Advanced Illness

Financial Guidance for Cancer Survivors and Their Families

National Endowment for Financial Education

Partnering for Financial Well-Being

American Cancer Society®

THE OFFICIAL SPONSOR OF BIRTHDAYS.®

Advanced Illness

Financial Guidance for Cancer Survivors and Their Families

"My husband finally came to me and told me that his cancer is back and things don't look good. He put off telling me as long as he could. Maybe he wanted to protect me, or maybe he didn't want to admit that this was really happening. But even without words, I already knew something was wrong.

Now we're starting down the road of treatment and tests again. The last time, he faced cancer as if he had entered a war. He was going to fight and win. I joined him in that fight. But now it's different. He seems drained and is withdrawn much of the time. I also know he feels guilty ... guilty because he might leave me and guilty that we've already spent so much money for his treatments.

I want to tell him that we'll manage, we'll be all right. But I can't seem to say what I want to say. Talking is so difficult right now. I do want him to know that we're still partners. We have built our lives together and faced our problems together, and we can face this together, too."

NATIONAL ENDOWMENT FOR FINANCIAL EDUCATION

Partnering for Financial Well-Being

American Cancer Society®

Table of contents

Gaining control

When you learn that you have advanced cancer and that the outlook for the future is not good, you may be overwhelmed with emotions. The sense of loss and fear could make you feel paralyzed and unable to think. There may be times when thousands of frightening thoughts race through your head. You may feel isolated. But as alone as you may feel, help is all around you. It's there from the people who love you, and from the health care team helping you through this time. Now more than ever, it's time to tap into these sources of help and strength.

Then, little by little, you face your fears and concerns. As time passes, one of your concerns may be your finances. You may have questions, such as: "How much medical coverage do I have?" "How do I pay for my care and still take care of those who depend on me?" "How can I let my family know my wishes?" "How can I make sure they are taken care of after I am gone?"

This information is to help you better understand your financial choices and be ready for the future so that you can keep as much dignity and quality in your life as possible.

Getting the support you need

Would it be better if I didn't tell others about my diagnosis?

You may have a strong desire to protect the feelings of the people you love. You may even think about not telling them about what's been going on and the bad news you're dealing with. But even if you haven't said a word, your loved ones most likely know that something is wrong. By sharing with them, you allow them to join you in your struggle. You can all work together and make the most of the time you have. Remember, cancer must be dealt with on many levels, and social support can be just as important as medical support.

Ask your doctor about meeting with your family so the burden of delivering this news is not entirely yours. Then, talk with your oncology social worker, psychologist, or therapist. This person can work with you and your loved ones so everyone can begin to cope with the fact that treatment is no longer helping.

Taking care of the whole person

If you or a loved one is facing advanced cancer, you'll need to deal with the illness physically, emotionally, and spiritually. Here are some tips that may help you:

Don't think you should always have a positive attitude.

When coping with advanced cancer, it's very normal to feel a sense of mourning, loss, sadness, and fear. To move through these feelings, you first have to acknowledge them. Then, you can work toward finding safe and healthy ways to deal with them.

Let go of the need to protect others.

Being honest with loved ones is better than hiding bad news. Often, when you try to protect others, it has the opposite effect: they feel left out, hurt, and isolated. In many ways, cancer is a family disease. It affects not only you, the patient, but also the people whom love you. Those who care about you must find their own way of coping with your diagnosis. Openness from you can help them.

Include the children.

If you have young children, you may be tempted not to tell them about the changes in your outlook for the future. But children sense when something is wrong and may blame themselves if the situation is not explained to them. Even if they don't fully understand, it's important to be open and honest with them about what's going on. Try to talk to them in a way they can understand. Let them know it's OK to ask questions.

Seek out others being treated for cancer.

It can be very helpful to talk to others who are going through the same things you are facing. You can express your feelings about your illness and your uncertain future, as well as share information and strategies for coping with these changes.

Talk with an oncology social worker or psychologist experienced in helping people with cancer.

These professionals can help clarify the medical choices you face. For example, different doctors may recommend different treatment options. Talking with a social worker or psychologist can help you make the medical choices that are right for you. They also may be able to help you support your loved ones, find ways to manage pain, and cope with the changes that come with knowing you have a limited time to live.

Seize what opportunities you do have.

You can choose how to spend your time so you can get as much joy as you can from your life. This is a good idea for all of us, but few people take advantage of it until faced with a crisis.

Make the connection between your body and your mind.

Decreasing your emotional distress can help you feel better. At the very least, it will improve your quality of life. Relaxation techniques, stress management, and social support can make you better able to cope with cancer and the changes you are facing.

Decisions about work

What should I do about my job?

If you have been working, you will need to decide how long you can continue to work and if you want to do so. Or, you may have to decide if you will ever be able to go back to work.

Your health may not allow for the stress and demands of a job. Also, your job may not seem as important now. You may have different priorities. Still, your job may give you a sense of control, enjoyment, accomplishment, and/or hope. And it may be something you can do to distract yourself from your health issues. Ask your doctor to help you decide if and when it is time to leave your job for good.

Of course, if your job performance begins to decline, it would be best to leave on your own terms. You don't want to be let go from your job and lose valuable benefits.

