

Legal Guide *for the* Seriously Ill

Seven Key Steps to Get Your Affairs in Order



American Bar Association Commission on Law and Aging
for the National Hospice and Palliative Care Organization

Table of Contents

Acknowledgements	2
Using This Guide	3
Step 1. Plan How to Pay for the Health Care You Need	4
Step 2. Make a Plan to Manage Your Health and Personal Decisions	14
Step 3. Make a Plan to Manage Your Money and Property	20
Step 4. Plan for the Care of Dependents	30
Step 5. Know Your Rights As a Patient	34
Step 6. Know Your Rights As an Employee	41
Step 7. Get Your Legal Documents in Order	46
Conclusion	49
Appendix: Finding Legal Help	50

Copyright © American Bar Association and National Hospice and Palliative Care Organization, 2009

The views expressed herein have not been approved by the House of Delegates or the Board of Governors of the American Bar Association and, accordingly, should not be construed as representing the policy of the American Bar Association.

Acknowledgements

We thank the knowledgeable reviewers who commented on our draft guide: Elizabeth Miller Angevine, Miller & Angevine; Nathan A. Kottkamp, McGuireWoods; Howard S. Krooks, Elder Law Associates, PA; Thomas J. Murphy, Murphy Law Firm; and Helen Cohn Needham, Needham Mitnick & Pollack.

We also thank the National Hospice and Palliative Care Organization (NHPCO) for recognizing the need for and supporting development of this consumer guide on legal issues facing the seriously ill. Christin (Coco) Regas, MSW, Consumer Programs and Services Director, provided valuable guidance throughout the project.

Ellen M. Klem, JD, Staff Attorney
Charlie P. Sabatino, JD, Director
Lori A. Stiegel, JD, Senior Staff Attorney
American Bar Association Commission on Law and Aging

November 2009

Using This Guide

The onset of a serious illness or injury can affect much more than a person's health. Knowing what steps to take to get your financial and legal affairs in order is often vitally important not only to you, but to your loved ones.

This guide provides you information on several steps to consider if you face serious illness or injury. Specifically, this guide explains "seven key steps" in short and simple terms and provides tips and resource links that will give you much more detailed information and guidance, as needed.

For each of the seven key steps, several core elements are identified. Below the overview, more detail about each element is provided in the left column and additional resources are identified in the right column.

The arrangement of the steps in the guide does not reflect either the importance or the specific order for taking action on the seven key steps. In many cases, several of the steps may be addressed at the same time. Finally, depending on your circumstances, some of the steps may not apply to you or there may be other legal considerations that are beyond the scope of this general purpose guide. In addition, this guide reflects the laws in effect in the first half of 2009 (or earlier, if that is more appropriate). Federal and state laws change regularly so the information provided may be out-of-date when you read it. Check referenced Web sites or see a lawyer to determine if more current information is available.

Step 1: Plan How to Pay for the Health Care You Need

The Basics



Several benefits and financial strategies may be pieced together to maximize financial resources for you and your family during this time. Below is a list of benefits that are explained in more detail in the “Decisions & Action Steps” that follow.

- 1.1 Workers’ Compensation Benefits** or employer-based disability benefits may be available to you if you are employed at the time of illness or injury.
- 1.2 Social Security Disability Benefits** are available to most adults prior to age 66 (or 67, depending on birth date) who cannot work at all because they have a medical condition that is expected to last at least one year or result in death.
- 1.3 Veterans Benefits.** Veterans and certain family members may be entitled to income benefits, health care benefits, or both from the Veterans Administration.
- 1.4 Medicare** provides basic health-care benefits to persons over age 65 and also to persons who have received Social Security disability benefits for at least two years. Hospice is a key Medicare benefit for persons with life-limiting illness.
- 1.5 Medicaid** provides comprehensive medical and long-term care benefits to many low-income adults and children, including older or disabled persons. Each state defines its criteria for eligibility. Most state Medicaid programs include hospice benefits. Many low-income persons have both Medicare and Medicaid.
- 1.6 Private Health Insurance** is the primary source of medical coverage for those under age 65. Private plans vary quite a bit in their scope of coverage, including coverage of new, cutting-edge treatments, and coverage of hospice and comfort care. Private long-term care insurance helps pay for extended periods (usually two or more years) of nursing home care, assisted living, home care, adult day care, and respite care.
- 1.7 Assisted Living Facility or Continuing Care Retirement Communities.** If you live in one of these, you may have certain long-term care support services available.
- 1.8 Accelerated Death Benefits.** If you have life insurance, you may be able to get payments from it during your lifetime by receiving accelerated death benefits or a viatical settlement (sale of the policy to an investor).
- 1.9 Reverse Mortgage.** Home owners with substantial equity in their homes can convert that equity into cash by getting a reverse mortgage through the HUD/FHA Home Equity Conversion Mortgage program. These mortgages do not need to be repaid until the house is sold in the future.
- 1.10 Tax Deductions and Credits.** Do not overlook possible deductions and credits that are available and most useful when you face high medical and long-term care expenses.
- 1.11 Bankruptcy** is the most extreme option for dealing with crushing debt caused by catastrophic medical expenses.

Decision & Action Steps

1.1 If employed, check your eligibility for employer-based disability benefits.

Workers' compensation provides benefits to you for injuries and illnesses that "arise out of and in the course of employment." There must be some connection between your work and your illness or injury. Most employees are covered. Your employer will have claim forms for you to file with the insurance company that covers your employer. If your claim is denied you have a right to appeal.

Federal employees may be entitled to compensation for personal injury or sickness under the Federal Employees Compensation Act (FECA).

Even if workers' compensation does not apply to your situation, many employers provide short-term and/or long-term disability insurance. Such policies may provide benefits regardless of the cause of the illness or injury. Check with your human resources office.

1.2 Check your eligibility for Social Security disability benefits.

Social Security pays benefits to people under full retirement age (66 to 67, depending on your birth date) who cannot work at all because they have a disabling medical condition. To be eligible:

- The condition must be expected to last at least one year or result in death.
- Your disability must be medically documented and the applicable guidelines are strict. Partial disability or short-term disability does not qualify for benefits.
- You must have worked a certain amount of time in covered employment, relative to your age.

Resources & Tips

A useful starting point for information on workers' compensation in all 50 states is online at: www.workerscompensation.com

[Www.SSA.gov](http://www.SSA.gov) has a great deal of information about disability benefits and the application procedures, as well as information about all other aspects of Social Security, including Supplemental Security Income (SSI).

Decision & Action Steps

The spouse and dependents of the disabled worker may also receive monthly benefits from Social Security.

Your benefit amount is determined by a formula related to how long you worked and how much you earned.

Supplemental Security Income or SSI provides additional income to you if your income, including Social Security disability benefits, is very limited or if you have not worked enough time to be covered by Social Security disability.

1.3 If you are a veteran, find out what veterans' benefits you may qualify for.

The Veterans Administration offers a broad array of benefits to veterans, including:

- compensation and pension benefits;
- health care benefits;
- long-term care benefits, including nursing home care;
- pharmacy benefits;
- burial benefits; and
- survivor's benefits.

Eligibility conditions and scope of benefits can be confusing and complicated, and waiting lists can present barriers, but do not overlook these options.

1.4 Check your eligibility for Medicare.

If you are over age 65, you likely already receive Medicare benefits. If under 65 and disabled under the definition used by Social Security, you are eligible after a two-year waiting period from the onset of disability.

Resources & Tips

See the Veterans Administration Web site: www.vba.va.gov/VBA

The Web page also includes a listing of Veterans Service Organizations (VSOs) available to assist veterans nationwide.

United States senators and representatives offer constituent services for the people they represent in Congress. Staff members provide services such as contacting federal agencies for problems with veterans benefits. For more information, visit the Web sites of your U.S. senators (<http://www.senate.gov/>) and representatives (<http://www.house.gov/>).

Much more information about hospice can be found at www.caringinfo.org

The federal Web page for Medicare at www.medicare.gov provides a wealth of information about benefits, as well as useful tools for comparing hospitals, nursing homes, health plans, and prescription drug plans.

Decision & Action Steps

- Medicare benefits are defined by the federal government. Besides the traditional fee-for-service Medicare coverage, other coverage options are available today, including managed care and special care options. There is also a Medicare prescription drug benefit.
- The most important benefit to be aware of for persons with a serious and life-limiting illness is the Medicare hospice care benefit.

Hospice Care

Hospice care is a team-oriented approach to expert medical care, pain management (including outpatient medications), and emotional and spiritual support tailored to the patient's needs and wishes. Care can be provided in the person's home, or in freestanding hospice centers, hospitals, and long-term care facilities. Support is also provided to the person's loved ones.

Eligibility for Hospice

You are eligible for Medicare hospice benefits if:

- You are eligible for Medicare Part A (hospital insurance); and
- A doctor certifies that you have a terminal condition—that is, a life-limiting illness that may be expected to result in death in six months or less if it runs its normal course; and
- You receive care from a Medicare-approved hospice program; and
- You choose hospice care instead of the regular Medicare covered benefits for your life-limiting condition. Keep in mind, just because you choose hospice care for your

Resources & Tips

The primary annual overview of Medicare benefits, *Medicare and You 2009*, is downloadable from that Web site. A new version is published every year.

Public interest groups that advocate for consumers' access to Medicare services include: the Center for Medicare Advocacy, see www.medicareadvocacy.org, and the Medicare Rights Center, www.medicarerights.org

State Health Insurance Counseling and Assistance Programs (SHIPs) provide free advice on a variety of health coverage questions, including:

- Choosing a health care plan
- Understanding and deciding between types of Medicare plans
- Understanding your Medicare bill
- How/whether to purchase additional health insurance (Medigap policies, long-term care insurance, etc.)
- Understanding how to appeal payment denials

Decision & Action Steps

life-limiting condition, does not mean you give up Medicare for other conditions. You are still entitled to Medicare coverage of treatments for medical needs unrelated to the life-limiting condition.

Hospice care is also usually covered under state Medicaid programs, most private insurance plans, HMOs, and other managed care organizations. But if you don't have Medicare or Medicaid or insurance that covers hospice, don't let worries about cost keep you from contacting hospice. While each hospice has its own policies concerning payment, many offer services based on need, rather than on the ability to pay.

1.5 Check your eligibility for Medicaid.

For adults without minor children, eligibility for Medicaid health benefits depends on (1) being either over age 65 or meeting the state's criteria for disability and (2) having limited income and assets. Most persons facing serious illness should inquire into Medicaid coverage sooner rather than later, because health and long-term care costs can quickly exhaust a patient's resources.

