
Fighting Cancer with
Knowledge and Hope

Yale University Press Health & Wellness

A Yale University Press Health & Wellness book is an authoritative, accessible source of information on a health-related topic. It may provide guidance to help you lead a healthy life, examine your treatment options for a specific condition or disease, situate a health care issue in the context of your life as a whole, or address questions or concerns that linger after visits to your health care provider.

For a complete list of titles in this series, please consult yalebooks.com.

Joseph A. Abboud, MD, and Soo Kim Abboud, MD, *No More Joint Pain*

Thomas E. Brown, PhD, *Attention Deficit Disorder: The Unfocused Mind in Children and Adults*

Patrick Conlon, *The Essential Hospital Handbook: How to Be an Effective Partner in a Loved One's Care*

Richard C. Frank, MD, *Fighting Cancer with Knowledge and Hope: A Guide for Patients, Families, and Health Care Providers*, 2nd ed.

Michelle A. Gourdine, MD, *Reclaiming Our Health: A Guide to African American Wellness*

Marjorie Greenfield, MD, *The Working Woman's Pregnancy Book*

Ruth H. Grobstein, MD, PhD, *The Breast Cancer Book: What You Need to Know to Make Informed Decisions*

James W. Hicks, MD, *Fifty Signs of Mental Illness: A Guide to Understanding Mental Health*

Steven L. Maskin, MD, *Reversing Dry Eye Syndrome: Practical Ways to Improve Your Comfort, Vision, and Appearance*

Mary Jane Minkin, MD, and Carol V. Wright, PhD, *A Woman's Guide to Menopause and Perimenopause*

Arthur W. Perry, MD, FACS, *Straight Talk about Cosmetic Surgery*

Eric Pfeiffer, MD, *Winning Strategies for Successful Aging*

Catherine M. Poole, with DuPont Guerrey IV, MD, *Melanoma: Prevention, Detection, and Treatment*, 2nd ed.

Madhuri Reddy, MD, MSc, and Rebecca Cottrill, RN, MScCH, *Healing Wounds, Healthy Skin: A Practical Guide for Patients with Chronic Wounds*

E. Fuller Torrey, MD, *Surviving Prostate Cancer: What You Need to Know to Make Informed Decisions*

Barry L. Zaret, MD, and Genell J. Subak-Sharpe, MS, *Heart Care for Life: Developing the Program That Works Best for You*

Fighting Cancer

with *Knowledge & Hope*

A Guide for Patients, Families,
and Health Care Providers

Second Edition

RICHARD C. FRANK, MD

Illustrations by Gale V. Parsons

Yale University Press

New Haven & London

Published on the foundation established in memory of William Chauncey Williams of the Class of 1822, Yale Medical School, and of William Cook Williams of the Class of 1850, Yale Medical School.

First edition 2009. Second edition 2013.

Copyright © 2013 by Richard C. Frank, MD. All rights reserved. This book may not be reproduced, in whole or in part, including illustrations, in any form (beyond that copying permitted by Sections 107 and 108 of the U.S. Copyright Law and except by reviewers for the public press), without written permission from the publishers.

Yale University Press books may be purchased in quantity for educational, business, or promotional use. For information, please e-mail sales.press@yale.edu (U.S. office) or sales@yaleup.co.uk (U.K. office).

Printed in the United States of America.

Library of Congress Cataloging-in-Publication Data

Frank, Richard C., 1963–

Fighting cancer with knowledge and hope : a guide for patients, families, and health care providers / Richard C. Frank, MD ; illustrations by Gale V. Parsons. — Second edition. pages cm. — (Yale University press health & wellness)

Includes bibliographical references and index.

ISBN 978-0-300-19061-8 (pbk.)

1. Cancer—Popular works. I. Title.

RC263.F695 2013

616.99'4—dc23 2012050119

A catalogue record for this book is available from the British Library.

The information and suggestions contained in this book are not intended to replace the services of your physician or caregiver. Because each person and each medical situation is unique, you should consult your own physician to get answers to your personal questions, to evaluate any symptoms you may have, or to receive suggestions for appropriate medications.

The author has attempted to make this book as accurate and up to date as possible, but it may nevertheless contain errors, omissions, or material that is out of date at the time you read it. Neither the author nor the publisher has any legal responsibility or liability for errors, omissions, out-of-date material, or the reader's application of the medical information or advice contained in this book.

This paper meets the requirements of ANSI/NISO Z39.48-1992 (Permanence of Paper).