One benefit that may be available to you and very valuable at this time is long-term disability. If you have this type of insurance, read the policy carefully. Be sure to look at the following:

- **Definition of disability.** How does the policy describe disabled? Do you fit this description? It may help to speak with a human resources representative (or your insurance agent if it is a private policy) about the details of the policy. They may be able to help you figure out the best way to qualify for benefits.
- **Monthly benefit amount.** Benefits vary. If it is an employer plan, it will probably pay you 60% to 70% of your income. If you bought the policy, the benefit will be the amount you chose.
- **Benefit period.** How long will the plan pay a benefit?
- **Waiting period.** How long must you wait before you get a check? It helps to know this. Then you can think about ways to make ends meet until your first disability check comes.
- **Residual or partial disability.** Though this is not common and you may not be up to it, your policy may allow you to work part time and collect part of the benefit. The policy also may allow you to return to work on a part-time basis after being on disability and not lose your entire benefit.
- **Taxability.** If you paid the premium for your long-term disability insurance, the benefit is income tax-free. If your employer paid the premium, the benefit is taxable. This may have a big impact on your cash flow. If you paid a portion of the premium, that percentage of the benefits will be tax-free. Be sure to find out what portion of your benefits will be taxable.
- **Coordination of benefits.** If your employer pays for your plan, your disability check may not always be 60% to 70% of your wages. This most often happens when you also are getting funds from Social Security or some other program. For example, if you earn $2,000 a month and your company's disability plan covers 70% of your wages, you should be able to get $1,400 a month in disability benefits. But if you're also getting $400 a month in Social Security benefits, and your plan has a coordination of benefits provision, this amount will be subtracted from the $1,400. Your disability check would now be $1,000. You'll need to remember this when making your budget.

Some people buy their own disability plans. For these people, the rules are different. Once you meet the plan's definition of disability, you will be paid a specific amount, say $1,400 a month. If you are getting $1,400 from the insurance company, as well as $400 a month in Social Security benefits, your total monthly income is $1,800.

- **Social insurance rider.** If you bought your own disability policy, find out if you included a social insurance rider. The rider will pay you additional benefits unless and until you get government benefits, such as Social Security Disability Income (SSDI).

  For example, say your policy pays you $1,400 a month once you qualify for benefits. If your policy has the Social Insurance Rider, it may pay an additional $400 a month. You must then apply for Social Security (or Railroad Retirement) benefits. If you get turned down, the extra $400 a month would continue. Then your total monthly benefit would be $1,800. But if you are approved for Social Security benefits, you wouldn't get the $400 from the rider. Your total benefits might still be $1,800, but $400 would be sent by Social Security. Depending on your policy, the government benefit amount is subtracted dollar for dollar from the rider benefit amount, or the entire benefit amount stops regardless of the amount of the government benefit.

You may decide to leave work so you can focus on your loved ones and other things that are important to you at this time. But if you choose to keep working, it is a good idea to tell your employer about your health status. Why? Because of the Americans with Disabilities Act (ADA) and the Family and Medical Leave Act (FMLA). These laws give you options for your work situation.

- **Americans with Disabilities Act.** You may not think of yourself as disabled, but this act also protects the rights of people with cancer. This federal act says that the employer must make a "reasonable accommodation" to allow you to do your job. A reasonable change may include working flex-time, working from home, or using special equipment at work. The changes needed must not cause the employer "undue hardship." One major point to keep in mind is that, to be covered under the act, your boss must know about your health. The act applies to businesses with 15 or more workers.
- **Family and Medical Leave Act.** This act requires employers with 50 or more workers to provide up to 12 weeks of unpaid leave. You should be aware that leaving before you qualify as disabled may cost you future disability benefits. You can use this time to take care of yourself. A family member also may be able to take a leave to help care for the person with cancer. To qualify, employees must have worked at least 1 year and 1,250 hours. Again, to be covered by the act, you need to tell your employer (and any primary caregiver's employer) about your health.

Many employers are very supportive and will work with you while you are dealing with cancer. Still, it's a good idea to keep careful records of all talks with the employer or people in the benefits office. Also, keep copies of your performance reviews. Legal assistance is available if you feel you have been treated unfairly at work. (See the "General resources" section on page 18.)

Health insurance coverage

What choices are open to me now?

It is important to keep good health insurance coverage if you already have it. This can help you and your family avoid financial hardship. Know how your current coverage works. If your employer provides your plan, find out what you have to do to keep it.

If you do not have coverage or if your health plan at work is not enough, you may want to look into individual coverage. But you can expect to face the complete underwriting process and may be turned down by a number of insurance companies and HMOs. And even if you are accepted, the cancer care may not be covered for at least 12 months. (Pre-existing condition exclusion periods are covered below.) Also, know that the cost of these policies or medical plans will be high.

State-mandated Insurance Programs

As part of the new health care law, states are now able to offer subsidized premiums to people who have been denied insurance because of pre-existing conditions. If a state chooses not to run their program, it will be administered by the federal government for that state. These programs are called high-risk insurance pools or Pre-Existing Condition Insurance Plans. Individuals in these programs must still pay part of the monthly premium.

For more information on the high-risk insurance pool offered in your state, visit www.StateHealthFacts.org and enter "high risk pool eligibility" (with the quotes) in the search box. For the most current information on the health care coverage available in your state, go to www.healthcare.gov.

