



*End-of-Life
Financial Issues*

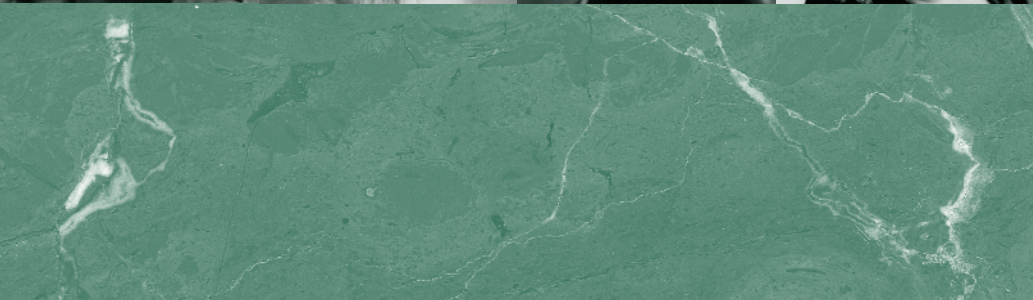




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Introduction

There are many challenges individuals—and their families—face at the end of life. One that can be particularly difficult is financial planning. How do I pay for health-care and living expenses? What happens when I can't handle my own financial affairs? Do I have enough to take care of my family?

End-of-life financial planning takes extra effort, but you are not alone. Caring Connections, a program of the National Hospice and Palliative Care Organization, is working to provide easy access to



reliable, end-of-life financial information and resources. We hope that the information in this booklet will help you understand your options and choices—and take away some of the mystery and anxiety you may be feeling about money issues at this stage of life. Above all, we hope it frees you to focus on what matters to you most.





Chapter 1

Assess Your Financial Situation—and Keep Control

Money worries can keep you from enjoying the important things in life—family, friends, favorite activities. That’s true at every stage of our adult lives, not just at the end of life. But you may be feeling more anxious about money now.

The good news is that there are some simple steps you can take, with help from family and friends as you need it, to eliminate or minimize those worries—and keep control over your money. The first step is to determine where you stand financially. What money and assets do you have? How quickly can your assets provide money if you need it? What goals involving money do you want to be sure to accomplish? Information in this chapter can help you answer these, and other, questions.

Make a Financial Inventory

A financial inventory is a list of:

- Your financial assets and loans, account numbers, and company and contact information
- Important documents and paperwork and where those can be found
- Key people to contact

A financial inventory worksheet may help you get started. The worksheet, titled *My Financial Inventory*, can be downloaded from the Resource section of www.caringinfo.org. Once completed, keep it in a safe place—and tell a trusted relative or friend where you keep it.

Determine Where You Stand

Now that you have your financial inventory, you can organize the information and develop a snapshot of your total financial situation by using the worksheet titled *Your Assets, Liabilities, and Net Worth* (download the worksheet from www.caringinfo.org). To complete this worksheet:

- Write down the “fair market value” of everything you own, including your home, car, savings, and investments, then add these up. These are your total assets. Fair market value is the amount you could get if you sold these possessions and is not the same as an insurance value. For example, you can go to www.kbb.com to see the Kelly Blue Book value for your car and to investment Web sites to determine the value of your stocks and mutual funds. You also can hire an appraiser to come to your home and determine the market value of your possessions.



- Write down the full amounts (not just the monthly payments) of what you are legally required to repay on your home, car, credit cards and other loans, and add them up. These are your total liabilities. You may have made financial commitments to others that are not legal liabilities, such as making tuition payments for a child or grandchild. The best way to ensure your money pays for those commitments after your death is by leaving instructions in your will (read more about wills on page 13). In the case of tuition

payments, the school may have a program that lets you pay in advance. Check with the financial aid office.

- Subtract your liabilities from your assets to learn your net worth. The higher your net worth, the more comfortable your financial position. Don't be discouraged if your net worth is a small number, or even a negative. There are sources for financial help that you can turn to for help if you need it (see page 27).

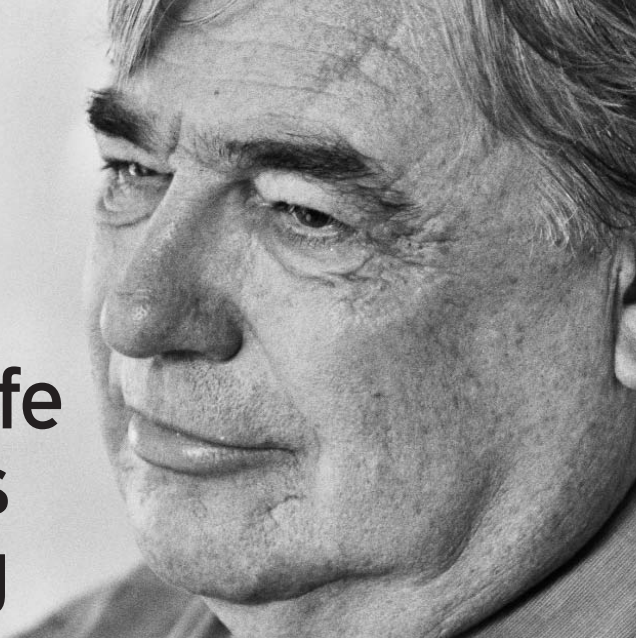
Set Goals

Based on the clear picture you now have of your financial situation, determine what goals you want to accomplish that involve money. You may want to name someone to handle money matters for you when you no longer can. You might want to use assets like your house or retirement fund to provide cash to pay bills. Maybe you have grandchildren or a favorite charity you want to leave money to. Setting goals is easy—just jot down some possible goals on a piece of paper—or on the My Financial Goals worksheet. (This worksheet can be downloaded from the Resource section of www.caringinfo.org.) Then prioritize them, starting with the goal that is the most urgent or important to you.

Chapter 2

Put End-of-Life Decisions in Writing

This section deals with personal issues that are important, but often difficult to face, such as how bills and expenses will be paid if you aren't able to, what medical care you want to receive if you can't voice your wishes, who you want to take care of your children after your death, and how you want to give your money and possessions to others upon your death. You may have been thinking about these matters and have made decisions about them. Now take the next step and put those decisions in writing. You may rest easier—and free your loved ones from the difficult task of making medical and financial decisions for you without knowing your wishes.



Prepare For the Time When You Cannot Handle Money Matters

If you're worried about how your bills will be paid, checks deposited, or investments made when you no longer have the energy or ability to do it yourself, there's a solution. By filling out a simple legal document called a durable power of attorney, you can give a relative or friend the legal right to handle money matters for you when you can no longer handle them yourself. (A general power of attorney only gives another person the legal right to do this for you while you are capable of handling your finances yourself. When you no longer can, the general power of attorney ends. Because that's when you want help the most, be sure the document you create is a "durable" power of attorney.)

You'll want to carefully consider who you name to handle your affairs. Naturally, it should be someone you trust very much—and someone who agrees to do things according to your wishes. The document will be canceled upon your death and your financial matters will be handled according to your directions in your will. A few notes about durable power of attorney preparation:

- State laws describe how a durable power of attorney must be prepared. Some states even require the use of a specific form, so you'll want to be sure you get the correct one for your state.
- Unsure where to go to get the forms you need? Ask your health-care provider for suggestions or call the local Legal Aid Society (www.findlegalhelp.org) or Area Agency on Aging (www.n4a.org).
- Office supply stores may carry durable power of attorney forms and your state Bar Association or Medical Society may be able to help.



- Some financial software also contains legal forms and there are many online resources that offer these forms for a small fee.
- In most cases, you will not have to file a copy of the document with your state. The exception is when real estate transactions are involved.
- Once you have filled out and signed your form, you may need to have it notarized (banks usually provide notary service). Some states also require witnesses to watch you sign the form and then sign it themselves.
- It can be a good idea to consult a lawyer to make sure your legal documents provide the protection you want.

