

TIPS FOR BECOMING AN EFFECTIVE SUPPORT PARTNER

10TH EDITION

Breast Cancer
Support Partner
Handbook



JUDY C. KNEECE, RN, OCN

Breast Cancer
Support Partner
Handbook

**TIPS FOR BECOMING AN
EFFECTIVE SUPPORT PARTNER**



JUDY C. KNEECE, RN, OCN



Copyright © 2023 Judy C. Kneece, RN, OCN

2023: 10th Edition, 1st Printing

All rights reserved. Reproduction or use of editorial or pictorial content in any manner is prohibited without written permission, except in the case of brief quotations embodied in articles or reviews. Readers accessing an on-line version of this work in an authorized manner are permitted to download or print one copy for personal viewing. Other reproduction, distribution or use of copyrightable content without the express written consent of the copyright owner is prohibited. Permission can be requested by contacting the author at: 8420 Dorchester Road, Suite 102, North Charleston, SC 29420.

No patent liability is assumed with respect to the use of the information contained herein. While every precaution has been taken in the preparation of this book, the publisher and author assume no responsibility for errors or omissions. Neither is any liability assumed for damages resulting from the use of the information contained herein. This book has been written to enlighten support partners and motivate them to discuss the issues with the healthcare team. Patients should determine the best treatment protocol based on physicians' recommendations and their own needs, assessments and desires.

All trademarks used in this book are the property of their respective owners.

ISBN: 978-1-886665-21-7

Library of Congress Control Number: 2023911381

Printed in the United States of America

Published by EduCare Publishing Inc.

Illustrations: Renee Cannon, Debra Strange

To Order:

EduCare
8420 Dorchester Road, Suite 203
North Charleston, SC 29420
Phone: 843-760-6064 or Fax: 843-760-6988
www.educareinc.com

Table of Contents

Understanding the Vital Role of Your Support	iv
Copyright	vi
Dedication	vii
Acknowledgements	viii
About the Author	xi
The Voices of Experience	xii
Dear Support Partner	xv
Chapter 1 What Is a Support Partner?	1
Chapter 2 The Initial Diagnosis	5
Chapter 3 Dealing With Your Own Emotional Pain	11
Chapter 4 Understanding the Impact on the One You Love	17
Chapter 5 What Do I Do First?	25
Chapter 6 Helping Children Cope	29
Chapter 7 Health Insurance and Employment Issues	35
Chapter 8 Support Groups	41
Chapter 9 Understanding Breast Cancer	45
Chapter 10 Breast Cancer Decisions	55
Chapter 11 Surgical Decisions	63
Chapter 12 Reconstructive Surgery	77
Chapter 13 Facing Surgery Together	93
Chapter 14 Resuming Communications ... What Do I Say?	99
Chapter 15 Understanding the Pathology Report	109
Chapter 16 Treatments for Breast Cancer	121
Chapter 17 Your Partnership in Recovery	135
Chapter 18 Sexuality After Breast Cancer	155

Chapter 19	Future Fertility173
Chapter 20	Emotional Adjustment to Breast Cancer181
Chapter 21	Managing the Fear of Recurrence189
Chapter 22	Shared Insights on Coping199
	Recommended Reading204
	Resources206
	References207
	Glossary208
	Index225

About the Author



Judy C. Kneece, RN, OCN, is a certified oncology nurse with a specialty in breast cancer. She began her career as a Breast Health Navigator in a hospital where she developed her concept of patient navigation in 1991. She started EduCare Inc. in 1994 to train other nurses in patient navigation.

During the past twenty-nine years, EduCare has been a leader in developing educational materials and in training nurses to support breast cancer patients. Judy has trained over 2,300 nurses to fill the Breast Health Navigator role in hospitals, breast centers and physicians' offices. Over 500 hospitals and breast centers have used her Comprehensive Strategic Planning principles to implement breast care programs that emphasize pre-treatment interdisciplinary care conferences and the role of the Nurse Navigator.

The first edition of this book was published in 1995 and was a pioneer in the area of addressing the unique needs of breast cancer support partners. Over 740,000 patients have used the companion book, *Breast Cancer Treatment Handbook*, as a recovery guide through breast cancer. Judy has authored six other books about breast care and created the *COPE Library*, a collection of over 600 breast health patient education topics.