Pre-existing condition exclusion periods

A word of caution: When joining a health plan, you may face a pre-existing condition exclusion period. (A pre-existing condition is a health problem that you had before you joined your medical plan.) When this happens, your plan will make you wait before they pay any costs of that medical problem. The wait often is around a year. As a person with cancer, you have a serious pre-existing condition.

One of the things the new health care law addresses is pre-existing condition exclusion periods. It does not allow insurance companies to deny coverage for pre-existing conditions (such as diabetes or cancer) in children starting in September 2010 and in adults starting in 2014. In the meantime, there are rules about pre-existing condition periods that may help you. If you have met the following, then a pre-existing condition exclusion period doesn't apply to you:

- You have had medical coverage for 18 months, and you have not had a break in health coverage of 63 consecutive days or more.
- You have already met a pre-existing condition exclusion period, and you have not been without health coverage for 63 or more consecutive days.
- You have not had a break in health coverage for 63 consecutive days or more.

When looking at health insurance coverage, remember that even a poor plan is better than none. Be sure to discuss your situation with an insurance agent who specializes in health care plans.

If you are on Medicare now, you may be able to add more coverage with a Medigap policy or a Medicare Advantage plan. If you get an add-on policy within 6 months of going on Medicare, you won't have a pre-existing condition exclusion period. After 6 months on Medicare, you likely will have to wait before the Medigap plan would help pay your medical bills.

Can the government help me?

There are some government programs that may help if you don't have medical coverage. But to qualify for many of these programs, your income and assets must be very low.

Medicare

Are you currently collecting Social Security Disability Income? (See the explanation in the next section, "Other sources of income.") If so, keep track of the number of months you've been on SSDI. After you have received coverage for 24 months, you will be eligible for Medicare. This is the same Medicare that a person receives at age 65. But if you are disabled, you may get it sooner.

Hill-Burton Program

A number of hospitals and other medical facilities get money from the federal government so they can offer free or low-cost services to those who are unable to pay. This is called the Hill-Burton Program.

Each medical facility chooses which services it will provide at no charge or at a reduced cost. Services covered by a government program, such as Medicare and Medicaid, or by some other health insurance policy, aren't eligible for Hill-Burton coverage. But Hill-Burton may cover services not covered by the other government programs.

Eligibility for Hill-Burton help is based on your family size and income. Income is calculated based on your actual income for the past 12 months, or your past 3 months' income times 4, whichever is less. You can apply for Hill-Burton assistance at any time, before or after you receive care.

To find a Hill-Burton facility in your area, call 1-800-638-0742; Maryland residents call 1-800-492-0359. You can also look online at www.hrsa.gov/gethealthcare/affordable/hillburton. Once you find a Hill-Burton facility, the Admissions, Business, or Patient Accounts office can tell you how to apply for Hill-Burton assistance.

Medicaid

Medicaid is a government program that covers the cost of medical care. To get Medicaid, your income and assets must be below a certain level. These levels vary from state to state. Some people try to qualify for Medicaid by giving away their assets. But anything they give away up to 5 years before applying for Medicaid is still counted toward their income. So, giving away assets could delay qualifying for this program. It is also a federal crime to help someone dispose of assets for the purpose of qualifying for Medicaid. Be aware that many health care providers will not take Medicaid patients. This may limit your choices and, possibly, your quality of care.

Other sources of income

If I can't work, how can I have an income?

First, find out if you have long-term disability insurance. This type of policy often replaces 60% to 70% of your base income. Long-term disability policies are described in the section called "Decisions about work" on page 4.

If you do not have this type of insurance, some government programs may be able to help you. These programs pay you a monthly income as long as you are disabled.

Social Security Disability Income

If you've been working for many years, money has most likely been taken out of your paycheck for Social Security. If you're self-employed, the self-employment tax you pay covers your Social Security contribution. If you paid into Social Security, you may qualify for disability benefits. But you must meet Social Security's very strict definition of disability. If you get turned down, reapply. Many cases end up being approved after an appeal.

But don't count on Social Security Disability Income (SSDI) for the needs you have right now. Even if your claim is approved, benefits do not begin until the sixth full month of disability. This means you have at least a 5-month waiting period. And the approval process takes a long time. It may take many months – or even a year – before a decision is reached.

Your income has nothing to do with whether you qualify for SSDI. To find out how much you would get from SSDI, fill out Social Security Statement Request Form SSA-7005.

- If you are age 25 or older, Social Security sends these statements out every year, about 3 months before your birthday.
- You can also get a statement by calling 1-800-772-1213 and asking for Form SSA-7005, the Request for Social Security Statement. Complete the form and return it to the Social Security Administration. Social Security will process the form and mail you a copy of your work history and an estimate of what your benefits would be at this time.
- You may also request a statement through Social Security's Web site at www.ssa.gov. Click on "My Social Security" on the left side of the page.

Supplemental Security Income

If you have not worked much or your income was very low, you may be able to get Supplemental Security Income (SSI). To get SSI, your income and assets must fall below a certain level. These levels and the amount you could get from SSI vary from state to state. You must also meet the Social Security Administration's definition of disability.

Life insurance

What happens to the life insurance I have at work if I leave on disability?

If you have life insurance through your job, look into taking your policy with you. You may be able to convert it to an individual permanent policy without proof of insurability. But you will have to pay the premiums, which most likely will go up quite a lot.

Your employer may have a policy with a feature called a "waiver of premium rider." This means that you keep your group policy, but you do not have to pay the premiums if you are under a certain age (stated in the policy) and totally disabled for at least 6 months.

