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Third Edition

Financial Considerations for Patients

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PATIENT RESOURCE CANCER GUIDE

**Financial Considerations
 for Patients, *Third Edition***

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When you find out you have cancer, you probably don't initially think of the financial burden you're facing. You want to spend your energy getting healthy and back to a normal life, and then figure out the rest later. The financial aspect of cancer, however, can have a huge impact on your overall health, happiness and well-being during your cancer journey, and feeling confident about your finances can help you tackle your treatment wholeheartedly.

The cancer-related expenses you experience will be unique to you, dependent on your diagnosis, your recommended treatment plan, your follow-up care and your level of insurance coverage. Managing these expenses is crucial: A 2013 study found that people with cancer are more than twice as likely to declare bankruptcy than people without cancer. Understanding your insurance, planning your budget and seeking financial assistance can keep you from becoming a part of this statistic. By spending the time to increase your knowledge and management of financial matters, you can take control of your financial situation right from the start.

Types of cancer-related costs

Cancer-related costs can be grouped into two types of expenses: medical and lifestyle. The medical expenses – including medical office visits, tests, treatments, drugs and caregiving – are the most obvious additions to your spending.

Less obvious are the increases in your routine living expenses because of new, cancer-related costs. After a cancer diagnosis, you may spend more money on transportation and travel, legal help and financial services. You may also need to hire help for child or elder care, meal preparation or housecleaning. And if possible, you might want to set aside extra money to enjoy special activities or trips with your family and friends to help ease the stress of this difficult time. These additional expenses are a heavy burden on their own but are even more substantial when combined with the possibility that your income may be reduced if you and/or your significant other are unable to work the same number of hours during your treatment.

Unfortunately, your cancer-related costs don't end when your treatment is over. One study found that male survivors spend \$4,000 more and female survivors spend \$3,000 more than their cancer-free peers every year. You will need to budget for follow-up care, frequent screenings and checkups, and you might have to adjust to



a permanently reduced income if you aren't able to return to your regular work hours.

Talk to your health care team

Cancer-related costs can add up quickly, so it's vital to talk to the members of your health care team about the cost of your cancer care. They understand that treatment can be expensive and may create financial hardship, so don't be embarrassed to bring it up. One study found that while more than half of the patient participants wanted to talk to their doctors about costs, only 19 percent actually did—and it paid off. Fifty-seven percent of the patients who had conversations with their doctors about their financial concerns felt that it helped significantly decrease their costs, and even more felt it decreased their anxiety during the course of their treatment.

Many people are hesitant to ask about cutting costs because they fear their treatment will suffer. However, depending on your specific insurance coverage, your doctor may be able to prescribe alternative treatment options

that are less expensive but just as effective. For example, intravenous chemotherapy drugs given in your doctor's office are usually covered by medical insurance, but oral chemotherapy drugs that you take at home are usually covered through the insurer's prescription benefit program. In either case you may have to pay out-of-pocket expenses, but one option may be much cheaper than the other.

Your health care team is an excellent resource for answers to your financial concerns. Be sure to talk to the financial staff at your doctor's office about your insurance policy and out-of-pocket expenses.

Seek financial assistance

Before you become totally overwhelmed, know that there are hundreds of resources that provide financial assistance in a variety of categories, including child care, personal items (wigs, mastectomy bras, ostomy supplies, etc.), counseling services, legal help, wish fulfillment and transportation.

Social workers, advocates, financial counselors and patient navigators at your medical facility can refer you to local organizations that can help, and many advocacy groups and other nonprofit organizations will also point you toward sources of financial assistance. Federal laws also offer benefits, protect you from the loss of health insurance and guard against discrimination on the basis of your health. And don't forget your family and friends. They can help you search for financial assistance and offer advice on what would be most helpful for you.

This guide

This publication aims to give you the tools to tackle your finances during your cancer journey. You'll learn what questions to ask your doctor about treatment costs and how to manage your cancer-related paperwork. You will also find out how to handle insurance matters and navigate health care-related laws. And just in case, you'll find some tips on what to do if your bills surpass your income. Information about the cost of clinical trials and estate planning is also included, as is a list of organizations that offer financial assistance programs. Lastly, throughout this guide you will be directed to additional websites that can help you navigate the financial aspects of cancer. ■

Managing cancer-related paperwork is an unexpected challenge for many patients, but well-organized paperwork is integral to handling financial matters. The following information provides a step-by-step approach to organizing your important records and documents.

Find a helper

Consider asking a family member or friend to help you before you start organizing, as this can be useful on many levels as you undergo treatment. There may be times during your illness when you just don't want to deal with paperwork or don't have the energy to focus, and your helper can be ready to step in. Additionally, your helper may have suggestions on how to organize your files, and once your system is in place, he or she can help you locate documents when necessary.

Designate a work area

Select one consistent place in the house where you will handle all of your paperwork-related tasks. This area should have a desk or table, a chair, a computer (if you plan to pay some of your bills online or store your paperwork electronically), a printer and a filing system. Some other helpful office supplies include:

- Pens and pencils
- Paper or notebooks
- Calculator
- Stapler and/or paper clips
- Three-hole punch
- Envelopes and stamps
- A document scanner

Choose a system for filing and storage

You have your choice of a wide range of filing systems, including individual pocket folders, three-ring binders and accordion-type file organizers. In addition, you can choose to keep your files in a filing cabinet, a desk drawer, a desktop divider, plastic totes or cardboard boxes with lids. If you're unsure of which filing or storage system to use, visit a nearby office supply store and browse the aisles for ideas.

If you prefer to keep your documents electronically, you can avoid the need for boxes or folders and ensure the safety of your documents in case of natural disasters. However,

storing files electronically means you must scan receipts and documents, which requires time. You also must regularly back up the files and make sure your helper knows your usernames and passwords to access your computer and the files.

No matter which method you choose, resist the urge to simply place everything in one file labeled "cancer" or "insurance," as it will quickly become too large to manage. Aside from that, there's no right or wrong system. The most important thing is that the system is easy for you (and your helper) to use.

Get creative

Being creative and consistent can make organizing paperwork easier. Using different colored files, labels, stickers, pens and pencils can help you identify specific types of documents more easily, as long as you are consistent. Also be consistent in how you file; for example, following alphabetical order for your files and chronological order for your documents will make your paperwork easy to find.



Document your choices

After you decide on an organizational system, make a separate, well-organized document that contains a list of the file categories, the location of important documents, life and household instructions (including a bill payment schedule), and relevant contact information. These notes will make it easy for you and your helper to file paperwork, retrieve documents, pay bills and manage household responsibilities.

? QUESTIONS TO ASK YOUR HEALTH CARE TEAM

- ▶ **Who is the best person in the office to talk to about health insurance and payments?**
- ▶ **Will this person help me work with my health insurance company/provider?**
- ▶ **How much is my co-pay for each office/clinic visit? When is it due?**
- ▶ **Do you offer any payment plans or charity care options?**
- ▶ **Will I be billed separately for laboratory tests or procedures?**
- ▶ **Can lab work be performed by a provider in my network?**
- ▶ **If I require other services, will they be performed by a provider who is in-network for my insurance plan? (This is especially important for those providers you don't meet in person as a patient, such as the radiologist and anesthesiologist.)**
- ▶ **Can I get an estimate of the total cost of the recommended treatment plan?**
- ▶ **If the recommended treatment plan is too expensive for me, are there other options that are less expensive but just as effective?**
- ▶ **Is my treatment schedule flexible enough to accommodate my job, my caregiver's schedule or child/elder care?**
- ▶ **Is the medication prescribed covered by my health insurance plan's preferred-drug list?**
- ▶ **Are there patient assistance programs available for the anti-cancer drug(s) you recommend?**
- ▶ **What expenses will I have if I join a clinical trial? How do I find a clinical trial that matches my diagnosis?**
- ▶ **Does the office offer free or low-cost transportation or reduced parking fees to patients?**
- ▶ **Are there nearby hotels or lodging that offer free or reduced costs to patients?**
- ▶ **What can I do now to help manage my future medical costs? Are there any nonmedical things that could have an impact on my future medical needs (for example, diet changes, weight changes, daily exercise, vitamins, etc.)?**

Create your own paperwork

In addition to keeping documents from your insurer and health care providers, you should create and file your own paperwork (see Table 1):

- Complete a budget worksheet (see page 4) every month to track your finances and become better prepared for your expenses.
- Take notes of any tips from your health care team about managing your finances so that you have them available when you need them (for a list of questions to ask, see sidebar on page 2).
- Write down the dates of your appointments for office visits, treatments, diagnostic tests and other procedures. (These dates become important when matching documents from your insurance company and health care providers.)
- List the drugs you're taking and the dates your prescriptions are filled.
- Keep a record of insurance-related correspondence, including the date, the name of the person with whom you spoke (or wrote), and notes from the call (or a copy of the letter).
- List the contact information for all of your health care providers, home maintenance and utility companies, and employers.
- Write down life and household instructions, including details about legal, financial and family matters.
- Keep a list of expenses that are not reimbursed by your insurer, such as office visit co-pays, prescription drug co-pays, mileage for transportation to and from appointments, and meals and accommodations (if your treatment facility is far from your home). You may be able to deduct these expenses on your federal income tax return if you itemize your medical expenses. The rules for deductions often change, so consult a tax adviser or visit the Internal Revenue Service (IRS) website (www.irs.gov).