Judy's background working in a hospital as a Breast Health Navigator gave her new insights into the needs of women and their families who were going through a diagnosis of breast cancer. Judy has conducted extensive research on the experiences of breast cancer patients by holding national focus groups on breast cancer, recurrent breast cancer and sexuality issues after chemotherapy treatment. Her research serves as a basis for understanding the needs of patients and their families.

In 2015, the National Consortium of Breast Centers (NCBC) awarded Judy the Inspiration Award for her work in breast cancer, citing: *"For unrelenting devotion to the journey of women with breast cancer, for developing the field of patient navigation from diagnosis to survivorship, and for providing education to breast care professionals and for all those in need, the National Consortium of Breast Centers expresses its deepest gratitude for your service to our patients."*

CHAPTER 1

What Is a Support Partner?

Cancer is one of the most terrifying words in the English language. When you hear the word applied to someone you love, its meaning amplifies and grows to paralyzing proportions. At this time, you may find yourself in a state of shock, fearful about the future, and confused about what you can do and how you can best help the one you love. By default, you have inherited a critical new role—**Support Partner**.

Your relationship to the one diagnosed may be as a spouse, significant other, sibling, child or friend. The commonality of the relationship is that the patient is someone for whom you care deeply and are committed to helping through this unknown journey of a breast cancer diagnosis. You are her support partner—a role that she did not have to recruit you for, but that you willingly volunteered for because of your deep caring and commitment to her well-being.

The role requires you to take immediate action to support your loved one, yet the role has no formal training readily available on how to best help. There is no “Breast Cancer Support Role 101” training to prepare you to know what to do or say, where to go for help or how to be the most supportive person to someone you love.

The goal of this book is to fill this void and help you to understand how you can successfully fulfill the role of support partner.

The Role of the Support Partner Defined

You have inherited a new role of support partner for a breast cancer patient. Some people may call you a caregiver, but your role is different from that of the medical team. Doctors and nurses work to heal the body. You work toward recovery, too, but your job also includes moral support.

What else does the role of support partner include? It is best described by the *American Heritage Dictionary* (Fourth Edition):

- **support v.** 1. To bear the weight of, especially from below. 2. To hold in position so as to keep from falling, sinking or slipping. 3. To be capable of bearing; withstand. 4. To keep from weakening or failing; strengthen. 5. To provide for or maintain, by supplying with money or necessities. 6. To furnish corroborating evidence for. 7. To aid the cause, policy or interests of. 8. To endure; tolerate. 9. To act in a secondary or subordinate role to.
- **support n.** 1. a. The act of supporting. b. The state of being supported. 2. One that supports. 3. Maintenance, as of a family, with the necessities of life.
- **partner n.** 1. One that is united or associated with another in an activity or a sphere of common interest. a. A spouse, relative or friend.

A support partner is someone who helps you maintain your balance during a crisis; someone bound to you by a relationship, commitment or a common bond of interest. Support partners stand alongside the ones they love as a stabilizing force, sharing the emotional and physical burdens.

The Unexpected Challenge

As you have no doubt experienced first-hand by the time you are reading this book, a breast cancer diagnosis stresses and shakes the equilibrium of not only the patient, but those closest to her. However, the stress experienced by the support person often goes unnoticed. “*Does anyone recognize how stressful this is on my life?*” is often the unspoken thoughts of support partners as they struggle with their new role.

Why is the role of support partner so difficult? Dr. Marilyn T. Oberst, developer of the Oberst Caregiving Burden Scale, investigated the role of support partners during their loved one’s cancer experience and concluded:

Learning to live with cancer is clearly no easy task. Learning to live with someone else’s cancer may be even more difficult, precisely because no one recognizes just how hard it really is to deal with someone else’s cancer.

Yes, living with someone else’s cancer is a challenge; but it is one which can be mastered successfully. The key is to learn how to manage and balance the emotional and physical demands.

Learning From the Experience of Others

The best way to learn is from others who have faced and met the challenge of filling the role of support for a breast cancer patient. Because peers can add much needed understanding and guidance, many examples quoted in this book are from other support partners.