If you have life insurance that you bought on your own, keep it active by paying the premiums on time. Also, find out if the policy has a waiver of premium rider. This generally means the policy's premium is paid by the insurance company if you are under the age stated in the policy and totally disabled for at least 6 months. This could save you money and keep your policy in effect.

There may be other options to keep your life insurance policy in force without paying the premiums. You may want to talk with your insurance company about your options.

Do I really need to read my insurance policy?

Yes. Everyone should review their important papers from time to time. First, look for features that you may have overlooked before, such as the waiver of premium rider discussed above. Second, make sure the person you originally named as the beneficiary is still the person you would name today. (The beneficiary is the person who will get the money from your life insurance policy if you die while the policy is active.)

Also, make sure you understand the difference between the named beneficiaries and the people you named in your will. For example, say you named one person in your will to get all of your estate and you named someone else as beneficiary on your insurance policy. That beneficiary will get the insurance benefits, not the person you named in the will.

No one needs my life insurance money. Should I cancel my policy and save some money now?

It is usually best to try to keep any coverage you have. Even if no one is dependent on you, your life insurance money could help pay any unpaid medical bills after your death. And if you have "whole life" insurance, you may be able to use it as a source of cash while you are alive. (Term life insurance does not offer this option, since it only pays if you die.)

Take time to review the whole situation – your state of health, and the best time and way to use your insurance benefit. Before making a decision, get professional financial advice. There are different ways to draw money from your life insurance, but some can leave you with debts. It is important to understand exactly what you are getting into.

Loans

Depending on the type of life insurance you have, you may be able to use your policy as the basis for getting a loan from the insurer or from a lending institution. In most cases, permanent or cash value policies can be used to get loans. A term life insurance policy – the type most often offered by employers – has no cash value. But you may be able to use your term insurance (or other types of life insurance policies) to get a viatical loan. (See the next sections.) Loan proceeds can be set up so that you could still qualify for government programs, such as SSI. When considering a loan, remember these points:

- You still have to pay premiums on the policy.
- A loan from the insurer will only have to be paid off at death or ultimate surrender of the policy.
- You will have to make regular payments if you get a loan from a bank.
- Interest will be charged on the loan.

Accelerated death benefit

Your life insurance company may offer a pre-death payment. This is done only when life expectancy is less than 1 or 2 years. Check with your insurer to see if your policy offers this. Keep in mind that getting accelerated death benefits may keep you from qualifying for some government programs. Some companies will allow you to add this benefit even while the insured is terminally or chronically ill.

Viatical settlement

You may be able to sell your life insurance policy to a company for a portion of its value. This is called a viatical settlement. These settlements are available to most people who are diagnosed as terminally ill, and the amount of money paid often depends on life expectancy. The payment may range from 20% for someone with a life expectancy measured in years, to 80% for someone who has months to live.

The money you get from this settlement could keep you from qualifying for some government programs. But the viatical/settlement funds are income tax-free if certain rules are met.

Before making a decision about your life insurance, think over your options carefully. Talk about this matter with a professional financial planner or insurance agent and a partner or trusted friend. The Life Insurance Settlement Association lists companies that make viatical settlements. Call 407-894-3797, or visit their Web site at www.thevoiceoftheindustry.com.

Your retirement plan

A retirement plan can be a source of cash, even if you do not use the money for retirement. It can be a way to fund a disability. You may even be able to get some of the funds if you are still employed and meet the plan's hardship provisions. Read your benefits book so that you fully understand your plan.

If you are under age 59½, you may be able to avoid the 10% penalty for early withdrawals from your employer's retirement plan (or IRA) if you meet the IRS definition of disability.

Upon death, the balance in your retirement plan goes to your beneficiary. If you can, get financial advice about naming beneficiaries on these plans. How your beneficiary is related to you affects how soon the money must be paid out by the plan. And the beneficiary will have to decide how to take the proceeds. Each option has different tax consequences. Urge your beneficiary to talk with a financial planner or insurance agent before accepting the funds.

Managing debt and credit

Should I pay off my credit card bills so my family doesn't have to worry about them?

High out-of-pocket costs often come with a serious illness like cancer. You may have some large debts. While you want to pay off all your credit card balances, it may not be a good idea. Make at least the required minimum payment. But it is important to have easy access to cash.

If you have a family and want to protect them from having to pay off the balances when you die, consider the following:

- Keep all credit card balances on cards that are only in your name.
- Consider getting *credit life insurance* on the cards. Credit life pays off the balance on the credit card if you die. Few credit card companies ever ask you medical questions. Please note: While the credit life insurance companies don't ask medical questions, they often issue policies with pre-existing conditions clauses. This is a way to protect themselves against people getting the insurance on their deathbeds. Read over the policy carefully before enrolling. (Most financial advisors recommend not having this kind of insurance for the average consumer because it can be expensive. But it may be a good option for someone with cancer.)
- Consider getting *credit disability insurance* on the cards. Credit disability makes your minimum monthly payment for you for a period of time, usually a year, if you become disabled. In most cases, you don't have to prove your ability to be insured. But there is often a pre-existing condition exclusion period. In most cases, this period is 6 months. To get the benefit, you must have the coverage for 6 months before becoming disabled from a pre-existing condition. If you became disabled during the first 6 months, credit disability would not pay. Depending on your expected outcome, credit disability is another option to look into.

