



American Society of Clinical Oncology

Making a world of difference in cancer care

Managing the Cost of Cancer Care

Practical Guidance for Patients and Families

INCLUDES HEALTH REFORM LAW INFORMATION

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ABOUT ASCO

The American Society of Clinical Oncology (ASCO) is the world's leading professional organization representing physicians of all oncology subspecialties who care for people with cancer. ASCO's more than 30,000 members from the United States and abroad set the standard for patient care worldwide and lead the fight for more effective cancer treatments, increased funding for clinical and translational research, and, ultimately, cures for the many different types of cancer that strike an estimated 12 million people worldwide each year.



ABOUT CANCER.NET

The best cancer care starts with the best cancer information. Well-informed patients are their own best advocates and invaluable partners for physicians. Cancer.Net (www.cancer.net) brings the expertise and resources of the American Society of Clinical Oncology (ASCO), the voice of the world's cancer physicians, to people living with cancer and those who care for and care about them. All the information and content on Cancer.Net was developed and approved by the cancer doctors who are members of ASCO, making Cancer.Net an up-to-date and trusted resource for cancer information on the Internet. Cancer.Net is supported by the Conquer Cancer Foundation, which provides funding for breakthrough cancer research, professional education, and patient and family support.

Managing the Cost of Cancer Care

TABLE OF CONTENTS

Introduction.....	4
Understanding Costs Related to Cancer Care.....	5
Understanding the 2010 Health Reform Law	8
Questions to Ask	12
Financial Resources.....	16
Getting Organized.....	20
Insurance Examples.....	22
Glossary	23

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INTRODUCTION

The cost of cancer care can be high. There may be expenses that you hadn't planned for during your care. Financial costs can be a burden for people with cancer today, and these costs may affect the medical decisions that you and your doctor make.

The American Society of Clinical Oncology (ASCO) is working with oncologists across the country to increase doctor-patient communication on this crucial topic. ASCO is the world's leading professional organization representing doctors who care for people with cancer.

If you are a person with cancer, understanding what costs to expect before starting treatment can help you manage the financial impact of cancer in the most effective way possible. ASCO created this guide to help you talk with your health care team about coping with the costs of cancer care. The guide includes tools and resources to assist you in financial planning before, during, and after treatment.

Whether you have private health insurance, government insurance (such as Medicare or Medicaid), or no insurance, it is important for you to talk openly with your health care team soon after diagnosis about the costs of your care. This may include medical costs—such as the price of a specific drug—as well as additional costs—such as transportation costs to and from the cancer center—that could make getting the best cancer care more difficult.

Out-of-pocket expenses can quickly add up and affect your family budget. These costs are also the reason some people don't follow or complete their cancer treatment plan. However, not following your treatment plan for any reason could put your health at risk and lead to even higher health care costs in the future.

Your health care team can help you identify costs related to your treatment options, suggest ways to help reduce or manage medical and associated costs, and refer you to support services that address the financial difficulties many people with cancer face.

UNDERSTANDING COSTS RELATED TO CANCER CARE

After you are diagnosed with cancer, it is important to think about the different types of costs that could add up during your treatment and recovery periods. This will help you determine what kind of budgeting, support, or financial assistance you may need. Your personal costs will depend on several factors, including the length and type of your cancer treatment plan and the extent of your health insurance coverage.



Some costs may be more obvious to you than others. For instance, many people quickly think about how much a particular medication will cost for them based on their insurance coverage. However, there are also other costs—often called “hidden costs”—you will need to consider. These are the costs of daily living that increase due to the illness and its treatment.

For instance, your expenses for gasoline and parking fees will go up a lot if you need to receive daily radiation therapy at a facility 20 miles away from your home. Or, a new expense is added to your budget if you need child care every Tuesday so you can go to the doctor’s office for chemotherapy. At the same time, you may need to work less—and earn less money—because of the demands of the treatment schedule.

To get started, it may be helpful to group the different types of costs based on your budget and needs. Common financial categories for cancer care include:

- **Doctor Appointments:** This includes payments for the medical care you receive at each doctor visit, such as a physical examination or check-up. In most situations, your insurance provider requires you to pay a fee called a co-payment, or co-pay, each time you visit the doctor. The amount of the co-pay is set by the insurance company, not the doctor or doctor’s office. In addition, there will typically be a separate payment needed for each laboratory test, such as a blood or urine test, done as part of your appointment.