Many patients and their support partners have openly shared their pain and efforts to make “sense out of a senseless situation.” They have shared in hopes that those who inherit the role will learn from their experiences. I once was told, *“If you want to find your way out of a forest, it is not as helpful to ask a forester, who knows all about the trees, but to ask someone who was lost but managed to find the way out of the forest.”* This book contains the experiences of those who managed to find their own way through the forest of the breast cancer experience.

It is now my desire to help you understand the challenge of living with the pain of someone else’s breast cancer diagnosis, and to assist you in becoming a more effective support person. This requires a delicate balance of taking care of her needs, while you also take care of yourself.

This book is not designed as a comprehensive manual on coping as a support partner. Instead, it is a combination of life experiences from patients, their support partners and my clinical experience. I urge you to reach out to other professionals—counselors, physicians, nurses and support groups—to complete your understanding of the “support” role.

Throughout this book, you will also gain an understanding of the basics of the breast cancer treatment process. You will learn effective and supportive techniques to ease the process, and you will find additional resources available to assist you. The support role is not an easy one, but it is one from which you can learn and grow as you provide one of the most powerful tools for recovery from breast cancer—effective support.

Remember . . .

- *Your role as a support partner is one of the most important components for the emotional recovery of the one you love.*

Support Partner Perspectives

“When Anna went for a breast biopsy, I thought it would just be a cyst, like her mother had had. The biopsy was no big deal; besides, it was so simple it was being done as an outpatient procedure. Anna was only 32—too young for cancer. When her pathology report came back with the diagnosis of ‘cancer,’ I went into an emotional shock that lasted for days. It had never occurred to me that it would be cancer. I could not sleep at all the first few days. My mind kept torturing me with the fact that Anna could die and I would be a widower at 28.”

—Brian Cluxton, Support Partner

“Shock and fear best describe my first reaction. This was only supposed to happen to other women—not my wife. We were both in a daze. But one thing was for sure; my wife and I were in this together from the start.”

—Al Barrineau, Support Partner

“My mom—the strong one in my life—had been diagnosed with cancer. The thought of ‘you can die from cancer’ instantly flooded my mind. This thought tore my heart out. I could not even imagine what life would be like without her in my life. I was only 24—too young to be without her.”

—Krystle Brown-Shaw, Support Partner

“When Lisa called to tell me her biopsy was positive, I was shocked. ‘Not my little sister!’ Lisa was young and healthy. As Lisa and I cried and talked, we knew that we had to regroup and get our emotions under control because we now had to tell our mother. That was not going to be easy. We had to present a united front for her.”

—Rosemary J. Delaney, Support Partner



CHAPTER 3

Dealing With Your Own Emotional Pain

At the time of diagnosis, all attention from medical staff, family members and friends is directed toward the patient—naturally, because she has breast cancer. Yet, as a support partner, it is also a very difficult and painful time for you. You may be feeling overwhelmed by expectations from yourself, and others, to be strong and emotionally supportive for your loved one. You may even fear letting others see you cry as you strive to remain emotionally strong. Behind the strong facade, though, everything in your body is crying out for relief from the unexpected emotional pain. Your heart is breaking, too.

You may be surprised that you are experiencing such strong emotional reactions—after all, she is the one with cancer. It may be helpful to know that a strong emotional response, usually internalized, is common for those supporting a cancer patient. In fact, clinical studies by Casselith, Oberst and James discovered that spouses revealed a higher incidence of emotional symptoms than did the patient for up to the first 180 days after a diagnosis of cancer. This study validated the emotional challenges support partners face as they are thrust into the role of support for someone with cancer. As a support person, you, too, will find that your own emotions need to be acknowledged and addressed.

It is very important for the patient's emotional recovery, as well as your own, that you recognize your own emotional distress and take steps to have your own needs met. At this time, just as she needs a support network, you also need people with whom you can talk and honestly share your feelings in a supportive environment.

Close emotional attachments cause support partners to suffer emotions that are similar to the emotions of the person who is diagnosed. You may be surprised to find that you experience and mirror many of the same emotions as your partner—shock, numbness, disbelief, confusion, anger, sadness and depression. While you may manifest your emotions differently because of your personality, the underlying emotions are the same.

