

FRANKLY
SPEAKING
ABOUT CANCER

Coping *with the*
Cost of Care



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Prologue

Hearing that you or someone you love has cancer can be overwhelming. Questions abound: Will I (or my loved one) survive? How will my family be affected? Will my insurance cover my care? Will I be able to work through treatment or will I need to take time off from work? Will my family be burdened with huge expenses? For some, the questions come all at once. For others, they arrive one by one. Having a plan to deal with these questions is vital.

It's hard to talk about money. However, having open conversations about money and the cost of cancer care can help you become better informed about your options for help. You may be able to reduce the financial impact of treating a cancer diagnosis.

Asking for and accepting help can also be hard. Many families facing cancer have shared with the Cancer Support Community that financial worries are a significant source of stress, and they don't know where to turn. This book is a starting place to learn how to talk about the financial side of cancer and where to go for help.

This book is for people who want to know more about managing the cost of cancer care. It can be difficult to find one place where people affected by cancer could learn about practical matters such as insurance coverage, Medicare and Medicaid, co-pay assistance, Patient Assistance Programs, Social Security, health care reform, and other resources to help manage cancer-related finances. The goal of this book is to provide a road map to the financial side of the cancer experience.

Two important questions to ask about managing the financial aspects of cancer are: “What financial impact will my cancer diagnosis and treatment have on my life?” and “Am I able to coordinate the financial piece of my cancer care right now?”

Do you have a friend or family member who can help you? If not, ask your doctor to refer you to an oncology social worker, financial counselor or to a nonprofit organization for help managing financial issues. Many people diagnosed with cancer ask someone else for help to keep up with the financial aspects of care. The key is that *someone* must address these issues.

Being empowered is important when it comes to paying for cancer treatment. Information about the cost of treatment and treatment-related issues can be confusing, and it is easy to feel overwhelmed. Unfortunately, ignoring these issues will not make them go away.

Avoidance can lead to even greater anxiety down the road.

During the emotion-filled time of diagnosis and early treatment, the tendency can be for financial concerns to take a back seat. Some people are scared to discuss cost with their treatment team, fearing that if they ask about it and cannot afford it, treatment will be delayed, or a less effective treatment will be proposed. Others are simply not focused on the cost of care. Some mistakenly assume that if they have insurance, the cost of care will be covered in full.

Help is Available

There are many options to help you pay for your care. The Cancer Support Community has gathered credible and valuable information from many sources to create this book. We hope this information will help you deal with the significant financial matters related to cancer and the potential life changes that cancer can bring. The resources for financial assistance discussed in this book may not address all of your cancer-related expenses or prevent you from accumulating medical debt. But, this information can help you regain some control and formulate a plan for how to best deal with the financial aspects of care.

With this book as your guide, it is our aim that you will access these resources to navigate and ease the financial burden of cancer.



HOW WILL HEALTH CARE REFORM AFFECT MY (OR MY LOVED ONE'S) CANCER CARE?

The Patient Protection and Affordable Care Act (commonly referred to as Health Care Reform or the ACA) was signed into law on March 23, 2010. The 2018 tax reform bill may have made changes to your healthcare. Please contact CSC's toll-free Cancer Support Helpline® if you have questions about your coverage. The information in this book is up to date as of April 2020.

- As of January 1, 2014, there are two new ways to get health insurance coverage: through a new category of eligibility for Medicaid, and the creation of State Health Insurance Marketplaces.
- As of 2014, health insurance companies are no longer able to deny coverage to individuals with pre-existing medical conditions, impose pre-existing condition exclusions, or charge someone more because of their pre-existing condition.
- Private health insurance companies, Medicaid and Medicare must offer certain preventive and screening services free of charge (no co-pays or co-insurance) and without applying the insurance and without applying the charges to your deductible. For more information see www.HealthCare.gov.
- Insurance companies can no longer impose **lifetime caps** or annual limits on coverage of essential health benefits.
- Insurance companies are no longer allowed to rescind (cancel) your policy unless you intentionally lied on your application.
- Adolescents and young adults may now remain covered on a parent's health insurance policy until age 26.
- Insurance companies are required to offer an internal and external appeals process.
- Some of these protections apply differently to grandfathered plans, retiree-only plans, Medicare, Medicaid, and Medigap plans.

How to Use this Book

CHAPTER 1

Provides an outline of potential costs associated with cancer care. It lists questions you can ask your health care team and identify where you might need help. Here you will find information on:

- What to do if you don't have health insurance
- Questions to ask your health care team about cancer care costs
- Tips on how to manage expenses related to cancer care

CHAPTER 2

Provides a more detailed discussion of health insurance. Here you will find information on:

- Private health insurance
- State Health Insurance Marketplaces
- COBRA coverage
- HIPAA plans
- Medicare and Medicaid
- Communicating with your health insurance company
- Consumer protections in the ACA
- When you can sign up for certain plans

CHAPTER 3

Discusses various aspects of employment, disability, finances and medical debt. Here you will find information on:

- Working through treatment, taking time off, and talking with your employer.
- Family and Medical Leave Act (FMLA)
- Social Security Disability benefits
- Managing medical debt

CHAPTER 4

Describes resources that are available to help you pay for prescription medication. Here you will find information on:

- Prescription insurance (Including Medicare Part D)
- Patient Assistance Programs (PAPs)
- Specialty tiers and pharmacy benefits

CHAPTER 5

Provides practical resources to help you understand and cope with the cost of cancer care. Included are programs that provide financial assistance. There is also a glossary of cost-related terms. Words you see in **green** throughout the book can be found in the glossary.



Gathering Cost Information

Thinking about paying for cancer care is overwhelming, but I've learned you CAN manage the cost. I'd definitely pick up a book that helped me get a handle on it.

— Jeanne, breast cancer survivor

This chapter provides an outline for potential cancer-related costs, as well as questions to ask when gathering information. Understanding what costs to expect is an important first step in gaining a sense of control. Many people coping with a cancer diagnosis have little experience with the health care system and even less with the financial aspects of treatment.

There will always be financial surprises during the cancer experience. However, the more you know, and the sooner you know it, the better you will be able to cope.

Even with health insurance, treatment for cancer in the United States is expensive. There are **out-of-pocket** costs, including **co-insurance, deductibles, co-pays**, out-of-network costs and non-covered services. There are ways to manage these costs, but first you must understand what they are, so you can avoid potential issues.

Naturally, you want the best care. Gathering information about the expenses associated with treatment is not about accepting less than your best treatment options. It is about being able to make an informed decision and a plan to obtain the best care while maintaining the highest quality of life possible. Financial planning on the front-end can allow for fewer surprises and less worry on the back-end.

In this chapter we list potential expenses that you may want to ask about as you begin to gather information on the costs of cancer care. You will also find suggestions for specific questions you might ask your health care, insurance, and financial teams during your fact-finding mission. While the list is long, it is unlikely you will incur all of these expenses.

Practical Tips

1. Make sure that you and your providers submit any bills to your insurance company in a timely manner. Many insurance companies will not pay a claim submitted after the time period specified in the policy.
2. Submit all medical expenses even if you aren't sure whether they are covered. If you don't submit it, the insurance company definitely won't pay it!
3. Review bills and keep accurate records of claims submitted, both pending and paid. This usually includes matching bills you receive from providers with **Explanations of Benefits (EOBs)** you receive from the insurance company.
4. Keep copies of anything related to your claims. You can do this yourself, or you can ask a friend or family member to help. (Ask someone who is organized!) Examples of items you should have on file include:
 - medical bills from all health care providers
 - claims filed
 - reimbursements or payments from insurance companies received and EOBs
 - dates, names, and outcomes of contacts made with insurers and others
 - non-reimbursed or outstanding medical and related costs
 - dates of admission to hospitals or other health care facilities, clinic visits, laboratory work, diagnostic tests, procedures, treatments
- medications received and prescriptions filled
5. Get a notebook or accordion folder to record all of your expenses, conversations with the insurance company, doctor's appointments, exams, and other pertinent information (e.g., the date, time and with whom you spoke, what they said and contact information, how long spent on the call).
6. There are a number of resources in the cancer community to help you organize this information. For example, the **LIVESTRONG** Guidebook is available free of charge (shipping and handling charges will apply) to anyone affected by cancer (www.livestrong.org/what-we-do/program/livestrong-guidebook).
7. Get an accordion folder to help you file things so you can find them easily.
8. Pick a certain day to be 'health care bill day.' Use this allotted time to work on the task of keeping everything organized. This will help to compartmentalize the task and keep it from taking over your everyday life.
9. Identify an easily accessible place in your house that will not be disturbed by others where you can store your bills, paperwork, and other items.

HOW DO I GET HEALTH INSURANCE?

On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act (commonly referred to as Health Care Reform or the ACA), which provides you with more health insurance options, consumer protections, and access to health insurance even if you may now have a **pre-existing condition**. These are discussed further in Chapters 2 and 3.

One of the options that may be available in your state is a high-risk insurance pool for individuals with pre-existing medical conditions. Some states have chosen to close their risk pools, now that there are new options through the State Health Insurance Marketplaces. To learn more about your state, visit: www.healthcare.gov/marketplace-in-your-state/

The ACA created two new ways to get health insurance coverage. First, some states have expanded access to their Medicaid programs to all adults with household incomes under 138% of the Federal Poverty Level (FPL). To find the current federal poverty level, visit, www.healthcare.gov/glossary/federal-poverty-level-FPL. However, there are some states that are not offering this new option. For more information, visit: www.healthcare.gov/what-if-my-state-is-not-expanding-medicaid.

The second new way to access health insurance is through the State Health Insurance Marketplaces. Each state has its own Marketplace; however, more than half the states have their Marketplace run by the federal government and those Marketplaces can be accessed at www.HealthCare.gov. If you are not sure if you live in a state with a state or federally-run Marketplace, visit www.HealthCare.gov and pick your state, then it will direct you to your state Marketplace.

Marketplaces provide a one-stop shopping location for people to learn about the private health insurance plans available to them in their state. Individuals who choose plans in the Marketplace may be eligible for financial assistance to purchase those plans, depending on their income. Marketplaces will also screen people to see if they are eligible for Medicaid. You can also visit <http://finder.healthcare.gov> for information about your health insurance options outside of the Marketplace.

In addition, as of January 1, 2014, health insurers are no longer able to deny coverage to individuals with pre-existing conditions.

If you are currently uninsured, Chapter 2 explains the different types of insurance that might be available to you.

If you are worried that you or a loved one might have cancer, and you have not been able to obtain diagnostic tests, you can contact your local Department of Health. Some states have free screening programs for certain types of cancer. The number for your local health department will be in the yellow pages of your phone book or online. You can also check to see if there is a **free clinic** in your area. The National Association of Free Clinics provides a listing at: <http://nafclinics.org/clinics/search>.

If you or your loved one is a veteran, the Department of Veterans Affairs (VA) may be a resource for health care. To find out if you or a loved one is eligible for health care through the VA, you can contact the Enrollment Coordinator at your local VA health care facility. The number for the nearest VA hospital should be in your local phone book or at: www.va.gov/directory/guide/home.asp

If you or a loved one has already been diagnosed with cancer and is uninsured, ask to speak with an oncology social worker or financial counselor at the facility that provided the diagnosis. These individuals should be able to guide you through the process of obtaining treatment, applying for health insurance coverage, or qualifying for hospital **charity care**.

I would've liked to talk at the front end about the cost of care as opposed to waiting. I really think it would have been easier if we knew what was going to happen and what bills we were going to see coming in.

— Kathy, breast cancer survivor



I think all of us when we look at cancer... want closure so we can move on with our lives. The financial aspect can be the most difficult to resolve.

— Sue, breast, melanoma, and metastatic lung cancer survivor

Questions for your health care team or hospital personnel

- Who can I speak with to see if I'm eligible for Medicaid or other health insurance options?
- What is the estimated total cost of the prescribed treatment plan?
- Are there less expensive options for treatment? How effective are they?
- Does this facility have a free or reduced-cost care program? If so, what are the requirements?
- Who should I see to discuss a payment plan?
- Who can I speak with about options for outside financial assistance?
- Can you help me apply for financial assistance?
- Are there **clinical trials** in which I can participate? How might this affect the cost of my care?
- How do I apply?
- Does the manufacturer of my recommended medication offer a free or discounted drug program for uninsured patients?
- Are there charitable foundations that can help me with the cost of medications or care?

IF YOU HAVE HEALTH INSURANCE

While health insurance covers some of the cost of cancer care, there are costs not covered. It can be confusing to determine what health insurance will and will not cover. Understanding the costs is an important step in feeling empowered and more in control as you make important treatment decisions. Throughout the remainder of this chapter, we identify treatment-related expenses that you *may* have if you have health insurance.

Be sure to provide your health care providers with ALL of your insurance cards, including those for separate secondary coverage, Medigap plans, and prescription discount programs.

If your insurance coverage changes, be sure to update your health care team immediately.

Deductibles

A **deductible** is an amount that the patient must pay **out-of-pocket** before the insurance company begins to pay anything towards health insurance claims. If you have a deductible, the amount will usually be printed on your insurance card. You can also contact your health insurance company to find out your policy's deductible. Deductibles are paid on an annual basis, so at the beginning of your plan year, your deductible will usually start over. Your insurance company will be able to tell you how much of the required annual deductible you have already paid during that year.



INSURANCE CASE MANAGERS

Many health insurance companies assign insurance case managers to assist insured individuals diagnosed with cancer. These trained individuals (often registered nurses or licensed social workers) will follow your case closely, helping to coordinate care and insurance benefits. If you or a loved one is diagnosed with cancer, it may be helpful to contact your insurance company to ask if they will assign you a case manager. The case manager should be able to answer many of your questions.

