

# Managing the Cost of Cancer

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Founded in 1944, CancerCare® is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include case management, counseling and support groups over the phone, online and in person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by master's-prepared oncology social workers.

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CancerCare®  
National Office  
275 Seventh Avenue  
New York, NY 10001

Toll-free 800-813-HOPE (4673)  
Fax 212-712-8495  
Email [info@cancercare.org](mailto:info@cancercare.org)  
Web [www.cancercare.org](http://www.cancercare.org)

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# Managing the Cost of Cancer

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## EDITOR

### **Leonard Saltz, MD**

*Medical Oncologist, Memorial Sloan Kettering Cancer Center,  
Professor of Medicine, Weill Cornell Medical College*

*Cancer is a very expensive illness. Even with health insurance, many people are financially unprepared for the out-of-pocket expenses associated with their medical care.*

This booklet will help you better understand health care insurance and provide you with the tools you need to cope with the cost of cancer.

Out-of-pocket expenses for people being treated for cancer fall into three general categories:

**Direct medical costs.** Doctors' fees, hospital charges and medication costs may or may not be covered, even if you have health insurance. For example, many people find that their insurance provides only limited coverage for prescription drugs.

**Related costs.** The costs of home care, transportation to and from treatment, over-the-counter medications and medical supplies can add up, and are often not covered by health insurance.

**Daily living expenses.** Costs for food, child care, housing, utilities and other daily living expenses may suddenly become difficult to pay if a person with cancer stops working.

# Getting Organized

Being organized can give you a greater sense of control over your life and priorities, including financial matters. Here are some tips to help you get and stay organized.

**Understand your coverage.** If you have health insurance, read your policy carefully to understand the terms of your contract. See the “Understanding Your Health Insurance” section of this booklet for additional information.

**Keep track of important papers.** Many people find it helpful to keep their records and paperwork in one place for easy reference. Important documents include:

- Copies of medical records
- Prescription medication information
- Health insurance records
- Disability insurance
- Long-term care insurance
- Veterans benefits

**Keep a diary of your medical expenses and any communications related to your finances.** This will help you anticipate and prepare for expenses related to your treatment, and can be useful if you need to dispute a charge. On a related note, determine which bills must be paid immediately, which can be delayed and those for which you can arrange a payment plan.

**Learn what you may be entitled to.** There are government programs called entitlements that provide financial and other help to people in certain groups, such as those with cancer. A hospital or community social worker can direct you to the governmental agencies that oversee these programs.

# Understanding Your Health Insurance

Your insurance policy outlines your benefits and any coverage limits. Additionally, you will likely be given a summary plan description (sometimes called a certificate of coverage) which will outline the provisions of your policy in clear terms. If you don't receive a summary plan description, you can request it from your insurance provider.

Here are some of the most important policy provisions for you to understand (and to ask questions about as needed):

- The medical procedures and expenses that are covered
- Your deductible amount
- The services that require a co-payment and/or the payment of co-insurance
- The plan's pre-authorization requirements
- The company's appeal process should a claim be denied
- Coverage provided for a second opinion
- The need for a referral to see a health care provider other than your primary care doctor
- How to find in-network health care providers
- The fertility preservation options available within your plan
- Coverage provided related to travel and lodging
- Coverage provided for the costs of a clinical trial
- The availability of a Patient Navigator if needed



# Health Insurance Terms

**Claim:** A claim is a bill from your health care provider (e.g., doctor or hospital). Your health care provider sends a claim to your insurer to be reimbursed.

**COBRA (The Consolidated Omnibus Budget Reconciliation Act):** COBRA is a law that lets you keep your insurance for at least 18 months after leaving employment. You pay the full cost of the premium plus an administrative fee.

**Co-insurance:** The percentage of a medical charge you are expected to pay after your deductible has been met. For example, if you have a 30% co-insurance, you would pay 30% of a given medical bill while your health insurance would cover 70%.

**Co-payment (Co-pay):** The fixed out-of-pocket cost you are expected to pay upfront for your health care services. The amount can vary depending on the type of health care service. Some health care services may require you to pay co-insurance in addition to a co-payment.

**Deductible:** This is the amount of money you are expected to pay out-of-pocket towards your health care each year, before your health care insurer pays.

**Denial:** When an insurance company denies payment for a treatment or procedure.



**Flexible Spending Account (FSA):** A financial tool that allows you to put pre-tax money from your paycheck into a designated account to pay for certain medical expenses, such as co-pays. You decide how much money per paycheck goes into your FSA account. It's important to estimate your yearly medical expense that would qualify for payment from the FSA, because the funds typically do not carry over from year to year. Talk with your employer to learn about the options available to you.

