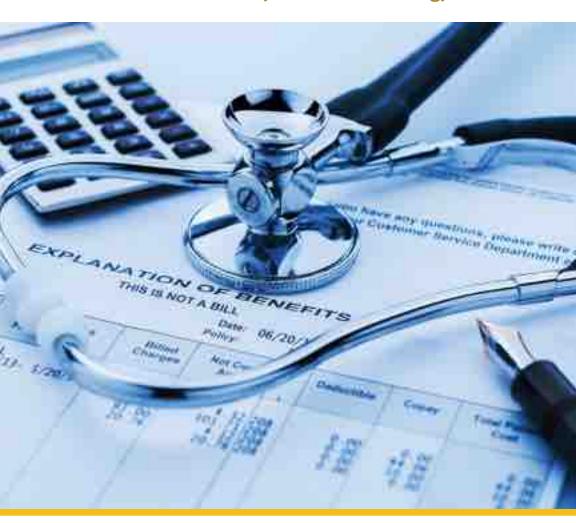
ASCO answers

Managing the Cost of Cancer Care

Guidance and Resources for Patients and Families from the American Society of Clinical Oncology



Cancer.Net

ASCO Cancer.Net

ABOUT ASCO

Founded in 1964, the American Society of Clinical Oncology, Inc. (ASCO®) is committed to making a world of difference in cancer care. As the world's leading organization of its kind, ASCO represents nearly 45,000 oncology professionals who care for people living wizth cancer. Through research, education, and promotion of the highest-quality patient care, ASCO works to conquer cancer and create a world where cancer is prevented or cured, and every survivor is healthy.

ASCO furthers its mission through Cancer. Net and Conquer Cancer, the ASCO Foundation.

Cancer.Net (www.cancer.net) brings the expertise and resources of ASCO to people living with cancer and those who care for and about them. All the information and content on Cancer.Net is developed and approved by members of ASCO, making Cancer.Net an up-to-date and trusted resource for cancer information.

Conquer Cancer (www.conquer.org) funds research into every facet of cancer to benefit every patient, everywhere. Conquer Cancer helps turn science into a sigh of relief for patients around the world by supporting groundbreaking research and education across cancer's full continuum.

Learn more at www.ASCO.org. Follow us on Facebook, Twitter, LinkedIn, and YouTube.

MILLIONS OF PEOPLE RELY ON CANCER.NET FOR:

- Information on 120+ cancer types
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MANAGING THE COST OF CANCER CARE

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ASCO ANSWERS is a collection of oncologist-approved patient education materials developed by ASCO for people with cancer and their caregivers.

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INTRODUCTION

Having cancer can be expensive. You might have unexpected expenses in addition to the cost of treatment. These can be a source of stress and anxiety for you and your family.

These unexpected costs might even keep you from completing your cancer treatment. This increases your health risks and may lead to higher costs in the future.

In this booklet, you will learn how to:

- Find out the medical costs and other costs of cancer care
- Talk with your health care team about managing or lowering these costs
- Find information and resources to help you plan for costs before, during, and after cancer treatment

Making a financial plan can help you lower your stress and focus on your health and well-being.

Understanding the Costs of Cancer Care

Your personal costs will depend on several factors.

- The type of cancer treatment you have
- How long you need treatment
- Where you get treatment
- Your health insurance
- Whether you have other insurance that pays what health insurance does not

Medical Costs and Hidden Costs

Some costs are more obvious than others. For example, you might think about how much a medicine costs with your insurance. But you also need to consider the hidden expenses of cancer. These are the expenses that go up because you have cancer and need treatment. You may also need to work less, so you earn less money.

Categories of Medical and Other Costs

Consider these categories to help you adjust your budget appropriately.

Doctor appointments. This includes payments for care you receive at each doctor visit. Your insurance provider usually requires you to pay a co-payment, or co-pay, at each appointment. The insurance company sets the co-pay amount, not the doctor. You may also have to pay for each laboratory test, such as a blood or urine test, imaging scan, or other procedures.

What Is Financial Toxicity?

Financial toxicity is a term for financial hardship related to a medical condition and treatment. If you experience financial toxicity, you might:

- Have difficulty paying bills or supporting your family because of cancer or medical bills
- Not be able to afford your medications or other treatment, even if you have insurance
- Go into debt to pay bills and treatment costs, or take many years to pay off the bills from your cancer treatment

Where to Get Help

Doctors, hospitals, and other health organizations are more aware of financial toxicity. Many want to help and will work with you to manage the cost of cancer care.

To start, contact your insurance company and learn what you will need to pay for your cancer care. Even if insurance pays, you will probably need to pay something for each bill, and you might need to pay all the bills until they reach a certain amount (this is called your deductible). Your doctor and other health care team members can help you give the insurance company specific information.

Also, ask your doctor if you will need to miss work for cancer treatments or side effects. Ask your employer about medical leave and other options if you must miss work. A social worker or financial counselor can help you learn your legal rights about taking leave from work.

Financial toxicity is real. It can cause mental, emotional, and physical problems. It can keep you from getting your full cancer treatment and cause stress that slows down your recovery. If you have any concerns about cost, start talking with your health care team, insurance company, and employer.