Prepare For the Time When You Cannot Voice Your Health Care Wishes

Accidents, illness, and the aging process can take away the ability to make and communicate decisions about our own health-care. By preparing for that time now, you can make sure your friends and family won't be faced with the dilemma of trying to decide what you would want. You can make your end-of-life wishes known in several simple legal documents. You don't have to go to a lawyer unless you want legal advice. Think of these documents as gifts to your family and friends—gifts of peace of mind.

Advance Directives

Advance directives are legal documents that enable you to plan for and communicate your end-of-life wishes. They are used only when you are unable to make decisions or communicate your wishes for yourself.

There are two unique types of advance directives—living wills and health-care powers of attorney. Advance directives that meet your state's legal requirements are available to you free of charge by calling the Caring Connections HelpLine at 800-658-8898 or by visiting www.caringinfo.org. Learn more about what advance directives are, what happens if you complete an advance directive, and other important information on the Advance Care Planning pages of www.caringinfo.org. Click Advance Care Planning, then click on What are Advance Directives?

Five Wishes

Millions of Americans have filled out this document to let their family and doctors know how they want to be treated if they cannot speak for themselves. It not only covers how you wish to be treated medically, but also personally, emotionally, and spiritually. Copies of Five Wishes are available for a small fee and can be ordered at www.agingwithdignity.org. The Five Wishes document is legal in all but 12 states. To find out if your

state accepts Five Wishes as a legal document click Five Wishes States on the screen.

Take Care of the People You Care About Most After You're Gone

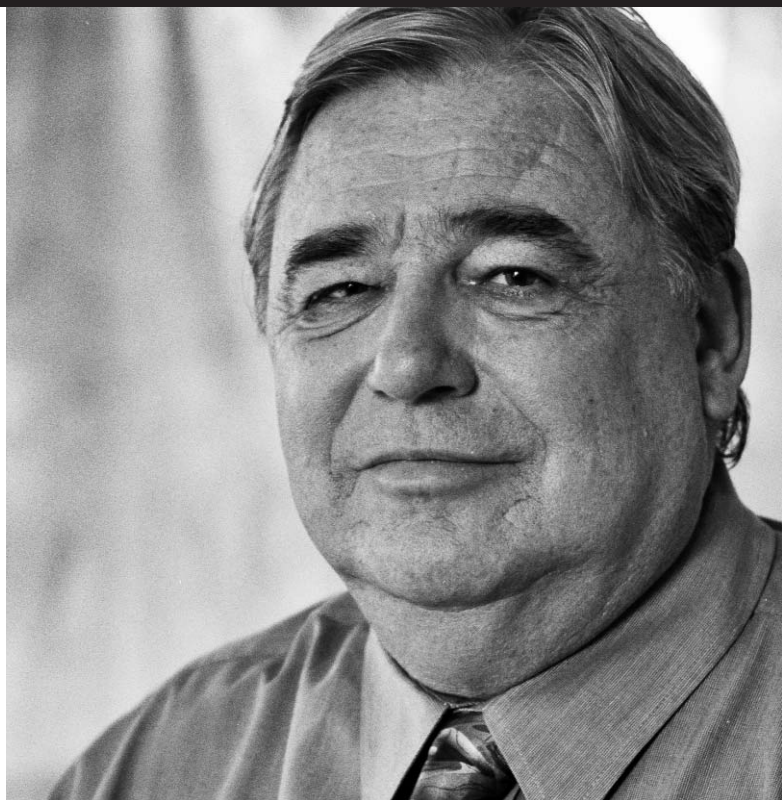
It can be tempting to think that your spouse or grown children will be able to figure out how to divide up your money and possessions after your death. But this responsibility can be complicated legally and difficult emotionally, especially when family members disagree. There are three things you can do to eliminate disagreements and make sure everyone receives exactly what you want them to receive:

- Make a will
- Update your beneficiaries
- Consider setting up Payable-on-Death accounts

Wills

Every adult should have a will, also called a last will and testament. Married individuals and those in committed relationships should each have separate wills. A will is a legal document that says who will receive your money, property, and other assets when you die and how you want your heirs, or beneficiaries, to receive those assets. If you have young children, you also can use your will to name a guardian for them. The “executor” you choose is responsible for carrying out the details of your will. Because there are so many money matters involved, consider choosing a trusted person who understands financial issues as your executor—or a knowledgeable third party such as a bank or law firm.

If you die without a will, the state will decide who will get your assets and who will look after your children. Wills can be



complex documents, and they must meet the requirements of your state's laws. You don't have to use a lawyer to help with your will. Some people, especially those with young children or who have significant financial assets, find it helpful to work with a qualified estate lawyer to help them draft a will—or update it when they want to make a change. You can change the details of your will anytime, as long as you are mentally capable.

Some of the information you'll want to gather before making your will includes:

- Your financial inventory listing all your personal assets, such as home, car, savings accounts, investments, furniture
- Names and addresses of family, friends and organizations you plan to name as your beneficiaries

- A list of what you want to leave specifically to each person and organization
- If you have young children, the names and addresses of the people who have agreed to be their guardians
- The name and address of your executor

If you would like legal advice and assistance in making your will, but don't know a lawyer, the information in "How to Find a Qualified Estate Lawyer" on page 17 may be helpful.

Beneficiaries

If you own a life insurance policy, or have a retirement plan at work or at a bank or brokerage firm, you were asked to name one or more beneficiaries to receive the money directly at your death. You might have named secondary beneficiaries, too, in case the first ones died. As you near life's end, and especially if your family situation has changed due to death, divorce, or remarriage, look at all your beneficiary selections. Are they up to date? Do they match the wishes stated in your will? If one person is named in your will to receive money from your life insurance policy, but another is listed on your policy as the beneficiary, the person named in the policy as the beneficiary will get the money.

Payable-on-Death Accounts

By setting up your bank, brokerage, or other type of account as a Payable-on-Death (POD) account, you can name a beneficiary to receive all the money in that account directly when you die. The beneficiary, who can be a person or an organization such as a favorite charity, cannot get money from your account while you are alive. POD accounts, which also are called Transfer-on-Death (TOD) accounts, generally are easy to set up at banks, brokerage firms, and other financial institutions. There may be a fee. Ask your banker, broker, or financial advisor for information about setting up your account as a POD.

Share Your Decisions

Even if you have made your end-of-life decisions and completed all the necessary legal documents, there's one more step to take to make sure your decisions will be followed. Share your decisions with family and friends, health-care providers, faith leaders, and legal and financial advisors. If you're not sure how to start an end-of-life conversation, you can find some helpful advice at *Communicating Your End-of-Life Wishes* at www.caringinfo.org; click Advance Care Planning, then click on *Communicating Your End-of-Life Wishes*. Also, let everyone know where your legal documents can be found. There's a place to list these on your *My Financial Inventory* worksheet (see page 6).

Let People Know Where You Keep Important Papers and Records

Keep your durable power of attorney, advance directives, and will in a safe place in your home and let people know where that is. Although a safe deposit box sounds like a good place to keep these important documents, it has two big drawbacks: The box is only available when the bank is open and only to people who are signers on the box with you. You could keep originals in your box for safekeeping and keep copies at home.

A checklist of some household records (or copies of records) that are best kept in a safe deposit box can be downloaded from www.caringinfo.org. The checklist, titled *Where to Keep Important Papers and Records*, also includes a list of documents to keep in a safe place at home, where they are more easily and immediately available.