To my patients, who have granted
me the great privilege of being their
oncologist

In memory of my mother, Nina Frank,
for a lifetime of encouragement,
inspiration, and supreme love

To my wife, Miriam,
and to my boys,
Adam and Sam,
for your love, support, and encouragement

The journey of a thousand miles begins with a single step.

—Lao Tzu

Contents

Foreword by Edmundo Bendezu xi

Preface to the Second Edition xv

Preface to the First Edition xvii

Acknowledgments xxi

PART I Exposing Cancer

1 First Steps 3

When First Diagnosed: “What Should I Ask?” ♦ Cancer Pitfalls

2 What Is Cancer? 13

The Three Essential Properties of Cancer ♦ Understanding How Cancer Spreads

3 Diagnosis, Staging, Curability 28

Making a Diagnosis of Cancer ♦ Determining the Extent or Stage of Cancer ♦ Estimating Curability

- 4 Understanding Specific Cancers 59
Carcinomas ♦ Blood and Lymph Cancers ♦ Myeloproliferative Neoplasms ♦ Sarcomas ♦ Brain Tumors
- 5 Why Cancer Develops 92
Cancer and the Blueprint for Life ♦ Family Cancers ♦ Cancer and the Environment ♦ Why Do Only Some People Get Cancer?

PART II Attacking Cancer

- 6 How Cancer Grows: The Basis of Cancer Treatments 125
Cancer Develops over Decades ♦ Cancer Grows by Organized Chaos ♦ Cancer Can Grow Unpredictably ♦ Cancer Is Survival of the Fittest ♦ The Devil Is in the Details
- 7 Cancer Treatments Revolve around Metastasis 137
After Surgery: “Why Do I Need Chemo If I’m Cancer-Free?” ♦ Eye on the Prize: Complete Cancer Eradication ♦ When Surgery Is Not the First Step ♦ Metastatic Disease: Cure versus Control ♦ How a Treatment Strategy Is Chosen ♦ Cancer in the Older Individual ♦ The Role of Surgery in Metastatic Cancer ♦ The Role of Radiation Therapy in Metastatic Cancer
- 8 Cancer Treatments at Work 167
A New Era of Hope ♦ Targeting the Lifelines of Cancer ♦ Chemotherapy ♦ Targeted Therapies ♦ Hormone Therapies ♦ Radiation Therapy ♦ Why Do Cancer Treatments Sometimes Fail?
- 9 Personalized Cancer Medicine: Tailoring Treatment to the Patient 200
Focus on Prostate Cancer: Targeting Testosterone ♦ Targeted Approaches in Other Cancers ♦ Genetic Profiling of Cancer

10 Harnessing the Immune System 211

Releasing the Brakes on the Immune System ♦ Cancer, Stress, and the Mind-Body Connection ♦ Alternative Cancer Therapies ♦ In Search of Evidence

11 Get Prepared to Survive 225

Live for Today ♦ Physical Challenges of Survivors ♦ Psychological (Emotional) Challenges of Survivors ♦ Survival Is Spelled LMNOP ♦ Final Thoughts

Appendix 1 Types of Cancer Medicine 239

Appendix 2 For More Information 244

Glossary 247

References 253

Index 273

This page intentionally left blank

Foreword

Fighting Cancer with Knowledge and Hope provides you with the information you need to survive cancer. But above everything else, Dr. Frank gives you the wisdom to knock out the despair and depression brought on by cancer. He gives you a needed dose of tranquillity.

Dr. Frank does something very important in this book, and that is to truly demystify cancer. I am not in favor of using that word without an explanation. Demystification evaporates the mystery of cancer, so that you can see clearly and stand courageously wherever you are. Fear disappears, because you finally come to understand the old syllogism: “A human being is mortal. I am a human being. Therefore, I am mortal.”

Being mortal can be a blessing if we believe an old Greek myth. In that story, a man who did not want to die begged the gods to grant him immortality and eternal youth. Tired of his pestering, they gave him his request. He grew old, watched his family die, and saw his friends pass away. The people he loved were gone, leaving him lonely and in despair. He again begged the gods, this time to allow him to die. They agreed, and he died the happiest man on earth.

In James Hilton’s novel *Lost Horizon* (as well as in the film starring

Ronald Coleman) the strangers who landed in the Himalayan valley of Shangri-La became bored with eternal youth. They escaped and thus completed their destiny as human beings to become old and die.

Cancer is the hands of the gods, reminding us that we are mortal. Dr. Frank's book is the kind hand of a brilliant oncologist who lets you know that it is not yet your time to die, that you can still enjoy your old age, that you can still live without pain, that when you have to go, you can go painlessly, leaving your loved ones in peace, having completed many unfinished projects and business.

