

Chapter 1

Recognizing the Realities of Chemotherapy and Radiation

In This Chapter

- ▶ Taking time to absorb the news
 - ▶ Finding your way in a new culture
 - ▶ Sorting out treatments and side effects
 - ▶ Building a support team
 - ▶ Changing to reflect a new perspective
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You've been told that you have cancer. You may have seen it coming, but more likely this news came out of nowhere to frighten you and shake up your world.

Cancer! How can that be?

Here's how: The Centers for Disease Control reports that more than 18 million new cases of cancer have been diagnosed since 1990, and the government agency estimates that at least 1.3 million new cases will be diagnosed in 2005. One out of every four Americans dies of cancer. In fact, the American Cancer Society announced in January of 2005 that cancer has surpassed heart disease as the leading cause of death for people under 85 in the United States.

On the other hand, more than ever before the words *cancer* and *death* do not necessarily belong in the same sentence. Each day brings news of improvements in screening tests and in treatments. And, happily, survival rates for cancer are at an all-time high in the United States. So, instead of spending time and energy asking "Why me?", we encourage you to take a deep breath and get ready to begin your journey through cancer treatments.

In this chapter, we talk first about taking time to come to grips with your diagnosis. Then we offer suggestions on how to choose a doctor. Next, we present a road map of the rest of this book, where every twist and turn on your journey is clearly marked.

Making Peace with Your Diagnosis

The longest journey begins with a single step, or so an ancient Chinese proverb tells us. You have many steps in store as you make your way through the coming months. But before you take the first step, you have an important task.

Registering your emotions

“First,” says one woman we know who was diagnosed with cancer in 1997, “you scream.” She is right, even if that scream is silent. This is a logical emotional response. After all, you have never before heard the words, “You have cancer.” When you do hear these terrifying words, you may have to ask that the doctor repeat the bad news. Some people recall that on first hearing them, these words sound dim and far away. Others report that their bodies begin to tremble involuntarily. And others appear to remain stonily silent, even as their minds race. Whatever your first reaction, you need time to make peace with your diagnosis.

Taking time to process the news

More likely than not, you won’t be thinking clearly at first. You may start to tally up the people you know who have died of cancer, and you probably will wonder if you’re going to die, too. At this point, you simply don’t have enough information to know what the future holds. You may find yourself totally focused on the diagnosis, but that focus may be chaotic, with hope and fear fighting for your attention even as you try to frame important questions for your doctor.



Give yourself a break. Adjusting to the news that you have cancer takes time. Complete acceptance — if there is such a thing — won’t come in a day or a week or even a month, but gradually, you will adjust to the diagnosis. Long before that happens, you may find yourself heading into the operating room for cancer surgery or preparing for your first chemotherapy or radiation

appointment. Don't be surprised if, from time to time, you experience the same shock and fear all over again that you felt when you first heard the news.

Experiencing a range of emotions

About that recurring shock and fear: These are completely normal emotions. In fact, you likely will go through repeated periods of denial, anger, bargaining, depression, and acceptance. You may recognize these as the stages that people experience when confronting death. In this instance, you are experiencing the loss of life as you know it, the loss of good health, and the loss of feelings of immortality, so it makes sense that you experience these stages, even if you have treatable cancer.



Expect to take more than one ride on the emotional roller coaster as you move back and forth between a range of feelings. This process definitely involves taking two steps forward and one back.

Over time, you will come to recognize when your emotional well-being is at risk, and you will take comfort in knowing that a period of emotional upset most likely will be followed by a period of calm.

Telling family and friends

Early on, after you have processed the news about your diagnosis and are ready to talk about it, you likely will want to tell family members and close friends so they can make themselves available to provide emotional support — and practical help as well. Many people who are newly diagnosed also want to speak with someone who has had cancer, someone who already has been through treatments and lived to tell the tale. In fact, you may find yourself having an exceptionally keen interest in hearing these tales! If you don't know who to call, you may want to ask your doctor if she can have a survivor get in touch with you.



This is a good time, as you begin to gather information about your diagnosis and potential treatments, to talk with someone who has been there. That said, every individual — for a variety of reasons — experiences cancer and the treatments differently, so remember that the details of someone else's story may not apply to you at all.