Remember, people react differently. Some people will strike out at others when angry. Others may withdraw from the person with whom they are angry. The underlying emotion is the same, even though the response is different. The important thing to remember is that you will find yourself experiencing many emotions, some of which may be new to you. For most people, dealing with a cancer diagnosis is a new experience, requiring new coping skills. It is normal to experience a wide range of emotions during the crisis created by the diagnosis. You and the patient have both been forced to confront a dreaded enemy.

Grieving Your Loss

How do you start to heal your emotional pain? You begin by verbally expressing that this is an extremely difficult and sad time for you because of all the future unknowns that must be faced. This acknowledges your grief. Some people find it difficult to openly express these feelings to others for fear that they may appear weak or not in control. The opposite is true. Sharing your feelings of grief shows that you are very much attuned to what is occurring in your life. Expressing feelings honestly will not weaken your relationship but will strengthen it and will help reduce the intensity of your emotions. Expressing grief is a natural and helpful way for your emotional healing to begin.

Ann Kaiser Sterns summed up the scary feeling grief causes when she said, *“The experience of grief is not mental illness—it just feels that way sometimes.”* At times you may feel a complete loss of control over life as you once knew it. At other times you may feel as if you are “losing it” mentally. This feeling is common and is a part of working through a new life crisis.

Holding Back Emotions

Many support partners try to hold back their deep emotional pain and avoid crying in front of anyone. This is not helpful for you or the patient.

Tears do not signal a “loss of control” but are more likely to convey the solidarity you feel with her. Crying is a sign that you are dealing with your emotions in a perfectly healthy and natural way. Seeing your tears will often give her the unspoken permission to share her own intense feelings and fears with you, knowing that you are very much in tune with her emotional pain.

Crying is therapeutic. After a good cry, we feel a sense of emotional release. It is similar to a rain that leaves the air clear and clean when it is over. Nicholas Wolterstroff said, *“Tears are salve on our wounds.”* Gregg Levoy in *Psychology Today* shared, *“The amount of manganese stored in the body affects our moods, and the body stores 30 times as much manganese in tears as in blood serum.”* Biochemist Will Frey explained, *“The lacrimal gland, which determines the flow of tears, concentrates and removes manganese from the body.”* Frey has also identified three other chemicals stored up by stress that are released by crying.

If you have forced yourself to be brave and hold back your tears, now is the time to emotionally free yourself. It is okay to cry, and may even be helpful. Tears are a sign that you are in touch with reality and are dealing with the losses that a crisis brings. Covering and internalizing your stress will manifest itself in future physical stress symptoms. Expressing your emotions reduces internalized stress and eliminates many physical problems that can be caused by stress.

Finding Your Support

As the primary support person for a cancer patient, you will find it helpful to identify someone with whom you can talk and who understands exactly what you are feeling. This person could be a friend, family member, professional counselor, chaplain, priest, pastor or spiritual leader. You need someone to whom you can pour out all of your fears, anxieties and emotions, knowing that you will not be judged but will be offered emotional support and guidance. It often comes as a surprise that many of the people closest to you don't understand when you try to share. They have never had to deal with what you are going through, and they feel the best way they can help is to cheer you up or help you get your mind off of your problems. Being cheered up and distracted is okay, but this is not what you need now. Everyone needs at least one person to whom they

can talk freely, knowing that no matter what, they will be listened to and supported.

Cancer treatment centers often offer support services, such as caregiver support groups, social workers, chaplains and counselors, who are trained to help you adjust and perform in your new role of cancer patient support. Professional counselors are skilled at crisis intervention and can identify your existing strengths and coping skills. They can help you sort out your fears and concerns and find helpful ways to face the decisions ahead. You will find that counseling professionals act as a “safe place” and allow you to say anything you think or feel, without upsetting anyone.

Ask your healthcare provider or social worker for a recommendation. Remember, you need support, too. You need someone who recognizes the demands placed on a support partner and who can share this experience with you and help you master your new role. The stronger you become, the more help you can give to the patient.

Remember . . .