Ironically, cancer cells don't want to die; they want to be immortal. They want to obliterate human destiny and to reproduce endlessly by the billions. When the bells strike the final hour for their human host, they all die as the body enters into the kingdom of not-this-world, into the kingdom of eternal peace, the kingdom of a dream without nightmares.

The great Peruvian poet César Vallejo wrote, "After all, one is half-dead, and half-alive, in this life." This is probably true; however, cancer can save you from this human condition and show you a good side effect. It makes you shout, "After all, I am still alive!" And then, knowing you may die, you start living intensely. If you are a good person, you become a better person. If you are not good, you become good. Your life instinct becomes sharp as a knife. Dr. Frank shows the enormous energy spent by the human body in fighting cancer for twenty, thirty, or more years. This concentrated life force, like a huge army, works to defeat cancer for a few or many years of life, with the help of surgery, radiation therapy, and the wonder drugs of chemotherapy and targeted treatments. Their side effects are nothing compared with what you get from them: a transitory reprieve from the way of all flesh.

If you are not a cancer patient, and you carry in your genes the defect that will strike you down sooner or later, this book will give you the strength you need for the big fight.

I have read many books about cancer, from Dr. Linus Pauling's *Cancer and Vitamin C*, Dr. Virginia Livingston-Wheeler's *The Conquest of Cancer*, and Dr. Max Gerson's *A Cancer Therapy* to Claudia I. Hen-

schke's *Lung Cancer*, Dr. Carolyn D. Runowicz and Dr. Sheldon H. Cherry's *The Answer to Cancer*, Adam Wishart's *One in Three*. This book, however, stands out from the crowd. Dr. Frank shows what is happening in that mysterious world of cancer research, of anticancer drugs that are being discovered and tested every day, and of that incomprehensible and baffling world of genetics and cancer.

I know you will feel as I do, that this book produces knowledge, hope, and optimism.

Edmundo Bendezu, PhD
Professor of Spanish Literature
University of Nebraska
Lincoln, Nebraska
San Marcos University
Lima, Peru

This page intentionally left blank

Preface to the Second Edition

In 2011, I attended the annual meeting of the American Society of Clinical Oncology in Chicago. I was one of thousands of cancer physicians and scientists from across the globe who gather every year to learn about the latest accomplishments in the treatment of cancer. These meetings are filled with reams of data and numerous incremental advances, though often the conclusion from one oncologist to another is, “Nothing major.” But not this year. We all sat rapt as we heard of major breakthroughs in the treatment of metastatic melanoma, a cancer for which no significant advances had occurred for decades. We heard two remarkable presentations: one describing how targeting melanoma cells by attacking a genetic mutation leads to major shrinkage of tumors, the other on achieving greatly improved survival rates by unlocking patients’ own immune systems to attack the cancer. We in the audience immediately realized that the era of “targeted therapy” and “cancer immunotherapy” had resoundingly arrived.

By the next year, 2012, the ability to analyze hundreds of genes in an individual cancer specimen became a reality in the day-to-day practice of oncology, ushering in the era of “personalized cancer medicine.” With

so much progress occurring so rapidly, it became clear that an updated edition of *Fighting Cancer with Knowledge and Hope* was needed.

At the same time, I have embarked on my own spiritual journey to better understand myself, my patients, and the people around me. Everyone's life contains ups and downs, moments of pain and moments of joy, but mostly many small moments. I have learned that living a life that is more mindful, present, and in "the now" can help one cope with anything that life brings our way, even cancer. This has made me a better physician, more able to counsel cancer patients on strategies to survive and enjoy each day. I fully embrace all the approaches of integrative medicine, such as massage, acupuncture, meditation, and yoga, that foster inner peace and relaxation. I have come to believe that these approaches also improve a patient's immune system and longevity.

The second edition of *Fighting Cancer* contains the original core explanations of cancer but includes key medical updates throughout. A new first chapter directly informs cancer patients what to ask and what to avoid. New chapters on personalized cancer medicine and the latest immune therapies will enable cancer patients to understand what these new approaches are all about. The final chapter on survival has been rewritten to reflect my own new way of thinking about the "mind-body" connection and how to best keep these in harmony for optimal survival.

I hope you enjoy this second edition of *Fighting Cancer with Knowledge and Hope*. And I thank you for continuing to allow me to guide you through the maze of this complicated disease.