How to Find a Qualified Estate Lawyer

Because there are so many types of laws, lawyers usually specialize in one area of the law. For help preparing end-of-life documents, especially wills, it's a good idea to look for a specialist in estate planning. How do you find an estate lawyer who can help you, who will be easy to work with, and whose fees will be affordable? Start by taking these steps:

- Ask family, friends, doctors, faith leaders, social workers or your local hospice for recommendations.
- Call your local bar association and ask for a list of estate planning lawyers or Elder Law specialists. Elder Law is a relatively new legal area that, depending on the lawyer, can include help with estate planning, as well as with Medicare and Social Security, and issues such as long-term care and health-care decision making. To find a lawyer or legal information in your state, go to www.abanet.org; click on the right hand column for Find Legal Help and click your state on the map that appears on the screen.
- If your city or county has a Legal Aid Society, and you qualify for assistance, you may be able to get free or low-cost help with legal issues, including your estate. Look under Legal Aid in the business pages of your phone book—or go to www.abanet.org; click on the right hand column for Find Legal Help and click your state on the map that appears on the screen.
- Talk with two or three lawyers about your needs. This can be done over the phone. Some questions to ask:
 - Will the lawyer provide a free consultation for an initial interview?

- How long has the lawyer been in practice?
- What percentage of the lawyer's practice is estate planning? (The higher the better.)
- What experience does the lawyer have working with people who are at the end of life? A lawyer with experience in handling cases like yours should be more efficient and knowledgeable, and that may save you money.
- What type of fee arrangement does the lawyer require? Are the fees negotiable?
- What type of information do you need to provide?
- Ask for referrals. Ask lawyers you're considering working with to give you the names of clients you can contact.



Chapter 3

Learn About Palliative and Hospice Care Costs and Benefits

Palliative care, a relatively new medical term, has been provided by hospice programs for more than 30 years. It is now being used by other health-care providers to help people who are seriously ill. Palliative care and hospice focus on helping a person be comfortable by addressing issues causing physical or emotional pain or suffering. The goals of palliative care are to improve the quality of a seriously ill person's life and to provide support to their family during and after treatment. The goals of hospice are to relieve symptoms and support patients with a life expectancy of months, not years, and their families. Hospice is a defined set of services, while palliative care is not.

If you are considering palliative care or hospice, www.caringinfo.org has information on subjects ranging from Choosing a

Hospice and Choosing a Palliative Care Program to What is Hospice? and How Does Hospice Work?

Two of your biggest questions may be how much palliative care and hospice costs and how you will pay for it. Hospice is covered under the Medicare Hospice Benefit, the Medicaid Hospice Benefit and most private health insurance plans. Palliative care may be covered by Medicare, Medicaid, or your private health insurance or long-term care insurance plan, HMO, or other managed care organization. If you don't have insurance, or your insurance does not cover hospice, don't let worries about cost keep you from contacting hospice. While each hospice has its own policies concerning payment, it is a tradition of hospice to offer services based on need, rather than on the ability to pay.

What Palliative Care Benefits Are Available?

Palliative care primarily involves services by health-care providers such as hospitals, hospices, or other community health providers to improve the quality of a seriously ill person's life and to support that person and his or her family during and after treatment. Read more about palliative care at www.caringinfo.org. Click Hospice, located at the top bar; then, click on What is Palliative Care?

Medicare

If you have Medicare (www.medicare.gov) Part B (medical insurance), it may cover some treatments and medications that provide palliative care, including visits from doctors, nurse practitioners and social workers. Medicare does not use the term palliative, so coverage is provided by standard Medicare Part B benefits. The palliative care provider (the organization offering you the services) will bill Medicare for services provided, but be sure you understand what co-pays or fees, if any, you will be asked to pay. Ask about your responsibility for

fees and request a fee schedule before agreeing to receive services.

Medicaid

If you are covered by Medicaid (www.cms.hhs.gov; click on Medicaid), a health insurance plan for people with low income and few assets, it may cover some palliative treatments and medications, including visits from doctors. Medicaid does not use the term palliative, so coverage is provided by standard Medicaid benefits. The palliative care provider (the organization offering you the services) will bill Medicaid for services provided, but be sure you understand what co-pays or fees, if any, you will be asked to pay. Ask about your responsibility for fees and request a fee schedule before agreeing to receive services.

Private Insurance, HMOs, Managed Care Programs

Many private health insurance plans provide some coverage for palliative care, as part of their hospice or chronic care benefits. If you own a long-term care policy, there may be palliative care benefits provided by that policy. Check with your health insurance or long-term care insurance representative.





Do I Have Hospice Benefits?

Medicare, Medicaid, private insurance plans, HMOs, and other managed care organizations usually provide hospice benefits. Keep in mind that these benefits reflect these facts about hospice:

- Hospice focuses on caring, not curing. Your hospice team will provide expert medical care, pain management, and emotional and spiritual support tailored to your needs.
- Hospice is a philosophy of care and can be delivered to wherever the patient calls home. In most cases, care is provided in the patient's (or another person's) home. It also is provided in freestanding hospice centers, hospitals, and other long-term care facilities.
- Hospice services are available to patients of any age, religion, race, or illness. You can continue to receive hospice for as long as your physician and hospice team, upon assessing your condition, determines that your illness continues to be life-limiting.

Medicare

There is a specific benefit for hospice called the Medicare Hospice Benefit. You can get the Medicare Hospice Benefits if:

- You are eligible for Medicare Part A (hospital insurance); and
- Your doctor and the hospice medical director certify that you have a life-limiting illness and have six months or less to live if your illness runs its normal course; and
- You sign a statement choosing hospice instead of curative treatment and standard Medicare-covered benefits for your life-limiting illness; and
- You enroll in a Medicare-approved hospice program. (More than 90 percent of hospices in the United States are Medicare certified.)

Other, non-terminal medical conditions you may have will be covered by your standard Medicare benefits.

Medicaid

There is a specific benefit for hospice called the Medicaid Hospice Benefit. If you have a low income and few assets, you may qualify for Medicaid (www.cms.hhs.gov; click on Medicaid, then click on Medicare Benefit Policy Manual), a health insurance plan that helps people who cannot afford to pay some or all of their medical bills. Almost every state has a Medicaid Hospice Benefit. To find out if your state does, call the Caring Connections HelpLine at 800-658-8898.

Private Insurance, HMOs, Managed Care Programs

It is very likely that your private health insurance plan includes a hospice benefit. If you own a long-term care policy, it may include hospice benefits. To find out, talk with your health insurance or long-term care insurance representative. Also ask if there are any limits on the amount of hospice care benefits your insurance will pay for. If there are, talk with a hospice representative about financial resources you may be able to tap into if your hospice benefit limits are exceeded. It's a good idea to do this before enrolling in hospice. Keep in mind that you will not be asked to leave hospice simply because you cannot continue to pay for your care.



What Hospice Costs are Covered?

Hospice benefits are provided on a per day (per diem) basis to the hospice provider. The hospice benefit is comprehensive, which means that all services, medications and equipment related to the person's hospice diagnosis are paid by the hospice. This can save patients and families a tremendous amount of money in co-pays and direct expenses because the highest co-pay a hospice can charge under Medicare or Medicaid is \$5.

Specific services are found on www.caringinfo.org, then click on Financial Planning located at the top of the Web page. Then, click on Who Pays for Hospice and Palliative Care?

What Hospice Costs are Not Covered?

Generally, Medicare, Medicaid, and private insurance will not pay for:

- Treatment, including medications, equipment and supplies, for conditions unrelated to the life-limiting illness.
- Care from physicians or other health-care providers that is not set up by hospice.
- Room and board if you live at home, in a nursing home, or in a hospice residential facility.
- Emergency room visits, inpatient facility care and ambulance transportation, unless arranged by your hospice medical team.



Chapter 4

Sources of Financial Help

If you are 65 or older, Medicare probably will be your primary source of end-of-life financial help for medical care, including hospice. If you are younger than 65, and are covered by a health insurance plan at work, that plan likely will provide the most financial help with medical and hospice expenses. Don't be afraid to contact your employer when you receive a diagnosis of a life-limiting illness. Find out exactly what medical care benefits your plan will provide. Does it cover disability? Hospice? If you have hospice benefits, is there a limit on the amount your plan will pay for?

