

FULLY UPDATED 2ND EDITION

"Prepares the breast-cancer patient for any eventuality.  
Honest and extremely helpful." —*Harvard Women's Health Watch*



# Living Well Beyond Breast Cancer

A Survivor's Guide  
for When Treatment  
Ends and the Rest  
of Your Life Begins

Originally published as *Living Beyond Breast Cancer*

MARISA C. WEISS, M.D.,  
AND ELLEN WEISS

Fully Updated Second Edition

# Living *Well*

# Beyond

# Breast

# Cancer

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A Survivor's Guide

for When Treatment

Ends and the Rest

of Your Life Begins

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**Marisa C. Weiss, M.D.**

**Ellen Weiss**



THREE RIVERS PRESS • NEW YORK

This book cannot and must not replace hands-on medical care or the specific advice of your doctor. Use it instead to help you ask the right questions, make the right choices, and work more closely with your doctor and other members of your health care team.

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Published in the United States by Three Rivers Press, an imprint of the Crown Publishing Group, a division of Random House, Inc., New York.  
www.crownpublishing.com

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Previous editions of this work have been published as *Living Beyond Breast Cancer* by Times Books, a division of Random House, Inc., New York, in 1997, and by Three Rivers Press, an imprint of the Crown Publishing Group, a division of Random House, Inc., New York, in 1998.

Library of Congress Cataloging-in-Publication Data  
Weiss, Marisa C.

[Living beyond breast cancer]

Living well beyond breast cancer : a survivor's guide for when treatment ends and the rest of your life begins / Marisa C. Weiss, Ellen Weiss.—Fully updated 2nd ed.

p. cm.

Originally published: Living beyond breast cancer. New York : Times Books, 1997.

Includes index.

1. Breast—Cancer—Popular works. 2. Breast—Cancer—Psychological aspects.  
3. Adjustment (Psychology) I. Weiss, Ellen. II. Title.

RC280.B8W396 2010

616.99'449—dc22

2009020648

ISBN 978-0-307-46022-6

Printed in the United States of America

Design by Meryl Sussman Levavi

10 9 8 7 6 5 4 3 2 1

Revised Edition



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# Contents

Acknowledgments	ix
Introduction: Living Well Beyond Breast Cancer	xi

## **PART ONE**

### **Treatment Over, On with Your Life**

1. Over, Not Over	3
2. Support: Building a Network	15

## **PART TWO**

### **Additional Care Beyond Treatment**

3. You and Your Doctors: Continuing Care	33
4. You and Other Health Care Professionals: Allied Care Team	63
5. Tests: Peer, Poke, Prod	76
6. After Mastectomy: Re-creating a Breast—With or Without Surgery	109
7. Ongoing Therapy: Hormonal, Herceptin, and Other Treatments	141

## **PART THREE**

### **Coping with Side Effects of Treatment**

8. Fatigue and Loss of Energy	163
9. Understanding and Controlling Pain	173
10. Swelling (Lymphedema), Stiffness, and Skin Changes: Prevention and Management	205
11. Hair Loss and Nail Changes: Terrible but Temporary	230



12. Bone Health: Weaknesses and Strengths	247
13. Thinking and Remembering: Clearing the Fog and Sharpening Your Mind	268
14. Menopause and Growing Older: Hot and Cold, Wet and Dry	285

**PART FOUR**

**Caring for Your New Self**

15. Sleep: Restoration and Renewal	315
16. Your Immune System: Blows and Boosts	329
17. Sustenance: Nutrition and Supplements	338
18. Weight and Exercise: Gains and Losses	358
19. Intimacy, Sex, and Your Love Life	380
20. A Child in Your Future: Fertility, Pregnancy, Adoption	399

**PART FIVE**

**Preventing and Managing Recurrence**

21. Reducing the Risk of Breast Cancer	425
22. Recurrence: If Cancer Comes Back	443
23. Endings: Comfort, Closure, and the Circle of Life	459
Conclusion: Through Crisis Comes Opportunity	481
Index	487





# Acknowledgments

**W**e are deeply grateful to the many individuals who infused our book with their extra special blend of expertise, wisdom, spirit, humor, warmth, and compassion. The principal editor of our book, Lindsay Orman, was a pleasure to work with and did an absolutely amazing job. The care and attention and intelligence she brought to her task was beyond anything we could have imagined, or anything other writers we know have experienced. Emily Timberlake guided the book to its launching with thoughtful dedication.

So many voices are heard in this book: the people who shared their stories with us, the patients and their families Marisa has had the privilege of taking care of, and those who have shared our mission. Each person has contributed in a most personal way—eagerly or reluctantly, expansively or cautiously—with honesty and courage and verve—moved by the desire to help others. The book would have fallen flat without the voices of these many good friends. (Most of their names have been changed to protect their privacy.)

We want to acknowledge the diligence, dedication, and unflagging spirit of these many friends—it's impossible to thank them enough. We have also had help from a generous and distinguished group of professionals, and we want to thank them for their invaluable contributions: Zonera Ali, Robert Allen, Jayne Antonowsky, Rachael Brandt, Irene Card, Ned Carp, Carol Cherry, Robin Ciocca, Jan Clark, Martha Denckla, Dianne Dunkelman, Beth DuPree, Brenda Eastham, Barbara Fowble, Kevin Fox, Patricia Ganz, Paul Gilman, Robert Goodman, Generosa Grana, Jennifer Griggs, Barbara Hoffman, Clifford Hudis, Carole Kaplan, Harvey Karp, Rosalind Kleban, Anton Kris, Maria LoTempio, Geralyn Lucas, Cynthia Lufkin, Christina Meyers, Kathy Miller, Lillian Nail, Larry Norton, Kutluk Oktay, Steve Osborne, Edith Perez, Barbara Rabinowitz, Joan Ruderman, Andrea Rugh, Jennifer Sabol, David Sachs,



Romayne Sachs, Andrew Saykin, Mitchell Schnall, Sandra Schnall, Helena Schotland, Leslie Schover, Lynn Schuchter, Joseph Serletti, Gloria Shattil, Lillie Shockney, Robert Smink, Alan Stolier, Margo Weishar, Beverly Whipple, Eric Winer, Anna K. Wolff, and Liza Wu.