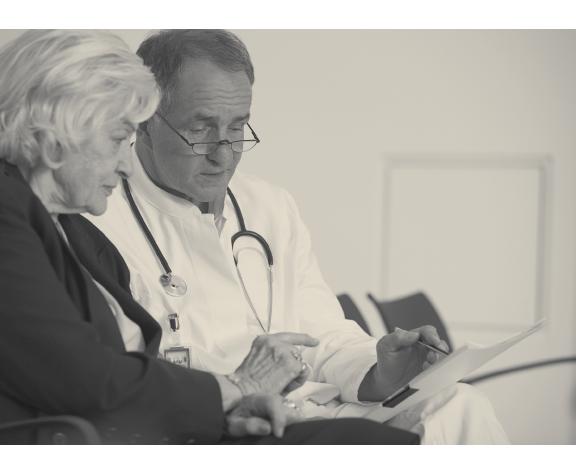
Cancer treatment. This includes payments for care you receive during your cancer treatment, such as each radiation therapy or chemotherapy visit. If you are in a clinical trial, you might have other factors to consider. How long treatment takes is different from person to person. Ask how often and how long you may have treatment costs.

Medication. This includes payments for medicines prescribed during your treatment period. These can include chemotherapy, targeted therapy, immunotherapy, or medicines to help with side effects.

Transportation and travel. These costs depend on where you receive treatment and how you get there. Examples include gas, tolls, parking, taxis, bus or train fares, and airplane fares. If you receive treatment far from home, you may also need to pay for a place to stay.

Family and living expenses. This category includes the expenses of running your household and caring for your family during cancer treatment. For example, you may need child care, elder care, help with household tasks like cleaning, or counseling.

Caregiving, at-home care, and long-term care. This includes extra care that you may need. For example:



- Hiring someone to make meals or take you to and from appointments
- Staying at a nursing care facility
- Hiring a home health aide

Employment, legal, and financial issues. This includes the costs of professional help with employment, legal, or financial issues. Professionals may help with:

- Coping with a loss of wages by the patient or caregiver
- Learning about employment rights under the law
- Writing a will or advance medical directives
- Figuring out medical expenses for income taxes

You may be able to subtract some of your medical expenses from your income on your taxes. These are usually expenses that insurance does not cover, such as the cost of miles you drive to and from appointments, some costs of prescription drugs, and even the cost of meals if you stay at the hospital or doctor's office for a long time. Subtracting these from your income is called a "deduction." It lowers your total income so you may pay less federal income tax. Talk to an accountant or other tax advisor to learn if this is an option for you.

Finding Help with the Costs of Cancer Care

Talk with members of your health care team about managing or lowering the costs of care. You can talk with:

- Oncology (cancer) financial counselors
- Oncology social workers
- Case managers
- Oncology nurses
- Your doctor

These people can tell you about support services and financial resources. Consider talking with someone from your doctor's office or health insurance company to learn more about the cost of your care. Family members and friends can also help you manage your finances.

For help with financial challenges, learn about services available from national and local organizations on page 20 or online at **www.cancer.net/financial**. If your finances cause you a great deal of stress, speaking with a counselor may be helpful. Visit **www.cancer.net/support** for more information.

HEALTH INSURANCE

In the United States, you usually need health insurance to receive health care. This includes insurance to cover or offset the costs of cancer care.

Most people get health insurance through their employer or through a government program such as Medicare or Medicaid. If not, you may also buy your own insurance. Visit **www.HealthCare.gov** or call 800-318-2596 to learn more (the number for people with hearing problems is 855-889-4325). The main federal law about health insurance is called the Patient Protection and Affordable Care Act, also called the ACA.

Your medical costs depend on the type of insurance you have. The information below describes the main types. For many types of insurance, you pay a set fee each time you see a doctor. This is called a co-payment or co-pay. You can learn more about many health insurance terms in the cost and insurance dictionary on page 24.

Private Health Insurance

There are different types of private insurance plans. Two common ones are health maintenance organizations, or HMOs, and preferred provider organizations, or PPOs.

HMO. This type of private insurance has a network of specific health care providers. You choose a primary care doctor or other health care provider in your network. That person will make many medical decisions about your care, such as whether you need to see a specialist.

HMOs often have the lowest costs for private health insurance. But they limit what they will pay in these ways:

- You have fewer choices of doctors and hospitals. Your HMO only pays for doctors and hospitals that are members of their network. They might make an exception for emergencies or care you need that they do not provide. Many HMOs allow you to visit doctors outside the plan for a higher fee (called "out-of-network" care).
- You need permission, called a referral, from your primary care doctor to see a specialist.
- You may need the HMO's approval before non-emergency hospital visits and some care from specialists. You might also need to contact your HMO within 24 hours of getting any emergency care. If not, they may not pay the cost.
- Your HMO may not cover all types of services.

PPO. This type of private insurance has a group of health care providers who provide care for less than they charge people without insurance. The providers include doctors, other

health care professionals, and hospitals. PPOs usually have more in-network doctors than HMOs. PPO health plans are typically more expensive than plans using an HMO.

Most medical costs are covered when you visit a doctor in your PPO network. You may see any doctor without a referral. But you may pay much more of the bill if you see a doctor who is not in your PPO's network.