Preface to the First Edition

Cancer is a frightening and complicated illness. Those affected by it face a series of new challenges after hearing the words “It’s cancer.” On being diagnosed, most people feel alone, as if nobody can truly relate to their innermost fears. They will receive advice from well-meaning friends and family and will seek answers in magazines and books and on the Internet. They will meet with specialists and strive to get the best medical care possible. They will challenge themselves to eat right, exercise right, live right, think positively, accept treatments diligently, and suffer side effects bravely. And they will often strive to contain their fears from their loved ones and caregivers.

Although the chances of beating cancer improve every year, the road to survival is often not easy. A cancer patient may need to undergo surgery and suffer pain and an altered body image and receive radiation treatments that may cause mouth sores, diarrhea, or skin irritation. They may be treated with chemotherapy and fight to keep their bodies intact while confronting hair loss, weakness, lowered immunity, and strange reactions to potent drugs.

Cancer patients may travel long distances or make frequent trips for

their treatments, battling inconvenience and a diminished quality of life. They may face new financial burdens to pay for their medical care. They may choose to participate in research studies and experience rollercoaster fear and hope as a result of receiving unproven but promising treatments.

All cancer patients will, throughout their cancer journeys, suffer the anxiety of not knowing if their treatments are working or for how long their treatments will work or if they will survive their cancer.

With all these cancer-related issues to think about, it may come as a revelation to many battling cancer that throughout their cancer odyssey, they will rarely think clearly about the disease itself. Cancer patients think a great deal about what cancer is doing to their lives and to their bodies, and understandably so. They also concentrate on their choice of treatment and caregivers.

But why do so few focus healing thoughts on the very disease that has become the focus of their lives? Based on the multitude of questions I field daily from cancer patients and their loved ones, there is clearly a burning desire to better understand the cancer process. I believe the main reason that many people feel overwhelmed when it comes to trying to make sense of cancer is that few people know what the disease is or how to think about it.

The very thing that has turned a person's life upside down is a mystery to them.

My motivation to write this book stems directly from the words of my patients—more specifically, the burning questions that so many of them have and rarely get answered to their satisfaction. When first diagnosed, most patients want to know why they got cancer and if it could have been caught earlier. After deciding on the most appropriate treatment, many want to know how those treatments work and, if they should fail to control the cancer, why they failed. The answers, of course, are specific to each individual, and in most cases, accurate answers are truly not available. Yet after hearing the frustrated words of a vibrant woman dying from stomach cancer—“What the hell is this beast inside of me? I feel like I have no control over anything that is going on inside my

body”—I knew that more information needed to be made available to those who want answers or at least as much knowledge as possible.

The main goals of this book are to enable you to appreciate:

1. What cancer is and how it grows;
2. How oncologists determine the best treatment for each patient and what the different treatment strategies are; and
3. How to visualize cancer treatments at work in the body.

My purpose is to impart knowledge and a fresh perspective on some of the most complicated but essential aspects of cancer that have thus far received little attention. These include descriptions of the development, growth, and death of cancer (with treatment), written in a way that any reader without previous scientific knowledge will understand. I also include those aspects of practical cancer management that I have found most important in my day-to-day practice, such as how to cope in the face of a poor prognosis, facing fears of chemotherapy, and the distinction between chemotherapy and newer, targeted medicines. I hope you will find, as one of my patients did, that “reading this book is like having a conversation with your oncologist.”

By reading this book, you will come to understand that *no two cancers are exactly alike*. Two individuals with the exact same cancer diagnosis will almost certainly experience their diseases differently. Their cancers will grow at different rates, affect their bodies in distinct ways, and respond uniquely to the same treatments (one person’s cancer may disappear with a treatment, whereas another’s may grow while receiving the same treatment). Yet despite these differences and complexities, all cancers share features that explain why a cell anywhere in the body can become a cancer cell. Further, these shared biological roots explain why many of the same treatments are being applied to treat a wide range of cancers, such as angiogenesis inhibitor therapies that alter blood flow to a tumor. Thus, regardless of the type of cancer you may have or are interested in, the principles described in this book are directly relevant to it.

In Part 1, I draw on actual patient case histories, from my hematology and oncology practice, to explain the behavior of cancer in the body,

how the different cancers are staged, and how oncologists estimate curability. Current thinking about the causes of cancer and the best means to prevent it is also covered.

In Part 2, I cover why oncologists recommend a particular sequence of surgery, chemotherapy, and/or radiation. Next, I explore how the major forms of cancer-fighting drugs (chemotherapy, targeted therapies, and hormone therapies) work to shut down cancer growth. Illustrations accompany the discussions to cement deeper levels of comprehension; they help you visualize and capture with your “mind’s eye” the essence of how treatments attack cancer. No longer will you feel like an innocent bystander, blindly accepting bewildering medicines for an impenetrable disease.

