



## Foreword

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**T**HE NEWS ABOUT CANCER is better than ever. Even though more people are being diagnosed, fewer people are dying from the disease, and people are living longer and better with cancer. They're also learning how to live well with, through, and beyond it.

In the last twenty-five years, there have been dramatic advances in the diagnosis and treatment of cancer. These advances across most cancers have resulted in improved outcomes, leading to larger numbers than ever before of disease-free, long-term survivors, as well as prolonged survival for those who have developed *metastatic* disease.

But as the number of those living with cancer rises, so does the burden on the health care system. As a result, patients are finding themselves in the position of having to take control of their own care plans. In essence, they have become empowered health care consumers. In a *New York Times*/CBS News poll of 1,111 adults in February 2005, 44 percent of patients who received a diagnosis sought more information about treatment options from sources who were not their physicians—including the Internet, friends, relatives, and even other doctors. Slightly more than half of surveyed patients who received a diagnosis were given multiple treatment options—and one-third made the decision on their own. Those between 45 and 64 years old were most likely to take their medical care into their own hands by making informed, educated decisions about their treatments.

Patients need to work to overcome the three most common stressors from cancer: loss of hope, loss of control, and a sense of isolation. They must become educated and empowered. More than ever, today's cancer patient is captain of his or her own treatment team.

Still, unless cancer patients have effective support and resource teams in place to buffer against the trauma of the diagnosis and treatment, as well as to help navigate the many choices they have in every aspect of this life-transforming disease, they and their families will struggle daily with daunting decisions that most of us hope we will never have to

make. In many ways, it takes a village—a cancer support community—to help guide the patient through the labyrinth of choices in dealing with issues ranging from dealing with the shock of initial diagnosis to creating a living legacy and a meaningful life.

Through powerful, first-person testimonies from members of the Cancer Support Community, as well as a plethora of the best tips, evidence-based research, treatment, and support information currently available, *Reclaiming Your Life After Diagnosis: The Cancer Support Community Handbook*, will help you, the cancer patient, feel empowered, positive, and focused on healing. You'll learn how to live well with your disease—no matter what the road ahead may bring.

Wherever you are in the continuum of the cancer experience (newly diagnosed, in active treatment, in post-treatment, or a long-term survivor), this book has something to offer you.

—*Mehmet Oz, MD*, Professor and Vice Chair,  
NY Presbyterian/Columbia

## The Cancer Support Community: A Bold New Vision in Cancer Care

*When you have cancer, you don't focus on what's happened. Rather you look forward to what is to come and what will be—that's called survival.*

MADELINE,  
*advanced breast cancer survivor*



■ IN THE UNITED STATES there are currently 12 million cancer survivors who need support and hope to continue to live well. Unfortunately, those numbers are projected to increase significantly as more people are diagnosed with cancer every year. In 2012, approximately 1.6 million more people will be diagnosed—and that number is expected to increase dramatically as 77 million Baby Boomers age.

At the Cancer Support Community (CSC), we are committed to providing the comprehensive care this growing population needs. CSC formed in 2009, when The Wellness Community and Gilda's Club Worldwide, two of the foremost cancer-support organizations in the United States, joined forces. We base the foundation of our work on the pivotal report issued in 2007 by the Institute of Medicine (IOM) in Washington, D.C. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, which states that, “Today, it is not possible to deliver good-quality cancer care without addressing patients’ psychosocial health needs.” This means that comprehensive cancer care must address the social, emotional, spiritual, and financial impact of a diagnosis. In addition, we are beginning to see an important shift in medical care, known as “patient-centered” care, that recognizes that the patient and his or

her family must be at the center of care and actively involved in making key decisions and setting medical and life priorities. The Cancer Support Community is taking the lead in ensuring that people with cancer receive the best possible care, so that *all* of their needs are met, as described in this landmark IOM report. This book will help guide the growing number of cancer patients—and survivors, whose numbers have quadrupled since 1970—on how to do just that.