Your PPO might have the following limits:

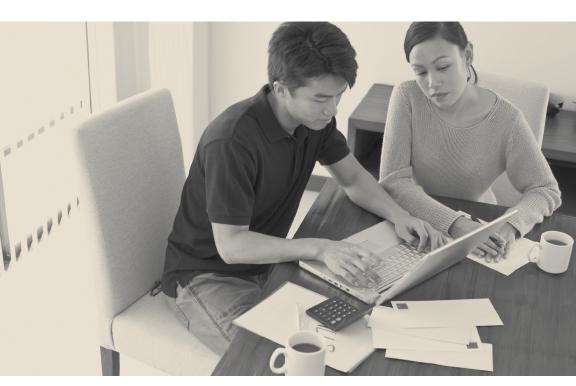
- You may need to get approval from your primary care doctor, called precertification, for some types of care. This is more likely if you are getting out-of-network care.
- Some types of services may not be covered.

Government Insurance Programs

Medicare

Medicare is the federal health insurance program in the United States. It covers people 65 and older and some disabled Americans. It has different parts.

- Medicare Part A covers inpatient care (such as hospital care), skilled nursing care, hospice care, and some home care services.
- Medicare Part B covers physician services, outpatient care, physical and occupational therapy, many cancer drugs given in medical offices and clinics, and some medical



- supplies. You are not required to have Medicare Part B. But if you do not get it when you first get Medicare, you might have to pay a late fee to get it later.
- Medicare Part C allows certain hospitals, doctors, and centers to provide your Part A and B benefits. If you have Part C, you would go to those places for your care. Part C is also called Medicare Advantage. Medicare Advantage plans sometimes include benefits for prescription drugs.
- Medicare Part D covers prescription drugs. You are not required to have it. If you do, it may pay for prescription medications that Part A and Part B do not.

Medicare does not cover all health care costs. So you might consider getting private health insurance to help with expenses that Medicare does not pay for. For example, this insurance can help you pay co-payments and other expenses. These insurance policies are sometimes called "Medigap" policies.

Medicaid

The federal and state governments both fund Medicaid. Each state has its own Medicaid program. So it depends on your state if you qualify and what services Medicaid provides.

Medicaid traditionally covers people who have a low income and are older or have a disability. It may also cover some people in families with children under 18. Some states chose to expand Medicaid under the ACA. These states may cover care for other adults with low incomes.

How Insurance Works

It is important to understand an insurance plan's specific benefits and limitations. These examples show how co-pays, co-insurance, and deductibles work in general. You should also talk with someone at your health insurance company. They can explain the details of your plan.

Example 1: Co-pays

Anna needs to see 2 specialists this week. Dr. Martinez charges \$100 per visit. Meanwhile, Dr. Jones charges \$500 per visit. Anna's insurance requires her to pay a \$20 co-pay to visit a specialist. How much will she need to pay at each appointment?

Answer: Anna's out-of-pocket costs will be \$20 for each appointment. That is a total of \$40. Co-pays are a set amount. This means Anna's payment does not depend on the total bill amount.

Find more information about Medicare and Medicaid at **www.cms.gov** and **www.medicare.gov**. Visit **www.HealthCare.gov** for information about Medicare and Medicaid under the ACA.

Example 2: Co-insurance

Martin needs to see 2 specialists this week. Dr. Andrews charges \$100 per visit. Meanwhile, Dr. Lee charges \$500 per visit. Martin's insurance requires a 20% co-insurance for specialist visits. How much will the doctors charge him for the appointments?

Answer: Martin will pay Dr. Andrews \$20. He will pay Dr. Lee \$100. A co-insurance payment is calculated by multiplying each bill by the co-insurance percentage. It is not a set amount like a co-pay.

- Dr. Andrews will charge Martin \$20 because 20 percent of 100 dollars is 20 dollars.
- Dr. Adams will charge Martin \$100 because 20 percent of 500 dollars is 100 dollars.

Example 3: Co-insurance and deductibles

Jasmine has a deductible of \$2,000 a year. She has not had any medical expenses yet this year. Her co-insurance for a hospital visit is 20%. She recently had a surgery that cost \$10,000. How much will she need to pay?

Answer: Jasmine will pay \$3,600 out of pocket for her procedure. The steps below explain how:

- **Step 1.** Subtract Jasmine's deductible amount from the total bill: 10,000 dollars minus the 2,000 dollar deductible is 8,000 dollars.
- **Step 2.** Multiply the leftover amount by the co-insurance percentage: 8,000 dollars multiplied by 20 percent is 1,600 dollars. This is Jasmine's co-insurance amount.
- **Step 3.** Add the deductible and the co-insurance amounts: 2,000 dollars plus 1,600 dollars is 3,600 dollars.

What happens if Jasmine has another identical surgery in the same year? She already paid her deductible for the year. So, she would only have the co-insurance payment. That would be \$2,000 because 10,000 dollars multiplied by 20 percent is 2,000 dollars.

Other Types of Insurance

Health insurance covers some costs of cancer care. But one plan does not usually cover all the costs. Other types of insurance are available to cover additional expenses. Prices for each type of insurance vary based on several factors.

Supplemental insurance. This insurance helps cover expenses your main insurance does not cover. Or it may cover the costs you pay as part of your existing plan. These include deductibles, co-insurance, co-payments, and other out-of-pocket expenses. Check the cost and insurance dictionary on page 24 if you are not certain what these terms mean. Supplemental insurance may also offer other benefits. For example, it might pay if you lose money because you cannot work.

Disability insurance. This replaces income you lose if your health keeps you from working. It pays if you have a long-term illness or injury. Employers and government programs are the main providers of disability insurance. But you can also buy a policy on your own before you get sick or hurt.