Managing the money you have

What can I do if most of my money is gone?

Your goal should be to get the best use out of the money you still have. Possible sources of cash are:

- Retirement plans
- Life insurance
- Credit cards
- Entitlements from the government
- Long-term disability insurance
- Medical insurance
- Reverse mortgage (explained on the next page)

If you still have some assets, keep them as handy as possible. Keep your money in stable investments, such as money market accounts, money market mutual funds, savings accounts, or certificates of deposit. Think about working with a financial advisor.

Coping with your finances

Coping with your finances, and possibly debt, at the same time you're coping with the changes that come with advanced illness is draining and hard to do. Here are a few tips to ease the burden:

- Ask friends and family to help you. If you can't face the bills that have been collecting in the basket on the table, call in someone to open and organize them. Have this person separate them into groups, such as medical bills, household bills, credit card statements, taxes, and so on. Also, look carefully for any benefit checks. Often, these get lost in stacks of bills.
- Rank the bills in order of priority. Your helper can do this. Your rent or mortgage, utilities, taxes, and medical expenses should be at the top of your bill-paying list.
- Negotiate for smaller payments. Often, your creditors will work with you. Most creditors would prefer that you make small payments, even $10 a month, rather than pay nothing at all.
- Try to understand your creditors' position. Give them a telephone number and hours that you can be reached, and ask them to communicate with you in writing.
- Work out a payment plan. Organizations like CredAbility (formerly known as the Consumer Credit Counseling Service) can help you make a payment plan to satisfy your creditors. Their phone number is listed in the business section of your local phone book.
- Talk with an oncology social worker. They can also help with financial issues and may be able to help you find sources of financial aid.
- Ask your hospital about financial counseling. Some hospitals offer free financial counseling.
- Try to find a few spare dollars to treat yourself. Buying small items, like an article of clothing or a new book, can help your outlook.

Reverse mortgage

If you are at least 62 years old and own your home (or nearly own it), you may be able to convert part of your home's equity into cash. The most common type of equity conversion is called a reverse mortgage. A reverse mortgage is a loan against your home that doesn't have to be repaid for as long as you live there. The loan is repaid at a future time – usually, when the last surviving borrower dies, sells, or moves from the home.

It is possible that a reverse mortgage can give you money to pay medical bills or other expenses. The funds can be paid in a lump sum, monthly payment, or line of credit. Still, it is a loan, and the debt grows over time. This debt includes the cash advance plus interest charges. It may also include closing costs, origination fees, servicing fees, and so on. Once all the costs of the program are added in, it could be an expensive loan. But in most cases, this type of loan will never exceed the value of your home. Having a reverse mortgage may affect qualifying for some government programs. Before agreeing to a reverse mortgage, potential borrowers should get competent advice from a trusted advisor on the pros and cons of this option.

There are many types of reverse mortgage programs offered by private, public, and federally insured lenders. No one program works best for everyone. A word of caution: as already stated, before deciding on a reverse mortgage, have the proposal reviewed by a financial advisor. Many non-profit consumer groups, such as AARP, have education classes on reverse mortgages. The government requires that anyone who wants to take out a reverse mortgage get approved counseling to be sure they understand its pros and cons. You can learn more about reverse mortgages (also known as a home equity line of credit or home equity conversion mortgage) on the US Department of Housing and Urban Development's (HUD) Web site at www.hud.gov/offices/hsg/sfh/hecm/hecmhome.cfm.

Other important plans

How can I be ready when my health begins to decline?

You may be used to making your own financial decisions. But it's best to be prepared for the time that you may become unable or just too tired to make decisions for yourself. There are things you can do now to prepare for this.

Planning for your medical care

These are some of the documents you can use to make sure that others know what kinds of medical treatment you want, should you become too sick to tell them directly. Though it may be hard to do, discuss these issues with your medical team and your loved ones ahead of time so that everyone knows what you want.

Health care proxy. In a health care proxy, you name someone to make health care decisions for you if you cannot. Each state has its own laws governing health care proxies. The person you name should know and be committed to following your wishes. This person should be able to make decisions for you based on what they think you would want. Copies of your proxy should be given to a trusted loved one and to your doctor. A copy of the proxy also can be placed in a safe deposit box.

Living will. A living will allows you to specify the types of life-sustaining medical care you would want – or not want – if you are unable to communicate those choices. It generally applies only when you are unable to speak for yourself and are terminally ill or permanently unconscious. It only gives written instructions about certain things that might happen and does not cover every health care situation that could come up. This means it may not cover your specific situation when you need it. These issues are things you will need to discuss with your family and health care team ahead of time, but it is even better to have it all in writing. Having these issues clearly resolved to your satisfaction will give you and your family peace of mind. Copies of a living will should be given to someone you trust or family members, as well as to your doctor, nurse, hospital, and anyone else who is caring for you. You can change or end a living will at any time.

Estate planning

If you have not already done so, it's time to make sure all of your estate planning documents are in place and are up to date. Each of these documents is described below.

Durable power of attorney. A durable power of attorney is a legal document that allows you to name someone to act on your behalf in money matters. This may mean paying your bills or signing your name on financial transactions. Copies of the power of attorney should be given to your nominated executor or lawyer. A copy also should be given to the person granted the power of attorney, and a copy can be placed in a safe deposit box.