Each state defines its disability criteria and financial criteria differently. The rules are complicated, so independent, professional legal advice is a good idea.

Medicaid covers most everything Medicare covers and more, such as long-term care in a nursing home. If one is eligible for both Medicare and Medicaid, Medicaid will cover Medicare premiums, deductibles, and co-payments, and services not covered by Medicare but covered by Medicaid, such as long-term care. Most state Medicaid programs also cover hospice care.

1.6 Check Your Private Health Insurance Coverage.

If you have health insurance through your employer or under your own policy, ask for details about the extent of coverage and criteria for:

Resources & Tips

- Understanding your Medicare rights and protections and how to submit a complaint about medical care or treatment.
- You can find the SHIP program in your area on the Medicare.gov Web site at: www.medicare.gov/Contacts/staticpages/ships.aspx

Apply for Medicaid through your local social services, public welfare, or human services agency.

Medicaid rules regarding financial eligibility can be very complicated. SHIP programs (see above) can help you understand the process.

Legal advice may also be advisable. (To find a lawyer, visit Appendix: Finding Legal Help.)

To find out if Medicaid covers hospice in your state, call the National Hospice and Palliative Care Organization at 1-800-658-8898.

For further information, the starting point is your insurance company.

If questions or concerns remain after talking to your insurance company, your state's insurance commission may be a helpful source of information and problem

Decision & Action Steps

- rehabilitation benefits (for long-term recoveries or stabilization of one's condition);
- long-term care benefits (in a nursing home or other extended care facility);
- palliative care benefits (pain and symptom management); and
- hospice benefits.

Most private health insurance does not cover long-term care at home or in a residential facility. For that coverage, you must have a private long-term care insurance policy. Under these policies, benefits are normally triggered by the need for help in two or more "activities of daily living" (bathing, eating, dressing, toileting, mobility, or continence), or alternatively, by having a cognitive impairment, such as Alzheimer's disease.

Important!

1. You are entitled to a copy of the actual policy criteria and scope of coverage explanation, and not just a verbal explanation over the phone.
 2. If denied benefits, you have a right to appeal. Other than the time and expense, there is nothing to lose and everything to gain by appealing.
- 1.7 If you live in an assisted living, continuing care, or other residential facility, utilize its services to the maximum.**

The range of facilities with supportive care varies widely. Assisted living facilities typically provide housing plus some package of supportive services and amenities. Continuing care facilities additionally provide nursing home care services. However, the size and appearance of these facilities, as well as the costs, payment

Resources & Tips

solving. The Web site of the National Association of Insurance Commissioners, at www.NAIC.org, provides links to each state's insurance commission.

For useful, consumer-oriented information and advice about assisted living, as well as other long-term care settings, check out these Web pages:

- The National Senior Citizens Law Center, www.NSCLC.org, includes useful consumer advice on assisted living, as well as other long-term care settings.

Decision & Action Steps

arrangements, and scope of services they provide vary dramatically.

These facilities also vary in the extent to which they are regulated by states. It is important to find out the licensure or certification requirements for the facility you are considering. The facility's admission contract is a legal binding contract. It may be the only place that your rights and obligations are spelled out. So it is important to review admission contracts closely for explanations of:

- your financial obligations;
- your entitlements to services and amenities;
- the flexibility you have in maintaining your own living environment, and
- your rights in the event the facility seeks to impose changes in any of the above.

Finding a facility, especially in a large city, can be daunting. You may find helpful resources from your local area agency on aging or support group, such as the Alzheimer's Association. Also see the resources under Step 5-2. Insist on high quality of care in the hospital, nursing home, or community setting.

1.8 If you have life insurance, inquire about accelerated death benefits or viatical settlements.

Some life insurance policies have an "accelerated death benefit." This benefit means that you can receive a pre-payment of all or some of the policy's death benefit while you are living. To use this benefit, you must have been diagnosed with a serious medical condition. These funds can help you pay for the cost of care or supportive services. A portion of the benefits may still be payable after death to your beneficiaries.

Resources & Tips

- The Assisted Living Consumer Alliance (ALCA), <http://www.assistedlivingconsumers.org/>, is a national collaboration of groups and individuals working to promote consumer safety, choice, and rights in assisted living.

TIP: Even if the facility does not provide all the supportive services you need, you may be able to piece together services from multiple sources (e.g., the facility, Medicare, informal family care) in order to stay where you are if that is your preference.

Before working with a broker or company offering a viatical settlement, check with your state insurance regulator on the status of the broker and the extent to which viatical settlements are regulated in your state.

- You can find your state insurance regulator through the Web page of the National Association of Insurance Commissioners at: http://www.naic.org/state_web_map.htm

Decision & Action Steps

Another alternative for a sick policy-holder is to sell the policy to an investor at a price discounted from the face amount. The investor immediately pays you the sale price. These are called viatical settlements. They can be very risky transactions for both the original policyholder and the investor, so you should exercise caution and thoroughly investigate before entering into a viatical settlement.

1.9 Consider a Home Equity Conversion Loan (Reverse Mortgage).

If you are at least 62-years-old and have substantial equity in your home, a reverse mortgage may enable you to borrow against that equity to receive cash. The cash may be in the form of a single lump sum, a monthly payment, a line of credit, or a combination of all three. The loan does not have to be repaid until you sell or move from your home or die, whichever happens first. The amount you receive is based on your age, the value of your home, and your equity in the home, along with the current interest rate and other factors.

While these loans enable you to tap the equity in your home without incurring monthly payments, they are expensive in initial and ongoing costs. The costs of the loan include:

- An origination fee
- Mortgage insurance premiums (both initial and ongoing)
- Closing costs
- Ongoing servicing fees
- Continuing interest on the amount borrowed (either at a variable or fixed market rate).

Resources & Tips

- For more information on viatical settlements, see: <http://www.growthhouse.org/viatical.html>

AARP's Web site, www.aarp.org/money/revmort, provides accurate guidance on reverse mortgage options, including a financial calculator and a free reverse mortgage handbook, titled *Home Made Money*.

The U.S. Department of Housing and Urban Development also provides detailed information about the FHA's home equity conversion mortgages at: www.hud.gov/offices/hsg/sfh/hecm/hecmhome.cfm

Tip: Federal law requires counseling of all applicants for a federally insured Home Equity Conversion Mortgage. Private, non-federally insured reverse mortgage products appear from time to time and are generally to be avoided because they are typically more costly and much riskier to consumers.

Decision & Action Steps

A protective feature of these loans is that the maximum amount you or your estate will ever owe cannot exceed the value of your home. Use only lenders offering the Home Equity Conversion Mortgage, because these are insured by the Fair Housing Authority (FHA) and are regulated.

1.10 Do not overlook possible tax deductions and credits.

Talk to a tax advisor about your eligibility for tax breaks resulting from serious illness, disability, or significant medical expenses. These may include:

- *Tax credit for dependent care.* Employed taxpayers who care for an incapacitated parent, spouse, or other dependent in their homes may claim a tax credit for household or day-care expenses that enable the taxpayer to be employed.
- *Tax credit for the elderly or disabled.* People with disabilities and persons age sixty-five or older may be entitled to a tax credit if their nontaxable benefits or adjusted gross income are below certain levels.
- *Medical expenses.* You may deduct the cost of medical care for yourself, your spouse, and your dependents if the costs exceed 7.5 percent of your adjusted gross income.
- *Individual Retirement Account* distributions. If received before age 59 ½, they are normally subject to an early withdrawal tax. However, if they are made because you are totally and permanently disabled, they may be exempt.
- *Long-term care insurance.* Benefits received under a tax-qualified long-term care insurance policy are normally not taxable, and all or part of the premiums paid

Resources & Tips

The IRS provides a free online publication *Tax Guide for Seniors* (Pub. No 554). Also potentially helpful is Pub. No. 524, *Credit for the Elderly or the Disabled*.

The AARP Tax-Aide program provides free tax counseling to taxpayers. Visit the program online at <http://www.aarp.org/money/taxaide> to find the Tax-Aide site nearest you.

Decision & Action Steps

for the policy may be deductible as a medical expense.

- *Workers' compensation* benefits for an occupational sickness or injury are normally fully exempt from tax. Likewise, payments received by federal employees for personal injury or sickness under the Federal Employees Compensation Act (FECA) are normally not taxable.
- *Disability benefits* under privately owned policies on which you pay the premiums may not be taxable.
- Other benefits you receive as compensation for sickness or injury may not be taxable.

1.11 Consider Bankruptcy As an Option of Last Resort.

Bankruptcy does not pay for healthcare, but it may be an option of last resort to relieve you from debt. If you need to use this option, you are not alone—over one million Americans are forced to file for personal bankruptcy each year, and about half of these are caused by illness and medical debt.

Resources & Tips

See the Federal Trade Commission publication *Before You File for Personal Bankruptcy: Information About Credit Counseling and Debtor Education*, available at: www.ftc.gov/bcp/menus/consumer/credit/debt.shtm

Tip: If you consider bankruptcy, you should get competent legal advice about its benefits, disadvantages, and costs. You can find legal help by going to the American Bar Association Web page www.FindLegalHelp.org

More General Resources

Eldercare Locator, local information, referral resources, and contact information for state and local agencies, from the U.S. Health and Human Services Department. Available online at www.eldercare.gov/

Step 2. Make a Plan to Manage Your Health and Personal Decisions

The Basics



If you are seriously ill, it is likely that others will have to make health-care decisions for you at some point. It is important to plan for this in advance. Advance health-care planning doesn't require you to anticipate every medical decision. Rather, you need to think about and decide:

- 2.1 Who you want to be your **decision maker** (your health care agent, proxy, or surrogate) if you are unable to make decisions on your own?
- 2.2 What **guidance** you would want to give your health-care decision maker for making health decisions for you?
- 2.3 How you will **communicate** the above? This is where health care advance directive documents, such as the power of attorney for health care and the living will, come in.

Two more decision tasks described below spring directly from advance health-care planning:

- 2.4 Consider **organ or tissue donation**.
- 2.5 Consider making **burial and memorial plans**.

Decision & Action Steps

2.1 Pick a health care agent.

The first step is to choose the person whom you want to legally authorize to make your health care decisions if you are unable to speak for yourself. This person is called your health-care agent, proxy, surrogate, health-care representative, or other term. The label used depends on your state.