We are deeply grateful to our Breastcancer.org friends and Board of Directors: Ray Westphal, Amanda and Conrad Radcliffe, Jenifer and Jeff Westphal, Stevie Lucas, Lisa Kabnick and John McFadden, Peggy and Bruce Earle, Betty Moran, John Chappell, Barbara and Henry Jordan, Marjorie Findlay and Geoffrey Freeman, Sean Rooney, Barbara and Larry Cohen, Jill and Tom Nerney, Noreen Fraser, Patty and Gary Holloway, Aileen and Brian Roberts, Jerry Crowther, Glenn Crowther, Michael Hirschhorn, JoAnn and Joe Thomson, Roz and Chuck Epstein, Sallie and Charlie Grandi, Betty and Phil Harvey, Judy and Michael Mealey, Patty and Brian Holloway, Marge Tabankin, Richard and Maureen Yelovich, Jack Lynch, Elaine Thompson, Sarah Peterson, Erin Dugery, Kathy Schneider, Jessica Laufer, Denise and David Jordan, Sara Vance and Michelle Waddell, Fiona and Lee Yohannon, Lisa Petkun, Eleanor Davis, Shari Foos, Joanne Gillis-Donovan, Richy Glassberg, Sheri Lambert, Christopher Lyons, Jim Monastero, Susan Muck, Nina Montee-Karp, Larry Norton, Debbie and Sam Schwartz, and Hope Wohl. We want to extend a very special thanks to each member of our amazing Breastcancer.org and Lankenau Hospital teams, and to our friends from the Living Beyond Breast Cancer organization.

Always there for support, advice, comfort, care, and feeding, our families patiently endured our neglect and absence as we worked away at this book. Thank you, Elias, Henry, Isabel, and David Friedman, and Leon Weiss—you who waited with such good grace till all this book business was finished and still remembered who we were. Plus a big thanks to our other family champions: Alice, Eve, Nathaniel, Philip, and Stephen Weiss, and Adele Friedman; Aaron, Daniel, Lena and Rob Walker; Cindy Kling; John, Ella and Owen Spencer; Lauren, Sara, and Livia Weiss; Sara Manny, Adam and Ethan Weiss.

And we want to thank each other: for patience and good humor, for holding back and holding on, for drive, energy, and the right word. Close as we are, as mother and daughter, we have a new appreciation for each other's depths and gifts.

*Marisa Weiss and Ellen Weiss*







# Introduction

## *Living Well Beyond Breast Cancer*

**L**ife has thrown you a curve: breast cancer. What do you do with that hit? There is only one you—you are unique, after all—and you have worked so hard to protect your life from the threats and challenges of this disease: subjecting yourself to all manner of tests, procedures, surgery, chemo, radiation, and hormonal therapy, as well as countless medications and then remedies to deal with side effects. You may not have known what was up, down, or coming round the next corner. But here you are: done! It's now time to find your path through recovery to living *well* beyond breast cancer with the best information, solid guidance, new hope, and determination.

Remember, the purpose of all that treatment, all your work, was to give you back your life: joy, fun, comfort, meaning, pleasure, security. And the main reason for writing this book is to help you reclaim, rebuild, and reenergize your life, understanding that you are not alone, as you may have feared.

For sure, you are not alone. In the eleven years since the original publication of this book, the amount of medical information about breast cancer has more than doubled. Almost three million more Americans have joined the ranks of the three million already diagnosed with the disease—and major medical advances have given more and more of these people the chance to live *well* beyond breast cancer.

To make the most of the latest and greatest, you need to be in the know, informed by your link to medical care—your primary care physician. Easier said than done when the average length of a doctor visit has shrunk to seven minutes! So what do you do? Turn to resources available in print, online, wherever.



I wrote this book—together with my mother, Ellen Weiss, a writer and breast cancer survivor—to give you the best medical information and guidance to help you live as long as possible with the best quality of life, and to reassure you that you are not alone. Each page will help you understand the challenges in your path and provide you with many ready-to-use practical solutions to speed your total recovery and reclaim your life.

As a physician specializing in breast cancer for over twenty years, I have had the honor of taking care of thousands of women and men, and their families, facing breast cancer. It wasn't long after I started practicing that I understood the high level of distress that my patients endured on completion of initial treatment. Rather than feeling thrilled to have the breast cancer experience behind them, they were uneasy, often anxious: *What do I do now? Am I really cured? Is it safe for me to get pregnant? Can I take hormones? How do I get rid of extra weight? How do I manage the lingering side effects of treatment? How do I extinguish those horrible hot flashes? How can I stay asleep through the night? What should I tell the man I've just met? How do I deal with the fear of recurrence? What should I be eating, taking, and doing to reduce the risk of recurrence? Does my diagnosis put my daughter at risk?* My patients desperately wanted an intelligent, in-depth, reliable response to their questions as they moved from “I have breast cancer” ahead to “I am leading a normal life.”

To provide the best answers to my patients and to countless others beyond the scope of my practice, I started the program Life After Breast Cancer at the University of Pennsylvania twenty-one years ago, then a year later the nonprofit organization Living Beyond Breast Cancer. Both are still thriving today. But to provide a 24/7 resource for medical information for people worldwide, we needed something more. So in 1999, I started the nonprofit organization Breastcancer.org and have worked tirelessly at making it the number one resource in the world for breast health and breast cancer information and the most visited online community for the exchange of personal experience and expertise. I am immensely proud of these absolutely indispensable organizations and all of the wonderful, talented, and dedicated people who run them. Nonetheless, I am most aware of the power and comfort that only comes from a book you can hold in your hand, in the intimacy of time and place.



To provide you with your personal, private, and convenient resource on survivorship, we wrote the first edition of this book, *Living Beyond Breast Cancer*, in 1997. We have been deeply gratified by the many letters and emails we've received telling us how helpful, of the moment, our book has been. And we've been inspired by the demands for a second edition. Thus, we are extremely proud to present our newly titled, fully updated book: *Living Well Beyond Breast Cancer*—our way to help give you countless new opportunities for living a life of health and happiness.



# Treatment Over, On with Your Life





# Over, Not Over

*I never forget. Cancer has become part of my consciousness, part of my society. With every cancer death, my heart turns over. I'm always amazed at how other people take their lives for granted, as if they'll live forever.*

*I became assertive, someone I'd never been. I had a new voice. I said whatever I felt, like a cranky old lady. I knew nobody would stop me. I took my husband to an auction, my first post-treatment outing; I bought a few things, and he asked, "What are you going to do with this junk?" I exploded—I just couldn't help myself: "You should be thanking God I'm interested in something again!"*

*Right after treatment I felt very old, and lost, like I was looking into my grave. I got help, and it took a while, but I came around to feeling reborn, reinvented.*

## First Things First

**I**t's over. Treatment, that is. You've survived the initial ordeal. Now what? No one hands you an instruction manual as you go from under treatment to beyond treatment. From Geralyn Lucas' book *Why I Wore Lipstick*:

I make a list of everything I want to do. Should I quit my job, leave my husband, travel the world? I decide that maybe the most courageous thing I can do is to try to return to my regular



life, with the knowledge that there is nothing regular about it. Since everything has changed, how could we remain the same?

Maybe it's been two weeks, maybe two years, maybe twenty. But no matter how little or how much time has passed, the breast cancer experience is never *completely* over. Active issues, leftover concerns, and reminders can dog you every day or pop up just once in a while.