Be prompt

Try to file new information as soon as you can. Filing papers immediately not only avoids the possibility of misplacing something, but it also keeps paperwork from piling up, which can feel overwhelming. Studies show that encour-

▼ | **TABLE 1 | DOCUMENTS TO ORGANIZE AND STORE**

Category	Specific documents	Filing tips
Statements and bills from health care and insurance providers	<ul style="list-style-type: none"> • Account statements • Explanation of benefits (EOB) forms • Papers from health, life, disability and long-term care insurance providers: <ul style="list-style-type: none"> ◦ Policies ◦ Benefits ◦ Other materials • Copies of all claims filed • Explanations of benefits paid • Records of insurance payments 	<p>Ask your insurance company if you can be assigned a case manager so you can always talk to the same person.</p> <p>Attach any written correspondence (letters or emails) and/or notes from phone calls to the related document, making sure you include the date of the correspondence and the name of the person with whom you communicated.</p>
Receipts for health care-related expenses	<ul style="list-style-type: none"> • Pharmacy receipts • Meal, gas and lodging receipts (if you traveled for treatment) 	<p>If the receipt is not itemized, attach it to a list of exactly what you purchased and why you purchased it.</p> <p>Consider attaching small receipts to a larger blank piece of paper to ensure they're not lost or damaged.</p>
Medical records and reports	<ul style="list-style-type: none"> • Treatment reports • Hospital discharge summaries • Operative reports • Pathology reports 	<p>Consider having a different file for each type of report to make paperwork easier to locate.</p>
Financial contact information	<ul style="list-style-type: none"> • Names, titles, addresses, email addresses, phone numbers and fax numbers for anyone who helps with financial matters: <ul style="list-style-type: none"> ◦ Financial counselor ◦ Social worker ◦ Staff member at a financial assistance organization ◦ Accountant, tax preparer, etc. ◦ Any others 	<p>Keep dated notes from your correspondence with these people.</p>
Health care contact information	<ul style="list-style-type: none"> • Names, titles, addresses, email addresses, phone numbers and fax numbers for all of your health care providers: <ul style="list-style-type: none"> ◦ Surgeons ◦ Oncologists ◦ Nurses ◦ Psychiatrists/psychologists ◦ Rehabilitation specialists ◦ Dietitians ◦ Pathologists ◦ Others 	<p>Keep dated notes from your correspondence with these people.</p>
Life, health, financial, legal and household documents and instructions	<ul style="list-style-type: none"> • Details of financial accounts and retirement plans • Life and disability insurance payout information • Advance directives • Living will • Health care proxy • Durable power of attorney • Bill payment schedule • Contact information for home maintenance and utility companies • Contact information for family members, employers and schools 	<p>Make sure these documents are clearly labeled and easy to understand so your helper can easily step in for you.</p>

tering a large amount of paperwork reduces the motivation to organize and can progress into a larger problem. When a new bill arrives, be sure to note the date you received it directly on the bill and attach any related papers to it (for example, copies of claims, cor-

respondence about the bill, etc.). Put the bill and attachments in an "Unpaid Bills" folder until you pay it, at which time you can move it to the most appropriate folder. Schedule this work for a time of day that's best for you, both in terms of your schedule and how you feel. ■



SAMPLE

BUDGET WORKSHEET

▶ Consider making additional copies for future use.

MONTH:	Estimated	Actual
Sources of income		
Take-home salary (after taxes and deductions)	\$	\$
Social Security/Supplemental Security Income	\$	\$
Disability benefits (short-term or long-term)	\$	\$
Investments	\$	\$
Total income	\$	\$
Routine expenses		
Mortgage	\$	\$
Utilities	\$	\$
Groceries	\$	\$
Credit cards	\$	\$
Car loan	\$	\$
Other loans	\$	\$
Cellphone plan	\$	\$
Cable or satellite television plan	\$	\$
Housecleaning or landscaping services	\$	\$
Insurance premiums (health, life, house, car, etc.)	\$	\$
Child or elder care	\$	\$
Total routine expenses	\$	\$
Out-of-pocket medical expenses		
Health insurance deductible	\$	\$
Co-payments or co-insurance	\$	\$
Prescription drugs	\$	\$
Transportation for care (including parking fees)	\$	\$
Medical supplies, devices	\$	\$
Caregiving/at-home care	\$	\$
Meal preparation	\$	\$
Legal or financial services	\$	\$
Counseling (self or other family members)	\$	\$
Total medical expenses	\$	\$
Special expenses		
Extra activities	\$	\$
Travel	\$	\$
Education	\$	\$
Other	\$	\$
Total special expenses	\$	\$
Total expenses (sum of routine expenses, medical expenses and special expenses)	\$	\$
Total after expenses (total income minus total expenses)	\$	\$



While insurance makes paying for cancer care easier, it's unlikely that even the best health insurance plan will cover every cancer-related cost.

According to a report based on calls to the Patient Advocate Foundation, the most common insurance-related problems for cancer patients are:

- High out-of-pocket and prescription costs
- High cost of insurance premiums when unable to work
- Challenges gaining access to preferred treatment options
- Confusion navigating insurance pre-authorization requests and denials

In one survey by the American Cancer Society, about 5 percent of insured people with cancer said they delayed or opted against treatment because of cost. Don't be part of that 5 percent: Learn the ins and outs of your insurance plan to make sure you get the coverage you need.

Coverage basics

Whether you are seeking preventive care, care after an accident or injury, or treatment for an ongoing illness or disease, health insurance helps patients find care and afford the care provided by their doctors. Health insurance ultimately helps patients pay the cost of their medical care by contributing financially toward a portion of the total bills.

Many Americans' health insurance is sponsored by an employer, and today more and more employees are being asked to pay a larger portion of the premium to maintain that coverage. Your ability to afford premiums and other cancer-related expenses can be difficult during your journey with the disease. Although it may be a financial challenge, try to pay your premiums in full and on time so that you're not dropped from your plan. If you need to change insurance plans, make sure the new one takes effect before the previous policy expires.

Additional challenges present themselves if you're unable to work for a period of time, making it difficult to keep your employer-sponsored insurance. However, two federal laws offer some protection for keeping your health insurance in place: the Family and Medical Leave Act (FMLA)

PATIENT NAVIGATORS AND PATIENT ADVOCATES



Patient navigators, or patient advocates, are trained experts who can help lead you through many challenges in the health care system, including insurance issues. Patient navigators are often nurses, social workers or community health workers, and some are cancer survivors themselves. They offer assistance with a wide range of services, which may include helping with insurance forms, coordinating doctors' visits and arranging transportation to and from treatment.

You can find patient navigators in hospitals, patient advocacy organizations and the community. To find a patient navigator to work with you, call the patient relations department of your hospital or provider to see if it has a patient advocate or navigator program. You can also reach out to any of the national disease and patient advocacy nonprofits, which will help connect you to an advocate who serves patients at no cost. There are also community advocates available to help patients, some of which will charge a fee for their services. During your advocate search, be sure to clarify the specific services provided to ensure they match your needs.

and the Consolidated Omnibus Budget Reconciliation Act (COBRA) (see page 10 for more information).

As part of the Affordable Care Act, everyone is required to purchase a health insurance plan to cover their medical needs or face a financial tax penalty. If you do not have insurance, try to get coverage as soon as possible. Under the Affordable Care Act, the government must maintain an exchange in each state, also known as a Health Insurance Marketplace, which allows people to compare and select an affordable health insurance plan to meet their needs. These marketplaces are a central point for those who do not have employer-sponsored insurance, those who have previously been denied coverage because of a pre-existing condition (such as cancer), or those who are interested in switching from their current plan. In addition, the marketplace in your state might screen you for additional resources to help make the insurance affordable, with many consumers qualifying for Premium Insurance Tax Credits that will reduce the premium cost each month. However, Health Insurance Marketplaces are only available during open enrollment periods or during periods of special enrollment applicable to specific scenarios.

Depending on your scenario, you may qualify for government-assisted health insurance, including Medicaid or Medicare. Medicaid programs are designed to help those with limited means gain high-quality care, and insurance programs are managed by each state. Review the guidelines and eligibil-

ity in your state to see if this is an option for you. Medicare is a federal health system designed for those age 65 or older or those who are disabled. To learn about the eligibility and process for qualifying for Medicare, visit www.medicare.gov.

Become familiar with your insurance plan

No matter whether you have a private insurance plan or one managed through the government, four primary types of health insurance are available:

- Health maintenance organizations (HMO) or exclusive provider organizations (EPO)
- Preferred provider organizations (PPO) and point of service plans (POS)
- Fee-for-service plans
- High-deductible health plans (HDHP)



SURVIVOR VOICE

▶ **LEIBEL HARELIK**

▶ prostate cancer survivor

“My treatment is expensive, and I often have to search for financial assistance. But I have learned that you have to be your own advocate. I have good and bad days, but I live without fear.”

They differ in many ways, including which doctors and hospitals are part of the plan. With HMO or EPO plans, your insurance covers you only when you are cared for by the participating doctors and hospitals within the plan network. With PPO and POS plans, you have the option of seeing a doctor not included in your network. In this scenario, your insurance provider agrees to pay a portion of the bills but you're responsible for the remaining amount, typically resulting in a higher out-of-pocket portion. Fee-for-service plans offer even more flexibility in which doctor you can see, but you are responsible for a set percentage of every bill, and that total can fluctuate based on the care you sought that month. Depending on the cost of services you're seeking, a fee-for-service structure could result in low out-of-pocket expenses or high costs for cutting-edge treatments or procedures. Medicare and Medicaid plans can also be structured as HMO, EPO, PPO, POS or fee-for-service.