In choosing an agent, ask yourself who knows you well and would be able to act on your wishes, regardless of their own feelings. The person should also be someone who can be a strong advocate for you and who could handle conflicting views of family members, friends, and medical personnel.

Resources & Tips

For help in selecting a health care agent:

- *Consumer's Tool Kit for Health Care Advance Planning*, ABA Commission on Law and Aging. Available free at: www.abanet.org/aging. This work book contains guidance for picking an agent, as well as helping you define your values and goals.
- *Health-care Agents: Choosing One and Being One*, by Caring Connections. Online at www.caringinfo.org/PlanningAhead/AdvanceDirectives/ChoosingHealth-careAgents.htm

Decision & Action Steps

Try to avoid naming co-agents. It creates a potential for disagreement. If you decide to name co-agents, be sure to provide for a mechanism if there is a disagreement, i.e., if there are three co-agents, the majority rules. But do name a successor or alternate agent, if you can, in case your primary agent becomes unavailable.

Some states disqualify certain persons from serving as agent, e.g., a current health care provider. Find out your state's rules. (See Resources under Step 2.3 for sources of state-specific advance directive forms.)

2.2 Talk to loved ones about what guidance you would want them to follow in making health decisions for you.

Your decision-maker and others need to know your wishes in order to honor them. You don't need to anticipate every medical decision or treatment decision. What is important is that your agent knows what is important to you if you can't speak for yourself. If your agent knows what quality of life is acceptable to you, and your values and priorities, the agent will be able to evaluate whether the treatment offered will accomplish your goals.

If you have a condition that you know could involve certain life-sustaining procedures (such as the use of a ventilator for serious pulmonary disease) and you have firm and clear wishes about what you want done, then very specific instructions are helpful. But otherwise, your guidance can best focus on your values and goals of care.

Resources & Tips

- *Making Medical Decisions for Someone Else: A How-To Guide*, ABA Commission on Law and Aging: www.abanet.org/aging/pdfs/genlproxyguide2009.pdf

Resources to help you think about your values and priorities:

- *Consumer's Tool Kit for Health Care Advance Planning*. Described above. See Step 2-1.
- Caring Connections. This program of the National Hospice and Palliative Care Organization provides several more in-depth resources at: <http://www.caring-info.org/resources/brochures.htm>
 - End-of-Life Decisions
 - Leaving a Legacy
 - Saying Goodbye
 - Conversations Before the Crisis
 - If You or Someone You Love Is Very Ill
 - Artificial Nutrition and Hydration at the End of Life
 - Care and Comfort at the End of Life
 - Communicating End-of-Life Wishes
- To learn more about the kinds of medical decisions individuals near the end of life may face, see Hank

Decision & Action Steps

2.3 Communicate your wishes with an advance directive.

There are two parts to communicating your wishes. First, talk to your agent, family, spouse/partner/significant other, and doctor about what is most important to you under your current and likely future circumstances. These discussions can be difficult, but may be the most effective thing you do for loved ones and for yourself.

Second, complete a health care advance directive, that will do both of the following:

- a. Formally appoint your health care agent or proxy. This is typically called a “power of attorney for health care” or “proxy directive,” but has other names, too. You can also identify anyone whom you do not want to be involved in decision-making for you. If there is simply no one suitable to be your agent, then your best option is to give written guidance, as follows.
- b. Write down any guidance or instructions you want your agent or anyone else to follow. This part of your directive is commonly called a “living will.” Although there are many advantages to putting your wishes in writing, you don’t have to give written guidance. It can be done through your conversations with your agent, family, and friends. But you may find it reassuring to have it in writing, especially if you have strong wishes about any matter. And, it will also provide more certainty to your decision-makers.

Resources & Tips

Dunn, *Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Measures Only and the Elderly Patient* (A & A Publishers, Inc., Herndon, Va. Web site: www.hardchoices.com).

There are numerous resources providing advance directive forms:

- For state-specific advance directive forms and instructions for all 50 states and the District of Columbia, see www.caringinfo.org, above.
- You can also get advance directive forms for your state from most hospitals, agencies on aging, many state bar associations, and medical societies. Lawyers also commonly provide advance directives as part of estate and health-care planning.
- *Five Wishes*, published by Aging with Dignity, is a widely-distributed advance directive that focuses on talking about health care wishes and personal needs in a straightforward way. It can be used in most, but not all, states. [Www.agingwithdignity.org](http://www.agingwithdignity.org)
- *A Guide to Living Wills and Health Care Proxies*, by Harvard Medical School. This guide and form provides a more medically-oriented advance directive addressing six illness scenarios. See: www.health.harvard.edu/special_health_reports/A_Guide_to_Living_Wills_and_Health_Care_Proxies.htm

Decision & Action Steps

Living wills typically spell out one's wishes in the event of life-limiting condition, vegetative state, or the end-stage of a chronic condition (such as Alzheimer's disease). There is a tendency to assume that a person with a living will does not want life-sustaining treatment in these circumstances, but that is a misperception. Your health care advance directive can request the use of all available treatments, the stopping of treatments, or anything in between under any circumstances you specify.

Important: Do-Not-Resuscitate Orders

There's another kind of directive that is important for patients with life-limiting or end-stage chronic conditions living in the community or anyplace other than a hospital. For these individuals, using CPR (cardio-pulmonary resuscitation) if their heart or breathing stops may not be medically effective or desired. Talk to your doctor about the pros and cons of CPR, given your condition. If CPR is not wanted, your doctor can write a *Do-not-attempt CPR Order* (also called an *Out-of-Hospital DNR Order* or *Comfort Care Only Order*). Once signed, your doctor provides you with a special DNR form or bracelet that emergency personnel and other health-care professionals should recognize and respect. In other words, if a medical crisis arises and someone calls 911, emergency personnel will not attempt CPR and will provide only comfort care.

2.4 Consider organ and tissue donation.

Consider making an organ or tissue donation to help others. The need for organs far exceeds the number of available donations. You can complete an organ donor wallet card to keep on your person or include your wishes in your advance directive and authorize your health care agent to consent to organ or tissue donation. Some states also allow organ donation information to be printed on your drivers' license. It is also possible to donate one's organs or entire body for purposes of medical research or education.

Resources & Tips

There are many specialized advance directive forms developed by and available from various religious organizations and advocacy groups geared to the particular beliefs or circumstances of the group.

For Comfort Care or Out-of-Hospital DNR orders, ask your doctor for more information about its availability.

Tip: Your agent under your power of attorney for health care has a right to access your medical records and health information. But be aware of how the federal privacy rule applies to your agent and family members. See Step 5.4 Know your right to access to your medical records, for more information.

A great deal of information on this subject can be found at: www.organdonor.gov

Decision & Action Steps

2.5 Make burial and memorial plans.

You can make burial plans informally by meeting with a funeral director to discuss and choose options without any pre-payment. Or you can opt for a prepaid plan. It is important to be aware of your rights and risks under a prepaid plan. Even if you make no formal plans, providing some guidance to your loved ones about funeral or memorial events may help them make emotionally-difficult decisions and financial choices during stressful times.

There are two types of prepaid plans:

- A. Insurance-funded plans. Under these plans, consumers buy an increasing-benefit life insurance policy from a funeral director or cemetery. The price of the goods and services is usually guaranteed. Upon death, the policy proceeds are paid to the funeral director or cemetery.
- B. Pre-need trusts. Instead of purchasing an insurance policy, the buyer of a pre-need trust pays the funeral director or cemetery an amount for guaranteed goods or services to be provided at the time of death. The seller holds the money in a trust fund.

Prepaid plans may be a legitimate choice for some consumers, but they may also have serious pitfalls, sometimes including hidden expenses, substantial penalties for cancellation, a limited selection of funeral homes or cemeteries, and financial instability.

To protect yourself, you should:

- obtain all of the relevant information before purchasing a plan of either type;
- comparison shop using the general price list funeral homes are required to give you under the Federal Trade Commission's Funeral Rule;

Resources & Tips

The Federal Trade Commission maintains a consumer information Web page on funerals at: <http://www.ftc.gov/bcp/menus/consumer/shop/funeral.shtm>

You can write down your instructions on the *My Funeral Choices* worksheet available at: http://www.caringinfo.org/UserFiles/File/PDFs/PlanAFuneral/My_Funeral_Choices.pdf

The Funerals Consumer Alliance (FCA) provides objective funeral advice, including online pamphlets and articles on your legal rights and options as a funeral consumer. Visit the FCA online at: <http://www.funerals.org/>, or call them at (800) 765-0107.

For more information on burial and memorial benefits for veterans, contact your regional Veterans Affairs office at (800) 827-100 and <http://www.cem.va.gov>

Decision & Action Steps

- if you are receiving public benefits, such as Medicaid, get legal help to insure the plan or trust will not cause eligibility problems; and
- keep a record of all the payments made to the funeral director or cemetery in a place where they can easily be found by your friends and family in the event of your death.

Memorial Events

If you want to provide any directions for memorial events, consider the following:

- Write them down and share them with loved ones in advance. Don't rely on your will to provide instructions, since it may not be read until after memorial events.
- Address readings, music, or ceremonies you want included.
- Identify any charity or other organization to which you would like memorial gifts be made in your name.

More General Resources

Caring Connections—This program of the National Hospice and Palliative Care Organization provides several consumer resources, at: www.caringinfo.org

Handbook for Mortals: Guidance for People Facing Serious Illness, by Joanne Lynn, MD, and Joan Harrold, MD (NY: Oxford University Press, 1999). A comprehensive and readable 242-page guide to dealing with serious, eventually fatal illness.

American Medical Association, State Medical Society Web sites, available at: <http://www.ama-assn.org/ama/pub/about-ama/our-people/the-federation-medicine/state-medical-society-Web-sites.shtml>

Eldercare Locator, local information, referral resources, and contact information for state and local agencies, from the U.S. Dept. of Health and Human Services Department. Available online at <http://www.eldercare.gov/>

Resources & Tips

Tip: If you want your estate to pay the costs for family or friends to travel to your memorial events, it is helpful to include that information in your will. Such an instruction will help avoid any doubt about your intent.

Tip: Before designating a charitable donee, consult the Better Business Bureau Wise Giving Alliance, which helps donors make informed giving decisions, available at: <http://www.bbb.org/charity>

Step 3. Make a Plan to Manage Your Money and Property

The Basics



Planning for the management of your financial affairs ensures that, while you are alive, you will be able to maintain control over your money and property to the greatest extent possible no matter what condition you are in. Planning requires you to think clearly about who you would want to manage your money and property if you were seriously ill and how you would want them to do so.

