



When you or a loved one has cancer, you are focused on the disease, treatment, and doctors. Many people forget to ask questions that can help them to manage the costs associated with facing cancer—important questions like “How much will this cost?” and “How can I manage the costs?” The Cancer Support Community (CSC) has prepared this booklet to help you understand the financial aspects of a cancer diagnosis. There will be many physicians and

health centers involved in your care. While they will work together for you, they each will bill you separately. It can get confusing. We hope that this booklet will help you learn more about your options, know what questions to ask, and take control of your treatment and costs.


**CANCER SUPPORT
COMMUNITY.**



Costs Related to Cancer Care

Cancer treatment and follow-up appointments can take place over a few months or even years. This care can be costly. Keeping up with the costs can be overwhelming. If you have an insurance plan with deductibles and out-of-pocket maximums, your biggest costs will occur in the first 2-3 months after diagnosis and the first 2-3 months of each new insurance year. Because of this, the sooner you understand your costs, the better off you may be. You may find it helpful to work with a financial counselor. Contact CSC's Helpline or other organizations listed on the last 2 pages of this booklet.

INSURANCE ISSUES

If you don't have health insurance, contact CSC's Helpline or see pages 4-5 in our *Frankly Speaking About Cancer: Coping with the Cost of Care* book. If you have health insurance, it's important to learn about the specifics of your policy, including:

- What's covered
- Co-payments or co-pays (a dollar amount set by your insurance provider required to be paid by a patient each time care or a drug is received). There are co-pays that you pay for some services—like \$20 for an office visit or \$15 for a prescription drug refill.
- Deductibles (what you must pay out-of-pocket before your insurance company will begin to cover claims). You most likely have a deductible to pay before your insurance will start sharing the cost of services with you.
- Co-insurance (the percentage you pay in cost sharing). Once you meet your deductible,

TERMS YOU SHOULD KNOW

PREMIUM: The amount you and/or your employer pay each month to maintain insurance coverage.

CO-PAYMENT (CO-PAY): The amount your insurance requires you to pay each time you receive care.

DEDUCTIBLE: The amount of approved health care costs you must pay out-of-pocket each year before your insurance begins paying any costs.

CO-INSURANCE: The percentage of costs you pay after meeting your health care plan's annual deductible.

EXPLANATION OF BENEFITS (EOB): A document that outlines what portion of your health care provider's charges will be paid by your insurance plan.

OUT-OF-POCKET MAXIMUM: The most you have to pay for covered services in a plan year. After you spend this amount on deductibles, co-pays, and co-insurance, your health plan pays 100% of the costs of covered benefits.

your insurance may pay 80 percent and you pay 20 percent.

- Other out-of-pocket costs
- How to best use your insurance benefits. A good place to start is with your health insurance card. Your insurance card will have phone numbers you can call to learn more about your policy.



Questions to Help You Lower Costs of Care

You and your loved ones can take an active role in your care decisions. The more you learn, the more you can help to reduce unexpected costs. Asking questions and making informed choices can affect your care and your final costs. Below are some key questions to keep with you. Use the answers to help manage your care and treatment decisions.

LEARNING ABOUT YOUR DIAGNOSIS AND TREATMENT

- What is my diagnosis?
- Is this cancer treatable? If so, what are my treatment options?
- How sick will I be?
- What will I be able to do or not do?
- Can I keep working? For how long?
- What will my life be like during treatment?
- What will my future look like after treatment? Should I expect long-term side effects? Should I expect to be able to work after treatment is finished?
- Will I receive a care plan to help me understand the details of my cancer and treatment?
- Is a clinical trial right for me? How would that choice change the costs and my health in comparison to other choices? Are any of the costs of a clinical trial treatment covered?
- Do I have to get permission from my insurance company for anything related to my cancer treatment and diagnosis?

PAYING FOR YOUR CARE

- What are the direct and indirect costs of the treatment options available to me?
- Will my insurance cover these treatment options?
- What will this cost me out of my own pocket?
- Do I qualify for a different insurance plan?
- What are my expected payments? When are they due?
- Are there any payment plans that can help me?
- Who can I speak with to understand other bills that may not come from my doctor's office: tests, screenings, imaging, hospitalizations, emergency care?



Questions to Help You Lower Costs of Care (CONTINUED)

PAYING FOR YOUR CARE

- Are these treatment providers in my insurance company's network?
- Can I look for help to pay my bills and cover my other expenses? How do I apply?
- If I decide that I can't afford a treatment, who can I speak with to help me to find other options?

QUESTIONS FOR YOUR HEALTH CARE TEAM

- Is there a person who can help me with insurance and financial questions in my doctor's office?
- Where can I find other help with treatment or drug costs, daily living costs, transportation, and other costs?
- Who can help me with choices so that I can keep working?
- What about help taking time off from work or if I can't work any longer?
- What if I am at risk for losing my insurance?
- If I am no longer able to work, how do I apply for disability benefits? Who can help me with this?