Anatomy of a Health Insurance Card

FRONT

1 ABC Insurance

2 PPO

3 Member Services: 1-234-567-4910

4 ID XXX123456789 Group ABCD

5 Member: JOHN SMITH

6 ME Rx

7

8

BACK

9 Hospital Precertification
800-123-4567

10 Mental Health / Substance Abuse Service Information Authorization
800-123-4567

11 ABC Pharmacy Services
Member 800-123-4567 Provider 800-123-4567

12 To locate Preferred Providers, call 800-123-4567.

13 Claims and Correspondence should be sent to:
Mail Administrator, PO Box 12345, ABC, NY 12345

Important information about your policy can be found on your insurance card. **Every insurance card looks slightly different**, but these are some **key elements** to look for:

1. Insurance company name
2. Type of policy (HMO, POS, PPO)
3. Phone number to call with questions (May be on the front or the back of the card)
4. Member ID number (May include letters and/or numbers)
5. Member name
6. Medical coverage (ME) offered under your policy
7. Prescription coverage (Rx) offered under your policy
8. Group number (If it's a group policy)
9. Phone number the hospital should call if you must be admitted
10. Phone number to call for mental health services
11. Prescription coverage information
12. Phone number to call to locate **in-network** providers
13. Address for written communication

PHYSICIAN/PROVIDER EXPENSES

These expenses include payments for the care you receive at each doctor visit such as a physical examination or checkup. Many plans require that you pay a fee, called a **co-payment** or **co-pay**, each time you visit the doctor, unless the visit is only for preventive care. Your insurance company may require different co-pay amounts for primary care doctors versus specialists. An oncologist is usually considered a specialist.

The amount of the co-pay is set by the insurance company, not the provider. There may be a separate payment needed for each laboratory test, such as a blood or urine test that is done during your appointment. An insurance company representative will be able to tell you your co-pay amount, and it may be printed on your insurance card. You always want to ensure that you know whether or not all of your health care providers and facilities are covered in-network by your health insurance plan, to avoid higher out-of-pocket costs.

Questions for your insurance company representative or health care team

- Do I have a co-pay for each doctor visit?
- If I have a co-pay, how much is it?
- If I see someone other than the doctor (such as a physician assistant or nurse practitioner), do I still have to pay the co-pay?
- Is this office in-network or out-of-network?
- Is this service considered **preventive care**? If so, why am I being charged a co-pay?
- When is the co-pay due? At the time of the visit? Or will I be billed later?
- Is there the possibility of getting a co-pay waiver if I'm making multiple trips to see the doctor?

- Will I be billed separately for tests and scans such as blood tests and CAT scans?
- Will laboratory tests be covered by my insurance?

Questions for your health care team

- What is your policy when referring to other doctors or facilities? Do you routinely check to see if the person or facility you're referring me to is a preferred provider within my health insurance company's network of providers, or is that my responsibility?
- Can all labs and visits be done at one time so I am not paying multiple co-pays?

TREATMENT-RELATED EXPENSES

Treatment-related expenses are costs associated with the treatment of cancer such as chemotherapy or radiation. Depending upon your insurance plan, you may be required to pay a co-pay at the time of each treatment. If the recommended treatment is considered experimental, investigational, or **off-label**, your insurance company may not cover some aspects of the care such as the cost of the medication or the cost of the entire treatment. Even if experimental or off-label, if the treatment is medically necessary, consider appealing any denials of coverage by your insurance company. Talk to your treatment team to learn more about your specific treatment plan.

Questions for your insurance company representative or health care team

- Can I get an estimate of the total costs to me based on the treatment plan recommended by my doctor(s)?
- Will there be a co-pay for each individual treatment?
- What do you recommend if I cannot afford this prescribed treatment plan? Are there other equally effective, less-expensive options for treatment?
- Does my health insurance company need to approve any — or all — of the treatment plan before I begin receiving therapy? What needs approval?
- What is not covered under my health insurance if I'm admitted to the hospital?
- What is not covered under my health insurance if I'm treated as an outpatient?
- Do I have out-of-network benefits? If so, what will I have to pay to see an out-of-network specialist?

- Are there organizations who might provide financial assistance with my co-pays?

Questions for your health care team

- Is the treatment facility you are recommending in my health plan's network? If not, can you help me find a facility within my plan network?
- Are there ways to change my treatment schedule, to work around my job or childcare?
- If my ability to work will be impacted, is there someone to assist me with applying for medical leave or disability insurance?
- Is the treatment that you are recommending likely to affect my fertility (ability to have children). If so, are there fertility preservation options available to me and what will they cost? If my insurance will not cover these options, are there organizations that may help with these costs?

CLINICAL TRIAL EXPENSES

Clinical trial expenses are a subcategory of treatment expenses. Clinical trials are part of a long and careful research process. Studies are done with patients to find out whether promising approaches to treatment are safe and effective. Such trials usually compare the new treatment to the existing standard of care. They are sometimes called experimental or investigational. If you are interested in participating, there are many additional questions you should ask to determine which trials are available and the risks and benefits of each.

There may be charges associated with the clinical trial depending upon the trial and your insurance coverage. These expenses are usually not more costly than treatment that is not part of a trial, but it is important to ask about these costs before you begin a clinical trial.

Under the ACA, as of January 1, 2014, most insurance companies are required to cover the cost of any routine care that you would have received during standard treatment. Some states have additional protections for consumers. For more information, see www.cancer.gov/about-cancer/treatment/clinical-trials/paying/insurance or contact your state's insurance agency.

Questions for your insurance company representative or health care team

- What expenses will I have if I join a clinical trial?
- How do the costs I would incur while participating in the clinical trial compare with the costs I would incur while receiving the standard treatment? Does one cost more than another?
- Can I be reimbursed for any of the costs of the clinical trial, including travel and lodging?
- Does my state require coverage of routine care costs if I participate in a clinical trial?
- If coverage for a clinical trial is denied, who can my doctor talk to discuss this further?

My husband is an accountant and this is sometimes hard even for him.

— Cancer Support Community participant

PRESCRIPTION EXPENSES

Costs associated with prescription medication are one of the most quickly rising and confusing aspects of cancer care. They *can* be managed. The first step is to understand what your prescription costs will be.

Co-pays are a set amount you must pay for a given prescription, such as \$20 or \$50. **Co-insurance** is a percentage of the total cost of the prescription that you must pay. More expensive medications have higher co-insurance amounts. As of 2018, 43 states and DC require insurance companies to cover oral chemotherapy similar to the way they cover intravenous (IV) chemotherapy. This is called oral chemotherapy parity. These laws can significantly reduce the amount you may have to pay for your treatment. If you do not live in one of these states, and you are facing high out-of-pocket costs for your oral chemotherapy treatment, talk with your health care team about your options.

Prescription coverage is discussed in detail in Chapter 4.

Questions for your pharmacist or health care team

- Is this medication on my health insurance plan's **formulary** or **preferred drug list**?
- What is my co-pay for this prescription medication?
- Can we regularly go over my list of medications to see if there are ways to lower my prescription drug costs?
- What are the programs offered by pharmaceutical companies and nonprofits that can help cover the costs of my prescription(s) for cancer treatment or side effects?
- Is this prescription a one-time cost, or will it be an ongoing expense?
- Is there a less expensive drug (**generic medication**, over-the-counter, or **brand-name**) that will be equally as effective?

- Does my state require similar out-of-pocket costs for oral chemotherapy as intravenous (IV) chemotherapy?

Questions for your insurance company representative

- Are oral chemotherapies covered under my major medical insurance benefit or my prescription drug benefit?
- Do I have a mail-order prescription medication option? Would it be less expensive?
- If a medication is not covered, how can I apply for an **exception** for coverage?
- I have Medicare coverage, is this drug covered under Part B or Part D?

HOME HEALTH CARE AND HOSPICE CARE EXPENSES

Home health care and hospice benefits are different but related, so it is helpful to understand both in order to coordinate them.

Home health care refers to health care provided by a skilled professional such as a nurse, social worker, or physical therapist in a home setting. Usually, your health insurance policy will only cover home health care visits if the provider is delivering a **skilled need**. Examples of this are teaching about a new medication, showing how to change a bandage or dressing, or providing physical therapy in the home.

Hospice is a type of home care and is focused on symptom and pain management, usually near the end of life. Insurance coverage of home health care and hospice care varies. For more information about hospice, visit www.caringinfo.org.

Questions for your insurance company representative or health care team

- Do I have a home health care benefit? If so, what does it cover? Is there a maximum number of covered visits?
- Are there co-pays associated with home health care visits?
- Do I have a home hospice benefit? What does it cover? Is it separate from my home health benefit? Is there a **lifetime cap** of covered services?
- What is the best way to utilize both of these benefits?
- Will there be a co-pay for each individual home health or home hospice visit?
- Do I have to use a preferred provider? If so, who are the preferred providers?
- To ensure coverage, does my health insurance company need to preapprove the home health or home hospice care before it is started?
- What are my alternatives to home health or home hospice care?
- I have a long term care insurance plan that covers home health care. How do I access these benefits?

REHABILITATION CARE EXPENSES

Sometimes during the course of cancer treatment, individuals benefit from a stay in a rehabilitation hospital or similar facility. A rehabilitation facility is different from long-term or **custodial** care in a nursing home. Depending on the type of cancer, the individual's needs, and the recommended treatment, there may be a need to learn new skills or simply increase physical strength or stamina. Rehabilitation coverage varies greatly, so advocating for what you or your loved one needs with your insurance company, your treatment team, and rehabilitation facilities is crucial.

Questions for your insurance company representative or health care team

- Do I have a rehabilitation benefit? If so, what will it cover?
- Does my insurance company have preferred providers?
- What is the process if I would like another facility to be paid as a “preferred provider”?
- If I haven't met my rehabilitation goals before my insurance benefit runs out, how will that be handled?

Questions for your health care team

- What are the goals of my stay in a rehabilitation facility?
- How long do you estimate I will need to stay at the rehabilitation facility to meet these goals?
- Why are you recommending a rehabilitation facility instead of outpatient rehabilitation or rehabilitation at my home?

Questions for the rehabilitation facility

- If insurance will not cover my stay, do you offer a discounted rate to people paying out-of-pocket?

Are you faced with an upcoming treatment decision that may be impacted by your financial situation?



If so, Cancer Support Community may be able to help. Cancer Support Community's treatment decision support counseling program - Open to Options® - helps you identify important questions about your treatment options based upon your personal need, which may involve financial challenges related to affording cancer care. To obtain this free service, contact the Cancer Support Community at 888-793-9355 or contact your local affiliate and ask if they offer Open to Options®.

PRIVATE DUTY, LONG-TERM, AND CUSTODIAL CARE EXPENSES

Unlike home health care, private duty, companion, and **custodial care** are usually not covered by health insurance. Private duty or custodial care includes services such as having someone drive to your home to fix meals or drive you to medical appointments. Similarly, long-term care is usually not covered by health insurance. Long-term care usually involves extended care at a nursing home or other specialized facility for a longer period of time than rehabilitation care.

Generally, Medicare does not cover long-term care, but does cover some care at a skilled nursing facility and home health care. For more information, see www.Medicare.gov.

Medicaid provides coverage for some long-term care in a facility and at home. Eligibility and services vary from state to state. See www.Medicaid.gov for more information.

Questions for your health care team

- Are there local organizations that provide low-cost or free private duty care or other services?
- Are there ways to change my treatment schedule, if necessary, to work around my caregiver's job schedule?
- Should I plan financially for long-term medical care such as a nursing home or hospice care?
- Are there organizations that can help me plan financially for long-term care?
- Are there organizations that can help me understand my state's Medicaid rules?

Questions for your insurance company representative

- Are private duty care and long-term care covered under my health insurance policy?

Questions for the private duty agency or long-term care facility

- Do you have a special rate for people paying out-of-pocket?
- What types of payment plans do you have?
- Should I apply for state long-term care Medicaid?

MENTAL HEALTH CARE AND COUNSELING EXPENSES

Many people affected by cancer find it helpful to meet with a counselor, psychotherapist, psychologist, psychiatrist, or other licensed mental health professionals during the cancer experience. Talk with your health care team about what type of mental health care or counseling might be beneficial for you and ask them to make a referral. One-on-one meetings with a psychotherapist, psychologist, or psychiatrist are often covered under the mental health benefit of health insurance plans. The Cancer Support Community and other cancer support organizations offer support groups facilitated by trained professionals at no cost.

Questions for your health care team

- Does your organization provide individual counseling to people affected by cancer? If so, is there a cost?
- If there is a cost, do you accept my insurance?
- If you do not provide individual counseling, who do you recommend?
- Is there an organization that can provide low-cost or free counseling or support to my family?

Questions for your insurance company representative

- What is my mental health benefit?
- Are there in-network and out-of-network providers? What is the difference in coverage?

Where can I get a list of in-network providers?

- If so, what is covered and how do I access this benefit?
- Is **pre-authorization** required?
- Is there a co-pay for each visit?
- How many visits may I make before a new authorization or further authorization is necessary?
- Are there counselors on the **insurance panel** specially trained and experienced in working with people affected by cancer?
- If not, what is the process for having a therapist trained to work with those affected by cancer paid at the same rate as a member of the panel?



In a 2019 survey done by Cancer Support Community, 78% of respondents indicated that they had experienced emotional distress as a result of the cost of cancer care.

ADDITIONAL FAMILY AND LIVING EXPENSES

Normal living expenses do not go away when you or someone you love has cancer. In fact, some people find that they have additional expenses such as special nutritional supplements, childcare and/or eldercare. It can be helpful to anticipate these expenses as you gather information.

Questions for your health care team

- If I have trouble paying for basic items, like food or heat, due to the cost of my cancer treatment, what organizations can help me?
- If I need nutritional supplements, will they be covered by insurance? If not, is there a program to help me?
- Where can I get low-cost or free child or elder care services during my treatment?
- Are there ways to change my treatment schedule, to work around my child's school schedule (or elder's appointment schedule)?
- If I need a wig or other supplies, will it be covered under my insurance? If not, is there somewhere I can get one free or at a reduced cost?

TRANSPORTATION EXPENSES

Transportation expenses include the cost of travel to receive treatment whether it is by car, bus, train or plane. It may also include the price of hotels or other lodging. A big unexpected expense for some people is the cost of parking while receiving treatment.

Questions for your health care team

- Is there free or low-cost transportation?
- Do you have free or reduced parking rates?
- Are there organizations that can provide free transportation, including airfare, or help me pay for transportation to and from appointments?
- If I am traveling a long distance, are there free or reduced-cost hotels or lodging?

Questions for your insurance company representative

- Are transportation and/or lodging costs covered under my health insurance policy?

Questions for your tax preparer

- Which transportation costs related to health care are considered to be medical expenses for tax purposes? What documentation do I need?

LEGAL EXPENSES

For most people, legal issues and expenses aren't the first thought after a diagnosis of cancer. However, some people can benefit from professional guidance related to health insurance coverage, addressing lost wages, learning about employment rights under the law, appealing Social Security Disability decisions, figuring out medical expenses when filing income taxes, writing a will, or creating a **living will** or **advance directives**.