Will. Your will directs how and to whom your assets will be distributed. You also use your will to name a guardian for your minor children and any assets that would become theirs. It's important to keep your will in a place that can be accessed by others. Don't put your will in a safe deposit box. (The box may be sealed for a short time after a death.) You can keep your will with your local registrar of wills, at home with your other important papers, or with your attorney or executor.

Living trust. To manage your assets, consider using a living trust. This would allow you to name a trustee to manage the assets in the trust. But be sure that this is the best approach for you. Setting up a living trust can be costly, so it may make sense only for those with assets of more than $250,000. Know that at your death any part of your estate that is not in the trust will be subject to probate.

Letter of instructions. This isn't a legal document, but it is helpful to the people who must settle your estate. Think of the instructions as a guide for family members or other loved ones to help them through the short term.

In the instructions, you can name someone to take in and look after minor children or pets – at least in the short term. This is useful if the guardian named in your will lives out of state. You may want to write out directions on what kind of funeral or memorial service you want or details on what you want your loved ones to do with your belongings. You also can list names and telephone numbers of those who should be contacted immediately upon your death. This could include relatives; your lawyer, attorney in fact, accountant, or financial advisor; the human resources manager at your job; your insurance agent; and so on.

You should list where you have your important papers and any bank and investments accounts. Also, note the name of the person to contact at each of these organizations. You can leave details on the locations of safe deposit boxes or keys and/or combinations to home safes or gun cabinets. Passwords or codes to home alarm systems, voice mail, and other things your loved ones may need to access are also very helpful.

Give copies of the instructions to your executor, trusted family members, or other loved ones. It's wise to give a copy of the instructions to at least one trusted person who lives near you, so they can act on your behalf right away.

Be sure you talk with the people who will need to carry out the letter of instructions. This way they can ask questions, and you can explain what you want and why. This can eliminate – or at least reduce – conflicts that could come up after you are gone.

Memorial letters, recordings, or videos. Although not part of your legal paperwork, there are other things you can do to help the loved ones you must leave behind. For example, you may want to read some of your children's favorite books and record it for them to listen to in the future. Maybe you'd like to write letters or make videos that would be shared on special days, such as holidays, graduations, or wedding days, that will come after you are gone. Though you may not be able to change the fact that you will not be there in the future, there may be ways you can still be part of the lives of the people you love. Take time to think about ways that you may be able to bring comfort and good memories to the people you love even after you're gone.

How can I make this financially easier for my family?

Having your important documents in place will go a long way toward helping your family – emotionally as well as financially. Estate documents get rid of the guesswork. They allow your family or other loved ones to clearly know your wishes. And this can prevent conflicts and bitterness later on.

Make sure that a relative or other loved one has easy access to at least some of your money after you die. If you are married, make sure your spouse is listed on checking and savings accounts. When accounts are listed in both names (a joint account), the assets pass quickly to the survivor without going through probate. If you don't have a joint account, you can ask your bank to set up a POD (payable upon death) account, so that money is transferred to the person you have named without going through probate.

Probate is the process of carrying out the directions in the will. It also ensures the will is valid. The probate process may take months. So if your family will need money right away, make sure they can get to it.

But be careful about whom you name on a joint account. At your death, the survivor owns the assets. He does not legally have to use them to pay your final expenses or distribute them as you specified.

If I plan my estate, doesn't that mean I've given up hope?

No. Estate planning is not a sign of giving up. It simply means facing a difficult reality. Death is not optional; it will happen to all of us someday. That doesn't mean it will happen today or tomorrow. Maybe it won't happen for many months or even years. And maybe it won't even be caused by cancer. Still, you will make things a lot easier for your family and other loved ones if they know your wishes.

Getting organized

How can I be sure everything is in order?

If the documents we've discussed are in place, you've taken a big step toward getting organized. But you may still have other financial questions or concerns. One option is to talk things over with a financial advisor. If you don't already have an advisor, read our booklet called *How to Find a Financial Professional Sensitive to Cancer Issues*. You can get a copy by calling the American Cancer Society at 1-800-227-2345, or you can read it online at www.cancer.org.

Try to be as open as possible with your loved ones about your finances and desires. This may be a hard step, particularly for them. Few of us are comfortable with the idea of death. We tend to think of death more in terms of "if" rather than "when." And sharing a list of "who gets what" often makes loved ones a bit crazy. But keep in mind that this kind of preparation can help prevent unpleasant arguments and hurt feelings later. It is amazing how ugly it can get when someone dies and it isn't clear who is supposed to get certain possessions.

Urge your loved ones to read the booklet *Coping Financially With the Loss of a Loved One*, which is also available from the American Cancer Society. It details the money issues they may face in the future. Be patient if your loved ones seem uncomfortable. Remind them that you plan to be around as long as possible, but you want to have your affairs in order. Maybe you've wanted to do this for years and now have the push you need to take care of things. Your openness now will help them later on. Someday your loved ones will have to cope with your estate while they're coping with losing you. It will be easier for them if they know your wishes. It will also show them that you faced death, as well as life, on your own terms. That's a good lesson for all of us.

What else should I do?

Try to remember what is important in your life. Do what you can, as soon as you can, to take control of your finances. Use the suggestions in this booklet to help reduce financial stress. Getting your finances in order and making things easier on your family will give you peace of mind. Then you can move on with living your life, spending time with loved ones, and doing the things you enjoy.

