

## TABLE OF CONTENTS

WELCOME	4
● What You Will Find in NBCCF's Guide to Quality Breast Cancer Care	8
● How NBCCF Developed the Quality Care Core Values and This Guide	9
● Board of Directors of the National Breast Cancer Coalition Fund 2001-2002	11
● Feedback Survey	
ACCESS	13
● Finding Affordable Care	14
–If you have health insurance, learn how it works.	14
–If you don't have health insurance, look for free or low-cost services.	15
–Get time off work.	19
● Getting Comprehensive Care	19
–Learn about the standard of care for breast cancer .	20
–Think about joining a clinical trial.	20
–Think about traveling to a bigger care center .	21
–Know your rights as a breast cancer patient.	21
–Ask about coordination of care.	22
INFORMATION	27
● Understanding Your Diagnosis	28
–Learn exactly what your diagnosis is.	28
–Why are these questions important?	30
–Ask for a copy of your pathology report.	33
–Get a second opinion about your diagnosis and pathology .	34
–Ask your doctors if they will keep your breast tissue.	35

(continued)

*The National Breast Cancer Coalition Fund's Guide to Quality Breast Cancer Care is made possible in part by the Avon Products Foundation through the Avon Breast Cancer Crusade, and the Joyce and Irving Goldman Family Foundation.*

This Guide is for information only. It is not meant to take the place of a doctor's advice. It can't replace your doctors' knowledge or judgment. Each patient's case is different. It is important to talk about all your concerns with your doctors. Confirm with your doctor any information you get from the Guide. If you have a medical emergency, get professional help right away.

● Using Evidence-Based Information	37
—Take the time you need.	37
—Ask questions.	37
—Get more than one opinion about your treatment choices.	37
—Learn about evidence-based medicine.	38
—Learn the difference between risk reduction and prevention.	44
—Keep track of your health care information.	45
<b>CHOICE</b>	<b>47</b>
● Choosing Your Doctors and Care Centers	48
—Find the best doctor for you.	48
—Know who is on your team before you start treatment.	48
● Making Decisions About Your Care	50
—Be involved in your care. Or ask a friend or family member to do that for you.	50
—Learn about your treatment choices.	50
—Ask yourself some hard questions.	55
<b>RESPECT</b>	<b>57</b>
● Being Valued	58
—To get respect, give respect.	58
—Meet as people rather than as a doctor and a patient.	58
—Take your time seriously.	58
—Complain when you need to.	59
● Keeping Your Records Private	59
—Ask about confidentiality.	59
—Know your rights.	60
● Being Treated as a Whole Person	61
—Ask for a comprehensive treatment plan.	61
—Be sure your plan reflects your values.	61
—Learn about follow-up care.	62
—Learn about complementary and alternative medicine (CAM).	63
<b>ACCOUNTABILITY</b>	<b>67</b>
● Getting the Right Treatment at the Right Time	68
—Read this guide cover to cover.	68
—Be a good advocate for yourself.	68
● Being a Responsible Patient	69
—Be honest with your doctors.	69
—Be responsible for your choices.	69

● Having a Way to Fix Problems	70
– Identify the source of the problem.	70
– Read your health insurance policy carefully.	70
– Find out about the appeals process under your health plan.	71
– Get copies of your medical records.	72
– Learn about your illness.	72
– Write an appeal letter.	72
– Ask your doctor to help with your appeal.	72
– You may want to get help from a lawyer.	73
– Be prepared to fight for your health.	73
<b>IMPROVEMENT</b>	<b>75</b>
● Becoming a Breast Cancer Activist	76
– Become a member of NBCC.	76
– Build your advocacy skills.	77
– Take NBCCF’s Project LEAD.	78
– Fight for health care reform.	78
● Learning from Patient Care	79
– Learn about clinical trials.	79
– Improve the laws about clinical trials.	79
– Increase access to clinical trials.	79
– Learn about health outcomes research.	79
● Measuring What Matters	80
– Learn more about quality measures.	80
– Help measure the quality of breast cancer care.	81
<b>CONCLUSION</b>	<b>82</b>
<b>GLOSSARY</b>	<b>83</b>
<b>RESOURCES</b>	<b>99</b>
● Helpful Organizations and Why We Recommend Them	99
● 10 Things to Know When Judging Medical Resources on the Web	107
<b>INDEX</b>	<b>109</b>
<b>ABOUT NBCCF</b>	<b>115</b>
● What Makes NBCCF Different	115
● What NBCCF Has Done So Far	116
● Guide Order Form	
● NBCCF Membership Contribution Form and Envelope	