- *As a support partner, learning to live with someone else’s cancer is difficult, but it is a task that can be mastered.*
- *Acknowledge your own tears and emotional pain as a normal, helpful response and not as a “weakness.”*
- *Find someone with whom you can talk and who understands your role and the challenges you face as a support partner.*

Index

~ A ~

alkylating agent ... 134, 212
alopecia ... 212
anesthesia ... 84, 99, 213
anger ... 10, 16, 22
aromatase inhibitor ... 133, 134, 213
autologous reconstruction ... 84, 87, 213
axillary lymph node dissection (ALND)
... 71, 213

~ B ~

bilateral ... 84, 214
biological response modifier ... 133,
134, 214
biopsy ... 67, 214
birth control ... 171
blood counts ... 128, 155, 214
brachytherapy ... 130, 214
BRCA1 and BRCA2 ... 51, 67, 214
breast anatomy ... 52
breast cancer ... 49, 214
hereditary ... 49
sporadic ... 49
staging ... 119, 226
breast implants ... 69, 84, 214
breast reconstruction ... 81

~ C ~

cancer ... 49, 214
cancer cells ... 51, 72, 114, 125, 214
cancer diagnosis ... 9
cancer surgery ... 74
capsular contracture ... 86, 214

chemotherapy ... 52, 62, 70, 127, 142,
215
dose-dense ... 128, 216
drugs ... 134
side effects ... 142
clinical trial ... 39, 135, 215
communication
children ... 33
friends and co-workers ... 42
guidelines ... 106
support partner ... 103
core biopsy ... 71, 215
CT scan ... 130, 216

~ D ~

DCIS ... 75, 125
delayed reconstruction ... 83
depression ... 10, 16, 185, 199, 216
DIEP reconstruction ... 88, 216
ductal carcinoma in situ (DCIS) ... 54,
217

~ E ~

edema ... 165, 217
employment ... 39
estrogen ... 166, 177, 217
estrogen receptors ... 132, 151, 217
external beam radiation ... 130, 217

~ F ~

Family and Medical Leave Act ... 41,
217
fatigue ... 143, 165, 217

INDEX

fertility ... 177, 217
finances ... 40
fine needle aspiration ... 71, 218
flap
 free ... 87, 218
 pedicle ... 87, 224

~ G ~

gamma-detection probe ... 72, 218
genetic testing ... 51, 126, 218
gluteal flap ... 91, 218
growth rate, cancer ... 55, 127, 228

~ H ~

hair loss (alopecia) ... 145
health insurance ... 39, 83
HER2/neu ... 50, 61, 117, 127, 219
hormonal therapy ... 52, 126, 132, 177, 219
hormone receptor assay ... 117, 219
hot flashes ... 133, 149, 219

~ I ~

immunotherapy ... 52
implant
 fixed-volume ... 85
 saline ... 85, 86
 silicone ... 86
 tissue expander ... 85
infertility ... 165, 177, 219
infiltrating breast cancer ... 54, 219, 220
inflammatory breast cancer ... 30, 72, 82, 115, 220
informed consent ... 135, 220
insomnia ... 148
internal breast radiation ... 130, 220
internal mammary nodes ... 196, 220
intravenous (I.V.) ... 128, 220
invasive breast cancer ... 114

~ L ~

latissimus dorsi reconstruction ... 88, 91, 220
lobular carcinoma ... 53, 115
lumpectomy ... 61, 67, 75, 130, 221
lymphedema ... 83, 132, 221
lymph node evaluation ... 71
lymph nodes ... 67, 72, 131, 196, 221
lymph node status ... 116

~ M ~

mammogram ... 67, 221
margins ... 116, 221
mastectomy ... 61, 67, 100, 221
menopause ... 142, 165, 179, 222
modified radical mastectomy ... 76, 222
mood swings ... 142, 150
MRI ... 198, 221

~ N ~

nadir ... 143, 222
necrosis ... 218
neoadjuvant chemotherapy ... 70, 222
night sweats ... 149
nipple reconstruction ... 93
nipple-sparing mastectomy ... 78, 223
nuclear grade ... 116, 223

~ O ~

Oncotype DX® ... 118, 126, 223

~ P ~

painful intercourse ... 169
pathologist ... 113, 223
pathology report ... 113
port ... 128, 224
prognosis ... 224