CSC's programs are for people of all ages with any type or stage of cancer. Online and onsite CSC services such as professionally led support groups, educational workshops, nutrition and exercise programs, and stress-reduction classes empower people affected by cancer to learn vital skills that enable them to regain control, reduce isolation, and restore hope—regardless of the stage of their disease.

With more than forty-five years of history, CSC is empowering people affected by cancer to live better lives in the face of cancer; addressing individual needs and creating strong links to a community of support and hope. Currently there are fifty CSC affiliate locations around the United States; more than one hundred satellite locations; centers abroad in Israel, Japan, and Canada, ten affiliates in development; and a wide range of resources, support programs, and networking opportunities online at [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org). As a leader in the field, we also partner with a wide variety of organizations that include our own community-based affiliates, hospitals, community oncology practices, and research institutions and other nonprofit organizations to ensure that patients and families are getting the care, support, and resources they need to manage a cancer diagnosis.



*The cancer journey is difficult. That's why it's best to take it with the support of friends and loved ones. The Cancer Support Community provided me and my caregivers with additional strength by hosting a support group of wonderful women (Bosom Buddies) and many other helpful programs. After five years of cancer survivorship, I remain very active with this community, which has given so much to me. Now I can try to give a little back to others facing this journey.*

MARION CHERRY,  
*community member, Cancer Support Community, Montana*

## About This Book

There are plenty of books available about cancer. Some are clinical, while others are personal journeys from survivors offering advice on everything from choosing the right doctor to alternative care. Like many other people with cancer, you might be looking for one book that tells you just about everything you need to know—in a positive, honest, and easy-to-understand manner. If so, you will most definitely benefit from the broad scope of detail in this book. *Reclaiming Your Life After Diagnosis: The Cancer Support Community Handbook* contains facts about cancer, treatment options, and side-effect management, without forgetting that you are a human being faced with major life issues. More than anything else, you need to hear from others who have *really* been there, done that, and are inspired to tell about it. Like them, you'll want to be an active participant in your own treatment—to grow from this experience and to regain your sense of control and hope.

## Guidance, Support, and Powerful Action Plans

Broken into four sections that span the cancer continuum from diagnosis through a sometimes unpredictable future, *Reclaiming Your Life After Diagnosis* is the first book to cover everything you and your family need to know about being active participants in your own long-term plan for well-being. With so many cancer patients becoming survivors, living longer and better has become an increasingly important point of focus for the Cancer Support Community and its team of experts. At the end of each chapter, you'll find a *Patient Action Plan* with specific steps you can take now. These will help you put the main concepts expressed in each chapter to practical and immediate use.

With accurate information and compassionate understanding, this book addresses the physical, emotional, social, and practical needs of today's cancer patient, caregiver, and survivor—preparing you for wellness that can follow you throughout the rest of your life.

Join us at a CSC affiliate near you—or anytime online at [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org). We're here for you!

*I came through the red doors and it was like a breath of fresh air.  
They all treated me like they had known me for years.*

COMMUNITY MEMBER,  
*Gilda's Club, Desert Cities*



Part One

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# **Becoming Empowered**





## Chapter 1

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# Understanding Cancer

*Cancer changes many of the day-to-day aspects of living, but the pursuit of happiness can go on during the fight for recovery if you want it to.*

HAROLD BENJAMIN,  
*founder, The Wellness Community  
(now the Cancer Support Community)*

**t**HE NATIONAL CANCER ACT of 1971 declared a “War on Cancer” that started a significant crusade against a deadly disease. Since then, many strides have been made to improve early detection and develop safer and more effective treatments. In fact, the number of cancer survivors in the United States has quadrupled since 1970. Some cancers have had dramatic increases in cure rates, including Hodgkin’s disease; specific blood, testicular, and thyroid cancers; and some childhood cancers. Yet, as our population ages, more and more people will be diagnosed with cancer. In 2012, it is estimated that 1.6 million Americans will be diagnosed. That translates to one in *every* two men and one in *every* three women who will be diagnosed with cancer in their lifetime. According to the National Cancer Institute (NCI), cancer has replaced heart disease as the leading cause of U.S. deaths for people under the age of 85.