Questions for your health care team

An oncology social worker can be very helpful in responding to these questions.

- Who can I talk with if I've lost income because of my cancer?
- If I have questions about my rights as an employee with 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 get low-cost or free help with estate planning and legal issues, such as writing my will or granting a power of attorney or creating a guardianship for my child?

- Who can help me with a living will or advance directives?
- Who can help me if my insurance company is not following the law?
- Where can I go if I have been wrongfully denied a government benefit that I believe I qualify for?

Questions for a legal professional

- Do you have a reduced rate or pro bono (free) program for people affected by cancer?
- Do you or do you know of other organizations that provide free or low cost legal advice and services specifically to people affected by cancer?



2

Health Insurance

I have an insurance case manager, so I was able to call her with questions along with the standard 800 numbers. It's amazing how much information she gets for me.

— Stephanie, brain cancer survivor

Although many of us have health insurance, it is usually not until we have to use it that we learn about the specifics of coverage and how to best use our insurance benefits. If you feel overwhelmed by the thought of learning about your insurance coverage, you are not alone. It is important, however, to understand your policy.

The best place to learn about the specifics of your health insurance policy is from your health insurance company. If you have an **insurance case manager**, he or she will become familiar with the specifics of your situation and talk with you about coverage issues.

If you do not have a case manager, you may want to ask to speak to the same insurance representative each time you contact the insurance company. If you have an employer-sponsored health plan, your Human Resources representative should also be able to answer questions about your policy.

To help you prepare and to make it easier to speak with your insurance provider, in this chapter we explain the different types of health insurance. We also provide tips for effectively communicating with your insurer. The glossary defines many terms related to health insurance and financial issues.



There are two types of group health insurance policies: insured and self-insured. It is important to know what type of plan you have, because some consumer protections apply differently to each type of plan.

PRIVATE HEALTH INSURANCE

Private insurance plans are those offered by private health insurance companies, rather than the government. There are two subcategories of private health insurance, **group policies** and individual policies. Group health insurance policies are often available through employers, unions, and some trade associations. Individual policies and individual family policies are obtained directly from the insurance company, through a State Health Insurance Marketplace, or through an insurance broker.

There are two types of group health insurance policies: insured and self-insured. It is important to know what type of plan you have, because some consumer protections apply differently to each type of plan. This can be confusing. For information, ask your human resources representative or call the number on your health insurance card to find out what type of group health plan you have.

Whether your health insurance is part of a group policy or an individual policy, it could be one of several types.

Health Maintenance Organization (HMO)

In exchange for a **premium**, an HMO provides comprehensive health care. In a traditional HMO, you have a **Primary Care Provider (PCP)** as your first contact for almost any health care need. Your PCP must provide a

referral to another provider such as a specialist, hospital, or other health care facility in order for the HMO to cover the service. These providers or facilities usually have a contract with the HMO. When medically necessary, exceptions are made to permit you to use providers or facilities that do not contract with the HMO. Your HMO is contractually obliged to cover all services that are covered by your plan even if there is no appropriate provider within its network.

Point-of-Service Plan (POS)

A point-of-service plan has slightly more flexibility. The primary care doctors in a POS plan usually make referrals to other doctors or specialists in the plan, but you can go outside the plan. If the doctor or facility you choose is out-of-network, you will usually pay a higher co-pay or co-insurance.

Preferred Provider Organization (PPO)

This type of plan offers the patient access to a network of approved doctors, called **in-network** doctors or **preferred providers**. In a PPO, patients typically do not need a referral for specialist care. When using the preferred providers, most of your medical bills are covered. If you use out-of-network providers, you pay more of the bill out-of-pocket. PPOs are typically more expensive, but they do offer greater choice.

Exclusive Provider Organization (EPO)

This type of plan is similar to an HMO, in that patients are required to use a specific network of providers who participate in the plan. Unlike an HMO, you do not need to select a PCP, nor do you need to contact your PCP for referrals to specialists. But, you should check with the plan to be sure the provider is in your network. It is a good idea to get plan confirmation in writing before going to a health care provider as these lists change from time to time.

Fee-for-Service (FFS)

Fee-for-service plans are rare. They allow you to choose any doctor, change doctors at any time, and go to any hospital in the United States. In an FFS plan, you are responsible for keeping track of your own medical claims and expenses. FFS plans pay only a set percentage of an amount that is **usual and customary** in your area. The usual and customary rate may be less than the bill from your doctor. You must also meet a yearly deductible before an FFS health insurance policy will begin to pay claims.

Coverage terms

Each type of health insurance will provide different coverage in terms of how much you are required to pay out-of-pocket for your care. For example, they will differ in the annual deductible amounts, co-pay or co-insurance amounts, and how much and what types of prescriptions they will cover.

After September 23, 2010, insurance companies are no longer allowed to impose a lifetime limit on benefits and, as of January 1, 2014, they can no longer impose **annual limits** on the dollar value of coverage on essential health benefits.

A pre-existing condition is a health condition that you had before you joined your medical plan. Health insurance companies can no longer deny you health insurance coverage because of a pre-existing condition nor can they impose **pre-existing condition** exclusion periods on a policy.

Before the ACA, if you were diagnosed with cancer, some insurance companies would go back to your original application to see if you made any mistakes or left out any information. However, under the ACA, insurance companies can no longer cancel your policy unless you intentionally lied on your application or you stop paying your premiums.

If you have been diagnosed with cancer and are now looking for insurance, it is important to understand what the policy will and will not cover with regard to your cancer care. Be sure you know what the insurance company considers to be related to your cancer care.

STATE HEALTH INSURANCE MARKETPLACES

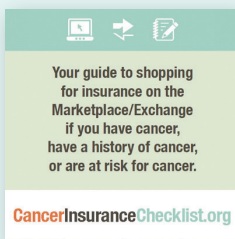
One of the changes to our health care system that was contained in the ACA was the creation of State Health Insurance Marketplaces. Each state has its own Marketplace; however, more than half the states have their Marketplace run by the federal government and those Marketplaces can be accessed at www.HealthCare.gov. If you are not sure if you live in a state with a state or federally-run Marketplace, visit www.HealthCare.gov and pick your state, then it will direct you to your state Marketplace.

Marketplaces provide a one-stop shopping location for people to learn about the private health insurance plans available to them in their state. Individuals who choose plans in the Marketplace may be eligible for financial assistance to purchase those plans. There are two types of financial assistance:

1. premium tax credits, which help to lower the cost of your monthly premium, and
2. cost-sharing subsidies, which lower the cost of your co-pays, co-insurance amounts, and deductibles.

Marketplaces will also screen people to see if they are eligible for Medicaid.

Some employees who are offered health insurance by their employer may be able to find better or cheaper coverage through the State Health Insurance Marketplaces. How expensive or good the employer's plan is will decide if an employee gets financial assistance to buy a plan through the Marketplace. In addition, if an employer offers the employee coverage that does not also include the employee's spouse, the spouse may be able to find coverage through the State Health Insurance Marketplaces.



THE CANCER INSURANCE CHECKLIST is an easy-to-use guide to assist people with cancer, a history of cancer or at risk for cancer in choosing a health insurance plan on the health insurance marketplaces. The Cancer Insurance Checklist and its Spanish translation, Cancer Insurance Checklist: Guía de Cobertura Médica para Personas con Cáncer, were developed through a partnership of 19 cancer and advocacy organizations led by the Cancer Support Community.

Available at www.CancerInsuranceChecklist.org and www.SegurosMedicosYCancer.org, the Cancer Insurance Checklist walks you through the process of evaluating and comparing plans' coverage for cancer-related services and the costs associated with that coverage. There are also links to additional resources on the websites.

COBRA COVERAGE

Some people with cancer leave their job temporarily or permanently. If you receive health insurance coverage through your employer, and you leave your job, your employer may no longer pay for any part of your health insurance coverage. However, you probably have options to continue this health care coverage.

For someone who loses or leaves his or her job, the Consolidated Omnibus Budget Reconciliation Act (**COBRA**) is a federal law that allows someone to temporarily continue their employer-based health insurance by paying the full cost of the insurance themselves.

Coverage through COBRA can be expensive, and it is time-limited. On the other hand, COBRA coverage can give you time to plan for future coverage. If your COBRA premium is too expensive or if you are interested in looking at other options for coverage, check your State Health Insurance Marketplace when you first become eligible for COBRA, as you have a special enrollment period to buy Marketplace coverage when your employer-sponsored coverage ends. You may also qualify for financial assistance to help cover the costs of buying a plan through the Marketplace or be able to access the new category of Medicaid coverage.

COBRA Eligibility

You are usually eligible for COBRA if:

- you have voluntarily left a job through which you had health care coverage
- you have involuntarily lost your job and employer-based health insurance without cause
- your employer reduced your work hours so that you were no longer eligible for insurance benefits
- your health insurance was through a loved one's employer, and your loved one voluntarily or involuntarily left his or her job
- your health insurance was through a loved one who becomes eligible for Medicare
- you had health insurance through a loved one, and he or she dies
- you had health insurance through a spouse's employer and you separate or divorce

Most, but not all, employers are federally mandated to offer COBRA coverage. Employers that do *not* have to offer COBRA coverage include:

- The federal government
- Certain church-related organizations
- Employers who do not have 20 or more employees for at least 50% of the year.

If you are not covered under federal COBRA insurance, you may find that your state offers insurance known as state COBRA or COBRA Continuation plans. For more information on state COBRA plans contact your state’s department of insurance.

How COBRA Works

You must sign up for COBRA coverage within 60 days and pay the monthly premiums dating back to the start of your COBRA coverage within 45 days of the date you elected coverage. Traditionally, coverage will continue as long as you pay the premiums on time for up to 18-36 months, depending on the **qualifying event** (see chart below).

When your COBRA coverage ends, you can find a plan in your State Health Insurance Marketplace at www.HealthCare.gov, check to see if you qualify for Medicaid in your state, or you can look at the **HIPAA plan** options in your state. HIPAA plans are also known as **federally insured** or **guaranteed issue** plans.

HIPAA plans are different from COBRA. With COBRA you are extending the coverage you once had through an employer-sponsored health plan. When you purchase a HIPAA plan, you are buying new insurance. This means you should compare all the HIPAA plans for which you are eligible and pick the one that is best for you.

MAXIMUM LENGTH OF COBRA COVERAGE BASED ON QUALIFYING EVENT

COBRA Qualifying Event	Qualified Beneficiaries	Maximum Coverage
Termination of employment or reduction in hours	Employee, Spouse, Dependent Child	18 months
Employee enrollment in Medicare	Spouse, Dependent Child	36 months
Divorce or legal separation from the employee	Spouse, Dependent Child	36 months
Death of employee	Spouse, Dependent Child	36 months
Loss of dependent child status	Dependent Child	36 months

Tips About COBRA Coverage

- If you want COBRA coverage, be sure to notify your former employer within 60 days that you would like to continue your coverage. If you have not notified them within 60 days, you will no longer be eligible for COBRA.
- Be sure to make your COBRA premium payments in a timely manner. If you are even a day late with a payment, you can lose your coverage. Consider sending payments with a “return receipt requested.”
- If the Social Security Administration (see Chapter 3) determines that you became disabled before becoming eligible for COBRA or within the first 60 days of being covered by COBRA, you may be able to extend COBRA by up to an additional 11 months.
- If your employer ceases to maintain any group health coverage (goes out of business, declares bankruptcy, or cancels health coverage for all of its current employees), you will lose your coverage as well. However, you can find a plan in your State Health Insurance Marketplace, or you may be eligible for a HIPAA plan or to convert your group health insurance plan into an individual plan.
- If you become eligible for Medicare benefits after electing COBRA coverage, your COBRA coverage will end. However, your dependents can still be covered by COBRA for the remainder of the term.
- If you qualify for a new group health plan such as through a new job, you may no longer be eligible for COBRA benefits. This may be the case even when the new coverage is not as good as your previous employer’s plan.
- If you choose to convert your COBRA policy to an individual health plan, your COBRA benefits will end.

...health insurance knowledge was more important than anything else.

— CSC participant

MEDICARE

Medicare is a federal health care insurance program providing coverage to:

- Individuals who are entitled to Social Security retirement benefits who are 65 years of age or older
- Individuals who are under the age of 65 years but have been receiving Social Security Disability Insurance (SSDI) for not less than 24 months
- Individuals entitled to Railroad Retirement benefits or Railroad Retirement disability benefits
- Individuals with end-stage renal disease (ESRD) — permanent kidney failure requiring dialysis or a kidney transplant
- Individuals with Amyotrophic Lateral Sclerosis (ALS)

Similar to private insurance, Medicare has several types of coverage that provide different types of benefits:

Fee-for-Service Medicare

This is the original version of Medicare that is similar to a private fee-for-service health insurance plan. FFS Medicare consists of two parts:

- Medicare Part A covers inpatient care in hospitals and similar settings. Medicare Part A premiums are free for most Medicare beneficiaries.

- Medicare Part B covers medically necessary services such as doctor visits and outpatient care. Part B is voluntary, and you must pay a monthly premium. How much you will need to pay depends on your level of income.

Importantly, Medicare Parts A and B typically pay only 80% of the usual and customary charges, leaving the patient to pay the other 20%. Outpatient radiation and chemotherapy are both Part B covered expenses. Without Medigap or other secondary coverage, cancer patients are responsible for 20% of the cost of their treatment. Individuals receiving Medicare, particularly those over 65, can purchase a Medicare supplement plan known as **Medigap** to cover the other 20%.

It is important to purchase Medigap coverage as soon as possible after becoming eligible for Medicare, to ensure the lowest premiums. In addition, the pre-existing condition protections in the ACA do not apply to Medigap plans, so make sure to follow the enrollment deadlines.

If you cannot afford Medicare Part B premiums, or the costs of your care that Part B does not cover, you may apply for assistance. For more information see www.medicare.gov or contact 1-800-633-4227.



I'm on Social Security Disability, and have a Medicare Part C plan. I'm in the chronic illness plan, so I was automatically assigned a case manager. Initially a nurse came to my home every month to check up on me and make sure I had everything. They're close enough they can do a house visit. It's all part of the plan which is great!