You also may want to speak with your boss, as your work schedule and obligations may be directly affected by your treatments. Who else needs to know?

That depends on what type of person you are: The type who needs to tell as many people as possible, or the type who wants to tell as few people as possible. You know yourself best and will act accordingly.

Gathering Information

Knowledge is power! In Part I of this book, we help you get acquainted with the facts about cancer — which actually is more than 100 different diseases — and we describe the tests available to help determine the best treatment for you.

Up until the moment of your diagnosis, you may not have known much about cancer — what it is or how it works (which we discuss in Chapter 2). Now, of course, you want to find out more so you can have an idea about what the coming year holds for you. That's a good, positive approach. A poster passed among people going through cancer treatments reads, "When you know the facts, you can make a plan."

Before you make your plan, your doctor will provide you with specific information about your cancer and recommend appropriate treatments. A number of sources can supply general information, including

- ✓ This book
- ✓ Other books
- ✓ Free booklets published by health agencies
- ✓ Web sites (see Chapter 25 for some recommendations)
- ✓ Newspaper and magazine articles

Some people whip through every bit of reading material available on the type of cancer that they have. Others confine their reading to material that specifically relates to the immediate situation. (We think the latter is a wiser approach.)



You don't have to learn enough to earn a degree in cancer, and you don't have to mold yourself into the perfect patient. Your job is to educate yourself about your specific cancer, get through your treatment, and get on with your life.

Shopping for Cancer Specialists

When we say that it is your job to educate yourself about your cancer and your treatments, please don't think that the responsibility rests entirely on

your shoulders. You will have help — a lot of it. Some people first learn that they have cancer from a surgeon or another specialist. When it comes time to do the tests that determine the extent of the cancer — and you can read more about these tests and how to assess your results in Chapter 3 — you need to see a *medical oncologist*, a medical specialist who treats cancer. If radiation therapy is recommended for you, your medical oncologist will refer you to a *radiation oncologist*, a medical specialist who treats cancer patients with radiation therapy.

Finding good doctors

These cancer specialists and other doctors along the way will direct your care and serve as important members of your support team. In Chapter 14, we offer some suggestions for building good relationships with your doctors. Of course, before you can build relationships, you have to choose the doctors. A number of factors come into play, including

- ✓ The type of cancer you have
- ✓ Your age
- ✓ Your general health
- ✓ The number of doctors or medical centers available where you live
- ✓ Your insurance coverage — or lack of it

Obviously, you want the best care that you can get. Given the state of health-care today, some choices will be up to you and some will not, no matter what your specific circumstances. In any case, you most likely don't want to choose a doctor simply by opening the telephone book and picking one with an office close to your home.

Here are some sources to help you choose your cancer doctors:

- ✓ Your primary care doctor (internist or family doctor) or surgeon
- ✓ The referral department of a large medical center
- ✓ Your local medical society
- ✓ Professional medical associations
- ✓ A relative or friend who has personal experience with cancer

When you have a name or two in hand, make an appointment for a consultation. Ask the receptionist what you need to do to make any test results, x-rays, or surgical reports available to the doctor. After that information is gathered, sit down with the doctor and hear what he has to say.



If you have a friend or family member who can accompany you for your first visit to the oncologist, take advantage of that help. Another pair of oars could be helpful as you navigate these unfamiliar waters!

Afterwards, think about what you heard. Think about how you felt while you were hearing it. Think about spending the next several months carrying out a treatment plan under the direction of this particular doctor. If you have found a good fit for you, then proceed.



If for any reason you're not satisfied with what you hear, or you are uncomfortable about how you feel, make an appointment with the next doctor on your list.

Second opinions are common in oncology, and most oncologists expect and encourage you to seek one, just so you are comfortable as you proceed with your treatment. A good closing question with the oncologist is "Who would you go to see if you were me and you wanted to be sure that you were on the right path?" If you think that the doctor is uncomfortable with this question, move on!

Preparing to embrace a new culture

After you have chosen a doctor, you quickly will become aware that not only are you in the hands of a new medical professional, but you are entering what may seem like an entirely new culture full of people who speak a new language. (For a crash course in the language, see the glossary in the appendix.) There is much to learn about your particular cancer, of course, but that is just the beginning.

