ASCOanswers

Managing the Cost of Cancer Care

Practical Guidance for Patients and Families

Cancer.Net®

Doctor-Approved Patient Information from ASCO®

ABOUT ASCO

Founded in 1964, the American Society of Clinical Oncology (ASCO) is the world's leading professional organization representing physicians who care for people with cancer. With more than 30,000 members, ASCO is committed to improving cancer care through scientific meetings, educational programs, and peer-reviewed journals. ASCO is supported by its affiliate organization, the Conquer Cancer Foundation, which funds groundbreaking research and programs that make a tangible difference in the lives of people with cancer.

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.

ASCO patient education programs are supported by:

CONQUER CANCER FOUNDATION
of the American Society of Clinical Oncology

Managing the Cost of Cancer Care

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Introduction

The cost of cancer care can be high, and there may be extra expenses you hadn't planned for during this time. The financial impact of a cancer diagnosis is often a major source of stress and anxiety for people with cancer and their families. And for some, these out-of-pocket costs are a major reason why they don't follow or complete their cancer treatment plan. However, not following your treatment plan for any reason can put your health at risk and lead to even higher costs in the future.

This booklet has been designed to help you identify the medical and associated costs of cancer care and talk openly with members of the health care team about reducing or managing them. It includes tools, information, and resources that will assist you in financial planning before, during, and after treatment. By figuring out soon after a cancer diagnosis what costs you can expect, you will be able to manage your financial concerns in the most effective way possible so that you or a family member gets the best possible care.

Understanding the Costs Related to Cancer Care

After a diagnosis of cancer, it is important to think about the different types of costs that could add up during treatment and recovery. 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 type and length of the cancer treatment plan and the extent of your health insurance coverage.

Some costs might be more obvious to you than others. For instance, many people quickly think about how much a particular medication will cost 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 a chronic (long-term) illness and its treatment.

For example, your expenses for gasoline and parking fees will go up a lot if you need to travel 20 miles to a radiation therapy facility every day for treatment. Or, new expenses might be added to your budget, such as if you need childcare every Tuesday so you can go to the doctor's office for chemotherapy. At the same time, because of the demands of the treatment schedule, you may need to work less, which may result in earning less money.

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.

Cancer treatment. This includes payments for the medical care you receive during your cancer treatment, such as each radiation therapy session. If you are participating in a clinical trial, there may be other cost-related factors to consider. In general, cancer treatment can take anywhere from a few days to a few months or even 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. This includes payments for the specific medicines prescribed during your treatment period, such as chemotherapy and drugs to help manage common side effects.

Transportation and travel. 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. Depending on where you decide to receive treatment, you may also need to pay for a hotel or other lodging.

Family and living expenses. This includes costs related to running your household and caring for your family during cancer treatment, such as childcare, elder care, and coping support.

Caregiving, at-home care, and long-term care. This includes any additional care a person with cancer may need, such as hiring a person to fix meals or drive the patient to each medical appointment. It could also include extended nursing care at a specialized facility or the assistance of a home health aide.

Employment, legal, and financial issues. This includes the costs that arise when a person needs professional guidance on employment, legal, or financial issues related to a cancer diagnosis. This may involve addressing loss of wages by the patient or caregiver, learning about employment rights under the law, figuring out medical expenses during income tax filing, or writing a will.

Thinking about all of these potential costs may make you feel anxious about the future. However, financial resources, like those listed at the end of this booklet, as well as a representative from your doctor's office and/or health insurance provider, may be able to help you better understand these costs. If you continue to feel overwhelmed about your financial future, ask for help from a trusted family member, friend, social worker, or another member of the health care team.

JASON'S STORY

Jason, an 8-year-old boy, was diagnosed with lymphoma. His 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, although the family has insurance, Jason's mother found out the policy has limitations in covering medical costs.

A social worker met with Jason's mother soon after Jason's diagnosis as part of the center's standard procedures for new patients. The social worker and Jason's 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, Jason's mother says that, although not solved, the family's ongoing cancer-related costs are being effectively managed.