In the final chapter, you will learn the coping strategies recommended by those who have survived cancer so that you are in the right frame of mind to face the disease.

This book will be useful as an aid during various aspects of your treatment. While receiving chemotherapy or radiation therapy, you can use the pictures showing how that treatment works so that you can guide the therapy with your mind. The visualization of cancer dying and the body healing is an important tool because it enables you to engage your mental energies on the task at hand; doing so will promote a sense of calm in dealing with the disease.

If you are a cancer patient, I must tell you that I do not know if focusing your thoughts on cancer will help you live longer. But with a greater understanding of the disease you are battling, you will feel more in control of your situation. And with more control, you will be more relaxed and better able to cope with the many ups and downs that every cancer patient experiences.

I wish you long life and victory over cancer.

Acknowledgments

I am especially indebted to my agent, Jacques de Spoelberch, for his steadfast support and encouragement of this work as well as his wisdom and friendship; Jean Thomson Black, executive editor at Yale University Press, for her vision and integrity and for enabling this second edition to be published; and the late Gale V. Parsons for her tremendous contribution to this work.

I am so grateful to the many talented and giving individuals who provided essential feedback to me as I wrote this book: Elizabeth April-Fritz, Carol Avery, EdD, RNC, Edmundo Bendezu, PhD, Mary Ann Bendezu, RN, Susannah Carillo, Michele Dailey, LMFT, Bridget DeBartolomeo, RN, Nancy Gennaro, MSW, Andrew Jaffe, Francoise Jaffe, PhD, MSW, Ann Jakubowski, MD, Jennifer Long, APRN, Kesav Nair, MD, Rita Ort, RN, Phyllis Osterman, Margaret Raleigh, Valerie Solis, RN, Phyllis and Stephen Steinbrecher, Lynn and Bill Thompson, Linda Versea, APRN, and Richard Zerkowitz, MD. It is certainly not enough, but thank you all very much!

Special thanks to the staff at Yale University Press, especially Laura Jones Dooley, senior manuscript editor, for her excellent editing of this

Acknowledgments

book, as well as Jenya Weinreb, managing editor, and Sara Hoover. I also wish to thank Jill Golrick, head of library sciences at Norwalk Hospital, for always being so helpful.

I gratefully acknowledge the tremendous work of the staff of the Whittingham Cancer Center, the oncology section of the Norwalk Medical Group, the 6E inpatient and outpatient oncology units of Norwalk Hospital, and the Mid-Fairfield Hospice. Your attention and devotion to the individual is what great cancer care is all about. It is my privilege to be a part of such a caring environment.

A note of thanks also goes to Ms. Diane Blum, CEO of the Lymphoma Research Foundation and editor of cancer.net.

Most important, a most loving thank-you to my wife, Miriam, for her love and support, many insightful comments, and putting up with me at all times, especially as I wrote this book in the thicket of raising two active boys. And to those beautiful children, Adam and Sam, thank you for your wonder and smiles and for giving us such pride and joy. Finally, to my sister, Shawn, social worker par excellence, sister without rival, thank you for your great inner strength, for a lifetime of friendship and caring, and for your insight into the needs of cancer survivors.

Part I

Exposing Cancer

This page intentionally left blank

I

First Steps

When Cheryl was diagnosed with lung cancer, it came as a complete shock. She was always healthy, ate the right foods, maintained a trim physique, and exercised regularly. Plus, she had never smoked. When she developed a persistent cough six months before I met her, her primary care physician treated her with antibiotics for possible bronchitis. The cough did not improve, so a chest X-ray was performed. This showed an abnormality in the right lung, and a CT scan followed. The findings were startling. The right lung was dotted with multiple little tumors throughout, with a dominant mass where the lung meets the major bronchial tube and enlarged lymph nodes in the middle of the chest. Surrounding the lung was an abnormal collection of fluid called a pleural effusion. Cheryl was told that she probably had lung cancer and that it was in the fourth stage.

The doctors withdrew some of the fluid, and it did contain cancer cells, a type called adenocarcinoma. Cheryl began chemotherapy treatments, and her condition seemed to improve. She put up with the side effects, which were extreme. The paclitaxel and carboplatin that she received caused fatigue, hair loss, and loss of appetite. She became de-

pressed. After three months of treatment, a CT scan showed that the tumors were growing rather than shrinking. She started to feel hopeless.

