



Breast Cancer Resources

When I was diagnosed with breast cancer in 2006 at the age of 48, the doctor handed me a few pamphlets and asked me when I wanted to schedule the surgery. I felt shell-shocked. I actually scheduled the surgery before going home and realizing that I needed a whole lot more information—and a second opinion—before doing anything.

I spent several months reading books and researching my options—and getting two second opinions—before taking action.

I wish I'd had a guide to tell me the right steps to take after hearing that diagnosis, and to point me to the most useful and responsible websites. This page is an attempt to create that guide. It is a personal list of the resources that I found most useful on my journey, and is by no means a comprehensive list of everything out there.

Contributions are welcomed—please [e-mail me](mailto:ninab@softress.com) (ninab@softress.com) with useful information, book recommendations and links. I am especially interested in good links and resources for lymphedema, which I don't have yet.

Let me know what you want to see here. This is only the beginning.

Nina Birnbaum

WHAT TO DO IF YOU'RE DIAGNOSED WITH BREAST CANCER 7 Steps to Take if You're Diagnosed with Breast Cancer

1. Slow Down. Get as much information as possible from your doctor.

Find out:

- How large is the tumor? What type is it?
- Is it palpable (can you feel it)?
- What are your risk factors?
- What are your treatment options?

Ask your doctor how much time you have to make a decision. According to [Dr. Susan Love](#) “Whatever treatment you decide on, you'll have to live with it for the rest of your life—and giving yourself a week or two to think it over won't shorten that life.”

2. Get a second opinion—even a third, from another hospital or treatment center. Doctors and pathologists may interpret your results differently or prefer alternate

treatment methods.

Be sure to bring your test results, mammography films, and pathology slides if requested. Have a friend come with you to take notes (and give emotional support), so you can concentrate on what the doctor is saying.

3. If your doctor has recommended a biopsy, tell her about all medications, vitamins or herbs you are taking. Some, especially anti-inflammatories and anti-oxidants, can cause increased bleeding. Make an appointment with the hospital nutritionist to find out what is safe to continue taking before biopsy or surgery.

4. Get a small notebook or make a binder. Use it to keep your appointments, take notes, and keep a card from every doctor you see. At home, keep a file with copies of all your reports, bills, and information from your doctor.

5. Talk to two different plastic surgeons about your reconstruction options—before your breast surgery. There are many different reconstruction options, and length of surgery and recovery times vary considerably.

Be sure you know what all your choices are so you can decide what's right for you. [The Reconstruction Guidebook](#), by Kathy Steligo is an excellent resource.

6. Reach out to a support group like SHARE or Gilda's Club, your hospital's social worker, or a friend with breast cancer. It's helpful to share your questions and feelings with women who have already experienced what you are going through now.

7. Educate yourself. A good breast cancer book will help you understand your cancer and make informed decisions about your treatment. Several good ones are:

[Dr. Susan Love's Breast Book](#), by Dr. Susan Love

[The Breast Cancer Survival Manual](#), by Dr. John Link

[Just Get Me Through This! The Practical Guide to Breast Cancer](#), By Deborah A. Cohen and Dr. Robert M. Gelfand

Your hospital's breast cancer library or resource room will have a wealth of information. Make use of it, or check out some of the websites listed at

Softress.com/breastcancer.html

Knowledge is power, and will help you make the right decisions for you.

BREAST CANCER BOOKS

General Breast Cancer Information

[Dr. Susan Love's Breast Book](#), by Dr. Susan Love

[The Breast Cancer Survival Manual](#), by Dr. John Link

[Just Get Me Through This! The Practical Guide to Breast Cancer](#), By Deborah A. Cohen and Dr. Robert M. Gelfand

Complimentary and Alternative Medicine for Breast Cancer

[*Choices in Healing*, by Michael Lerner](#)
[*Alternative Medicine Magazine's Definitive Guide to Cancer: An Integrative Approach to Prevention, Treatment, and Healing*](#)
[*American Cancer Society's Complete Guide to Complementary and Alternative Cancer Methods, 2nd Edition*](#)