— Nancy, metastatic breast cancer survivor

Medicare Advantage

Medicare Advantage, also known as Medicare Part C, offers managed care plans under the Medicare benefit. These options are similar to private health insurance HMOs and PPOs, and vary by area. To find plans available to you, visit www.medicare.gov/find-a-plan/questions/home.aspx. Each Medicare Advantage plan must provide **minimum essential coverage** specified by Medicare and may offer additional services. Each plan sets its own premiums, deductibles, co-pays and co-insurance, and must also have appeal procedures. Medicare Advantage plans can be cost effective options for access to coverage, but you are limited to using providers within the plan's network.

Medicare Part D

Medicare Part D is the portion of the Medicare benefit that covers outpatient prescription drugs. It will be discussed more fully in Chapter 4.

The Centers for Medicare and Medicaid Services (CMS) can provide more information

on Medicare and Medicaid coverage. For more information, visit www.medicare.gov, or call 1-800-633-4227.

Medigap policies

These health insurance policies supplement Fee-For-Service Medicare benefits. Medigap coverage varies but is typically designed to pay portions of medical bills that Medicare doesn't pay including deductibles, co-insurance, and, sometimes, charges above Medicare covered amounts. Some Medigap policies will also cover items that Medicare does not cover. If you join a Medicare Advantage plan you cannot also have a Medigap plan. Medigap policies only cover your additional expenses if you are in fee-for-service Medicare. It is important to apply for a Medigap plan during the **open enrollment** period or you may lose access to this option. Enrollment is guaranteed for seven months when you are first eligible for Medicare; however, not all states offer Medigap plans for people who are under 65.

MEDICAID

Medicaid provides health care benefits to low income individuals who meet eligibility requirements. Medicaid programs are jointly funded by the federal government and state governments. Each state administers its Medicaid program, and eligibility criteria and benefits vary from state to state. A person who is eligible for Medicaid in one state is not necessarily eligible in another. However, generally, a person must have a very low income and be eligible based on having a disability, having a dependent child, or being over 65, though some states have extended eligibility further. To make it even more confusing, some states use a different name for the program such as Medical Assistance, Medi-Cal or TennCare.

In addition, the ACA created a new category of eligibility for Medicaid, which includes all adults with household incomes under 138% of the Federal Poverty Level (FPL). To find the current federal poverty level, visit www.healthcare.gov/glossary/federal-poverty-level-FPL. However there are some states that are not offering this new option. For more information, visit: www.healthcare.gov/what-if-my-state-is-not-expanding-medicaid.

In the states that are expanding their Medicaid programs, this new category of eligibility is only based on household income levels, not assets or other resources.

Since eligibility criteria and benefits are different in each state, if you have questions about Medicaid, the best place to start is www.HealthCare.gov, or call 800-318-2596, which will direct you to your state Marketplace. After answering some income questions, the Marketplace will let you know if you are eligible for Medicaid in your state and will give you information about how to apply. You can also ask a social worker or financial counselor at your treatment facility for more information.

Medicare and Medicaid

You may be eligible to receive both Medicare and Medicaid benefits. If you are over 65 or disabled and have very limited income, Medicaid might cover what Medicare does not. Make sure to give your providers both your Medicare and your Medicaid cards to make sure that your services are covered. If you have both, generally you can obtain covered services at little or no cost. In general, if you have both Medicare and Medicaid, the only time you can be billed for a medical service is if the service is not covered by Medicaid, the health care provider informed you of this ahead of time, and you agreed to pay for the service yourself.

There are several categories of Medicaid available only to Medicare recipients. If a Medicare beneficiary qualifies, the **Qualified Medicare Beneficiary Program (QMB)** will pay Medicare monthly premiums, co-payments, and deductibles. Another program, Low Income Subsidy (LIS), will only pay for the Medicare Part B monthly premium.

To find out more about health coverage options if you are currently receiving Medicare, a good resource is the State Health Insurance Assistance Program. A list of the programs in each state is available at www.medicare.gov/contacts/#resources/ships, or call 1-800-633-4227.

I had genetic testing done, but my insurance (Medicaid) said they wouldn't pay for it. It was a \$5,000 test! I couldn't afford it. But I said I would be willing to make a payment plan, and they sent me the paperwork. Then I found out Medicaid picked up the test after all. It gets so confusing sometimes.

— Beth, breast cancer survivor



DO YOU HAVE BOTH MEDICARE AND MEDICAID?

You may be eligible to receive both Medicare and Medicaid benefits. If you are over 65 or disabled and have very limited income, Medicaid might cover what Medicare does not.

COMMUNICATING WITH YOUR INSURANCE COMPANY

Just about anyone who has phoned a health insurance company will tell you it can be frustrating. There are often long wait times and it can be challenging to explain your question and understand the answer. As you've probably become aware, health insurance has a language of its own.

Effective communication with your insurance company is crucial. Learning more about what your policy does and does not cover will help you better work with your insurer to make sure you receive all the benefits and coverage to which you are entitled. You will also be better prepared to deal with any questions or disputes you may encounter.

Who Can Help

To find out more about your coverage, you can speak with:

- The employee benefits manager or human resources personnel at your place of employment (or your loved one's place of employment)
- The insurer's customer service department
- A case manager assigned by your health insurance company
- Your cancer care team social worker
- The hospital financial counselor

- Your state's consumer advocacy office. They help consumers with problems or questions about an insurer. To find your local consumer advocacy office, you can search online, contact a social worker at your cancer center or contact your state Attorney General's office
- Organizations listed in Chapter 5, that can assist with navigating your insurance coverage
- The Centers for Medicare and Medicaid Services, if you are insured with a federal health plan such as Medicare or Medicaid
- The U.S. Department of Labor's Employee Benefits Security Administration if you are insured through an employer-sponsored group health plan

Appealing Insurance Denials

Unfortunately, it is not unusual for claims to be denied or for insurers to say they will not cover a test, procedure, or service that your doctor ordered. If you have established a working relationship with a customer service representative or insurance case manager, it will be easier to manage this situation. Regardless, you can **appeal** your health insurance company's decision, and you may be able to get the decision overturned. Some plans refer to appeals as "grievances" or "complaints."

If you want to appeal a decision, you may want to first check with your health care team to see if there is someone on staff who can help you. Your treatment facility may have someone who is familiar with the appeals process and knows individuals at your insurance company.

If the appeal is for coverage of a specific medication, some manufacturers may also be able to help you with your appeal.

If you choose to file the appeal yourself, remember that while you may feel angry that the insurance company has denied one of your claims, courtesy and a cool head will increase your chances of success. It is perfectly normal to be frustrated, irritated, or angry that a claim was denied. However, how you share that frustration and anger may affect the success of your appeal.

Before you call the insurance company, you may want to role play this conversation with someone else. Ask someone to act as the insurance company representative while you play yourself. This will give you an opportunity to express your frustrations in a safe environment and further refine your approach to the situation. Taking a step back from an upsetting situation with the insurance company can benefit you. Yelling at the insurance company's customer service representative or medical director is not likely to be effective.

If your appeal is denied, you still have options. You can ask for a final decision in writing and then file an external appeal. However, if your issue is urgent, you don't have to wait to get a final decision from your insurance company before filing an external appeal. An external appeal involves a review of your claim by an independent organization outside of your insurance company. All private health insurance plans are now required to have external appeals processes.

Additionally, you can also request help from your state's Consumer Assistance Program, your state's insurance agency or the Department of Labor if you are insured under a federal policy. For more information, visit www.cms.gov/CCIIO/Resources/Consumer-Assistance-Grants/. There are also nonprofit organizations that can provide detailed information about insurance appeals such as the Patient Advocate Foundation and the **LIVESTRONG** Foundation. These resources can be found in Chapter 5.

Tips for Appealing a Denial of Coverage

- Make sure you have a copy of the denial letter. If you don't already have a copy, ask the insurance company to send you a copy of the denial letter.
- Make note of the deadline by which you must submit an appeal in order for it to be considered.
- The denial letter must document the specific reason the claim or pre-authorization was denied.
- Get a copy of your current insurance benefit plan. This may be available online, or you may have to request a copy of it in writing.
- If you receive health insurance through your employer and you are comfortable sharing information about your medical condition with your employer, consider asking your employer for help communicating with the insurance company.
- Consider asking a family member or a friend to “quarterback” or take the lead and help manage the appeal, paperwork, etc., which can lessen the stress of an appeals process.
- Ask what you need to do to request a “doctor-to-doctor” conversation. This is a process by which your doctor can talk directly to the medical director at the health insurance company.
- As you go through the appeals process, take careful notes about whom you speak with (name and direct phone number), when (date and time), and the nature of the call.
- Be certain to exhaust all external appeals that are available in your state.
- Hang in there. Appeals often require persistence. Careful note taking will allow you to hand off the process to someone who is helping you if you want to take a break from all the phone calls. For more information and assistance in the appeals process, see pages 60-63 for a list of organizations that may be able to help.

The rehab hospital agreed my husband would be a good candidate for their program, and they had the bed space available. Then we needed approval from the insurance company. They initially denied us coverage because we didn't actually have any rehab coverage with our policy. But there is an emergency 24 hour appeal process. We've done this at least 3 times and each time, our insurance company has been great and created a rehab benefit. They saw it would be cheaper for them in the long run to let my husband participate in rehab rather than sending him home before he was ready.

— Elise, caregiver



3

Employment, Disability & Finances

My insurance company was just wonderful, which is not to say that I didn't come out with some debt. And debt is painful for everyone, but it can be managed.

— Julie, breast cancer survivor

In addition to health insurance issues, most people affected by cancer have questions about employment, disability, finances, and medical debt. This chapter will provide an overview of these issues.

EMPLOYMENT

Working through treatment

If you or a loved one has cancer, it doesn't mean that there will be a need to work less or leave the job, although some people do. There is not one "right" answer about working full-time, part-time or not at all during treatment.

For some, treatment requires frequent or lengthy hospital visits or stays which can get in the way of work. There may be days when there is a need to take time off for treatment or because of the effects of the cancer or the treatment. Your health care team may be able to offer advice on the likelihood of your treatment affecting your ability to work so it is important to talk with them about what you do in your job, as well as your priorities. Everyone is different, so consider what is best for you.

Talking with your employer

Many people diagnosed with cancer wonder if and how much they should tell their employer. You may be worried that you will be treated differently or that you will become a topic of office conversation.

Whether and how much you tell an employer is an individual decision. Some people find it helpful to tell their employers about their cancer diagnosis, while others wish to keep it private. Do what feels right to you.

An advantage to letting your boss know is that it may be less stressful if you need to rearrange your work schedule or miss work due to treatment or its side effects. However, you may not be required to disclose your exact diagnosis, if you do not wish to. As long as you can do your work, with or without assistance, there are laws to protect you from discrimination due to your cancer diagnosis.

The **Americans with Disabilities Act (ADA)** protects workers against discrimination in the process of hiring, firing, promotions, and many other activities. The law also requires that employers make **reasonable accommodations** so that people with disabilities are able to function in the workplace. Reasonable accommodations are situation-specific and might include modifying a work schedule or making the physical workplace accessible. The ADA does not apply if you are no longer able to perform the **essential functions** of your job.



THINGS TO CONSIDER WHEN DECIDING WHETHER TO WORK THROUGH TREATMENT

1. Do I enjoy my work and/or find it a welcome distraction?
2. Have my career priorities changed?
3. What does my health care team recommend?
4. Can I complete my work functions while in treatment?
5. What are the common side effects of my cancer treatment and how might this affect my work?
6. How would taking time away from work affect my income?
7. How much sick leave do I have?
8. If I take time off from work, will the Family and Medical Leave Act apply?
9. Do I live in a state with a state-sponsored short-term disability insurance program?
10. Do I have a disability insurance benefit through my employer? If so, how much will it pay?
11. Do I have private disability insurance? If so, how much will it pay?
12. Will I qualify for long-term Social Security Disability Insurance (SSDI)? If so, do I have savings to carry me through the 5-6 month waiting period?
13. If I decide to stop work temporarily or permanently, how will this affect me and others?
14. If I decide to stop work, what will I need to do to keep my health insurance?



The HR person in my office helped me complete the short-term disability paperwork. She was very helpful.

— Stephanie, brain cancer survivor

If you talk with your employer, prepare beforehand by talking with your treatment team about how much time you may need to be away from work. You can also ask if they have recommendations about your work schedule. Make a list of any accommodations you might need. If you aren't sure what you'll need, be sure to say that you'll get back to your boss as soon as you know more. Do your part to keep the channel of communication open.

It is also important to explain to your boss that cancer treatment is a fluid process and what you know or are experiencing today might be different as you progress through treatment and recovery. This will help manage expectations at work if something changes along the way.

After you speak with your boss, it's wise to make some notes. No matter what your relationship with your boss, it's good practice to keep records of your conversations regarding your cancer diagnosis. If you receive a reasonable accommodation, ask for it to be documented. You may also want to make a copy of any recent performance reviews and any positive statements about your work. Also, make note of anything that could indicate you are being discriminated against. In the unlikely event that you have problems with your employer in the future, careful records can prove invaluable. Some states provide additional protections regarding accommodations. Check with your state's fair employment agency.

For more information about talking with your employer, or for other employment and cancer-related questions, visit Cancer and Careers at www.cancerandcareers.org or call 646-929-8031.

Family and Medical Leave Act (FMLA)

Like the ADA, the Family and Medical Leave Act is a federal law that protects individuals who need to take time off from work due to their own illness or to care for a loved one.

All private employers who employ 50 or more people for 20 or more workweeks in the current or preceding calendar year, and state and local governments of any size, must offer FMLA benefits. The FMLA entitles eligible employees to take up to 12 workweeks of unpaid, job and benefit-protected leave in a 12-month period for specified family and medical reasons.

To be eligible for FMLA benefits, an employee must:

- have worked for the employer for a total of 12 months
- have worked at least 1,250 hours over those 12 months

- work at a location in the United States or in any territory or possession of the United States where at least 50 employees are employed by the employer within 75 miles of where the employee works

Eligible employees can take leave:

- to care for a spouse, parent or child with a serious health condition
- to take medical leave when the employee is unable to work because of a serious health condition (cancer treatment generally qualifies as a “serious health condition”)

Importantly, employees may take FMLA leave intermittently. This means an employee can take leave in separate blocks of time for a single qualifying reason or reduce his or her usual weekly or daily work schedule. The law does say that when leave is needed for planned medical treatment, the employee must make a reasonable effort to schedule treatment so as not to unduly disrupt the employer’s operation.