# Welcome

## NBCCF'S GUIDE TO QUALITY BREAST CANCER CARE

**The National Breast Cancer Coalition Fund (NBCCF) is made up of millions of breast cancer activists nationwide. We get questions every day from breast cancer patients about their care. Everyone has the same basic question. What can I do to get quality care? This guide is our answer to that question. It is for everyone facing breast cancer and everyone who wants to help them.**

This is our best advice for getting good breast cancer care. It's what we tell our families and friends. Our advice is based on:

- our experiences as patients,
- our work with doctors, nurses, and researchers,
- our review of medical evidence,
- what we know about the health care system, and most importantly,
- our commitment to getting better breast cancer care for all women.

NBCCF believes that being informed can help you get better care. Patients who know more about their care choices tend to worry less and get better results.<sup>1</sup>

### **The Problem**

If you live in the United States, you can get excellent breast cancer care. But you could also get care that is wrong for you. This can happen even with good insurance and good doctors. Some breast cancer patients get very poor care. NBCCF is fighting for a better system. But for now, you need tips for getting care that is right for you.

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<sup>1</sup> Siminoff LA. Improving communication with cancer patients. *Oncology (Huntington)* 1992;6(10):83-87.

## Quality Breast Cancer Care: NBCCF's Vision

What does quality breast cancer care really mean? You hear the word “quality” often. But it means different things to different people.

Doctors and hospitals describe quality health care in a confusing way. They call it “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional medical knowledge.”<sup>2</sup>

Others say what quality is *not*. They might describe it as:

- too much care (such as unneeded tests or drugs),
- too little care (such as not getting surgery you need), or
- the wrong care (such as mistakes or care not based on evidence).

But what about the patient’s point of view? Of course you need the right treatment and drugs at the right time. But the “right” care can be a very personal choice. Two patients with the same diagnosis may choose different treatments.

Still, quality care is not just personal taste. It’s not a popularity contest either. Sure, you want to avoid rude doctors and long waits. But you can get good parking, sparkling water while you wait, a relaxed doctor visit—and leave with the *wrong* diagnosis.

That’s why it’s important to have doctors and nurses who:

- give skilled breast cancer care in a respectful way and
- understand the latest medical evidence.

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2 Institute of Medicine. *Ensuring Quality Cancer Care*. 1999.

Good breast cancer care is based on evidence. This means that medical research has shown that the care could help you.<sup>3</sup> But other parts of your care are just as important. NBCCF's vision of quality care brings together six core values:

- **ACCESS** to all the care you need when you need it
- **INFORMATION** that is complete and correct
- **CHOICE** about your doctors and your treatment
- **RESPECT** in all parts of your health care
- **ACCOUNTABILITY** in all parts of the health care system
- **IMPROVEMENT** in the system so breast cancer care continues to get better

## How to Use this Guide

This guide is in six parts, one for each of the six core values. These values form a framework that helps us think about and judge care. They overlap, so the guide covers some topics more than once. You can read the guide in any order.

There is a lot of information in this guide. We strongly recommend that a friend or loved one reads this guide with you. She or he can help you keep track of and sort all the information.

We wish this guide could answer all your questions about breast cancer. But we know it does not. There are *no* best answers for many important questions. For others, there are no answers at all. NBCCF is fighting for more and better research to solve the mysteries of breast cancer. For now, we hope this guide will help you get better breast cancer care.