Breast Reconstruction Information

[*The Reconstruction Guidebook*, by Kathy Steligo](#)

The book is also available on [Amazon](#)

Preparing for Mastectomy

[*Prepare for Surgery, Heal Faster*](#), (book and workshop) by Peggy Huddleston also available at [Amazon](#)

Preparing for breast surgery mentally and physically will help you and your family get through it better and help you heal faster. I cannot recommend this book and workshop enough. Many hospitals offer the 1-hour workshop based on the book. In New York, you can take the free workshop (and get the book free as well) at [NYU](#), regardless of whether you are a patient there.

Recovery After Mastectomy

[*Recovering from Breast Surgery: Exercises to Strengthen Your Body and Relieve Pain*](#), by Diana Stumm

FINDING THE RIGHT DOCTOR FOR YOUR BREAST CANCER CARE

If you live in a large urban area, you probably have many hospitals and breast cancer centers to choose from. Research their websites and find one that suits your needs (I looked for one that was CAM [Complimentary and Alternative Medicine] friendly). When you meet with the doctor, be sure there's good rapport between you, as she will be taking charge of a very important part of your life!

If you can't get to a large medical center, many offer a "second opinion service." Do a web search for "second opinion service" to find one that will work with your insurance. I can't give better advice about finding a good doctor, getting a second opinion and checking a doctor's credentials than these About.com pages (or [download pdf](#) (JV: *Link to PDF, attached*):

[How To Find A Good Doctor](#)

[Getting a Second Opinion](#) (4 page article: follow links at end of each page)

[How to Check a Doctor's Credentials](#)

BREAST RECONSTRUCTION OPTIONS

Research your breast reconstruction options before you have surgery, as your surgery will be tailored to the type of reconstruction you choose. I found that, unfortunately, not all plastic surgeons are forthcoming about all forms of reconstruction—they may only tell you about the types that they perform. So it's wise to [read up](#) and do as much online research as you can before making a decision.

Silicone vs. Saline Breast Implants

A wide range of implant styles are available today, including saline, silicone, cohesive gel, and even soy oil! Controversy still surrounds the safety of breast implants, especially silicone implants. Silicone implants were approved by the FDA only for breast reconstruction—not elective augmentation—for over a decade and did not gain approval until 2006. Newer silicone implants are a lot safer than what was available in the 1980s. Many doctors feel the most advanced type of silicone breast implant is the [cohesive gel](#) or “gummy bear” (no kidding!) implant—a firm type of “crosslinked” silicone that has a much lower risk of leakage. (Full disclosure: this is the implant that I chose.) Getting insurance to pay for cohesive gel implants may be difficult as they are still “in trials” in the U.S., although the implants have been used successfully worldwide since the early 1990s. [Canada resoundingly approved them in 2006](#). In New York, these doctors are participating in the trial: [Dr. Peter Cordiero](#) at Memorial Sloan Kettering Cancer Center. (You must have your mastectomy at Sloan Kettering as well.) [Dr. Norman Schulman](#) at Lenox Hill Hospital.

BREAST RECONSTRUCTION AND BREAST IMPLANT INFORMATION

Facing Our Risk

[Facing Our Risk](#) is “a nonprofit organization for women with increased risk of cancer due to family history and genetic status, and for members of families in which a BRCA mutation may be present.” This page provides a good overview of all the options available for reconstruction. A good general resource for treatment information, as well.

Just Breast Implants

This [privately-maintained site](#) links to manufacturer information, consent forms, and studies on just about every type of implant.

Center for Microsurgical Breast Reconstruction

[These plastic surgeons](#) specialize in the various new “free flap” procedures. The site provides detailed information about these types of reconstruction.

Johns Hopkins University “Ask An Expert” page

[Spend some time here](#) to find answers to questions you didn’t even know you had. This is set up like a forum, but all the questions are answered by Johns Hopkins medical staff. Extremely useful for both reconstruction questions and general information.