Financial resources

Sometimes financial resources can impact other benefits you receive. The impact depends on many factors, as outlined in the chart below. It is recommended that you get the advice of a competent advisor to be sure that you know the impact of the various options.

Sources of health care	Issues
Medical insurance	Must continue paying premiums
COBRA	18- to 36-month extension of group health benefits Must pay premium
Hill-Burton Program (low- or no-cost health care) 1-800-638-0742 (in Maryland, 1-800-492-0359) www.hrsa.gov/gethealthcare/affordable/hillburton	Must use Hill-Burton facilities Not all services are available Eligibility based on family size and income (income below current poverty guidelines) Only a limited number of Hill-Burton facilities nationwide
Medicare 1-800-633-4227 or 1-800-MEDICARE www.medicare.gov	Eligibility based on eligibility for Social Security benefits, Railroad Retirement benefits, and certain other health problems Must pay for part B of program
Medicaid (contact your state office) www.medicaid.gov	Eligibility based on family size, assets, and income
Affordable Care Act or Patient Protection and Affordable Care Act (PPACA) www.healthcare.gov	New benefits are provided by the PPACA of 2010. Benefits include helping more children get health coverage, ending lifetime and most annual limits on care, and giving patients access to recommended preventive services without cost-sharing.
Veteran's Benefits 1-800-827-1000 to be connected to the local office www.va.gov	Service-connected problems generally are covered. May require low income for certain benefits May require some deductibles

Long-term care benefits	Issues
Long-term care insurance	Must pay premiums (usually not required when receiving benefits) May create income tax debt May affect qualifying for government benefits Must meet definition required for benefits (usually federal definition for chronically ill) Premiums may be all or partly tax deductible.
Hill-Burton Program	See "Sources of health care" above.
Veteran's Benefits	See "Sources of health care" above.
Medicaid (state program)	Eligibility based on family size, assets, and income
Accelerated death benefits (some life insurance policies)	Must be terminally or chronically ill (contact insurance company) May create income tax debt May affect qualifying for government benefits Must meet definition required for benefits (usually federal definition for chronically ill, or more restrictive)

Sources of income	Issues
Disability Income Insurance	Must pay premiums until the insurance company allows you to stop May affect qualifying for government benefits Must meet definition of disability as defined by policy
Reverse Mortgage	Creates income tax obligation Lender makes payments to the borrower. Loan is repaid after last remaining borrower leaves home. May affect qualifying for some government benefits May require payments over time Requires mandatory counseling Must be homeowner age 62 or older Should be reviewed by competent advisor – careful research may be needed to avoid losing too much in fees and interest
Social Security 1-800-772-1213 www.socialsecurity.gov	Must be disabled or retired May create income tax debt May affect qualifying for other government benefits
SSI (Supplemental Security Income) 1-800-772-1213 www.socialsecurity.gov	Must be disabled, over age 65, and/or blind Must meet income restrictions May affect qualifying for other government benefits
Temporary Aid to Needy Families (TANF)	Must meet low-income guidelines May require disability May require employment history

Sources of lump-sum cash	Issues
Assets (sale of stock, real estate, etc.)	May create income tax debt May affect qualifying for government benefits
Home Equity Loan (may be lump sum or line of credit)	Home is put at risk. Must have equity in home Must make regular payments Must pass credit check
Family/Personal Loan	Requires repayment May strain family relationships May require collateral
Whole Life Insurance Policy Loan (from a life insurance company)	Death benefit is reduced by the amount of the loan and accrued interest. Policy must have "cash value." Often must continue premium payments
Block Grants (funds given to states by the federal government to run programs within defined guidelines that provide services)	Must meet family income limits May affect qualifying for government benefits
Accelerated Death Benefits (life insurance)	Must keep policy in force Must be terminally ill (contact insurance company) May create income tax debt May affect qualifying for government benefits
Viatical Loan (borrow from investor using life insurance as collateral) or Viatical Settlement (sell life insurance policy to investor)	May create income tax debt Must own policy Must meet definition of terminally or chronically ill May affect qualifying for government benefits

General resources

Assistance organizations

The American Cancer Society can give you current information, print materials, and guidance about cancer issues and the special issues that come at the end of life. We can also give you information about other cancer organizations that may be able to help you. Call 1-800-227-2345 anytime, day or night, or visit www.cancer.org.

Other community organizations

Local social services offices may offer general assistance to those who meet low-income requirements. Check your phone book for agencies in your area. You can also ask these organizations if there is anyone else you might call.

AARP
Toll-free number: 1-888-687-2277
(1-888-OUR-AARP)
Web site: www.aarp.org

CancerCare
Toll-free number: 1-800-813-4673
(1-800-813-HOPE)
Web site: www.cancercare.org

American Childhood Cancer Organization
Toll-free number: 1-800-858-2226
Web site: www.acco.org

HUD Home Equity Line of Credit (Home Equity Conversion Mortgages) for Seniors
Telephone: 202-708-1112
Web site: www.hud.gov/offices/hsg/sfh/hecm/hecmhome.cfm

Leukemia & Lymphoma Society
Toll-free number: 1-800-955-4572
Web site: www.lls.org

National Cancer Institute
Toll-free number: 1-800-422-6237
(1-800-4-CANCER)
Web site: www.cancer.gov

State Health Insurance Commission
(to get insurance for the uninsurable)
See your local phone book for this phone number.