INDEX

prophylactic mastectomy ... 76, 224
prosthesis ... 81, 225

~ R ~

radiation ... 30
 side effects ... 132
radiation oncologist ... 225
radiation therapy ... 52, 126, 129, 225
range of motion ... 140, 225
recommended reading ... 208
reconstruction ... 225
 delayed ... 216
 immediate ... 219
 procedures ... 87
recurrence ... 193, 225
remission ... 135, 225
residual disease ... 136

~ S ~

second opinion ... 22, 39, 62
sentinel lymph node biopsy ... 72
sentinel lymph node mapping ... 72, 226
SERMs ... 134, 226
sexuality ... 159
simple mastectomy ... 76
skin-sparing mastectomy ... 77, 226
SSRIs ... 149, 189, 226
support groups ... 45
support partner ... 5
 emotions ... 15
surgery ... 97
surgical decisions ... 67
surgical scar ... 163

~ T ~

tamoxifen ... 133, 134, 180, 227
targeted therapy ... 52, 113, 134, 227
tissue expander ... 83, 227
total mastectomy ... 76

TRAM flap reconstruction ... 89, 227
treatment ... 125
treatment decisions ... 59
triple negative breast cancer ... 50, 118,
 228
tumor ... 52, 55, 228
tumor characteristics ... 115

~ U ~

ultrasound ... 228

~ W ~

weight gain ... 147
wire localization ... 228

BREAST CANCER SUPPORT PARTNER HANDBOOK

TIPS FOR BECOMING AN EFFECTIVE SUPPORT PARTNER

TOPICS INCLUDE:

- Understanding the Emotional Adjustment to Breast Cancer
- Becoming an Effective Support Partner
- Communicating Effectively
- Helping Children Cope
- Understanding Surgical, Treatment and Reconstruction Options
- Understanding the Pathology Report
- Understanding Treatment Side Effects
- Managing the Fear of Recurrence

ALSO INCLUDED:

- Inspirational and Emotional Support
- Experiences of Four Support Partners
- Focus Group Data on Side Effects After Breast Cancer Treatment
- Full-Color Illustrations, Charts and Graphs
- Resources, Recommended Reading and Glossary



Judy C. Kneece, RN, OCN, has trained over 2,300 nurses internationally to serve as Breast Health Navigators to coordinate the clinical, educational and support needs of patients. She has authored seven books on breast cancer and benign breast disease, including a companion book to this book, the *Breast Cancer Treatment Handbook*.

An important key to emotional and physical survivorship of a patient is having a supportive person beside her that is educated and engaged in her care. Friends, partners or family members who use the *Breast Cancer Support Partner Handbook* as a guide will learn how to help a patient feel embraced, empowered and supported during her breast cancer journey.

—Anna Cluxton, MBA, Survivor

President (2010–2012), Board of Directors, Young Survival Coalition

This book needs to be available when the word cancer is first spoken. It helped me to know that my partner's reactions were normal ... and so were my responses.

—Rev. Sinclair E. Lewis, M.Div. D.D.

Methodist Pastor, Support Partner

Often spouses, family and friends want to offer positive support, but the uncertainty of taking the right steps or saying the right words may hold them back. The *Breast Cancer Support Partner Handbook* will ease your concerns. It offers a complete resource on every topic imaginable relating to breast cancer so that you can be an effective support partner.

—Lisa Martinez, RN, BSNM, JD, Survivor

Founder, Executive Director of The Women's Sexual Health Foundation

From the opening chapter to the last, this book addresses relevant issues in short, easily absorbed chapters with down-home advice from other partners and experts... It explains the disease and treatment options, offers powerful emotional advice on the sexual relationship after the disease, explains communication intricacies and how to balance daily living with the fear of recurrence... All of the necessary information needed is in one handy book.

—Merle O'Rourke Thompson, Ph.D., Survivor

Reviewer, Journal of the National Cancer Institute

ISBN 978-1-886665-21-7



9 781886 665217 >

WWW.EDUCAREINC.COM

HEALTH / PSYCHOLOGY

8420 DORCHESTER ROAD, SUITE 102
NORTH CHARLESTON, SC 29420 • 843.760.6064