Implant Info

[Nicole Cummings](#) describes her informative site as “A Positive Online Web Site about Breast Augmentation.” As you browse this site, be aware of her point of view!

Center for Women and Families

[This nonprofit](#) provides a well-researched page detailing some of the problems related to silicone and saline breast implants.

Statement from FDA hearings on safety of silicone breast implants

[Statement by Sidney M. Wolfe, MD at FDA Hearing on Silicone Gel Breast Implants.](#)

AFTER MASTECTOMY

Don’t try to be superwoman after your mastectomy. Plan to have family and friends take care of you for at least a week. Your range of arm motion will be limited and you’ll probably feel weak for a while. Sleeping is difficult as there are no comfortable positions!

Be prepared with comfortable pants and button- or zip-up shirts as you won't be able to pull anything over your head for a while.

Physical therapy can help you with stretches and exercises to regain full arm movement. Ask your doctor for a referral to a physical therapist; don't assume the same exercises you did before surgery will help—they may even be harmful. Push-ups are NOT a good idea at this time!

If you have no access to physical therapy, [Recovering From Breast Surgery: Exercises to Strengthen Your Body and Relieve Pain](#), by Diana Stumm is a good guide.

After surgery, you will probably be left with one or more “drains,” tubes that allow fluids from the surgery site to drain outside the body. They can be painful if allowed to pull on the incision site. One of the nicest things you can do for yourself is to purchase a “mastectomy camisole,” with pockets for the drains, before surgery since you'll be living in it for several weeks afterward. [SofteeUSA](#) makes one that is incredibly comfortable and their customer service is wonderful. Don't balk at the price; it's well worth it. The site says your insurance may pay for it, but mine didn't.

Your doctor will provide you with a surgical bra after your surgery. However, you will probably want more than one! You will need supportive, front-opening bras for support. [Make Me Heal](#) has a vast selection of post-surgery bras and reconstruction-related products but they're quite expensive. Zip front cotton sports bras are very comfortable and much less expensive. The least expensive zip-front bra is from [Hanes.com](#). [BareNecessities.com](#) carries models from Nike, Jockey and Moving Comfort. You may not want to wear underwire bras any more after you're fully recovered, but nice “wire-free” or “wireless” bras that fit well are almost impossible to find in stores. Both [BareNecessities.com](#) and [FreshPair.com](#) have great selections, prices and customer service.

BREAST CANCER COMMUNITY AND BREAST CANCER FORUMS

SHARE

<http://www.sharecancersupport.org/>

866-891-2392

(NOTE: the website does not work well with the Firefox browser. Use Safari or Explorer instead.)

Support groups and educational programs in New York City and a nationwide hotline staffed by survivors. An excellent first call to make.

From the website: “We are breast cancer and ovarian cancer survivors and we are here to help you. SHARE has nationwide hotlines staffed by trained and knowledgeable volunteers who are cancer survivors. We also run support groups and educational programs for women with breast or ovarian cancer in the five boroughs of New York City. In other areas, our hotline volunteers can find a support group and resources where you live.”

Gilda's Club

<http://www.gildasclub.org/>

“Clubhouses” in 21 cities worldwide. Offers support for all types of cancer, not just breast cancer.

From the website: “To provide meeting places where men, women and children living with cancer, along with their families and friends, can join with others to build a personal network of social and emotional support as an integral part of cancer treatment. Free of charge and non-profit, Gilda's Clubs offer support and networking groups, seminars, workshops, specialized children's programs and social events, in a nonresidential and home-like setting.”

BreastCancer.org Community Knowledge Exchange

[BreastCancer.org](#) maintains an extremely active breast cancer forum. A wide range of topics addresses just about every situation and diagnosis.

CarePages

Provides on-line communities and a place for people to create their own web pages, news and tips.

From the website: “CarePages are free, easy-to-use Web pages, brought to you by [Revolution Health](#), that help family and friends communicate when a loved one is receiving care.