Cheryl was used to having her ducks in a row. As a grade-school teacher for thirty years, she kept those little darlings in line and well taught. In addition to her healthy lifestyle, she had a loving husband and long, solid marriage. How could she have developed lung cancer? And why wasn't the chemotherapy working? Cheryl's ducks were all over the floor, and her spirit was at its lowest. It was at this point that we met.

My first action was to request that a sample of Cheryl's tumor be sent to a specialized laboratory for molecular testing, specifically for genetic analysis of a gene called EGFR, short for epidermal growth factor receptor. The EGFR gene gives rise to the EGFR protein, which is present on the surface of many of the most common cancers and is one of many molecules that fuel the growth of cancer. Its importance is most evident, however, when it is the main driver of a cancer. This is best determined by analysis of the EGFR gene: if the genetic code contains a mutation in a critical region, then EGFR is the main power source of the cancer, galvanizing its expansion and spread in the body. In this case, blocking the EGFR protein from firing would shut the cancer down.

Cheryl hit pay dirt. Her cancer contained a mutation in exon 18 of the EGFR gene. Intensive and exciting research over the past several years has proven that patients whose lung cancers contain mutations in EGFR can have their cancers successfully treated and their lives significantly prolonged by a pill that prevents the EGFR protein from firing. In the United States, the pill is called erlotinib (Tarceva). In other parts of the world, gefitinib (Iressa) is used. Cheryl would now be treated with a "targeted therapy" that hones in on one specific target in a cancer cell and has fewer side effects than most chemotherapy drugs. She could not believe her ears when I told her that she would soon be feeling much better again. She was in disbelief and cried tears of joy when I told her that her life would now be measured in years, rather than months.

Welcome to the ever-evolving landscape of cancer care. Old therapies are being replaced by newer and smarter ones. Cancers that were pre-

viously considered “terminal” from the start are now being converted into chronic diseases in many situations. The therapies are more sophisticated, the care is more complicated, and the needs of patients are greater than ever. It is critical for all cancer patients to be involved in their own care, to understand all their options, and to aim to live life to its fullest throughout their battle with cancer.

The fight starts with knowledge, always contains hope, and must be guided by common sense in order to avoid certain pitfalls (see “Cancer Pitfalls,” below).

When First Diagnosed: “What Should I Ask?”

A NOTE OF CAUTION: The following questions should be asked of your surgical, medical, and radiation oncologists. Although other types of doctors may actually make the diagnosis of cancer, they are not expert in determining treatment strategies and prognoses for cancer. More in-depth answers to each question are contained in the chapters that follow.

1. *What is the specific type of cancer I have?* Most types of cancer come in different varieties. For example, in non-small cell lung cancer, it may be adenocarcinoma, squamous carcinoma, or another type. A breast cancer is typically invasive ductal or lobular carcinoma or ductal carcinoma in situ. A non-Hodgkin’s lymphoma can be one of thirty varieties, the most common two being follicular lymphoma and diffuse large cell lymphoma. The cancer discussion must start with the specific diagnosis. Know yours.

Helpful hint: Obtain a copy of the pathology report and go through it with your oncologist.

Advice: Ask if it would be helpful for the pathology specimen to be reviewed by a pathologist at another center, referred to as a “second opinion in pathology.” Sometimes, these reviews lead to changes in the type or extent of a cancer, resulting in a change in its management.

This is especially important for some types of lymphoma and breast cancer.

What is the grade of the cancer? Pathologists will often assign a “grade” to cancer that is an indication of its aggressiveness. Grade has to do with how closely the cancer resembles the normal tissue from which it is derived or how “differentiated” the tumor is. Grade is typically divided into three categories: low, intermediate, or high grade, or well, moderately, or poorly differentiated. The higher the grade, the less differentiated the cancer, the more aggressive it tends to be. In prostate cancer, grade is given a number, called the Gleason score.

Helpful hint: The pathology report will indicate the grade of the cancer.

2. *What are the molecular markers of my cancer?* The molecular markers of a cancer refer to the higher-level analysis of a cancer specimen, testing it for specific genes and proteins. These markers are usually performed because they help guide the type of therapy recommended. (Consult chapter 9, “Personalized Cancer Medicine,” for discussion of this complicated issue.)

