People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibility of their recovery. People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibility of their recovery.
People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibility of their recovery.
Dedicated to all the people affected by cancer who shared their stories, experiences, and wisdom to make this guide possible.
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FREQUENTLY ASKED QUESTIONS

1. Who can I ask for help to learn more about the cost of care and the resources available to me?
   See Chapters 2 and 3, especially page 32.

2. What if I cannot pay for my prescription medication?
   See Chapter 5.

3. I don’t have health insurance. What do I do?

4. How do I know what my health insurance will cover?
   See Chapters 2 and 3.

5. How can I find out how much I will have to pay for my cancer care?
   See Chapters 2 and 3.

6. I can’t afford my health insurance premiums. What are my options?
   See Chapters 3 and 6.

HOW WILL HEALTH CARE REFORM AFFECT MY (OR MY LOVED ONE’S) CANCER CARE RIGHT NOW?

The Patient Protection and Affordable Care Act (commonly referred to as Health Care Reform or the ACA) signed in March 2010 has mandated many important changes including:

- Existence of a Pre-Existing Condition Insurance Plan (PCIP). The PCIP makes health coverage available to you if you have been denied health insurance by private insurance companies because of a pre-existing condition. For more information see Chapter 3 and www.healthcare.gov.

- Health insurance companies can no longer deny children less than 19 years of age coverage due to pre-existing conditions.

- Insurance companies can no longer charge co-pays for preventive services. For more information see www.healthcare.gov.

- Insurance companies can no longer impose lifetime maximums and beginning in 2014, annual limits will be eliminated.

- Insurance companies are no longer allowed to rescind (invalidate) your policy unless you intentionally lied on your application.

- Many children can now be covered on a parent’s policy until age 26.

- Insurance companies will be required to have both an internal and external review process. This change will be phased in as new health insurance policies are written.

1 Throughout this book, words highlighted in green will be explained in the Glossary (Chapter 7).
It is your job to jump in and find what you can find — there are resources out there. You have to go out and look for where all that support is, taking names, kicking doors. It’s not going to come easily.

— Carl
multiple myeloma survivor
You Are Not Alone

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 my family be burdened with huge debt? 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 cancer.

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.
The very first question you should ask about managing the financial aspects of cancer is: “Am I able to coordinate the financial piece of my cancer care right now?” If you answer “No,” perhaps you can ask a friend or family member to do this for you.

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

This book is for people who want to know more about managing the cost of cancer care. Until now, it has been 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.

The Cancer Support Community empowers people with cancer to become “Patient Active” — meaning that people who actively participate in their recovery, along with their health care team, will improve the quality of their lives and may enhance the possibility of recovery. Similarly, those who love someone with cancer can also take an active role in the cancer journey.

Being Patient Active is particularly 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 magically 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 (the physicians, nurses, social workers and others providing care), fearing that if they ask about it and cannot afford it, treatment will be delayed, or a “lesser” treatment will be proposed. Others are simply not focused on the cost of care. Still others assume that if they have insurance, the cost of care will be covered in full.

In a recent (2009) survey at the Cancer Support Community, nearly 70% of respondents acknowledged they had some unexpected expenses during cancer treatment.
The Good News!

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 be enough to cover all of your cancer-related expenses or prevent you from accumulating medical debt. 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 conquer the financial burden of cancer. Additionally, by actively coping with the cost of cancer care, you will feel less alone, gain a greater sense of control, and feel increasingly hopeful about the future.

HOW TO USE THIS BOOK

Since the information may be new and can be overwhelming, use this book as a guide. You don’t have to learn it all at once. Read at your own pace.

- **Chapter 2** provides an outline of potential costs associated with care. It lists questions you can ask your health care team and others to help you estimate costs and identify where you might need help.

- **Chapters 3 - 5** provide a more detailed discussion of financial aspects of care such as insurance, COBRA, disability, and prescription coverage.

- **Chapter 6** provides practical resources to help you understand and cope with the cost of cancer. Included are programs that provide financial assistance to people with cancer.

- **Chapter 7** provides a glossary of cost-related terms. Words you see in green throughout the book can be found in the glossary.

Cancer brings many challenges. We hope the information provided here will help you feel a greater sense of control over the demanding financial aspects of cancer.

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.
When you’re talking to someone and they ask you a question about how you are doing or what’s going on, explain to them what’s going on. I was diagnosed in August, which meant that with my insurance, between August and the end of the year I was going to have to pay a $10,000 deductible and $5,000 out of pocket. When I was talking with my best friend, he asked what was going on, so I told him. We didn’t talk any more about it, but about a week before Christmas he called me and said, “I’m going to send you something FedEx. Are you going to be home?” I said “Yeah.” The next day I got a check for over $15,000 via FedEx. He had canvassed my graduating high school class — there were only 120 of us — and they had taken up more than $15,000 to cover my deductible and out-of-pocket. So when people ask, tell ’em. Tell ’em what’s going on!

— Carl, multiple myeloma survivor
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
# Chapter 2 / Gathering Cost Information

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Gathering Cost Information

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. It is difficult to form a plan until you understand what to expect. Many people coping with a new cancer diagnosis have little experience with the health care system and even less with the financial aspects of cancer.

_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
After you have completed the majority of fact finding about potential expenses and resources, you are likely to have a pretty good idea of what to expect related to the cost of care. There will always be financial surprises during the cancer journey. The more you know, however, the better you will be able to cope with the unexpected.

If possible, it is helpful to gather cost of care information before cancer treatment begins. If this is not possible, try to gather the information as soon as possible. Sometimes treatment needs to begin immediately, before you have time to gather all of the information related to cost.

Naturally, you want the best care no matter what the cost! 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.

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

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. Remember, at this stage you are simply gathering information about the costs you might expect during the cancer journey. In Chapters 3 – 5 we provide suggestions for managing these costs.

While the list is long, it is unlikely you will incur all of these expenses.
While a cancer diagnosis is scary in the best of situations, it can be even more frightening to face cancer without health insurance coverage. You do have options, however, and excellent treatment is available to many.

In March 2010, the President signed the Patient Protection and Affordable Care Act (commonly referred to as Health Care Reform or the ACA), which will most likely provide you with more health insurance options, consumer protections, and possibly even access to health insurance despite the fact that you may now have a pre-existing condition. These are discussed further in Chapters 3 and 4.

If you do not have health insurance at the time of your diagnosis, private health insurance may be difficult to obtain after your diagnosis. If you are currently uninsured, but were covered under a group health insurance policy less than 63 days ago, it is wise to check immediately with your insurance company about whether you can sign up for COBRA or a HIPAA plan. (These are discussed at length in Chapter 3.) If you’ve been uninsured for more than 63 days, your task will be more challenging. However, it can be done!

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 for advice. 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. 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://freeclinics.us/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. It may also be found at: http://www2.va.gov/directory/guide/home.asp

If a symptom is life-threatening, you should go to a hospital emergency room. By law, anyone who goes to the emergency department requesting examination or treatment for a medical condition must be provided with appropriate care to determine if he or she is suffering from an emergent medical condition. If this is the case, then the hospital is obligated to either provide treatment until the patient is stable or to transfer the patient to another hospital.

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. Some who are uninsured are able to set up payment
plans or negotiate a discounted payment with the treating facility. Others may qualify for Medicaid, county medical care, or hospital charity care.