No matter what type of plan you have, it's crucial to carefully review your coverage and be familiar with the summary of patient responsibilities. If your plan is a high-deductible health plan, you have a set deductible that must be paid before the insurance contributes to the cost of your care. The most important details to understand are your out-of-pocket expenses and the processes for filing claims



“Whenever possible, don’t pay for the service in dispute until the appeal process has been completed.”

and appealing denials. This summary information is included in the paperwork sent to you upon enrollment. If you would like more detailed information that includes the specific language governing your policy, you have the right to request that from your insurer at any point. For cancer patients, understanding

how much of clinical trial costs are covered by your insurance is important as you consider the factors in deciding whether to participate in a trial (see box on page 7).

If you have Medicare, learn about your coverage by reviewing the most recent version of the “Medicare and You” handbook, which you can find at www.medicare.gov.

For Medicaid or community-run insurance plans, this information can be requested through your insurer’s patient services representative.

Out-of-pocket expenses

The term “out-of-pocket expenses” includes the amount you’re expected to pay for services associated with your medical care, excluding your monthly premium. These include your deductible, co-pay and co-insurance, and they vary across plans. When you review your plan, look for answers to the following questions:

- What is my annual deductible?
- Do I have a separate deductible for prescriptions?
- When does my plan year start/end?
- Do I have a co-pay or a co-insurance plan?
- Is there a maximum or annual out-of-pocket limit?
- Is there a yearly limit on reimbursement for certain services?

In addition, review the list of covered services so you know exactly which tests and types of care are included. Also check to see if your insurer has to preapprove your cancer treatment plan and if second opinions are covered. This information can help you avoid delays in treatment.

To comply with the Affordable Care Act, your plan must include prescription drug coverage. Review the plan’s list of preferred drugs, also known as their “formulary,” and know your co-pays. Preferred drugs are those that have the highest coverage by your insurer, which means smaller co-pays for you. In addition, understanding which drugs and types of drugs are included within your plan’s specialty tier (or highest tier) is important. Many cancer patients find that the newest drugs on the market are within the specialty-tier category, which will result in high out-of-pocket costs if these are prescribed by your doctor.

GLOSSARY OF TERMS

- ▶ **Claim:** A request for payment based on the terms of your insurance policy.
- ▶ **Co-insurance:** Generally, the percentage of medical care that you are responsible for paying after meeting your deductible.
- ▶ **Co-pay:** The fixed amount you must pay for specific types of medical care.
- ▶ **Deductible:** The amount you must pay before your insurance begins reimbursing fees.
- ▶ **Explanation of benefits (EOB):** A statement provided by your health insurance company explaining what medical treatments and/or services were paid on your behalf.
- ▶ **Health Insurance Exchange/Health Insurance Marketplace:** A central hub for those seeking health insurance where the user can review plan options, see the premium rates for each, and enroll in the plan they select.
- ▶ **Premium:** The amount you pay each month to keep insurance coverage.
- ▶ **Premium Insurance Tax Credits:** Tax credits from the federal government given to individuals who qualify that reduce the cost of health insurance premiums. These credits are available to use immediately to offset insurance costs, unlike other tax credits that are received when filing your taxes. Consumers whose income is between 100 to 400 percent of the federal poverty level may be eligible for these credits. These credits are also referred to as “insurance subsidies.”
- ▶ **Reimbursement:** Compensation or repayment from your insurance company for health care services you paid for out-of-pocket.

Knowing your plan is critical to maximizing your coverage benefits as you seek care for your cancer. Even if you realize that your plan does not cover all of your needed care at an affordable rate, it's best to know in advance so you can budget appropriately and seek additional resources to help. If you find you need help affording your care, numerous programs, organizations and charities are available to support cancer patients with these expenses.

If you have Medicare, programs such as the Low Income Subsidy (Extra Help) can assist with costs such as monthly premiums, annual deductibles and prescription co-pays. You can learn about these programs in the "Medicare and You" handbook, which you can find at www.medicare.gov.

Filing claims

Always file claims and bills for reimbursement immediately, even if you're not sure whether the expense is covered. This will prevent bills from piling up and will get you your payment as quickly as possible. If your provider is filing claims directly with your insurer on your behalf, be sure to review closely any documentation to ensure accuracy.

Following each treatment or visit to the doctor, it's important to review each account statement you receive from your health care providers and ask about any charges that don't look right. This will help you catch errors early and ultimately reduce the time and costs spent correcting them. You have the right to request additional clarification on any element within your bill that you don't understand.

In addition, when you receive Explanation of Benefits forms (EOBs) from your insurer, review them against your health care provider's statements to make sure you and your providers have submitted all charges for reimbursement. Consider stapling or securing these together for future reference.

Be sure to keep a complete record of your claims and bills, noting which ones have or have not been reimbursed. Also keep copies of the paperwork related to your claims (EOBs, receipts, etc.) to make it easier to file an appeal if necessary.

If you have a Medicare Supplement Insurance policy (Medigap) or secondary health insurance, make sure Medicare knows about the plan, and check your Medicare Summary



THE FINANCIAL SIDE OF CLINICAL TRIALS

Clinical trials are the driving force behind advances made in cancer treatments. Yet patient participation in clinical trials is low and concerns about cost have been a major barrier. In fact, in one survey, 60 percent of respondents said they had not participated in a trial because they thought their insurance company would not provide reimbursement, and 42 percent said they chose not to participate because they were worried about the amount of out-of-pocket expenses. Under the Affordable Care Act, however, all insurance companies must cover the routine patient costs from an in-network provider associated with an approved clinical trial, making trials a much more affordable option than before.

An approved trial is defined as a trial in any phase that is aimed at preventing, detecting or treating cancer or another life-threatening disease. It must either be federally funded or approved, be conducted under an FDA investigational new drug application, or be exempt from the necessity of an FDA investigational new drug application. If you want to participate in an unapproved trial, your insurance may refuse to cover it, so talk to your insurance provider before proceeding.

Health care costs associated with your medical care while participating in a clinical trial fall into two categories:

- **Patient care costs** are costs related to the normal treatment plan associated with your diagnosis and/or general ailments. These include costs related to going to the doctor, any stays in the hospital and certain testing procedures, and these are covered by your insurance according to your plan language.
- **Research costs** are costs directly related to the clinical trial study, such as the study drug, study-related procedures, testing performed for research purposes and additional doctor visits. These are typically covered by the trial sponsor.

Even with expanded clinical trials coverage, be sure to discuss costs with the clinical trial administrators and reach out to your insurance company to clarify coverage. Before the clinical trial begins, ask for a detailed list and clarification of what services will be covered by the trial sponsor, as well as what isn't covered but recommended as part of follow-up and ongoing care. This will help identify some of the costs that are likely not covered by your plan. For example, your insurance company may not consider the follow-up tests and scans provided solely for data collection and analysis as part of routine patient costs. Locate current clinical trials seeking patients at one of the following websites:

- **Center for Information and Study on Clinical Research Participation:** www.searchclinicaltrials.org
- **Coalition of Cancer Cooperative Groups:** www.cancertrials-help.org/cancer-trial-search
- **My Clinical Trial Locator:** www.myclinicaltriallocator.com
- **National Cancer Institute:** www.cancer.gov/clinicaltrials/search
- **National Institutes of Health:** www.clinicaltrials.gov

It's important to emphasize that federal requirements associated with the Affordable Care Act do not apply to grandfathered health plans. The federal law does not pre-empt any state laws that require a clinical trials policy for state-regulated plans. The federal requirements are minimums, but states may impose additional requirements.

Notices to confirm that Medicare has passed on claims to the additional insurer after it has paid its part.

Appealing denials and uncovered services

Occasionally, your insurer may deny a claim or decline to cover a doctor-ordered test or service. Don't be discouraged by a denial; instead, look into the problem and consider appealing it. Sometimes the denial is simply the result of improper or incomplete documentation. To appeal a denial:

- First confirm what services your insurance plan covers as written in your plan details.
- Call your insurer's customer service department and ask for an explanation of the denial; don't be afraid to ask to speak to a supervisor.
- Write down when you call, the name of the person with whom you speak and details of the conversation.
- If your phone call to the insurance company does not resolve the issue, ask your doctor to assist you in appealing the insurer's decision. For example, your doctor can help by writing a letter to the insurance company to justify why the test or service was ordered. Letters from providers addressing the stated reason for your specific denial should be included within your appeal submission.
- Review the appeal instructions listed on the denial letter from the insurer, paying close attention to timelines for submission documents.

If your insurance agency denies your claim appeal for services covered within your plan language, you then have the right under the Affordable Care Act to apply for an external appeal. This is a process in which an outside organization reviews your claim and has the power to overturn the insurer's denial, if appropriate. Check your denial notice for instructions on how to request an external review.

- Whenever possible, don't pay for the service in dispute until the appeal process has been completed.
- If you ever feel like your insurer has treated you unfairly, contact the regulation body that oversees your type of insurance (Table 1).

▼ | **TABLE 1 | HEALTH INSURANCE REGULATORS**

Various regulating bodies oversee health insurance plans. If you have a problem you are unable to resolve with your insurance carrier, contact the appropriate regulating body for guidance.