What's next?

- ✓ Tests to take
- ✓ Treatments to undergo
- ✓ Side effects to endure
- ✓ Strategies to implement to manage those side effects

More specifically, just to give you a few examples, you will find yourself wondering about the following:

- ✓ Your blood cell count
- ✓ Survival statistics

- ✓ How radiation works
- ✓ Long-term effects of chemotherapy
- ✓ How to avoid nausea
- ✓ Where to buy a wig
- ✓ Long-term effects of radiation
- ✓ How to care for your skin
- ✓ Clinical trials of new and (potentially) better treatments

And that's just part of your new culture!

Sound confusing? That's why you have this book. We walk you through every step. But first, we have some advice. While you are learning the new language and sorting out your place in the new culture, you also want to keep your eye on the future.



When you have a treatment plan in place, grab a calendar and mark on it the proposed schedule for your chemotherapy and/or radiation treatments. Seeing exactly how long all this will take also allows you to see all those dates left on the calendar *after* treatment, when your life will once again be your own.

Considering Options

Part II of this book is all about options — treatment options, choices regarding delivery of treatments, and the possibility of participating in a clinical trial. Here too you can find complete information on bone marrow and stem cell transplants.

Understanding chemotherapy and radiation

Medical science is currently learning about and testing some ways to turn off the misguided cells that undergo a mutation and get busy transforming into cancer cells that attack the body. Today, chemotherapy and radiation are the time-tested standard treatments for most cancers. Many people diagnosed with cancer have both treatments, sometimes concurrently and sometimes one after the other. Some people have just one.

Basically, most chemotherapy is *systemic*; it involves any number of anti-cancer drugs that sweep through every cell in the body. In contrast, most radiation therapy is *local* or *regional*, meaning treatments are aimed specifically at the site of a tumor or at nearby places the tumor may have spread.

How do these two treatments work? Check out Chapter 4 for details on chemotherapy. We discuss more than half a dozen different types of anti-cancer drugs. Also, though most chemotherapy drugs are delivered directly into a vein, some are injected into a muscle or a tumor. Some chemotherapy drugs even come in pill form. Who knew? Well, if you didn't, see Chapter 4.

Looking for the inside story on radiation therapy? In Chapter 5, you find out about the two main types of radiation therapy — external beam radiation and brachytherapy — as well as some additional types of treatment.



Sometimes your doctors provide you with information and allow you to decide which treatment to pursue. Don't hesitate to ask what choice the doctor would make for a family member, as that may help you with your decision.

In any case, carefully evaluate the benefits and risks of all your treatment options. The decisions you make today may well affect the rest of your life.



Treatments for life-threatening diseases often carry long-term physical costs, such as decreased organ function now or increased risk for other diseases ten years down the road. Paying the price is always easier if you are well-informed before you begin treatments.

Looking into clinical trials

One important option to consider is whether to participate in a clinical trial. These trials, or tests, of new treatments or new combinations of tested treatments lead the way in cancer research. That means the participants in clinical trials are on the cutting edge of medical science. We spell out the pros and cons in Chapter 6, where you also find questions you may want to ask your doctors, as well as reports from participants who have chosen to be part of clinical trials.

Taking a chance on a transplant

Sometimes, in cases where cancer does not respond completely and permanently to standard treatments, doctors recommend bone marrow and stem cell transplants. This is serious stuff, medical miracles of the first order — or

so we hear from individuals whose lives have been saved as a result of a transplant. Chapter 7 tells you everything you need to know about the purpose of transplants, the different types, how transplants are done, what to expect afterwards, and how to prepare yourself emotionally.

Exploring Virtual Chemotherapy

There is nothing like the real thing, of course, but in Part III of this book, you come as close to experiencing chemotherapy and all the side effects as you can without actually feeling the powerful anticancer drugs drip into your body.

Getting started on chemo

That first day of chemo, as fearful as it seems in the anticipation, most often doesn't turn out to be as bad as you may expect. In Chapter 8, we take you step by step through your first appointment. In this book, we say repeatedly that you don't have to go through cancer treatments alone. Here, we go so far as to recommend what to eat for breakfast and what to wear! Later in the chapter, we clear up any misconceptions about when to take anti-nausea medication. You also find suggestions on how to get the support you need from family and friends as you go through treatments.