Planning how your money and property (your estate) will be distributed beyond your lifetime is driven by the goals of planning for the welfare of your loved ones and leaving a legacy. People who have larger estates may also consider avoidance of estate taxes and probate.

If you do nothing and have no will, your property will pass by what are known as intestate succession laws. These laws distribute your property among your spouse and children and next of kin; the distribution may not be the plan you would want. Thus, in order to avoid an unintended result, proper planning is highly recommended.

For lifetime and after-death planning, you will want to consider the following legal tools:

- 3.1 Joint ownership of bank accounts or other property, with a “right of survivorship.”**
- 3.2 Power of attorney.** This is a legal planning tool virtually every adult needs.
- 3.3 Inter-vivos or “living” trust.** Trusts can be a valuable tool for the management of substantial assets.
- 3.4 Appointment of a representative payee.** If you need to manage only Social Security or other government benefits, this tool may be sufficient.
- 3.5 Plan for business succession.** This is especially important for businesses with multiple partners or equity owners.
- 3.6 Eligibility for public benefits.**
- 3.7 Last will and testament.**
- 3.8 Use of will alternatives.**
- 3.9 Creation of an “ethical will.”**

Decision & Action Steps

3.1 Consider joint ownership of bank accounts and other property.

Joint ownership of property with a right of survivorship is a common ownership arrangement used both as a property management tool and a will substitute. A surviving joint owner becomes the sole owner (or owners if more than one) when one joint owner dies.

Bank accounts are commonly held this way, as well as title to automobiles, a house, or stocks and bonds.

When you title anything in more than one person's name there are risks. Caution is advised!

- Joint owners of financial accounts have complete access to the money in the account. If untrustworthy, they can take it all.
- The funds in the account may be available to pay the joint owner's debts.
- The owner of a car may be liable if the joint owner gets in an accident.
- If you have provided in your will that the funds in the account are to go to a person other than the joint owner, the joint ownership may defeat your plan.

3.2 Consider drafting and executing a financial power of attorney.

A power of attorney is a written authorization for a person you name to act on your behalf for any purpose you spell out in writing. In most states, a power of attorney that provides that it will remain in effect when you, the principal (the person giving the power of attorney), become unable to communicate or is otherwise incapacitated is known as a durable power of attorney (DPA). (For information on powers of attorney for health care, see Step 2.3 Communicate your wishes with an advance directive.)

Resources & Tips

Tip: Joint Ownership: It may be safer to use a **power of attorney** over property rather than naming someone to be joint owner. To learn more about why it may be safer, seek advice from a lawyer. (To find a lawyer, see the Appendix: Finding Legal Help.)

Caution: When you title anything in more than one person's name there are risks. For example the owner of a car may be liable if another owner gets in an accident. Be sure you understand these risks.

Tip: The following 21 states have enacted standardized form powers of attorney by statute, although more states are considering such legislation: Arkansas, Arizona, Arkansas, California, Colorado, Connecticut, District of Columbia, Idaho, Illinois, Minnesota, Montana, Nebraska, New Mexico, New York, Ohio, Oklahoma, Rhode Island, Tennessee, Texas, Virginia and Wisconsin. There is no single place to find these forms, but try searching for "power of attorney form" on your state's official Web site. You may also want to visit your state bar association's Web site to see if they have

Decision & Action Steps

A financial power of attorney is particularly helpful for managing titled property, like financial accounts, a house, or a car when the principal becomes incapacitated. It is a general DPA if it covers all financial matters. It is a special DPA if it covers limited financial matters.

Several things are important to consider in the creation of a power of attorney:

- The document should meet the specific legal requirements of the state you live in and any other state in which you have property.
- The document should be tailored to your specific situation and needs. Even if you use a form, it should be modified to suit your needs. There is no such thing as a “standard” power of attorney.
- The person you choose to act on your behalf (your “agent”) will have tremendous power over your property and finances. It is like giving the agent a blank check, so it is essential that you select someone who is trustworthy.
- It is a good idea to seek advice from a lawyer. A lawyer can ensure that your document meets your state’s requirements and that the powers you give your agent are spelled out in language that will be legally effective. A lawyer can also advise you about ways of preventing misuse of your power of attorney by your agent.

Remember: A durable power of attorney terminates when the agent learns or should have learned of the principal’s death.

3.3 Consider establishing an inter-vivos or “living” trust.

A trust is a legal arrangement created by contract. Under a trust, a person or institution (the trustee)

Resources & Tips

forms, explanations, other publications on powers of attorney. To find your state bar association’s Web site, visit: <http://www.abanet.org/barserv/stlobar.html>

For more information on how to find a lawyer, see Appendix: Finding Legal Help.

The Family Caregiver Alliance fact sheet, *Durable Powers of Attorney and Revocable Living Trusts*, has useful information on durable powers of attorney. The fact sheet is available online at: http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=434

The American Bar Association Guide to Wills and Estates: Everything You Need to Know About Wills, Estates, Trusts & Taxes is a basic overview of estate planning.

Decision & Action Steps

holds title to property for the benefit of another person or persons (the beneficiaries). The person who creates the trust is called the grantor or the settlor.

Even if you are not rich, a trust may be a useful tool. A trust can be used to provide for management of your assets during your incapacity, to avoid probate, and to make provisions to care for minors or disabled persons at your death.

Several things are important to consider in the creation of a trust:

- Trust language is complex, difficult, and lengthy.
- A trust's terms can have undesired tax consequences, as well as consequences for future eligibility for public benefits, such as Medicaid long-term care benefits.
- Trust drafting should be done by a lawyer experienced in estate planning and, if necessary, public benefits law. For more information on how to find a lawyer, see Appendix: Finding Legal Help.
- Trusts can be expensive. Costs include: the legal expense of having the trust drafted, the cost of transferring your property into the trust, and significant management fees if a professional trustee is used.
- You must make sure that property actually gets transferred into the trust. Because the trustee's authority is limited to only those assets in the trust, if property is not transferred, you will have wasted the money spent creating the trust.

3.4 Consider a representative payee or fiduciary.

If you receive benefits from Social Security, Supplemental Security Income (SSI), civil service,

Resources & Tips

Available online at:

<http://www.abanet.org/abastore/>

Tips: Trusts

- Beware of high-pressure sales tactics about the benefits of living trusts. Because each state is different, you should beware of sweeping generalizations.
- Financial institutions provide professional management of trusts, but they are costly. They are often only appropriate or feasible to use in the management of very large estates.

The Federal Trade Commission has a “Facts for Consumers” publication on living trusts entitled, *Living Trust Offers: How to Make sure They're Trustworthy*. See: www.ftc.gov/bcp/edu/pubs/consumer/products/pro08.shtm

A Guide for Representative Payees, published by the Social Security Administration, provides information on how to be a representative payee, including an income and expenses

Decision & Action Steps

railroad retirement, the Department of Veterans Affairs, or some state pension funds and need help managing the income from those benefits, it may be appropriate to ask the agency to name someone to manage those funds for you. The agency may refer to that individual as a representative payee or as a fiduciary.

Several things are important to think about when considering a representative payee or a fiduciary:

- Even if you have a power of attorney, the agency paying your benefits may choose not to follow it, and require a representative payee or fiduciary be appointed.
- Someone must apply to the relevant administrative agency to be named as representative payee or fiduciary. The agency will then determine whether it should appoint the applicant as a representative payee or fiduciary, based on evidence of the beneficiary's incapacity. Medical and other evidence will be required.
- Once a representative payee or fiduciary has been appointed, he or she has the authority and the duty to manage the relevant income for the benefit of the beneficiary. Under Social Security Administration rules, a representative payee must file fairly simple annual reports according to SSA instructions.
- The authority does not extend to any other income or assets.

3.5 Consider making a plan for succession of your business, if you have one.

If you are the sole owner of a business, you should consider:

1. Signing a power of attorney giving someone you trust the authority to run your business, including signing checks and contracts, when you are unable to handle the business

Resources & Tips

worksheet. Available online at:

<http://www.ssa.gov/pubs/10076.html>

Applications for representative payees of benefits under the Civil Service Retirement System and the Federal Employees Retirement System are available online at

www.opm.gov/Forms/pdf_fill/ri20-007.pdf

Legal Guide for Small Business, by the American Bar Association, is a complete and easy guide to understanding the small-business owner's legal responsibilities and options. Available online at: **<http://www.abanet.org/abastore/index.cfm?section=main&fm=Product.AddToCart&pid=2350200>**

Decision & Action Steps

yourself (for more information on powers of attorney, see action Step 3.2 Consider drafting and executing a power of attorney); and

2. Developing and implementing a succession plan that spells out how, to whom, and when your business will pass to others.

If you own your own business with others, you should have a buyout agreement. A buyout agreement, also known as a buy-sell agreement, should state what will happen when one member wants to leave the company, or worse, gets divorced, dies, becomes too disabled to work, or goes bankrupt.

Because business laws and regulations are so complex and vary from state to state, you should seek the advice of an attorney experienced in working with small businesses. For more information on how to find a lawyer, see the Appendix: Finding Legal Help.

3.6 Consider applying for public benefits.

There are a variety of public benefit programs designed to assist persons who are experiencing job loss, illness, or disability. Medicare and Medicaid were already covered in Step 1. Other potentially useful benefit programs include:

- unemployment insurance;
- Temporary Assistance to Needy Families (TANF);
- food stamps;
- rental assistance;
- energy assistance;
- earned income tax credit;
- child tax credit; and
- state prescription drug benefit programs.

When applying for public benefits programs keep the following tips in mind:

Resources & Tips

GovBenefits.gov is the official benefits Web site of the U.S. government, with information on over 1,000 benefit and assistance programs. Available at: <http://www.govbenefits.gov/>

Benefits QuickLINK, by AARP Foundation, helps you find and apply for low- and no-cost programs that can help you stay healthy, cover basic expenses, assist older relatives, and support children in your care. Visit Benefits QuickLINK online at: <http://www.aarp.org/money/lowincomehelp/quicklink/>

BenefitsCheckUp, by the National Council on Aging, is the nation's most comprehensive Web-based service to screen for benefits programs for seniors with limited income and resources. BenefitsCheckUp includes more than 1,650 public and private benefits programs from all 50 states and the District of Columbia.