Fortunately, thanks to a greater awareness of the ways that cancer can impact a person’s entire life, treatment is becoming more comprehensive. In addition to medical advances, increased attention is now being paid to social and emotional well-being, with a focus on quality of life after diagnosis. The Cancer Support Community (CSC) has dedicated many years to addressing the issues of quality of life and the fight for recovery, as an integral part of the medical care for people affected by cancer.

## What Is Cancer?

The term “cancer” is a generic name that applies to more than one hundred diseases that share similar characteristics. Cancer occurs when

- an abnormal cell appears in the body;
- the cell continues to divide and subdivide after it should have stopped;
- the new cells eventually form a clump, called a tumor, which, if unchecked, will grow large enough to interfere with the delivery of nutrients and oxygen to nearby organs.

Cancer cells can survive in parts of the body other than where they originated.

This is called *metastasis*.

Our bodies consist of a collection of cells that perform specific functions. Each is linked to the others, operating in a highly regulated manner. In a normal cycle, a cell is born, matures, performs its designated function, and then “dies.” At this point, it must be replaced by a new cell. This is accomplished when a nearby cell divides in half, and then those two divide, and so on, until the exact number of required new cells is reached. Under normal circumstances, the birth and death of a cell is an exquisitely precise process.

Problems arise when, for reasons still unknown, a normal cell divides to replace other cells and gives birth to an abnormal cell. This abnormal cell does not stop dividing when it is supposed to and refuses to die on schedule. Such cells, if unchecked, divide and subdivide endlessly and eventually join together to form a tumor. As the tumor becomes larger, it impedes the functioning of nearby organs by intruding on their space and interfering with their supply of oxygen and nutrients. Eventually, unless the growth is stopped, or the tumor is removed, the healthy organs are destroyed.

There are two types of abnormal cells. The first can survive only at its place of origin and forms a tumor where it originates. This is called a benign tumor, which can often be surgically removed, thereby ending the problem. The other type of abnormal cell, called a malignant cell, is more dangerous, because it does not stop dividing when it is supposed to and can thrive any place in the body. This ability to travel and survive

in other parts of the body is called metastasis. Cancer cells can form a tumor at the primary site (the breast, colon, or lung), as well as in other parts of the body where the tumor has metastasized.

For cancer to be treated successfully, not only must the original tumor be identified and controlled, but the spread of disease, or metastasis, must also be stopped.

A leading contemporary theory states that abnormal cells may commonly proliferate in our bodies as a normal course of health. The reason that these proliferating cells do not become cancerous may be that our immune systems are strong enough to destroy

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*In 2010, the National Institutes of Health estimated that the overall cost of cancer was \$263.8 billion—and that cost is rising.*

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the cancer cells as they appear. Video has actually shown cancer cells being attacked and destroyed by immune system cells, as if in battle. It's an inspiring sight. Some cancer patients use that image to visualize their bodies responding in a proactive manner.

*I remember when my Mom was first diagnosed with cancer. This was a totally foreign experience. I didn't know who to turn to or what to do about it. By coming to The Wellness Community, I found a connection with people—something I really needed. I knew that I could find other resources that would help us too.*

TILDA,  
long-distance caregiver



## **The Immune System: Our First Line of Defense**

The immune system is intricately designed to protect the body from disease. It can also defend against “foreigners” that invade through a break in the skin, via food or other ingested matter, in the air we breathe, or through the rays to which we are exposed. For cancer to take hold, the malignant cell appears when the immune system is too weak to rid the body of it, or it does not recognize the cancer cell to be a problem worth

fighting. This view of cancer is generally known as the immune surveillance theory.