For example:

- ◆ Is a breast cancer hormone positive (ER and PR), Her2 positive, or triple negative? For each situation, treatment would involve hormone therapies (such as tamoxifen), Her2-directed therapies (such as trastuzumab or Herceptin), or chemotherapy, respectively. Should a genetic test, such as an Oncotype DX, be performed in order to determine whether chemotherapy is necessary?
- ◆ Is a lung cancer EGFR or ALK gene positive (in other words, do the genes contain a mutation)? If so, then treatment might involve erlotinib (Tarceva) or crizotinib (Xalkori), respectively, rather than chemotherapy.
- ◆ In advanced colon cancer, is it KRAS gene wild type or mutated? If KRAS wild type, then cetuximab (Erbix) or panitumomab (Vectibix) may be of benefit; if KRAS is mutated, these drugs would not work.

Advice: Ask your oncologist if molecular testing has been or will be done on the cancer specimen and what the results mean in terms of prognosis and treatment.

3. *What stage is the cancer in?* The stage of a cancer has to do with its extent in the body. For most of the common cancers, stage is divided into I, II, III, and IV. The higher the stage, the further the cancer has traveled in the body from its original starting location. Stage is determined after a “staging workup” that may include surgery, imaging tests such as CT, MRI, and PET scans, or other specialized tests, such as endoscopic ultrasound for gastrointestinal cancers (esophagus, stomach, rectum) or a bone marrow biopsy for those diagnosed with a blood cancer.

Helpful hint: Ask the doctor if other tests are needed to complete the staging workup.

4. *What is the prognosis? Is it likely, possible, or unlikely that the cancer can be cured?* These questions take bravery to ask at first, but it is vital to have some sense of the realistic curability of the cancer. Even if a cancer is not curable, that does not mean that it is not treatable or that the affected person cannot live for years with the cancer. At some point, these questions must be confronted or the patient and family will enter a cancer pitfall.

Advice: Asking about prognosis helps you and your loved ones realistically come to terms with the type of battle you are up against and what time frame you are dealing with. Try your best to hear it as information, as an estimation, not as a fate or guarantee, because every patient is unique. Most important, the answer should never extinguish hope.

5. *What treatments are recommended, and what are their possible side effects?* This discussion should include the different options for treatment, such as different chemotherapy regimens or surgery versus radiation for prostate cancer, and which might be the best fit for you. You and your oncologist will take into consideration your medical condition, the particular side effects that you wish to avoid, treatment logistics, and what you are willing to do and put up with.

Helpful hint: When educating yourself about cancer therapies, there are no dumb questions! Make sure all your questions are answered by

the doctors, nurses, and other professionals at your disposal. And although friends and family undoubtedly mean well, it is best not to rely on them for medical information.

6. *Should I get a second opinion?* A second opinion may be helpful for peace of mind to confirm the results and recommendations you have heard. If you are dealing with an uncommon cancer, then a second opinion is essential. But it is not necessary if the recommendations are straightforward and the oncologists and treatment center in your community are well-established and trusted.

Helpful hint: The decision to seek a second opinion is a personal one. Trust your own judgment about your health care providers. If you don't feel you need one, then you probably don't. If one is medically necessary, your oncologist will suggest it or help make arrangements for one.

Advice: If you desire a second opinion, get one from a different type of treatment center than the one you will receive treatment at. If you intend on being treated at a large cancer center, obtain a second opinion with an oncologist in your community to see what he or she can offer. If you will receive treatment in a community setting, get a second opinion at a large cancer center to take advantage of any expertise that may be found there. It may turn out that the doctors cooperate in your treatment and you get the best of both worlds.

When planning for a second opinion, you cannot merely ask the first oncology office to "send all the records" and expect things to be in order.

Once you have committed to a second opinion, you must make *three calls*: (1) to the office of the oncologist you have already seen, asking for their records to be faxed to the doctor providing the second opinion; (2) to the pathology department or laboratory that processed your biopsies or tumor specimen, asking them to send the pathology slides and a tissue block (if requested) to the referral doctor or his or her pathology department; and (3) to the radiology department or office where you had your imaging tests performed, requesting that they make CD-ROM

copies of your X-rays and CT, MRI, or PET scans. Carry these CDs to your appointment for the referral doctor to review.

7. *Where should I be treated?* Advertisements abound in every media outlet in the United States about the superiority of one cancer center over another. The message that some centers have a cure that others do not is false hope and very detrimental to patients and families, willing to go to any lengths to help their loved ones with cancer. I have seen more than a few patients and families greatly inconvenience themselves for care, only to regret their decisions later. Sometimes more is less. Be aware that there are cancer treatment standards and guidelines that all oncologists follow (see the resources listed in appendix 2 to learn about these). On the other hand, there are reasons to travel for treatment as outlined below. As you make treatment decisions, keep in mind:

Surgery: Outcomes are better with experienced and highly trained cancer surgeons for most cancer surgeries, especially esophagectomy for esophageal cancer, the Whipple procedure for pancreatic cancer, and gynecologic cancers (ovarian, uterine, cervical). Patients with uncommon cancers, such as brain tumors, sarcomas, and head and neck cancers, should have surgical second opinions at high-volume centers before choosing a surgeon.