Susan G. Komen for the Cure
Toll-free number: 1-877-465-6636
(1-877-GO-KOMEN)
Web site: www.komen.org

United Way
Find your local chapter in the phone book.

Credit reports

Check your credit profile regularly. Call the 3 major credit reporting agencies to find out how to get a copy of your report from each.

Equifax
Toll-free number: 1-800-685-1111
Web site: www.equifax.com

Experian
Toll-free number: 1-888-397-3742
Web site: www.experian.com

TransUnion
Toll-free number: 1-800-888-4213
Web site: www.transunion.com

Find a financial planner

Refer to the American Cancer Society booklet called *How to Find a Financial Professional Sensitive to Cancer Issues*, which is available by calling 1-800-227-2345 or on our Web site, www.cancer.org.

Job discrimination protection

For information about protection against job discrimination, call the Equal Employment Opportunity Commission (EEOC). Find the office nearest you by calling 1-800-669-4000. The TTY number is 1-800-669-6820. Or, you can find the office nearest you on their Web site at www.eeoc.gov.

Medicare information

If you have questions about Medicare, call the Medicare hotline at 1-800-633-4227 (1-800-MEDICARE) or visit their Web site at www.medicare.gov

Glossary

Americans with Disabilities Act: This federal law says employers with 15 or more workers must make reasonable accommodations so disabled people can do their jobs. A reasonable change may include working flex-time, working from home, or using special equipment at work.

Attorney in fact: This is a person given the power to act on behalf of another through various documents. This can be any competent adult. See *Durable power of attorney* and *Health care proxy*.

Disability income insurance: A type of insurance that pays some money each month to people who are injured or sick and cannot work. Disability income plans can be either short term or long term. If you buy your own disability insurance, the benefits are free of income tax. If your employer pays for it, the benefits are taxable.

Durable power of attorney: A legal document that allows you to name someone to act on your behalf in money matters. This may include paying your bills or signing your name on financial paperwork.

Family and Medical Leave Act (FMLA): This law says that employers with 50 or more workers must usually give up to 12 weeks of unpaid leave. The leave can be taken to care for yourself or certain family members with a serious illness.

Health care proxy: A document that names someone to make health care decisions for you if you cannot. (It is sometimes referred to by other names.)

Living trust: A document where you name someone to manage all – or most – of your assets in a trust. Setting up a living trust may be costly, but it can help protect assets in the trust from public disclosure and the probate process.

Living will: This allows you to state the types of life-sustaining medical care you would want – or not want – if you are unable to communicate those choices.

Social Security Disability Income (SSDI): This federal government program pays monthly income benefits if you are disabled. You must meet specific guidelines and strict disability guidelines to be eligible for benefits. You also must have paid at least the minimum amount into the Social Security system. (Your employer takes this money out of your paycheck automatically. To have paid enough money into the system, you must have worked a specific number of years.)

Supplemental Security Income (SSI): This government program pays benefits to low-income people who are unable to work. To qualify, income must be below a certain amount. That level is set by the state in which you live.

Viatical settlement or **life settlement:** A transaction where a person sells their life insurance policy to a company for a portion of its value. The amount of money paid often depends on life expectancy. The payment may range from 30% for someone with a life expectancy measured in years, to 80% for someone who has months to live.

Will: A legal document that says how and to whom your assets will be distributed after your death. If you die without a will (called "intestate"), your assets will be distributed according to the laws of the state you live in.

Notes

Notes

Other publications in this series

In Treatment
Financial Guidance for Cancer Survivors and Their Families

Off Treatment
Financial Guidance for Cancer Survivors and Their Families

How to Find a Financial Professional Sensitive to Cancer Issues
Financial Guidance for Cancer Survivors and Their Families

Can I Be Prepared If Cancer Occurs?
Financial Guidance for Those with Concerns about Cancer

Coping Financially with the Loss of a Loved One
Financial Guidance for Families

These booklets are available by calling the American Cancer Society at 1-800-227-2345 or by visiting our Web site, www.cancer.org.

American Cancer Society®

NATIONAL ENDOWMENT FOR FINANCIAL EDUCATION

Partnering for Financial Well-Being

Advanced Illness: Financial Guidance for Cancer Survivors and Their Families was written and prepared as a public service by the Denver-based National Endowment for Financial Education®, or NEFE®.

NEFE is an independent nonprofit foundation committed to educating Americans about personal finance and empowering them to make positive and sound decisions to reach financial goals. The National Endowment for Financial Education, NEFE, and the NEFE logo are federally registered service marks of the National Endowment for Financial Education. For more information about the National Endowment for Financial Education, visit www.nefe.org.

Note: Over time, legislative and regulatory changes, as well as new developments, may cause this material to be outdated. This booklet is meant to provide general financial information; it is not meant to be a substitute for or to supersede professional or legal advice.

NATIONAL ENDOWMENT FOR FINANCIAL EDUCATION

Partnering for Financial Well-Being

American Cancer Society®

We **save lives** and create more birthdays
by helping you stay well, helping you get well,
by finding cures, and by fighting back.

cancer.org | 1.800.227.2345 | 1.800.228.4327 (TTY)

For cancer information, answers, and support, call your American Cancer Society 24 hours a day, 7 days a week.

No.350003-Rev.09/13