Patient Story

Elyse is a social worker who is working with the family of an 8-year-old boy with lymphoma. The child's treatment requires many appointments, resulting in significant lost wages for his mother, who is raising her three children by herself. Her employer gives her the time off without difficulty, but time away from work is time unpaid. And, while the family has insurance, they found out their policy has limitations in covering medical costs.

Elyse met this family soon after the child's diagnosis as part of the center's standard procedure for new patients. Elyse and the mother worked together to identify several programs that could help, including Social Security disability benefits, a local service at their cancer center, and two programs funded by national childhood cancer organizations. Today, Elyse says that, although not solved, the family's ongoing cancer-related costs are being effectively managed.

- **Cancer Treatment Costs:** This includes payments for the medical care you receive during your cancer treatment, such as each radiation therapy session.

If you're participating in a clinical trial, there may be other cost-related factors to consider. Some aspects of your treatment may not be covered by insurance. In general, cancer treatment can take anywhere from a few days up to months or years, so you will need to map out, with the help of a doctor or nurse, how often and for how long you may have these out-of-pocket costs.

- **Medication Costs:** This includes payments for the specific medicines prescribed during your treatment period, such as chemotherapy and drugs to help relieve common side effects.
- **Transportation Costs:** This includes expenses you may have due to traveling to and from the doctor's office and/or treatment facility, whether it is by car, bus, train, or airplane. This category may also cover the price of hotels or other lodging needed.
- **Family and Living Expenses:** This includes costs related to running your household and caring for your family during your cancer treatment, such as child care, elder care, and coping support.

- **Caregiving, At-home Care, and Long-Term Care:** This includes additional costs of the care that a person with cancer may need, such as fixing meals or driving the patient to each medical appointment. It could also include extended nursing care at a specialized facility.
- **Employment, Legal, and Financial Issues:** This includes the costs that arise when a patient needs professional guidance on employment, legal, or financial issues related to their diagnosis. This includes such topics as addressing loss of wages of the patient or caregiver, learning about employment rights under the law, figuring out medical expenses during income tax filing, or writing a will.

Once you've outlined your cost categories, you can begin to think about the specific, individual costs in each one. If you feel overwhelmed, ask for help from a trusted family member, friend, or member of your health care team. In this booklet, there is a section that offers a list of questions in each of these categories for you to ask while planning for your financial future.



UNDERSTANDING THE 2010 HEALTH REFORM LAW

In March 2010, the Patient Protection and Affordable Care Act—often called simply Health Reform—was signed into law, changing several rules regarding health care insurance coverage in the United States. For people with cancer, this new law covers areas regarding both the cost of and access to care. Some changes took effect immediately, and others will take effect in the coming years. Highlights of the new law are summarized below and are adapted from information from the Kaiser Family Foundation, unless otherwise noted. This list is not intended to be a complete outline, but rather is meant to provide an overview of major areas of health reform relating to the cost of and access to cancer care. More details can be found at the federal government's website of www.HealthCare.gov.



How Does Health Reform Help You Now?

General Insurance Reform

- Private health plans are not allowed to place a lifetime limit (called a cap) on the dollar value of a person's coverage. Subject to certain restrictions, insurers are permitted to place an annual limit on the dollar value of coverage until January 1, 2014, but will not be permitted to enforce annual limits after that date.
- Insurers cannot take away coverage except in cases of fraud. Previously, insurance companies could revoke coverage for an error or technical mistake in a patient's insurance application. This practice is now illegal.
- Insurance plans that offer dependent coverage are now required to make coverage available to adult children up to age 26 (although

certain “grandfathered” group health plans may exclude such coverage if the adult child is eligible to enroll in a health plan through his or her own employer.)

- Dependent children under age 19 cannot be denied coverage for pre-existing conditions.

For People Without Health Insurance

- Uninsured individuals with pre-existing medical conditions now have access to a temporary national high-risk insurance pool program. U.S. citizens and legal immigrants who have been uninsured for at least six months are able to enroll for coverage through this high-risk pool and receive subsidized premiums. (Effective until January 1, 2014.)
- States must establish a website to help residents identify coverage options in a standardized format. This includes the federal government’s HealthCare.gov website, which provides information on the new law and insurance options for consumers.