Upon return from FMLA leave, an employee must be restored to his or her original job or to an equivalent job with equivalent pay, benefits, and other terms and conditions of employment. If you are unable to return to work after the equivalent of 12 workweeks away, your employer may have the option to terminate your employment. However, if you have used your 12 workweeks and you need a short amount of time to complete your treatment or recovery, you may be able to ask for this additional time off as a reasonable accommodation under the ADA.

Some employers also allow colleagues to donate accrued sick leave or paid-time-off to coworkers in need. You can check with your human resources representative to see if this is an option for you. Other employers offer FMLA-like benefits even if they are not subject to the law or provide other leave benefits. You should check your employee manual or union contract to see what other leave benefits might be available to you. Also, some states have more beneficial medical leave laws.



While on FMLA leave, your employer is required to maintain your health insurance coverage on the same terms as if you continued to work. If part of the health care premium was being deducted from your paycheck, you will need to make arrangements to pay your share while on leave.

DISABILITY BENEFITS

Social Security Disability Insurance (SSDI)

Social Security Disability Insurance (SSDI) is a federal program through the Social Security Administration that provides, after a waiting period, a monthly payment to people who have worked for a sufficient period of time, paid Social Security taxes, and are deemed “disabled” by Social Security. In addition to the monthly check, after two years of receiving this monthly benefit, SSDI recipients are also entitled to Medicare.

Social Security defines “disabled” as “unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment that is expected to result in death or has lasted, or can be expected to last, for a continuous period of 12 months.”¹ Social Security defines “substantial gainful activity” as any work activity where you earn more than a specified amount (in 2020, \$1,260 or more per month for those who are not blind and \$2,110 or more for those who are blind). Given this definition, if you are working and are being paid more than \$1,260 per month, then Social Security is unlikely to deem you disabled.

If you are not working due to your cancer treatment, and you think you might want to apply for Social Security Disability, it is wise to do so sooner rather than later. The Social Security Disability Determination process can take months or even years to get your application approved and even longer if you have to appeal. If you apply and then you find you are able to return to work, you can simply retract your application. On the other hand, if you are expecting to return to work and are not able to do so, your application process will already be under way.

Eligibility for SSDI

You may be eligible to receive SSDI if you:

- Have worked long enough and recently enough in jobs covered by Social Security. However, younger workers may qualify with fewer credits
- Have a medical condition that meets Social Security’s definition of a disability

¹ www.ssa.gov

Applying for Social Security Disability

Starting an application for Social Security Disability is easy to do. You can call 1-800-772-1213; go online to www.socialsecurity.gov/disability; or visit your local Social Security office. Some basic information will be gathered during this initial contact. A Social Security Administration (SSA) representative will then offer you the choice of a face-to-face appointment, a phone meeting or you can complete the application process online.

When applying for benefits, you may need to provide the following information:

- Social Security number
- Birth certificate or other proof of age
- Names, addresses, and phone numbers of doctors, hospitals, clinics, and institutions that treated you, and the dates of treatment
- Names of all medications being taken

In each state there is a state agency, Disability Determination Services (DDS), that makes the medical decision on behalf of the Social Security Administration. The DDS will contact your health care providers directly to obtain your medical records. It doesn't hurt, however, to provide these records directly if you have them. The doctors at DDS use the medical records provided by your doctor(s) to determine whether you meet the criteria to be deemed disabled by Social Security.

You should be sure that all of your current medical conditions appear in your medical records as well as any limitations those conditions may have caused you in your ability to work. Sometimes people have more than one medical condition and treatment notes are incomplete as to what you are not able to do.

Representatives of Social Security generally prefer to speak directly with the disability applicant. However, if an applicant is not able to communicate for some reason, the representative will accept other arrangements.

You will be contacted by SSA regarding their decision.

The Social Security Administration has a program called Compassionate Allowance. Under this program, Social Security has an obligation to provide decisions quickly to applicants whose medical conditions are so serious that they obviously meet disability standards. There are many diagnoses that will automatically qualify an individual for disability in an average of 6 to 9 days, although benefits do not begin until the 5 month waiting period is complete. For more information see www.ssa.gov/compassionateallowances.

If you are approved

You will receive an approval letter that includes the date which they deemed you disabled, referred to as your onset date. This date is important because it will determine when your waiting period begins. This waiting period is a time when you do not receive SSDI checks. You must wait five full months after your onset date before you will receive benefits. For example, if your onset date is June 15, you will not be eligible to start receiving benefits until December. Because payments are paid out for the previous month, you would receive your check for December in January.

If you are using COBRA for your insurance and the date your disability began was on or before your first 60 days of COBRA coverage, you can contact your COBRA administrator to let them know you wish to exercise your right to extend your COBRA benefit for 11 months. This will allow you to carry your COBRA insurance for up to 29 months. You only have 60 days from the time you receive your approval letter from SSDI to exercise this right.

After you have completed the waiting period, your disability benefit payments will begin. The amount of your monthly payment is calculated using a formula that takes into account how much you have paid in Social Security taxes over the years.

You will continue to receive SSDI benefits as long as you continue to be disabled and meet other eligibility requirements. However, the SSA may periodically review your case to see whether you are still disabled. The frequency of the reviews depends on the expectation of recovery.

After 24 months of receiving SSDI payments, you will be eligible for Medicare.

If you are not approved

If your application for SSDI benefits is denied, you may appeal the denial. Directions for the appeals process are included with the letter of denial. On average, 60 percent of SSDI applications are denied initially. If you decide to appeal, you must make your appeal request in writing or online within 60 days from the date you receive SSA's denial letter.

There are several levels of appeal:

In most states, you will first ask for **reconsideration** — a complete review of your application by someone who didn't participate in the initial decision. The reviewer will look at any evidence submitted when the original application was sent and any new evidence.

If that does not work...

You can request a hearing by an **administrative law judge (ALJ)**. This option gives you the opportunity to explain your situation as well as provide any new or missing information for your file. If you are concerned about attending this hearing alone, you are entitled to bring a “representative” with you. Often, people choose to hire a lawyer who specializes in disability cases to help with this level of appeal.

If the ALJ doesn't find in your favor you can...

Request your case be heard by an **Appeals Council**. The Appeals Council looks at all requests for review. However, they will deny a request if they believe that the decision of the hearing was correct. If the Appeals Council agrees to review your case, it can either decide your case or return it to an administrative law judge for further review.

If this doesn't work, the last level of appeals is to...

Appeal through the Federal Court System to overturn the Appeals Council denial of disability. The letter that the Social Security Administration sends explaining the Appeals Council's decision will also provide information regarding how to ask a federal court to look at your case.

If you are initially denied SSDI but this decision is later overturned, your onset date of disability may date back to your original

application. Some individuals who are deemed disabled after a lengthy appeals process receive a **retroactive payment** of past-due payments. This retroactive payment equals the amount the person would have received based on their onset date if they had been receiving checks all along.

The retroactive payments can go back up to twelve months prior to the date of your application, if your disability began prior to your application date.

Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI)

Because SSDI and SSI are both administered by the Social Security Administration, they are often confused. However, they are different programs with different eligibility criteria and benefits. SSI pays monthly benefits to the elderly, the blind, and people who have disabilities *and* very low income.

The medical requirements to be deemed disabled are the same under both SSDI and SSI. If you have a very low income and minimal savings and other assets you may qualify for SSI benefits. These would begin immediately. You would be able to receive these monthly payments during the waiting period, if you qualify for SSDI.

It is also possible that you could receive these payments for the duration of your disability if you have not paid enough into the Social Security system to qualify for SSDI or if your SSDI payment is below the current SSI payment rate. SSI payments are usually substantially lower than SSDI payments.

If you qualify for SSI, you may qualify for Supplemental Nutrition Assistance Program (SNAP, formerly Food Stamps) and Medicaid.

State Disability Insurance Programs

A few states offer state-funded disability insurance. California, Hawaii, New Jersey, New York, Rhode Island, and Puerto Rico offer short term disability insurance benefits to individuals who are unable to work because of a medical condition. Plans, benefits, and eligibility vary from state to state. For more information, visit your state's insurance agency website.

Employer-Sponsored Disability Insurance

Some employers offer short and/or long-term disability insurance coverage to their employees.

If you are not sure if you have disability insurance through your employer, ask your human resources representative. He or she should be able to tell you about your benefits and where you can find more information. Employer-based disability policies typically

provide regular payments that are between 50 percent and 70 percent of your salary.

Importantly, you may qualify for employer-based disability even if you don't qualify for Social Security Disability. Employer-based disability policies do not always use the same definition of disability as the Social Security Administration does.

If you qualify for a government-based disability insurance such as SSDI, SSI, or a state program and employer-sponsored disability insurance at the same time, check with your Human Resources representative to see if you will be able to receive both payments in full. Sometimes employer-sponsored disability plans adjust their payment to account for any Social Security Disability payment you receive. If you receive retroactive government disability benefits, you may be required to pay back any benefits you have already received from your employer-sponsored short or long term disability insurance provider.

Private Disability Insurance

It is possible to purchase private disability insurance, and some individuals have purchased a policy prior to receiving a cancer diagnosis. If you have private disability insurance, contact the company or the agent from whom you purchased the policy for details on how to file a claim.

OTHER SOURCES OF INCOME AND FINANCIAL SUPPORT

After maximizing your health insurance benefits and income options, most people affected by cancer still find unexpected expenses. Depending on your situation, you may have other options for income and financial assistance. These may include charities and community resources, as well as retirement funds (such as a 401(k) or IRA), **reverse mortgages**, and life insurance possibilities.

Due to potential tax consequences and implications for your long-term financial situation, keep in mind that options such as cashing in retirement accounts or life insurance policies should be considered very carefully. It is recommended that you seek the advice of a financial professional or advisor when making these types of decisions. However, for some people who have accrued substantial debt through the course of treatment, these options can provide welcome relief.

The good news is there are financial resources available to help people affected by cancer. It can feel like a full-time job exploring the financial assistance possibilities. Consider asking friends or family members to help you learn more about income and financial resources.

For assistance with paying your health insurance premiums, there is a program in some states called the Health Insurance Premium Payment (HIPP) Program. The HIPP Program is a Medicaid program that can help pay for

your private health insurance premiums if you otherwise qualify for Medicaid. The details vary from state to state, but contact your state's Medicaid program for more information.

In addition, if you are caring for a family member, then you may be able to get paid through a state Medicaid program. The details vary from state to state, but this benefit is often called the In-Home Support Services (IHSS) Program. Contact your state's Medicaid program for more information.

In 2020, five states (California, New Jersey, New York, Rhode Island, and Washington) provided caregivers with paid family leave benefits. Visit your state's website & search for "paid family leave." CA: www.paidfamilyleave.org; DC: <https://does.dc.gov>; MA: www.mass.gov; NJ: <https://www.nj.gov/labor/fli/fliindex.html.html>; NY: www.paidfamilyleave.ny.gov; RI: www.dlt.ri.gov/tdi; WA: www.esd.wa.gov.

The National Council on Aging created a web-based program www.benefitscheckup.org that can help connect you with resources for which you might be eligible.

Nonprofit Organizations

There are a variety of nonprofit organizations that may be able to help you cover parts of your medical care and other costs. Different programs and services work differently. You can find additional information in the Resources section of Chapter 5.

Some programs may provide grants to help cover treatment costs or other living expenses. Others may provide a specific service, such as transportation or temporary lodging. Available help may vary from community to community.

Talk with your treatment team for more information.

Community Resources

Your city, county, or state government may have helpful resources. Most local governments have programs that offer food and housing assistance, although the qualification criteria may be very strict. To find out about programs such as Section 8 Housing, Supplemental Nutrition Assistance Program (SNAP), and Senior Housing, contact your local Department of Social Services. Some areas have a different name for this department such as Department of Family and Children's Services. You should be able to find the number in the Government section of your local phone book.

Faith-based organizations such as local churches, synagogues, temples, and mosques

may also provide assistance for people with cancer. Many will help even if the person is not a member of that particular organization or religion.

Some hospitals also have private funds available for patients in need. These community-based groups will not be listed in our Resources section because they are specific to your geographic area. A social worker at your treatment facility or community center, the United Way, and/or the American Cancer Society may be able to direct you to specific local resources.

Finally, many cancer survivors have received financial assistance from friends, family, and coworkers. This assistance can take many forms. Sometimes friends are anxious to know what they can do and are excited by the opportunity to host or attend a party, concert, or other event to raise funds for your treatment or living expenses. Coworkers often feel good about being able to contribute to a collection or online fundraiser taken up in your name. Saying “yes” to these offers can feel uncomfortable, but it may help to consider how you would feel if you were the one offering assistance.

Retirement Funds

If you have money invested in an IRA, a 401(k) or defined contribution retirement plan, you may be able to borrow or cash in your plan to

help cover your medical expenses. You may be able to access this money fairly quickly. As mentioned earlier, you should consider the implications very carefully, preferably in consultation with a financial advisor. There may be taxes and penalties involved if you access money from your retirement plan.

Some employers allow employees to borrow from their retirement fund. The interest rate on the loan is usually reasonable, and if you pay the loan back on time (usually within 5 years), there is no penalty for the withdrawal.

However, if you don't pay the loan back, it's considered an early withdrawal, and you will have to pay the penalty.

Having unreimbursed medical bills for yourself or your spouse does qualify as a reason for a "hardship" withdrawal. However, this does not excuse you from paying both regular income tax and the 10% early withdrawal penalty on the funds.

The website www.survivorshipatoz.org is an excellent source of additional information.

Life insurance

If you have a life insurance policy, this may also be a source of funds. Since you probably purchased the policy to provide financial support to your family, these options should be considered carefully and with the advice of a financial advisor. There may be a variety of

ways to obtain cash from your life insurance. Keep in mind that different options may be available depending on the type of policy that you have.

Loans

You may be able to get a loan from your insurance company or other lending institution using your life insurance policy if you have a permanent type of policy such as Whole Life or Universal Life. If a loan is available, details will be stated in the policy.