Chemotherapy: The administration of chemotherapy is supervised by a medical oncologist. Although every doctor is different, chemo is chemo wherever it's given. There is no good reason to travel further than you need to for standard chemotherapy unless guided by strong preferences for treatment setting or a specific doctor. Make this as convenient as possible. If you take toxic therapies far from home, you may enter a cancer pitfall.

Radiation therapy: You should feel confident about the experience of the radiation oncologist supervising your radiation therapy. Inquire about the age of the equipment at their facility, ensuring that it is updated and current. Ask about quality and safety measures and make sure that these are monitored throughout your treatments. Radiation therapy is often a daily venture over several weeks so only travel if medically necessary.

Clinical trials: Participation in a cancer research study or clinical trial

is the only way to access promising new therapies not yet approved for general use. They may be good options as the first treatment or later in the course of your cancer. Be aware that high quality cancer research occurs in the community as well as at larger centers. Inquire with the treatment centers around you by calling their research departments. You may also search on the Internet to learn what is available in any region: an excellent starting point is www.clinicaltrials.gov (and see the resources listed in appendix 2). Discuss the merits and risks of participating in a research study with your oncologist.

Helpful hint: All of your treatments need not be in one hospital. You may choose to have surgery at one hospital and chemotherapy and radiation at another without burning any bridges, offending anyone, or compromising your care.

Advice: Keep abreast of advances in cancer medicine by listening to the nightly news and by subscribing to reputable newspapers and websites (see the resources listed in appendix 2). Bring items that you hear about to the attention of your oncologist.

8. *What else should I ask? What have I missed?* In the frantic first steps of learning about the cancer you have and how best to treat it, you will forget about one of the most pressing concerns that go with the diagnosis: the psychological and emotional impact that cancer will exert on you and your loved ones. You cannot do this alone, meaning only with doctors and nurses. You must have a support system of family, friends and ideally at least one counselor or therapist who is skilled in caring for your spirit. You may also benefit from talking with others in a similar situation as yourself. If you do not nurture your soul along the way, you will run into serious trouble down the line. If your treatment center does not offer these services to you, seek them out (see the resources listed in appendix 2).

Advice: Regardless of how strong you are, I advise you to speak to a counselor about your life situation, hopes, and fears. You have no experience with being a cancer patient, and it is important to have a lifeline to call on when the need arises within you. The only guarantees about cancer are that it causes stress and that you need love and support to get through it successfully.

Cancer Pitfalls

Every cancer patient is at risk for a cancer pitfall. I have compiled this list during my twenty years' practice as an oncologist at a world-famous cancer center and an excellent community cancer center. Being aware of them is the best way to avoid them.

- ◆ *Thinking the grass is greener.* It is human nature to take for granted what we have in our own backyard. When it comes to cancer care, some people think they have to travel and inconvenience themselves in order to receive great care. Cancer care can be very stressful, inconvenient, time consuming and costly. My advice is to first meet with your local cancer providers and then seek a second opinion or treatment elsewhere if that suits you better.
- ◆ *Listening to others instead of yourself.* "You can't go to that hospital! My friend Jack's aunt Millie had a horrible experience there a few years ago." Sadly, this would be enough to steer some people away from a hospital or a doctor's office. A cancer patient has to be on guard for the well-meaning but often unhelpful advice of others, some they may not even know. My advice is to make decisions about care for yourself. Your family and loved ones should be part of the decision, but in the end they should respect your decision, whatever it is. It is your life, after all.
- ◆ *Accepting poor communication.* It is vital to have good communication with your oncologist. This may take some time, as in any relationship, but eventually there should be a familiar bond that enables you to express your thoughts and feelings about any aspect of your cancer care. If your doctor is too busy to address your needs, ask to set up an appointment with more time allotted. If that doesn't work, it may be time to interview another oncologist.
- ◆ *Accepting poor care.* Wherever you receive treatment, you should be made to feel that you are an individual and not just a number. Your caregivers should have an appreciation of your lifestyle and life situation and the challenges you may face outside of cancer. Your care should be compassionate and, to every extent possible, attentive to