QUESTIONS FOR YOUR INSURANCE COMPANY

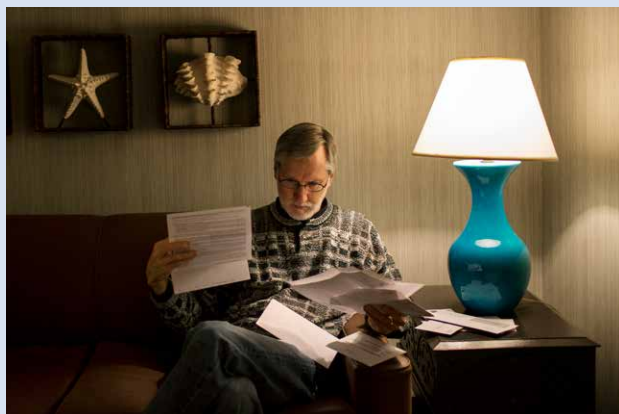
- What does my insurance plan cover and allow for cancer care?
- What about counseling and supportive services like nutrition and social services?
- Are there limits to how much insurance will pay for the year?
- Are there limits to what insurance will pay for this policy (called a lifetime maximum)?
- What does my insurance plan say I have to pay for each visit to the doctor's offices, to a hospital, or to the emergency room?
- What does my insurance plan say I have to pay for each cancer drug, lab test, and cancer related test?
- Are there insurance limits or rules for what I pay for cancer drugs?
- Does the insurance make me get the drugs I need from a specific doctor or pharmacy?
- Do you have a cancer case manager available to help me?

Other Resources for Patients Related to Costs of Cancer Care and Support

CSC has gathered valuable information from many sources to create an online guide for patients managing the costs of cancer treatment. These materials provide patients and their families with detailed information on:

- Gathering Cost Information
- Health Insurance
- Employment, Disability, & Finances
- Prescription Medications
- Additional Resources and a Glossary of Terms

These resources can be found at www.CancerSupportCommunity.org/cost. Additional Cost of Care materials can be ordered at Orders.CancerSupportCommunity.org.



THE FIRST STEP IN MANAGING THE COST OF CANCER TREATMENT? ASK FOR HELP

Cancer Support Community's TOLL-FREE Cancer Support Helpline (1-888-793-9355) is for anyone affected by cancer. The helpline is open Monday through Friday from 9:00 a.m. – 9:00 p.m. Eastern Time. You are welcome to call anytime and leave a message with your name and contact number, and one of our counselors will call you back. You can also CHAT ONLINE with one of our Helpline Counselors at www.CancerSupportCommunity.org/chat.

COMMON MEDICAL COSTS

Some of the most common things that affect costs are:



YOUR OVERALL HEALTH

Your health outside of cancer can affect your total costs of care. If you have other conditions, like heart disease or diabetes, make sure you and your doctors are watching them closely. Ask your doctor who you should call at their office if you experience symptoms. They will guide you as to whether or not it is an emergency and where to seek care. Talk with your doctors about how to stay as healthy as possible.



SITE OF CARE COSTS

Your insurance plan may limit where you can go for care. The costs of your care may be different depending on where you go. The cost can also change based on whether the physician or facility is considered to be in or out of your covered network. You have the right to call different hospitals or physicians to ask about potential costs of treatments before you decide where to seek care.



OTHER DAILY LIVING COSTS

Many things can affect your costs during this time. You may wonder about childcare, parent care, transportation, parking, special diets, and other costs of living with cancer. Even though these are not direct medical costs, they can add to your costs of care. Help may be available for some of these services, so be sure to ask your health care team.



PSYCHOTHERAPY AND COUNSELING

You or your loved ones may need help with the stress of living with cancer. Help may be available from many different sources. Check with your physician's office and find resources by calling CSC's Cancer Support Helpline at 1-888-793-9355 or chat at www.CancerSupportCommunity.org/chat.



PROFESSIONAL SERVICES (PHYSICIANS/PROVIDERS)

You may see many doctors during your care. Each will have their own charges. Your insurance plan rules may mean you pay more for some visits or doctors. For example, the co-payment for a visit to a primary care physician may be less than the co-payment for a visit to a specialist like a cancer physician. Check first to see if a doctor is in the "Approved Network" for your insurance plan. Know the insurance rules about doctors. Also, know if you need to ask permission from your primary care physician to see a doctor before you go.



EMPLOYMENT AND FINANCIAL ISSUES

For many, coping with working (or not working) is a big challenge. This can lead to other financial stresses, like disability, leaving work, and estate planning. There are often costs associated with employment choices. It is important to address your financial concerns and know your options at the start of your treatment, if possible. The Cancer Support Community has information and resources on employment and cancer at www.CancerSupportCommunity.org/employment-and-cancer. Additional resources can be found on the last page of this booklet.