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<sup>3</sup> Evidence-based medicine has been defined as the conscientious, explicit, and judicious use of current best evidence in making clinical decisions about the care of individual patients.

Sackett D, et al. Evidence-based medicine: what it is and what it isn't. *British Medical Journal* 1996;312:7-12.

## **A Few Tips for Using the Guide**

**You have time to learn about your options.** We know that breast cancer is terrifying and feels urgent. But for most women, there is no need to rush into treatment. You have time to find the right doctors and care centers. And you have time to become an informed patient. NBCCF recommends that you take the time. That way you can make choices that are best for you.

**Use our glossary.** We have tried to write this guide in plain language. But there are some medical terms you need to know. Is there a word colored **teal** that you don't know? You will find the word's meaning in the glossary at the back of this book.

**Choose your reading wisely.** There are thousands of books, brochures, and web sites that tell you about breast cancer. But you don't need that many resources. We won't waste your time sending you to hundreds of breast cancer groups or resources. Instead we give you the most important information and a few resources you can trust.

Most of the groups we suggest you contact give helpful information on their web sites. We list their web addresses and phone numbers under the "Resources" tab. What if you don't have access to the Internet? You can call the groups and ask them to mail you their information. Also, public libraries often have free access to the Internet.

## **Please Tell Us What You Think!**

This guide is for you, and you can make it better. We use your feedback to make changes. We change this book each time we print a new version. We also want to hear about how you are using this guide. And we want to hear about how you are making breast cancer care better in your area. So *please* take the time to fill out the survey at the end of this section. We will listen!

# What You Will Find

IN NBCCF'S GUIDE TO QUALITY BREAST CANCER CARE



## ACCESS

- Ideas for how to pay for your care
- The types of care you should expect

## INFORMATION

- Tips on understanding your diagnosis
- Help finding trustworthy information on your disease
- Information about pathology reports, second opinions, evidence-based medicine, and more

## CHOICE

- Ways to choose your doctors and care centers
- Ideas on how to make decisions about your care

## RESPECT

- Tips for getting the respect you deserve
- How to protect your private medical information
- Information about complementary and alternative medicine

## ACCOUNTABILITY

- How the health care system should work
- What to do when things go wrong

## IMPROVEMENT

- How to join NBCCF to improve breast cancer care for everyone
- Ways of improving the whole health care system

# How NBCCF Developed

## THE QUALITY CARE CORE VALUES AND THIS GUIDE

NBCCF's Guide to Quality Breast Cancer Care is a project of its Quality Care Initiative. The initiative began in January 1999. The first goal was to describe a vision of quality breast cancer care. That vision is built around six core values: Access, Information, Choice, Respect, Accountability, and Improvement. NBCCF believes that these values make up the essence of quality care.

The next goal was to write this guide for breast cancer patients. The guide is meant to help patients to:

- judge the quality of their health care,
- understand medical evidence, and
- find and get the highest-quality care there is.

We designed the guide to be easy to read, easy to hold, and interesting to look at. NBCCF worked on the guide very closely with its Quality Care Advisory Committee. The committee brings many different points of view to this project. It includes:

- breast cancer survivors and activists,
- health caregivers, including primary care doctors, surgeons, oncologists, and radiologists,
- experts on health care laws,
- researchers,
- support and community group leaders, and
- adult education experts.

The guide was also reviewed by NBCCF's Board of Directors, staff, field coordinators, and others.

NBCCF is grateful to everyone who helped with the guide.