Regulating body	Insurance plan	Contact information
Your state's insurance department/ commission	<ul style="list-style-type: none"> • Individual health plans • Marketplace plans sold in state-operated marketplaces • Group plans (not employer-based) • Employer-based group plans • Medigap policies 	Depends on your state; search the Web for "[Your State] insurance commission" or "[Your State] insurance department"
Centers for Medicare & Medicaid Services	<ul style="list-style-type: none"> • Medicare • Medicaid • Marketplace plans sold in federally operated marketplaces 	www.medicare.gov www.medicaid.gov www.cms.gov/ccio/index.html
Defense Health Agency	<ul style="list-style-type: none"> • TRICARE 	www.tricare.mil
U.S. Department of Veterans Affairs	<ul style="list-style-type: none"> • Veterans' health care system (including CHAMPVA) 	www.va.gov/healthbenefits

- Some services and treatment options may be denied for coverage by your insurance plan because they are excluded from it. If services are not covered, it's your responsibility to cover the full cost of these items. By knowing your plan language, submitting required pre-authorizations, maintaining regular communication with your insurer, and gaining cost estimates from your providers in advance, you can minimize unexpected bills for excluded services.

Work with people who can help

Many people can help you handle insurance matters. Doctors' offices typically have a billing person; the cancer care team usually includes a social worker; and most medical facilities have financial counselors and patient navigators on staff. If you can, try to work with the same person for your financial help. These people can help by:

- Answering and clarifying any questions you have about your medical bills
- Providing an estimate of the cost of your cancer treatment and telling you if the cost might exceed your coverage limit
- Setting up a payment schedule for your costs with terms you can afford
- Helping you accurately process insurance claims and appeals
- Providing copies of documentation related to your bill
- Referring you to outside financial assistance organizations or charities that can

help if you have difficulty paying expenses not covered by insurance

- Recommending additional resources to keep you informed about various insurance and financial matters, including publications, pamphlets, booklets and Web resources

In addition, health insurance companies often have case managers who can assist with financial matters. Call your insurance carrier and ask if a case manager can be assigned to work with you on your claims.

If you find that dealing with these matters is too draining during treatment, look to someone you trust to assist. Family members, caregivers or friends can sometimes be a great resource to help you stay organized, research and gather information, or help you initiate communication with various parties.

Don't become discouraged if you run into roadblocks with your insurer. Instead, seek out avenues to help you overcome the roadblocks so you can continue the treatment that's best for you. ■

ADDITIONAL RESOURCES

- AARP Health:** www.aarphealthcare.com/home.html
- Cancer Insurance Checklist:** www.cancerinsurancechecklist.org
- Cancer Legal Resource Center:** www.cancerlegalresourcecenter.org; 866-999-3752
- Insure Us Today:** www.insureustoday.org
- Patient Advocate Foundation:** www.patientadvocate.org/publications



Several health care laws exist at the federal level, and while most of these laws are not directed specifically at cancer care, their content addresses protections and benefits that affect people with cancer as well as their families. You should become familiar with these laws to understand your legal rights regarding access to care, insurance protection, benefits and anti-discrimination.

The descriptions of the laws that follow provide only highlights of the most important information for people with cancer. Also note that eligibility criteria and definitions of such terms as “employer,” “employee” and “pre-existing condition” vary across these laws. For more details and definitions, refer to the contact information for the governing bodies of the laws (see sidebar below).

Patient Protection and Affordable Care Act

The Patient Protection and Affordable Care Act of 2010 is also known as the Affordable Care Act or the Health Reform Act. It regulates health insurance coverage in the United States in the hopes of making it more accessible and affordable while still ensuring high-quality care.

Accessibility

Some key components of the law related to access to care include the following:

- The act enables adult children to stay on a parent’s plan until their 26th birthday.

- Health insurance companies cannot deny coverage for a pre-existing condition.
- Health insurance plans cannot stop coverage when a person becomes sick.
- Enhanced preventive benefits and screenings are available at no cost for all insured parties.
- A formalized list of “essential health benefits” ensures all insurance policies provide minimum coverage for services within 10 categories of care (see sidebar on page 10).
- Annual and lifetime limits on essential health benefit services have been removed, which is particularly helpful for cancer patients.
- Creation of “marketplaces” helps consumers find and enroll in affordable health coverage.
- Coverage has been improved for patients participating in clinical trials.
- Employer-based group plans cannot impose waiting periods of more than 90 days for coverage.

Affordability

The Affordable Care Act ensures that health insurance companies will not be allowed to charge higher fees based on a person’s current or previous health status, and it limits the amount of money people must pay for out-of-pocket expenses and deductibles. Insurance companies are no longer able to place annual or lifetime limits on care and benefits considered part of the essential health benefits. However, they are permitted to put a yearly dollar limit and a lifetime dollar limit

on nonessential health benefits. Many people are also eligible to receive help paying their monthly premiums through Premium Health Insurance Credits, which are frequently referred to as “subsidies.”

Quality of care

The Affordable Care Act sets standards for the quality of care for all people, especially with regard to the prevention and treatment of cancer. First, the law mandates that health insurers eliminate co-pays for prevention services recommended by the U.S. Preventive Services Task Force. For example, a co-pay is not required for colorectal cancer screening for adults older than 50, for annual mammograms for women older than 40, or regular Pap smear testing. In addition, all new health insurance plans must include coverage of cancer treatment, including treatment focused on pain management and other quality-of-life issues and follow-up care. The law also provides an increased coverage level for those participating in a clinical trial. (See page 7 for more information about clinical trials.)

Health insurance marketplaces

All U.S. residents can now find and secure health insurance in their region through a central online hub. This service allows users to compare available plans and enroll directly in a plan that meets their needs. Navigators and application counselors are also available in each state to help patients make informed decisions during the selection process. To be directed to your state’s marketplace, visit www.healthcare.gov. Unless you have a special circumstance, you can only enroll in an insurance plan through the marketplace during special enrollment periods every winter. The next open enrollment period for most marketplaces begins Nov. 15, 2014, and ends Feb. 15, 2015. Be sure to check the open enrollment period for your state’s marketplace because it may be different.

The Affordable Care Act is a complex law and includes many features beyond what is described here. Visit www.healthcare.gov to learn what the law means to you.

Women’s Health and Cancer Rights Act

The Women’s Health and Cancer Rights Act requires that most insurance plans that cover

GOVERNING BODIES OF THE LAWS

Find more information about these laws on the websites of their governing bodies, or call for additional details.

- ▶ **Affordable Care Act:** www.healthcare.gov; 800-318-2596
- ▶ **Americans With Disabilities Act:** www.ada.gov; 800-514-0301
- ▶ **Consolidated Omnibus Budget Reconciliation Act (COBRA):** www.dol.gov/dol/topic/health-plans/cobra.htm
- ▶ **Family and Medical Leave Act (FMLA):** www.dol.gov/whd/regs/compliance/whdfs28.pdf; 866-487-9243
- ▶ **Health Insurance Portability and Accountability Act (HIPAA):** www.dol.gov/ebsa/faqs/faq_consumer_hipaa.html
- ▶ **Hill-Burton Act:** www.hrsa.gov/gethealthcare/affordable/hillburton/hillburton.pdf; 800-638-0742
- ▶ **Social Security:** www.socialsecurity.gov; 800-772-1213
- ▶ **U.S. Department of Veterans Affairs – Agent Orange:** www.publichealth.va.gov/exposures/agentorange

mastectomies must also cover breast reconstruction. Under the law, mastectomy benefits must cover the following:

- Reconstruction of the breast that was removed by mastectomy
- Surgery and reconstruction of the other breast to make the breasts look balanced after mastectomy
- Any external breast prostheses (breast forms that fit into your bra) that are needed before or during the reconstruction
- Any physical complications at all stages of mastectomy, including lymphedema

The law applies to group health plans (started on or after Oct. 1, 1998) that cover the medical and surgical costs for mastectomies. The deductible and co-pay (or co-insurance) for breast reconstruction must be the same as those for other covered surgeries.

Consolidated Omnibus Budget Reconciliation Act (COBRA)

COBRA is designed to help people access health insurance coverage if they lose their coverage through an employer for an established reason (“qualifying event”). The law applies to an employee or an individual covered by an employee’s plan (such as a spouse).

Qualifying events include stopping work, reducing work hours, divorce or legal separation, or death of the employee.

COBRA does not provide free coverage. Rather, it’s an option to keep your same insurance coverage at the employer’s group rate (plus a 2 percent administration fee) without an interruption of coverage. Because most employers frequently contribute funds to pay a portion of the monthly premium, patients using COBRA should expect to pay more than the amount paid during employment. In most cases, COBRA can be used for up to 18 months; longer coverage is available in some situations.

Health Insurance Portability and Accountability Act (HIPAA)

When most people hear “HIPAA,” they think of privacy issues related to health care information. Privacy is an important component of HIPAA, but the law was established in 1996 to protect insurance coverage by making it more “portable” when moving from one job to another and/or when moving from one health insurance plan to another. Many of the aspects of this law were also addressed as part of the Affordable Care Act.