The ACA has also created multiple ways for many people with pre-existing conditions to get health insurance. Beginning in 2014, health insurers will no longer be able to deny coverage for pre-existing conditions. From 2010-2014, individuals with pre-existing conditions may be able to get health insurance coverage through the new Pre-Existing Condition Insurance Plan (PCIP). Also under the ACA, after September 23, 2010, insurance companies are not allowed to deny coverage to children under 19 because they have a pre-existing medical condition. To find out more about the PCIP in your state, go to https://www.pcip.gov/StatePlans.html.

It can feel overwhelming to face cancer without health insurance. Many without insurance are able to obtain excellent care, but it usually takes persistence and creativity.

**Benefit and Payment Options if You are Uninsured**

**Questions for your health care team or hospital personnel:**

- Are there health insurance options in my state for people with pre-existing medical conditions such as a high-risk pool?
- Who can I speak with to see if I’m eligible for Medicaid or other assistance?
- What financial options exist for cancer patients who are uninsured?
- What is the estimated total cost of the prescribed treatment plan?
- Are there less expensive options for treatment? How effective are they?
- Who should I see to discuss reducing the fees?
- 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?
- Does this facility have a free or reduced-cost care program? If so, what are the requirements?
- Does the manufacturer of my recommended medication offer a free or discounted drug program for uninsured patients?
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 you will incur 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.

### Deductibles

A **deductible** is an amount that the insured (the patient) must pay out-of-pocket before the insurance company begins to pay health insurance claims. If you have a deductible, your deductible 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 usually 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.

Many health insurance companies assign insurance case managers to 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 wise 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.

---

*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
FIGURE 1 / ANATOMY OF A HEALTH INSURANCE CARD

Much of the information about your policy can be found on your insurance card. Some insurance companies include more information on the card; some include less. The elements noted may also be in a different place on the card.

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

ABC Insurance
Member Services: 1-234-567-4910

Member: JOHN SMITH
ME Rx

PPO

ID XXX123456789 Group ABCD

Hospital Precertification
800-123-4567

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

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

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

Claims and Correspondence should be sent to:
Mail Administrator, PO Box 12345, ABC, NY 12345
PHYSICIAN/PROVIDER EXPENSES

These expenses include payments for the care you receive at each doctor visit such as a physical examination or check-up. Many plans require that you pay a fee, called a co-payment or “co-pay,” each time you visit the doctor. The amount of the co-pay is set by the insurance company, not the 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. Your insurance company may require different co-pay amounts for primary care physicians versus specialists. An oncologist is usually considered a specialist.

Under the ACA, after September 23, 2010, insurance companies are not allowed to charge you a co-pay for preventive services such as a mammogram, other screenings, and immunizations. If you aren’t sure if particular services are considered preventive, ask your doctor or your insurance company.

Questions for your insurance company representative or health care team:

- Do I have a co-pay for each physician visit?
- If I have a co-pay, how much is it?
- If I see someone other than the physician (such as a physician assistant or nurse practitioner), do I still have to pay the co-pay?
- Is this service considered preventive care? If so, am I being charged a co-pay when I shouldn’t be?
- When is the co-payment 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 physician?
- 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 physicians or facilities? Do you routinely check to see if the person or facility you’re referring to is a preferred provider with my insurance plan, or is that my responsibility?
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. Talk to your treatment team to learn more about your specific treatment plan.

Questions for your insurance company representative or health care team:

- Who can help me 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 is my co-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?
- Are there ways to change my treatment schedule, to work around my job or childcare? (These are important questions to ask if you are worried about the cost of missing work or paying for childcare while you are receiving treatment.)

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. Talk to your treatment team to learn more about your specific treatment plan.
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.

In 2014, the rules about what insurance companies can charge when you are in a clinical trial will change. Insurance companies will be required to cover the cost of any routine care that you would have received during standard treatment. Some states currently have these requirements. For more information see http://www.cancer.gov/clinicaltrials/payingfor/laws 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 physician speak with to discuss this further?

My husband is a CPA and this is sometimes hard even for him.

— CSC 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.

Prescription coverage is discussed in detail in Chapter 5.

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 non-profits 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, over-the-counter, or brand-name) that will be equally as effective?

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?
Home health care and home 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.

**Home hospice** is the highest level of home care and is focused on symptom and pain management, usually near the end of life. Insurance coverage of home health care and home hospice care varies.

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?
- Do I have a home hospice benefit? What does it cover? Is it separate from my home health benefit? Is there a **lifetime maximum** 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?
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?
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.

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?

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?
Many people affected by cancer find it helpful to meet with a counselor, psychotherapist, or other licensed mental health professionals during the cancer experience. One-on-one meetings with a psychotherapist are often covered under a 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:**

- Does my insurance have a mental health benefit?
- If so, what is covered and how do I access this benefit?
- Is prior 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 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?
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 may not always be possible to be there when your child comes home from school or to drive your mother to an appointment as you did before the cancer diagnosis. It can be helpful to anticipate these expenses as you gather information about the cost of cancer care.

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 are the organizations that can help me?
- If I need nutritional supplements, will they be covered by insurance? If not, is there a program to help me get supplements that are free or at a reduced price?
- Where can I get low-cost or free child or elder care services during my treatment?
- Are there ways to change my treatment schedule, if necessary, 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?

Frankly Speaking About Cancer with the Cancer Support Community is an internet talk radio show that aims to inform and inspire people to live a better life with cancer. Every week the show features physicians, researchers, celebrities, patients, survivors, and caregivers to offer news on cancer developments and tools that anyone affected by the disease can use to live well. Visit www.VoiceAmerica.com and tune in every Tuesday at 1 p.m. PST/4 p.m. EDT.
TRANSPORTATION EXPENSES

Transportation expenses include the cost of travel to receive treatment whether it is by car, bus, train, or airplane. It may also include the price of hotels or other lodging needed if you travel for treatment. A big unexpected expense for some people affected by cancer is the cost of parking while receiving treatment. Some costs for transportation to medically necessary treatments are considered medical expenses which may be tax-deductible.

Questions for your health care team:

• Is there free or low-cost transportation for your patients?
• Do you have free or reduced parking rates for your patients?
• Are there organizations that can provide free transportation, including airfare if necessary, or help me pay for transportation to and from treatments and medical appointments?
• If I am traveling a long distance, are there free or reduced-cost hotels or lodging near the treatment facility?

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?

• Who can help me with a living will or advance directives?

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?
MANAGING THE COST OF CARE

When you have completed your fact-finding mission, you will have a better idea of what to expect with regard to the financial cost of cancer care. You may also want to consider a professional financial planner to help you get a clearer picture of your financial health and outlook. A financial planner will work with you to review all of your finances — your job benefits, income, investments, insurance, and all your expenses. There are financial planners who have particular interest or expertise in working with cancer patients. See Chapter 4 for more information about choosing a financial planner or advisor.

Keeping accurate records is vital to managing your cancer-related finances. Organizing medical bills, insurance claims, and payments can help you and your loved ones better manage your money and lower your level of stress. If you already have a system for handling your budget and expense records, this may be relatively easy. If you are not accustomed to closely monitoring your finances, there are many resources available to you as you will see in the following chapters.

PRACTICAL TIPS FOR STAYING EMPOWERED WHEN COPING WITH THE COST OF CARE:

- Get a notebook to record all of your expenses, conversations with the insurance company, doctors appointments, exams, and other pertinent information (date, time and with whom, what they said and contact information, how long spent on the call).

- Get an accordion folder to help you file things so you can find them easily.

- 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.

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

— Stephanie

brain cancer survivor

Health Insurance
Health Insurance

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.
**PRIVATE HEALTH INSURANCE**

Private insurance plans include plans not funded by 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, sometimes through an insurance broker. 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 insurance-covered service. 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.