Elimination of Co-pays for Preventive Services

Cancer prevention and risk-reduction strategies can lower the physical, emotional, and financial burden of cancer and improve the overall health of cancer survivors, including reducing the risk of the cancer coming back or the chance of a second cancer. The new law includes several provisions to increase access to cancer prevention services:

- Private health insurance plans issued after September 23, 2010, are required to eliminate co-pays for preventive services recommended by the U.S. Preventive Services Task Force (USPSTF; www.uspreventiveservicestaskforce.org) including but not limited to:
 - Screening tests for colon cancer for adults over 50.
 - Annual mammograms for women over 40. Other services to prevent breast cancer will also be covered, including a referral to genetic counseling and a discussion of chemoprevention for certain women at increased risk.
 - Regular Pap tests to screen for cervical cancer and coverage for the HPV vaccine, which can prevent cervical cancer.
 - Tobacco cessation interventions, such as counseling or medication to help individuals quit smoking.

- Co-pays for Medicare-covered preventive services recommended by the USPSTF have been eliminated. The Medicare deductible for colorectal cancer screening tests have also been eliminated. Both changes were effective January 1, 2011.

Appealing Health Plan Decisions

- Beginning with plan years starting after July 1, 2011, insurance companies that deny payment for a treatment or service are required to conduct internal appeals at the patient's request within specific timelines: 72 hours after receiving an appeal for urgent medical care; 30 days for non-urgent care you have not yet received; and 60 days for services you have already received. If after the internal appeal, you are still denied coverage, you have the right to request an independent external review. If the external review overturns the denial of services, your insurance company is required to cover the payment or services requested in your claim.

How Will Health Reform Help You in the Future?

General Insurance Reform

- Adults cannot be denied coverage for pre-existing conditions. (Effective January 1, 2014.)
- Waiting periods for coverage greater than 90 days will be eliminated by January 1, 2014.

For People Without Health Insurance

- Most U.S. citizens and legal residents will be required to have health insurance beginning in 2014. Exemptions can be granted for financial hardship, religious objections, American Indians, those without coverage for less than three months, undocumented immigrants, people in jail, people for whom the lowest cost plan option exceeds 8% of an individual's income, and those with incomes below the tax filing threshold. (In 2011, the threshold for taxpayers under age 65 was \$9,500 for singles and \$19,000 for couples.) Penalties for not having health insurance will be phased in beginning in 2014.
- Medicaid coverage will be expanded to individuals with incomes up to 138% of the federal poverty level who are under 65 and who are not

otherwise eligible for Medicare. (The poverty level was \$18,530 for a family of three in 2011.) (Effective January 1, 2014.)

- State-based health insurance exchanges will be established to help people and small businesses with the purchase of coverage. Premium and cost-sharing credits will be available to individuals and families earning between 139% to 400% of the federal poverty level. The Office of Personnel Management, a federal government agency, will begin contracts with health insurance providers to offer at least two multi-state plans in each exchange. (Effective January 1, 2014.)

Elimination of Co-Pays for Preventive Services

- Co-pays for Medicaid-covered preventive services recommended by the USPSTF will be eliminated, effective January 1, 2013.

For Individuals Participating in Clinical Trials

- As of January 1, 2014, insurers will not be allowed to limit or drop coverage to an individual choosing to participate in a clinical trial, and insurers will be required to cover the routine patient costs associated with participation in clinical trials. This applies to clinical trials to treat cancer, in addition to other life-threatening diseases.

Patient Story

Amy is a social worker working with a 56-year-old man with cancer of the tongue. His treatment included radiation therapy five times a week and chemotherapy once a week. The patient lives in the same city as the cancer center, but has difficulty getting there since his local support system is limited to a few friends. His sole income is his monthly Social Security check, and he's uninsured because, despite being a U.S. citizen, he doesn't have the documentation needed to apply for Medicaid. His treatment plan also includes skin creams and nutritional supplements, but he couldn't afford them and so he abandoned treatment briefly.

This patient was referred to Amy through his health care team upon his diagnosis. She located a city-sponsored transportation program, and funds from a charity supplied this patient with the nutritional formula and creams he needed. She also helped him access resources that covered his medication costs. He was able to finish treatment and continues to get regular follow-up care.

QUESTIONS TO ASK

What and Who to Ask

Bringing up your financial concerns to others is difficult—especially if you don't know what to say, or who to ask. It's not always clear who the best person is to answer your questions, so talking with your doctor is a good start. Try starting the talk by saying: "I am worried about costs related to my cancer treatment. Can we talk about my concerns?"

Your doctor may not have all of the answers to your financial questions but can give you resources to help you get the best possible information. Several people and groups will help you find answers, including doctors and their support staff, nurses, social workers, case managers, patient advocacy organizations, and your employer's human resources department. And, people from your insurance company can help on questions about your specific health care coverage.