The Family and Medical Leave Act (FMLA)

Established in 1993, FMLA requires that employers (with at least 50 employees) provide up to 12 weeks of unpaid, job-protected leave to eligible employees for certain family and medical reasons. The leave can be for the employee’s serious health condition or for the serious health condition of an immediate family member, defined as a spouse, child (typically younger than 18 years) or parent. The act defines “serious health condition” in several ways, most of which apply to cancer. The law also requires that the employer maintain the same terms of the employee’s health insurance benefits for the duration of the covered leave. If you pay all or part of the health insurance premium, you must make arrangements to continue to pay your portion during the leave. Leave can be taken all at once or in shorter blocks of time, but it must all be related to a single reason. You can also use FMLA to work part-time instead of full-time for a certain period.

You do not need to show medical records to your employer to use FMLA, but your employer does have the right to request that you provide medical certification demonstrating evidence of a serious health condition for you or the family member for whom you are serving as a caregiver. A doctor must complete and sign this certification note; in general, the necessary information includes when the illness started, whether you will need a single block of time or shorter blocks, an estimated time when you can return to work, and whether additional treatment will be needed after your leave is completed.

In 2008, FMLA was expanded to provide longer leaves for an employee (up to 26 work weeks) to care for an armed forces member with a serious illness. The employee can be a child, parent or next of kin of the armed forces member.

Social Security Disability benefits

In some instances, people with cancer may be entitled to Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits. The primary eligibility requirement is disease that is severe enough to prevent you from performing “substantial gainful activity.” The Social Security Administration requires medical documentation of the type, extent and site of the primary, recurrent or

WHAT ARE “ESSENTIAL HEALTH BENEFITS”



Essential health benefits are defined within the Affordable Care Act as a set of health care services that must be covered by certain plans.

Insurance and small group policies must cover these benefits in order to be certified and offered within the Health Insurance Marketplace, and all Medicaid state plans also include essential health benefits. The Affordable Care Act ensures individual and small business health plans offered outside of the marketplace must also contain this comprehensive package of items and services.

Under the Affordable Care Act, essential health benefits are defined to include the following general categories. Under the law, each state may add or further define the services included within each category:

- ▶ **Ambulatory patient services (outpatient care you get without being admitted to a hospital)**
- ▶ **Emergency services**
- ▶ **Hospitalization**
- ▶ **Maternity and newborn care (care before and after your baby is born)**
- ▶ **Mental health and substance use disorder services, including behavioral health treatment (this includes counseling and psychotherapy)**
- ▶ **Prescription drugs**
- ▶ **Rehabilitative and habilitative services and devices (services and devices to help people with injuries, disabilities or chronic conditions gain or recover mental and physical skills)**
- ▶ **Laboratory services**
- ▶ **Preventive and wellness services and chronic disease management**
- ▶ **Pediatric services (including oral and vision care)**

metastatic tumor; an operative note (if surgery was done); a pathology report; records noting recurrence, persistence or progression of disease; details on drugs and/or radiation treatment; response to treatment; and the presence of treatment-related side effects.

The criteria for eligibility vary according to the type of cancer. The number of applications for SSDI (for all types of disability) is very high, and more than 60 percent of initial applications are denied.

Several hundred cancers are on the Compassionate Allowances list, which typically qualifies a person with a minimum amount of objective medical information while also expediting the approval time frame. Once approved, a disability designation serves as a gateway for additional benefits and frequently provides broader eligibility for charity assistance.

Hill-Burton Act

Established in 1946, the Hill-Burton Act is the earliest of the government health care-related laws. The law requires that any medical care facility that used federal funds for construction (to build, expand or renovate) must provide a percentage of its services free or at a low cost. Eligibility for free or low-cost care is based on family size and income; a person whose income is within the poverty guidelines is eligible for free care, and low-cost care is provided for people with incomes somewhat higher than those considered to be at the poverty level.

A facility sets aside the money for care under the Hill-Burton Act at the beginning of the year, and the funds are used on a first-come, first-served basis. Each facility determines the services to be provided at low or no cost. The act does not cover services that are covered by private insurance, Medicare or Medicaid. All Hill-Burton facilities are listed at www.hrsa.gov/gethealthcare/affordable/hillburton/facilities.html.

U.S. Department of Veterans Affairs (VA)

The VA created programs to help veterans receive health care related to hazardous exposures. Some of these have been linked to a wide range of cancers. For example, Agent Orange (Vietnam War) has been linked to lymphoma, lung cancer, multiple myeloma, prostate cancer, soft tissue sarcoma and

ANNUAL AND LIFETIME LIMITS

→ **For insurance plans beginning on or after Jan. 1, 2014, group health plans are prohibited from imposing annual limits on the dollar value of essential health benefits. That is, patients cannot be denied services included within this list because their care exceeded a specific dollar value during that year. In addition, you cannot be subject to lifetime limits for care within the essential health benefits during the entire time you are enrolled in a plan.**

To understand what services within your plan are not considered essential benefits and may be subject to limits or denials, request this information directly from your insurer. Grandfathered individual plans are excluded from the annual limit prohibition but are not able to impose lifetime limits for essential health benefits.

chronic lymphocytic leukemia. As a veteran, an exposure to a hazardous material may entitle you to free medical care and other benefits as long as you have the ability to prove that your illness began during (or was worsened by) your military service. Visit <http://benefits.va.gov/compensation/claims-post-service-exposures-index.asp> to determine if you're eligible and to learn more.

Genetic Information Nondiscrimination Act (GINA)

Genetic testing has become an important factor in the diagnosis and treatment of some types of cancer. For example, genetic testing can detect the presence of hereditary genetic abnormalities that increase the risk of breast and colorectal cancers. Under GINA, employers with more than 15 employees cannot discriminate on the basis of genetic information in hiring, firing, layoffs, promotions, assignments or salary. The law protects against discrimination by employers and health insurers on the basis of a person's own genetic tests, genetic tests of family members, or the presence of a genetic disease or disorder in one or more family members.

With regard to health insurers, denial of coverage and higher premiums based on either the results of genetic testing or the use of genetic counseling are not allowed under GINA. The law applies to group health plans, individual plans and Medicare supplemental plans. GINA also bans insurers from requesting or requiring genetic tests.

Americans with Disabilities Act

Although people with cancer prefer not to think of themselves as "disabled," they are protected under the Americans with Disabilities Act. The law protects against discrimination in the workplace and applies to private

employers who employ 15 or more people, as well as labor unions, employment agencies and government agencies. Under the law, all employees, regardless of medical condition or medical history, must be treated equally, especially in terms of the benefits offered to them. The law protects not only an employee but also his or her spouse or dependent children, and it prohibits employers from screening out a potential employee who has a child with cancer (or a disability).

Learning about the benefits available to you and the processes for getting these benefits can consume a great deal of time. Consider asking a family member or friend for help in searching for information and/or completing applications if your time and energy are limited.

The Resources section beginning on page 15 of this guide includes several nonprofit organizations that can help you with financial matters, including benefits related to these federal programs. ■

ADDITIONAL RESOURCES

American Cancer Society: www.cancer.org

Agent Orange and Cancer

Americans with Disabilities Act: Information for People Facing Cancer

Family and Medical Leave Act (FMLA)

What is COBRA?

American Society of Clinical Oncology

(patient website): www.cancer.net

Veterans and Cancer

InsureUStoday.org: www.insureustoday.org/marketplaces; 866-207-8023

A User's Guide to Health Insurance Marketplaces

Patient Advocate Foundation:

www.patientadvocate.org; 800-532-5274

Survivorship A to Z:

www.survivorshipatoz.org/cancer

Hill-Burton Act: Free or Low Cost Care

W

hile estate planning is a task many people prefer to avoid, experts recommend that you take care of it early in life. Although it's often emotionally difficult, estate planning has benefits that bring peace of mind and a sense of security. For example, it:

- Documents your wishes regarding the distribution of your assets
- Ensures you receive the level of medical care you want
- Reduces the burden of difficult decisions and tasks on loved ones

What is estate planning?

Estate planning is preparing and documenting a plan of how to dispose of your property before or after death. It usually involves completing advance directives, naming a power of attorney, developing a will and possibly establishing trusts. Regardless of how much money you have, your health or your age, you should have a plan that states how to transfer your assets to the people you choose. If you don't write down your wishes, they can be challenged and perhaps never carried out as you want.

The first step in estate planning is to gather paperwork related to your assets (see sidebar). In general, assets include bank accounts, real estate, investments (stocks and bonds) and an inventory of personal possessions. Next, you will choose people you trust to carry out your decisions when you are no longer able. You will also determine who inherits the assets in which

▷ DOCUMENTS NEEDED TO PREPARE FOR ESTATE PLANNING

- Life and health insurance policies
- Bank account statements
- Real estate documents
- Stocks and/or bonds
- Retirement accounts
- Deeds of trust
- Internet user names and passwords
- Contact information for banks, insurance agents, etc.
- Inventory of assets, including valuables and personal items of note



“Estate planning is an ongoing process, not a one-time event. Your plan should be reviewed and updated as your family size, financial situation and estate laws change over your lifetime.”

you have not already named beneficiaries; most likely, you have already named beneficiaries in life insurance policies, retirement plans and annuities.

Advance directives

An advance directive is a set of written instructions that states what specific actions should be taken when a person's health prevents him or her from making decisions due to illness or incapacity. Also known as a “living will,” the advance directive tells your doctor what types of life-sustaining treatment you want and helps ensure you receive the level of care you wish. The primary reason for advance directives is to ensure your wishes regarding your health care choices – including the types of medical procedures you want administered or withheld as well as end-of-life decisions – are carried out.