CarePages help Families:

- Create a virtual meeting place on the web
- Share news and photos as often as needed
- Receive emotional support during a time of need

Positive Health Magazine's Breast Cancer Page

Not exactly community, but a excellent group of supportive and informative articles to read if you've just been diagnosed.

GENERAL BREAST CANCER INFORMATION

Center for Disease Control (CDC) Breast Cancer Page

Basic information; list of clinical trials; link to [National Cancer Institute Complimentary and Alternative Medicine](#) page

Mayo Clinic

BreastCancer.org

My personal favorite site. Provides a huge amount of information, professionally moderated forums, and on-line conferences and webinars with medical professionals. From the website: “[breastcancer.org](#) is a nonprofit organization dedicated to providing the most reliable, complete, and up-to-date information about breast cancer. Our mission is to help women and their loved ones make sense of the complex medical and personal information about breast cancer, so they can make the best decisions for their lives.”

Dr. Susan Love Research Foundation

Excellent educational site.

[Breast Cancer Action](#)

Breast Cancer Action is a nonprofit grassroots organization founded by breast cancer survivors. It is one of the few sites with no connections to corporate or pharmaceutical sponsors. Look to this site for in-depth reports on the pros—and cons—of drugs and treatment options, including both conventional and complimentary therapies. The site is a bit difficult to navigate but well worth the effort. Their [breast cancer treatment information](#) page links to a vast amount of information and studies not available on the more mainstream sites.

[National Breast Cancer Coalition](#)

This grassroots advocacy site contains a lot of good information on political initiatives and advocacy, in addition to some medical and treatment information, study links and position papers. Their [Guide To Quality Breast Cancer Care](#) is the best resource for learning how to navigate the system.

[Medline Plus](#)

Medline Plus is run by the National Institutes of Health and links directly to studies and medical journals. The reading can be pretty heavy going if you're not a medical professional, but it's the best place to find information "straight from the horse's mouth." Check out their ["breast cancer encyclopedia"](#)

[Center for Medical Consumers](#)

The Center For Medical Consumers is a nonprofit advocacy organization founded to "provide access to accurate, science-based information so that consumers could participate more meaningfully in medical decisions that often have profound effects upon their health." Their huge database of news, articles and information covers medical issues from treatment to regulation to hospital reporting to advocacy. Their site does not offer a search function, but it's interesting to dig around.

COMPLIMENTARY AND ALTERNATIVE MEDICINE (CAM) FOR BREAST CANCER

Complimentary and alternative medicine (CAM) for breast cancer—including herbs, acupuncture, vitamins and diet—is becoming more accepted by mainstream medicine as therapies and co-therapies for breast cancer. Many [hospitals are embracing complimentary medicine](#).

I strongly advise against self-medication, especially when it comes to breast cancer. Complimentary and alternative therapies are strong medicine and should be used under the care of an experienced practitioner. Be sure to let both of your medical teams (conventional and alternative) know what supplements and medicines you are taking to avoid potential interactions.

Finding responsible information on alternative cancer therapies is difficult. The [books listed above](#) are good sources. Good information is available online, too, but you need to dig for it—lots of what's out there is unscientific or just plain untrue. (Conversely, websites that trash alternative medicine indiscriminately, such as "Quackwatch" are poor resources too.) If you're researching alternative therapies online, follow these guidelines:

- Don't trust anyone promising a "cure."
- Articles should be referenced—look for references and footnotes linking to studies. If it's not referenced, look for something that is.

- Research your keywords on [Google Scholar](#). If it doesn't come up here, chances are there's no science to back it up.
- Look for independent research. Don't rely on product sites for reliable information about products they sell; look at the studies they reference to confirm their claims.
- Read books.

[National Center for Complimentary and Alternative Medicine](#)

Provided by the National Institutes of Health. Comprehensive and conservative. Includes links to clinical trials.

[National Cancer Institute's Complimentary and Alternative Medicine Page](#)

Provided by the National Institutes of Health. Comprehensive and conservative. In-depth information on a select group of alternative cancer therapies.