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# Board of Directors

NATIONAL BREAST CANCER COALITION FUND 2001-200 2

## The Board of Directors of the National Breast Cancer Coalition Fund is made up of representatives from these groups:

**1 in 9: The Long Island Breast Cancer Action Coalition**—New York

**African-American Women in Touch**—Indiana

**Alamo Breast Cancer Foundation**—Texas

**California Breast Cancer Organizations**—California

**Georgia Breast Cancer Coalition**—Georgia

**Hadassah, the Women's Zionist Organization of America**—New York

**JRI Health/Justice Resource Institute**—Massachusetts

**Kentucky Cancer Program**—Kentucky

**Linda Creed Breast Cancer Foundation**—Pennsylvania

**Massachusetts Breast Cancer Coalition**—Massachusetts

**The Mautner Project for Lesbians with Cancer**—Washington, DC

**Metropolitan Washington D.C. Chapter of NBCC**—Washington, DC

**Minnesota Breast Cancer Coalition**—Minnesota

**Minority Women with Breast Cancer Uniting, Inc.**—Ohio

**National Breast Cancer Coalition Fund**—Washington, DC

**National Education Association**—Washington, DC

**National Women's Health Network**—Washington, DC

**Nueva Vida**—Maryland

**Oncology Nursing Society**—Pennsylvania

**Revlon Breast Center, UCLA Oncology Services**—California

**Rhode Island Breast Cancer Coalition**—Rhode Island

**SHARE**—New York

**Susan Love M.D. Breast Cancer Foundation**—California

**Virginia Breast Cancer Foundation**—Virginia

**Women's Community Cancer Project**—Massachusetts

**Y-ME National Breast Cancer Organization**—Illinois

**Young Survival Coalition**—New York

**NBCCF's Network** — NBCCF has a national network of breast cancer advocates led by NBCCF's field coordinators. NBCCF's advocates have a lot of information about breast cancer care. Often, you can find the most helpful information right in your area. To see if there is an NBCCF field coordinator near you, please call NBCCF at 1-800-622-2838.



# Tell Us What You Think!

We want to know what you think about this guide. Please take a few minutes to answer the questions below. Skip any that you don't want to answer.

We will use your answers to make the guide better. Your answers will also help us understand who is using the guide. Finally, you will be helping us find ways to get the guide to more people. We will not use your answers for anything else.

## Circle the letters that apply.

- How easy was it to find your way around the guide?
  - very easy
  - easy
  - neither easy nor hard
  - hard
  - very hard
- How easy was it to understand the information in the guide?
  - very easy
  - easy
  - neither easy nor hard
  - hard
  - very hard
- How helpful are the six core values when you think about quality care?
  - very helpful
  - helpful
  - neither helpful nor confusing
  - confusing
  - very confusing
- How much of the guide's information will you use to make health care choices? These could be choices for your own care. Or you could be helping someone else make choices.
  - more than half
  - about half
  - less than half
- How did you find out about this guide?  
(Circle all that apply.)
  - NBCCF's web site
  - NBCCF's newsletter
  - at an NBCCF meeting
  - at my doctor's office or care center
  - from a group I belong to
  - from a family member
  - from a friend
  - from a newspaper
  - from a magazine
  - over TV or radio
  - other \_\_\_\_\_
- Please check the sentences that describe you.  
(Circle all that are true.)
  - I am worried I might get breast cancer.
  - I am worried I might have breast cancer.
  - I have breast cancer and am getting care.
  - I had breast cancer and have finished getting care.
  - I am a family member of someone with breast cancer.
  - I am a friend of someone with breast cancer.
  - I am a breast cancer activist.
  - I am a health care giver.
  - I am a breast cancer researcher.
  - Other \_\_\_\_\_
- What country do you live in? \_\_\_\_\_
- If you live in the United States, which state or territory do you live in? \_\_\_\_\_
- What is your sex?
  - female
  - male
- How old are you?
  - 18 or under
  - 19-24
  - 25-34
  - 35-44
  - 45-54
  - 55-64
  - 65-74
  - 75 or over
- What is your race?
  - African-American/Black
  - Asian
  - Caucasian/White
  - Hispanic
  - Native American
  - Other \_\_\_\_\_
- How much education do you have?
  - some high school
  - high school graduate
  - some college
  - college graduate
  - master's degree
  - doctoral degree
- Would you like to get information about the National Breast Cancer Coalition?
  - Yes
  - No

(If you circled "Yes," please give your contact information on the other side of this form.)

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