Next, use the questions below to help focus the discussion. **You don't need to ask all of these questions—just choose the ones most important to your diagnosis and your financial situation.** Select the ones you are most concerned about, and ask those first. If you think the doctor is the best person to answer your questions, let the doctor's office know ahead of time that you have some questions that you'd like to ask the doctor during your appointment, so enough time can be scheduled. Be sure to write down the answers so you can go back to your notes later. And, remember: these talks between you and your health care team will continue during your care.

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/provider?
- 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?
- Is there a limit to how much my insurance will cover for my treatment? If so, are my medical bills likely to reach that amount?
- I already have health insurance. What does the health reform law mean for me?

- I don't have health insurance. What does the health reform law mean for me?
- Where can I find help in organizing my expenses, so I can keep track of incoming bills and plan my budget?

Doctor 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 laboratory tests, such as blood tests? Are they covered under my health insurance?
- Does my insurance cover other doctor visits, such as for a second opinion?

Cancer Treatment Costs: General

- 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 don't 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 facility you are recommending in my health plan's network?
- If I need to be admitted into the hospital, what is covered under my health insurance?
- If I receive treatment as an outpatient, what is covered under my health insurance?
- 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 individual treatment?
- Where can I get low-cost or free counseling or support to help me cope with my diagnosis?

Cancer Treatment Costs: Clinical Trials

- What expenses will I have if I join a clinical trial?
- 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 of the clinical trial?

Medication Costs

- What is my prescription co-pay for this drug?
- Is 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 medications for 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?

Associated Expenses: Transportation

- 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 facility?

Associated Expenses: Family and Living Expenses

- 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 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?

Associated Expenses: Caregiving, At-Home Care, and Long-Term Care

- Are there ways to change my treatment schedule, if necessary, to work around my caregiver's job and schedule?
- Could we talk about 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 hospice care?

Associated Expenses: 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 his or her 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

The following national organizations offer help for people with cancer with financial challenges. People should contact organizations directly to learn more about the specific programs and services, including eligibility criteria. Since programs and services change constantly, this list is not inclusive and readers are encouraged to visit ASCO's patient information website, Cancer.Net (www.cancer.net) to find additional organizations and support.

General Financial and Co-Pay Assistance

American Cancer Society
www.cancer.org
800-227-2345

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

CancerCare
www.cancercare.org
800-813-4673

The Leukemia and Lymphoma Society
www.lls.org
800-955-4572

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

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

Cancer Financial Assistance Coalition
www.cancerfac.org

The MAX Foundation
www.themaxfoundation.org
888-462-9368

CureSearch: Childhood Cancer Resource Directory
www.curesearch.org/resources
800-458-6223

National Council on Aging
www.benefitscheckup.org
202-479-1200

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

National Marrow Donor Program
www.marrow.org
888-999-6743

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

NeedyMeds, Inc.
www.needymeds.com

**Partnership for Prescription
Assistance**
www.pparx.org
888-477-2669

**Patient Access Network
Foundation**
www.panfoundation.org
866-316-7263

Patient Advocate Foundation
www.copays.org
866-512-3861

Patient Services Inc.
www.uneedpsi.org
800-366-7741

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

Together Rx Access Card
www.together-rxaccess.com
800-444-4106

Patient Story

Pamela was 44 when she was diagnosed with breast cancer four years ago. She has metastatic breast cancer. She had held a demanding job that required a lot of travel, but the intensive chemotherapy treatment schedule and side effects meant she had to first cut back on her hours and ultimately leave her position. While employed, her health insurance and long-term care insurance benefits provided good coverage, but then she had to leave her job.

With the assistance of a financial counselor at her treatment facility, she applied for several programs. Due to her young age, she does not qualify for most programs, but she has been approved for both Medicare and Social Security disability coverage. She is thankful for her financial counselor helping her in completing the paperwork needed, and she notes that the Medicare prescription drug coverage is particularly important with her ongoing treatment costs today.