If you are younger than 65 and don't have health insurance, you may be eligible for government programs such as Medicaid. Keep in mind, too, that hospice will not turn you away if you are unable to pay for care.

They will work with you to ensure you receive comfort and care at the end of life.

Where can you turn for financial help if you need it to pay medical expenses, and take care of your family while paying bills and expenses? First, take a look at your own financial assets, the ones you listed on your My Financial Inventory worksheet (see page 6). You may be able to get help from your insurance policies, retirement savings, or equity in your home.

The second source of possible financial help is government and community resources, including Social Security benefits, Area Agencies on Aging, drug assistance plans, resources for veterans, or specialized support organizations. Finally, you may be able to free up some money by managing debts.

Don't miss any opportunity to get help if you need it. The information in this section can help you take advantage of some or all of these resources, depending on your personal situation. There are also some tips for protecting yourself against financial fraud. If you're feeling overwhelmed, the last section of this chapter lists some additional sources of financial advice.

Insurance

Insurance plans can be important sources of end-of-life financial assistance and support.

Health Insurance

If your company's health insurance plan offers hospice benefits, you will be able to use those benefits for the rest of your life—or until you reach the plan's hospice benefit limit. If your plan does not offer hospice benefits, you still may want to keep coverage in that plan as long as possible, both for you and family members. First, check to see if your plan has a "disability extension of benefits." This means that, even though you are no

longer covered by the plan generally, your illness may continue to be covered.

Family and medical leave

If there is no disability extension, take advantage of the Family and Medical Leave Act (FMLA) if you can. (www.dol.gov. On the left hand column, click on workers under the heading of audience. Then, click on Family and Medical Leave Act (FMLA).) All companies with 50 or more employees are required to offer FMLA. This law gives you the right to take up to 12 weeks of unpaid leave and stay on your employer's health-care plan during your leave. You will have to continue to pay your portion of the premium. After your leave is used up, you may be able to extend insurance coverage further through the Consolidated Omnibus Budget Reconciliation Act (COBRA) (www.dol.gov. Then click on Health Plans & Benefits. Select COBRA under subtopics.).

Extending health insurance

COBRA lets you and covered family members keep health insurance for a period ranging from 18 to 36 months. Companies with 20 or more employees are required to offer COBRA. Your employer must tell you how to take advantage of COBRA if it's available. Your cost will go up because you probably will have to pay the full premium, including the amount once paid by your employer, but your coverage will be the same as current workers. Family members covered by your plan can decide separately to take COBRA.

There is a program similar to COBRA for federal government workers called Temporary Continuation of Coverage (TCC) (www.opm.gov. Under the heading of Most Requested, located on the right hand side column, click Health Insurance. Located at the right hand column, type TCC under Search the Insurance Page. TCC will list a number of ways for you to read the information.). Ask your personnel office about this program and request a copy



of Temporary Continuation of Coverage Under the Federal Employees Health Benefits Program, Pamphlet RI 79-27.

Other options for paying for health-care

What if your COBRA coverage runs out or you can't get it because your company doesn't have to offer COBRA benefits? You may be eligible for health insurance through your state or other programs discussed in the following section.

Health insurance through your state

Your state may have health insurance laws that give people better ways to continue health insurance coverage than private insurance. To find out about your state's programs, go to the Kaiser Family Foundation Web site (www.statehealthfacts.org) and click your state on the map. You also can check with your state insurance department. For a state-by-state listing,

visit the National Association of Insurance Commissioners (NAIC) (www.naic.org) Web site or call the NAIC Help Desk at 816-783-8500.

If you don't have health insurance

Here are some programs to check out if you don't have health insurance:

- Medicare (<http://www.medicare.gov>) can pay 100 percent of your hospice costs and a portion of other medical costs if you are disabled or age 65 or older.
- Medicaid (www.cms.hhs.gov; click on Medicare) can pay 100 percent of your hospice costs, plus your Medicare premiums, deductibles, coinsurance, and some costs Medicare does not cover if you have low income and limited assets.
- Free health clinics in your community can provide some medical services.
- Many hospices provide care to people regardless of their ability to pay. Contact the National Hospice and Palliative Care Organization HelpLine at 800-658-8898 for a listing of hospices in your area.

Health savings accounts

If you have been contributing to a health savings account, you can withdraw money tax free to pay your “qualified medical expenses” or those of a spouse or dependent children. These expenses include medical care and services, dental and vision care, and over-the-counter drugs. You may be able to pay medical insurance costs as well, such as COBRA premiums and Medicare premiums, deductibles, co-pays, and coinsurance. The U.S. Treasury Department Web site (www.treas.gov. Under the heading of Taxpayers, located on the right hand column, click Health Savings Account HAS.) has information about health savings accounts, including answers to frequently asked questions.

Life Insurance

- Life insurance through an employer. If you have life insurance through an employer, ask if your policy has a “waiver of premium” benefit. The waiver generally means you won’t have to pay the policy’s premiums if you become permanently disabled due to illness or accident. If there is no waiver benefit, you may be able to change the policy to a personal policy when you leave your job, but you will have to pay the entire premium yourself.
- Life insurance you bought yourself. If you have a personal life insurance policy, find out if it has “accelerated death benefits.” If it does, you may be able to get a portion of your policy’s death benefits paid before death if you are expected to live for only six to 12 months. However, these benefits may affect your ability to qualify for some government programs, including Medicaid.

If you have a cash-value policy (whole life, universal life, and others), you might simply terminate the policy and take the cash value. If you want to keep the policy, you might be able to borrow up to 90 percent of the cash value. But you will have to pay interest on what you borrow and possibly a fee. Call your insurance agent or company and ask how much cash value is in your policy, how much you can borrow, at what interest rate and if there are any fees. You don’t have to repay the amount you borrow, but you’ll have to continue to pay interest and the amount your family receives at your death will be lower. Borrowing from a life insurance policy could result in owing income taxes, so you might want to talk with a tax professional when considering this option.

Another possible option is to sell all or a portion of your life insurance policy to a company for a percentage of its face value, generally between 50 and 80 percent. This is called a “viatical settlement” or a “life settlement.” The company receives the



proceeds from your policy upon your death instead of your heirs. A life expectancy of two years or less usually is required. Check out potential buyers of your policy very carefully before taking action. Talk with several and compare costs. For information about these settlements, and tips for selling a life insurance policy, read the National Association of Insurance Commissioners brochure, *Understanding Viatical Settlements* (www.naic.org, then click on consumer alerts, located at the bottom of the left hand column. Then, click on viatical settlements, located under the subheading of life insurance.). Another information resource is the Life Insurance Settlement Association (LISA). You can contact the association at www.lisaassociation.org or 407-894-3797.



Long-term Care Insurance

If you have a long-term care policy, contact your insurance company about your benefits and when they start. If your policy has a “Premium Refund at Death” benefit, be sure your family members and beneficiaries know. They will receive premiums you have paid on your policy up to the time of your death, minus any benefits the policy paid for your care.

Disability Insurance

Disability insurance provides income to people who become sick or hurt and are unable to work.

- Disability insurance through an employer. There are two kinds of employer disability plans:
 1. Short-term disability: Some states require employers to pay short-term disability benefits to employees who are unable to work for a year or less.
 2. Long-term disability: These plans typically replace between 60 and 70 percent of your monthly income for at least a year if you cannot work. Coverage might even continue until age 65 or for life if you meet the plan's definition of disability. You will have to pay taxes on income you receive from an employer's disability plan.

If your employer provides your plan, it is subject to what's called "coordination of benefits." This means that the amount of your disability check may be reduced if you also receive benefits from Social Security or another state or employer-sponsored program.

- Disability insurance you bought yourself. If you have a disability policy from a private insurance company, any money you receive will be free of income taxes and the coordination of benefits does not apply.