Decision & Action Steps

- Be prepared to visit the public benefits office more than once, and be prepared for long waits.
- Bring documentation with you. Generally, you will need your birth certificate; your Social Security numbers; proof of income for household members; proof of assets, such as bank statements and deeds; and documentation of household expenses, such as rent receipts and utility bills.
- File the necessary application as soon as you can, even if you need to come back to the Social Security office with more documents. Generally, your benefits will be paid retroactively from the application date.
- Do not be discouraged if you encounter unfriendly or unhelpful caseworkers or a lot of red tape.
- Get legal help if you run into problems. To find a lawyer, see Appendix: Finding Legal Help.

3.7 Consider making a will.

A last will and testament is a legal document that provides for the distribution of some or all of your property after death. It can be changed or revoked at any time if you are still of sound mind.

“Sound mind” simply means:

- you understand you are executing a will;
- you know the general nature and extent of your property;
- you know the people who would normally be expected to share in your estate (lawyers like to call these people the “natural objects of your bounty,” but that does not necessarily mean that you have to give your property to any of them); and

Resources & Tips

Available online at:

<https://www.benefitscheckup.org/>

Tip: A standard will?

There is no such thing as a standard will. Every will should be tailored to the individual’s particular estate. Because of this, it is best to use a qualified lawyer.

Caution: If you die without a valid will or trust, and do not transfer your property in some other way (such as through insurance, pension benefits, or joint ownership), the state will decide how your property will be distributed. This is known as dying intestate (without a will).

For more information about wills and estate planning in general, see:

www.abalawinfor.org or
www.abanet.org/rppt/public

Decision & Action Steps

- you can say who you want to get your property when you die, and explain why.

Important! Any property you have that passes to someone on your death through joint ownership, trust, or contract, or because the person was named as a beneficiary under an annuity, retirement benefit program, or life insurance, will not be controlled by your will. (For more information, see Step 3.8 Understand will alternatives.)

Property passing under a will goes through probate. Probate is the court-supervised process that determines the validity of your will and oversees the distribution of assets that pass under your will. Some argue that it is a process to be avoided because of burdensome procedures and expenses. This concern is often overstated. The process differs by state. Many states have very simple, low-cost probate procedures.

If you are married and live in a state where community rules control property rights of spouses, these rules will also control where community property goes at death if there is no will and even if there is a will. Each community property state's rules are different. It is important to get legal advice as to how these rules affect your choices. (For more information on how to find a lawyer, see Appendix: Finding Legal Help.)

Unequal or unusual bequests may lead to family disputes. Knowing the people who would normally be expected to share in your estate does not mean you have to give your property to any of them, except generally for your spouse. In almost all states a spouse is legally entitled to a portion of the estate. But as a practical matter, the making of unusual bequests of substantial assets increases the likelihood of a legal challenge to your will later on. If you want to make an unusual bequest, it may be wise to consider getting legal advice.

Other key actions:

If you already have a will, make sure it still works for you. Wills don't expire, but your changing family and

Resources & Tips

For a more thorough guide, see: *The American Bar Association Guide to Wills & Estates*, 3d edition (2004).

IRS Publication 555, *Community Property* (May 2007), is helpful for residents of the nine community property states, Arizona, California, Idaho, Louisiana, Nevada, New Mexico, Texas, Washington and Wisconsin. See: <http://www.irs.gov/publications/p555/ar02.html>

Tip: The big picture. Today, wills control a smaller portion of one's estate than in previous generations because of the growing number of financial planning options. In thinking about your estate plan, it is important to look at all the components of your financial plan and see the big picture. It is also important to have good records of all your financial interests. See Step 7. Get Your Legal Documents in Order for more guidance on this.

Decision & Action Steps

financial situation can make an old will inappropriate for your current situation. If you become a resident of a new state your old will should still work, but because differences in the law can create problems you should have your will reviewed by a qualified lawyer.

Coordinate who will inherit what, both under your will and outside of probate. Make sure your entire estate is distributed as you planned. Non-probate assets are discussed in Step 3.8 immediately below.

3.8 Understand will alternatives.

Will alternatives pass property directly to others without going through probate. Assets handled this way are sometimes referred to as non-probate property.

Examples of will alternatives include:

- **Joint ownership and trusts. See Steps 3.1 and 3.2 above.**
- **Life insurance.** Life insurance is an especially useful tool to plan for the financial welfare of dependents, because one pays relatively little up front for a substantial benefit. However, it may be impossible to purchase after the onset of serious medical conditions. If you already have life insurance, make sure your beneficiary designations are still the persons you want.
- **Transfer on death deeds and payable on death accounts.** Many states now allow title in real property to be held in one person's name, transferable on death to another person named in the deed. These are called "Transfer on Death" deeds or TOD deeds. The same can be done with a bank account or other titled property. The beneficiary receives no interest in the property until the owner's death. TOD deeds and payable on death accounts are a simple and inexpensive alternative to trusts.

Resources & Tips

For more information about will alternatives, visit www.abalawinfo.org and www.abanet.org/rppt/public

The American Bar Association Guide to Wills & Estates, Everything You Need to Know About Wills, Estates, Trusts & Taxes, 3d ed., (Random House, 2009).

Available online at:

<http://www.abanet.org/abastore>

There are different types of life insurance, e.g., life and term insurance. For more information about the differences and how they relate to your specific situation, talk to your insurance agent or other trusted financial advisors.

Decision & Action Steps

- The proper form for creating payable on death status depends on the nature of the property and the state you live in.
- **Retirement accounts and annuities.** These financial arrangements permit you to identify someone as recipient of the benefits at your death. Check any such accounts to make sure the person designated is still the person you want to receive the benefit.
- **Gifts and loans.** Giving your property away before death is another estate planning option, as are loans that are forgiven upon death. These strategies have significant tax implications and can create serious problems for future eligibility for public benefits, such as Medicaid long-term care benefits, so it will be wise to get legal advice. To find a lawyer, see Appendix: Finding Legal Help.

3.9 Consider creating an “ethical will.”

Ethical wills are writings in which you share your values, blessings, life’s lessons, hopes and dreams for the future, love, and forgiveness with your family, friends, and community. They are not considered legal documents, but they are one important way to leave a personal or spiritual legacy to loved ones.

More General Resources

This step has discussed important legal decisions and tools. While we recommend getting legal advice, there are an abundance of self-help publications and computer programs available on the market. For example, Nolo Press provides information on wills and estate planning online at <http://www.nolo.com/resource.cfm/catID/FD1795A9-8049-422C-9087838F86A2BC2B/309/>

The American Bar Association Guide to Wills & Estates, Everything You Need to Know About Wills, Estates, Trusts & Taxes, 3d ed. (Random House, 2009). Available online at <http://www.abanet.org/abastore>

The American Bar Association Real Property Trust & Estate Law Section maintains a Web site—<http://www.abanet.org/rppt/public/home.html#top>—with helpful information and resources for the public.

Resources & Tips

Tips: Gifts and Loans:

- If it is a gift, be clear about whether it is a pure gift or an advancement of an inheritance.
- If you make a loan, be clear about the terms for repayment. If the unpaid balance is to be forgiven, is the forgiven amount to be part of that beneficiary’s share of the estate?
- Don’t hide what you are doing. Be clear and document it.

There are a growing number of resources on ethical wills. See www.ethicalwill.com and the book *Ethical Wills: Putting Your Values on Paper*, by Barry K. Baines (Perseus 2001).

Step 4. Plan for the Care of Dependents

The Basics

To ensure your minor children, disabled children, beneficiaries, and pets are taken care of in accordance with your wishes, you should consider these options:



- 4.1 **Custody/guardianship of minors or other dependents**
- 4.2 **Special needs trust for disabled persons**
- 4.3 **Protection of beneficiaries from themselves, their creditors, ex-spouses, etc.**
- 4.4 **Plan for your pets**

Decision & Action Steps

4.1 **Consider establishing custody/guardianship of minors or other dependents.**

A guardian is someone who has the legal authority and duty to care for another's person or property because of infancy, incapacity, or disability.

You can nominate or appoint a guardian for your children, rather than have the court select one for you.

Several things are important to consider when making plans for a guardian:

- Consult with the person you name to be sure he or she wants the job, and name an alternative guardian in case your first choice changes his/her mind or dies before the child is grown.
- Discuss with the guardian your views on education, moral upbringing, religion, and any other matters important to you.

Resources & Tips

Online resource centers like Nolo Press's *Guardianship of Children*, can be useful. This Web site includes articles and Q & A on the subject of guardianship of children. Available online at: <http://www.nolo.com/resource.cfm/catID/5F2ECF95-E8DD-4A04-A0A6FEB1213633FE/118/122/186/>

Decision & Action Steps

- Make plans to ensure the financial security of the guardianship arrangement.

In some states you can go to court to have a person named standby guardian—which means the person doesn't become guardian until a specific event happens, such as your incapacity. For more information on standby guardians, talk to a lawyer. In other states, you appoint the person in your will or other document, and the court formally appoints the named person as guardian at the time needed and a petition is filed for appointment.

4.2 Consider creating a special needs trust for a person with a disability.

Trusts, which enable property to be used and managed properly for a beneficiary, can be very helpful in planning for the care of a disabled child or other person with disability. However, trust planning must be handled carefully in cases where the disabled individual relies on public benefits, such as Medicaid or Supplemental Security Income. An outright distribution to the disabled individual of assets, or general instructions to use the trust for support, could cause the disabled individual to lose eligibility for public benefits. In these situations, a special-needs trust should be considered. A special-needs trust allows the beneficiary to receive goods or services paid for by the trust, without jeopardizing his or her eligibility for public benefits. It serves to supplement public benefits. (For more information on trusts, see Step 3. Make a Plan to Manage Your Money and Property.)

The law imposes strict requirements and limitations on these kinds of trusts. Therefore, you should have an attorney experienced not only in trust law, but also in Medicaid, Social Security, and public-benefits law give you advice and draft the trust. Any trustee appointed should also have some understanding of the relevant public benefits programs.

Resources & Tips

There are three professional associations of attorneys who do special-needs work and which provide information and attorney referral information:

- The Special Needs Alliance:
www.specialneedsalliance.org
- The National Academy of Elder Law Attorneys: www.naela.org
- The Academy of Special Needs Planners:
www.specialneedsplanners.com

Online resource centers like Nolo Press's Special Needs Trusts, can be useful. This Web site includes articles and Q & A on special needs trusts. Available online at: <http://www.nolo.com/article.cfm/objectId/99F4B4FB-8170-4ACB-93B4688F4E0F7247/309/298/ART/>

Decision & Action Steps

4.3 Protecting beneficiaries, as needed, from themselves, their creditors, ex-spouses, etc.

To protect beneficiaries from themselves, their creditors, ex-spouses, and others, you should consider establishing a spendthrift trust. In such a trust, money is set aside and managed for a particular beneficiary rather than given to them outright.