CARE

(Rehabilitation Care, Long Term Care, Home Health Care, and Hospice Care)

Cancer can make it hard for you to do regular daily activities. It is possible that you may need services like rehabilitation, long term care, or home health care. These services can help you to regain strength and skills. Hospice care may also be used along the cancer journey. If needed, help can be found for these type of costs.



INSURANCE PLAN BENEFITS

Your own insurance plan has rules about what it will or won't cover. If your insurance plan does not cover something, you may be responsible for the cost if you choose to receive the service. Your physician can help, but you should know what your plan covers and what it doesn't.



DIAGNOSTIC SERVICES

There are many laboratory, imaging, and diagnostic tests that can be used to find out more about your cancer. This information can help you and your doctor decide which treatment options are best for you. Diagnostic services includes lab and x-ray services. Insurance can set tight rules for these costs and may choose to exclude some tests, or to limit coverage for others. Ask about the rules, and ask your doctor to follow the rules, so that you don't pay extra.



TREATMENT RELATED

(Cancer Drugs, Supportive Care Drugs, Prescriptions, and Radiation Treatments)

There are often many choices for treatments. Some may cost more than others. Ask your doctor about your treatment choices. Ask if you can fill prescriptions with your doctor or a pharmacy—that can change your costs.



HOSPITALS AND EMERGENCY ROOMS

These cost a lot. Sometimes cancer patients go to the hospital when they could have gone to their doctor's office and received the same care for a lower cost. Work with your doctor to understand your symptoms and possible side effects. You can reduce your costs if you can manage your care with your doctor and stay as healthy as possible.

PRACTICAL TIPS TO HELP YOU LOWER COST OF CARE

Here are some ways that you can seek help and start to lower your costs of care. Cancer is complicated. There will be a team of care providers helping you through the journey. It is very hard to predict the actual total costs for each person. Two people with the same exact diagnosis may have much different costs. In general, to lower the costs of dealing with cancer, patients and their loved ones can:

TIP ONE

KNOW YOUR TREATMENT PLAN AND YOUR DIAGNOSIS When comparing treatment costs, or asking for help, it's often very important to know what your treatment plan is. Write down the names of drugs that you are receiving and the name and stage of your cancer diagnosis. It will also be helpful to know your overall treatment plan. This can help you know if you will have surgery at some point, receive radiation, and/or receive chemotherapy, etc.

TIP TWO

REVIEW YOUR INSURANCE COVERAGE Some insurance plans may offer low premiums, but provide limited coverage for complex diseases like cancer. Ask questions before choosing an insurance plan. Ask about what you will pay for and if there are limits for what is covered. Ask which doctors, hospitals, labs, tests, x-rays, or drugs will be covered before choosing them.

TIP THREE

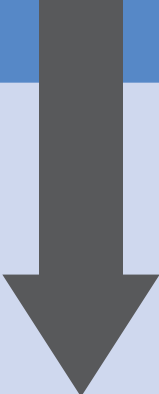
USE SCREENING AND WELLNESS PROGRAMS Learn your own risks for cancer. Try to catch cancers early or prevent them. If you are already dealing with cancer, you may have an increased risk for developing others. Look for screenings and wellness programs to help.

TIP FOUR

CHOOSE PHYSICIANS AND FACILITIES CAREFULLY Make sure doctors, cancer centers, or hospitals are covered by your insurance. Ask questions about costs of treatment choices. Ask if there are any services that are not going to be covered. Ask for a written care plan. Bring someone with you to each visit to take notes and help you with questions.

TIP FIVE

GET A SECOND OPINION Compare choices and don't be afraid to ask about costs. The same treatment may have a different cost at a hospital or a private practice. Your co-pays and co-insurance costs may also vary. Drugs may be dispensed from a physician, hospital, or special pharmacy. The co-pay and co-insurance requirements can vary widely between those choices.



TIP SIX

STAY ON TOP OF YOUR HEALTH Take care of yourself. Watch for changes in your health and how you feel. Follow directions for managing your symptoms and treatment side effects. Talk to your doctors and nurses about taking care of other health issues (like diabetes, heart problems, and high/low blood pressure) while you are treating the cancer.

TIP SEVEN

STAY ORGANIZED This can be a confusing time. Make folders to keep important information in one place and easy to find. Request and store care plans from your doctors. Keep copies of test results, symptom and drug information, and your insurance plan. Make a contact list for your doctor offices, hospitals, insurance company, pharmacy, and others providing help to you. Make notes when you talk with insurance company staff. Include the date, the person's name, and what was said.