**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.

**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 deductible amount, co-pay or co-insurance amounts, and how much and what types of prescriptions they will cover.

Health insurance plans also include certain coverage limits or restrictions on what the insurer will cover, such as annual limits or maximums. Once a patient’s yearly medical bills reach the annual limit, the plan no longer has to provide coverage. In some instances, however, insurance companies have agreed to continue to pay for care. You should know your policy’s annual limit. If you begin to approach the policy’s annual maximum, do not hesitate to discuss this with your providers and insurance case manager. You do have options.

Prior to ACA, individuals often worried not just about annual caps, but about lifetime maximums as well. After September 23, 2010, insurance companies are no longer allowed to impose a lifetime cap on benefits and, beginning on January 1, 2014, they may no longer impose annual limits on the dollar value of coverage.

Policies may also include pre-existing condition exclusions. A pre-existing condition is a health condition that you had before you joined your medical plan. If you join a new health insurance plan after you are diagnosed with or treated for cancer, you may have a waiting period before the new insurer will pay any claims they identify as related to the cancer.

However, there are some new rules about pre-existing conditions in the ACA. Beginning September 23, 2010, health insurance companies cannot impose pre-existing condition exclusions on policies for children up to the age of 19. Beginning on January 1, 2014, this protection will also apply to all adults.

After learning of your cancer diagnosis, some insurance companies may go back to your original application to see if you made any mistakes or left out any information. Even if your omissions were unintentional, the insurance companies could rescind your policy. However, after September 23, 2010, insurance companies are no longer allowed to cancel your policy unless you intentionally lied on your application.

Employer-sponsored health plans are prohibited from using pre-existing condition exclusion periods in some situations. If you had health insurance with a previous employer and do not have a coverage gap of more than 63 days (continuous coverage), a new plan has to credit the amount of time you had coverage against the plan’s pre-existing condition waiting period (creditable coverage). Pre-existing waiting periods with employer-sponsored group
If you have health insurance, it is crucial to do what you can to keep your coverage. Pay your insurance premiums on time and in full. Some recommend sending your payments “return receipt requested” or having the premiums paid automatically from your bank account. You will then have proof that the company received the payment. If your insurance is cancelled or lapses, it may be difficult, expensive, or even impossible to get a new private insurance policy.

policies are limited to 12 months, and in some states may be shorter.

Unfortunately, individual and individual family policies can and usually do have pre-existing clauses. 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.

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

— CSC participant

THE PORTAL (www.healthcare.gov)

Figuring out your options for health insurance can be confusing and overwhelming, which is why the federal government created The Portal. The Portal is a website (www.healthcare.gov) where you can answer a few simple questions and receive customized information about the various health insurance options for which you may be eligible.

Some of the options you may find on the portal include:

• Individual health coverage offered by health insurance issuers
• Medicaid coverage
• Children’s Health Insurance Program (CHIP) coverage
• State health benefits high risk pool coverage
• Pre-Existing Condition Insurance Plans
TIPS FOR KEEPING AND GETTING THE MOST OUT OF PRIVATE INSURANCE

1. Check to see if your insurance company will assign you an insurance case manager. If you are assigned an insurance case manager, maintain regular communication and keep the person abreast of your treatment progression.

2. If your insurance company does not assign a case manager, ask if you can speak with the same representative for each call.

3. Keep careful notes of each phone call to the insurance company: who you spoke with, his or her extension, length of the call, and what you asked and were told.

4. 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.

5. 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

6. 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!

7. Submit your bills in a timely manner. Many insurance companies will not pay a claim submitted after the time period specified in the policy.

8. Look carefully at the health insurance options your employer provides. In some cases, you may find that a different type of health insurance better fits your current situation. You may be able to change insurance options during open enrollment with an employer. Contact your Human Resources representative to find out more.
COBRA COVERAGE

Some people with cancer leave their job temporarily or permanently. If health insurance is a benefit of employment and the employee leaves the job, the employer may no longer pay for any part of the health insurance. 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. COBRA provides an important safety net for most people.

Coverage through COBRA can be expensive, and it is time-limited. Premiums of more than $1000/month are not uncommon. On the other hand, the cost of cancer care without insurance is usually far more than $1000/month. COBRA coverage can give you time to plan for future 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 employer-covered 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

If your employer goes out of business, you will not qualify for COBRA since the employer is no longer offering a health plan.

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 Mini-COBRA or COBRA Continuation plans. For more information on state COBRA plans contact your state’s department of insurance.
How COBRA Works

The employer’s health plan administrator must provide notification of your right to elect COBRA coverage within 14 days of the job loss or other qualifying event. It is up to your employer to inform the insurance company that you are eligible for COBRA. You must sign up for coverage within 60 days and pay the monthly premiums dating back to the start of your COBRA 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.

Most COBRA plans do not send a monthly bill or reminder, so consider marking the date the premium is due on your calendar or some other place where you will be sure not to forget. If you are even a day late with a premium the insurance company may cancel your COBRA coverage, and they do not have to reinstate it.

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 and paid the premiums 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 you are deemed disabled by the Social Security Administration (See Chapter 4), you can extend your COBRA coverage by an additional 11 months. You must notify your COBRA administrator of your wish to extend coverage within 60 days of receiving the letter stating that you have been deemed disabled by Social Security.

- 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. You may be eligible for a HIPAA 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.
If you are eligible for COBRA because you or your loved one left or lost a job, COBRA will last for 18 months. An additional 11 months of coverage may be available if the Social Security Administration deems that a person became disabled. Social Security Disability benefits are discussed in Chapter 4.

### Maximum COBRA Coverage Based on Qualifying Event

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<th>COBRA Qualifying Event</th>
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<td>Loss of dependent child status</td>
<td>Dependent Child</td>
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**HIPAA Plans**

If you exhaust your COBRA coverage but are not yet eligible for Medicare or some other type of health insurance, a HIPAA plan, also known as a federally insured plan or guaranteed issue plan, may be an option.

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.

To be eligible for a HIPAA plan you:

- Must no longer have an option under COBRA, either because you have used all of your 18 or 36 months of coverage (depending on your qualifying event) OR your particular plan is no longer available (e.g., insurance company has gone out of business, your employer no longer offers health insurance coverage to other employees, etc.)
- **Cannot have a break in health insurance coverage longer than 63 days**
- Must be ineligible for Medicare, Medicaid, or any other form of group coverage

If you are coming to the end of COBRA coverage or are having difficulty affording COBRA coverage, you may want to contact your state’s insurance agency for more information about how to exercise your state’s HIPAA plan options, whether it be a private individual insurance plan, converting your COBRA plan into an individual plan, or accessing your state’s high risk insurance pool. Under federal law, you have a right to purchase a HIPAA plan if you meet the criteria. Every insurer who writes health insurance policies in your state must offer a HIPAA plan. When you call to ask about this option you may need to clarify that you are asking about “guaranteed issue plans” or “HIPAA plans” to be sure the insurance company understands what you are requesting.
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, particularly in the beginning, 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 health 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
- Each state has a consumer advocacy office that regulates or oversees private insurance companies and plans that operate in the state. They also 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
- 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

As you develop a relationship and work with your health insurance company, it is helpful to remember that in theory you both have the same goal — to get you the best, most cost-effective care possible. Keeping this in mind can help you frame your conversations.

Appealing Insurance Denials

Unfortunately, in today’s health care system 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.

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 resubmit the claim until you exhaust the insurance company’s internal appeals process.