When it's all over, just when you think you should be celebrating this huge accomplishment, you may feel worse than you did during treatment. How confusing and disorienting. It starts to make sense when you realize that all parts of your life have been touched by the breast cancer experience. It may have taken over your life: bills, taxes, job, vacation, housework, and even children were put on hold.

Now, with the end of treatment, you have to adjust back to normal. But is that really possible? The fact is, life changes after breast cancer treatment. Normal will never look and feel exactly the same. The only thing you can do is to go forward with the rest of your life, one step at a time. You have to find and create your new normal. Many of you speak of how changed you are, almost renewed. This is my hope for each of you as you read my book: a chance to renew your life, one that brings you comfort, meaning, joy, fun, and hope.

Throughout this book, I will help you understand the challenges and identify the solutions to help you live well beyond breast cancer. We'll start by looking at the issues you'll begin facing immediately after treatment.

## Challenges

**Y**ou can cope with this new life. Countless women have done it and are doing it. When you feel as wobbly inside as a new toddler or as stiff and creaky as a little old lady, draw strength from these other survivors. They understand that your cheery front is covering up the vulnerable, exhausted you. And unlike many others, they appreciate this new you. In time, you will, too.

When chemo is all over, the supportive care is over, too. You're worn down by the accumulated side effects of all your treatments with nearly

no pick-me-ups. That's when many of my patients tell me they barely feel as if they're among the living.

## Separation Anxiety

After months or more of concentrated attention on you, your illness, and your therapy, you come to that moment when the days mapped out for you by hour and procedure come to an end. Many of my patients felt thrown into an emotional limbo: “‘Come back in three months,’ the doctor said. I felt like I was *dumped*, and I was so frightened,” Janet recalled.

Your health care team provided emotional support you may not have fully appreciated when so many things were happening to you at once—and at the end of your whirlwind treatment experience, you suddenly miss it. “I felt more scared after treatment was over than I did before it started,” said Genia. “During treatment I had peace.” The scheduled routine and plan of attack were very comforting, and now they're gone. “When treatment ended, I didn't know what to do with myself,” Christy recalled.

With the end of treatment, your family and friends generally conclude the disease is beaten and done with. There's usually a shower of congratulations and celebrations. But you don't feel like yourself. You're still feeling disoriented and conflicted: profound relief and exhilaration mixed with uncertainty and forced enthusiasm. “I dreaded going to my own end-of-treatment party,” one woman said. You're expected to feel great and back to normal and ready to get on with your life, but instead you feel lost. Separation anxiety takes on new meaning.

## Lingering Concerns

As you move forward, a string of troubling questions can pollute your peace of mind:

- What do I do now?
- Where's my support?
- Can I really get along without my doctors and nurses?
- When do I get to see my doctor again?



- Now that I don't see my doctors every day or every week, how do I get all my questions answered?
- What about that new treatment that I just heard about on TV—does it apply to me?

Flooded with these kinds of questions, you can feel fearful and insecure—making you wonder: *Can I ever handle my life on my own again?*

## **Cancer Worry**

Even if you've been discharged by your doctors, there's likely still that cancer worry in a corner of your mind: "Every time something hurts or I get sick, I think the cancer has come back."

You may also fear that the cancer might grow back because you are no longer doing anything active to keep it away. Annamarie's coping mechanism was ceaseless activity: "I got depressed . . . cancer was still on my mind twenty-four hours a day. I started looking for things I could do, things I still had to decide about, like diet, exercise, tamoxifen, anything I could possibly do to avoid recurrence." You may also worry whether the treatment really worked, whether you're fit to be discharged.

Cancer worry is something you must learn to manage and live with. "Like a whale that moves into your living room" is how one patient described her lingering fears of breast cancer. "Over time, the whale gets smaller, but it never quite goes away completely. A tenant you can't get rid of. Maybe it gets down to the size of a magazine rack. Once in a while you bump into it, and sometimes it swells up into your face again, like when you have a mammogram and they call you back for extra views."

Cancer worry dogs most of the people I take care of—a little or a lot. They carry it with them indefinitely, even as year after year proves them disease-free. Over time, the burden gradually gets processed, loosens its grip, and gets put in its place.

## **Denial**

Quite a number of people shut the door after treatment, saying cancer is over and done with. That may be the only way for them to deal with





what's happened. Five, ten, or more years may pass without processing that cancer experience, leaving important issues unresolved and the accompanying fear and anxiety buried deep. They may go on to other things without any difficulty, living their lives without active fear.

Then along the way, something may happen that sets things off:

- A suspicious mammogram
- A bout of arm edema
- Heavy media coverage during Breast Cancer Awareness Month
- A close friend or family member diagnosed with breast cancer
- A daughter reaches her mother's age at diagnosis.
- The recurrence of, or a new, cancer

These events jolt them from the wall of denial where they'd previously sought refuge and into a harsh new reality where buried emotions may erupt with destructive force.

## **Low Energy Versus High Expectations**

You're likely to be bombarded by heavy expectations upon the end of treatment—from yourself and others. Everything you put off till you got your strength back is waiting for you, but you're still dogged by fear and fatigue. You just can't handle it!

The uncertainty of the past, present, and future is still with you, overwhelming and exhausting you. "Not knowing what will be is worse than knowing the worst. It was a living hell." The hardest thing to deal with is this uncertainty—it can consume all your energy.

Even high-energy women are laid low. "I gave up on my superwoman image. It was costing me too much." Some of these formerly high-powered women feel discouraged, useless, and unable to accomplish anything important. "It takes all day to do one thing!" You may be able to do little more than finish up treatment and begin the recovery process.

So there you are, projects waiting, not knowing where to start, still exhausted. And there's your family, waiting for you to take over again, looking for the attention they've been missing all this time. Christy recalled, "I had to act like I could just flip a switch and not be a cancer patient—as if it were possible."



Family members and close friends can only meet some of your needs some of the time. By the time treatment is over, their energy, goodwill, and empathy may bottom out. For Donna's husband, the issue was simple: "I don't want to hear about your illness anymore. Put it away. It's done." "If there are no 'support receptors' in your family, you may not be able to put them there," commented Molly. Support can be as much a part of your cure as anything else; unfortunately, you may need it most when you find it dwindling.

## **Depression**

Is it any wonder that many people become depressed after their main treatment is over? You are most vulnerable to depression at the time of diagnosis and again when your treatment is completed. "I thought I was dealing with everything just fine, but I wasn't. I couldn't. Everything fell in on me. I became clinically depressed shortly after the end of my chemotherapy."

While depression upon diagnosis seems obvious, experiencing depression at the end of treatment is unexpected and counterintuitive. But it's pretty common to be overwhelmed with feelings of helplessness that can peak after treatment is over. It's normal to find yourself angry, sad, and depressed in this period of transition.

There is some good news to help move you through this funk. Time alone solves some things, and there may be some calm after the storm. But you can't just kick back, expecting, waiting, and hoping for things to get better on their own. Don't neglect troubling symptoms. Now is the time to *take care of your whole self*. With this book and through Breastcancer.org, we'll help you find and create small and big opportunities for recovery and renewal.