Hospital insurance. This provides limited coverage for hospital stays. It usually pays a fixed amount each day for a certain number of days. You might buy this type of insurance if your main insurance has a limit on what they pay for hospital care.

Long-term care insurance. This covers the costs of long-term care, such as nursing home care. You might decide to buy this because most private insurance and Medicare plans only pay a limited amount for long-term care.

If You Do Not Have Health Insurance

Under the rules of the ACA, you may buy insurance from the U.S. government's health insurance marketplace or from an independent broker (person who sells insurance). You can find a plan for yourself, your family, or your small business.

You can get help paying for insurance if you earn less than a certain amount of money. You can learn if you qualify for help at **www.HealthCare.gov**. You might also qualify for Medicaid from your state.

Health Care and the Law

The ACA made some rules for health insurance companies. These rules say that insurance companies:

May not refuse to sell you insurance because you had a health condition in the past, or refuse to pay for a condition you had before you got the insurance. Companies call a health condition you had in the past a "preexisting condition." The law says they must pay for it unless they meet a special rule.



- May not charge you more because you are female, male, or have a specific health condition, such as cancer.
- May not limit the amount they pay in your lifetime. In the past, insurance companies were allowed to stop paying after a certain amount. Now they must keep paying, even if you need a lot of care, such as cancer care.
- May not stop paying its part of your bills. They must pay their part unless you or someone else tries to cheat the insurance company.
- May not cancel your insurance if they find a mistake in your application.

Insurance companies must:

- Give you benefits in 90 days or less if you join a group insurance plan, such as your work plan.
- Allow your children to use your health insurance until age 26, if they are covered by your plan.

■ You pay nothing for some tests and services

Some tests and services can lower your cancer risk. So the ACA says insurance companies must pay for them. The U.S. Preventive Services Task Force recommends these services. They include:

- Colorectal cancer screening tests if you are age 50 to 75
- Mammograms every 1 to 2 years, if you are a woman over 40. Companies must also pay for some other services to prevent breast cancer. For example, if you have a higher



risk of breast cancer, you can talk about your risk with a genetic counselor or talk to a doctor about medication to help prevent cancer.

- Cervical cancer screening and the HPV vaccine, with some rules
- Help to stop smoking, including counseling and medication

■ If your insurance will not pay

When your insurance company says they will not pay for something, you can ask again. For example, you can write a letter. Or, your doctor might write one. This is called an appeal. The company must answer within a certain time. This is:

- > 72 hours after you send an appeal for urgent medical care
- > 30 days for non-urgent care, if you did not get it yet
- 60 days for care you already received

If the company says no, you can ask to have their decision reviewed by an independent review organization or, in some states, the federal government. This is called external review. Your insurance company must pay if the external review says so.

If You Are in a Clinical Trial

Clinical trials are research studies that involve volunteers. If your insurance started January 1, 2014, or later, your insurance company cannot limit what they pay if you are in a clinical trial. They must pay for all your routine health care related to the approved clinical trial. Also, they may not stop your insurance if you are in a clinical trial. This is called "dropping" your insurance.

The company can limit what they pay if your insurance started before January 1, 2014. It can also stop paying for your health care if you join a clinical trial.

ORGANIZING YOUR FINANCIAL INFORMATION

Keeping track of all the financial paperwork involved in your cancer care is very important to do, but it can quickly become overwhelming. Here are some ways to stay organized and take control of your information.

Keep Good Notes

Write down information about phone calls, such as calls with your insurance company. Keep notes on the date, the name of the person you talked to, and what was said. Ask your health insurance company if you can have a case manager. This way you can talk with the same person each time you call. Keep current copies of all insurance policies and include the case manager's name and phone number in any messages or letters about your insurance.

Keep track of all your medical expenses. Include what your insurance company has paid or not paid. You can keep notes on the date you received care, how much you paid, what the insurance covers, and the provider's name.

Good notes might help you claim some credit on your taxes for what you paid. Talk to a tax professional, such as an accountant, about which medical expenses qualify.

Create a Record of Your Financial Information

Financial information to save during cancer treatment includes:

- Hospital, doctor, and treatment bills.
- Insurance claims and your explanation of benefits, or EOB, which tells how much the company will pay.
- Insurance company letters to approve or deny treatment.
- Doctor's letters about why you need treatment, or notices that the insurance company authorized your treatment.
- Other receipts, such as pharmacy bills.
- Notes or recordings of conversations about finances. You might have these conversations with your doctor, someone else at the clinic or hospital, or someone from your insurance company.

Ways to Organize Your Information

You can save information by the specific date or the type of information it is. You can use:

- **Paper file folders.** You might want to put different types of papers in different colors of folders. You can put the papers in each folder in order by the date.
- **Computer spreadsheets.** You can create columns for the appointment date, doctor's name, amount you paid, insurance claim information, and other notes.
- ▶ Electronic health records. Your doctor's office may give you access to your own records through a website. Your insurance company might also have a website where you can find information, including what was paid and what you might owe.
- Apps and the cloud. You can scan paper files into a computer program or save them to a separate folder in a secure place in the internet.

Pamela's Story

Pamela was 44 when she was first diagnosed with breast cancer 4 years ago, and now she has been diagnosed with metastatic breast cancer. Pamela used to have a demanding job that required a lot of travel. Because of her treatment schedule and the side effects from the medication, Pamela decided to cut back on her hours and then ultimately leave her job. While employed, her health insurance and long-term care insurance benefits provided good coverage; however, she wasn't sure what to do about insurance after leaving her job.