A few states, including California, Hawaii, New Jersey, New York and Rhode Island, offer programs that provide income to workers who cannot work due to disability, but whose disability was not caused by work. These programs serve as a safety net, providing some income until a worker can qualify for Social Security Disability Insurance (SSDI). Payment amounts are generally small (a percentage of your salary) and payments are made only for a short time—a year or less. If you live in one of the states with this program, ask a social worker or your HR manager for help with contacting the appropriate state agency.

Retirement Savings

Do you have a retirement savings plan at work, such as a 401(k) or 403(b) plan, or an IRA you opened on your own? Most of these plans allow you to withdraw money without penalty if you become permanently disabled or use the money to pay medical bills that exceed a certain percentage of your income. IRAs can have more penalty-free withdrawal options than employer retirement plans, so, if you have left your job, it might be a good idea to “roll over” savings in your employer plan to an IRA.

Talk with your retirement plan administrator or a representative at the company managing your IRA about withdrawal options given your life-limiting illness. Be aware that you may have to pay income taxes on money withdrawn from most retirement plans and the amount you receive may affect your ability to receive government assistance.

If you have earned a pension from an employer, you might be able to start getting payments from the pension fund—even if you are not yet 65. Contact the employer’s pension plan administrator.

Money in Your Home

Some people have more money tied up in equity in their homes than they have in savings. If this is true for you, and you are at least 62 years old, you might consider a “reverse mortgage” loan, a specialized program offered under guidelines of the U.S. Department of Housing and Urban Development (HUD) (www.hud.gov). The amount of the loan will be less than the full value of the home. You can take the money in a lump sum, as fixed monthly payments, as a line of credit, or some combination of these methods. There is no restriction on how you can use the money. You don’t have to give up title to the house and you don’t have to pay off the loan until you are no longer able to live at home, you sell the home, or you die. Be aware that these kinds of



loans can have high initial costs and also may affect whether you qualify for some government programs, including Medicaid.

The most popular and generally less expensive reverse mortgages are federally insured Home Equity Conversion Mortgages (HECM). In 2006, the maximum amount you could borrow ranged from \$362,790 in high-priced areas to \$200,160 in rural and non-metropolitan areas. Another kind of reverse mortgage is the Fannie Mae HomeKeeper loan. The maximum loan amount in 2006 is \$417,000. For more information about reverse mortgages or to find a lender who makes these loans, contact the Reverse Mortgage Lenders Association at www.reversemortgage.org or 866-264-4466. Many nonprofit organizations, such as AARP (www.aarp.org), offer consumer information and classes about reverse mortgages.

Social Security

Two Social Security programs—Social Security Disability Income (SSDI) and Supplemental Security Income (SSI)—may provide monthly income if you are under age 65 and meet the government's strict definition of disability, which is:

- It must be the result of a mental or physical condition that has lasted, or is expected to last, at least one year, and
- You must not be able to do “substantial” work. This means you are unable to earn more than a specific amount of money each month—\$860 in 2006.

Social Security Disability Insurance (SSDI)

If you have held a job and paid Social Security taxes, you may be eligible for monthly payments from the Social Security Disability Insurance (SSDI) program. The Social Security statement you receive every year tells you if you qualify for disability income and how much you could receive. If you are eligible for SSDI, it also tells you whether your spouse and children can get benefits, too. The amount depends on how much you paid in Social Security taxes when you worked. If you need a copy of your statement, call Social Security at 800-772-1213 or go online to www.socialsecurity.gov. Under the heading Resources, located on the right hand column, click on Your Social Security Statement.

Supplemental Security Income (SSI)

The Supplemental Security Income (SSI) program gives money to adults and children who are disabled, have limited income, do not have much in savings or financial assets, and have little or no work history. In 2006, the maximum monthly payment is \$603 to an individual and \$904 to couples. The amount you receive depends on your situation, including what help you receive from friends and relatives and where you live. People

who get SSI usually get food stamps and Medicaid, too. Some states will add money to the amount SSI gives. To find out more, call Social Security at 800-772-1213, or visit www.ssa.gov, then under the heading Disability and SSI, you can click on any of the subjects for more information about SSI.

How to Apply for SSDI and SSI

You can apply for SSDI or SSI by scheduling an interview in person at your local Social Security office or over the phone. The person who interviews you will ask for a lot of personal information about you and the conditions that limit your ability to work in order to fill out a Disability Report Form, SSA-3368. You also may fill out the Disability Report Form online (www.ssa.gov, then under the heading Disability and SSI, you can click on any of the subjects for more information about SSDI) and take it to the interview or mail it to the person who will be interviewing you.

It's usually best to apply for benefits with someone at the Social Security office rather than simply submitting an application online. It can take several months to hear if you are approved for SSDI payments so it's a good idea to apply as soon as you leave your job—even if you are getting money from your employer. If approved, your first SSDI check will arrive in the sixth month after Social Security finds you disabled. The first five months are considered an SSDI waiting period and you will not get any SSDI checks during those months. SSI checks can start coming sooner because there is no waiting period for SSI. In fact, if you have limited income or savings, you may get SSI while waiting for SSDI.

Area Agencies on Aging

The Older Americans Act, created to respond to the needs of Americans ages 60 and over, provides funding for Area Agencies on Aging and Title VI-Native American Aging Programs. Some of the many services these programs provide include community resource information and referral assistance; health insurance counseling to help older Americans understand their options and rights under Medicare and other insurance alternatives; caregiver support; transportation to medical appointments; and home health services. Call the Eldercare Locator at 800-677-1116 to find the Area Agency on Aging or Title VI program closest to you. You can learn more about these programs online at www.n4a.org.

Drug Assistance Programs

There are programs, other than Medicare Part D, that provide drugs free or at very low cost to people who have no prescription coverage and are struggling to pay for their drugs. You may need your doctor's approval. Thanks to a coalition of health-care providers, drug companies, and patient advocacy organizations called the Partnership for Prescription Assistance, you can go online to www.pparx.org or call 888-4PPA-NOW (888-477-2669) and find out what assistance programs you qualify for.

Resources for Veterans

If you are a veteran, you (and your dependents) may qualify for health, pension, and burial benefits from the government. To learn more, contact the Department of Veterans Affairs at 800-733-8387 or www.vba.va.gov.

Specialized Support Organizations

Many national nonprofit organizations, such as the Alzheimer's Association, National Kidney Foundation and American Cancer Society, have local chapters that can provide helpful information, support, and, sometimes, financial assistance. Check with your hospice social worker or your local phone directory for contact information.

Managing Debts

If you feel overwhelmed by your bills, the following ideas may help:

- Contact the companies you owe money to, such as credit card companies and your mortgage lender, and try to negotiate smaller payments or more time to pay. Most lenders will be willing to work with you to create a manageable repayment plan, especially if you call before you miss payments.
- Pay credit card debts with the highest interest rates first, if possible. If you cannot pay the entire amount, at least pay more than the minimum required every month to cut down on interest charges.

Protecting Yourself Against Financial Fraud

These tips are offered by *FDIC Consumer News*:

- Try to deal only with businesses and organizations you know or that have been recommended to you.
- Get key details of offers in writing and check them out before agreeing to anything.
- Closely monitor your credit card bills and bank statements.
- Recognize the classic warning signs of fraud—unsolicited offers that sound too good to be true; requests to send money before a product or service is delivered; pressure to say “yes” quickly to a proposal.

If you suspect your name or credit cards are being used improperly, contact the fraud department of one of the three major credit bureaus.

Equifax – 800-525-6285

Experian – 888-397-3742

TransUnion – 800-680-7289

If you suspect problems in a bank or investment account, call your financial institution.



Financial Advice

Financial matters can be complicated, but there are many resources to help you handle them.

Personal Financial Planning Information Sources

- Look for books, magazines, and Web sites. For example, visit the National Endowment for Financial Education's Web site at www.nefe.org.
- A librarian can guide you to other sources of reliable information as well. Check out the resources listed at www.caringinfo.org.