Loans Secured by the Face Value of a Life Insurance Policy

There are some companies that allow patients with advanced cancers to access a portion of their life insurance policy in the form of a loan. These loans are designed to provide patients with access to cash through a loan secured by the life insurance policy, while trying to preserve a portion of the policy death benefit for the family. This option is not dependent on the cash value of the policy and instead focuses on the face value of the policy, which means that group policies, term life policies, Federal Employee Group Life Insurance and other policy types may be used for these loans. Funds received from these loan programs are generally non-taxable. Also, in many cases these loans can be structured without impact on existing needs-based assistance.

Accelerated death benefit

You may also have the option of receiving a “pre-death” benefit from your life insurance company if your life expectancy is less than 1-2 years. This type of provision is fairly new, so you may have it even if it is not mentioned in your policy. Ask the insurance company for more information.

Viatical Settlements

This is the sale of a life insurance policy for cash. The policy owner (called the viator) sells his or her life insurance policy to a third party for a single, smaller lump sum cash payment. The lump sum payment may be tax free if the insured’s life expectancy is less than two years, otherwise the lump sum payment may be considered income. The purchaser of the policy becomes the new owner and sole beneficiary of the policy. When the viator dies, the entire death benefit from the policy goes to the new beneficiary. If an insured is receiving needs-based assistance, careful consideration of the impact of a policy sale is required to ensure that the payment does not disqualify the insured from their benefits.

As with all these options, it is important to think about the short- and long-term consequences for you and your family. If you are able, consult with a financial advisor to understand the impact of using your life insurance policy to help with your financial needs during your treatment.

Reverse Mortgage

A **reverse mortgage** (also called a lifetime mortgage) is a loan to a homeowner that allows the owner to get cash from the equity in the property as one lump sum or multiple payments. A reverse mortgage could work well for a person who has few assets other than a home.

To qualify for a reverse mortgage, the borrower must be at least 62 years old. There are no minimum income or credit requirements, but there are other requirements. With most reverse mortgages, the money can be used for any purpose. However, the borrower must pay off any existing mortgage(s) with the proceeds from the reverse mortgage. Typically, the loan from a reverse mortgage doesn’t have to be repaid until you move out of the home, the house is sold, or the last borrower dies. When one of these things occurs, the heirs have the option to pay off the loan and keep the property or to sell it to pay off the debt.

Before borrowing, applicants must seek third party financial counseling from a source approved by the Department of Housing and Urban Development (HUD) to make sure the borrower completely understands what a reverse mortgage is and how one is obtained.

MANAGING MEDICAL DEBT

If you take an active approach to coping with the cost of your cancer care, you're likely to feel more in control. That said, in today's health care system, even after you have found every single resource that can help with the cost of care, many people still find that they accrue medical debt. Cancer care is expensive, and insurance does not typically cover all the bills. If you owe the bill and have no other means of paying it, try to work out a payment plan with the provider.

There are other ways you can be proactive as well. Pursuing the resources listed in Chapter 5 is one way. Another is to contact your creditors ahead of time and let them know what is going on. Some credit card and mortgage companies may temporarily change your payment requirements and/or interest rate. Sometimes individuals can negotiate with creditors to either decrease the amount owed or lengthen the period of the loan.

The strain of being in debt can be tremendous. It can be tempting not to open bills out of fear of frustration or to toss them in a box never to be seen again. This will cause difficulties later on. It is best if you keep up with the bills on at least a monthly or twice monthly basis.

If you are disputing your bill (e.g. you have filed an insurance appeal, believe there is an error, or were wrongly denied a government insurance program), do not be pressured into paying the bill until the dispute is resolved. If the bill has gone to collections, most collection agencies will put a hold on the bill until the dispute is resolved.



If your bills include student loans, you should look into whether you qualify for deferment, forbearance or a complete discharge of your loan based on disability. See www.studentaid.ed.gov/sa/repay-loans for more information.

If bill collectors are calling or you are receiving notices that bills have been sent to collection, you may want to take some deep breaths before responding. With your support system, develop your plan of action. The website www.survivorshipatoz.org has suggestions for managing medical debt and negotiating with creditors. And remember, if there is no money, then there is no money. No matter what a bill collector says, you have no reason to feel ashamed. Additionally, there is a federal law that protects consumers from unfair debt practices, including harassment by bill collectors. If you feel that you are being treated unfairly by a creditor, contact your state's Attorney General's office.

Coping with the cost of care will look different for each individual. Sometimes declaring bankruptcy is the best option. The bankruptcy system was designed for financial crises such as a cancer diagnosis. For more information about bankruptcy and finding legal assistance, visit www.lawhelp.org or www.NCLSN.org. A good financial advisor can help you identify options if you are accruing substantial medical debt.

Choosing a Financial Planner or Advisor

Financial advisors and planners can be very helpful as you manage the cost of cancer care, and it's very important to find a qualified professional.

You may want to ask:

- About the professional's credentials. Three common credentials in this profession are CFP (Certified Financial Planner), ChFC (Chartered Financial Consultant), and PFS (Personal Financial Specialist).
- Whether the professional has experience working with individuals with cancer.
- The number of years of experience of the professional.
- What issues the professional sees as most important in your situation. What financial planning process would the professional recommend in your situation?
- Is the person you're considering familiar with all aspects of medical coverage, disability benefits, life insurance, accelerated benefits, viatical settlements and reverse mortgages?
- Is he or she familiar with the employee rights of cancer patients?
- How are the financial advisor's or planner's fees determined? Does he or she charge a flat fee, receive a commission from the sale of financial products, or both?



In 2009, a study conducted by researchers at Harvard University found that 62% of the people who filed personal bankruptcy in 2007 cited medical causes as a primary reason for filing.



Prescription Medications

The drug companies will give the medicine for free sometimes, but only if you apply.

— Nancy, metastatic breast cancer survivor

The cost of prescription medications to treat your cancer may represent a significant portion of your medical expenses. Prescriptions may include oral chemotherapies, anti-nausea drugs, and other medications.

There are many resources to help pay for prescription medications. This chapter will discuss two categories of potential help with affording your prescriptions: insurance (including Medicare Part D) and patient assistance programs.

PRESCRIPTION INSURANCE (INCLUDING MEDICARE PART D)

Most health insurance policies include a prescription drug benefit. Often this benefit is managed for your insurance company by a different company. This means you have to call a different number when you have questions about your prescription coverage. The number to call should be on your insurance card. Just as you've done with your health insurance company, it's a good idea to write down when you call, whom you speak with, and their phone extension.

Most likely, your insurance plan's prescription drug coverage includes a **formulary** or a **preferred drug list**. The formulary includes most **generic** and some **brand-name medications** that are already approved by your plan to be prescribed by your doctor. On-formulary medications can usually be prescribed without any pre-authorization. Every company has a different formulary, and the list changes often.

Prescription coverage can take several forms. Some plans will cover drugs that are on-formulary and not on-formulary, but you will generally have to pay more for non-formulary drugs. Other insurance plans may cover only on-formulary drugs and deny payment for all others without some sort of preapproval process. The majority of formularies are **tiered**, to either a flat co-pay amount or a co-insurance percentage. Tier 1 includes generic drugs and usually cost the least. As prescription medications have grown more expensive, the tiering has grown more complicated. Usually each tier has its own co-pay or co-insurance.

If your doctor prescribes a drug that isn't on your health insurance plan's formulary, you'll usually discover this when you try to fill it at the pharmacy. Your pharmacist may call you or, when you go to pick up the prescription, the cost may be more than you expected.

If this happens, first find out from your pharmacist if there is another medication on your insurance company's formulary that is in the same class and does the same thing as the one prescribed. If there is, you or your pharmacist can call your doctor to ask his or her opinion about switching to the on-formulary medication. Often the two medications are virtually the same. Your doctor may feel that the on-formulary medication will be just as effective and be happy to change your prescription.

If your doctor feels strongly that you should take a particular medication that is not on your formulary, you can request an **exception** and plans have a process through which a drug may be approved on a case-by-case basis.

In these situations the company may require proof that you have already tried other medications and that they either failed you or you experienced adverse effects from them. This is called **step-therapy**. If your coverage is still denied, an appeal process is usually available. If your doctor believes step therapy would be dangerous, you or your doctor can file an appeal.



ASKING FOR AN EXCEPTION

An exception is an initial request for your health insurance plan to reconsider a coverage decision regarding your drug benefits. For example, you might ask for an exception if:

- a prescription drug you need is not on your policy's formulary
- a prescription needs pre-authorization or has limits or step-therapy requirements

- a drug is covered but you would like for it to be covered at a higher level

Whether you are covered by Medicare, Medicaid, or private insurance, you and your doctor can work together with the insurance provider to pursue an exception. For additional assistance, contact the Patient Advocate Foundation. Contact information can be found in Chapter 5.

Medicare Part D

Medicare Part D is the prescription benefit for Medicare recipients. Unlike Medicare Part A, you must choose to enroll in Medicare Part D, and for most plans there is a monthly premium. Your Part D monthly premium can vary based on your income. If your income is above a certain limit, you will pay a little more each month. Medicare Part D plans are modeled on a standard benefit design that includes a deductible, initial coverage period, coverage gap and catastrophic coverage.

The Medicare Part D benefit is administered by private companies. Within certain limits, plans can vary the costs and benefits within the standard benefit structure. Each plan also has its own formulary. There are many plans to choose from so you will want to compare them for costs, benefits and availability of your drugs before making your coverage selection.



THE MEDICARE PART D STANDARD BENEFIT IN 2020

- You pay a \$435 deductible, meaning that you pay out-of-pocket the first \$435 of retail drug costs.
- After you meet your plan deductible, you enter the initial coverage period. During this phase you pay 25% of retail drug costs until you have paid out-of-pocket \$6,350 in drug costs (including deductible, copays and co-insurance).
- Then you are eligible for catastrophic coverage, and you will pay 5% or \$8.95 for brand name and \$3.60 for generic, whichever is greater, for your covered drugs per month for the remainder of the year.

The ACA has been shrinking the donut hole bit by bit each year since 2011 by reducing the cost-sharing amount that you have to pay for prescription drugs. Until 2019, the amount of cost sharing depended on whether a drug was generic or brand name. But starting in 2020, once you reach the coverage gap you'll pay 25% of the cost for your plan's covered prescription drugs independently of whether a drug is generic or brand name.



CLOSING THE COVERAGE GAP

This table shows how the coverage gap has been closing over the last few years.

Year	Brand	Generic
2018	35%	44%
2019	25%	37%
2020	25%	25%

Medicare provides a program that helps pay for prescription drugs for people with limited income and resources. This Medicare Low Income Subsidy (LIS) program is called “Extra Help.” If you qualify you will receive substantial savings on Part D drugs. You can apply for Extra Help at the Social Security website (<https://secure.ssa.gov/i1020/start>) or by calling 1-800-772-1213.

Many states also offer help paying drug plan premiums and/or other drug costs. Find out if your state has a program by contacting your State Pharmaceutical Assistance Program (www.medicare.gov/pharmaceutical-assistance-program/state-programs.aspx). Many drug manufacturers also have programs to help patients with their drug costs (see page 58 for more detail).

Additionally, chemotherapy-related prescription medications may be covered by Medicare Part B rather than Medicare Part D if the chemotherapy is also available intravenously. If you are told that you have no coverage for a medication through Medicare Part D, ask if it is covered by Medicare Part B. If this is the case, you may be able to obtain the drug through your doctor's office or you will need to find a pharmacy that accepts Medicare Part B. Many mail-order pharmacies and pharmacies located near or in hospitals accept Medicare Part B.

Open-enrollment for Medicare occurs each year between October 15 and December 7. During this period anyone can join, switch, or drop a Medicare plan. The change will take effect on January 1 as long as the plan gets your request by December 7. If you qualify for Extra Help, you may be able to obtain Medicare Part D coverage at any time. Even if you are enrolled, it is important to reevaluate the plan you are in to ensure that the formulary has not changed or the medications you need haven't shifted. There could possibly be a more cost effective plan available.

You may want to ask your health care team what medications you are likely to need over the coming year. You can then use the Medicare "Plan Finder" (available at www.medicare.gov) to determine which plan in your area has a formulary that is most advantageous to you.

The Centers for Medicare and Medicaid Services (CMS) can provide more information on their website at www.medicare.gov, or by phone at 1-800-633-4227. Another good resource is the State Health Insurance Assistance Program (SHIP). A list of the programs in each state is available at www.medicare.gov/contacts/ or call 1-800-633-4227.



In a recent survey by the Cancer Support Community, 33% of respondents acknowledged that they had unexpected expenses due to prescription co-pays.

PATIENT ASSISTANCE PROGRAMS (PAPs)

If you do not have prescription medication coverage, have limited prescription insurance, or have a number of prescriptions, you may have difficulty paying for all of them. In these instances, Patient Assistance Programs (PAPs) may be available to help. These are funded by state governments, charitable organizations, and pharmaceutical companies.

Nearly every pharmaceutical company has a PAP for many of the medications that each particular company makes. These programs provide discounted or free medication to people who qualify. Some PAPs can facilitate an exception and/or appeal process with your insurance company for coverage of particular medications. While there are financial criteria to qualify for most if not all of these programs, the criteria can be very generous. If you need help, it's wise to apply.

In addition to the programs provided by the drug companies, several nonprofit organizations have developed programs to help patients with prescription costs including co-pays. For more information, see Chapter 5.

Help is available! The Partnership for Prescription Assistance is a good place to start: www.pparx.org.

When an insurance company assigns a case manager, that seems to really help a lot. They explain the financial stuff — what the insurance covers, what's going on at the insurance company, what's going on with your FMLA leave, what's going on with your short-term disability, or when to switch to long-term disability. I think that was one of the best things about the insurance company.

— Kathy, breast cancer survivor

Pharmaceutical Company Patient Assistance Programs

The following list of programs is not exhaustive. We have selected the programs most commonly used by cancer patients. Each company provides assistance only for medications it manufactures. If you are not sure which pharmaceutical company makes the medication(s) you have been prescribed, you can ask your health care team or pharmacist for help. Some companies have more than one patient assistance program. The information below is a starting place for gathering information about possible assistance. For more information, visit www.needymeds.org or www.pparx.org.