Taking care of your immune system

Because anticancer drugs kill healthy cells as well as diseased cells, you are particularly prone to infection while undergoing chemotherapy. That's bad, because you simply won't have the resources to fight off bacteria that means to do you harm. The good news is that doctors can prescribe immune and bone marrow stimulants to help boost your immune system and help your body fend off infections. In addition to medical interventions, there are plenty of preventative measures that you can take to help protect yourself. Read all about it in Chapter 9.

Signing up for side effects

Even people who have never known anyone diagnosed with cancer seem to know a complete litany of the side effects that accompany this powerful

head-to-toe therapy. Never mind that many people taking anticancer drugs are troubled by just a few side effects — and some of those to a limited degree. Everybody wants to get into the act!

In Chapters 10 and 11, you can find details about the serious and not-so-serious side effects of chemotherapy. Here are just some of the side effects we cover:

- ✓ Nausea
- ✓ Fatigue
- ✓ Neuropathy (nerve damage)
- ✓ Mouth and throat sores
- ✓ Depression
- ✓ Infertility
- ✓ Temporary hair loss

Before you panic and assume that you will experience every possible side effect known to result from chemotherapy, we want to say something that we say often in this book, simply because it's comforting to hear.



Every person experiences cancer treatments differently, but no one person is likely to be troubled with every side effect from any one treatment.

No matter which specific side effects you must endure, in this book you find plenty of practical suggestions on how to manage them.

Trying on Radiation Therapy for Size

True to the title of this book, detailed information on what to expect from radiation therapy follows just after we inform you about what to expect from chemotherapy. That's what Part IV is for.

Getting set up for the first treatment

Ask about your first treatment — and in Chapter 12, we answer. You can read all about how radiation therapy is devised specifically for your body. You discover that undressing for the therapy takes longer than the therapy itself. And, we make suggestions about how to care for your skin. If you are looking

for ideas on how to get the support you need from family and friends, we provide them here.

Managing side effects

Contrary to popular opinion, people who undergo radiation therapy are every bit as subject to side effects as people who undergo chemotherapy.



Just because Chapter 13 provides details on a long list of side effects, this does not mean that you will experience every last one.

Here are some of the typical side effects from radiation therapy that are described in this chapter:

- ✓ Fatigue
- ✓ Reddened skin
- ✓ Inflamed mucous membranes
- ✓ Diarrhea
- ✓ Nausea
- ✓ Lymphedema (swelling of an arm or leg because of fluid accumulation)
- ✓ Permanent hair loss
- ✓ Depression

We don't simply list possible side effects and then leave you wondering what to do. Plenty of practical suggestions on how to manage those side effects also are included in Chapter 13.

Sending for Help

A recurrent theme in this book is the importance of putting together a support team to help you get through cancer treatments. Some teams are small — tight circles of medical professionals and family members. Other teams may be much larger and include all manner of healthcare professionals, spiritual advisors, and members of support groups. We take a look at all these possibilities in detail in Part V. Regardless of the size of your team or whether you all choose to wear matching T-shirts or baseball caps, having a support team is an important success strategy.

Making room on the team bus

We suggest in Chapter 14 that you let the doctors sit at the front of the team bus, right behind your immediate family and dearest friends. Who comes next? Perhaps a psychologist, if you think you would benefit from that type of help. Next, we propose that you consider looking at a number of complementary therapies that may help you reduce stress as you go through treatments. Practitioners who provide these therapies include

- ✓ Massage therapists
- ✓ Yoga teachers
- ✓ Reiki practitioners
- ✓ Tai chi instructors
- ✓ Meditation instructors
- ✓ Fitness experts

Now, you may be interested in working with only one or two of these individuals — you may not have the time, energy, or funds to take on any more. We encourage you to do that.



Let's face it: Cancer increases stress at both emotional and physical levels. Sometimes, a little body work from a certified practitioner is just what the doctor ordered.