Professional Financial Advisors

- To find one who is right for you, ask friends, family members, or hospice workers to refer you to someone they know and work with.
- You might want to interview several advisors before choosing one.
- Ask about credentials (such as CPA, CFP®), experience, services, costs, and references.
- Make sure you are comfortable with the advisor you select.

Chapter 5

Plan a Funeral/ Memorial Service



Few people are comfortable talking about funerals. But making funeral arrangements is one of the most difficult responsibilities families and friends face after someone dies. It also is one of the most expensive purchases many people will make in their lifetime. When still in shock from their loss, people can spend more than is needed on a funeral—and more than they can afford. It could even be much more than you want them to spend on your funeral. You may wonder how you can ease the emotional and financial burden on your loved ones—and have the kind of service or life celebration you want. One way is to plan your funeral/memorial service before you die. The information in this section will help you understand what funerals cost and how to plan and pay for a funeral.

What Funerals Cost

Funeral costs vary widely and depend on the type of funeral you choose. The Federal Trade Commission estimates that the average cost of a basic funeral with burial is around \$6,500, but can easily exceed \$10,000 if additional services are included, such as obituaries, flowers, and receptions. The cost of cemetery plots is on the rise, too, because of increasing land and maintenance costs. Cremation, a less-expensive option, is the choice of about one in three Americans. “No-frills” cremations can cost between \$400 and \$1,800; additional services can drive the cost to close to \$5,000.

How to Plan Your Funeral

Planning your funeral before you die has two steps: Making decisions about the kind of funeral or memorial service you want and “shopping” for services.

Shopping is the best way to get the most for your dollar, and, by planning now, you will have the time to talk with several funeral service providers and compare prices. Funeral homes are required to give you a written General Price List for their services—or provide prices over the phone.

You can make arrangements for your funeral or memorial service directly with a funeral home or through a funeral planning or memorial society. They can help you make a list of your product and service choices and keep a copy for you, usually at no charge. You also can write down your instructions on the My Funeral Choices worksheet (available at www.caringinfo.org) and give copies to your heirs, faith leader, and others who might be involved in making funeral arrangements. If you include funeral instructions in your will, be sure a copy of the will is easy to find so your instructions can be read and followed.



How to Pay for Your Funeral

You can pay in advance for some or all funeral or memorial service expenses. It's a good idea to find out if there are state laws that protect your money and ensure it will be used to pay your funeral expenses when the time comes. Here are some questions to ask before paying any money in advance:

- What does this amount cover? Only products (casket, burial vault) or products and funeral services?

- What happens to the money after I pay it? Some states require funeral homes and cemeteries to invest a portion in a state-regulated account or buy a life insurance policy with death benefits assigned to the funeral home or cemetery.
- Can I cancel the contract and get my money back if I change my mind? Will I get all my money back?

Three alternatives to paying in advance are:

- A Payable-on-Death (POD) savings account. In many states, the money in this account can go quickly and directly to a funeral home, or to an heir who has promised to use the money to pay for funeral costs.
- A special life insurance policy purchased through a funeral home or other facility. The funeral home generally is the beneficiary of the policy.
- A prepaid trust account set up through a funeral home or other facility. This might include a burial trust established under Medicaid rules.

Benefits for Veterans

You may have veterans' benefits for burial services.

All veterans, some civilians who have provided military-related service, and some Public Health Service personnel are entitled to free burial in a national cemetery, a grave marker (at any cemetery), and a flag. Spouses and dependent children also are entitled to a lot and marker, but only in a national cemetery. There will be no charges for opening or closing the grave, a vault or liner, or setting the marker in a national cemetery. For more information, contact your regional Veterans Affairs office by calling 800-827-1000, or go online to www.cem.va.gov.

Chapter 6

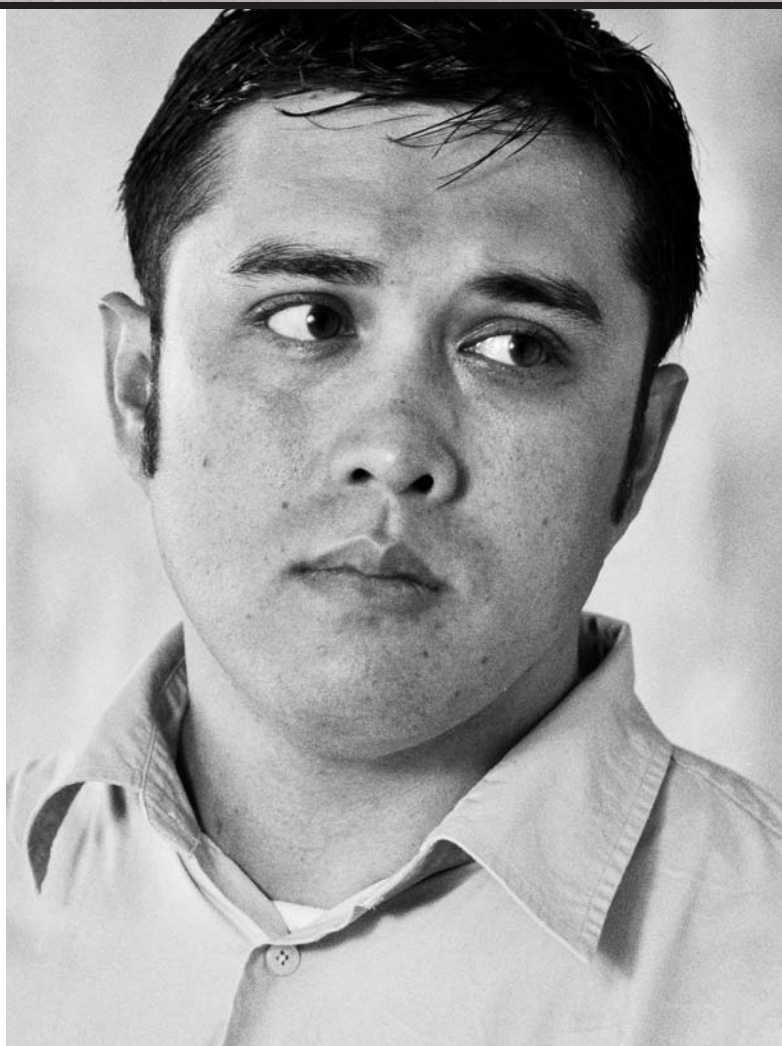
Talk About and Encourage End-of-Life Decision-Making

Talk is the single most important thing that family and friends can do to prepare for the death of someone they love. While difficult, the end of life can be amazingly rich.

Learning, insight, and love are possible to the last breath—and beyond. Talking about this time makes a rich ending more likely. Money may be one of the hardest subjects to talk about, but it also may be one of the subjects that most worries both you and your loved ones.

One way to break down the barriers to a conversation about money is to examine your own concerns and worries and talk about those with your loved ones. Also, look for events and openings that can give you a way to start the conversation. Conversation triggers might be:





- Newspaper articles
- Television shows
- Magazine articles and books
- Family occasions
- Financial matters



For example, maybe you've just completed your taxes. You might ask your loved one if he or she has ever been concerned about making sure bills are paid. Sadly, there are regular news stories about people incapacitated by accident or illness whose family members are fighting over their care. This is a natural opening to ask what your loved one's wishes would be in those circumstances and how you want to be able to make sure their wishes are met.

Handling Emotions

Family emotions and the desire to maintain traditional roles (parent/child, big brother/little brother) can sometimes put a damper on conversations. If you are a family member and seem unable to get a financial talk started, consider asking an objective third party to lead the conversation, such as an attorney, a faith leader, or a social worker. This can free your loved one to talk more comfortably and openly. Also, don't accept the claim that "Everything has been taken care of" unless you have seen details of what that means. Financial matters are complex and your loved one's decisions may have consequences they are not aware of. Naming someone other than a spouse to inherit ownership of a family home, for example, can result in unexpected taxes.