With the assistance of a financial counselor at her treatment center, Pamela applied for several programs. She was approved for both Medicare and Social Security disability coverage. She is thankful her financial counselor could help her complete the paperwork needed, and she notes that the Medicare prescription drug coverage is particularly important with her ongoing medication costs.

Plan Ahead and Ask for Help

It's hard to know exactly how much cancer and its treatment will cost. But you can reduce your stress by planning ahead. Expect that your total income may be lower while you have cancer because of medical bills or time away from work. Think about using automatic bill payment for your regular monthly bills, like utilities and rent or mortgage, so you can focus on the new paperwork that you have.

You can also ask a friend or family member to help you manage your bills. They can help you adjust to a new household budget during cancer treatment. They can also help you find community groups or information to help. Ask your health care team for more financial resources. For example, talking with a social worker might help you find ways to lower your costs.

There are many online tools and mobile apps that can help you organize your finances and prepare for the expenses of cancer care. With some early planning and organizing, cancer-related bills and paperwork can be less stressful for you and your family.



QUESTIONS TO ASK ABOUT COST

Talking about your financial concerns with others is often difficult, especially if you don't know what to say. Talking with your doctor is a good place to start. Other people and groups who can help you find answers include:

- Nurses
- Social workers
- Case managers
- Financial counselors
- Patient or nurse navigators
- Patient advocacy organizations
- Your employer's human resources department
- The insurance company, especially for questions about your specific insurance coverage

To start a conversation about your finances, you might want to say: "I am worried about costs related to my cancer treatment. Can we talk about my concerns?"

Next, use the questions below to help focus the discussion. You don't need to ask all of these questions. Choose the questions that are most important to your diagnosis and your financial situation. Or you can add your own questions. Remember, you can keep having these conversations with your health care team during your treatment.

Insurance Coverage and Medical Bills

- Who handles concerns and questions about health insurance in this office or medical center?
- Will this person help me work with my health insurance company?
- Will this person help me figure out my medical bills and the codes on the bills to make sure they are correct?
- If an insurance claim is denied, who can help me file an appeal?
- Who can help me organize my expenses, keep track of incoming bills, and plan my budget?

Appointments

- How much is my co-pay for each doctor visit?
- When is this payment due?
- If I need multiple visits to a doctor's office, is there a policy where I can pay the co-pay only once or not at all (called a waiver)?
- Do you offer any payment plans?
- Will I be billed separately for tests, such as blood tests, or scans? Are these tests covered under my health insurance?
- Does my insurance cover other doctor visits, such as for a second opinion?

General Cancer Treatment Costs

- Who can help me estimate the total cost of the recommended treatment plan?
- If I cannot afford this treatment plan, can we consider other treatment options that do not cost as much?
- Does my health insurance company need to approve any or all of the treatment plan before I begin treatment?
- Do you have any financial conflicts of interest in recommending this plan for me?
- Is the treatment center you are recommending in my insurance plan's network?
- What expenses does my health insurance cover if I need to be admitted to the hospital?
- What expenses does my health insurance cover if I need to be treated as an outpatient?
- Are there ways to change my treatment schedule, if necessary, to work around my job or child care?
- Will there be a co-pay for each treatment session?
- Where can I get low-cost or free counseling or support to help me cope with my diagnosis?

Clinical Trials

- What expenses will I have if I join a clinical trial?
- What costs are already covered?
- How do the costs of the clinical trial compare with the costs of the standard treatment? Does one cost more than another?
- Can I be reimbursed for any of the costs associated with the clinical trial?

Medication Costs

- What is my prescription co-pay for this drug?
- ls this prescription a one-time cost, or will it be an ongoing expense?
- Is this medication on my health insurance plan's preferred drug list?
- Can I switch to a less expensive brand-name drug within the same drug class?
- Is there a generic drug available that will have the same effect? Is it less expensive?
- Can we regularly go over my list of medications to see if there are ways to lower my drug costs?
- For managing side effects, is there an over-the-counter medicine that has the same effect as the prescribed drug? Is it less expensive?
- Are there programs that can help cover the costs of my drug(s) for cancer treatment or side effects?

Transportation and Travel Costs

- Is there free or low-cost transportation for patients at the medical center where I will have treatment?
- Are there reduced parking rates for patients at the medical center or doctor's office?
- Is there an organization that can help me pay for transportation to and from treatments and medical appointments?
- If I am traveling a long distance, are there free or reduced-cost hotels or lodging near the treatment center?

Family and Living Costs

- If I have trouble paying for basic items, like food or heat, due to the cost of my cancer treatment, are there organizations that can help me?
- Where can I get low-cost or free child care or elder care during my treatment?
- Where can I get free or low-cost personal items, such as a wig, if needed?
- Is there an organization that can provide low-cost or free counseling or support to my family?

Other Costs for Care

Are there ways to change my treatment schedule, if necessary, to work around my caregiver's job and schedule?

- Could we talk about the costs of care if I don't have a family member or friend to go with me to appointments or care for me at home?
- Are there local organizations that can give low-cost or free home care or other services?
- Should I plan financially for long-term medical care, such as a nursing home, or for hospice care?