Some states mandate insurance companies to have an external appeals process as well, where your claim is reviewed by someone who does not work for the insurance company. Although not all states currently offer consumers the right to an external appeals process, as of September 23, 2010, the ACA requires that all insurance plans (except plans that were in existence before 3/23/10) have an internal and external appeals process. Once you exhaust your internal appeals, make sure to utilize the external appeals process.

If you purchased your plan before March 23, 2010, there’s still hope! At the beginning of the next plan year, your insurance company will also have to establish an internal and external appeals process.

Additionally, you can also request help from the consumer services division of your state’s insurance agency or the Department of Labor if you are insured under a federal policy. There are also nonprofit organizations that can provide detailed information about insurance appeals such as the Patient Advocate Foundation and the Cancer Legal Resource Center. These resources can be found in Chapter 6 of this book.
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. The case manager said she’s seen enough people ‘bounce back’ into the hospital because they didn’t go to rehab.

— Elise

TIPS FOR APPEALING A DENIAL OF COVERAGE FROM YOUR HEALTH INSURANCE COMPANY

- 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.

- Ask the insurance company representative to document the specific reason the claim or prior 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.

- Consider involving your employer. Your employer is the health insurance company’s customer.

- 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 any external appeals process that might be 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 64-66 for a list of organizations that may be able to help.
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. There is a schedule of benefits and all the features of a traditional fee-for-service insurance plan. FFS Medicare consists of two parts:

- **Medicare Part A** covers inpatient care in hospitals and similar settings. Medicare Part A is 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 for it (the premium) each month. How much you will need to pay depends on your level of income.

Importantly, Medicare Parts A and B typically pay only 80 percent of the usual and customary charges, leaving the patient to pay the other 20 percent. Individuals receiving Medicare, particularly those over 65, can purchase a Medicare supplement plan known as **Medigap** to cover the other 20 percent.

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 1-888-MEDICARE (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 and you already have a Medigap plan, your Medigap plan will not work with your Medicare Advantage 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.

Medicare Advantage

Medicare Advantage, also known as Medicare Part C, offers managed care plans under the Medicare benefit. These options vary by area. Each Medicare Advantage Plan must provide minimum 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 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 5.

The Centers for Medicare and Medicaid Services (CMS) can provide more information on Medicare and Medicaid coverage. For more information, you can look online at www.medicare.gov, or call their hotline at 1-800-MEDICARE (1-800-633-4227).

I’m on Social Security Disability, and I now 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 just to check up on me and make sure I had everything. They’re close enough they can stop by my house, and do a house visit. It’s all part of the plan which is great!

— Nancy, metastatic breast cancer survivor
MEDICAID

Medicaid (the Medical Assistance Program) is a group of health insurance programs that provide 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. To make it even more confusing, some states use a different name for the program such as Medical Assistance, Medi-Cal or TennCare.

Since eligibility criteria and benefits are different in each state, if you have questions about Medicaid, the best place to start is your local Department of Family and Children’s Services or Department of Social Services. This can also be confusing because each state has a different name for this department. However, you can look in the Government section of your local phone book, or visit your county or state website for information. You can also ask a social worker or financial counselor at your treatment facility for more information.

Finally, you can contact the Centers for Medicare and Medicaid Services directly at www.cms.gov/medicaid/consumer.asp.

Even within each state there are many different Medicaid programs. Most states have a program for people with significant medical needs, in which Medicaid eligibility is extended to higher-income people who have high medical costs. These programs may be referred to as “Medically Needy Medicaid” or “Spend-down Medicaid.”

If you are uninsured or are worried that you soon may lose your health insurance, it is advisable to apply for Medicaid, even if you don’t think you will meet the income criteria. Keep records of the application process because many other financial assistance programs require proof that you have applied for Medicaid. Most of these programs will consider you for assistance if you have applied for and been denied Medicaid. However, if you have not applied they may require that you do so before they will consider you for their program.

Keep in mind that it is extremely difficult to qualify for Medicaid if there is more than one person in your household who is currently working. Do not think that Medicaid is your only option. You may have the option to enroll in your state’s high risk insurance pool.
**Medicare and Medicaid**

You may be eligible to receive both Medicare and Medicaid benefits. 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/static/allstatecontacts.asp](http://www.medicare.gov/contacts/static/allstatecontacts.asp), or call 1-800-MEDICARE (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
My insurance company was just wonderful, which is not to say I didn’t come out with some debt. And debt is painful for everyone, but it can be managed.

— Julie
breast cancer survivor
Employment, Disability, Income, and Debt

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

The HR person in my office helped me complete the short-term disability paperwork and said, “You take as long as you need. If we need to, we’ll do all the paperwork to put you on the long-term disability when that time comes.” She was very helpful. Now I’m on long-term disability. My concern is more about going off long-term back into full-time employment. I’m not worried about my employer taking me back or that type of thing. I just want to know how soon I can go back.

— Stephanie, brain cancer survivor
**EMPLOYMENT**

**Working through treatment**

If you or a loved one has cancer, it doesn’t necessarily 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 through treatment and recovery. Everyone is different, so consider what is best for you at each point in cancer treatment.

**THINGS TO CONSIDER WHEN DECIDING WHETHER TO WORK THROUGH TREATMENT**

- Do I enjoy my work and/or find it a welcome distraction?
- Have my career priorities changed?
- What does my health care team recommend?
- Can I complete my work functions while in treatment?
- What are the common side effects of my cancer treatment and how might this affect my work?
- How would taking time away from work affect my income?
- How much sick leave do I have?
- If I take time away from work, will the Family and Medical Leave Act apply?
- Do I live in a state with a state-sponsored short-term disability insurance program?
- Do I have a disability insurance benefit through my employer? If so, how much will it pay?
- Do I have private disability insurance? If so, how much will it pay?
- 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?
- If I decide to stop work temporarily or permanently, how will this affect me and others?
- If I decide to stop work, what will I need to do to keep my health insurance?
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 if you talk about your cancer.

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 whatever feels right to you.

An advantage to letting your boss know that you or your loved one is undergoing treatment for cancer is that down the road it may be less stressful if you need to rearrange your work schedule or miss work due to treatment or its side effects. As long as you can do your work 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, training opportunities, 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.

If you decide to talk with your employer, prepare beforehand by talking with your treatment team about how much time you may need to be away from work during and after treatment. 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.

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.

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 646-929-8032.
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 employers who employ 50 or more people for 20 or more workweeks in the current or preceding calendar year 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:

- work for a covered employer
- 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
- 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

The FMLA cites several reasons a covered employer must grant an eligible employee leave including:

- to care for a spouse, parent or minor 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.

While you are on FMLA leave, your employer is required to maintain your group 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 each pay period, you will need to make arrangements to pay your share while on leave.

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.

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.
DISABILITY

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.” Given this definition, if you are working and receiving a paycheck, Social Security will not deem you disabled.

Many people diagnosed with mid to late-stage cancer qualify for SSDI. 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 takes, on average, about 90 days. 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.

The Social Security Administration recently instituted 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 5-6 month waiting period is complete. For more information see www.ssa.gov.

You may be eligible to receive SSDI if you:

- Have worked long enough and recently enough in jobs covered by Social Security
- Have a medical condition that meets Social Security’s definition of a disability

2 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 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 physicians at DDS use the medical records provided by your physician(s) to determine whether you meet the criteria to be deemed disabled by Social Security.