Practicing good nutrition

Both chemotherapy and radiation therapy can cause changes in your eating habits, for a variety of reasons. In some cases, the treatment itself is responsible. In others, fatigue from the treatments can leave you too tired to eat. That's bad, because good nutrition is especially important during cancer treatments. Here are some reasons why:

- ✓ Eating well helps you keep your energy up.
- ✓ Good nutrition helps you manage side effects.
- ✓ A healthy diet can help your body fend off infection.

In Chapter 15, we talk about the importance of good nutrition and even suggest that you may want to add a registered dietitian to your support team.

If you opt not to do that, we make recommendations for a nutritious diet and bring you up to speed on the latest scientific thinking on protein, carbohydrates, fats, vitamins, minerals, and fluids — at least in regard to nutrition during cancer treatments. We also outline for you exactly what nutritional effects specific cancer treatments may have on your body.

Tending to your spirit

Making room in your life for a cancer diagnosis almost always also means asking yourself some of the really big questions — questions most often left to philosophers and spiritual leaders. Some of these questions include

- ✓ Who am I?
- ✓ Why am I here?
- ✓ What is my purpose?
- ✓ Why did I get cancer?
- ✓ Will cancer kill me?
- ✓ What is the point of living in a world where there is cancer?

These questions can lead to a great deal of stress, which can evolve into losing the will to go on or even to a complete loss of faith in the future. This is known as *spiritual distress*.

Who do you call in this situation? In Chapter 16, we talk about faith and make suggestions on how to bring up this topic with your doctors. We also talk about prayer and meditation as ways to reduce spiritual distress. And we recommend that you add a spiritual leader to your support team if you are so inclined.

Finding support from strangers

Sometimes, people going through cancer treatments find that their daily concerns, complaints, and fears may wear out some of the “inner circle” members of the support team. Sometimes, you can find a certain freedom and acceptance from a support group that can’t be found anywhere else. Is a support group right for you? Have a look at Chapter 17, where we can help you decide.

In that same chapter, you discover that support can come from many or one, and that you can meet at a hospital, in a church, in a freestanding community center — or in your own home, sitting at your computer. We also review the benefits of being part of a support group, as well as the risks.

Looking Beyond Cancer Treatments

When you're in the middle of chemotherapy or radiation treatments, sometimes it seems that this particular journey will never end. It will, of course, and in Part VI, you discover what to expect when that happens. As at the end of any meaningful road, you're likely to find several forks. In this case, you may want to explore lingering physical side effects of cancer treatments, the possibility of recurrence, and some emotional adjustments that are often required after treatments are complete.

Beginning anew

Don't for a minute expect that you never need darken your doctor's door after the last of your cancer treatments. On the contrary, you will be carefully monitored for years to come. In time, you'll even appreciate that fact.

In Chapter 18, you find out what to expect in terms of follow-up care — regular checkups and periodic screening tests — and you can look over a list of long-term side effects that may or may not trouble you. That list includes such physical problems as the following:

- ✓ Fatigue
- ✓ Pain
- ✓ Lymphedema
- ✓ Oral problems
- ✓ Bladder and bowel problems
- ✓ Early menopause
- ✓ Infertility or impotence

Also in Chapter 18, we propose that you craft a personal wellness plan to see you through the years to come.

Returning to square one

Some people finish cancer treatments and never have to confront this particular disease again. In Chapter 19, you get an idea of what to expect if that's not the case — if cancer recurs months or years after treatments end. If you're tempted to avoid this chapter because you expect only the worst, think again.



In many cases, a recurrence can be treated as a flare-up, and cancer can be considered as a chronic disease.

We lay out a plan of action in Chapter 19, should your cancer recur, and we also explain several reasons why the second time around may not be as trying as the first. If recurrence is as bad, or even worse, look here for information on palliative care and an explanation of the mission of hospice.

Making peace with a new you

After cancer, nothing is ever really the same again. Even if you are not troubled with long-term physical side effects as a result of treatment and even if your cancer never comes back, you'll likely find that you are different emotionally and that your standard mode of operating in the world has changed. Read all about that fact in Chapter 20, where we endeavor to help you define yourself anew after cancer.

This is the time that you get to decide all over again who to be, what to say about yourself, and how to make changes in your life that reflect your new perspective on the gift of time. Here, too, are tips on how to protect yourself as you head boldly into your brave new world.