AbbVie Patient Assistance Foundation

800-222-6885
www.abbviepaf.org

Amgen Assist®

888-427-7478
www.AmgenAssistOnline.com

Astellas Pharma's Xtandi Access Service

855-898-2634
www.astellaspharmasupportsolutions.com/

AstraZeneca's AZ&Me™ Prescription Savings Program

800-292-6363
www.astrazeneca-us.com/medicines/Affordability.html

Bayer's REACH

866-639-2827
Zero Copay for Bayer
www.nexavar-us.com/reach-financial-support/

Bayer's Xofigo Patient Assistance

855-696-3446
www.xofigo-us.com

Bayer's Zero Copay

866-581-4992
www.zerocopaysupport.com

Boehringer Ingelheim CARES Foundation Patient Assistance Program

800-556-8317
www.bipatientassistance.com

Bristol-Myers Squibb Patient Assistance Foundation, Inc.

800-736-0003
www.bmspaf.org

Celgene Patient Support®

800-931-8691
www.celgenepatientsupport.com

Eisai, Inc. Patient Assistance Program

866-613-4724
www.eisaireimbursement.com/

Genentech BioOncology® Access Solutions

888-249-4918
www.genentech-access.com/patient/biooncology.html

GlaxoSmithKline's Commitment to Access®

866-265-6491
www.gskforyou.com/

IncyteCARES

855-452-5234
www.incytecares.com

Johnson & Johnson's Patient Assistance Program

800-652-6227
www.jjpaf.org

Lilly Cares

855-559-8783
www.lilly.com/patient-resources

Merck Patient Assistance Program

800-727-5400
www.merckhelps.com

Novartis Oncology Patient Assistance Now

800-245-5356
www.patientassistancenow.com

Pfizer Oncology Together

877-744-5675
www.pfizeroncologytogether.com

Purdue Patient Assistance Program

800-599-6070
www.purduepharma.com/patients-caregivers/cost-savings/

Sanofi's Patient Connection™

888-847-4877
www.sanofipatientconnection.com

SeaGen Secure

855-473-2873
www.seagensecure.com

Teva Oncology's CORE

888-587-3263
www.tevacore.com

Together with TESARO

844-283-7276
www.togetherwithtesaro.com



Resources & Glossary

I think the internet is a good source of information, and so are support groups. My treatment team also provided information.

— Jackie, metastatic breast cancer survivor

Based on your specific situation, you may want to pursue a variety of financial resources. This chapter is meant as a comprehensive — although not exhaustive — list of organizations, government agencies, and other resources that may be able to help.

RESOURCES BY SERVICES PROVIDED	Financial Planning Tools	Understanding Health Insurance (including COBRA)	COBRA Premium Assistance
American Cancer Society (ACS)	•	•	
American Society of Clinical Oncology (ASCO)	•	•	
Association of Oncology Social Work (AOSW)	•		
Cancer and Careers	•	•	
CancerCare	•	•	
Cancer Legal Resource Center (CLRC)		•	
Cancer Support Community	•	•	
Centers for Medicare and Medicaid Services (CMS)			
Co-Pay Relief Program			
Corporate Angel Network			
Feeding America			
Good Days (formerly Chronic Disease Fund)			
Healthcare.gov		•	
HealthWell Foundation			•
Joe's House			
Leukemia and Lymphoma Society (LLS)		•	•

Info about Medicare and Medicaid	Other Financial Support	Prescription Medications	Managing Medical Debt	Travel/Lodging Help	Employment and Disability
•	•	•	•	•	•
•		•	•	•	•
	•				•
•	•	•	•	•	
•		•	•		•
•		•	•		•
•		• (Medicare Part D)			
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RESOURCES BY SERVICES PROVIDED	Financial Planning Tools	Understanding Health Insurance (including COBRA)	COBRA Premium Assistance
LIVESTRONG Foundation	•	•	•
National Coalition for Cancer Survivorship (NCCS)	•	•	
National Energy Assistance Referral (NEAR)			
National Organization for Rare Disorders (NORD)	•	•	•
National Patient Travel Center			
NeedyMeds			
Oncology Nursing Society (ONS)	•		
Partnership for Prescription Assistance			
Patient Access Network Foundation (PAN)			•
Patient Advocate Foundation (PAF)	•	•	
Patient Services, Inc. (PSI)			•
Social Security Administration			
State Health Insurance Assistance Programs (SHIP)			
Survivorship A-Z	•	•	
Triage Cancer	•	•	
United Way			
ZERO - The End of Prostate Cancer			

Info about Medicare and Medicaid	Other Financial Support	Prescription Medications	Managing Medical Debt	Travel/Lodging Help	Employment and Disability
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					•
		• (Medicare Part D)			
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	•				

ALPHABETICAL LIST OF RESOURCES

American Cancer Society (ACS)

800-227-2345
www.cancer.org

The ACS provides a wealth of information and tools for managing the financial and legal issues related to your cancer. ACS also operates the Health Insurance Assistance Service, which helps people determine if they qualify for public programs like Medicaid or other low-cost private plans.

American Society of Clinical Oncology (ASCO) / Cancer.Net

888-651-3038
www.cancer.net

ASCO is a nonprofit organization with more than 30,000 members from the field of oncology. ASCO's patient information website—Cancer.Net (www.cancer.net)—brings the expertise and resources of ASCO to people living with cancer and those who care for and about them.

Association of Oncology Social Work (AOSW)

847-686-2233
www.aosw.org

AOSW is a nonprofit, international organization dedicated to the enhancement of psychosocial services to people with cancer and their families. Their website provides a list of resources for financial information. In addition, they provide a free database to search for an oncology social worker in your area.

Cancer and Careers (CAC)

646-929-8032
www.cancerandcareers.org

Cancer and Careers, founded in 2001, is a national nonprofit organization that empowers and educates people with cancer to thrive in their workplace by providing expert advice, interactive tools and educational events. Cancer and Careers services include a comprehensive website, free publications in English and Spanish, legal and insurance information, career coaching, resume review, and national events and speaking engagements for employees with cancer and their health care providers and coworkers.

CancerCare

800-813-4673
www.cancercare.org

CancerCare's free services include professional counseling and support groups, educational publications and workshops, and financial assistance. Under the CancerCare Co-Payment Assistance Foundation, CancerCare assists qualifying individuals with insurance who are undergoing treatment for cancer to afford their high co-payments for chemotherapy and targeted treatment drugs. For more information on CancerCare Co-Payment Assistance Foundation visit www.cancercarecopay.org.

Cancer Legal Resource Center (CLRC)

866-843-2572
www.cancerlegalresources.org

The CLRC is a national, joint program of the Disability Rights Legal Center and Loyola Law School Los Angeles. The CLRC provides free and confidential information and resources on cancer-related legal issues to cancer patients, survivors, caregivers, health care professionals, and others coping with cancer.

Cancer Support Community (CSC)

888-793-9355

www.CancerSupportCommunity.org

In 2009, The Wellness Community and Gilda's Club joined forces to become the Cancer Support Community. The combined organization provides the highest quality social and emotional support for people impacted by cancer, at no cost, through a network of more than 50 licensed affiliates, over 100 satellite locations and a vibrant online community.

Centers for Medicare and Medicaid Services (CMS)

www.cms.gov

CMS is the government entity responsible for Medicare and Medicaid. For comprehensive information about Medicare and especially Medicare Part D call: 800-633-4227. For comprehensive information about Medicaid see: www.Medicaid.gov.

Corporate Angel Network

866-328-1313

www.corpangelnetwork.org

Corporate Angel Network is a nonprofit organization that arranges free air transportation for cancer patients traveling to treatment using the empty seats on corporate jets.

Feeding America

800-771-2303

www.feedingamerica.org

Feeding America network provides food assistance to more than 25 million low income people facing hunger in the United States. They have a network of more than 200 food banks serving all 50 states, the District of Columbia and Puerto Rico.

Good Days® (formerly known as Chronic Disease Fund)

877-968-7233

www.mygooddays.org

Good Days® is a nonprofit charitable organization that helps underinsured patients with chronic disease, cancers or life-altering conditions obtain the expensive medications they need. They assist patients throughout the United States who meet income qualification guidelines and have private insurance or a Medicare Part D plan but cannot afford the co-payments for their specialty therapeutics.

HealthCare.gov

800-318-2596

www.healthcare.gov

The United States health insurance exchange website.

HealthWell Foundation

800-675-8416

www.healthwellfoundation.org

The HealthWell Foundation helps individuals afford prescription medications they are taking for specific illnesses. The Foundation provides financial assistance to eligible patients to cover certain out-of-pocket health care costs, including prescription drug co-insurance, co-payments, deductibles, and health insurance premiums.

Joe's House

877-563-7468

www.joeshouse.org

Joe's House is a nonprofit organization providing a nationwide online service that helps cancer patients and their families find lodging near treatment centers.

LawHelp.org

www.LawHelp.org

LawHelp helps low and moderate income people find free legal aid programs in their communities, answers to questions about their legal rights, and find forms to help with their legal problems.

LIVESTRONG Foundation

855-220-7777

www.livestrong.org/wecanhelp

The LIVESTRONG Foundation provides free support, information and tools to help people affected by cancer. Print and online resources help people deal with changes and challenges during all phases of the cancer journey. LIVESTRONG Navigation Services offers free, confidential, one-on-one support including counseling and referrals to resources in your area for psychosocial, financial, and insurance concerns. All services are available in both English and Spanish.

Leukemia and Lymphoma Society (LLS)

888-557-7177

www.LLS.org

LLS is a nonprofit organization dedicated to funding blood cancer research and providing education and patient services. They have information on managing the financial challenges that occur when diagnosed with a blood cancer, as well as a Co-Pay Assistance Program. They also provide general disease information, support services and clinical trial searches.

National Cancer Legal Services Network

www.NCLSN.org

NCLSN is a coalition of legal service providers that promote the increased availability of free legal services programs for people affected by cancer.

National Coalition for Cancer Survivorship (NCCS)

877-622-7937

www.canceradvocacy.org

NCCS offers free publications on insurance and employment issues for people living with, through, and beyond cancer. You can also listen to the Cancer Survival Toolbox, an audio-program that includes a section on Finding Ways to Pay for Care.

National Energy Assistance Referral (NEAR)

866-674-6327

<https://liheapch.acf.hhs.gov/referral.htm>

NEAR is a free service for people who want information on where to apply for the Low Income Home Energy Assistance Program (LIHEAP), which may pay a portion of the energy bills of eligible low income persons.

National Organization for Rare Disorders (NORD)

800-999-6673

www.rarediseases.org

NORD is a federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD administers programs to assist uninsured or under-insured individuals in securing life-saving or life-sustaining medications whose income is too high to qualify for Medicaid but too low to pay for their prescribed medications.

NeedyMeds

800-503-6897

www.needymeds.org

NeedyMeds is a free, online clearinghouse to help people who cannot afford medicine or health care costs.

Oncology Nursing Society (ONS)

866-257-4667

www.ons.org

The Oncology Nursing Society (ONS) is a professional association of more than 39,000 members committed to promoting excellence in oncology nursing and the transformation of cancer care.

Partnership for Prescription Assistance (PPA)

www.pparx.org

Medicines enable patients to live longer, healthier lives. The Partnership for Prescription Assistance® (PPA), a nationwide effort sponsored by America's biopharmaceutical research companies, has helped more than 10 million uninsured and underinsured Americans get information about programs that provide prescription medicines for free or nearly free. PPA provides a single point of access to more than 475 patient assistance programs, including nearly 200 offered by biopharmaceutical companies.

Patient Access Network Foundation (PAN)

866-316-7263

www.panfoundation.org

The Patient Access Network (PAN) Foundation is an independent, national 501 (c) (3) organization dedicated to helping federally and commercially insured people living with life-threatening, chronic and rare diseases with the out-of-pocket costs for their prescribed medications. Partnering with generous donors, healthcare providers and pharmacies, PAN provides the underinsured population access to the healthcare treatments they need to best manage their conditions and focus on improving their quality of life. Since its founding in 2004, PAN has provided nearly 1 million underinsured patients with over \$3 billion in financial assistance, through over 60 disease-specific programs.

Patient Advocate Foundation (PAF)

800-532-5274

www.patientadvocate.org/gethelp

PAF is a national nonprofit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability relative to their diagnosis of

life threatening or debilitating diseases. Among resources offered are the Underinsured, Uninsured, and Financial Resource Directories, which help individuals and families locate valuable resources and seek alternative coverage options or methods for better reimbursement.

PAF's Co-Pay Relief Program

866-512-3861

www.copays.org

The Patient Advocate Foundation Co-Pay Relief Program provides direct financial support to insured patients, including Medicare Part D beneficiaries, who must qualify financially and medically to access pharmaceutical co-pay assistance. The program offers personal service to all patients through the use of call counselors guiding patients through the enrollment process.

Patient Travel Referral Program

www.patienttravel.org

The Patient Travel Referral program, a program of Mercy Medical Angels, provides information about all forms of charitable, long-distance medically-related transportation and provides referrals to all appropriate sources of help available in the national charitable medical transportation network.

Patient Services, Inc. (PSI)

800-366-7741

www.patientservicesinc.org

PSI is a nonprofit organization which has led the charge to provide much needed patient assistance, soliciting donations to fund thousands of patients and their families in a myriad of disease areas.

Social Security Administration (SSA)

800-772-1213

www.ssa.gov

SSA is the government agency with oversight for Social Security Disability Insurance and Supplemental Security Income.

State Health Insurance Assistance Programs (SHIP)

800-633-4227

www.medicare.gov/contacts

Available in every state, these programs assist people with health insurance questions, particularly related to Medicare and Medicaid.

Survivorship A-Z

www.survivorshipatoz.org/cancer

Survivorship A-Z is a web-based resource providing practical, legal and financial information.

Triage Cancer

424-258-4628

www.TriageCancer.org

Triage Cancer is a national, nonprofit organization that provides cancer survivorship education, beyond diagnosis, to patients, survivors, caregivers, advocates, and healthcare professionals, through educational events, a speakers bureau, and online materials and resources.

United Way

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www.unitedway.org

The United Way is an excellent source of information about local charities and programs that may be able to provide financial and resource support.

ZERO The End of Prostate Cancer

888-245-9455

www.zerocancer.org

ZERO is a national nonprofit organization with the mission to end prostate cancer. They lead the fight to end the disease by advancing research, encouraging action, and providing education and support to men and their families. ZERO joined forces with the PAN Foundation to provide comprehensive support for patients with advanced prostate cancer. Financial assistance is available to patients with metastatic castrate resistant prostate cancer who qualify.

Cancer Support Community Resources

Cancer Support Community's resources and programs below are available at no charge.