**Health Insurance Portability and Accountability Act (HIPAA):** HIPAA gives you the right to control who receives information contained in your medical records. You will be given HIPAA forms to read and sign the first time you visit a health care professional or are admitted to a hospital. Signing these forms verifies that you know your rights to control your medical information.

**Insurance Broker:** A person, not employed by an insurance company, that finds the best policy for someone who wants insurance.

**Network:** A network is a large group of health care professionals, pharmacies and hospitals that are selected and preferred by an insurance company to provide care.

**Network Provider (In-Network Provider):** The insurer selects health care professionals or hospitals to be a part of their insurance plan or network. These preferred health care providers or institutions generally result in lower costs to the insured person than out-of-network providers.

**Out-of-Network or Non-Network Provider:** Health care professionals or hospitals not a part of a health care provider's insurance coverage. Going out-of-network generally results in higher costs to the insured person.

**Patient Navigator:** Navigators provide guidance through the health care system and help with any issues, challenges or barriers. They may offer practical assistance with financial support, transportation and child care. In addition, they may assist in coordinating care with other health care team members.

**Pre-authorization:** Some insurance policies require that major medical procedures, including radiology procedures such as PET scans and MRIs, be pre-authorized by the insurance carrier.

**Premium:** A premium is the monthly fee paid to an insurer for health insurance coverage.

**Provider:** A provider is a health care professional (doctor, nurse, surgeon, etc.) or institution (hospital) that provides care.

**Referral:** A written order from your primary care doctor for you to see a specialist or receive certain medical services.



## ***If you do not have health insurance***

Being diagnosed with cancer without having health insurance can bring challenges that are stressful and emotionally difficult. There are avenues you can pursue to potentially obtain health insurance.

- **Your place of employment.** Talk to a representative from your human resources department about employer-offered health benefits that you may be eligible for.
- **Your spouse or domestic partner's plan.** If your spouse or domestic partner has a job that offers health insurance, find out if you're eligible to be covered.
- **COBRA.** If you have left a job recently and were covered by an employer's health insurance, you may be able to continue your coverage under COBRA (the Consolidated Omnibus Budget Reconciliation Act). This law requires employers to make health insurance coverage available through their plan to former employees for a minimum of 18 months after employment has ended. Beneficiaries are required to pay the premiums plus an additional administrative fee. Visit the U.S. Department of Labor website ([www.dol.gov](http://www.dol.gov)) to learn if you are eligible.
- **Your school.** If you are currently a full-time or part-time student, check with your college or university to see if they offer coverage.
- **Purchase it on your own.** You can contact an insurance broker, or visit [www.healthcare.gov](http://www.healthcare.gov) to find the Health Insurance Marketplace in your state.

- **Medicare and Medicaid.** Medicare is a government-provided health care plan for people 65 and older and those who have been receiving Social Security Disability Insurance benefits for a minimum period of two years. Medicaid provides health care services for people whose income falls under a certain level. Contact the Centers for Medicare and Medicaid Services (CMS) at 877-267-2323 or visit [www.cms.hhs.gov](http://www.cms.hhs.gov) to find out whether you are eligible for either of these programs.
- **Social Security.** Social Security Disability Insurance or Supplemental Security Income may be able to help with the cost of health insurance. For eligibility requirements, call 800-772-1213 or visit [www.socialsecurity.gov/disability/](http://www.socialsecurity.gov/disability/).



# Managing Expenses

Whether or not you have health insurance, here are a few things you can do to help manage your expenses.

- **Double check all bills and EOBs (explanation of benefits).** You'd be surprised how often billing mistakes are made. If you don't receive an itemized bill, ask for one. Look for incorrect dates of service (for instance, you shouldn't be billed for the room on the day you were discharged) and fees billed more than once for the same test or procedure.
- **Speak to a financial counselor in the hospital's business office.** The hospital may be able to set up a payment plan for the bills you have received. They may also be willing to consider any insurance payments to be "payment in full." Some hospitals have funds to offset medical services that aren't fully covered by insurance.
- **Negotiate payment plans** for your non-medical monthly bills with your utility company, phone provider and other creditors.
- **Seek out help from nonprofit organizations** such as the Patient Advocate Foundation (800-532-5274) or [www.patientadvocate.org](http://www.patientadvocate.org). You can also contact CancerCare to speak with a professional oncology social worker who can help you explore your options and find appropriate resources.
- **Utilize available programs.** For many people, expensive cancer medicines pose a financial challenge. Fortunately, there are many programs to help individuals get medications for free or at a low cost, some of which are made available by the pharmaceutical company that manufactures the drug. For more information, contact the Medicine Assistance Tool, listed in the Resources section of this booklet.

