Reading List

- Age Wave: The Challenges and Opportunities of an Aging America. Ken Dychtwald and Joe Flower. St. Martin's Press, 1989. \$19.95. 380 p.
- Aging is a Family Affair. Victoria Bumagin and Kathryn Hirn. Thomas A. Crowell, New York, 1979.
- Alzheimer's: A Caregiver's Guide and Sourcebook. Howard Gruetzner. John Wiley & Sons, 1992. \$14.95. 310 p.
- Answers: The Magazine for Adult Children of Aging Parents. 201 Tamal Vista Blvd., Corte Madera, CA 94925. (415) 924-4737, FAX (415) 924-7027.
- Aerobics of the Mind: Keeping the Mind Active in Aging. Marge Engleman. Venture Publishing, 1997. \$15.95.
- Beat the Nursing Home Trap: A Consumer's Guide to Choosing & Financing Long-Term Care. Joseph Matthews. Nolo Press Self-Help Law, 1993. \$18.95.
- The Caregiver's Guide: Helping Elderly Relatives Cope With Health & Safety Problems. Caroline Rob. Houghton Mifflin, 1991. \$14.95.
- Care Pooling: How to get the Help You Need to Care for the Ones You Love. Paula C. Lowe. Berrett-Koehler Publishers, 1993. \$14.95. 300 p.
- The Caregiver's Manual: A Guide to Helping the Elderly and Infirm. Gene B. Williams and Patie Kay. Citadel Press, 1995. \$14.95. 366 p.
- Care Log: A Planning & Organizing Aid for Long Distance Caregivers. Angela Heath. Impact Publisher/American Source Books, 1993. \$14.95. 66 p.
- The Caregivers' Roller Coaster: A Practical Guide to Caregiving for the Frail Elderly. Billie Jackson. Loyola University Press, 1993. 170 p.
- Caring for Your Aging Parents: A Planning and Action Guide. Donna Cohen and Carl Eisdorfer. Tarcher/Putnam. \$10.95. 272 p.
- Caring for Your Aging Parents: A Sourcebook of Timesaving Techniques and Tips. Kerri S. Smith. American Source Books, 1992. \$8.95. 117 p.
- Caring for Your Own Dead. Lisa Carlson. Upper Access Book Publishers, P.O. Box 457, Hinesburg, VT 05461. (800) 356-9315. \$12.95. 343 p.
- A Chart System & Guide for Home Care. Loyola Domeno. 2101 Carlmont Drive, Suite 204, Belmont, CA 94002-3407. \$22.50.
- Complaints of a Dutiful Daughter. Debbie Hoffmann. Video from Women Make Movies, 462 Broadway, Suite 500, New York, NY 10013. (212) 925-0606.
- The Complete Book of Trusts: Everything You Need to Know to Protect Yourself and Your Estate. Martin M. Shenkman. John Wiley & Sons, 1993. \$19.95. 291 p.
- Death: The Final Stage of Growth. Elisabeth Kubler-Ross. Simon & Schuster, 1975. \$8.95. 192 p.
- Elder Care: Choosing and Financing Long Term Care. Joseph Matthews. Nolo Press. \$20.95.
- The Family Carebook: A Comprehensive Guide for Families of Older Adults. Dennis E. Kenny and Elizabeth N. Oettinger. CAREsource Program Development Inc., 1991. 505 Seattle Tower, 1218 Third Ave., Seattle, WA 98101-3021. (206) 625-9128. \$12.95. 464 p.
- Final Details: Planning for Difficult Times. American Association of Retired Persons (AARP) Books.
- From Ageing to Sageing: A Profound New Vision of Growing Older. Zalman Schachter-Shalomi and Ronald S. Miller. Warner Books, 1995. \$21.95. 303 p.
- Giving Comfort: What You Can Do When Someone You Love Is Ill. Linda Breiner Milstein. Penguin Books, 1994. \$6.95. 132 p.
- Growing Older, Growing Better: Daily Meditations for Celebrating Aging. Amy E. Dean. Hay House, 1996. \$12.00.
- A Guide to Finding the Best Long-Term Care. Rena Dictor Le Blanc. P.O. Box 429, Woodland Hills, CA 91365-0429. 1992. \$13.50. 104 p.
- Helping Yourself Help Others: A Book for Caregivers. Rosalynn Carter. Times Books, 1994.
- Hiring Home Caregivers: The Family Guide to In-Home Eldercare. D. Helen Susik. Impact Publishers/American

- Source Books, 1995. \$11.95. 105 p.
- Home Planning for Your Later Years William K. Wasch. Beverly Craycom Publications, 1996. (800) 341-0880. \$19.95. 181 p.
- The Hospice Handbook. Larry Beresford. Little, Brown and Co., 1993. \$12.95. 166 p.
- How and Why We Age. Leonard Hayflick. Ballantine Books, 1994. \$24.00. 378 p.
- How to Care for Your Aging Parents: A Practical Guide. Nora Jean Levin. W.W. Norton, 1996. (212) 354-5500. \$11.00. 192 p.
- How to Survive the Loss of a Love. Melba Colgrove, Harold H. Bloomfield and Peter McWilliams. Bantam/Prelude, 1991. \$10.00. 212 p.
- In Her Own Right: The Institute of Medicine's Guide to Women's Health Issues. Beryl Lief Benderly. National Academy Press, 1997. \$29.95.
- In Our Fifties: Voices of Men and Women Reinventing Their Lives. William H. Bergquist, Elinor Miller Greensberg, and G. Alan Klaum. Jossey-Bass, Inc., 1996. \$25.00.
- The Jacoby & Meyers Law Offices Guide to Senior Citizens' Rights. Gail J. Koff. Henry Holt & Co., 1992. \$5.95. 95 p.
- Keeping Active: A Caregiver's Guide to Activities With the Elderly. Susan C. Walker. Impact Publishers/American Source Books, 1994. \$9.95. 126 p.
- Last Touch: Preparing for a Parent's Death. Marilyn R. Becker. New Harbinger Publications, Inc., 1996. \$11.95.
- Life Begins At 50: A Handbook for Creative Retirement Planning. Leonard J. Hansen. Barrons. 1990. \$12.95. 248 p.
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