## **Telling**

Disclosing your breast cancer experience can be hard or easy. Sometimes it just happens. "I didn't want to talk about it, and then this woman I'd just met at a party mentioned her work with breast cancer survivors, and I found myself telling her things I'd never told anyone, years and years after I'd been through with it. Maybe I was just waiting for the right



moment, or the right person.” Molly was a well-balanced, self-assured woman who surprised herself with the release of this flood of suppressed feelings.

For Sylvie, telling everyone she had breast cancer felt like a responsibility. “I don’t think it’s good for anybody to be quiet about this disease. Not if we want to find a cure, find the money for research, get women active in the cause.” Lily came from a prominent business family in a major city, and telling her story brought her into the public eye on TV and in the newspapers. “I was deluged. All kinds of organizations asked me to speak to their members, and I did. I believe a lot of women went and got mammograms because of my story, as they did with Betty Ford, Happy Rockefeller, and Nancy Reagan.”

Some of the women I’ve worked with are so self-conscious about their illness, they feel almost as though they’re wearing a sign and they need to explain: “I stood there in the supermarket, telling this sympathetic check-out clerk my entire history.” Others, however, mull over whether or not to share this painful experience with their closest friends. And how do you tell a new boyfriend or lover? (See Chapter 19, on intimacy.)

Others, like Gena, prefer to stay quiet. “I decided not to tell my friends—and my doctor told me not to. This was many years ago. I was very young. I didn’t want people clucking over me, feeling sorry for me, being nice to me just because I’d had breast cancer. I kept my mouth shut for twenty years. It was a different time.” Betsy would have agreed with Gena. “People ask me, ‘How *are* you?’ with this woeful eye. Like I’m so brave but really dying. Or they say, ‘How good you look!’ with real surprise, as though I should look half dead. Or I *do* look half dead and they lie through their teeth and say, ‘How great you look!’ Who needs all that?” No one really likes a pity party.

Of one thing most of you are sure: you don’t want friends telling you sad tales. Annamarie would stop people midbreath and say: “I only listen to stories with happy endings.” How can reasonable people be so thoughtless with misplaced reassurance? Maybe they think they must say something but don’t quite know what or how. Or maybe they’re expressing their own fears. Whatever the reason, these stories about sickness and death that others may want to unload can hurt. Stop them the moment you sense what’s coming. Use Annamarie’s “happy endings” line. There are plenty of stories with good outcomes for you to hear.



Telling may help others deal with your situation but may do little to help you. You're the one who can end up giving support, often getting the energy sucked out of you to help someone else. Still, most women do tell their friends and co-workers. "I don't like to be with people who don't know," said Florrie. "It makes it so much easier at work. And everyone is so supportive and kind, in many loving ways. Maybe I talk about it too much." Ginnie told her friends but she felt she had to hide it at work because she was worried about keeping her job and her health insurance.

## Solutions

**M**any of you come away from the breast cancer experience with a clearer view of what matters most in life. Cancer has changed your life. And maybe not surprising to you, but surely surprising to people who've never had cancer, is the repeated comment "My life is so much better now," or "We're a much closer family now than we ever were before." That does not include, however, the individuals and families that come apart, unable to manage this crisis. Between these extremes are the people who chug along much like everybody else, dealing with everyday issues and keeping their past health problems on a short leash.

### **The New You**

"I've chucked so much garbage." "I don't suffer fools." "I take risks I never did before." "I take better care of myself." "I'm more assertive." "I don't worry about unimportant details." "I won't let people take advantage of me." "I'm able to make changes I always needed to make." "I stop and look around at new things." "I'm much kinder to myself." "I take nothing for granted." "I don't waste time."

So many people who have been diagnosed with breast cancer have said to me: "I want to find meaning and fulfillment in each day. I want to build memories." Workaholics take time off. Trivial matters are seen for what they are. "I used to get all worked up in traffic; now I'm happy just sitting there." Laughter and merriment are prized; hugging takes on major importance.



Many of you say you no longer put off what you really want to do. “I’m doing things I’d talked about doing for years: I’m going to graduate school, for starters,” Vivian told me with pride. Just don’t take on too much: “I’ve been trying so hard to do all the things I enjoy. It’s too stressful—it’s wearing me out!” Jenny said with irritation. Knowing your priorities will help you save your energy for the things that matter to you most.

## **Managing Expectations**

For self-preservation and self-defense, you have to control and protect yourself from unreasonable expectations. Don’t let your family’s expectations for you get out of hand. Keep a reality check on work expectations. Even more important, don’t expect too much of yourself. Stop comparing yourself to others and judging your performance.

You may know someone who sailed through treatment, went back to work full-time the week after surgery, and seemed to take complete care of her family, job, house, and community obligations. Unlikely—but so what! If that’s not you (or most women I know), it’s not relevant. Stop measuring yourself against people who may be driving themselves into the ground. Keep your head, and make your family see you as you are and treat you as you need to be treated. Push back on expectations: saying no to a new request or demand often means saying yes to your recovery and renewal. Throughout this book, we’ll be giving you solutions for managing expectations and setting reasonable limits.

## **Fortifying Your New Support Network**

There is no reason to go through breast cancer treatment and recovery alone. That kind of isolation without support can itself be life-threatening. Your psychological needs deserve as much attention as your physical needs. You worked extremely hard to get the best treatment possible to protect your body against breast cancer; now it’s time to take the best care of your emotional needs and the whole you.

Other people who have experienced breast cancer can provide you with indispensable information and support. You don’t need to start from the beginning and explain everything all over again—they



understand. Florrie explained: “I decided to go someplace where others knew it wasn’t over, where I could tell this complete stranger about my history and feelings, knowing what we share.” This shared experience has been the foundation of many beautiful friendships.

For more on building your support network—whether online, by phone, in a group, or through a therapist—see Chapter 2.

## **Get Answers to Your Questions**

You need to acknowledge your fears, rid yourself of uncertainty, and set straight your misconceptions. Start by writing them down, putting your biggest concerns at the top of the list. Assign a go-to person or expert next to each entry. For example, here is just one of many steps you can take to get answers to the following sample questions:

- *Does my diagnosis increase my daughter’s risk?*  
~Talk to your family doctor and make an appointment with a genetics counselor to review your full family history and see if genetic testing would be useful.
- *How do I talk to my daughter about breast health?*  
~Check out my book *Taking Care of Your “Girls”: A Breast Health Guide for Girls, Teens, and In-Betweens* to learn how to get this delicate conversation going and to become knowledgeable about the kind of information she might ask about.
- *What’s my risk of recurrence?*  
~Talk to your oncologist and find out your chances of staying cancer-free and your risk of recurrence. Also ask what additional steps you can take to maximize your chances of doing well.
- *What about that new treatment I heard about on the news—would I benefit from it?*  
~Breastcancer.org presents research news every day along with a Take-Home Message, making it easy to discuss this with your doctor.