# CancerCare's Free Support Services and Programs

**It can be very difficult to receive a diagnosis of cancer, and adjusting to the necessary changes in your life can be challenging.**

CancerCare can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system, and offer information on support groups and other resources.



## Frequently Asked Questions

**Q: I am continuing to work through my cancer treatments. Are there workplace-related laws that I should be aware of?**

A: There are a number of laws that serve to protect your rights in the workplace.

**The Americans with Disability Act (ADA).** The ADA prohibits discrimination against people with disabilities. Employers with 15 or more employees must follow ADA guidelines. To qualify for ADA protection, you must:

- Meet the ADA definition of a “disabled person”
- Be able to perform the essential functions of the job
- Not pose a risk to your own or others’ health and safety
- Not cause “undue hardship” to your employer for any accommodations you might need

Here are some of the most common accommodation options under the ADA:

- Flexible work hours to meet treatment schedules and medical appointments
- Periodic breaks or a private area to rest or to take medication
- Approval to work at home
- Modification of office temperature
- Reallocation or redistribution of marginal tasks to another employee

Although the ADA does not require that an employee disclose a specific diagnosis, informing your employer that you have cancer may be necessary when requesting a reasonable accommodation. Be aware that employers have the right to offer alternative accommodations; the law requires an “interactive process” of discussion.

If you are seeking employment, you have the following rights under the ADA laws:

- Prior to making a job offer, an employer cannot ask if a job applicant has or had cancer or ask about their treatment related to cancer.
- An applicant does not have to tell an employer that they have or had cancer before accepting a job offer.
- An employer cannot ask any follow-up questions if an applicant voluntarily tells the employer that they have or had cancer. (An exception: the employer may ask the applicant to confirm their ability to perform the essential functions of the job. Employers are also permitted to ask applicants to describe or demonstrate how they would perform a job task.)

Most states have passed anti-discrimination laws that provide expanded protections.

For more information, call 1-800-514-0301 or visit the ADA website at [www.ada.gov](http://www.ada.gov).

**The Family and Medical Leave Act (FMLA).** The FMLA enables people dealing with a serious illness to take unpaid leave for up to 12 weeks within one calendar year. The FMLA applies to employers with 50 or more employees within 75 miles. Employers must continue to provide health benefits during the leave. The FMLA also applies to certain family members of people with serious illnesses.



To qualify, the employee must have worked with their employer for at least one year. Part-time employees are covered if they worked a minimum of 1,250 hours during the year. The leave does not have to be taken all at once but can be taken in blocks of time (intermittently).

To learn more, visit the U.S. Department of Labor's website at [www.dol.gov](http://www.dol.gov) and search for FMLA.

**Equal Employment Opportunity Commission (EEOC).** The EEOC is a federal agency that enforces the provisions of the ADA and FMLA and helps people who have been discriminated against in the workplace. For more information, or if you feel you are being treated unfairly, call 1-800-669-4000 or visit [www.eeoc.gov](http://www.eeoc.gov).

**Q: Can you tell me more about Medicare and Medicaid?**

A. Here is a description of these two government programs.

**Medicare**

Medicare is a federal health insurance program for individuals 65 or over. It may also be available to individuals who have been deemed "disabled" by the Social Security Administration for two years. There are four components to Medicare. It's important to know what coverage is provided in each component to receive the best care.

**Part A** covers certain inpatient hospitalization, hospice care and limited home care services. When an individual becomes eligible for Medicare, Part A is typically available with no monthly cost. If you have paid Medicare taxes while working, Part A doesn't require any premium.

**Part B** covers outpatient services like doctor's visits and preventive services. Part B includes a deductible that may change year to year.

**Part C** (also known as Medicare Advantage) offers private health plans and can be useful for those looking for all-in-one medical and drug coverage. However, some Medicare Advantage HMOs restrict which doctors and hospitals you can use. These plans must offer at least the same benefits as other parts of Medicare that are available but have different rules, costs and coverage restrictions.

**Part D** (also known as Medicare Prescription Drug Plan) covers outpatient prescription drugs.

Even with Medicare A and B there are still “gaps” in coverage. Most people with health insurance through Medicare choose to purchase a Medicare Supplement plan, available from many insurance companies or through an insurance broker.