### **Myths about Cancer**

Despite the fact that cancer has been a leading cause of death for decades, not everything you hear about it is true. Take a closer look at the truths behind some popular misconceptions.

- **Myth: Cancer is a death sentence.**

Today there are 12 million cancer survivors—in 1970 there were 3 million. The fact is, with better screening and treatment, more people are living with cancer—and beyond—than ever before.

- **Myth: You are powerless against cancer.**

There are actions, behaviors, and attitudes that you, your physician, and your health care team can use that will not only improve your quality of life, but also might enhance the possibility of recovery.

- **Myth: Surgery causes cancer to grow and spread.**

Surgery is often an important part of a successful treatment plan for cancer. Surgery does not affect the spread of cancer.

- **Myth: Disfiguring surgery is always part of cancer treatment.**

Some people with cancer need surgery, and some people do not. If you need surgery, you should know that reconstructive and plastic surgery is often used to avoid and correct disfiguring effects.

- **Myth: Terrible pain that cannot be relieved is part of cancer or its treatment.**

Some people do have pain with their cancer or treatment; other people do not. Most pain is treatable and can be relieved with modern pain-relief medicine and other treatments.

- **Myth: Chemotherapy will make you sick each time you get it.**

There are many medications and other treatments that are now given to help control the side effects of *chemotherapy*. They help you feel and stay well during and after your chemotherapy treatment.

- **Myth: Radiation treatment burns off your skin.**  
There are many skin-care treatments and other medications that can be used to protect your skin in preparation and during radiation.
- **Myth: Chemotherapy will always make your hair fall out.**  
Only some chemotherapy makes you lose your hair and, even then, only temporarily. It grows back a few months after treatment, but it may look somewhat different.
- **Myth: Having cancer and getting treatments means that you will be in the hospital all of the time.**  
Most cancer treatment is provided on an outpatient basis. Ask your doctor and nurse what you can expect.

## Gain Knowledge about Cancer Research Today

By 2020, the Healthy People goals established by the U.S. government have set the bar to reduce the number of new cancer cases, as well as the illness, disability, and death caused by cancer. In response, new categories of drugs are being developed to treat the disease, and scientists are exploring new mechanisms to better understand how the cancer cell functions at the most basic genetic level.

While some cancers can be cured, others may never entirely disappear and may require ongoing treatment to be controlled. As a result, many patients are living longer after a cancer diagnosis and often must learn how to achieve and maintain a better quality of life. In fact, for some, cancer can become a chronic illness to be managed and controlled over the course of many years until new treatments are discovered.

The number of people affected by cancer is increasing, as a result of improved early detection and better cancer treatments. Today, there are over 12 million cancer survivors alive in the United States, compared to only 3 million in 1970.

For the last several decades, common treatments have included surgery, radiation, and chemotherapy. While these are focused on destroying the tumor cells, they can damage normal cells as well. The newest category of cancer treatments are targeted therapies. These act in specialized ways to destroy or interfere with tumor cell growth, often not affecting normal cells. As a result, targeted treatment harms only cancer cells, causing fewer of the traditional treatment side effects, such as hair

loss and nausea. The newer treatments can also be combined with older therapies to enhance their effectiveness. You will find more information about how targeted therapies work, including details about cell growth and death, hormones, the immune system, and aspects of genes later in this book.

### Patient Action Plan

- **Research your cancer.**  
Gain as much knowledge as you can, as soon as you discover you have cancer. Know that knowledge is power.
- **Learn from others.**  
Seek out cancer support groups or organizations that can connect you with someone who's been there. You are not alone.
- **It's more than okay to ask questions.**  
Learn to become comfortable with asking your doctors any question that you have about cancer, support, and recovery.
- **Understand that cancer research is ongoing, and new treatments are always on the horizon.**  
Ask about clinical trials or innovations.