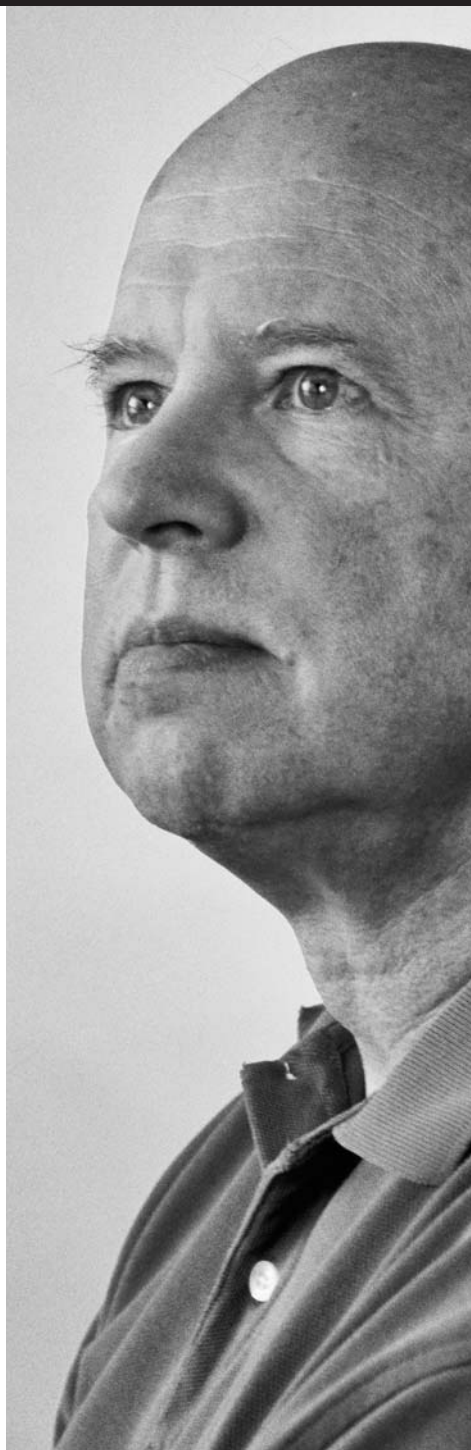
What information do you want to know—and have your loved one know—about his or her financial situation? Probably many things:

- What financial assets does your loved one have?
- Where are his or her legal documents?
- Is there enough money to ensure medical care and the family or spouse's ongoing needs?
- Where are insurance benefit papers kept?
- Are there special goals he or she wants to use money to achieve before or after death?
- Has your loved one chosen someone to handle money matters if he or she cannot?
- What medical care does your loved one want to receive if he or she can't communicate?

- Has he or she written a will stating how money and possessions are to be distributed after death?

The information and worksheets discussed in Chapters 1 and 2 can help you get answers to these questions and more from your loved one. As you help your loved one complete these worksheets—or find someone else to help them complete them—be sure to stay informed and make copies of worksheets and documents for yourself, other family caregivers and other possible heirs.

Although this information can be very important to have at the end of life, it provides a strong foundation for good financial planning at any stage of life. Discussing these issues with your loved one might even get you thinking about your own goals and financial planning.



What if We Disagree?

You're feeling very good about the conversations you're having with your loved one and then suddenly they tell you about a decision you don't agree with. What do you do? That depends on the decision and how strongly both of you feel about it. Talk about it. Share your concerns as positively as possible. Ask questions about your loved one's decision and how he or she arrived at it. If the decision means you will have to do something you know you can't, such as selling the family home, you can suggest that your loved one choose another person to be the decision maker.

Keep in mind that if you learn some financial assets will be going to your least favorite family member, there may be little you can do. You don't want to spend your last days and weeks with your loved one in arguments that leave ill feelings. As the saying goes, wisdom is knowing the difference between things you can change—and those you can't.



Chapter 7

Information for Family and Friends

Taking Care of Yourself— Hospice Benefits for Family and Friends

Full-time caregiving is hard work. It can be a rewarding experience, but exhausting as well. That's why you have to give yourself permission to think about your own needs as well as your loved one's needs. You can't take good care of someone else if you don't first take good care of yourself.

An important part of taking care of yourself is taking breaks. Your hospice team will offer to have volunteers come and sit with the patient or help you with chores to make things easier for you. They are there to help your family member and you, so be sure to tell them how they can help you.

If you are physically or emotionally exhausted from caregiving, talk to your hospice team about respite. Respite care gives you a break from daily caregiving while ensuring quality care for your loved one. For example, if you are caring for someone at home, the Medicare Hospice Benefit will pay for up to five days of care for your loved one in a private or semi-private room in a Medicare-approved facility such as a freestanding hospice facility, hospital, or other long-term care facility. One of the best gifts you can give your loved one in hospice is five days of “vacation” for you. You’ll come back to caregiving refreshed, relaxed, and ready to make the most of the time you have left with your loved one. Be sure to ask your hospice team if your insurance pays for respite, and, if so, for how long and under what kinds of circumstances.

Also, look into community resources that offer services to ease the financial, physical and emotional strain. These may include Meals on Wheels, caregiver training classes, support groups, and transportation. To learn more about caregiver support, visit www.caringinfo.org under the caregiving section.

Grief and Bereavement

Hospice will be there to provide comfort and support following your loved one’s death. Bereavement services are offered to caregivers and families for at least one year. These services can take a variety of forms, including telephone calls, visits, written materials about grief and support groups. You also might take advantage of individual counseling or learn about community resources that can help you through this difficult time. To learn more, visit the Grief section of www.caringinfo.org.

Hospice Benefits for Children Living with a Life-limiting Illness and Their Families

If your child has a life-limiting illness, you want to do everything you can to ease the child's pain and help them live fully in the time remaining to them. Lack of sleep, money worries, work pressures, the needs of other children, your spouses and relatives—everything has an effect on your ability to cope. The Partnership for Parents English Web site (www.partnershipforparents.org) or Spanish Web site (www.padrescompadres.org) can be a great source of support because the information comes from parents who have made this difficult journey before you.

Have you considered calling hospice? Hospice can provide incredible support to you, your child and your family, but you may be reluctant to call because you feel it means you are giving up. But you really aren't. Rather, you are getting support for your child and your family that will make everyone, especially your child, feel much better. Ask your doctor or social worker to call for you and make a referral if you'd rather not make the call yourself.

Although many hospices will provide care for children with a life-limiting illness, your child's doctor and the hospice medical director will evaluate the progression of your child's illness and determine if the time is right for hospice. Your doctor and hospice team will answer any questions you may have, tell you what to expect, and tell you what you can do to make your child more comfortable at this time.

Your health insurance may cover the same hospice services for a dependant child as it does for an adult. Talk with your health insurance representative. If you do not have health insurance,



your child may be eligible for Medicaid coverage if he or she is a U.S. citizen or a lawfully admitted immigrant, even if you are not. Eligibility for children is based on the child's status, not the parent's. Also, if someone else's child lives with you, the child may be eligible even if you are not because your income and resources will not count for the child.

Always check with your local hospice about available services. Remember, it is a tradition of hospice to offer services based on need, rather than on the ability to pay.



Chapter 8

Protecting Your Loved One from Financial Fraud

If your loved one is elderly, be aware that fraud and theft against the elderly are surprisingly common—and sometimes committed by people they know and trust. Here are a few warning signs to look for: Be suspicious if you notice a paid caregiver, such as a nurse or aide, becoming extremely interested in your loved one's financial affairs or reluctant to spend money on necessary medical treatment. Make sure your loved one is not being prevented from talking on the phone or returning calls. Watch for unauthorized withdrawals from checking or savings accounts and new or recently changed legal documents, especially the durable power of attorney for financial decisions.