Travel and Lodging Resources

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

Air Charity Network/Angel Flight America
www.aircharitynetwork.org
877-621-7177

Air Compassion America
www.aircompassionamerica.org
866-270-9198

Air Compassion for Veterans
www.aircompassionforveterans.org
888-662-6794

Angel Flight Samaritans
www.angelflightsamaritan.org
800-296-1217

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

Hope Lodge
www.cancer.org/hopelodge
800-227-2345

Joe's House
www.joeshouse.org
877-563-7468

LifeLine Pilots
www.lifelinepilots.org
800-822-7972

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

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



GETTING ORGANIZED

After a cancer diagnosis, many people find that becoming well-organized helps them gain a sense of control over all the information they receive, including financial information. To do this, first steps include finding out who best will answer the specific questions you have and setting up a personal organizational system. The following suggestions may help you organize your cancer care paperwork:

- Find the filing system that works for you. A filing cabinet or simple desktop divider with individual folders keeps key information all in one place and makes it quick and easy to find. File new information as soon as possible, so it doesn't get misplaced. Your files may include notes made during doctor appointments, copies of your laboratory test results, your personal insurance information, and contact information for your doctor's office, medical center, insurance company, support organizations, and others.
- Ask your health insurance company if you can be assigned a case manager, so you can talk with the same person each time you need to call. Also, maintain a written record of any conversations with all insurance company representatives, including the date, name of the person you spoke with, and what was said. Put the newest records at the front of your file, so you have a clear and up-to-date list of these discussions.

Patient Story

Alice, a 48-year-old married mother of two school-aged children, has been diagnosed with colon cancer. Her employment at a school provides her with health insurance, but the policy includes a \$3,000 deductible before any payments begin. Her local physician wants her treatment to start with a proven targeted therapy, but she is unable to make the initial deductible payment for the medication.

After she did some online research, she learned she is not eligible for most drug assistance programs because she has health insurance. Alice then reached out to a national organization that provided her with a grant to pay for the first treatment, which is now scheduled to begin. The social worker at the same organization was also able to help Alice prepare to talk with her children about the disease to help them better cope with their mother's illness.

- Keep current copies of all insurance policies and refer to them by name and number in any communications about insurance coverage.



- Write down the list of questions that are most important to you, using the suggestions in this booklet or others. Start with your most important questions to make sure these are answered first.
- Try to decide ahead of time how to adjust your budget to deal with any loss of income resulting from less time at work, or expenses that are not covered by insurance.
- List each task you need to accomplish between doctor appointments, and put a check mark beside each one when you complete it to mark your progress.
- Ask a friend or family member to help you keep track of your regular monthly bills, or consider using a bill-paying service to help keep your payments on time.

For more guidance, visit ASCO's patient information website, Cancer.Net (www.cancer.net).

INSURANCE EXAMPLES

Understanding the benefits and limitations of your health insurance policy can be challenging, but it is important to learn exactly what your coverage provides. The following examples may help illustrate how co-pays, co-insurance, and deductibles work. You are strongly encouraged to talk with a representative of your insurance provider, who can explain the details of your specific coverage.

Insurance Example #1: Co-pays

Let's say Anna needs to see two specialists this week: Dr. Smith and Dr. Jones. Dr. Smith charges \$100 a visit, and Dr. Jones charges \$500 a visit. If Anna's insurance states she pays \$20 co-pays for visits, how much does she pay out-of-pocket at the appointments?

ANSWER:

Anna will pay \$20 at each doctor's office. Since a co-pay is a set amount of money, the patient's payment doesn't depend on the amount of the bill.

Insurance Example #2: Co-Insurance

Let's say Martin needs to see two specialists this week: Dr. Andrews and Dr. Adams. Dr. Andrews charges \$100 a visit, and Dr. Adams charges \$500 a visit. If Martin's insurance states he must pay 20% co-insurance for visits, how much does he pay out-of-pocket at the appointments?

ANSWER:

Multiply each bill by the co-insurance percentage.

- Martin's payment to Dr. Andrews would be \$20, since $\$100 \times 20\% = \20
- Martin's payment to Dr. Adams would be \$100, since $\$500 \times 20\% = \100

Insurance Example #3: Co-Insurance and Deductibles

Let's say Kathy has a deductible of \$2,000 a year, and her co-insurance for a hospital visit is 20%. She had a surgery that cost \$10,000. How much does she have to pay out-of-pocket?

ANSWER:

Step One: Subtract the deductible from the total bill, so $\$10,000 - \$2,000 = \$8,000$.

Step Two: Then, multiply that difference by the co-insurance percentage, so $\$8,000 \times 20\% = \$1,600$. This gives the patient's co-insurance amount.

Step Three: Add together the deductible (\$2,000) and the co-insurance amount (\$1,600) to find the total amount that the patient would pay. In this example, Kathy would pay \$3,600.

GLOSSARY

ADA—The Americans with Disabilities Act. A national law that doesn't allow discrimination against people with disabilities. It requires employers to make reasonable accommodations in the workplace for qualified individuals with a disability. Learn more at www.dol.gov.