Properly established spendthrift trusts prevent the beneficiary's creditors, ex-spouses (or soon-to-be ex-spouses or other in-laws you don't trust), and future lawsuits from reaching the funds. This money will be used for the benefit of the beneficiary in the ways you direct—for example, to pay for education or a down payment on a home.

The most important thing to consider when establishing a spendthrift trust is who will oversee the management of the assets (the trustee). The trustee should be someone you trust, someone familiar with your values and what you would like to see done with the money, and someone who can say “no” to the beneficiary.

4.4 Consider making a plan for your pet(s).

A pet trust allows a person to set aside a sum of money to care for a pet in the event of an owner's death or incapacity.

As many as 39 states currently allow pet trusts.

When creating a pet trust, make sure to include:

- specific instructions for feeding, housing, and veterinary care;
- the name of the individual who will care for your pet; and
- the amount of money you put in the trust, which should be sufficient to care for the pet as directed.

Resources & Tips

Michigan State University College of Law's Animal Legal & Historical Web Center, has information on pet trusts. Available online at:
<http://www.animallaw.info>

ElderKit, by Fannie Mae, includes a pet information and instructions template. The template has a space for a pet's name, age, veterinarian's name and contact information, allergies, medication, and special instructions. Available online at:
www.fanniemae.com/global/pdf/aboutfm/responsibility/eldercare/elderkit.pdf

Decision & Action Steps

Resources & Tips

Another option is to “endow” a pet with a set sum of money. For instance, many shelters require a life care endowment to provide for pets until their natural death. A similar gift provision can name a specific person and an alternate (if that person can’t or won’t agree to the terms of the gift) to receive a living pet of a deceased person with a set amount of money to cover food, veterinary costs, etc.

More General Resources

The American Bar Association Guide to Wills & Estates, Everything You Need to Know About Wills, Estates, Trusts & Taxes, 3d ed. (Random House, 2009). Available online at:

<http://www.abanet.org/abastore>

The American Bar Association Section of Real Property, Trust and Estate Law Web site has information and publications for consumers. Visit the section online at: **<http://www.abanet.org/rppt/>**

AARP’s Estate Planning Section provides a wide variety of consumer publications and other valuable information for senior consumers, such as *Final Details: A Guide for Survivors When Death Occurs*. Contact the AARP Estate Planning Section, 601 E Street, NW, Washington, DC 20049; 1-888-OUR-AARP (1-888-687-2277).

Step 5. Know Your Rights As a Patient

The Basics



Patient rights come in a variety of forms from a variety of sources. Some are clearly set forth in statute, court decision, or regulation, such as the right to make medical decisions through a process of informed consent. Others may be stated only generally in professional or institutional standards, such as the right to dignity. Many states have passed laws creating patient bills of rights, but even without such laws, similar rights are recognized in ethical or clinical guidelines of professional health-care organizations. Your decision-making rights to have your wishes known and respected and to have a legally authorized proxy to speak for you when you are unable are addressed in Section 3.

Core rights most relevant to those with serious and eventually fatal conditions are your right to:

- 5.1 Good **pain and symptom management**
- 5.2 High **quality of care** in the hospital, nursing home, or home care setting
- 5.3 Consent to participation in any **experimental treatments**
- 5.4 Access to and privacy of your **medical records**
- 5.5 **Visitation** in hospital and nursing home settings

Decision & Action Steps

5.1 **Insist on good pain and symptom management.**

Severe pain or other distressing symptoms are not something you should accept as a “normal” part of living with a serious illness. You have a right to *palliative care*—that is, adequate pain and symptom relief. Be sure to describe your pain or other distressing symptoms to your health care providers. You also have a right to know about all pain treatment options that are available to you.

Resources & Tips

The National Hospice and Palliative Care Organization’s Caring Connections program has several useful publications. See their *Palliative Care Questions and Answers* at: http://www.caringinfo.org/LivingWithAnIllness/PalliativeCare/palliative_care_questions_answers.htm

Hospice programs are experienced in providing palliative care. Hospice care is an interdisciplinary approach to caring for those with a life-limiting illness that provides comfort, rather than curative, care. Pain control, counseling, including bereavement counseling for caregivers and family,

Decision & Action Steps

The term *palliative care* refers to more than just pain management. It concentrates on helping a person be comfortable by looking after the medical, emotional, social, and spiritual needs of the patient. Hospice and other palliative care providers have special training to provide this kind of care. Hospitals also provide palliative care. The goals of palliative care are to improve the quality of a seriously ill person's life and to support the person and their family during and after treatment.

Fact vs. fiction:

- Medical use of narcotic-based drugs (or opioids) is a recognized part of good medical practice.
- Medical use of opioids enables patients with serious pain to function at their highest possible level.
- By using opioids, pain can be managed in more than 95 percent of cases. Unfortunately, fears about the use of pain medications and their side effects can keep people from taking them.
- Don't be put off by fears that pain drugs may cause addiction.
- Physical dependence on the drug may occur, but that is a normal and manageable side effect of treatment and is not addiction.
- Most doctors do not have extensive training in pain management. Ask for doctors or other health-care professionals who are trained in pain management to work with you to check, treat, and manage your pain symptoms.

5.2 Insist on high quality of care in the hospital, nursing home, or community setting.

➤ **In a Hospital**

Some states have adopted “hospital patients’ rights” laws or regulations. But even without these laws, almost all hospitals are subject to standards established by the Joint Commission for the

Resources & Tips

and social services are all part of hospice care. Hospice may be provided at home, in nursing homes, hospitals, or special inpatient units.

Other excellent groups that can help you understand and receive good palliative care include:

- The American Pain Society, a multi-disciplinary professional association. See their *Guides for Persons with Pain* at: http://www.ampainsoc.org/pub/persons_with_pain.htm
- The American Pain Foundation, a non-profit organization serving people with pain. It has many resources on its Web site at: www.painfoundation.org

For Medicare patients—federal law gives you many rights regarding all your care. A good starting reference is an online brochure from the Centers for Medicare and Medicaid services, entitled *Your Medicare Rights and Protections*, available at: www.medicare.gov/Publications/Pubs/pdf/10112.pdf

Hospital Compare is a useful online tool created by the federal government. You can

Decision & Action Steps

Accreditation of Health-care Organization. Under these standards, hospitals are expected to have procedures in place to address your right:

- to reasonable access to care;
- to care that is considerate and respectful of your personal values and beliefs;
- to be informed about and participate in decisions regarding your care;
- to participate in the resolution of ethical questions that arise in the course of your care;
- to security and personal privacy and confidentiality of information; and
- to designate a decision-maker in case you become incapable of making health care decisions.

Patient Safety: Medical errors are one of the nation's leading causes of injury and death in hospitals. While all hospitals put a great deal of effort into preventing medical errors, you share some of the responsibility to prevent them. Take a look at the *20 Tips* brochure in the resource column.

➤ In a Nursing Home:

Most nursing homes are subject to federal standards and all are licensed by state regulatory agencies. Federal standards set a very high expectation for quality of care and quality of life, stating that residents are entitled to:

- care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with a comprehensive assessment and plan of care; and

Resources & Tips

compare hospitals in your area on how well they care for patients with certain conditions and on results from a survey of patients about the quality of care they received. Go to: www.hospitalcompare.hhs.gov

One guide everyone should read before stepping into a hospital is:

- *20 Tips to Help Prevent Medical Errors*, by the Agency for Health-care Research and Quality, available at: www.ahrq.gov/consumer/20tips.htm
- For children in care, take a look at this: *20 Tips to Help Prevent Medical Errors in Children*, available at: www.ahrq.gov/consumer/20tipkid.htm

Tip: Know who is treating you in the hospital. More than one physician will likely be involved in your care. And, you do not have to interact with medical and nursing students or permit them to perform a specific procedure if you don't want to. Yes, they need the experience, but it's your choice.

Nursing Home Compare is a useful online tool, created by the federal government. It has detailed information about every Medicare- and Medicaid-certified nursing home in the country and allows you to compare facilities using selected quality indicators. It also includes a Five Star quality rating system to help you compare facilities. Go to: www.medicare.gov/NHCompare

More information about federal residents' rights regulations can be found on the Web site of the National Senior Citizens Law Center (NSCLC) at:

Decision & Action Steps

- an environment that promotes maintenance or enhancement of each resident's quality of life.

Nursing homes do not always meet these standards. It often takes effort by the resident or residents' loved ones to ensure these rights are enforced. The resources to the right provide excellent guides to help you accomplish this.

You may also be entitled to receive hospice care in a nursing home. See Hospice Care, below and in Step 1.4.

Problems? If you need help and the nurse or administrator is not responsive, contact the *Long-Term Care Ombudsman* for your area. The ombudsman acts as an advocate for residents in long-term care facilities. The nursing home should have the contact information publicly posted.

➤ **In-Home Care and Hospice:**

Federal law and state licensing law regulate home care and hospice care programs.

Patients of Medicare-approved home health agencies and hospice have several rights. The home health or hospice agency must provide you with a written copy of them. They include the following:

- The right to choose your home health agency, although for members of managed care plans, the choices will depend upon which home health agencies your plan works with.
- The right to have your property treated with respect.
- The right to have your family or guardian act for you if you are unable.

Resources & Tips

www.nsclc.org/publications/Federal%20Regulations%20and%20Guidelines

Also on the NSCLC Web site are two very useful publications (available for purchase):

- *20 Common Nursing Home Problems and How to Resolve Them*
- *The Baby Boomer's Guide to Nursing Home Care*

The National Citizens' Coalition for Nursing Home Reform (NCCNHR) advocates for better resident care in nursing homes and assisted living facilities. Its Web site, www.nccnhr.org, offers a wealth of information and guidance to residents and their loved ones.