Health Insurance

The type of health insurance coverage you have plays a big role in the amount of out-of-pocket costs you can expect to pay throughout cancer treatment and recovery. The following information will help you understand the different types of health insurance and what medical costs they usually cover. Definitions for many of the terms used in this section are located in the *Cost and Insurance Dictionary* at the end of this booklet.

Private Insurance Plans

FEE-FOR-SERVICE COVERAGE

This type of plan generally does not place any restrictions on which doctors or hospitals you are able to use. You simply visit the doctor, hospital, or health care center of your choice, anytime or anywhere, submit a claim form, and the health insurance company pays the bill. Typically, you share some of the cost in the form of co-payments or co-insurance, and some types of services may not be covered. Although fee-for-service plans allow the greatest freedom in choosing doctors and hospitals, there may be restrictions on some services, including mental health services, physical therapy, home health care, investigational treatments, or alternative medicine.

HMO

As a member of an HMO, you pay a monthly premium and a small additional co-payment for each office visit. An HMO generally does not require you to submit any claim forms, unless you visit doctors who are not members of the plan. An HMO may be an actual health care center, in which all of the doctors in the office are part of the organization. In other cases, individual doctors contract with the HMO to care for patients covered under the plan. This agreement is known as an individual practice association. As with most insurance plans, covered services vary. For example, some types of mental health services, alternative medicine, and physical therapy may not be covered or only covered on a limited basis.

PPO

A PPO is a type of health insurance that covers most medical costs when a person visits doctors who are part of the plan's network of approved doctors. Unlike an HMO, a PPO

typically does not require you to see a designated primary care doctor who manages your care and controls your access to a specialist. A PPO may also be more flexible than an HMO in allowing visits to out-of-network doctors, although these visits usually require you to pay a larger portion of the bill. It may also require you to pay a deductible or co-insurance for some services. Some types of services, such as mental health services, physical therapy, home health care, investigational treatments, or alternative medicine may not be covered.

Government-Sponsored Insurance Programs

MEDICARE

Medicare is health insurance provided by the federal government for people 65 and older, as well as for some disabled Americans. People over 65 who are eligible for Social Security or Railroad Retirement benefits automatically qualify for Medicare, along with their spouse.

Medicare has different "parts" that serve different, sometimes complementary, purposes.

- Medicare Part A covers inpatient care (such as hospital care), skilled nursing care, hospice care, and a limited scope of home care services. These services are free.

- Medicare Part B provides financial coverage for doctor services, outpatient care, physical and occupational therapy, and selected supplies that are deemed medically necessary.

- Medicare Part C, also called Medicare Advantage, is an insurance plan managed by private Medicare-approved companies. It combines Medicare Parts A and B and may include prescription drug coverage.

- Medicare Part D is a benefit that people can enroll in that covers prescription drugs.

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 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 plan.

INSURANCE EXAMPLE #1: CO-PAYS

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 requires her to pay a $20 co-pay for specialist visits, how much does she pay out-of-pocket at the appointments?

Answer:

Anna will pay $20 at each doctor's office ($40 total). Because 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

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 x 20% = $20
- Martin's payment to Dr. Adams would be $100 since $500 x 20% = $100

INSURANCE EXAMPLE #3: CO-INSURANCE AND DEDUCTIBLES

Kathy has a deductible of $2,000 a year, and her co-insurance for a hospital visit is 20%. She recently 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: $10,000 – $2,000 = $8,000.

STEP TWO. Multiply the difference by the co-insurance percentage: $8,000 x 20% = $1,600. This gives Kathy'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 Kathy would pay: $2,000 + $1,600 = $3,600.

As you can see, Medicare does not cover all health care expenses. These expenses are called "gaps," and some people decide to purchase a Medigap policy to cover co-payments, co-insurance, deductibles, and other out-of-pocket expenses. During the past several years, there have been many revisions to the Medicare laws about what outpatient treatments are covered. Depending on a patient's Medicare plan, they may be responsible for a 20% co-payment if no other insurance is available.