Employment, Legal, and Financial Issues

- ▶ Who can I talk with if I've lost income because of my cancer?
- If I have on-the-job difficulties related to my cancer, who can help me understand my legal rights?
- If my caregiver has difficulties at their job because of my cancer, who can help us understand our legal rights?
- Where can I find out if my medical and related expenses can be deducted from federal income taxes?
- Where can I get low-cost or free help with estate planning and legal issues, such as writing my will or granting a power of attorney?



FINANCIAL RESOURCES

Bills and debt can add up quickly, so you might want to look for financial help soon after learning your diagnosis. Ask a member of your health care team who can talk with you about finances. They can also refer you to support services and financial resources.

Many organizations help people with cancer who are facing financial challenges. Contact these organizations directly to learn more about the specific programs and services available to you and your family. Programs and services change, so please visit Cancer.Net (www.cancer.net/financial) for the most current information and support resources.

National Organizations

- American Childhood Cancer Organization (855-858-2226, www.acco.org/financial) maintains a list of organizations that offer financial assistance to families of children with cancer.
- **The Assistance Fund (855-845-3663, www.tafcares.org)** provides financial support to chronically ill patients with high-cost medications.
- **CancerCare** (800-813-4673, www.cancercare.org) provides limited financial assistance for co-pays, transportation, home care, and child care. It also provides a list of sources for financial assistance and a database of other organizations that provide financial or practical help.
- **Cancer Family Relief Fund** (www.cancerfamilyrelieffund.org) is a charitable organization that provides grants to children whose parent or guardian is struggling with a diagnosis of cancer. These grants support the children's extracurricular activities so that they may feel some sense of normalcy as their parent or guardian focuses on treatment and recovery.
- **Cancer Finances** (www.cancerfinances.org) is an online tool to help guide you through some key topics that may affect your financial situation.
- **Cancer Financial Assistance Coalition (CFAC; www.cancerfac.org)** is a group of national organizations that provide financial help to patients. CFAC provides a searchable database of financial resources.
- **Good Days** (877-968-7233, www.mygooddays.org) provides financial support by covering co-pays for those with life-altering conditions.
- **HealthWell Foundation** (800-675-8416, www.healthwellfoundation.org) is a nonprofit organization that helps patients with a chronic, life-altering disease afford their medications when health insurance is not enough.

- **Leukemia & Lymphoma Society** (800-955-4572, www.lls.org/support/financial-support) has a patient financial aid program that provides limited financial assistance to help cover treatment-related expenses for patients diagnosed with a blood cancer, such as leukemia, lymphoma, or multiple myeloma, who have a significant financial need.
- **Medicine Assistance Tool (www.medicineassistancetool.org)**, previously called the Partnership for Prescription Assistance, is an online search engine that focuses on finding resources to help eligible patients pay for medicine.
- **National Foundation for Transplants (800-489-3863, www.transplants.org)** provides fundraising assistance for patients needing transplants, including bone marrow transplants.
- **NeedyMeds** (800-503-6897, www.needymeds.org) helps people locate assistance programs to help them afford their medications and other health care costs.
- Patient Access Network (PAN) Foundation (866-316-7263, www.panfoundation.org) helps patients with out-of-pocket costs from their treatment.
- **Patient Advocate Foundation (800-532-5274, www.patientadvocate.org)** provides education, legal counseling, and referrals for people with cancer who need assistance managing insurance, financial, debt crisis, and job discrimination issues.
- **Patient Services Incorporated (800-366-7741, www.patientservicesinc.org)** helps chronically ill patients afford the cost of their treatment.
- **RxHope** (www.rxhope.com) helps patients obtain free or low-cost prescription medications.
- *Triage Cancer* (424-258-4628, www.triagecancer.org) is a national, nonprofit organization that provides cancer survivorship materials and resources.

Help with Travel

- **Air Care Alliance** (www.aircarealliance.org) offers a listing of free transportation services provided by volunteer pilots and charitable aviation groups.
- *Air Charity Network* (877-621-7177, www.aircharitynetwork.org) coordinates free air transportation for children and adults in need through various organizations around the United States.
- Air Compassion for Veterans (857-228-4636, www.aircompassionforveterans.us) provides free air and ground transportation for ill, injured, and wounded veterans and their family for medical care.

- Along Comes Hope (805-322-1423, www.alongcomeshope.com) provides support for the families of children with cancer, through financial assistance with travel for treatment, creative emotional support programs, and advocacy.
- Angel Airline Samaritans (www.angelairlinesamaritans.org) facilitates free or reduced rate commercial airline tickets to and from distant specialized medical evaluations or treatments for people with cancer in need and their families.
- Angel Flight East (215-358-1900, www.angelflighteast.org) supports free air transportation for children and adults with medical conditions who need to get to treatment far from home.
- Corporate Angel Network (914-328-1313, www.corpangelnetwork.org) arranges free air transportation for people with cancer traveling to treatment using empty seats on private and corporate jets.
- LifeLine Pilots (800-822-7972, www.lifelinepilots.org) provide free air transportation for financially distressed passengers with medical and humanitarian needs.
- Mercy Medical Angels (757-318-9174, www.mercymedical.org) offers free or low-cost transportation for medical evaluation, diagnosis, or treatment.
- PALS (Patient AirLift Services) (888-818-1231, www.palservices.org) arranges free air transportation for people for medical diagnosis, treatment, or follow-up care who cannot afford or are unable to fly commercially.