Home Care Compare is a useful online tool, created by the federal government. You can compare 12 quality measures of care on every Medicare-certified home health agency. Go to: www.medicare.gov/HHCompare

The National Hospice and Palliative Care Program has a great deal of consumer information on its Web site at: www.caringinfo.org, including a useful brochure to help you know what to look for and what to expect from a hospice provider:

- *Hospice Care: A Consumer's Guide to Selecting a Hospice Program*, by Caring Connections, available at: www.caringinfo.org/LivingWithAnIllness/Hospice.htm

The National Association of Home Care and Hospice provides useful information on finding a good home care agency at:

Decision & Action Steps

- The right to complain to the state oversight agency about your treatment or care if it not provided properly or if staff shows disrespect for you or your property.
- The right to be given a copy of your plan of care, so you can ask questions about the type of services and staff the home health agency plans to provide to you and how often you can expect those services.

5.3 Know your rights related to experimental treatments.

There are several legal mandates and ethical guidelines that apply to medical research. Research funded by federal dollars must comply with detailed research regulations that address issues including:

- obtaining and documenting informed consent from research participants; and
- review of research protocols by Institutional Research Boards (IRBs) whenever human subjects are involved.

If you are asked to be a research subject, collect a great deal of information before making a decision. The primary goal of research is not to help the individual participating in the research; it is intended to advance the state of medical knowledge. There may, or may not be, a potential benefit to you. There may also be some danger.

Ask questions so that you thoroughly understand what you are getting into. See the resources to the right for suggested questions.

If the research involves drugs, be aware of the differences in research phases. Find out in which phase you would participate and what that means. Some states authorize patients to consent to participate in research in an advance directive. You should consult with a lawyer if this is a choice you want to make.

Resources & Tips

- *How Do I Select the Right Home Care Provider?* <http://www.nahc.org/consumer/selection.html>
- *What Are My Rights As a Patient of Home Care and of Hospice?* <http://www.nahc.org/consumer/rights.html>

When considering whether to participate in medical research, use a prepared list of questions. Two useful guides are:

- The National Cancer Institute (part of the National Institutes of Health) provides an online *Guide to Understanding Informed Consent*, including detailed questions to ask at: www.cancer.gov/clinicaltrials/conducting/informed-consent-guide
- The Alliance for Health Research Protection provides a good list of questions in *Informed Consent: The Subject's Right to Know* at: www.ahrp.org/InformedConsent/InformedConsent.php

Decision & Action Steps

5.4 Know your rights to access to your medical records.

The most important regulation of access and privacy rights is the privacy rule adopted under a federal law known as HIPAA (the Health Insurance Portability and Accountability Act of 1996).

The privacy rule standards address the use and disclosure of individuals' health information by organizations subject to the privacy rule. Most health care providers and insurance companies are subject to the privacy rule. The Office of Civil Rights, part of the U.S. Department of Health and Human Services, has responsibility for implementing and enforcing the privacy rule. Their Web site has lots of useful guidance on it.

Access to medical information and records is sometimes a problem faced by patients and their families. Some key points to be aware of:

- You are entitled to access your medical records and obtain copies of records for no charge or a reasonable charge.
- In addition to the federal privacy rule, each state has medical records laws. These laws may be even more restrictive than HIPAA.
- Your health care agent under a health care power of attorney that is now in effect (explained in Step 2.1) has a right to access to your medical information and records to the same extent you would. Any other individual authorized under state law to make health decisions for you has the same access to the information.
- Health care professionals may share medical information with other family or friends to the extent it is relevant to their involvement with the patient's care and the patient does not object. The problem here is that the decision to share information is within the discre-

Resources & Tips

A good explanation of the federal privacy rule, along with extensive Q&As, may be found on the Web site of the Office for Civil Rights at the Department of Health and Human Services: <http://www.hhs.gov/ocr/privacy/index.html>

For more information on state medical records laws, visit Georgetown University's Center on Medical Records Rights and Privacy online at: <http://hpi.georgetown.edu/privacy/records.html>.

Decision & Action Steps

Resources & Tips

tion of the provider. They don't have to share information with family members, unless the patient signs a HIPAA authorization. Ask your health care provider for their HIPAA authorization form and complete it naming the people who are not your authorized decision maker(s), but whom you want medical staff to talk to.

- Give a copy of the signed authorization form to the people who you want to have access to this information.

5.5 Know your hospital or nursing home visitation rights.

Generally, a spouse and anyone whose consent is required for medical care (i.e., parent of a minor, agent under a health care power of attorney, other authorized legal representative) is entitled to visitation virtually around the clock, subject to reasonable interruptions for treatment or care activities. For everyone else, hospitals and nursing homes may establish and enforce reasonable visitation hours.

Problems sometimes arise for gay and lesbian partners or for close friends of a patient. If designated an agent under your health care power of attorney, he or she should have the same access as a spouse. If not formally designated as your agent, then their visitation rights will depend on whether state or local law grants them civil union, marital, or decision-making rights.

Nursing Homes: Federal nursing home regulations, applicable to most facilities, require the facility to provide immediate access to a resident by the resident's health care agent, immediate family, or other relatives, subject to the resident's right to deny or withdraw consent. For all others who are visiting with the consent of the resident, the facility may set reasonable restrictions.

Step 6. Know Your Rights As an Employee

The Basics



If you are employed when you or a loved one is faced with serious illness or impairment, it is important to know your rights as an employee. Three groups of rights discussed in this chapter may apply to you, depending on your place of employment:

6.1 Taking leave for medical treatment or care. If you need to take leave to obtain medical treatment or to care for a family member, you may be eligible for unpaid, job-protected leave under the Family and Medical Leave Act or to be reasonably accommodated in taking leave under the Americans with Disabilities Act (ADA).

6.2 Benefit protections while employed. The Employee Retirement Income Security Act helps protect your health care and pension benefits while you are employed. The ADA also prohibits discrimination in job benefits.

6.3 Health benefit protections after leaving or losing your job. The Continuing Omnibus Budget Reconciliation Act of 1985 may allow you to buy health care coverage under your employer's health plan if you lose your employer's coverage because you leave or lose your job or have your hours cut.

Decision & Action Steps

6.1 Know your rights to family and medical leave.

Family and Medical Leave Act Leave

The Family and Medical Leave Act (FMLA) allows eligible employees to take up to 12 “workweeks” of unpaid leave for medical or family reasons during a 12-month period and have their jobs and benefits protected when they return to work. More specifically, an employee may take FMLA leave if the employee has a “serious health condition,” as defined by the law, or if the employee needs to provide care for a spouse, son, daughter, or parent who has a “serious health condition.”

Resources & Tips

Much more information about the FMLA is provided in the U.S. Department of Labor Employment Standards Administration Wage and Hour Division Fact Sheet #28: *The Family and Medical Leave Act of 1993* (Revised January 2009), available online at: <http://www.dol.gov/esa/whd/regs/compliance/whdfs28.pdf>

Tips:

- Talk to your employer's human resources staff or your supervisor about your eligibility for taking FMLA leave or about reasonable accommodations under the ADA for taking leave. But make sure any employer communications about your right to leave or how

Decision & Action Steps

Generally, when the employee goes back to work, the employer must return the employee to his or her job or an “equivalent job with equivalent pay, benefits, and other terms and conditions of employment.” If an employer provides health benefits to employees, the employer must continue to provide those benefits to the employee while he or she is on leave.

The FMLA is a federal law that must be followed by local, state, and federal government agencies; schools; and private-sector companies that have had at least 50 employees during 20 or more “workweeks” in the current or last calendar year. Eligible employees are those who have worked for that employer for at least 12 months and who have worked at least 1,250 hours during the preceding 12 months.

Americans with Disabilities Act Leave

The Americans with Disabilities Act (ADA) is a federal law that prohibits discrimination in employment practices against individuals with disabilities by employers with 15 or more employees. The law defines an individual with a disability as someone who has a physical or mental impairment that substantially limits one or more major life activities, has a record of such impairment, or is regarded as having an impairment.

The ADA does not provide for leave and job/benefits protection like the FMLA. Instead, it prohibits employers from discriminating against employees with disabilities in attendance and leave policies. Employers may be required to make “reasonable accommodations” in leave policies for employees with disabilities. Examples of reasonable accommodations might be allowing an employee with a disability to take unpaid leave or to have additional flexibility in taking leave.

Resources & Tips

these laws relate to your situation are in writing.

- If you are not protected under the FMLA or ADA, contact an agency that deals with employment issues in your state (www.workplacefairness.org provides a list of such agencies and other resources). Also, consider talking to a lawyer in your state about whether there are state or local laws that may protect you.
- Decide whether it makes sense to take FMLA leave or to request a reasonable accommodation under the ADA to take leave.

Answers to a number of questions about the coverage of the ADA are provided in the U.S. Equal Employment Opportunity Commission and U.S. Department of Justice Civil Rights Division “Americans with Disabilities Act Questions and Answers,” online at: <http://www.ada.gov/q%26aeng02.htm>

Decision & Action Steps

6.2 Know your rights regarding your health care and pension plans.

ERISA protections regarding health and pension plans

The Employee Retirement Income Security Act (ERISA) helps protect your health care and pension benefits while you are employed unless you are an employee of a federal, state, or local government, or of a church.

If your employer provides health care insurance, ERISA requires your employer to provide you with information about your health care plan. The law also protects you from being fired or discriminated against because you are using that plan.

ERISA also provides protections to certain employees whose employers offer retirement plans. The law does not require that employers provide retirement plans, but it does require employers who offer retirement plans to provide you with information about the plan and to manage and oversee the plan responsibly so that you receive the benefits promised to you.

For both health care and retirement plans, ERISA requires that your plan administrator have a reasonable process for challenging decisions it makes about your benefits, including payment amounts and denial of benefits.

ADA protections regarding health and pension plans

The Americans with Disabilities Act (ADA) requires employers with 15 or more employees to provide qualified individuals with disabilities (see explanation of the ADA in Step 6.1) an equal opportunity to benefit from the same employment-related opportunities available to employees without disabilities. The ADA prohibits employers from discriminating against qualified individuals with disabilities in recruitment, hiring, promotions,

Resources & Tips

Resources:

The U.S. Department of Labor has several useful resources:

- *Employee Retirement Income Security Act (ERISA)*—a good overview of the act and links to numerous subtopics are provided, available online at: <http://www.dol.gov/dol/topic/health-plans/erisa.htm>
- Fact Sheet: *Life Events Impact Health Benefit Needs*—an overview of health care benefits and issues to consider upon certain life events, such as marriage or the approach of old age, available online at: <http://www.dol.gov/ebsa/newsroom/fshealthcy.html>
- Fact Sheet: *Life Changes Require Health Choices—Know Your Benefit Options*. More detail than the previous fact sheet, available online at: http://www.dol.gov/ebsa/Publications/life_changes.html
- *What You Should Know About Your Retirement Plan*—a lengthy, detailed booklet with information and practical tips about pension plans, available online at: <http://www.dol.gov/ebsa/publications/wyskapr.html>

The Pension Rights Center also provides helpful resources:

- Pension Help contains links to sources of help with pension, profit sharing, and retirement savings plans problems, including six pension counseling and information projects, the National Pension Lawyers Network, and the Pension Assistance List. See: <http://www.pensionrights.org/help.html>

Decision & Action Steps

training, pay, social activities, and other privileges of employment. Privileges of employment include job benefits such as health insurance, disability insurance, life insurance, retirement account contributions, or pensions, in addition to leave benefits discussed in the previous section.