Once you’ve written out your concerns and ideas for addressing them, follow through to get the information you need. Answering your



questions and replacing myths with facts is very therapeutic and will expedite your recovery.

## Taking Care of Yourself

Stop and give yourself credit for the hard, hard work you've done to fight for your life.

Now you have to take the time to heal. Push back. Indulge yourself. Give yourself a reward. Treat yourself better. Go on a vacation. "Each year on my anniversary I am in a beautiful place, celebrating life," Jo told me. "If you feel like crying, do it. If you need help, get it. Give yourself time—the biggest gift—for recovery. Don't let anyone make you feel guilty, and don't take on things you're not ready for. It isn't as easy as one might think to put yourself first. Grab what you want and need. I was too brave, always protecting others. Now it's my time."

No normal human being has the time or emotional wherewithal to process the whole breast cancer experience until the major impact of treatment is over. This is one more reason why the end of treatment is such an unexpectedly hard time. "My stress and anxiety became more apparent to me after I finished therapy than when I was going through it," Donna reflected. "I was given this really big test—and I passed. I can wake up and not think first thing about cancer. I can go to work and feel good all day. There is life after cancer! I am who I am; I am not defined by that disease. Breast cancer is behind me."

## Moving Forward

**I**t's important to put the recent past in perspective as you focus on a healthy future. "I didn't choose this disease and I wasn't going to let it control me. I had a good life before, and this bad thing wasn't going to change my life for me. I was going to make life good again," Gena said. "You don't want to disappoint yourself; you don't want to let yourself down. So you make yourself come through. That was thirty years ago—and it has been good!"

You did everything you could do to become cancer-free using the best treatments available to you at the time. Moving forward, you will



continue to do whatever you can to be healthy. Of course no one is perfect—we can't kick bad habits instantly and completely. But we can set goals and start somewhere.

Form your own conclusions about what your life beyond breast cancer should be, because no one else can supply the answers you need. Many of you want to think of and plan for your future but are afraid to presume that you *have* a future. Don't let fear stop you. *You do have a future*, and you're not daring fate if you think about it and plan what you want to do for yourself, your family, your children, work, vacations, or retirement. You're no different from anyone else on this score, although you may bring a sharper appreciation for the idea of "future." And it's reasonable to hope that your future will mean years and years of a good life.

Remember: your future is built one step at a time. Step one is finding and creating your new normal. How long it takes to get there and what it's going to look like when you get there will reveal itself along the way. Progress isn't always steady, with one day better than the day past. You can take three steps forward, one step back, no step the next day, and then a side step before you make more forward progress again. There is no fixed number for how long it takes to get back to normal. My rule of thumb is that it takes at least as long as the time from diagnosis through the end of treatment.

As long as your overall path is forward, take comfort. Your patience and persistence will pay off. Build momentum whenever you can. Along the way you'll be rewarded as you see glimpses of your old self and piece together a new vision for yourself and your future.





## Support: Building a Network

*I found a woman from Johannesburg, South Africa, who is going through the same chemo regimen I went through and we connect two to three times a week on the Breastcancer.org discussion boards. I'm a big help to her and she gives me a lot of positive feedback.*

*The Breastcancer.org forums have intelligent and savvy women who are really well informed about breast cancer issues. No matter what their educational background, they know what they're talking about when it comes to breast cancer, like how to read a path report and that sort of thing. They can really answer any question that is bothering me.*

*I needed to go someplace where others knew it wasn't over. It was like going through an invisible wall, with cancer people on one side and everyone else on the other. I didn't need to explain—they understood. That was my support group. They helped me learn to trust my instincts, to take care of myself—nobody else can or will. That's what a support group does.*

*Getting someone at the other end of the phone was a godsend when I was lower than low, scared by my own shadow, and desperate for a glimmer of hope. That hotline volunteer performed a lifesaving 911 rescue mission for me.*

*Of all the resources I had, access to my chat room was the best. I could sound off without worrying about consequences, and the practical advice we shared was amazing.*

## **First Things First**

**M**any women believe that the stress in their lives may have caused their breast cancer. While no clear link has been found between stress and cancer risk, stress undeniably pollutes your quality of life. And dealing with breast cancer will definitely increase your stress. The good news is that stress is one of the things you can do something about. Support is *the* big stress reliever.

No matter what the source, support is your safety harness on the breast cancer roller coaster. Don't think you can manage this ride alone; don't even give it a try. It's too dangerous. Stubborn bravery earns you no points. This is not a game; this is no time to play the hero. This is your *life*. Now is the time to reach out for sustenance, to ask for and accept offers of support.

A lifeline of support can come from others like yourself, talking about what's on your mind, what you don't understand, what worries you, what scares you. Expressing all this out loud, in person, by phone or online, to someone else, can be very therapeutic. You need to hear that you are not alone, that other people in the same or similar situation have similar feelings. You also want to take the opportunity to profit from each other's personal wisdom, expertise, and example.

"My doctor said to me, 'You know, I happen to have here a patient that had the same kind of cancer you have, and hers was actually worse. And she talks about this, so I'm free to talk about it. It was spread throughout her body, and that was fifteen years ago and it's been gone since. The drugs these days are very powerful and helpful, and I know she would like to meet you.' I said, 'Wow, then this is not a death sentence!' And she said, 'Oh no, you're going to be fine.' Seeing someone who had been through it all, so happy and healthy, and so many years out, was a defining moment of hope. And that's what I want to do, talking to patients, imparting hope that way."

This chapter will focus on infusions of much-needed support.



## Challenges

**Y**ou may insist on doing everything on your own, and forcefully assert your independence and competency—in an attempt to take back control of your life after feeling so inadequate and disempowered by the whole breast cancer experience.

### **Running on Empty**

Are you finding leaks in your “energy tank” unrelated to the immediate demands of breast cancer treatment and recovery? Think about all the energy it takes to reveal your diagnosis to others, explain your situation, justify (and sometimes defend) your choices, reassure *them* that you’ll be okay, and then have to support *them* as they deal with their own emotional reaction. If it were just your children and people in your close support network, fine—but if it also includes co-workers, neighbors, acquaintances, and so on, you may find yourself entirely depleted. Or you might find yourself up against people in denial, pretending everything is okay. They can’t get the word *cancer* out of their mouths; to them it’s “the Big C,” too hard to even think about or imagine. A deep and wide feeling of isolation can envelop you.

The drain on your precious time is also exhausting. Think of all those “time robbers” who talk way too much, dragging out a simple conversation, refusing to get off the phone, calling at the wrong time, failing to recognize the hints and clues that you really, really gotta go. Are you also stuck with people who insist on talking about your health issues during what was supposed to be a relaxing get-together? They are all too much! You find yourself heading the other way, or lying, even hiding, to keep away from them. But as you avoid more people, your isolation deepens; what you really need is more support.