## **Medicaid**

Medicaid provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults and people with disabilities. Medicaid is administered by states in accordance with federal requirements. The program is funded jointly by states and the federal government.

## **Q: Can you share guidance on communicating with my health care team?**

A. Often, people are uncomfortable talking to their health care team about the cost of treatment. However, these are conversations that your health care team are very accustomed to, and can help ensure that you have access to the treatments you need. Physicians and insurance providers can sometimes work together to find ways to reduce the cost of treatment without reducing the quality of the care you receive.

The following is general guidance on communicating with your health care team.

As you manage your cancer, it's important to remember that you are a consumer of health care. The best way to make decisions about health care is to educate yourself about your diagnosis and get to know the members of your health care team, including doctors, nurses, nurse practitioners, physician assistants, dietitians, social workers and patient navigators.

**Start a health care journal.** Having a health care journal or notebook (either on paper or in a digital format) will allow you to keep all of your health information in one place. You may want to write down the names and contact information of the members of your health care team, as well as any questions for your doctor.

**Prepare a list of questions.** Before your next medical appointment, write down your questions and concerns. Because your doctor may have limited time, ask your most important questions first and be as specific as possible.



**Bring someone with you to your appointments or have them be present during telehealth sessions.** Even if you have a journal and a prepared list of questions or concerns, it's always helpful to have support during your appointments. The other person may also think of questions to ask your doctor or remember details about your symptoms or treatment that you may have forgotten.

**Write down your doctor's answers.** Taking notes will help you remember your doctor's responses, advice and instructions. You can also ask the person who accompanies you to take notes for you, either in your journal or on a tablet or smartphone.

**Record your visit if your doctor allows it.** Recording the conversation with your doctor gives you a chance to hear specific information again or share it with family members or friends. Incorporate other health care professionals into your team. Your medical oncologist is an essential member of your health care team, but there are other health care professionals who can help you manage your diagnosis and treatment:

- Your primary care physician should be kept updated about your cancer treatment and any test results.
- Your local pharmacist is a great source of knowledge about the medications you are taking. Have all of your prescriptions filled at the same pharmacy to avoid the possibility of harmful drug interactions.
- Make sure your oncologist knows of any other medical conditions you have or any pain you are experiencing so that they can consult with your primary care physician or specialists as needed.

Remember, there is no such thing as over-communication.

# Notes



# Resources

## **CancerCare®**

800-813-HOPE (800-813-4673)  
[www.cancercares.org](http://www.cancercares.org)

## **American Cancer Society**

800-227-2345  
Survivorship: During and  
After Treatment  
[https://www.cancer.org/  
treatment/survivorship-during-  
and-after-treatment.html/  
behealthyaftertreatment.html](https://www.cancer.org/treatment/survivorship-during-and-after-treatment.html/behealthyaftertreatment.html)

## **Cancer.Net**

Survivorship information from  
the American Society of Clinical  
Oncology  
[www.cancer.net/patient/survivorship](http://www.cancer.net/patient/survivorship)

## **FINANCIAL AND OTHER ASSISTANCE**

### **Cancer Financial Assistance Coalition**

[www.cancerfac.org](http://www.cancerfac.org)

### **Medicine Assistance Tool**

[www.medicineassistancetool.org](http://www.medicineassistancetool.org)

### **Patient Advocacy Foundation**

[www.patientadvocate.org](http://www.patientadvocate.org)

## **National Cancer Institute**

800-422-6237  
[www.cancer.gov/about-cancer/  
coping/survivorship](http://www.cancer.gov/about-cancer/coping/survivorship)

## **Cancer Support Community**

888-793-9355  
[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

## **Kaiser Family Foundation**

[www.kff.org/understanding-health-  
insurance/](http://www.kff.org/understanding-health-insurance/)

## **GOVERNMENT WEBSITES**

### **For information on COBRA**

U.S. Department of Labor  
[www.dol.gov](http://www.dol.gov)

### **To find the Health Insurance Marketplace in your state**

[HealthCare.gov](http://HealthCare.gov)  
[www.healthcare.gov](http://www.healthcare.gov)

### **For information about Medicare**

[www.medicare.gov](http://www.medicare.gov)

### **For information about Medicaid**

[www.medicaid.gov](http://www.medicaid.gov)

### **For information about Social Security programs**

[www.socialsecurity.gov](http://www.socialsecurity.gov)

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