Help with Housing

- Healthcare Hospitality Network (800-542-9730, www.hhnetwork.org) is an association of more than 200 nonprofit organizations that provide lodging and support services to patients, families, and their loved ones who are receiving medical treatment away from home.
- Hope Lodge (800-227-2345, www.cancer.org/hopelodge), from the American Cancer Society, gives people with cancer and their caregivers a free place to stay while receiving treatment in another city.
- Joe's House (877-563-7468, www.joeshouse.org) is a nonprofit organization providing a nationwide online service that helps people with cancer and their families find a place to stay when traveling away from home for medical treatment.
- Ronald McDonald House Charities (630-623-7048, www.rmhc.org) offer free or reduced-cost lodging for families of seriously ill children who are receiving treatment at nearby hospitals.

Local Resources

Local service or volunteer organizations such as Catholic Charities, Jewish Social Services, the Lions Club, Lutheran Social Services, the Salvation Army, and others may offer financial assistance. Some of these organizations offer grants to help cover the cost of treatment and other expenses. Others help with specific services or products, such as travel or medications.

A social worker or an internet search can give you a list of local organizations. You can also ask your hospital or clinic for a list of service organizations in the community.

Two national organizations that can help you find local resources are the American Cancer Society (800-227-2345, www.cancer.org) and the United Way (703-836-7112, www.unitedway.org).

Talk with your health care team about groups in your area that may be able to help. You

can use the space below to write down their contact information.				

COST AND INSURANCE DICTIONARY

Americans with Disabilities Act (ADA): A federal law that protects people with disabilities from discrimination. It requires employers to make changes in the workplace for people with a disability. Learn more at **www.dol.gov**.

Appeal: If your insurance company denies a payment, an appeal is asking your insurance company to change its decision. You can ask your insurance company to review its decision, called an internal review. If the company still denies payment after your appeal, the ACA allows you to have another, independent organization decide if payment should be made. This is usually called an external review.

Associated costs: Costs that are related to a cancer diagnosis but are not specifically for medical care. These are also called non-medical costs or hidden costs. Transportation and child care costs that go up during treatment are 2 examples of associated costs.

Case manager: A health care professional, often a nurse with experience in cancer, who helps manage and organize the care of a person with cancer before, during, and after treatment. At a medical center, a case manager may help patients manage treatment plans, manage health insurance approvals, and find support services. Insurance companies also have case managers.

Claim: A request for the insurance company to pay for medical services.

Clinical trial: A research study that tests new treatments or prevention methods to find out whether they are safe, effective, and possibly better than the best-known treatment, called the standard of care.

COBRA: Consolidated Omnibus Budget Reconciliation Act. A federal law that allows employees to keep their insurance coverage for a limited time after leaving their job or working less hours. Employees have to pay for their insurance.

Co-insurance: The percentage of health care costs a person pays after meeting the health care plan's yearly deductible. For example, an 80/20 co-insurance rate means that the insurance company pays 80% of approved health care costs, and the patient pays the remaining 20% of costs out of pocket.

Co-pay: A set fee, in dollars, that an insurance provider requires someone to pay each time care is received. For example, a visit to the oncologist may cost \$30 each time. The amount of the co-pay is set by the insurance provider, not the doctor's office. Also called co-payment.

- **Coverage:** The benefits and services an insurance company will pay for as part of an insurance policy.
- **Deductible:** The amount of approved health care costs an insured patient must pay out of pocket each year before the health care plan begins paying any costs.
- **Disability insurance:** Insurance that provides an income for a short term or a long term to a person with a serious illness or injury that prevents them from working.
- **Essential health benefits:** A set of services that an insurance plan is required to provide to patients. These services may be different depending on what U.S. state you live in. You can find more information at **www.HealthCare.gov**.
- **Family and Medical Leave Act (FMLA):** This federal law offers specific protections for employees when they are sick and when they must care for a spouse, child, or sick parent. Learn more at **www.dol.gov**.
- **Fee-for-service:** This is a type of private health insurance in which a person visits a doctor, submits a claim form, and the insurance plan pays the bill using a co-insurance structure. Deductibles are common.
- **Financial toxicity:** Financial hardship related to a medical condition and treatment. If you experience financial toxicity, you might have difficulty paying bills or supporting your family because of cancer or medical bills. You might not be able to afford your treatment or medications, even if you have insurance, or you might go into debt for many years to pay for your cancer treatment. Talk to a member of the health care team to learn the costs of your treatment. You can also ask them to help you work with your insurance company and other organizations so you can get treatment without financial toxicity.
- **HIPAA:** Health Insurance Portability and Accountability Act. This is a set of national rules that help protect the privacy of a patient's medical information, provide patients with access to their medical records, and help people with health problems, such as cancer, get health insurance for themselves and their family members. Learn more at **www.hhs.gov/ocr/privacy**.
- **HMO:** Health maintenance organization. This is a type of private health insurance. In an HMO, a person chooses a primary care doctor from an approved list of doctors, called the network. Specialist care must be approved by that primary care doctor, called a referral.
- **In-network care:** Health care providers or facilities that are part of an HMO or PPO plan's approved list or network are considered "in network." In general, in-network care costs less than out-of-network care.