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.
If you are approved

You will receive an approval letter that includes the date after which they have deemed you disabled, referred to as your onset date. This date is important because it will determine when your waiting period begins. You must wait five full months after your onset date before you will receive benefits. For example, if your onset date is June 15, 2012, you will not be eligible to start receiving benefits until December 2012. Because payments are paid out for the previous month, you would receive your check for December in January. This waiting period is a time when you do not receive SSDI checks but are considered disabled by Social Security.

If you are using COBRA for your insurance, and are within the first 60 days of that coverage, you should contact your COBRA administrator to let them know you wish to exercise your right to extend your COBRA benefit for an additional 11 months. You only have 60 days from the time you receive your approval letter from SSDI to exercise this right. This will allow you to carry your COBRA insurance for up to 29 months. This enables you to carry your COBRA coverage until you become Medicare-eligible.

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. Approximately 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:

1. 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.

2. 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 that specializes in disability cases to help with this level of appeal.

3. 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.

4. 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.

In addition, 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 will most likely qualify for Supplemental Nutrition Assistance Program (SNAP, formerly Food Stamps) and Medicaid. Medicaid can seem a welcome relief, especially if you are struggling to pay for COBRA insurance. It’s important to realize, however, that if you begin receiving SSDI payments after the waiting period, these payments may put you over the income limit for Medicaid. Before you drop your COBRA insurance in favor of Medicaid, it is important to consider whether your providers accept Medicaid and what you will do if you become ineligible for Medicaid. Once you drop COBRA you usually cannot get it back.

State-Funded Disability Insurance Programs

A few states offer state-funded disability insurance. Contact the oncology social worker at your treating facility, the Patient Advocate Foundation (www.patientadvocate.org), or the Cancer Legal Resource Center (www.cancerlegalresourcecenter.org) to find out if this is an option in your state.

Employer-Sponsored Disability Insurance

Some employers offer short- and/or long-term disability.

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.
There are disability claim forms to complete for your employer-sponsored disability policy. Your human resources representative should be able to provide these forms. Generally, you will need to take part of the application to your doctor for completion; you will need to fill out a portion; and your supervisor may need to complete a section.

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 both Social Security Disability Insurance and employer-sponsored disability insurance, 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 SSDI 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. Income from private disability policies is usually not taxable and is not considered when applying for state, federal, or employer based disability.

*I knew about short-term disability, but I didn’t know about long-term. I remember every year we signed up for insurance. I never paid attention to it; I had no idea what it was. So luckily the case manager I had helped me move from short-term to long-term disability when 26 weeks were up. I wasn’t in any condition to be returning to work.*

— Kathy, breast cancer survivor
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.

Now, the good news! There are financial resources available to help people affected by cancer. Many charities and non-profits help in small ways, but they do help. It can feel like a full-time job exploring the financial assistance possibilities. As suggested throughout this book, consider asking friends or family members to help you learn more about income and financial resources.

The National Council on Aging created a web-based program that can help connect you with resources for which you might be eligible. While it’s not specific to the needs of people affected by cancer, if you have internet access, you may want to check it out (www.benefitscheckup.org). Additionally, the Patient Advocate Foundation created the National Underinsured Resource Directory (www.patientadvocate.org/help4u.php), an online tutorial to help underinsured individuals and families locate valuable resources and seek alternative coverage options or methods for better reimbursement.

**National Non-profit Organizations**

There are a variety of non-profit 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 chapter of the book, Chapter 6.

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 will vary from community to community.

Examples of national nonprofit organizations that sometimes provide financial assistance include:

- American Cancer Society
- CancerCare
- Catholic Charities
- Jewish Social Services
- Lions Club

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**OTHER SOURCES OF INCOME AND FINANCIAL SUPPORT**

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While these organizations may be national in scope, they may have state or local branches. There are also national organizations serving people with particular cancer diagnoses. Talk with your treatment team for more information.

If you must travel a long distance for a second opinion and/or for treatment, transportation and lodging can be costly. Check with an oncology social worker or other member of your health care team to see if there is low-cost temporary housing in the area. There are also organizations such as the National Patient Travel Center (see Chapter 6) that may be able to assist with air transportation.

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, a.k.a. Food Stamps), 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, 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 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. Generally you may borrow up to 50 percent of the vested balance of your account up to $50,000. 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.

If you need more than 50% of your vested balance, your options are more costly. 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.

Again, when coping with substantial medical debt, it is best to contact a financial advisor for help. There are long-term and short-term consequences of loans and liquidation that are crucial to consider. The website www.survivorshipatoz.org is an excellent source of 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:

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.

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.

Viable settlements

This is the sale of a life insurance policy for cash. The insured person (called the viator) sells his or her life insurance policy to a third party for a lump sum cash payment. The payment is often only between 60
percent and 80 percent of the face value of the policy, but is usually tax free. The purchaser of the policy becomes the new owner and sole beneficiary of the policy and pays the premiums. When the viator dies, the entire death benefit from the policy goes to the new beneficiary.

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 all the pluses and minuses 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. Homeowners should make sure that they qualify for the loan before they invest significant time or money into the process. 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 which is approved by the Department of Housing and Urban Development (HUD). The counseling is a safeguard for the borrower and his/her family, to make sure the borrower completely understands what a reverse mortgage is and how one is obtained. You should contact a mortgage lender or financial advisor if you want more information about a reverse mortgage.
If you take a Patient Active approach to coping with the cost of your cancer care, you’re likely to feel less alone, more in control and better able to improve the quality of your life. 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 are concerned that you will accrue medical debt, you have already made a good start by reading this book. There are other ways you can be proactive as well. Pursuing the resources listed in Chapter 6 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.

The strain of being in debt, especially if it’s the first time you’ve ever had substantial 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 down the road. It is best if you or someone you ask for help keeps up with the bills on at least a monthly or twice monthly basis.

If bill collectors are calling or you are receiving notices that bills have been sent to collection, you may want to try taking some deep breaths before responding. With your support system, develop your plan of action. The website www.survivorshipatoz.org has excellent 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.

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. Another recent study (2009) by the Kaiser Family Foundation and the American Cancer Society indicates that people receiving treatment for cancer, whether insured or uninsured, face significant financial challenges.

Coping with the cost of care will look different for each individual. Sometimes declaring bankruptcy is the best option. Sometimes individuals can negotiate with creditors to either decrease the amount owed or lengthen the period of the loan. A good financial advisor can help you identify options if you find 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?
Five prescription medications

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

— Nancy
metastatic breast cancer survivor

Prescription Medications
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Prescription Insurance (Including Medicare Part D).................................................. 56
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Pharmaceutical Company Patient Assistance Programs.............................................. 60
Prescription Medications

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. On-formulary medications can usually be prescribed without any prior 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, or somewhere in between. 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 physician to ask his or her opinion about switching to the on-formulary medication. Often the two medications are virtually the same. Your physician may feel that the on-formulary medication will be just as effective and be happy to change your prescription.

If your physician 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.
Medicare Part D

Medicare Part D is the prescription benefit that Medicare recipients can now purchase. The details of this benefit can be confusing and change from year to year.

Unlike Medicare Part A, you must enroll in Medicare Part D, and for most plans there is a monthly premium. Starting January 1, 2012, 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. The Medicare Part D benefit is administered by private companies. You have a number of different plans to choose from, and each has its own formulary.