MEDICAID

Medicaid is a health insurance program paid for by the federal and state governments and administered by each state. It covers people who are eligible because they are elderly, blind, or disabled, as well as certain people in families with dependent children. Each state operates the program individually and determines who is eligible and what services are covered in that specific state.

For more information about Medicare and Medicaid visit www.cms.gov. Medicare information can also be found at www.medicare.gov.

HEALTH INSURANCE MARKETPLACES

On October 1, 2013, the health insurance marketplaces, or exchanges, opened for enrollment. Created as part of the 2010 Patient Protection and Affordable Care Act, the exchanges represent a new way for individuals and families to choose and purchase health insurance. Depending on where you live within the United States, you can compare different health insurance plans and prices and find one that works best for you. For people who do not currently have health insurance or are not covered by an employer, this marketplace may be helpful. For 2014, the open enrollment period runs through March 31, 2014. For coverage starting in 2015, the open enrollment period is November 15, 2014 through January 15, 2015.

ALICE'S 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.

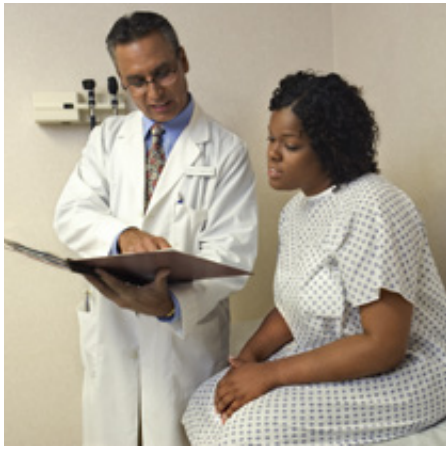
To explore and compare health insurance plans and learn more, visit the official resource for health insurance marketplaces, www.HealthCare.gov, or call 800-318-2596. Other resources that can help you understand more about your insurance options under the Affordable Care Act include the Health Law Helper (www.healthlawhelper.org) and the Cancer Insurance Checklist (www.cancerinsurancechecklist.org).

Other Types of Insurance

Although health insurance covers some of the costs of cancer care, other costs are not covered. Many of these additional expenses may be covered if you have purchased other types of insurance.

Supplemental insurance. A supplemental insurance policy helps cover expenses not covered by your primary insurance or the costs you pay as part of your existing plan. This policy generally covers deductibles, co-insurance, co-payments, and other out-of-pocket expenses. It may also offer additional benefits, such as compensation for lost earnings due to missed work.

Disability insurance. Disability insurance replaces income lost if you are unable to work due to a long-term illness or injury. Such coverage is often provided through your employer or government-sponsored programs, although individual policies are also available.



Hospital indemnity insurance. Hospital indemnity insurance provides limited coverage for hospital stays, usually a fixed amount each day up to a maximum length of stay. People may decide to purchase this type of insurance if their basic insurance plan limits coverage of hospital care.

Long-term care insurance. Because most basic private insurance plans and Medicare generally provide very limited coverage for long-term care, such as nursing home care, some people decide to get additional coverage to offset the costs of such care.

Additionally, some medical expenses not covered by insurance, including mileage for trips to and from appointments, prescription drugs, and meals during lengthy medical visits, can be deducted from federal income taxes. A tax advisor can help clarify these rules.

For a more detailed description of the different types of health insurance, visit www.cancer.net/insurance.

The Affordable Care Act and Cancer

In March 2010, the Patient Protection and Affordable Care Act, often called health care reform, was signed into law, changing several rules for health care insurance coverage in the United States. For people with cancer, this law affects both the cost of and access to medical care. Highlights of the Affordable Care Act are summarized below, many of which took effect January 1, 2014, unless otherwise noted. More details can be found at the federal government's website www.HealthCare.gov.

General Health 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, which means an insurance company cannot refuse to cover a person's health care for the rest of the person's life once a specific dollar amount has been reached.

- The law prohibits new plans and existing group plans from imposing annual dollar limits on most covered benefits (this does apply to non-essential benefits). This means that insurance companies cannot refuse to pay for care after you have reached a specific dollar amount for that year for any benefits that are covered. You may still be responsible for paying for benefits that are not covered under your plan.