CANCER SUPPORT HELPLINE®



Whether you are newly diagnosed with cancer, a long-time cancer survivor, or caring for someone with cancer, CSC's TOLL-FREE Cancer Support Helpline (1-888-793-9355) is staffed by licensed CSC Call Counselors available to assist you Monday-Friday from 9 am-9 pm ET. Our Call Counselors have been trained to answer your questions and link you to valuable information.

CANCER EXPERIENCE REGISTRY



The Cancer Experience Registry is designed to help people who have had a cancer diagnosis share their story, to learn about the experiences of others and to help transform the cancer experience. People who participate are connected to a network of support and resources. Findings from the Registry help us all better understand the social and emotional needs of people living with cancer and improve the ways in which care is delivered. Join today at www.CancerExperienceRegistry.org.

OPEN TO OPTIONS®



Free one-on-one treatment decision counseling is available with licensed mental health professionals who help patients process information and formulate a list of specific questions for the oncologist. Appointments can be made by calling 1-888-793-9355, visiting www.CancerSupportCommunity.org, or by contacting an affiliate providing this service.

AFFILIATE NETWORK SERVICES

Almost 50 locations plus more than 100 satellites around the country offer on-site support groups, educational workshops, yoga, nutrition and mind-body programs for people affected by cancer. For a full list of affiliate locations, visit www.CancerSupportCommunity.org or call 1-888-793-9355.

THE LIVING ROOM, ONLINE

"The Living Room" offers much of the same programming available at each CSC affiliate, online. You will find web-based support groups, discussion boards and social networking, a "build your own website" service, and educational materials for patients and caregivers. Join today at www.CancerSupportCommunity.org.

These services are made available with generous contributions from CSC supporters.

GLOSSARY

Administrative law judge (ALJ) — An official who presides at an administrative trial-type hearing to resolve a dispute between a government agency and someone affected by a decision of that agency.

Advance directive — A legal document that a person uses to make known his or her wishes regarding life-prolonging medical treatments. It can also be referred to as a living will, or health care directive.

Americans with Disabilities Act (ADA) — A federal law that prohibits discrimination against people with disabilities. It requires employers to make “reasonable accommodations” (see definition) in the workplace for individuals deemed to have a disability. “Disability,” for purposes of the ADA, means that you have, have a history of, or are regarded as having a physical or mental impairment that substantially limits one or more major life activities that the average person in the general population can perform. The ADA doesn’t include a list of conditions that are “disabilities.” It is determined on an individual basis.

Annual (insurance) limit — The amount an insurance plan will pay in total benefits over one plan year. Once a patient’s medical bills reach the total or “cap” for the year, the policy will not pay again until the following year. Sometimes there are annual caps for particular services such as home health. The ACA now prohibits annual limits on essential health benefits for all plans except grandfathered individual plans.

Appeal — A method of disputing the denial of a claim made to your insurance plan for payment of a service. You can appeal any claim denied by your medical insurance provider. This process may vary according to your insurance plan.

Appeals Council — A group of individuals who review Social Security Disability Insurance denials.

Brand name medication — Prescription medications are usually initially marketed under a specific brand name by the company that holds the patent. When patents run out, generic versions of many medications are marketed at lower cost by other companies.

Clinical trial — A clinical trial is a research study using patient volunteers that tests a new treatment or prevention method to find out if it is safe, effective, and possibly better than the current standard of care (the best known treatment).

COBRA — The Consolidated Omnibus Budget Reconciliation Act is a federal law that allows individuals who lose their jobs or experience another qualifying event to keep their health insurance coverage for an extended period of time, if they meet certain criteria and pay the premiums.

Co-insurance — The percentage of costs an insured patient pays after meeting a health care plan’s annual deductible. For example, an 80/20 co-insurance rate means that the insurance company pays 80% of approved health care costs, and the patient pays out of pocket the remaining 20% of costs. Co-insurance usually does not start until the insured pays an amount equal to a deductible.

Co-payment (Co-pay) — A dollar amount set by your insurance provider required to be paid by a patient each time care is received. For example, a visit to the doctor may cost a patient \$30 each time, and the insurance company will pay the balance of the visit's costs. The amount of the co-pay is set by the insurance provider and not the doctor's office.

Custodial care — Non-medical care to help individuals with activities of daily living, preparation of special diets and self-administration of medication not requiring constant attention of medical personnel. Providers are not required to have medical training.

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.

Donut hole — A commonly used term for the coverage gap in the Medicare Part D prescription benefit design.

Essential function — The essential functions of a job are those that are core to the position and the reason that the position exists.

Exception — An exception is an initial request for your health insurance plan to reconsider a coverage decision. You or your doctor may ask your plan to make an exception.

Explanation of Benefits (EOB) — A document from your insurance administrator that outlines what portion of the provider's charges are eligible for benefits under your insurance plan. An EOB is not a bill, but it explains what was covered by insurance. Your provider may bill you separately for any charges you're still responsible for.

External appeal — After all appeals within a health insurance company have been exhausted, insurance companies must offer an external appeals process, where the entity reviewing the appeal does not work for the insurance company. The new health care reform act mandates all insurance companies offer external appeals, although the effective date is being phased in as health insurance companies renegotiate policies.

Federally insured plan — See "HIPAA plan."

Formulary — A list of prescription medications that an insurance company prefers to cover. Health insurance company formularies usually include most generic medications but only a selection of brand-name drugs. "On-Formulary" refers to drugs covered by a specific insurance company.

Free clinic — According to the National Association of Free Clinics, "Free clinics are volunteer-based, safety-net health care organizations that provide a range of medical, dental, pharmacy, and/or behavioral health services to economically disadvantaged individuals who are predominately uninsured. Free clinics are 501(c)(3) tax-exempt organizations, or operate as a program component or affiliate of a 501(c)(3) organization. Entities that otherwise meet the above definition, but charge a nominal fee to patients, may still be considered free clinics provided essential services are delivered regardless of the patient's ability to pay."

Generic medication — Once the patent on a brand-name medication has run out, other drug companies are allowed to sell a version of the drug that is a duplicate of the original. Generic drugs are typically cheaper, and most prescription and health plans encourage use of generics.

Group policy — Group insurance is usually offered through an employer or some form of a trade association. It provides certain benefits that individual policies do not.

Guaranteed issue plan — See “HIPAA Plan.”

HIPAA plan — Also known as a “guaranteed issue plan,” HIPAA plans are health insurance policies issued regardless of your medical condition. There are strict qualification rules.

Home health care — Refers to health care provided by a skilled professional such as a nurse, social worker, or physical therapist in a home setting.

In Network — See “preferred providers.”

Insurance case manager — A professional, often a registered nurse or licensed social worker, who helps coordinate the care of an insured person before, during, and after treatment. A case manager may provide a range of services for patients including managing treatment plans, coordinating health insurance issues, and locating support services.

Insurance panel — An insurance panel is comprised of providers who have contracted with the insurance company to provide services. Often, to receive the maximum amount of coverage for a provider, you must select a provider who is on the panel. If there is no one on the panel who can meet your needs, you can appeal to the insurance company for an exception.

Lifetime (insurance) cap — The amount an insurance plan will pay in total benefits over the insured’s lifetime. Once a patient’s medical bills reach the total, or cap, the plan will no longer provide coverage. The ACA now prohibits lifetime caps for new policies.

Living will — A living will is a document that a person uses to make known his or her wishes regarding life-prolonging medical treatments.

Medicaid — A government-funded health insurance available to individuals and families who can demonstrate need as established through income and asset standards. The program is jointly funded by states and the federal government and administered by states. Medicaid eligibility and benefits vary from state to state.

Medicare — A government-funded health insurance usually available to United States citizens 65 years of age and over and those who have been receiving Social Security Disability benefits for 24 months. Medicare benefits are the same, regardless of where you live in the United States.

Medigap — A Medigap policy is health insurance sold by private insurance companies to fill the “gaps” in original Medicare plan coverage. Medigap policies help pay some of the health care costs that original Medicare doesn’t cover.

Minimum Essential Coverage — The type of health insurance coverage an individual needs to have in order to meet the ACA law that requires most U.S. citizens and those lawfully present in the U.S. to have health insurance coverage. Minimum essential coverage includes individual policies, employer-sponsored policies, Medicare, Medicaid, CHIP, TRICARE, and certain other types of coverage.

Off-label — The use of a medication for a purpose other than the use approved by the U.S. Food and Drug Administration (FDA). The FDA approves drugs as safe and effective for specific uses, for example, use for colon cancer or breast cancer. More than half of the uses of anticancer medications are for indications which are not specified as approved and indicated on the label. Some insurance companies may deny coverage for a medication that is used “off-label.” The federal government requires that Medicare cover these off-label uses for treating life-threatening conditions as long as certain requirements are met. This is true for many private insurers as well.

Open enrollment — Open enrollment is a period of time, usually occurring once per year, when employees of U.S. companies and organizations may make additions, changes or deletions to their health insurance coverage and other benefits. In most cases, employees can only make changes in benefits elections during open enrollment or when they have experienced a specific qualifying event. Medicare and State Health Insurance Marketplaces also have open enrollment periods.

Out-of-pocket — The portion of health care expenses a patient must pay when a treatment or service is not covered by insurance. This may include expenses directly related to your treatment such as doctor visits, laboratory tests, x-rays, and medications, as well as those that may not be directly related to your care, such as transportation to your doctor’s office or hospital, parking, or childcare.

Pre-authorization — Managed care type health insurance policies may require that a patient requests approval from the plan for specific services before the services are provided. This may include a treatment, procedure, or hospital stay. Case managers may be able to help with the pre-certification process.

Pre-existing condition — A medical condition that a person has prior to being covered by new insurance. Health insurance companies and health plans are no longer able to deny coverage based on a person’s pre-existing condition or impose a pre-existing condition exclusion period.

Preferred drug list — See “formulary.”

Preferred provider — Doctors or hospitals that are part of a network of providers approved by a health insurance plan. If you are enrolled in a PPO or POS plan, your out-of-pocket expenses will be less if you use a provider who is part of the plan. You will still get some reimbursement if you receive a covered service from a provider who is not in the network.

Premium — The amount a person or company pays each month to maintain insurance coverage.

Preventive services — Medical services provided to prevent or detect illness such as mammograms. Under the ACA, eligible individuals no longer have to pay co-pays, meet their deductibles, or pay co-insurance amounts for specific preventive services. A list is available at www.HealthCare.gov.

Primary Care Provider (PCP) — The doctor a person would normally see first when a health problem comes up. A primary care doctor could be a general practitioner, a family practice doctor, a gynecologist, a pediatrician, or an internal medicine doctor.

Qualified Medicare Beneficiary (QMB) — For Medicare beneficiaries who have very low income, this state-run program helps to pay Medicare A and B premiums and other cost-sharing such as deductibles and co-insurance. The QMB program will not provide benefits that Medicare would not ordinarily provide.

Qualifying event — With respect to COBRA eligibility, the event, such as leaving a job or divorce, that makes one eligible for COBRA coverage. The length of available COBRA coverage depends on the qualifying event.

Reasonable accommodations — Under the ADA, if an individual has been determined to be disabled, an employer must make a reasonable effort to allow the employee to continue working. What is “reasonable” depends on the specifics of each situation.

Reconsideration — In most states, the first level of appeal after a Social Security Disability Insurance claim has been denied.

Referral — When a doctor makes a recommendation for a patient to see another doctor, usually a specialist.

Retroactive payment — When disability benefit payments or income have been delayed or denied and are subsequently approved for an individual, the person may be entitled to a lump sum payment equal to the total amount of payments that would have been payable starting at an earlier date.

Reverse mortgage — A loan available to seniors based on home equity. Reverse mortgages may be payable as one lump sum or multiple payments. The obligation to repay the loan is deferred until the owner dies, the home is sold, or the owner moves permanently.

Skilled need — A medical or psychiatric need that can only be addressed by a specialized health care provider. Often health insurance will cover home health visits only if a skilled need is being performed.

Step therapy — The practice of first prescribing the most cost-effective and safest drug therapy for a medical condition. Only if the initially prescribed medication does not work does one progress to other more costly or risky therapy. The aims are to control costs and minimize risks.

Usual and customary — The typical or average cost for health care services within a specific geographic area. Usual and customary is often used by an insurance plan to decide how much it will pay for specific services. If a doctor's charges for services are higher than this average, the patient may have to pay the difference.

Tiered — In prescription medication insurance policies, the varying levels of coverage.

Cancer Support Community would like to recognize and thank all of those who contributed to *Frankly Speaking About Cancer: Coping with the Cost of Care*.

CONTRIBUTORS AND REVIEWERS

Association of Oncology Social Work
Cancer and Careers
Cancer Legal Resource Center
LIVESTRONG Foundation
National Coalition for Cancer Survivorship
Patient Advocate Foundation
Patient Access Network Foundation
Survivorship A-Z
Triage Cancer

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RESOURCES USED IN THE DEVELOPMENT OF THIS BOOK

American Cancer Society
www.cancer.org

American Society of Clinical Oncology
www.cancer.net

Cancer Legal Resource Center
www.cancerlegalresourcecenter.org

Partnership for Prescription Assistance
www.pparx.org

Patient Advocate Foundation
www.patientadvocate.org

Kaiser Family Foundation
www.kff.org

Medicare
www.medicare.gov

Social Security Administration
www.ssa.gov

Survivorship A to Z
www.survivorshipatoz.org

Triage Cancer
www.TriageCancer.org

CANCER SUPPORT COMMUNITY

The Cancer Support Community (CSC) is a global non-profit network of 175 locations, including CSC and Gilda's Club centers, health-care partnerships, and satellite locations that deliver more than \$50 million in free support services to patients and families. In addition, CSC administers a toll-free helpline and produces award-winning educational resources that reach more than one million people each year. Formed in 2009 by the merger of The Wellness Community and Gilda's Club, CSC also conducts cutting-edge research on the emotional, psychological, and financial journey of cancer patients. In addition, CSC advocates at all levels of government for policies to help individuals whose lives have been disrupted by cancer. In January 2018, CSC welcomed Denver-based nonprofit MyLifeLine, a digital community that includes more than 30,000 patients, caregivers, and their supporters that will enable CSC to scale its digital services in an innovative, groundbreaking way. For more information, visit www.CancerSupportCommunity.org. So that no one faces cancer alone®



The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professional to answer questions and learn more.

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