For most Medicare Part D plans, you will have a deductible for prescription medications. After paying this deductible, you pay 25% and the plan pays 75% of the contracted cost of the medication until you have reached a certain amount in total drug costs. This is called the “initial coverage limit.” In 2012 that limit is $2,930. In most plans you will be responsible

THE MEDICARE PART D
STANDARD BENEFIT IN 2012

- You pay $320 deductible
- You pay 25% of the cost of medicines until you pay a total of $972.50, including the deductible.
- You are now in the coverage gap (“donut hole”) and drug costs will be shared between you and the plan or manufacturer. The amount of cost sharing depends upon whether the prescribed drugs are generic or brand name, but can be as much as 50%.
- The coverage gap ends when total drug spending from all sources equals $6,657.50.
- You then enter the catastrophic coverage phase where you will pay a small co-insurance or co-pay for covered drugs during the remainder of the year.

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 prior 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 more information, contact the Patient Advocate Foundation or the Cancer Legal Resource Center. Contact information can be found in Chapter 6.
for only $972.50 of that amount. You will then be in the coverage gap, also known as the “donut hole.” Health reform law required that, beginning in 2011, the cost of prescription drugs in the coverage gap be shared between the enrollee and the plan or manufacturer. The amount of cost sharing depends on whether a drug is generic or brand name.

In 2012, once total drug spending has reached $6,657.50, the coverage gap closes. The following items all count toward you getting out of the coverage gap:

- Your yearly deductible, coinsurance, and co-payments
- The discount you get on brand-name drugs in the coverage gap
- What you pay out-of-pocket in the coverage gap

The drug plan premium and what you pay for drugs that are not covered do not count toward getting you out of the coverage gap.

Once you have left the coverage gap you enter the final phase of the Part D benefit, or “catastrophic coverage.” Here you will pay only a small co-pay or co-insurance amount for covered drugs during the remainder of the year.

The cost sharing requirements of the Medicare Prescription Drug benefit may be challenging to manage. Medicare and Social Security provide a program that helps pay for prescription drugs for people with limited income and resources. This Medicare Low Income Subsidy (LIS) program is also 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 (www.socialsecurity.gov) 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 (http://www.mymedicarematters.org/PrescriptionDrugs/CurrentCoverage/spap_contact.php). Many drug manufacturers also have programs to help patients with their drug costs (see pages 60 and 61 for more detail).

Another source of drug coverage is Medicare Advantage Plans (Medicare Part C) that also have a prescription drug benefit (MA-PD plans). Additionally, some chemotherapy-related prescription medications are covered by Medicare Part B rather than Medicare Part D. 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 Part D occurs annually, near the end of each calendar year. Beginning in 2011, for the 2012 Open Enrollment Period, the dates have changed to October 15–December 7. During this period anyone can join, switch, or drop a Medicare
drug plan. The change will take effect on January 1 as long as the plan gets your request by December 7. Those with a low income and assets 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.

If you have decided to purchase Medicare Part D coverage, selecting the best plan for your individual situation is important. 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 “Formulary Finder” tool on the Medicare website to determine which plan in your area has a formulary that is most advantageous to you. You may also want to ask your health care team or pharmacy if there is someone who can help you with this.

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-MEDICARE (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-MEDICARE.

**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, a PAP may be available to help. These are funded by state governments, charitable organizations, and pharmaceutical companies.

Nearly every pharmaceutical company has a Patient Assistance Program (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 non-profit organizations have developed programs to help patients with prescription costs including co-pays. For more information, see Chapter 6.
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 meant to be a starting place for gathering information about possible assistance. For more information you can check the website www.needymeds.org or www.pparx.org.

**Abbott**
Abbott Patient Assistance Foundation  
Phone: 800-222-6885  
www.abbottpatientassistancefoundation.org

**Amgen, Inc.**  
Amgen Assist®  
Phone: 888-427-7478  
www.AmgenAssistOnline.com

**AstraZeneca Pharmaceuticals**  
AstraZeneca Cancer Support Network (AZ CSN)  
Phone: 1-866-992-9276  
www.astrazeneca-us.com/help-affording-your-medicines

**Bayer HealthCare Pharmaceuticals**  
Onyx Pharmaceuticals  
REACH (Resources for Expert Assistance and Care Helpline)  
Phone: 877-322-4448  
www.nexavar-us.com

**Boehringer Ingelheim Pharmaceuticals, Inc.**  
Boehringer Ingelheim CARES Foundation Patient Assistance Program  
Phone: 800-556-8317  
http://us.boehringer-ingelheim.com/our_responsibilty/patients_families.html

**Bristol-Myers Squibb Company**  
Bristol-Myers Squibb Patient Foundation: Oncology Patient Assistance Program  
Phone: 800-861-0048  

**Celgene Corporation**  
Celgene Patient Support®  
Phone: 800-931-8691  
www.celgenepatientsupport.com

**Eisai, Inc.**  
Eisai, Inc. Patient Assistance Program  
Phone: 866-613-4724  
www.eisaipatientassistance.com
Eli Lilly & Company
Lilly Cares Foundation
Patient Assistance Program
Phone: 800-545-6962
www.lillycares.com

Genentech, Inc.
Genentech BioOncology Access Solutions
(Avastin, Herceptin, Rituxan, Tarceva, XELODA, ZELBORAF)
Phone: 888-249-4918
www.BioOncologyAccessSolutions.com

GlaxoSmithKline
GlaxoSmithKline Commitment to Access
Phone: 866-265-6491
www.gskforyou.com

Janssen Ortho Patient Assistance Foundation
Janssen Ortho Patient Assistance Foundation Patient Assistance Program
Phone: Procrit (800) 553-3851, or for Doxil (800) 609-1083, or for Zytiga (855) 998-4421
www.janssenaccessone.com

Merck and Company, Inc.
Merck Patient Assistance Program
Phone: 800-727-5400
www.merck.com/merckhelps

Novartis Pharmaceuticals
Novartis Oncology
Patient Assistance Program
Phone: 866-884-5906
www.patientassistanceonow.com

Pfizer, Inc.
FirstRESOURCE
Phone: 877-744-5675
www.pfizeroncology.com/sites/pop/pages/first-resource.aspx and
www.pfizerhelpfulanswers.com

Purdue Pharma
Purdue Patient Assistance Program
Phone: 800-599-6070

SANOFI
Patient Connection®
Phone: 888-847-4877
www.VisitSPConline.com

Teva Oncology
Cephalon Oncology Reimbursement Expertise (CORE)
Phone: 888-587-3263
www.tevacore.com
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
I think the internet is a good source of information, and so are support groups. The Wellness Community and my treatment team also provided information.

— Jackie
metastatic breast cancer survivor
CHAPTER 6 / RESOURCES
....................................................................................... 63
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.

The chart on pages 64 - 66 should help you identify at a glance which organizations may provide assistance in particular areas. You can then find more detailed information about the organizations in the alphabetical list.
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<td>Cancer Legal Resource Center (CLRC)</td>
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<td>Chronic Disease Fund (Prescription Assistance)</td>
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<td><strong>Financial Planning Tools</strong></td>
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<td>Corporate Angel Network</td>
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<td>Health Resources and Services Administration</td>
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<td>HealthWell Foundation</td>
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<td>Joe’s House</td>
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<td>National Coalition for Cancer Survivorship (NCCS)</td>
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<td>National Energy Assistance Referral (NEAR)</td>
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<td>National Organization for Rare Disorders (NORD)</td>
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<td>National Patient Travel Center</td>
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**Corporations and Nonprofit Organizations**

- Corporate Angel Network
- Feeding America
- Health Resources and Services Administration
- HealthWell Foundation
- Joe’s House
- Leukemia and Lymphoma Society (LLS)
- LIVESTRONG
- National Coalition for Cancer Survivorship (NCCS)
- National Energy Assistance Referral (NEAR)
- National Organization for Rare Disorders (NORD)
- National Patient Travel Center
- NeedyMeds
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<th>Organization</th>
<th>Financial Planning Tools</th>
<th>Understanding Health Insurance (including COBRA)</th>
<th>COBRA Premium Assistance</th>
<th>Info about Medicare and Medicaid</th>
<th>Other Financial Support</th>
<th>Getting Prescription Medications</th>
<th>Managing Medical Debt</th>
<th>Travel and/or Lodging Assistance</th>
<th>Employment and Disability</th>
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ALPHABETICAL LIST OF RESOURCES

Access Project
617-654-9911
www.accessproject.org

The Access Project is a resource center for local communities working to improve health and health care access. They have excellent tips for managing medical debt.