- 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.

- Adults and dependent children under the age of 19 cannot be denied coverage for pre-existing conditions. There may be exceptions for people covered under grandfathered individual plans.

- In the individual and small group market, the law eliminates the ability of insurance companies to charge higher rates because a patient is male or female or has a specific health condition.

- For plans that started on or after January 1, 2014, waiting periods for coverage greater than 90 days is prohibited from group health plans.

For People Without Health Insurance

- Most U.S. citizens and legal residents will be required to have health insurance starting 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 their income, and those with incomes below the tax filing threshold. Penalties for people who can afford health insurance but decide not to get it will be phased in during 2014.

- Individuals without insurance are able to purchase insurance from the health insurance marketplace (insurance exchanges). These exchanges help people and small businesses with the purchase of coverage. Premium and cost-sharing credits will be available to individuals and families earning up to 400% of the federal poverty level (in 2013, $45,960 for individuals and $94,200 for a family of four).

- States were required to 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.

- In 2012, the Supreme Court ruled that a state had the option to expand Medicaid coverage to individuals with incomes up to 133% of the federal poverty level who were under 65 and not otherwise eligible for Medicare. (In 2013, this amount was approximately $15,282 for an individual and $31,322 for a family of four.)

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 amounts of time: 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.

For People Participating in Clinical Trials

For plans beginning on or after January 1, 2014, insurers are not allowed to limit or drop coverage to an individual choosing to participate in a clinical trial. Grandfathered health plans are not required to comply with this requirement. This applies to clinical trials to treat cancer, in addition to other life-threatening diseases.

DANIEL'S STORY

Daniel, a 56-year-old man, was recently diagnosed with cancer of the tongue. His treatment includes radiation therapy five times a week and chemotherapy once a week. Although Daniel lives in the same city as the cancer center, he has problems 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.

Daniel was referred to a social worker through his health care team. The social worker located a city-sponsored transportation program and funds from a charity to cover the nutritional formula and creams Daniel needed. The social worker also helped him access resources that covered his medication costs. Because of this support, Daniel was able to finish treatment and continues to get regular follow-up care.

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. The following suggestions may help as you start to track your costs and set up a personal organizational system.

Create a filing system that works for you. A filing cabinet or simple desktop divider with individual folders helps keep important 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.

Use technology as an organizational tool. If you prefer to use a computer to keep track of important information, creating a spreadsheet with columns for the appointment date, doctor's name, amount paid, status of the insurance claim, and other important notes can help you see, at a glance, the status of payments for medical services. It is also possible to track financial information related to your cancer care online or using an app.

Request a case manager. 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. It is also important to keep current copies of all insurance policies and refer to them by name and number in any communications about insurance coverage.

Take good notes. Maintain a written record of all conversations you have with an insurance company representative, 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.

Keep track of all unreimbursed medical expenses. This information may include the dates of each service, the amount paid, and the name of the provider. You may be able to claim these expenses for tax purposes. (A tax professional can provide advice on current rules and eligible expenses.)

Plan ahead. Try to decide ahead of time how to adjust your budget to deal with any loss of income due to less time at work or expenses that are not covered by insurance.

Ask for help. Friends and family members are great resources if you need help keeping track of your regular monthly bills. You might also want to consider using a bill-paying service to ensure payments are made on time.

PAMELA'S STORY

Pamela was 44 when she was first diagnosed with breast cancer four 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, but the intensive chemotherapy treatment schedule and side effects meant she first had to cut back on her hours and ultimately leave her position. 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 facility, Pamela applied for several programs. Due to her young age, she did not qualify for most programs, but 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 treatment costs.

To get more tips for managing your cancer care, visit www.cancer.net/managingyourcare.

Questions to Ask

Talking about your financial concerns with others is difficult, especially if you don't know what to say. It's also not always clear who the best person to answer your questions is, so 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, patient advocacy organizations, and your employer's human resources department. In addition, people from your insurance company can help answer questions about your specific health care 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, just choose the ones that are most important to your diagnosis and your financial situation. And remember, these conversations with your health care team will continue throughout 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 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?
- 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 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 insurance plan's network?
- If I need to be admitted to 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 childcare?
- 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?