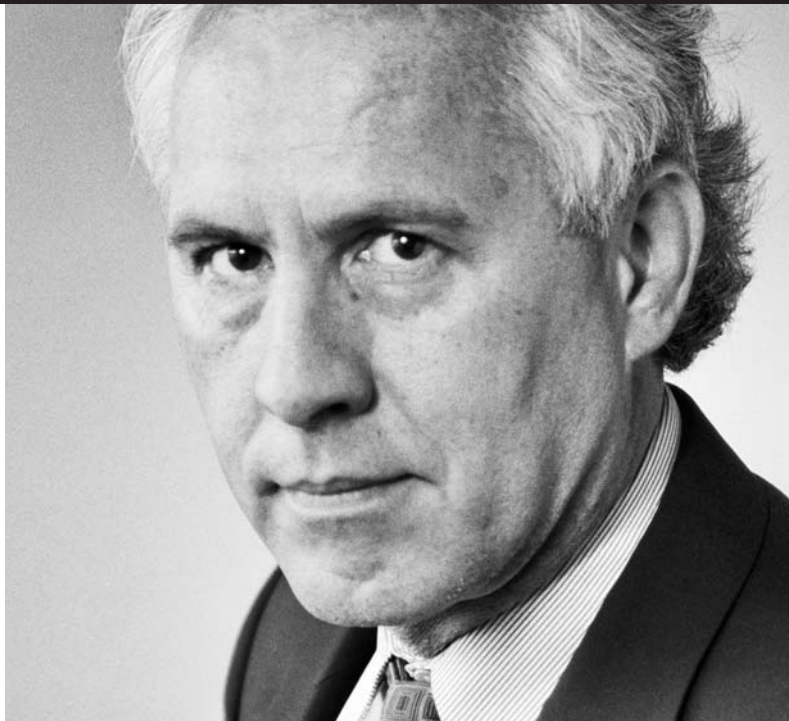
Protect your loved one against fraud by strangers posing as legitimate business

people, government officials, or other generally trusted individuals. Some of the most common “cons” used to trick elderly people into giving up money, property, or personal information include:

- Prize and sweepstake frauds – You’ve won a prize but have to send money to get it.
- Fraudulent investments – Usually with “guaranteed” and extraordinarily high rates of return.
- Charitable donation scams – They sound legitimate, but are not.
- Home or auto repair scams – Work is poor or isn’t finished.
- Loan or mortgage fraud – High-cost loans that can result in foreclosure.
- “I Need Your Help” scams – Someone claiming to be a bank examiner or police officer asks for cash or account information to help expose fraud.

Take these actions to protect your loved one against financial fraud:

- Recognize the classic warning signs of fraud—unsolicited offers that sound too good to be true; requests to send money before a product or service is delivered; pressure to say “yes” quickly to a proposal.
- Try to deal only with businesses and organizations you know or that have been recommended to you.
- Get key details of offers in writing and check them out before agreeing to anything.
- Closely monitor credit card bills and bank statements. With your loved one’s permission, you can check bank and credit



card statements online. Talk to your family member or friend about this if you are worried about fraud.

- Immediately report a fraud or theft. If you suspect your family member or friend's name or credit cards are being used improperly, contact the fraud department of one of the three major credit bureaus. That company will notify the other two.

Equifax – 800-525-6285

Experian – 888-397-3742

TransUnion – 800-680-7289

If you suspect problems in a bank or investment account, call the financial institution.

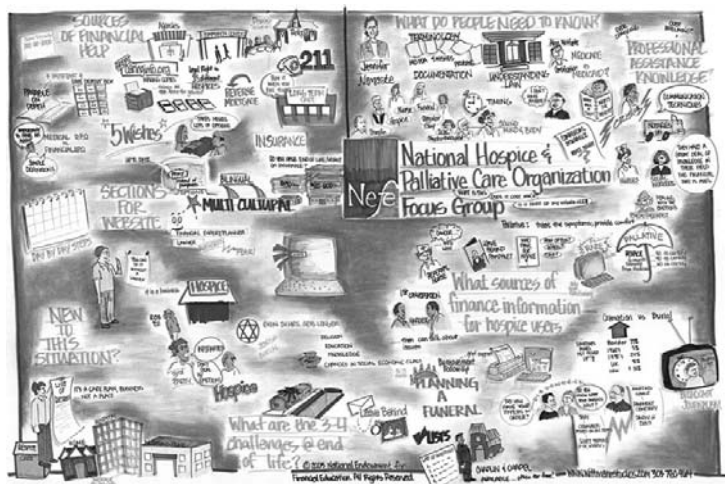
Source: *FDIC Consumer News*

Acknowledgments

Information in this booklet has been prepared for individuals facing life-limiting illness (Chapters 1 through 5) as well as for their caregivers (Chapters 6 through 8). Additional information can be found online at the Caring Connections Web site, www.caringinfo.org.

This booklet was prepared specifically for Caring Connections, a program of the National Hospice and Palliative Care Organization, as a public service by the Denver-based National Endowment for Financial Education® (NEFE®), Ted Beck, President and CEO; Brent A. Neiser, CFP, Director of Collaborative Programs; and Mary J. Schultz, Project Manager of Collaborative Programs.

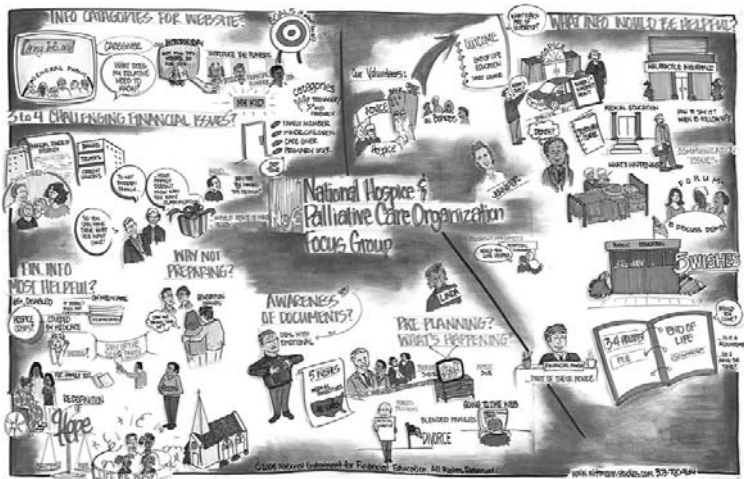
NEFE is an independent nonprofit organization committed to educating Americans about personal finance and empowering them to make positive, sound decisions to reach their financial goals at every stage of life. The National Endowment for Financial Education, NEFE, and the NEFE logo are federally



registered service marks of the National Endowment for Financial Education. For more information about the National Endowment for Financial Education, visit www.nefe.org.

Caring Connections, a program of the National Hospice and Palliative Care Organization, is a national consumer engagement initiative to improve care at the end of life. Caring Connections provides free resources and information on a range of end-of-life topics including advance care planning, caregiving, hospice and palliative care and grief to those looking for information and support. Kathy Brandt, MS, Vice President, Professional Leadership and Consumer and Caregiver Services, and Christin (Coco) Regas, MSW, Consumer Programs and Services Director were instrumental in providing feedback and their expertise to this project. State-specific advance directives and end-of-life brochures and information are available by:

- Visiting the web site at www.caringinfo.org
- Calling the HelpLines at 800-658-8898 or Linea Cuidando con Carino at 877-658-8896



This image represents the ideas and comments from two focus groups conducted with volunteers, grief counselors, chaplains and those working closely with hospice patients to create this project. Special thanks goes to Jennifer Ballatine for organizing and coordinating these focus group events.



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Partnering for Financial Well-Being

National Hospice and Palliative Care
Organization



Caring Connections

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www.caringinfo.org
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caringinfo@nhpco.org