American Cancer Society (ACS)
800-ACS-2345 (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. This website includes information on insurance issues, advice on what to do if your work situation changes, as well as how to find a professional financial advisor sensitive to cancer issues to help guide you. 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
571-483-1780 or 888-651-3038
www.cancer.net

The American Society of Clinical Oncology is a non-profit organization founded in 1964 with the overarching goals of improving cancer care and prevention. Nearly 30,000 oncology practitioners belong to ASCO, representing all oncology disciplines and subspecialties. Members include physicians and health-care professionals in all levels of the practice 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 care about them.

Association of Oncology Social Work (AOSW)
215-599-6093
www.aosw.org

AOSW is a non-profit, 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 is dedicated to empowering and educating people with cancer to thrive in their workplace by providing expert advice, interactive tools and educational events. Through a comprehensive website, free publications, career coaching, and a series of support groups and educational seminars for employees with cancer and their healthcare providers and coworkers, Cancer and Careers strives to eliminate fear and uncertainty for working people with cancer. Cancer and Careers reaches more than
160,000 people per year online, in print and in person, providing essential tools and information for employees with cancer.

CancerCare
800-813-HOPE (800-813-4673)
www.cancercare.org

CancerCare provides free, professional support services to individuals, families, caregivers, and the bereaved to help them better cope with and manage the emotional and practical challenges arising from cancer. CancerCare services include counseling and support groups, educational publications and workshops, and financial assistance. All services are provided by professional oncology social workers and are offered completely free of charge. Under the CancerCare Co-Payment Assistance Foundation, CancerCare assists qualifying individuals with insurance who are undergoing treatment for cancer, afford their high co-payments for chemotherapy and targeted treatment drugs. Eligibility is based on both financial and medical criteria supported by documentation. For more information on CancerCare Co-Payment Assistance Foundation visit www.cancercarecopay.org.

Cancer Fund of America, Inc. (CFA)
800-578-5284
www.cfaoa.org

CFA is a national agency helping cancer patients through patient assistance programs. They provide items such as liquid nutritional supplements and vitamins, lotions and ointments, food items, various medical supplies, and non-prescription medicine, toys, clothing, and hygiene items.

Cancer Legal Resource Center (CLRC)
866-THE-CLRC (866-843-2572)
www.CancerLegalResourceCenter.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
888-793-9355
www.cancersupportcommunity.org

The Cancer Support Community is an international non-profit dedicated to providing support, education and hope to people affected by cancer. Likely the largest employer of psychosocial oncology mental health professionals in the United States, CSC offers a menu of personalized services and education for all people affected by cancer. Its global network brings the highest quality cancer support to the millions of people touched by cancer. These support services are available through a network of professionally-led community-based centers, hospitals, community oncology practices and online, so that no one has to face cancer alone.
In July 2009, The Wellness Community and Gilda’s Club Worldwide joined forces to become the Cancer Support Community. By helping to complete the cancer care plan, CSC optimizes patient care by providing essential, but often overlooked, services including support groups, counseling, education and healthy lifestyle programs. Today, CSC provides the highest quality emotional and social support through a network of more than 50 local affiliates, 100 satellite locations and online.

**Centers for Medicare and Medicaid Services (CMS)**

[www.cms.gov](http://www.cms.gov)

CMS is the government entity responsible for Medicare and Medicaid.

For comprehensive information about Medicare and especially Medicare Part D see or call: (800) 633-4227 / [www.medicare.gov](http://www.medicare.gov).

**Chronic Disease Fund (CDF)**

877-968-7233

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

CDF is a non-profit 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.

**Corporate Angel Network**

866-328-1313

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

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

**Co-Pay Relief Program (CPR)**

866-512-3861

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

The Patient Advocate Foundation Co-Pay Relief Program (CPR) 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.

**Feeding America**

800-771-2303

[www.feedingamerica.org](http://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.
In 1946, Congress passed a law that gave hospitals and other health facilities money for construction and modernization. In return, they agreed to provide services to persons unable to pay and to make their services available to all persons residing in the facility's area. The program stopped providing funds in 1997, but about 200 health care facilities nationwide are still obligated to provide free or reduced-cost care.

**Health Resources and Services Administration (HRSA)**
800-638-0742  
[www.hrsa.gov/hillburton/default.htm](http://www.hrsa.gov/hillburton/default.htm)

**Joe's House**
877-563-7468  
[www.joeshouse.org](http://www.joeshouse.org)

Joe’s House is a non-profit organization providing a nationwide online service that helps cancer patients and their families find lodging near treatment centers.

**HealthWell Foundation**
800-675-8416  
[www.healthwellfoundation.org](http://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.

**LIVESTRONG**
855-220-7777  
[www.livestrong.org/cancersupport](http://www.livestrong.org/cancersupport)

LIVESTRONG 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 one-on-one support including counseling and referrals to resources in your area for psychosocial, financial, and insurance concerns.

**Leukemia and Lymphoma Society (LLS)**
800-955-4572  
[www.LLS.org](http://www.LLS.org)

The Leukemia & Lymphoma Society (LLS) is the world’s largest voluntary (nonprofit) health 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 Patient Financial Aid Program and a Co-PayAssistance Program. They also provide general disease information, support services and clinical trial searches.

**National Coalition for Cancer Survivorship (NCCS)**
301-650-9127 or 888-650-9127  
[www.canceradvocacy.org](http://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. All of the resources can be useful to the person diagnosed with cancer as well as their family members, friends and caregivers.

**National Energy Assistance Referral (NEAR)**
866-674-6327
http://liheap.ncat.org/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)**
203-744-0100 or 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. NORD works closely with certain pharmaceutical and biotechnology companies to ensure that certain vital medications are available to those individuals whose income is too high to qualify for Medicaid but too low to pay for their prescribed medications.

**National Patient Travel Center (NPTC)**
800-296-1217
www.patienttravel.org

The NPTC works with patients and significant others to try to assure that no one is denied access to distant specialized medical evaluation, diagnosis or treatment if they cannot afford long-distance medical air transportation. Using donated frequent flier miles and other options, NPTC works to arrange low-cost air tickets for people traveling a distance for treatment or a second opinion.

In addition to the resources in this chapter, please see pp. 60 - 61 for information about pharmaceutical company sponsored patient assistance programs.
NeedyMeds
www.needymeds.org

NeedyMeds is a free, online clearinghouse to help people who cannot afford medicine or health care costs. This website includes a wide range of information about services such as Discount Drug Cards, Medicaid websites, Federal Poverty Guidelines and other useful information.

Oncology Nursing Society (ONS)
866-257-4ONS (866-257-4667)
www.ons.org

ONS is a professional organization of over 35,000 registered nurses and other health care providers dedicated to excellence in patient care, education, research, and administration in oncology nursing.