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 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 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?

ASSOCIATED EXPENSES: TRANSPORTATION AND TRAVEL

- 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 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 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?

For more questions you may want to ask the doctor, visit www.cancer.net/questions.

Financial Resources

The following national organizations offer help to people with cancer who are facing financial challenges. You should contact these organizations directly to learn more about their specific programs and services, including eligibility criteria. Because programs and services continually change, visit Cancer.Net (www.cancer.net/support) to find the most current information, as well as additional organizations and support resources.

GENERAL FINANCIAL AND CO-PAY ASSISTANCE

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

Be The Match
www.bethematch.org
888-999-6743

Cancer*Care*
www.cancercare.org
800-813-4673

Cancer*Care* Co-Payment Assistance Foundation
www.cancercarecopay.org
866-552-6729

Cancer Financial Assistance Coalition
www.cancerfac.org

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

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

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

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

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

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

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

National Foundation for Transplants
www.transplants.org
800-489-3863

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

NeedyMeds
www.needymeds.org
800-503-6897

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.patientservicesinc.org
800-366-7741

RxHope
www.rxhope.com
877-267-0517

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

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

TRAVEL AND LODGING RESOURCES

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

Air Charity Network
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 Airline Samaritans
www.angelairlinesamaritans.org
800-296-1217

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

Healthcare Hospitality Network
www.nahhh.org
800-542-9730

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

PALS (Patient AirLift Services)
www.palservices.org
888-818-1231

Ronald McDonald House Charities
www.rmhc.org
630-623-7048

LOCAL RESOURCES

In addition to this national list, many organizations serve people in their local communities. 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 details.

Cost and Insurance Dictionary

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

Appeal: Asking your insurance company to reconsider its decision to deny payment for a service or treatment. You have the right to ask your insurance company to conduct a full and fair review of its decision, known as an internal review. If the company still denies payment after considering your appeal, the Affordable Care Act allows you to have an independent review organization decide whether to uphold or overturn the plan's decision, usually called an external review.

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

Case manager: A health care professional, often a nurse with experience in cancer, who 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 or reducing their hours, 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 the remaining 20% of costs out-of-pocket.

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; the insurance provider pays the rest of the visit's costs. The amount of the co-pay is set by the insurance provider, 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.

Essential health benefits: A set of services that an insurance plan is required to provide to patients. There can be no dollar limits each year on the cost that insurance pays for essential health benefits. According to the Affordable Care Act, plans offered in small group and individual markets must provide items and services in at least 10 categories for the plan to be certified and offered in the health care exchanges. Benefit categories include emergency services, preventive wellness and chronic disease management, and prescription drugs. More information is available at www.HealthCare.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.

Family and Medical Leave Act (FMLA): 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.

HMO: Health Maintenance Organization; 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).

HIPAA: Health Insurance Portability and Accountability Act. This is 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.hhs.gov/ocr/privacy.

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, but each state operates its program individually (including deciding who can receive Medicaid benefits 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.

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: Specific dates where eligible individuals are able to select or change to a new health care plan. Once this time ends, you may need to wait until the next open enrollment period, usually a year later, to join a health care plan, unless you qualify for a special enrollment period. Find additional information at www.HeatlhCare.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 are considered "out of network" (as opposed to being on an approved list or "in network"). 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 childcare during treatment; coordinating care among several doctors; and providing emotional support.

Patient Protection and Affordable Care Act: Often called "health care reform," this is a 2010 federal law that changed certain rules regarding health insurance coverage in the United States. Learn more at www.HealthCare.gov.

PPO: Preferred Provider Organization. This is a type of private 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. Starting in 2014, under the Affordable Care Act, insurance plans are not allowed to deny coverage or charge extra to individuals with a pre-existing condition. Learn more at www.HealthCare.gov.

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 geographic area that insurance plans use to decide how much they will pay for those services. If a doctor's fees for a service are 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 treating cancer.

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

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Phone: 571-483-1300 | Fax: 571-366-9530
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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