It's also wise to select a health care proxy. This person is someone you trust to make medical decisions on your behalf if you become unable to do so yourself. When you

decide who should have this responsibility, be sure to explain what you're asking of your proxy, why you picked him or her and confirm their willingness to act under this authority. Being a health care proxy is a great responsibility, so be sure to talk to the person you choose, and concisely convey your wishes. Your health care proxy needs to know about your end-of-life wishes, including what medical treatments you would want and whether or not you have an advance directive in place. Talking to your proxy means discussing values and quality-of-life issues as well as treatments and medical situations. Because you cannot anticipate every situation that could occur, your proxy may need to base a decision on what he or she knows about your values and your views of what makes life worth living. These are not simple questions, and your views may change. For this reason, talk to your proxy in depth and over time. This knowledge will make it easier for your proxy to make decisions if necessary.

It's important to note that advance directive documents only give general direction related to future care based on unknown and hypothetical specifics. Because you cannot predict when this may become applicable, designating a proxy allows someone you choose to make daily decisions based on current medical advice, treatment options and the specifics of the injury, illness or acute care that is needed.

Power of attorney

A power of attorney is a document that grants someone the authority to handle your financial, legal and (in some cases) health affairs if you are unable to do so yourself for any period of time. This is done in writing in front of a witness and notary. Your document should clarify the length of time and conditions in which this power is valid. Be sure to select a person you trust to make decisions on your behalf.

Wills and trusts

Creating a will allows you to state how you would like to distribute your assets and can also help avoid delays in carrying out your wishes. As part of drawing up your will, you will choose an executor, who will be responsible for using your assets to pay all of your final debts and expenses. You will also detail how you would like your remaining assets to be distributed by stating who your beneficiaries will be (spouse, family, friends and charities), what they will receive, and how and when they will receive their inheritance.

In addition, you can choose to leave assets to your beneficiaries outright or in the form of a trust. With a trust, you can specify the conditions under which your designated ben-

▷ REASONS FOR

UP-TO-DATE ESTATE DOCUMENTS

- ✓ Provide instructions for your medical care in times when you may be critically disabled, incapacitated or in need of hospice care.
- ✓ Minimize taxes, court costs, unnecessary legal fees and time delays processing your wishes following your death.
- ✓ Allow you to designate a guardian and an inheritance manager for minor children.
- ✓ Give you the opportunity to provide for family members or spouses, including those with special needs, without disrupting government benefits.
- ✓ Provide for the transfer of your business at your retirement, disability or death.
- ✓ Provide an opportunity to learn and make decisions about possible protections for your estate, including life insurance, disability income insurance, long-term care insurance, etc.
- ✓ Offer an opportunity to communicate your values (religious, social, civic responsibility, etc.) to those who will play an important role in making decisions on your behalf. This may give insight into how to proceed with decisions for which you've not provided specific direction.



eficiary receives an asset. For example, you may want to specify an age at which a minor child receives an asset. There are many types of trusts, so it's a good idea to work with an attorney experienced in estate planning to help you decide which is best for you. Because estate laws vary according to state, make sure the attorney you choose is familiar with the laws in your particular state.

Your will allows you to direct other decisions as well. For example, you can name a guardian for minor children and specify funeral arrangements. Planning your funeral preferences in advance will save your loved ones unnecessary expense and anxiety at a difficult time in their lives.

If you already have a will, check to make sure it's up-to-date and your heirs are named as you wish. If you need to make changes, write them down and bring the list to your attorney. Keep in mind that many of the documents you have prepared for use during your lifetime (such as a standard power of attorney or medical proxy designation) will automatically expire at the time of your death. Your will is the primary document of record that guides matters following your death. ■

? QUESTIONS TO HELP GUIDE YOUR DECISIONS

- ▶ **What kinds of life-sustaining treatment do I want?**
- ▶ **If I am unable to make my own health care decisions, whom do I trust to make the decisions for me?**
- ▶ **Whom do I want to handle my financial affairs if I am unable to do so myself?**
- ▶ **Whom do I want to inherit my assets? Are there specific instructions that I want followed?**
- ▶ **Do I want specific personal possessions to be passed on to certain loved ones?**
- ▶ **Are there any religious or spiritual beliefs that would dictate specific medical or funeral treatment?**

ADDITIONAL RESOURCES

American Cancer Society: www.cancer.org

Advance Directives

Cancer Legal Resource Center:
www.cancerlegalresourcecenter.org;
866-999-3752

Cancer Prevention Institute of California:
www.cpic.org

Estates: Planning Ahead (downloadable PDF)

Mayo Clinic: www.mayoclinic.com

Living Wills and Advance Directives for Medical Decisions

National Cancer Institute: www.cancer.gov
Advance Directives

Survivorship A to Z: www.survivorshipatoz.org
Estate Planning

By Andrea Blatt

No matter how well you plan your finances, you may find yourself in a situation where your bills become too big to pay. This situation is scary, but you should always remember that you are not alone in your struggle: One study showed that 68 percent of cancer patients and caregivers experience financial hardship during treatment. By remaining calm and organized, you can find ways to relieve your financial burden.

Get advice early

If you realize that paying your bills is getting more difficult, seek advice from a professional immediately. Many organizations, such as the Patient Advocate Foundation, provide free counseling to patients burdened by medical debt. They can help you apply for financial assistance and communicate with your doctors, insurers and creditors.

Reassess your finances

If you haven't already, take an in-depth look at how and where you spend your money each month. Try to find small steps you can take toward lowering the amount you pay in bills without hurting your health. Some examples are carpooling or taking public transportation to cut gas costs, shopping with coupons, removing data from your phone plan, avoiding eating out and canceling paid subscriptions to magazines, Internet sites or cable.

Ask for help

Be proactive in finding a solution to your monetary troubles by looking for financial assistance. Talk to the providers who have sent the bill and inquire about any financial assistance options they offer to help patients struggling with payment. Many times your doctor can provide an application for a charity care program, begin the process for requesting a discount or a reduced bill, or arrange an affordable payment plan for the remaining balance.

Many nonprofit groups have programs to help patients who can't pay their bills, including services like co-pay assistance, travel aid and child care (see list on pages 15-17). Apply for as many of these programs as appropriate. If you feel too tired or too stressed to handle this, ask someone you trust to find programs and help fill out the applications.

HELP IS AS CLOSE AS YOUR SMART PHONE



Finding help paying for your medications can be overwhelming, but thanks to the National Comprehensive Cancer Network's new phone application – the **NCCN Reimbursement Resource App** – help is just a few taps away. Download the application through the Apple iTunes Store or Google Play Store, and you can search for reimbursement for your medications by your cancer type or drug name, or just browse available reimbursement or assistance programs.

My Resource Search is a free, easy-to-use tool for on-the-go health care, financial tips and insurance help. Harnessing the power of the National Uninsured and Underinsured Resource Directories, the app allows both insured and uninsured patients the ability to quickly identify the community, national and charity programs that can assist in their health care needs. My Resource Search is perfect for patients currently experiencing a health crisis or providers who want to guide their patients to programs that may be able to reduce their barriers to care. My Resource Search is available for free through the Apple iTunes store or Google Play store.

The **Healthcare Bluebook** on the Apple iTunes store helps consumers save money by equipping them with "Fair Price" information about thousands of health care services and procedures that enables them to become smart health care shoppers. Due to price variances among providers, smart shoppers can save thousands of dollars on common procedures like MRIs, orthopedic surgeries, sleep studies and preventive screenings. Whether you have high deductible health insurance or no insurance at all, Healthcare Bluebook's Fair Price will tell you what you should pay for a procedure.

If you feel comfortable, reach out to your family and friends for financial help. This doesn't have to mean asking for direct financial donations. Your loved ones may be able to offer you food to cut your grocery costs, living space to reduce your rent, child care support, or even space in a family cellphone plan to lessen your phone bill.

Deal with debt

If your expenses outweigh your income, you may find yourself in debt. Communicate with your creditors to see if there's a way you can postpone paying off your debt or settle your debt at a slightly reduced rate. If this is possible for you, it could buy you time to get back on your feet.

If you absolutely cannot find a way to get out of debt, filing for bankruptcy may be an option on the table. If you're paying for necessities on your credit card, only making minimum payments on your credit card bills and avoiding calls from bill collectors – and you cannot foresee a change in your situation in the near future – you may want to consider filing for bankruptcy. Don't approach this option lightly, however: Declaring bankruptcy may mean giving up many of your assets – possibly including your house or car – and

could affect your ability to get loans later in life. If you think bankruptcy might be the right option for you, speak with a bankruptcy attorney to help you through the process, or you may qualify for free legal services through the court. Be honest with your attorney about your previous, present and anticipated financial concerns associated with your health care.