### **Buried Feelings**

Even if you have people within your family or support network to talk to, it may be hard to tell them what scares you. “My family needs my



support! I just can't burden them." You may be anxious to protect your family from your own worst fears, to avoid adding to their stress. It's almost as if you have an unspoken agreement to hide your true feelings.

Sadness and fear may have been buried, repressed, denied. "I was afraid that my sadness—especially if I talked about it—would make my cancer come back." It takes considerable emotional energy to keep all that trouble buried—energy better spent someplace else in your life. Stress that isn't released in some way or other can be destructive.

### **Loss of Confidence**

Your energy and ability to connect with other people—including close family and friends—may be severely limited by your feeling fatigued, disconnected, depressed, and anxious, making you too self-conscious, embarrassed, or exhausted to reach out, answer the phone, or write back with an update or even a quick thank-you. The way you think you look might also stop you from connecting to others: nothing seems to fit and you imagine you look awful, your hair is a mess or your wig is out of place.

It's unlikely that people perceive you as you see yourself. But even if all your self-doubts are true, it's still not sufficient reason to hide. Avoiding social interaction, refusing assistance, or not reaching out for help just when you need it most is a big mistake. You need the support that much more—and you're less likely to ask for it. A vicious cycle. More isolation.

### **Rejecting Support**

Unfortunately, only a small percentage of cancer survivors take advantage of support networks. Reaching out for help can be as great a challenge for some people as coping with the concept of cancer, particularly if there are issues to deal with that go beyond the issue of breast cancer. Many are used to being caregivers, not takers. Joining a support group calls for an overhaul of their whole value system and "method of operation."

Some people believe they must work out their problems on their own. It may be a function of denial; they push their anguish out of their



mind. “I got it. I had it cut out. I don’t want to talk about it again.” And they don’t, thinking, “If it ain’t broke, don’t fix it.” But many of these same women remain terrified inside, and breaking through this protective barrier—which can be eating away at their lives—may require professional help.

## Solutions

**T**he power and appeal of a support resource or network is that the stress and isolation that have become such a burden to you can be alleviated. Connecting with other people who’ve faced the same or similar challenges can be your greatest source of support—they know what breast cancer is all about, they’re familiar with the breast cancer lingo, they feel comfortable talking about the issues, and they know how to get back the energy no one can spare. Just finally acknowledging your fear and telling it to somebody else can diminish that fear and make you feel better. “You can explore ideas that surprise you, stimulate you, and move you to understand yourself as you may never have before.”

### Stop the Leaks

You need people in your life who can support you right now—not people who need you to support them. Pity-partiers and time robbers only drain your precious energy when you need it most. It’s much better to minimize your exposure to time robbers or avoid them entirely, at least for now. Staying away from some people is easier than others. It’s particularly difficult if the worst offenders are the people closest to you, like your mother, sister, or mother-in-law—the same people you may also be most dependent on in your everyday life.

Here are some steps you can take to manage personal encounters:

- Only accept obligatory invitations.
- Prearrange to leave social and family events early.
- Don’t engage in, escalate, or intensify a difficult conversation, especially if it’s one-on-one.



Just because someone says something to you doesn't mean you have to respond to it. Let any thoughtless comment roll out of that stupid mouth and onto the floor and into an imaginary garbage can.

For other types of communication, here are some suggestions:

- Choose mostly forms of communication that you can answer whenever you want: email, voice mail, Facebook, online discussion, or bulletin boards.
- Let emails and voice messages rest for at least a full day before responding (your instant answers will invite too many more of these unwanted emails, guaranteed).
- A note on nice stationery or note card via snail mail—in response to a phone call, email, or letter—works beautifully.
- Keep your responses polite, nice, simple, and short.
- Do not provide extra information and other hooks that will give anyone a reason to delve in deeper or trigger a whole new unwanted conversation.
- Politely set expectations and limits (only happy stories).
- Learn nice but firm ways to say “no, thanks” (e.g., “Thanks so much—but sorry, that doesn't work for me right now”).
- Avoid promises or new commitments.

Later on, you can reevaluate your approach—but only after you've made your way through the jungle of treatment and recovery.

## **Build Alliances**

Shaping people's perception of you is always a challenge—particularly during and after breast cancer, when you might feel like you're being watched or judged. You can influence how you are perceived. You may need to do a little caucusing with the people of influence in your life. Establish alliances with people who are in the know and are pleased to follow your wishes and ground rules; let a few of them know what's on your mind, what you plan to do, and how you want people to respond to you. Then ask for their help in getting the rest of the people in your life to follow along.



## Tap into Support Networks

A support network will help you restore the confidence that the diagnosis of cancer may have shattered, reclaim the control of your life that cancer has stolen from you, and draw you into a community of understanding people with whom you can quickly and fully connect. Together you can share good and bad news, exchange practical advice, make each other laugh, and work on your recovery and renewal. If you're an information junkie, searching out everything and anything about fighting cancer and staying healthy, support networks can be a great educational resource. (But you must still vet all information for yourself.)

Support comes in many different forms: support groups, online forums (including chat rooms, discussion boards, and bulletin boards), and telephone hotlines. You can pick more than one from the menu of options, and later change your lineup and mix of resources as new needs and preferences emerge. It's easy to be flexible with your choice of options, as support networks and groups are free to you—a compelling factor after the cumulative expense of this illness.

### *Online Support*

Online forums can do much of what face-to-face support networks did for people in the past. With the widespread availability of the Internet, people dealing with a burning question or serious health challenge have learned to make the support come to them, rather than have to travel out to get support.

The ability to communicate across vast distances—at any time of the day or night, according to your evolving needs and convenience—and to find comfort and support as well as knowledge, clarity, and confidence when you need them is a unique advantage of the Internet. It's hands down the fastest and easiest way to connect with other women who share your concerns. In the beginning you have your own screen name, which becomes your “official” online identity. But then over time, community members may choose to get to know each other further, share real names and contact information, and sometimes meet offline. Friendships—perhaps as groups or clubs—may develop.

Many online communities have a moderator, who oversees, guides, nurtures, and manages the various questions, activities, and dynamics. The



moderator (there can be more than one) helps facilitate positive interactions between the people utilizing the forums; at times she may intervene, resolve disputes, and establish calm if things heat up or boil over.

Once you sign up within a particular website's online community, you can participate at different times and in many different ways:

- **Right away**

You can connect at the same time with other people (live, “real-time,” or synchronous communication) primarily in a chat room. You have a conversation by typing online, similar to what you would have with voices by phone conference call.

- **Now or later**

You can connect to other people at the same or different times (asynchronous communication) through discussion boards, blogs, journaling, photo exchange, and bulletin boards. In each of these forums, you post your comment and others respond to it at their convenience. Sometimes you might jump into an ongoing conversation by posting a comment, and get included in a lively discussion. Or you can visit the forums, read the posts, and observe the dynamics without any direct participation.