TIP EIGHT

TRACK BILLS AND WHAT YOU SPEND Keep records for the dates of service, what you paid, what you paid for, and what insurers or others paid for. Keep track of the miles you travel for treatment. Some costs may be tax deductible. You should get a paper called the Explanation of Benefits (EOB) from your insurer when they pay claims. You can call your insurer and ask them to send you a copy of the EOB every time something is billed to them (if they do not do that already). If an insurance claim is denied, you can appeal the insurance company's decision. Ask your doctor's office for help. You may be able to review your bills with a financial navigator or billing counselor in your doctor's office.

TIP NINE

ASK FOR HELP You can find help in many places, including your insurance company, doctors, hospital, family members and friends, and local support groups. Some of these people may be called care managers, financial counselors, or patient navigators. Don't be afraid to ask for help.

TIP TEN

SEEK HELP FROM FOUNDATIONS AND PROGRAMS You can call foundation or assistance programs to learn what help is available. When you fill out forms, clearly write all the information requested, including information for your doctor's office. If a physician must sign for you to receive help, let them know. Make sure all of their information is correct (address, phone number, etc.) Keep copies of all completed forms for your records. Submit information on time if there is a deadline. If a form affects your drug refills, submit the form early enough that it can be processed to keep your refill on time. Let your doctor's office know about what you are doing with foundation or assistance programs.

Programs and Resources

Here is a partial list of patient assistance programs and resources for those dealing with cancer:

Aging Care[®] • www.agingcare.com

American Breast Cancer Foundation • www.abcf.org

The Assistance Fund • www.theassistancefund.org

Benefits Checkup[®] • www.benefitscheckup.org

Cancer and Careers (CAC) • www.cancerandcareers.org

CancerCare Co-Payment Assistance[®] • www.cancercarecopay.org

Cancer Financial Assistance Coalition • www.cancerfac.org

Cancer Finances Toolkit • www.cancerfinances.org

Cancer Support Community • www.cancersupportcommunity.org

Co-Pay Relief • www.copays.org

Compassionate Allowances • www.ssa.gov/compassionateallowances

Good Days • www.mygooddays.org

Genetic and Rare Diseases Information Center

www.rarediseases.info.nih.gov/guides/pages/96/patients-families-and-friends

Extra Help • www.ssa.gov/medicare/prescriptionhelp

HealthWell Foundation • www.healthwellfoundation.org

Leukemia & Lymphoma Society • www.LLS.org

National Organization for Rare Disorders • www.rarediseases.org

Need Help Paying Bills • www.needhelppayingbills.com

NeedyMeds • www.needymeds.com

Partnership for Prescription Assistance • www.pparx.org

Patient Access Network Foundation • www.panfoundation.org

Patient Advocate Foundation • www.patientadvocate.org

Patient Services, Inc. • www.patientservicesinc.org

RxAssist • www.rxassist.org

RxHope[™] • www.rxhope.com

Rx Outreach[®] • www.rxoutreach.org

General Cancer Information, Survivorship, & Support

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

CancerCare • 800-813-4673 • www.cancercare.org

Cancer.net • 888-651-3038 • www.cancer.net

National Cancer Institute (NCI) • 800-422-6237 • www.cancer.gov

NCI Clinical Trial Information • 800-422-6237 • www.cancer.gov/ClinicalTrials

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

Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below call 888-793-9355 or visit www.CancerSupportCommunity.org

Cancer Support Helpline® Whether you are newly diagnosed with cancer, a long-time cancer survivor, caring for someone with cancer, or a health care professional looking for resources, CSC's toll-free Cancer Support Helpline (888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Mon-Fri 9am - 9pm ET.

Open to Options® If you are facing a cancer treatment decision, this research-proven program can help you. In less than an hour, our trained specialists can help you create a written list of specific questions about your concerns for your doctor. Appointments can be made by calling 888-793-9355, visiting www.CancerSupportCommunity.org or by contacting your local CSC or Gilda's Club providing this service.

Cancer Experience Registry® The Registry is a community of people touched by cancer. The Registry works to collect, analyze, and share information about the experience and needs of patients and their families. To join, go to www.CancerExperienceRegistry.org.

Frankly Speaking about Cancer® CSC's landmark cancer education series provides trusted information for cancer patients and their loved ones. Information is available through publications, online, and in-person programs.

Grassroots Network CSC's Cancer Policy Institute provides updates on policy issues that impact the health and wellbeing of cancer patients and survivors. Join the Network to make your voices heard with federal and state policy makers. www.CancerSupportCommunity.org/join-our-movement

Services at Local CSCs and Gilda's Clubs Almost 50 locations plus 120 satellite locations around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost to the member.

The Living Room, Online Here you will find support and connection with others on discussion boards, a special space for teens, and personal web pages to keep your family and friends up-to-date.

THIS PROGRAM WAS MADE POSSIBLE THROUGH GENEROUS SUPPORT FROM:

