

# FRANKLY SPEAKING ABOUT CANCER

## Tips for Managing and Budgeting Your Cancer Costs



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When you or a loved one has cancer, you are focused on the disease, treatment, and doctors. Many people don't know to ask questions that can help them manage cancer costs – important questions like “How much will all of this cost?” and “How can I manage these costs?” The first half of this booklet can help you understand and find ways to lower your cancer costs. The second half can

help you estimate your total cancer costs. We hope that this will help you take control of your treatment and costs. Remember that you don't have to do this alone. There are financial counselors that can help.



# 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.

## 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 or a drug. *Examples of co-pays are \$20 for an office visit or \$15 for a prescription drug refill.*

**DEDUCTIBLE:** The amount of approved health care costs you must pay out-of-pocket each year before your insurance begins paying any costs. *Lower deductibles (like \$250 or \$500) mean you pay less money up front before your plan starts paying. High deductible plans can make you pay thousands out-of-pocket before your plan starts paying.*

**CO-INSURANCE:** The percentage of costs you pay after meeting your health care plan's annual deductible. *Once you meet your deductible, your insurance may pay 80 percent and you pay 20 percent.*

## 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.

**OUT-OF-NETWORK:** Any health care provider or service that is not a part of your health plan. Most plans do not pay for (or pay less for) services that are provided out-of-network.

**PRE-APPROVAL:** You or your health care provider must obtain approval from your health care provider before you receive certain services or they won't be covered.

**COBRA:** A federal law that allows many people to pay to stay on their work's health plan after they lose a job or otherwise lose access to coverage at work.

## INSURANCE ISSUES

If you don't have health insurance, contact CSC's Helpline (888-793-9355) or see pages 4-5 in our *Frankly Speaking About Cancer: Coping with the Cost of Care* book. (Available at

[www.CancerSupportCommunity.org/cost](http://www.CancerSupportCommunity.org/cost))

If you have health insurance, it's important to learn 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
- Co-insurance
- 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.
- Keep in mind that your health plan needs to be reviewed every year. Your coverage can change, even if you don't change health plans.

## CSC 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](http://www.CancerSupportCommunity.org/cost). You can also download or order these and other materials at [Orders.CancerSupportCommunity.org](http://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) can help you navigate financial issues, support you in making treatment decisions, and provide resources to help manage the costs of cancer and its treatments. The helpline is open Monday through

Friday from 9:00 a.m. – 9:00 p.m. Eastern Time. You can also CHAT ONLINE with one of our Helpline Counselors at [www.CancerSupportCommunity.org/chat](http://www.CancerSupportCommunity.org/chat).

# COMMON MEDICAL COSTS

Some of the most common things that affect costs are listed below. While this list can help you understand ways to lower your cancer costs, unexpected costs can always occur.



## 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](http://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](http://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 this type of cost.



## 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 include labs and imaging tests. 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, AMBULANCES, 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 very 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

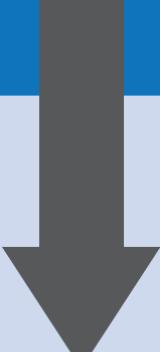
**USE SCREENING AND WELLNESS PROGRAMS** Learn your own risks for cancer. Try to catch cancers early or prevent them. If you are already dealing with cancer, you may have an increased risk for developing others. Look for screenings and wellness programs to help.

## TIP FOUR

**CHOOSE PHYSICIANS AND FACILITIES CAREFULLY** Make sure doctors, cancer centers, or hospitals are in-network and covered by your insurance. Ask questions about treatment costs. Ask if you can negotiate a discount, especially if you are uninsured or paying out-of-pocket. Ask if there are any services that are not going to be covered. Ask for a written care plan. Ask your doctor's office to help you appeal when your insurance company denies payment.

## 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. Tracking bills and what you paid may save you from paying duplicate bills.

**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 and be willing to accept it.

**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.

# Budgeting for Your Cancer Care Costs

Finances and health are two of the most common sources of stress. A cancer diagnosis combines both into one package. So it may feel completely overwhelming to sit down and think about the health care expenses you are likely to face.

But the sooner you are able to look at the impact of cancer care on your finances, the sooner you can plan for how to handle it. CSC created this budgeting worksheet to help you understand what your costs might be so that you can plan for them and get help as soon as you need it. We know it's not easy. But by taking the time to focus on this now, you may be able to reduce the bills you face later.

Consider getting help filling out this worksheet from a family member, trusted friend, financial navigator\*, or financial counselor. It is easier to complete this worksheet if you get help.

It's not easy to prepare for these costs. Getting treated for cancer isn't like buying a new TV. There's no tag showing the final, total cost up front. There's no simple way to compare costs among hospitals, as you would among stores. And, of course, selecting your TV's size in no way compares to deciding what treatment is most likely to give you the best chance of living well.

But there are questions you can ask, people you can turn to, and options to consider that can help you face — and possibly even reduce — some of these costs.



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## THINKING AHEAD

The worksheet that begins on page 11 can help you get a sense of how much your cancer care will cost. It will help you think about the medical bills you will be responsible for as well as other out-of-pocket costs that can add up quickly: parking fees, transportation and taxi fees, hotel stays, meals, and more.

Thinking through these potential costs can also help you think about ways to reduce some costs or possibly avoid others. If you think you may need financial assistance, look for it as soon as possible. It is much easier to find help for future costs than for costs that have already happened. See pages 22 and 23 for information on financial assistance programs.

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\* Call the *Cancer Support Helpline*® at 888-793-9355 or ask your health care team or business office of your clinic to get help in finding a financial navigator or counselor.



# Questions to Help You Lower Your 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.

## QUESTIONS ABOUT YOUR DIAGNOSIS AND TREATMENT

(Ask your health care team)

- 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?

## QUESTIONS ABOUT FINANCES

(Ask your health care team, a social worker, or a financial counselor)

- 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 TO HELP YOU LOWER YOUR COSTS OF CARE (CONTINUED)

### QUESTIONS ABOUT THE COST OF YOUR CARE

(Ask your health care team, financial counselor, or insurance company)

- 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?
- 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 ABOUT YOUR COVERAGE

(Ask your insurance company)

Write your answers on pages 11 through 13.

- What does my insurance plan cover and allow for cancer care?
- What about counseling and supportive services like nutrition and social services?
- Does my insurance plan cover complementary therapies to help with my cancer treatment?
- 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?

# YOUR INSURANCE COVERAGE

Most of the information about your insurance coverage can be found online in your insurance plan's handbook. You can also call your health plan and ask them to explain it to you. If you are covered by more than one health insurance, make copies of the next 3 pages or visit [www.CancerSupportCommunity.org/cost](http://www.CancerSupportCommunity.org/cost) to download more copies of these pages. Please note that the information about your insurance coverage should be filled out annually.

Fill in the blanks for each insurance policy that covers you.

■ Your insurance company is \_\_\_\_\_

■ Do you have Medicare? What kind:

Part A & Part B (Original) \_\_\_\_\_

Part C (Medicare Advantage) \_\_\_\_\_

Part D Drug Coverage \_\_\_\_\_

Medigap (Supplemental Medicare) \_\_\_\_\_

Other \_\_\_\_\_

■ What number do you call to understand your coverage and ask questions? \_\_\_\_\_



Whenever you call your insurance company, write down the name of the person you spoke to and the date and time. This can help if there is “a dispute of coverage.”

## NOTES

## YOUR INSURANCE COVERAGE (CONTINUED)

Call your insurer. Ask and write down the answers to these questions:

- What month does your plan year begin? (Many begin on January 1, but not all do.)

### TIP

If you are diagnosed in December, and your health plan re-sets in January, see if you can start treatment in January. That way, you will not be paying toward one year's out-of-pocket maximum in December and then the next year's in January. Your biggest expenses happen in the first few months after diagnosis and the first few months of each insurance plan year.

- What is your in-network deductible for the year? Is there just one deductible, or are there different deductibles for different treatments and/or a different deductible for prescription drugs?

- What have you already spent toward your deductible(s) this year? \$ \_\_\_\_\_

- Do you have an out-of-pocket maximum? If so, what is it? Is it different for in-network and out-of-network? Does it include prescription drugs? \_\_\_\_\_

### TIP

If you have an out-of-pocket maximum, then the most you will have to pay for covered services in a plan year will be your out-of-pocket maximum plus any expenses not covered by the out-of-pocket maximum (for instance, it may not cover prescription drugs or out-of-network treatment).

- What have you already spent toward your out-of-pocket maximum this year? \$ \_\_\_\_\_

## NOTES

Ask and write down the answers to these questions below:

- How can you be sure your doctor, hospital, pharmacy, and all your health care providers are in-network?

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- What is your in-network co-pay or co-insurance for:

A doctor's appointment? \_\_\_\_\_

Lab tests? \_\_\_\_\_

Scans? \_\_\_\_\_

Going to the Emergency Room? \_\_\_\_\_

Hospital stays? \_\_\_\_\_

Prescription medications to treat your cancer or manage side effects? \_\_\_\_\_

Also Ask About:

- Does your insurance cover and, if so, how much coverage does it provide for:

Home care? \_\_\_\_\_

Cosmetic items, like wigs and breast forms? \_\_\_\_\_

Counseling, therapy, or support groups? \_\_\_\_\_

Fertility treatments (if your cancer affects your fertility)? \_\_\_\_\_

**NOTES**



There are a resources that can assist you in finding information about your insurance policy, such as: your insurance case manager from your health insurance company, your health insurance broker, your financial advisor, and if you have an employer-sponsored health plan, your Human Resources representative should also be able to answer questions about your policy.

## ESTIMATING YOUR TREATMENT COSTS

Your cancer treatment plan is likely to include many different types of treatments. You may not know what you will need at the beginning, and your treatment plan may change. But by completing this form you can start to get a sense of what your treatment will cost and how to manage it. One way to make this less overwhelming is to get help from a loved one or financial counselor to fill this out. Please note that the information about your treatment costs should be filled out annually.

Ask your treatment team for the full name and stage of the type of cancer you have.

Your Diagnosis \_\_\_\_\_

### TO GET STARTED

Call your doctor or medical center and ask to speak with a financial counselor or financial navigator. Questions to ask them:

- What kinds of treatments you can expect and what their cost will be.
- What you can do to prepare for these costs.
- Can you set up a payment plan?
- Are there pharmaceutical assistance programs that can pay all or part of the cost of cancer drugs you may need?
- Will you qualify for any assistance programs?

Fill in the answers on the next 5 pages.



photo: Ed Cunicelli

Aetna, Anthem, and Kaiser Permanente are some of the insurers and providers that offer their patients online treatment cost calculators. These calculators can help give you a sense of what the charge will be for specific services. Ask your insurance company if they have a treatment cost calculator.

What if your insurer or provider does not have a cost calculator? Fair Health is a nonprofit that provides information about costs in your area for many medical treatments. For more information, visit **[www.fairhealthconsumer.org](http://www.fairhealthconsumer.org)** or call 855-566-5871.

Let's start estimating your medical costs for this insurance plan year. If you need to estimate costs for next plan year, make copies of this form before you start filling it out. You can also visit [www.CancerSupportCommunity.org/cost](http://www.CancerSupportCommunity.org/cost) to download more copies.

If you have a plan with an **out-of-pocket maximum** and are able to stay within the plan's network, that can give you a rough estimate of the total you may spend on medical costs (but not extra personal or household costs) in a plan year.

If your out-of-pocket maximum does not include prescription drugs or you are not able to stay within your plan's network, complete the relevant sections below to estimate your treatment costs for this plan year.



## Doctor's Appointments

What is your co-pay or co-insurance for each doctor visit? How often will you see your doctors?

### DO THE MATH ▼

Number of appointments per month		co-pay/ co-insurance cost		number of months left in your plan year			<b>ESTIMATED EXPENSE</b>
	x		x		=	\$	



## Scans, Diagnostic Tests, Biomarker Tests, and Genetic Tests

What is your co-pay or co-insurance for a scan? How often will you need one? What is your co-pay for any diagnostic tests, biomarker tests, genetic tests, or genetic counseling you will need this year?

### DO THE MATH ▼

Number of scans, tests, and/or genetic counseling expected this year		co-pay/co-insurance cost			<b>ESTIMATED EXPENSE</b>
	x		=	\$	

<b>SUBTOTAL OF ESTIMATED EXPENSES IN THIS PAGE</b>	=	\$
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## ESTIMATING YOUR TREATMENT COSTS (CONTINUED)

### Biopsy and/or Surgery

What is the estimated co-pay or co-insurance for your surgery, including surgeon, hospital, and anesthesiologist?

#### DO THE MATH ▼

What will your insurance cover and what are you likely to be expected to pay?			<b>ESTIMATED EXPENSE</b>
	=	\$	

### Radiation Therapy

Will you need radiation therapy? What is your co-pay or co-insurance for each appointment? How many appointments will you need?

#### DO THE MATH ▼

Number of radiation appointments in this plan year		co-pay/co-insurance cost		<b>ESTIMATED EXPENSE</b>
	x		=	\$

### Chemotherapy

Will you need chemotherapy? Will you receive one drug or a combination of drugs? What will your chemotherapy plus any drugs your team expects to use to treat or reduce their side effects cost?

#### DO THE MATH ▼

Number of rounds of chemotherapy in this plan year		cost of chemotherapy and expected prescription drug co-pays per round		<b>ESTIMATED EXPENSE</b>
	x		=	\$

**TIP** For all the therapies on these pages ask if there are other options that are as effective but less expensive. Ask about patient assistance programs and check the list of programs and resources on page 23 of this book.

<b>SUBTOTAL OF ESTIMATED EXPENSES IN THIS PAGE</b>	=	\$
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## Hormonal Therapy

Will you need hormonal therapy? How much will it cost?

### DO THE MATH ▼

Months you expect to be on hormonal therapy this plan year		cost per month		<b>ESTIMATED EXPENSE</b>
	x		=	\$

## Targeted Therapy or Immunotherapy

Will you need a targeted therapy or immunotherapy? Will it be a pill you take or come as an infusion? Is it covered by your insurance? What portion will they cover? Ask your team if they expect you to need any treatments to reduce side effects and what they cost per month.

### DO THE MATH ▼

Months (or number of rounds) you expect to be on targeted therapy or immunotherapy this plan year		cost per month (or per round)		<b>ESTIMATED EXPENSE</b>
	x		=	\$

## Out of Network

Will you need to see any out-of-network doctors?

### DO THE MATH ▼

Find out what you can expect to pay for these visits.		<b>ESTIMATED EXPENSE</b>
	=	\$

**TIP** Ask if there is a way to reduce the cost.

<b>SUBTOTAL OF ESTIMATED EXPENSES IN THIS PAGE</b>	=	\$
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## Palliative Care

Are you receiving palliative care?

Palliative care can improve the quality of life for people of any age and at any stage in a serious illness, whether that illness is curable, chronic, or life-threatening.

Palliative care specialists work as part of a team that can include palliative care doctors, nurses, nutritionists, massage therapists and others.

Talk to your doctor about palliative care. Is it covered by your insurance?

### DO THE MATH ▼

Find out what you can expect to pay for these visits.		<b>ESTIMATED EXPENSE</b>
	=	\$



## Clinical Trials

Are you participating in a clinical trial? Clinical trials will often cover the cost of experimental medications, but there are other costs that you may be responsible for, such as:

- Drugs used in the clinical trial that are approved for your type of cancer.
- Co-pays or co-insurance for scans you receive in the clinical trial that are considered routine care.

Questions to ask the clinical trial coordinator:

- what you and your insurance will be expected to pay for.
- what will the clinical trial pay for.
- who will pay for treatments to manage side effects that you experience from the experimental treatment.

### DO THE MATH ▼

I will be required to pay for		<b>ESTIMATED EXPENSE</b>
	=	\$

<b>SUBTOTAL OF ESTIMATED EXPENSES IN THIS PAGE</b>	=	\$
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## Other Health Costs and Prescription Drugs

What health costs do you have monthly? (Do you have other conditions that you visit doctors for? Do you pay to see a counselor or be part of a support group? What prescription drugs do you usually take monthly)?

### DO THE MATH ▼

Months in this plan year		other health costs you usually have monthly		ESTIMATED EXPENSE
	x		=	\$

<b>SUBTOTAL OF ESTIMATED EXPENSES IN THIS PAGE</b>	=	\$
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### ADD TOGETHER ALL YOUR ESTIMATED TREATMENT EXPENSES FROM PAGES 15-19 ▼

(add together all the subtotals in **GREEN** boxes).

SUBTOTAL FROM PAGE 15	=	\$
SUBTOTAL FROM PAGE 16	=	\$
SUBTOTAL FROM PAGE 17	=	\$
SUBTOTAL FROM PAGE 18	=	\$
SUBTOTAL FROM PAGE 19	=	\$
<b>THIS IS YOUR TOTAL ESTIMATED TREATMENT COST</b>	=	\$

If your insurance has an out-of-pocket maximum, compare your out-of-pocket maximum to your total estimated treatment costs. If your treatment and drug costs are covered by one out-of-pocket maximum, then the most you should have to pay in a plan year is the out-of-pocket maximum amount. However, any costs that are not covered by your out-of-pocket maximum (for example, drug costs or out-of-network costs on some plans) will not be capped. Instead, your total treatment cost will be the out-of-pocket maximum amount plus any expenses not covered by the out-of-pocket maximum.

# ESTIMATED HOUSEHOLD COSTS

If you keep a household budget, you know how quickly expenses can add up. Cancer will affect your budget in both little and big ways. Your household costs will probably change. If you are the head cook in your house, you will have less time to cook or look for bargains. You may end up eating out or ordering in. You may need to call a taxi instead of drive. You may need to hire someone to come in and clean your house. All of this can add up quickly.

## THINK ABOUT ▼

How much more will you spend than usual on transportation/travel costs?	\$
Do you have family that requires care that you will not be able to provide during your cancer treatment? Will you have to pay someone to perform this care? If so, how much will that cost?	\$
Will you need a home health aide while recovering? What will it cost?	\$
Will you have additional childcare costs? How much?	\$
Will you need house cleaning help? How much will that cost?	\$
Will your housing/home situation change because of your cancer treatment?	\$
Will you need temporary housing during treatment? What will it cost?	\$
What other additional household expenses (extra grocery costs, over the counter drugs, massages, acupuncture, etc.) might you pay this year due to your cancer treatment? How much will that cost?	\$
What other additional household expenses might you pay this year due to your cancer treatment? How much will that cost?	\$

## ADD TOGETHER ALL YOUR ESTIMATED HOUSEHOLD EXPENSES ▼

(add together all the amounts in **PURPLE** boxes).

<b>THIS IS YOUR TOTAL ESTIMATED HOUSEHOLD COST</b>
\$



There are resources to help reduce some of these costs. Have a family member or friend set up a website, like [MyLifeLine.org](http://MyLifeLine.org), that lets people who want to help you know what you need.

# CHANGES TO YOUR INCOME

If you are employed, being diagnosed with and treated for cancer is likely to affect your ability to work. This, in turn, can affect your income. You should know the answers to these questions:

What are your options for working during treatment? Can you work part-time? Are you able to work from home? How many sick or vacation days can you use to cover missed days? If you need to take an extended absence from work, what are your options for returning to work?

THINK ABOUT ▼	ESTIMATED INCOME CHANGE
If you think you will earn less than usual this year due to occasional or extended absences from work, try to estimate how much less you will earn:	\$
Have you asked your employer about options (for example, possible COBRA coverage) in case you are not able to work and continue with your current insurance? If you will have to start paying for your own insurance or COBRA coverage, how much will that cost this year:	\$
Do you qualify for social security disability? If so, how much will you receive this year?	- \$
Do you have short-term or long-term disability insurance that might help with costs and financial planning? If so, try to estimate how much they will pay this year:	- \$

## CALCULATE YOUR ESTIMATED CHANGE IN INCOME ▼

Add together how much less you will earn and how much you will pay for insurance that your employer used to pay **(BROWN BOXES)** and subtract any disability payments **(BLUE BOX)**.

<b>THIS IS THE TOTAL AMOUNT YOU ESTIMATE CANCER TREATMENT WILL AFFECT YOUR INCOME THIS YEAR</b>
\$



Your retirement plan may allow for early withdrawals, without penalties, for advanced illness in certain situations. Talk to your accountant or financial planner about your financial assets to see if they can be leveraged without penalty due to illness.

# Help with Assistance Programs and Resources

Many programs offer help to cancer patients with the costs of co-pays, co-insurance, and specific medications. A partial list of financial assistance programs, including help from pharmaceutical companies to help patients receive the treatment they need, can be found at [www.CancerSupportCommunity.org/help-managing-cancer-costs](http://www.CancerSupportCommunity.org/help-managing-cancer-costs).

Your local Cancer Support Community affiliate is a good place to start for help finding local resources and programs. To find a local CSC or Gilda's Club near you, go to [www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation) or call our Helpline at 888-793-9355.

Several other patient assistance programs and resources exist. You may contact them directly or work with your doctor's office or pharmacy to locate resources.

## KEEP TRACK OF LOCAL ASSISTANCE PROGRAMS THAT MAY BE RECOMMENDED FOR YOU HERE:

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## BILLS, BILLS AND MORE BILLS — HOW TO ORGANIZE THEM

Health care bills can be very confusing. You may get a bill that says “do not pay” because it’s not yet clear what your insurance will cover. You may get bills that say “pay this amount” but it’s not really clear what you are paying for. The best thing you can do: Get an accordion-type folder and organize the bills by month or by provider — whatever works for you. Staple the ones that go together. The process of organizing them may be all you are able to do at first. But just doing that first step will put you one step ahead. Consider asking a trusted friend or family member to help organize your bills so you know what your insurance has paid and what you are expected to pay.