You have countless online options for support at your fingertips. Breastcancer.org has the largest and most active online community of chat rooms and discussion boards on nearly every subject relating to breast cancer, operating twenty-four hours a day, seven days a week, and is thus a great place to find and connect with someone who matches your unique situation—whether in your local community or at a distance. It's a safe and nurturing place to get practical information and real support.

You have to poke around and find the forum and format that serves you best. While the huge menu can be overwhelming, flipping around from your home computer is certainly a lot easier than checking out a long list of face-to-face support meetings. Plus, you're never stuck in any online forum; you can drop in and out of the forums whenever you want.

These are some of the most popular online options for support:

**DISCUSSION BOARDS.** Discussion boards contain conversations started by the online community, conversations that get recorded and accessed





whenever a particular member gets online. Advice is shared and problems are worked out together. “These people understand me, more than in the real world!” one Breastcancer.org participant commented.

Breastcancer.org’s more than seventy discussion boards contain about two hundred thousand different conversations. Here are a few examples of topics they cover: Just Diagnosed, Waiting for Test Results, Help Me Get Through Treatment, Fitness and Getting Back into Shape, Humor and Games. Visitors are welcome to join any of them. Take your time looking for discussions most aligned with your interests and style of communication.

**CHAT ROOMS.** In chat rooms, everyone talks by typing in real time. There can be a few or many people in the chat room, who jump in and out of the conversation. The depth of conversations tends to be light, because the conversation flows so fast and topics shift very quickly. There is more opportunity for slower and deeper discussion when only a few people are in the chat rooms during off hours.

**YOUR PERSONAL NETWORK.** You can also utilize an online community to organize your own network of family and friends—particularly useful when you need help with day-to-day tasks such as: providing a ride home from a test or doctor appointment, cooking a meal for your family, or watching the kids when you’re in a pinch. In a typical scenario, one of your close friends or family members would facilitate scheduling of to-do list items. A system that spells out actionable to-do items takes the burden off you to ask people for needed help and instead allows people in your network to select tasks that best fit their schedules and talents. Breastcancer.org and Caringbridge.org offer this service.

**PERSONAL BLOGS AND JOURNALING.** A blog is like an online open diary where you can explain your diagnosis and treatments and share anything else you’d like with family and friends. Keeping a blog can help relieve the burden of explaining things over and over. It can also provide an easy way to share the facts of breast cancer with loved ones, as the basis for what you’ve done, what you’re doing, and what you’re planning to do. You can save a ton of time and energy by communicating this way.



Another big bonus to writing a blog or keeping a journal is the satisfaction, self-awareness, and emotional relief that can come from writing down your thoughts and expressing your feelings. A word of caution, though: when you're experiencing a rapid flow of intense new feelings, it can be very difficult and emotional. Go slow to avoid feeling overwhelmed. You may also want to journal more privately. (Some of the women I take care of have an offline journaling group that's facilitated by a writer and guided by a psychologist.)

**ONLINE PHOTO ALBUM OR SCRAPBOOK.** Sharing photographs, milestones, and memorabilia is a great way to show support and be supported. You may want to put up photographs or other images to highlight a reunion, vacation, or another special occasion to go along with your online posts. For example, Breastcancer.org community members often organize offline get-togethers and then share photos after the event.

### *Offline Support Groups*

A face-to-face support group is a natural way to get support if you like to talk and listen, to share your feelings, process your thoughts, tell your stories, and help solve some of your and other people's problems. "People who care about you won't let you off the hook. They urge courage and honesty—but they do it with great kindness and affection. It can be magic, what goes on in a group." They really want you to think about yourself and devote more attention to what's happening in your life. "It's time you came first." The social network of a breast cancer support group can help you overcome some of your fear of cancer, reestablish control over your life, and connect you to an understanding community of individuals.

Support groups may be organized by your personal situation: breast cancer stage (newly diagnosed, dealing with recurrence or advanced disease), treatment status (under or over treatment), or hospital affiliation. Some groups may be based on a theme, emphasizing a personal interest or concern, such as "How to Eat Organic" or "How to Talk to Your Children." It can be topical, pragmatic, or spiritual, focused, or wide-ranging. Or group members may have nothing else in common with each other besides this one thing, cancer.



Besides word of mouth, the most likely way to find a support group is through your treatment center or a local nonprofit organization such as the Wellness Community, Gilda's Club, or SHARE. Some women organize support groups on their own if there are no existing local options available.

Group meetings are usually scheduled once a week or once or twice a month for a one- or two-hour session, usually on a weekday evening. Sometimes groups allow an open-door policy, allowing you to attend only the meetings that interest you or fit your schedule, but some groups require that you attend most of the sessions in a series. There is no perfect-sized group, although many people have strong opinions about what works best. Basically, you want to have enough people to keep the conversation fresh, interesting, varied, and energetic without sacrificing a sense of trust and familiarity.

Participation in a support group can be a powerful experience, and only a trained facilitator can contain that power and deflect and channel it for the benefit of all present. The facilitator is usually a therapist or social worker who helps:

- Guide the progress of the group
- Keep the focus on the goals, spirit, and purpose of the group
- Make sure that everyone has a chance to participate and no one is allowed to take over or be put on the spot

The facilitator should be attentive, aware, authentic, knowledgeable, caring, practical—and able to create a therapeutic, tolerant, nonjudgmental, broad-minded environment so people can open up and share—and trust that their feelings, thoughts, and privacy will be respected. Occasionally, the facilitator must step in to handle challenging situations. When buried feelings finally start to come out, they may be disturbing to the person expressing them, as well as to the other people listening. Individual counseling may be recommended for people who are struggling or troubled. If conflicts emerge, the facilitator may need to enforce community rules to keep the group dynamics rolling smoothly and maintain positive interchange between group members.

Still, support groups don't work for everyone. "I couldn't sit there and listen to all those painful stories. I had enough to do just taking care



of myself; I couldn't deal with other women's complaints, as justified as they might be. I felt I was doing better than they were, and they were dragging me down."

### *Individual Counseling*

Millions of people with and without breast cancer benefit from one-on-one support with a mental health professional, which might include medication. The therapist could be a psychologist, psychiatrist, social worker, member of the clergy, or other empathetic individual. For your physical battle against breast cancer, you had a radiologist (to read the mammogram and other tests), a pathologist (to analyze the breast and cancer tissue), a surgeon, a radiation oncologist, and a medical oncologist. But most likely you've had no professional help for your emotional concerns. It's probably time you got it. If you decide that individual counseling would be helpful to you, ask your doctor or other members of a current support group or online community for recommendations.

### *Self-Help Groups and Other Options*

You might seek support from a nontraditional peer-led support group network, like a coffee klatch, a book club, or a self-help group. These often have more participants than a typical support group, plus an easy come-and-go arrangement. "It's another level of friendship. We deal with loneliness, isolation, fear—many of the issues I explored in the hospital-sponsored support group I was part of for a year. While it provides emotional support, nobody 'spills her guts' here. We tend to keep a little distance. We bring in speakers and focus more on education than unloading."