Don't sacrifice your health

No matter what your financial situation is, never alter or stop your treatment without talking to your doctor. Many cancer patients avoid filling prescriptions or receiving treatment when they're worried about paying the bills, but doing this can seriously damage your health. Your health care team can work with you to find a better solution. Never jeopardize your recovery from cancer because of financial difficulties. ■

ADDITIONAL RESOURCES

CancerCare: www.cancercares.org/financial

Cancer Financial Assistance Coalition: www.cancerfac.org

National Financial Resource Directory: www.patientadvocate.org/financial

Patient Advocate Foundation: 800-532-5274

BASIC LIVING EXPENSES

American Childhood Cancer Organization
www.acco.org, 865-858-2226

Brenda Mehling Cancer Fund (patients 18-40)
www.bmcf.net, 661-310-7940

Bringing Hope Home
www.bringinghopehome.org

Candlelighters Childhood Cancer Family Alliance
www.candle.org, 713-270-4700

Children's Cancer Recovery Foundation
www.childrencancerrecovery.org, 800-238-6479

**Cleaning for a Reason
(free house cleaning service)**
www.cleaningforareason.org, 877-337-3348

Family Reach Foundation
www.familyreach.org, 973-394-1411

The National Children's Cancer Society
www.children-cancer.org, 314-241-1600

Native American Cancer Research
www.natamcancer.org, 800-537-8295

Rise Above It (youth, young adults)
www.raibenefit.org

The Simple Dollar
www.thesimpledollar.com/lifeinsurance

Zichron Shlome Refuah Fund
www.zsrf.org, 718-GETWELL

CHILD CARE EXPENSES

AVON Foundation for Women
www.avonfoundation.org, 866-505-AVON

CancerCare
www.cancercare.org, 800-813-HOPE

Family Reach Foundation
www.familyreach.org, 973-394-1411

Mission4Maureen (brain cancer)
www.mission4maureen.org, 440-840-6497

Stupid Cancer
www.stupidcancer.org, 877-735-4673

EQUIPMENT/SUPPLIES EXPENSES

American Kidney Fund (dialysis patients)
www.kidneyfund.org, 800-638-8299

CancerCare
www.cancercare.org, 800-813-HOPE

Cancer Fund of America Inc.
www.cfoa.org, 800-578-5284

Friends of Man
www.friendsofman.org, 303-798-2342

Look Good...Feel Better
http://lookgoodfeelbetter.org, 800-395-LOOK

Lymphoma Research Foundation
www.lymphoma.org, 800-500-9976

**Marilyn Westbrook Garment Fund
(lymphedema)**
www.lymphnet.org/patients/westbrookfund.htm,
415-908-3681

Royal Crown of Glory Foundation
www.crownofgloryinc.org

GOVERNMENT ASSISTANCE

Administration on Aging
www.aoa.gov, 202-401-4634

Benefits.gov
www.benefits.gov, 800-FED-INFO

PatientResource.com

Breast and Cervical Cancer Treatment Act of 2000

www.cdc.gov/cancer/nbccedp/legislation/
law106-354.htm, 800-232-4636

Centers for Medicare & Medicaid Services
www.cms.gov, 800-MEDICARE

Hill-Burton Program
www.hrsa.gov/gethealthcare/affordable/hillburton,
800-638-0742

Legal Services Corporation
www.lsc.gov, 202-295-1500

Medicare Rights Center
www.medicarerights.org, 800-333-4114

Social Security Administration
www.ssa.gov, 800-772-1213

Social Security Disability Resource Center
www.ssdrc.com

State Children's Health Insurance Program
www.insurekidsnow.gov, 877-KIDS-NOW

State Health Insurance Assistance Program
www.shiptalk.org

U.S. Department of Veterans Affairs
www.va.gov/health/index.asp

GRANTS, SCHOLARSHIPS, AWARDS, CAMPS

American Childhood Cancer Organization
www.acco.org, 865-858-2226

**Cameron Siemers Foundation for Hope
(young adults)**
www.cameronsiemers.org

Camp Quality USA
www.campqualityusa.com, 303-671-0167

Camp Sunshine
www.campsunshine.org, 207-655-3800

Cancer for College
www.cancerforcollege.org, 760-599-5096

Cancer Recovery Foundation (camps)
www.cancerrecovery.org, 800-238-6479

Cancer Survivors' Fund (young adults, children)
www.cancersurvivorsfund.org, 281-437-7142

Casting for Recovery
www.castingforrecovery.org, 802-362-9181

Chai Lifeline
www.chailifeline.org

**Children's Oncology Camping
Association International**
www.cocai.org, 404-661-5753

Dream Street Foundation
www.dreamstreetfoundation.org,
424-248-0696

Eagle Mount
www.eaglemount.org, 406-586-1781

FinAid (links to assistance programs)
www.finaid.org/scholarships/cancer.phtml

First Descents (outdoor adventure experiences)
www.firstdescents.org, 303-945-2490

Jack & Jill Late Stage Cancer Foundation
http://jajf.org, 404-537-5253

Kids Camps.com
www.kidscamps.com/special_needs/
cancer_oncology.html

MaryEllen Locher Foundation
www.melfoundation.org

National Collegiate Cancer Foundation
www.collegiatecancer.org, 240-515-6262

Next Step

www.nextstepnet.org, 617-864-2921

Nicki Leach Foundation
www.nickileach.org, 904-686-1010

Patient Advocate Foundation
www.patientadvocate.org, 800-532-5274

Pediatric Brain Tumor Foundation
www.pbtfus.org, 800-253-6530

Planet Cancer
http://myplanet.planetcancer.org

Reel Recovery
www.reelrecovery.org

Ryan Mullaly Second Chance Fund
http://ryans2dchancefund.org

The SAMFund (young adults ages 17-35)
www.thesamfund.org, 866-439-9365

SeriousFun Children's Network
www.seriousfunnetwork.org, 203-562-1203

Special Love for Children with Cancer
www.speciallove.org, 888-930-2707

SuperSibs
www.alexlemonade.org/campaign/supersibs

**Susan G. Komen for the Cure
(search "college scholarships")**
www5.komen.org, 877-GO-KOMEN

Tim & Tom Gullikson Foundation
www.pbtfus.org/survivors/education/scholarships

The Ulman Cancer Fund for Young Adults
www.ulmanfund.org, 888-393-FUND

Victory Junction
www.victoryjunction.org, 877-VJG-CAMP

Women Beyond Cancer
www.womenbeyondcancer.org

HOME HEALTH CARE EXPENSES

AVON Foundation for Women
www.avonfoundation.org, 800-813-HOPE

The Bone Marrow Foundation
www.bonemarrow.org, 800-365-1336

Brenda Mehling Cancer Fund (patients 18-40)
www.bmcf.net, 661-310-7940

CancerCare
www.cancercare.org, 800-813-HOPE

HOUSING DURING TREATMENT EXPENSES

**Alex's Lemonade Stand Foundation for
Childhood Cancer**
www.alexlemonade.org, 866-333-1213

American Cancer Society (Hope Lodges)
www.cancer.org, 800-ACS-2345

American Childhood Cancer Organization
www.acco.org, 865-858-2226

Fisher House (military families)
www.fisherhouse.org, 888-294-8560

Hospitality Homes
www.hosp.org, 888-595-4678

Joe's House
www.joeshouse.org, 877-JOESHOU

**National Association of Hospital Hospitality
Houses Inc.**
www.nahhh.org, 800-542-9730

The National Children's Cancer Society
www.children-cancer.org, 314-241-1600

Ronald McDonald House Charities
www.rmhc.com, 630-623-7048

INSURANCE PREMIUM EXPENSES

American Cancer Society Health Insurance Assistance Service
www.cancer.org, 800-ACS-2345

CancerCare Co-Payment Assistance Foundation
www.cancercapecopy.org, 866-552-6729

The CHAIN Fund Inc.
www.thechainfund.com, 203-530-3439

Co-Pay Relief Program
www.copays.org, 866-512-3861

Foundation for Health Coverage Education
www.coverageforall.org

HealthWell Foundation (diagnosis-specific)
www.healthwellfoundation.org, 800-675-8416

Kaiser Family Foundation
http://kff.org/health-costs/report/a-consumer-guide-to-handling-disputes-with-your-employer-or-private-health-plan

Leukemia & Lymphoma Society
www.lls.org, 800-955-4572

The National Children's Cancer Society
www.children-cancer.org, 314-241-1600

NeedyMeds (links to assistance programs)
www.needymeds.org

Patient Services Inc.
www.patientservicesinc.org, 800-366-7741

Stupid Cancer
www.stupidcancer.org, 877-735-4673

LEGAL ISSUES

Administration on Aging (search for "legal assistance")
www.aoa.gov, 202-401-4634

American Bar Association
www.americanbar.org, 800-285-2221

Cancer and Careers
www.cancerandcareers.org

Disability Rights Legal Center
www.disabilityrightslegalcenter.org, 866-999-3752

LawHelp.org
www.lawhelp.org

Legal Services Corporation
www.lsc.gov, 202-295-1500

National Coalition for Cancer Survivorship
www.canceradvocacy.org, 877-NCCS-YES

National Health Law Program (links to assistance programs)
www.healthlaw.org, 202-289-7661

Patient Advocate Foundation
www.patientadvocate.org, 800-532-5274

Social Security Disability Resource Center
www.ssdrc.com

MEDICAL CARE EXPENSES

Andre Sobel River of Life Foundation (for children at partner institutions)
www.andreriveroflife.org, 310-276-7111

The Bone Marrow Foundation
www.bonemarrow.org, 800-365-1336

CancerCare
www.cancercapecopy.org, 800-813-HOPE

Cancer Survivors' Fund (young adults, children)
www.cancersurvivorsfund.org, 281-437-7142

Children's Leukemia Research Association
www.childrensleukemia.org, 516-222-1944

Fertile Hope
www.fertilehope.org, 855-220-7777

Q&A WITH THE PATIENT ADVOCATE FOUNDATION

An interview with Fran Castellow, MSED, President of Operations

By Ashley Tsue

► The Patient Advocate Foundation (PAF) is a nonprofit organization dedicated to helping patients who are facing obstacles in health care, such as financial difficulties, maintaining employment and lack of access to care. After more than 17 years, the group continues to serve as a liaison between patients and their employers, insurers and/or creditors.