Partnership for Prescription Assistance
888-4PPA-NOW (888-477-2669)
www.pparx.org

The Partnership for Prescription Assistance is a coalition of pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups that helps qualifying patients who lack prescription coverage get the medicines they need through the public or private program that’s right for them. Its mission is to increase awareness of patient assistance programs and boost enrollment of those who are eligible. Through this site, the Partnership for Prescription Assistance offers a single point of access to more than 475 public and private patient assistance programs, including more than 180 programs offered by pharmaceutical companies.

Patient Access Network Foundation (PAN)
866-316-PANF (866-316-7263)
www.panfoundation.org

PAN is a non-profit organization, unaffiliated with any of its donors, dedicated to assisting insured patients who cannot afford the out-of-pocket costs associated with their treatment needs.
Patient Advocate Foundation (PAF)  
800-532-5274  
www.patientadvocate.org  

PAF is a national non-profit 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 is the National Underinsured Resource Directory tutorial designed to help underinsured individuals and families locate valuable resources and seek alternative coverage options or methods for better reimbursement. (www.patientadvocate.org/help4u.php)

Patient Services, Inc. (PSI)  
800-366-7741  
www.patientservicesinc.org  

Patient Services, Inc. (PSI) is the “ground breaking” 501(c)(3) non-profit, charitable organization of its kind. Over two decades ago, PSI recognized the importance of providing a “safety net” for patients with chronic illnesses who were struggling to keep up with expensive premiums and co-payments. Since 1989, PSI 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.

The Portal (www.healthcare.gov)  
The Portal (www.healthcare.gov) is a website developed by the federal government where you can answer a few simple questions and receive customized information about the various health insurance options for which you may be eligible. Some of the options you may find on the portal include:

- Individual health coverage offered by health insurance issuers
- Medicaid coverage
- Children’s Health Insurance Program (CHIP) coverage
- State health benefits high risk pool coverage
- Pre-Existing Condition Insurance Plans
Social Security Administration
800-772-1213
www.socialsecurity.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. The site includes the ability to make a computer-generated profile, personalized to your legal, financial and social situation. The general information applies to all life-changing conditions, and is modified when appropriate for cancer.

United Way
211
www.liveunited.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.

Together Rx Access
800-444-4106
www.TogetherRxAccess.com

Together Rx Access provides a free prescription savings card for individuals who are not eligible for Medicare, do not have prescription drug coverage, and meet certain household income levels. The Together Rx Access Card was created by 10 pharmaceutical companies, providing access to more than 300 brand-name prescription and generic products.
The bottom line is, I do recovery well, and people who know me know that.

— Sue
breast, melanoma and metastatic lung cancer survivor
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.

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.


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.

Charity care — Some hospitals have programs to provide patients with free or reduced charge care. Often these programs are not advertised, so if you are wondering if this is an option you should ask your treatment team or the financial counselor at your treatment facility.

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.

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.
Companion care — See “Custodial care.”

Compassionate allowance — A Social Security Administration program which obligates Social Security to provide a decision quickly to applicants whose medical conditions are so serious that they obviously meet disability standards.

Continuous coverage — Group health insurers can impose only a 12-month waiting period for any pre-existing condition that has been diagnosed or treated within the preceding 6 months. As long as you have maintained insurance coverage without a break of more than 63 days (known as continuous coverage), your prior health insurance coverage is credited toward the pre-existing condition exclusion period.

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.

Creditable coverage — Refers to the HIPAA Act. If you have had health insurance with a previous employer and do not have a health insurance coverage gap of more than 63 days (see continuous coverage), any new group plan has to credit the amount of time you had coverage against the plan’s pre-existing condition waiting period.

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.

Emergent — Requiring immediate action.

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.

Experimental treatment — See “clinical trial.”

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, some states mandate that insurance companies 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 health 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.

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. For more information, see page 31.

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.”

Individual health insurance policy — Individual insurance policies are obtained directly from an insurance company, sometimes through a broker.

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.

Investigational treatment — See “clinical trial.”

Involuntary termination — Involuntary termination is a termination at the direction of the employer. Termination for gross misconduct may disqualify an employee and his/her family from COBRA coverage.

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.

Long-term care — Care provided in a facility such as a nursing home for an extended period of time. Long-term care is different from rehabilitation care.

Low Income Subsidy (LIS) — Medicare provides financial assistance for beneficiaries who have limited income and resources to help with prescription drug costs. Those eligible for LIS receive help paying for their monthly Medicare premium, yearly deductible, prescription coinsurance and copayments and no gap in coverage.

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.

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.

Onset date — With respect to Social Security Disability Insurance, the date after which Social Security determines that you qualified as disabled.
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.

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.

Panel — See “insurance panel.”

Pre-certification (or 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. Many health plans have a period of time in which they will deny all claims related to pre-existing conditions. HIPAA sets limits on how long an insurance company can deny coverage for a pre-existing condition and provides a credit for pre-existing health insurance.

Preferred drug list — See “formulary.”

Preferred provider — Physicians 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 (See Chapter 3), 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 ACA, individuals no longer have to pay co-pays for preventive services.

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.

Private duty care — See “custodial care.”

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 physician makes a recommendation for a patient to see another doctor, usually a specialist.

Rescind — To invalidate. Insurance companies have sometimes rescinded someone's health insurance policy. However, under ACA, insurance companies are no longer allowed to cancel your policy unless you intentionally lied on your application.

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 physician’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.

Vested — In a retirement account, the amount of money in the account that you own and would be able to take with you if you were to leave the company. Some companies “match” your contributions in some way but require that you remain a certain number of years before their matching funds become vested.

Viatical — A viatical settlement is the sale of a life insurance policy by the policy owner before the policy matures. The seller obtains an amount which is discounted from the face amount of the policy. The amount is usually in excess of the premiums paid or current cash value. The seller can use the money for any purpose.

Waiver — The relinquishment of some right or privilege. In the context of health insurance, companies can sometimes “waive” the requirement that you must pay a co-pay for every treatment visit, especially if you are receiving treatment several times a week.
Cancer Support Community would like to recognize and thank all of those who contributed to the success of Frankly Speaking About Cancer: Coping with the Cost of Care.

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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
Dignity Resources
Partnership for Prescription Assistance, www.pparx.org
Patient Advocate Foundation, www.patientadvocate.org
Kaiser Family Foundation, www.kaisercystealthfoundation.org
Medicare, www.medicare.gov
Social Security Administration, www.ssa.gov
Survivorship A to Z, www.survivorshipatoz.org

CANCER SUPPORT COMMUNITY’S FRANKLY SPEAKING ABOUT CANCER SERIES

Cancer Support Community’s Frankly Speaking About Cancer: Coping with the Cost of Care program is part of a national education program that provides support, education and hope to people affected by cancer and their loved ones. The programs consist of educational booklets, clinically facilitated workshops and online content at www.cancersupportcommunity.org.

Frankly Speaking About Cancer booklets feature information about treatment options, how to manage side effects, the social and emotional challenges of the diagnosis and survivorship issues.

All publications are FREE and are available ONLINE. Copies of this booklet are available by request. Frankly Speaking About Cancer workshops are dedicated to empowering patients, caregivers and loved ones to gain knowledge as it relates to each person’s specific situation with cancer. Our unique format offers participants an opportunity to connect with a medical professional outside of an oncologist’s office in a comfortable and relaxed environment. For more information about this program, the Frankly Speaking About Cancer series or Cancer Support Community, please visit our website or call us toll-free at 888.793.9355.
People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibility of their recovery. People with cancer who actively participate in their recovery along with their health care team will improve the quality of their lives and may enhance the possibility of their recovery.