### *Help for Partners and Families*

There are also support groups for partners or spouses who are dealing with the stress of their loved one's breast cancer situation. Some centers offer support groups specifically for children. Partners often are in real need of ventilating the concerns and tension that they are unable or reluctant to express at home to the person who is actually suffering from breast cancer. Hospitals or wellness centers are generally the organizers of these groups, having a large pool to draw upon. Lesbian



partners may have a harder time adjusting to this type of support group, because most participants are men, even though many of the issues are shared. Specialized chat rooms and discussion boards are also available for partners of people dealing with breast cancer.

## Selecting the Best Source of Support for You

Experts say that a take-charge person tends to recover faster and do better in the long run than someone who feels like a victim, stuck in disaster and unable to take constructive action. A support group is one important way to take action and propel yourself forward—with others, not alone. But not everybody should join a support group; not everybody is ready for a support group; not everybody needs a support group. There are people who get all the support they need from their existing networks of family and friends and online forums. And there are others who might benefit much more from one-on-one therapy.

### SUPPORT GROUPS ARE NOT FOR EVERYONE

A support group may not be for you if you:

- Tend to be impatient
- Prefer to talk much more than listen
- Dislike group process
- Are uncomfortable dealing publicly with difficult subject matter (like talk of recurrence)

### *Time-Sensitive Needs*

Timing is important, too, in terms of what kind of support you want and need and when you're ready for it. For example, it might be too soon to join a support group when you've just been hit with a diagnosis. Instead, you may first jump online to connect with others in the same boat—perhaps in Breastcancer.org's "Understanding Your Pathology Report" or the "Help, Just Diagnosed" discussion boards; or the Young Survivors Coalition's discussion boards for young women with young children. Or you might call Living Beyond Breast Cancer's help line (888-753-5222) or the Breast Cancer Network of Strength's hotline (800-221-2141). But some time later—three to six months, a year, or



maybe more—you may find yourself ready to look for personal exploration and renewal in the form of a support group. “It was a year till I had the energy for a support group,” Mary explained.

### *Group Disconnect*

Mismatches can stress rather than support you. Sylvia went to one support meeting. “Breast cancer amplifies everything. There were too many of other people’s issues and feelings I wasn’t prepared to deal with.” Nancy left her support session in tears: “Everyone there had someone at home for them. I had no one—no husband, no lover, and my mother had just passed away. There should be a group for someone who has nobody.” If you find yourself in what seems to be an inappropriate group, you’ll have to decide if it’s worth it to you to continue. For example, if you have noninvasive breast cancer (which doesn’t spread to lymph nodes or other parts of the body) and you share a group with women undergoing tons of chemotherapy for dealing with advanced breast cancer, you may leave the group’s session worried and convinced that you need to hurry up and get your own chemo. The reverse is also true: if you’re dealing with metastatic breast cancer, it’s hard to empathize with women who’ve been diagnosed with early-stage disease. It’s almost always worth the extra energy to leave and find a more suitable group if you’re in such a mismatched situation. If you find yourself in a support group or network that’s unsuited to your needs, try switching before giving up altogether. You do have other options.

Your doctor, nurse, or hospital may be able to come up with suggestions and ideas for establishing a support group or help network. Your support group facilitator can also help place you in the most suitable group for your needs. And don’t overlook your church, synagogue, or mosque as a source of support: your spiritual leader may be willing to organize a support group to meet your needs, as well as offer you immediate individual support and comfort.

## **Moving Forward**

**L**ife is a series of millions of moments. If the moment you’re in now is stealing your moxie, rocking your confidence, draining



## GROUP BURNOUT

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### Challenges

Support groups can experience burnout—particularly if they have been in existence for a long time. Reasons for burnout include:

- Flagging energy
- Loss of interest
- Distress due to deaths in the group
- Departure of an admired facilitator
- Rehashing the same issues as new people join the group
- Irritating group members
- Angry group members
- Poor organization (e.g., sessions canceled without notice)

### Solutions

The facilitator can:

- Reassess the group's purpose and goals
- Talk with other members to see if their needs are being met
- Reconfigure the group
  - ~ A new group may emerge with another focus.
  - ~ The same group may be revitalized.
  - ~ Individual members may shape up or ship out.
- Make a commitment to start and end the sessions on time; keep an up-to-date schedule online
- Help you find another source of support

Help is out there, and no one should be shy about looking for a caring connection, in person or online. You owe it to yourself to find support that works for you.

your energy, or pulling you down, remember that the moment will pass. You can ready yourself for your next moment, feel your strength—even if it's just little by little. Now is the time for you to make your support a top priority. Doing so will facilitate your recovery. Channel your energy into the thoughts and actions that will lift you up



and propel you forward. Don't overthink it; just try one type of support network or connection at a time, then later you can add another one or two into the mix. But you may have to open your mind to new possibilities outside your current comfort zone. Jump in and give it a chance over a few weeks before making any judgments or final decisions. The return on your investment will come: the precious support, comfort, new knowledge, and confidence you need to fortify and rebuild your future.





## About the Authors

**DR. MARISA C. WEISS** is the president and founder of the global non-profit organization Breastcancer.org. She has a thriving practice and has had multiple appearances on *Good Morning America*, CNN's *House Call*, the CBS *Early Show*, and NBC's *Today*. She serves as a medical expert to the *Wall Street Journal*, *New York Times*, *Washington Post*, ABCNews.com, MSN.com, and numerous magazines. She has also been a guest on NPR, CNN Radio, ABC Radio, CBS Radio, and Washington Post Radio. Dr. Weiss is the founder and past president of Living Beyond Breast Cancer (LBBC), a nonprofit organization. She is also the author of *Taking Care of Your "Girls,"* the first and only book on breast health for teen and tween girls, and the book *7 Minutes: How to Get the Most from Your Doctor Visit*. She currently practices at Lankenau Hospital in the Philadelphia area, where she serves as director of Breast Radiation Oncology and director of Breast Health Outreach, and she is a member of the Marine Biological Laboratory in Woods Hole, Massachusetts. She is a mother of three children and shares her recently emptied nest with her husband, David Friedman.

**ELLEN WEISS**, Marisa's mother, has served as editorial consultant to LBBC and Breastcancer.org. She co-authored the first edition of *Living Beyond Breast Cancer* and is the author of *Second-Hand Super Shopper*. An elementary schoolteacher and a mother of six children, she developed her writing skills, which found full expression in this book. A breast cancer survivor herself, with a family history on her father's side, she has a personal commitment to bringing the best information in the most caring form to the many women and their families facing this disease. She lives with her husband, Leon Weiss, close to Marisa, both in the Philadelphia area and in Woods Hole, Massachusetts.



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