What was the inspiration for PAF, and how did that influence the organization's mission?

The founder of PAF, Nancy Davenport-Ennis, personally became involved in legislative reform when she discovered her dear friend was battling both breast cancer and her insurance company. This motivated Nancy to create the Virginia Task Force for Insurance Reform, which was dedicated to reforming insurance coverage for cancer patients. Nancy's friend eventually lost her battle with cancer, but this experience inspired Nancy to draw up a business plan for a nonprofit organization geared toward helping patients who face the same obstacles. Thus, the Patient Advocate Foundation was born.

What services does PAF provide to cancer patients?

No patient should have to struggle alone, so our services are customized to help those with life-threatening, debilitating or chronic diagnoses currently experiencing barriers to care. Our expert case managers work alongside the patient or caregiver to identify solutions to problems surrounding insurance, medical debt, access to prescribed care, and employment challenges.

We also have a variety of social media networks, websites and portals that support patients and connect them to information. For instance, we have an online Web chat that patients can use to contact a case manager for real-time advice. Our experts also offer free webinars featuring topics that



address common areas of confusion, and our My Resource Search phone app helps patients quickly identify local and national assistance programs.

Does PAF offer financial assistance for cancer patients?

Our Co-Pay Relief Program provides direct financial assistance for qualified patients who have insurance to help them better afford their out-of-pocket costs. Patients, providers and even the pharmacy can initiate an application at www.copays.org on behalf of a patient facing one of the covered diseases.

How else can PAF support patients?

PAF is an active contributor to the education of patients, their families and caregivers. Our employees provide referrals to appropriate educational resources, including disease-specific literature, insurance information and financial resources. Also, PAF professionals have authored 28 patient educational publications that now make up our Patient Educational Resource Library. Titles include the "Managed Care Answer Guide," "Lighting the Way: A Practical Guide to Clinical Trials," and "The Greater Understanding" series, which provides practical guides for patients who need guidance for insurance issues.

How can a patient apply for assistance?

Patients can apply for all of our services, chats and webinars at www.patientadvocate.org. We can also provide general assistance for cancer patients at 800-532-5274 or via email at help@patientadvocate.org.

Jake Owen Raborn Foundation (pediatric only)
www.jakesfoundation.org, 888-356-JAKE

Linking ARMS Program (breast cancer)
www.cancercare.org, 800-813-HOPE

National Marrow Donor Program/Marrow Foundation Patient Assistance Program
www.marrow.org, 800-507-5427

Patient Access Network Foundation
www.panfoundation.org

Patient Advocate Foundation
www.patientadvocate.org, 800-532-5274

Sarcoma Alliance
www.sarcomaalliance.org, 415-381-7236

UnitedHealthcare Children's Foundation
www.uhccf.org, 952-992-4459

PRESCRIPTION EXPENSES

The CHAIN Fund Inc.
www.thechainfund.com, 203-530-3439

Children's Leukemia Research Association
www.childrensleukemia.org, 516-222-1944

Chronic Disease Fund
www.cdfund.org, 877-968-7233

Foundation for Health Coverage Education
www.coverageforall.org

HealthWell Foundation
www.healthwellfoundation.org, 800-675-8416

National Organization for Rare Disorders
www.rarediseases.org, 800-999-6673

NeedyMeds (links to assistance programs)
www.needymeds.org

Partnership for Prescription Assistance
www.pparx.org, 888-4PPA-NOW

Patient Access Network Foundation
www.panfoundation.org, 866-316-PANF

Patient Advocate Foundation Co-Pay Relief
www.copays.org, 866-512-3861

Patient Services Inc.
www.patientservicesinc.org, 800-366-7741

RxAssist
www.rxassist.org

RxHope
www.rxhope.com, 877-267-0517

Together Rx Access
www.togetherrxaccess.com, 800-444-4106

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

Allos Therapeutics Inc.
www.getasapinfo.com, 877-272-7102

Amgen Inc.
www.amgenassist.com, 888-427-7478

AstraZeneca
www.astrazeneca-us.com/help-affording-your-medicines, 800-292-6363

Bayer Healthcare Pharmaceuticals
866-575-5002

Boehringer Ingelheim
http://us.boehringer-ingelheim.com, 800-556-8317

Bristol-Myers Squibb
www.bms.com/products/pages/programs.aspx, 800-861-0048; Indigent Patient Assistance Program, 800-736-0003

Celgene
www.celgenepatientsupport.com, 800-931-8691

Centocor Ortho Biotech Inc.
888-222-3771

Dendreon
www.provengereimbursement.com, 877-336-3736

Eisai Inc.
www.eisaireimbursement.com, 866-613-4724

Genentech Inc.
www.gene.com/patients/patient-access, 888-249-4918

Genomic Health Inc.
www.oncotypedx.com/en-us/breast/patientscaregiversinvasive/insurance/insurance, 866-662-6897

Genzyme Corporation
www.genzyme.com/patients/patient-support-services.aspx, 800-745-4447

GlaxoSmithKline
www.gsk-access.com, 866-475-3678

ICI Pharmaceutical Novaldex (provides tamoxifen to patients with financial need)
800-456-5678

Johnson & Johnson Patient Assistance
www.jjpac.org, 800-652-6227

Lilly USA LLC
www.lillypatientone.com, 866-472-8663

Merck & Co.
www.merck.com/merckhelps, 800-727-5400

Millennium Pharmaceuticals Inc.
www.velcade.com/payingfortreatment.aspx, 866-835-2233

Novartis Pharmaceuticals
www.patientassistancenow.com, 800-245-5356

Pfizer Inc.
www.pfizerhelpfulanswers.com/pages/misc/default.aspx, 866-706-2400

Sanofi-Aventis
www.visitsponline.com, 888-847-4877

Searle Pharmaceutical Company
800-542-2526

TEVA Oncology
www.tevaco.com, 888-587-3262

RETREATS

Women Beyond Cancer
www.womenbeyondcancer.org

TRANSPORTATION & TRAVEL RESOURCES

The Air Care Alliance
www.aircareall.org, 888-260-9707

Air Charity Network
www.aircharitynetwork.org, 877-621-7177

American Cancer Society (Road to Recovery)
www.cancer.org, 800-ACS-2345

Angel Airline Samaritans
www.angelairlinesamaritans.org, 800-296-1217

Angel Airlines for Cancer Patients
www.angelairlinesforcancerpatients.org, 800-296-1217

Angel Flight Central
www.angelflightcentral.org, 866-569-9464

Corporate Angel Network
www.corpangelnetwork.org, 866-328-1313

Hospitality Homes
www.hosp.org, 888-595-4678

Lifeline Pilots
www.lifelinepilots.org, 800-822-7972

LIVESTRONG Foundation
www.livestrong.org

Mercy Medical Airlift
www.mercymedical.org, 888-675-1405

Miracle Flights For Kids
www.miracleflights.org, 800-FLY-1711

National Patient Travel Center
www.patienttravel.org, 800-296-1217

Operation Liftoff
www.operationliftoff.com

Patient AirLift Services
www.palservices.org

Veterans Airlift Command
www.veteransairlift.org, 952-582-2911

WISH FULFILLMENT

A Special Wish Foundation Inc.
www.spwish.org

Bear Necessities Pediatric Cancer Foundation
www.bearnecessities.org

Believe in Tomorrow National Children's Foundation (respite housing)
www.believetomorrow.org

Chef David's Kids
www.chefdavidskids.com

Children's Wish Foundation International Inc.
www.childrenswish.org

Clayton Dabney Foundation
www.claytondabney.org

Dream Factory
www.dreamfactoryinc.com

Dream Foundation
www.dreamfoundation.org

Family Village (links to wish-granting organizations)
www.familyvillage.wisc.edu/general/wish-grant-orgs.html

Give Kids The World
www.gktw.org

Her Heart's Wish
http://charity.lovetoknow.com/wish_granting_charities_for_adults

HopeKids
www.hopekids.org

Kids Wish Network
www.kidswishnetwork.com

Make-A-Wish Foundation
www.wish.org

Memories of Love
www.memoriesoflove.org

National Children's Leukemia Foundation
www.leukemiafoundation.org

Starlight Children's Foundation
www.starlight.org

Sunshine Foundation
www.sunshinefoundation.org

Western Wishes Foundation
www.westernwishes.org

Wishing Well Foundation USA Inc.
www.wishingwellusa.org



Navigating the financial aspects of cancer treatment can be challenging. We want to help.

PatientOne
1-866-4PatOne

Medication Access Support.

If you are facing financial obstacles associated with your cancer therapy, you may need support. The Lilly PatientOne program may help address financial and coverage issues for qualified uninsured, underinsured, and insured patients who are prescribed eligible Lilly Oncology products. It's the kind of support that may make access to medication easier, helping you focus on your treatment.

To learn more, visit www.LillyPatientOne.com or call **1-866-4-PatOne (1-866-472-8663)**.

Hotline Support | Reimbursement Assistance | Patient Assistance

Oncology