Associated costs—Costs that are related to the cancer diagnosis, but not specifically due to medical care given to treat the disease; also called non-medical costs. Transportation and child care during treatment are two common associated costs for people with cancer.

Case manager—A health care professional, often a nurse with experience in cancer, that helps coordinate the care of a person with cancer before, during, and after treatment. At a medical center, a case manager may provide a wide range of services for patients that may include managing treatment plans, coordinating health insurance approvals, and locating support services. Insurance companies also employ case managers.

Clinical trial—A research study to test a new treatment or drug.

COBRA—Consolidated Omnibus Budget Reconciliation Act. A federal law that allows employees in danger of losing health insurance under certain circumstances, such as leaving a job, to pay for and keep their insurance coverage for a limited time.

Co-insurance—The percentage of health care costs an insured patient pays after meeting a 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 out-of-pocket the remaining 20% of costs.

Co-pay—A set fee, in dollars, that an insurance provider requires a patient to pay each time care is received. For example, a visit to the oncologist may cost a patient \$30 each time; insurance pays the rest of the visit's costs. The amount of the co-pay is set by the insurance provider and not the doctor's office.

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 on either a short-term or a long-term basis to a person with a serious illness or injury that prevents the person from working.

Fee-for-service—This is a type of 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 and insurance caps are common.

FMLA—Family and Medical Leave Act. This federal law offers specific protections for employees during medical leave (when the employee is ill) and family leave (when the employee must care for a spouse, child, or parent who is ill). Learn more at www.dol.gov.

Insurance cap—The amount of money an insurance plan will pay in total benefits. Once a patient's medical bills reach the total, or cap, the plan will no longer provide coverage. (Under Health Reform, lifetime caps have been eliminated. Annual caps are allowed until January 1, 2014; see page 8.)

HMO—Health Maintenance Organization. This is a type of 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).

HIPAA—Health Insurance Portability and Accountability Act. A set of national rules that help protect the privacy of a patient's individual 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.cms.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 jointly funded by the federal and state governments, and each state operates its program individually (including deciding who can get Medicaid for 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 four parts: Parts A, B, C, and D. Part A covers in-patient hospital care. Part B provides financial coverage using premiums, deductibles, and a co-insurance structure for other medical expenses, such as doctor visits. Medicare Advantage plans, or Part C, are insurance plans managed by private, approved companies. And, Part D provides prescription drug coverage. Learn more at www.medicare.gov.

Out-of-network care—Health care providers or facilities that are not part of an insurance plan’s approved list or network are considered “out of network” (as opposed to being on an approved list or “in network”) in an HMO or PPO. Out-of-network care often costs patients more than in-network care and may involve a deductible and require pre-approval for certain services.

Out-of-pocket costs—Expenses that must be paid from a patient’s personal financial resources; any expense 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 offer numerous services including arranging financial support, transportation and child care during treatment; coordinating care among several doctors; and providing emotional support.

Patient Protection and Affordable Care Act—Often called simply “Health Reform,” this is a 2010 federal law that changes certain rules regarding health insurance coverage in the United States. See Page 8 for more details, and learn more at www.healthcare.gov.

PPO—Preferred Provider Organization. This is a type of health insurance in which a person has access to a network of approved doctors, called in-network doctors. In PPOs, patients typically do not need a referral for specialist care.

Precertification—The process of requesting approval from an insurance plan for specific services before they happen, such as a treatment, procedure, or hospital stay; also called pre-approval. Many hospitals and clinics have precertification coordinators, patient navigators, or case managers who help patients with cancer through this process.

Pre-existing condition—A medical condition that a person already has when enrolling in a new health plan. Many health plans have a period of time in which they will deny all claims related to pre-existing conditions. However, HIPAA sets limits on how long an insurance company can deny coverage for a pre-existing condition. (Several rules are changing regarding pre-existing conditions under Health Reform; see Page 9.)

Premium—The amount a person and/or company pays each month to keep insurance coverage.

Reasonable and customary fees—The average cost for health services in a geographic area that insurance plans use to decide how much they will pay for those services. If a doctor's fee for a service is higher than average, the patient must pay the difference.

Social Security Disability Insurance and Supplemental Security Income—These are two national programs that assist people with disabilities; each has specific medical requirements that a person must meet before getting these benefits. Both programs are administered by the Social Security Administration. Learn more at www.ssa.gov/disability.

Social worker—A professional who helps patients with cancer and their family members cope with everyday tasks and challenges before, during, and after treatment. Social workers, who may work for a hospital, a service agency, or a local government, 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 cancer.



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