Once you do pay a bill, write on it the date you paid it, how much you paid, and the check or tracking number. You may want to set up spreadsheets of your treatment costs, household expenses, and income. This can come in handy for questions about bills as well as deducting health and travel costs on your taxes.

# Programs and Resources

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

## **Aging Care®**

239-594-3222  
[www.agingcare.com](http://www.agingcare.com)

## **American Breast Cancer Foundation**

410-730-5105  
[www.abcf.org](http://www.abcf.org)

## **The Assistance Fund**

855-845-3663  
[www.theassistancefund.org](http://www.theassistancefund.org)

## **Benefits Checkup®**

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

## **Cancer and Careers (CAC)**

646-929-8032  
[www.cancerandcareers.org](http://www.cancerandcareers.org)

## **CancerCare Co-Payment Assistance®**

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

## **Cancer Finances Toolkit**

617-938-3484  
[www.cancerfinances.org](http://www.cancerfinances.org)

## **Cancer Financial Assistance Coalition**

424-258-4628  
[www.cancerfac.org](http://www.cancerfac.org)

## **Cancer Support Community**

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

## **Compassionate Allowances**

800-772-1213  
[www.ssa.gov/compassionateallowances](http://www.ssa.gov/compassionateallowances)

## **Co-Pay Relief**

866-512-3861  
[www.copays.org](http://www.copays.org)

## **Extra Help**

800-633-4227  
[www.ssa.gov/medicare/prescriptionhelp](http://www.ssa.gov/medicare/prescriptionhelp)

## **Financial Planning Association**

800-322-4237  
[www.plannersearch.org](http://www.plannersearch.org)

## **Genetic and Rare Diseases Information Center**

888-205-2311  
[www.rarediseases.info.nih.gov/guides/pages/96/patients-families-and-friends](http://www.rarediseases.info.nih.gov/guides/pages/96/patients-families-and-friends)

## **Good Days**

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

## **HealthWell Foundation**

877-968-7233  
[www.healthwellfoundation.org](http://www.healthwellfoundation.org)

## **Leukemia & Lymphoma Society**

800-955-4572  
[www.LLS.org](http://www.LLS.org)

## **National Organization for Rare Disorders**

203-744-0100  
[www.rarediseases.org](http://www.rarediseases.org)

## **Need Help Paying Bills**

[www.needhelppayingbills.com](http://www.needhelppayingbills.com)

## **NeedyMeds**

800-503-6897  
[www.needymeds.com](http://www.needymeds.com)

## **Partnership for Prescription Assistance**

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

## **Patient Access Network Foundation**

866-316-7263  
[www.panfoundation.org](http://www.panfoundation.org)

## **Patient Services, Inc.**

800-366-7741  
[www.patientservicesinc.org](http://www.patientservicesinc.org)

## **RxAssist**

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

## **RxHope™**

[www.rxhope.com](http://www.rxhope.com)

## **Rx Outreach®**

888-796-1234  
[www.rxoutreach.org](http://www.rxoutreach.org)

## **Triage Cancer**

424-258-4628  
[www.triagecancer.org](http://www.triagecancer.org)

# General Cancer Information, Survivorship, & Support

## **American Cancer Society**

800-227-2345  
[www.cancer.org](http://www.cancer.org)

## **CancerCare**

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

## **Cancer.net**

888-651-3038  
[www.cancer.net](http://www.cancer.net)

## **Leukemia & Lymphoma Society**

800-955-4572  
[www.LLS.org](http://www.LLS.org)

## **National Cancer Institute (NCI)**

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

## **NCI Clinical Trial Information**

800-422-6237  
[www.cancer.gov/ClinicalTrials](http://www.cancer.gov/ClinicalTrials)

## **Patient Advocate Foundation**

800-532-5274  
[www.patientadvocate.org](http://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](http://www.CancerSupportCommunity.org).

**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET.

**Open to Options®** — Need help making a cancer treatment decision? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking about Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs. [www.CancerSupportCommunity.org/FSAC](http://www.CancerSupportCommunity.org/FSAC)

**Services at Local CSCs and Gilda's Clubs** — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. [www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation)

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**MyLifeLine** — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at [www.MyLifeLine.org](http://www.MyLifeLine.org).

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at [www.CancerSupportCommunity.org/become-advocate](http://www.CancerSupportCommunity.org/become-advocate).

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This booklet is available to download and print yourself at [www.CancerSupportCommunity.org/cost](http://www.CancerSupportCommunity.org/cost). For print copies of this booklet or other information about coping with cancer, visit [Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org).

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