Important!

- Get and review the “summary plan description” for each type of plan you have.
- Monitor any statements that you receive from your employer or benefit plan administrator to make sure that they are correctly managing your benefits. If you think something may be wrong, talk to your employer’s human resources staff or your supervisor or the staff at the benefit plan administrator. If necessary, contact the U.S. Department of Labor or the appropriate agency in your state and consider getting legal advice.
- If your employer changes or ends a retirement plan, goes out of business, or merges with another company, see a lawyer to learn how your benefits may be affected and whether there is anything you need to do to help protect your benefits.

6.3 Know your health benefit protections after leaving or losing your job: COBRA.

Your rights to continuation of employer health benefits are defined by a federal law known as COBRA (the Continuing Omnibus Budget Reconciliation Act of 1985). COBRA allows most individuals who leave or lose their jobs or who have their hours reduced to buy coverage under their employer’s health care plan for a period of time. An employee’s spouse or dependent children may also be eligible for COBRA coverage.

Resources & Tips

- Links to numerous free, downloadable fact sheets at: <http://www.pension-rights.org/pubs/facts.html>

ADA Resource: These are the same Q&As referred to in Step 6-1: <http://www.ada.gov/q%26aeng02.htm>

Tips:

- If your circumstances change in a way that affects your or your spouse’s eligibility for health benefits—for example, you get divorced or separated or you or your spouse become eligible for Medicare—you should notify your employer(s) within sixty days of that event.
- COBRA rules are complex and there are important deadlines that must be followed. Talk to your employer or your human resources staff about them. If you

Decision & Action Steps

- This extended coverage is generally available for 18 months; however, coverage may be available for up to 36 months under some circumstances, including the death or disability of the employee.
- To be eligible for COBRA coverage, your employer must have had at least twenty employees, you must have been a participant in your employer's health care plan, and your employer must continue to provide a health care plan to its remaining employees. Certain employers are not required to offer COBRA coverage, but there may be other federal or state laws that require them to provide similar coverage.
- If you leave or lose your job or have your hours reduced for reasons other than "gross misconduct," your employer must give you information about COBRA coverage.
- Generally, individuals taking advantage of COBRA must pay for the full cost of the premium plus an administrative charge.
- Recognizing that unemployed workers may find it difficult to pay for COBRA coverage, the recently enacted American Recovery and Reinvestment Act of 2009 provides a 35 percent subsidy of the COBRA premium for up to nine months. The subsidy is only available to employees who involuntarily lost their jobs between September 1, 2008, and December 31, 2009, unless (a) they are eligible for other group health coverage such as Medicare or a spouse's health plan; (b) their income is too high, or (c) their employer's group health plan ceased to exist.

Resources & Tips

still have questions, get more information from the sources listed below or talk to a lawyer.

- If your employer says it is not required to provide COBRA coverage, contact your state's insurance department to ask if there is any state law or program that might be of help to you. If you think your employer is incorrectly telling you it is not required to provide COBRA coverage, consider contacting a state agency (see www.workplacefairness.org for resources) or getting legal advice.

COBRA Resources:

- Answers to a number of questions about COBRA coverage are provided in the U.S. Department of Labor FAQs about COBRA Continuation Health Coverage, available online at: http://www.dol.gov/ebsa/faqs/faq_consumer_cobra.html
- Information about the new COBRA subsidy and links to additional sources of information for employees and employers are provided in the U.S. Department of Labor Employee Benefits Security Administration COBRA Continuation Coverage Assistance Under the American Recovery and Reinvestment Act, at: <http://www.dol.gov/ebsa/cobra.html>
- An overview of issues and options to consider upon job loss is provided by the U.S. Department of Labor Fact Sheet: *Job Loss—Important Information Workers Need to Know to Protect Their Health Coverage and Retirement Benefits*, available online at: <http://www.dol.gov/ebsa/newsroom/fsjobloss.html>

Step 7. Get Your Legal Documents in Order

The Basics



To protect important legal documents and prevent confusion and delay, you should (1) organize your legal documents, and (2) let people know where they are kept. To do this:

- 7.1 **Collect all of your important legal documents**
- 7.2 **Store your important legal documents in a safe and accessible location**
- 7.3 **Let key people know where you keep important legal documents**

Decision & Action Steps

7.1 **Collect all of your important legal documents.**

The following legal documents should be collected:

- adoption papers;
- birth certificate;
- citizenship papers, if not born a U.S. citizen;
- death certificate of a spouse;
- designation of guardian;
- divorce papers;
- do-not-resuscitate orders;
- health care advance directives (health care power of attorney and living will);
- marriage certificate;
- durable power of attorney;
- prenuptial agreements;
- trust documents;
- veteran's discharge documents; and
- will.

Resources & Tips

Be Prepared: The Complete Financial, Legal, and Practice Guide to Living with Cancer, HIV, and Other Life-Challenging Conditions, by David S. Landay (St. Martin's Press, 1998), has a complete list of legal and non-legal documents.

Decision & Action Steps

7.2 Store your legal documents in a safe and accessible location.

Because a safety deposit box is only available when the bank is open and only to people who are signers on the box, you should:

- 1) only store copies there, and
- 2) make your executor, successor trustee, or financial agent a signer on the box, so they have access to its contents.

Original legal documents should be stored in a safe place at home or elsewhere where your family, agent, or legal representative will be able to find them easily.

- Some attorneys are willing to store the originals of documents they draft for you, while others will ask you to store the originals.
- Copies of your health care advance directives should be given to your health-care decision maker, doctor, and other health-care providers.
- Your agent or legal representative under your power of attorney, advance directive, will, or trust should also have a copies, and if you prefer, the originals.

7.3 Let people know where you keep important legal documents.

Now that you have collected and stored all of your important legal documents in a safe and accessible location, it is important to let people know where they are.

You can let people know where they are by:

- completing a document locator list;

Resources & Tips

A checklist of some household records (or copies of records) that are best kept in a safe deposit box is available online at: <http://www.caringinfo.org/index.cfm?page=540>

Some attorneys do not keep originals.

The F.I.L.E. by the Baltimore (Maryland) County Department of Aging provides family and friends with one centralized place for a summary record of:

- Financial information,
- Investments and insurance,
- Legal documents, and
- Estate management.

For more information on The F.I.L.E., contact the Baltimore County Department of Aging at: www.aginginfo@baltimorecountymd.gov; (410) 887-2594.

ElderKit, by Fannie Mae, includes a document locator list to keep track of the exact location of personal, financial, legal, and insurance documents. Available online at: www.fanniemae.com/global/pdf/aboutfm/responsibility/eldercare/elderkit.pdf

Tip: If you have documents stored in a safety deposit box, be sure to include the names of the signers on the box on your document locator list.

Decision & Action Steps

- keeping it in a location that is easy to find (i.e., your refrigerator door or labeled file); and
- sharing a copy with the person(s) who will need access to these documents in case of your incapacity, travel, or death.

Resources & Tips

More General Resources

Get It Together: Organize Your Records So Your Family Won't Have To by Melanie Cullen & Shae Irving, J.D., provides a complete system for structuring a records binder and easily organizing it for your loved ones. Available online at: <http://www.nolo.com/product.cfm/ObjectID/88F6BDC1-A030-48AF-95F9F15C9716ABCD/catid/20CEEE73-2677-4AF1-90597F7976CA2BCD/309/311/>

Financial Planning Guidance for Those Who Have Lost a Loved One, by Fidelity Investments, summarizes legal and financial steps that need to be taken after the death of a loved one. Available online at: <http://personal.fidelity.com/planning/investment/content/lossof.shtml>

Conclusion

Getting your financial and legal affairs in order when faced with a serious illness or injury is important and takes effort, but you are not alone. This guide provides financial and legal information and resources that we hope will help you understand your options, make informed decisions, and minimize some of the anxiety you may be feeling about your financial and legal affairs at this stage of life. Above all, we hope the guide frees you to focus on what matters to you most.

“Everything has been figured out except how to live.” Jean-Paul Sartre (1905-1980)

Appendix:

Finding Legal Help

To find a lawyer that meets your needs and budget, and is skilled in the area of the law that you have a legal problem with, or question about, you'll probably need to do some research. Some people rely on their own or a friend's contacts. Others find referrals through churches, local organizations, and support groups. The resources described below are a good place to start.

- The Web site of the American Bar Association (ABA) Commission on Law and Aging contains numerous links to resources that can help you locate a lawyer. Visit www.abanet.org/aging.
- State bar associations can provide information regarding lawyer referral services available in your state. The ABA Lawyer Referral Services Web site (<http://findlegalhelp.org>) provides direct links to the Web sites of state and local bar associations. Some states—California, Florida, New Mexico, North Carolina, South Carolina, and Texas—certify lawyers in specialty areas, such as estate planning.
- The National Academy of Elder Law Attorneys (NAELA) publishes a directory of elder law attorney members, including those certified in elder law by the National Elder Law Foundation; visit www.naela.com. NAELA members include lawyers with experience in legal issues affecting seniors and people with disabilities, including health care decision making, special needs planning, estate planning and disability benefit applications and appeals. Attorneys who are listed as a *certified elder law attorney*, or *CELA*, have had to pass an examination and meet other experience requirements to receive that certification.
- Persons 60 years of age and older have access to free or reduced-fee legal assistance through their local area agency on aging or the national Eldercare Locator at 1-800-677-1116. Visit www.eldercare.gov to find the Area Agency on Aging nearest you.
- The Special Needs Alliance (www.specialneedsalliance.org) and the Academy of Special Needs Planners (www.specialneedsplanners.com) are professional associations of attorneys who do special needs work. Visit them online to receive attorney referral information.