- **Insurance cap:** The total amount of money an insurance plan will pay. Once a patient's medical bills reach the total, or cap, the plan will no longer provide coverage. The ACA ended caps on how much a company will pay in 1 year or in your lifetime. For more information, visit **www.HealthCare.gov**.
- **Long-term care insurance:** Insurance that helps people with long-lasting illnesses or disabilities pay for non-medical daily services and care that ordinary health plans don't cover, such as help with eating, bathing, and dressing. Depending on the plan, care can be given in the home or outside the home.
- **Medicaid:** This is a type of government health insurance for people with low incomes who meet certain conditions. Medicaid is funded by federal and state governments, but each state operates its own program. States also choose who can receive Medicaid benefits in that state. Learn more at **www.cms.gov**.
- **Medicare:** This is a type of health insurance provided by the federal government for people 65 or older, as well as for some people who are disabled. Medicare is divided into 4 parts: Parts A, B, C, and D. Learn more on page 7 and at **www.medicare.gov**.
- **Non-essential benefits:** Services provided by an insurance plan that are outside the "essential benefits" category. Patients may be responsible for some or all of these costs.
- **Open enrollment:** A time of year when you can choose a new health plan. Once this time ends, you may need to wait until the next open enrollment period to join a health plan. This is usually a year later. But if you meet certain requirements, you might not have to wait. Find additional information at **www.HealthCare.gov**. Medicare participants can go to **www.medicare.gov** to learn about Medicare open enrollment. If you have private insurance, talk with a health insurance plan representative to learn more.
- **Out-of-network care:** Health care providers or facilities that are not part of an HMO or PPO plan's approved list or network. Out-of-network care often costs more than in-network care. Out-of-network care may involve a deductible and require pre-approval.
- **Out-of-pocket costs:** Expenses that must be paid from a patient's personal funds. Out-of-pocket costs are not covered by insurance.
- **Patient navigator:** A person, often a nurse or social worker, who helps guide patients, survivors, families, and caregivers through the health care system. Navigators can help with financial support, transportation, finding child care during treatment, organizing care among several doctors, and providing emotional support.
- Patient Protection and Affordable Care Act: A 2010 federal law that changed certain rules regarding health insurance coverage in the United States. Also called the ACA. Learn more at www.HealthCare.gov.

- **PPO:** Preferred provider organization. This is a type of private health insurance that gives a person access to a network of approved doctors, called in-network doctors. In PPOs, patients typically do not need a referral for specialist care.
- **Precertification:** Asking the insurance company for permission to get specific services before they happen, such as a treatment, procedure, or hospital stay. This is also called pre-approval. Many hospitals and clinics have precertification coordinators, patient navigators, or case managers who help people with cancer with this process.
- **Preexisting condition:** A medical condition that a person already has when enrolling in a new health plan. Since 2014, under the ACA, insurance plans are not allowed to deny coverage or charge extra to individuals with a preexisting condition.
- **Premium:** The amount a person or company pays each month to keep insurance coverage.
- **Reasonable and customary fees:** The average cost for health services in a specific place. Insurance companies use these fees to decide how much they will pay for services. If a doctor's fees for a service are higher than the reasonable and customary fees, then the patient must pay the difference.
- Social Security Disability Insurance and Supplemental Security Income: These are 2 national programs that help people with disabilities. Each has specific medical requirements that a person must meet before getting these benefits. Both programs are run by the Social Security Administration. Learn more at www.ssa.gov/disability.
- **Social worker:** A professional who helps people with cancer and their family members cope with everyday tasks and challenges before, during, and after treatment. Social workers may work for a hospital, a service agency, or a local government. They can help address financial problems, explain insurance benefits, provide access to counseling, and more.
- **Specialist care:** Health care given by a doctor who has been trained in treating a specific type of health problem or specific group of people. For instance, an oncologist is a doctor who specializes in treating cancer.

For more definitions of common words you may hear when talking with your health care team, visit **www.cancer.net/cancerterms.**

NOTES		

Looking for Other Patient Information Resources?

ASCO ANSWERS GUIDES

ASCO Answers Guides feature comprehensive information about the diagnosis, treatment, side effects, and psychosocial effects of a specific cancer type, as well as practical information for patients and families. Guides on survivorship and caregiving are also available.

ASCO ANSWERS FACT SHEETS

ASCO Answers Fact Sheets provide a one-page (front and back) introduction to a specific type of cancer or cancer-related topic. Each includes an overview, illustration, words to know, and questions to ask the health care team. Cancer.Net has more than 65 fact sheets available (including some in Spanish), covering different cancer types, diagnosis and treatment, and side effects.

ASCO ANSWERS BOOKLETS

ASCO Answers Booklets provide in-depth, practical guidance on specific topics in cancer care, including advanced cancer care planning, pain, cost of care, managing weight, palliative care, and stopping tobacco use.

For Patients and Caregivers: If you are interested in additional educational materials, visit **www.cancer.net/ascoanswers** to find all of our available materials in electronic format.

For Oncology Professionals: Bulk quantities of high-quality print materials are available for purchase. Visit **www.cancer.net/estore** or call 1-888-273-3508 to place your order.

To request free promotional materials for your practice, please send an email to contactus@cancer.net.

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WE WANT TO HEAR FROM YOU

If you found this material helpful or if you have comments or suggestions about how it could be better, please let us know at contactus@cancer.net.



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www.asco.org | www.cancer.net

For more information about ASCO's patient information resources, call toll-free 888-651-3038 or e-mail contactus@cancer.net.

To order more copies of this booklet, call 888-273-3508 or visit www.cancer.net/estore.

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