[University of Maryland Medical Center Breast Cancer Page](#)

[Complimentary and Alternative Medicine Index:](#)

[Whole Health MD](#)

From their website: "WholeHealthMD is a result of the collaboration of medical writing specialists, conventionally-trained physicians and integrative CAM specialists who practice in integrative medicine centers. The integrative medicine clinicians have practiced in centers operated from 1996-2000 by American WholeHealth. More recently we have had support from integrative clinicians from the Complementary Medicine Program at the University of Maryland."

[Mayo Clinic Drug & Supplement Information Page](#)

General information about drugs, supplements and interactions.

[The Moss Reports](#)

Dr. Ralph Moss's website containing his research on conventional and alternative cancer treatments. Anti-establishment; solid research.

[The Townsend Letter](#)

Great resource for natural medicine in general, written and edited by natural medicine-oriented MDs and NDs (Naturopathic Doctors). A bit tough to navigate, but worth the effort. Search [The Townsend Letter Archives](#) for "breast cancer" to find their articles.

COMPLIMENTARY AND ALTERNATIVE MEDICINE (CAM) FOR BREAST CANCER: HOSPITAL WEBSITES

[New York-Presbyterian \(Columbia and Cornell Universities\)](#) Scroll down the right side for links.

[Beth Israel's Center for Health and Healing](#)

[NYU Medical Center Consumer Health Library](#)

[Memorial Sloan Kettering Cancer Center](#)

TRADITIONAL CHINESE MEDICINE (TCM) AND ACUPUNCTURE FOR BREAST CANCER

[Breast Cancer Treatment with Traditional Chinese Medicine](#)

Description from their website: "This site explores an approach based on traditional Chinese medicine (TCM), a holistic medical system that can help you regain your natural healing ability."

[Traditional Chinese Medicine Information Page](#)

Good overview of TCM.

NATUROPATHY FOR BREAST CANCER

[University of Maryland Medical Center](#)

[HealthyWomen.org](#)

Short overview of the history and principles of naturopathy. Scroll down to the end for good information on how to find a qualified naturopath.

[Naturopath.com](#)

Description of naturopathy, homeopathy, and Traditional Chinese Medicine.

HOMEOPATHY FOR BREAST CANCER

[University of Maryland Medical Center](#)

[The American Institute of Homeopathy](#)

HOW TO FIND A NATUROPATHIC OR HOMEOPATHIC DOCTOR FOR BREAST CANCER: PROFESSIONAL ORGANIZATIONS

[American Association of Naturopathic Physicians](#)

The AANP maintains a database of members in every state.

[Oncology Association of Naturopathic Physicians](#)

Find an ND specializing in cancer treatment.

[North American Society of Homeopaths](#)

[National Center for Homeopathy](#)

NUTRITION AND BREAST CANCER

While eating better won't cure cancer, you can't go wrong with a healthy diet. At this point it's been scientifically confirmed that eating vegetables is good for you; processed food should be avoided, and organic food is higher in nutrients. But don't assume that everything else you hear is true. For instance, soy is heavily promoted as being a good breast cancer-preventive food. In fact, soy may actually increase some women's risk of breast cancer. Read up and talk to your doctor before adding soy supplements or more soy foods to your diet.

Community Breast Health Project
[Nutrition and Breast Cancer Part I](#)
[Nutrition and Breast Cancer Part II](#)

Highly recommended for first reading. The most well-researched yet readable article you'll find on diet and breast cancer, short of reading a book.

[BreastCancer.org Nutrition and Breast Cancer Page](#)

Short, balanced look at how selected foods benefit your body.

[Fats and Breast Cancer](#)

A good concise article that revises what you think you know about the health effects of different types of fat.

[World's Healthiest Foods](#)

This site provides detailed nutritional information on healthy fruits, vegetables, seeds, nuts and oils that strengthen you for your fight.

[Weston A. Price Foundation](#)

A vast holistic nutrition database. Includes a lot of surprising information you won't find on mainstream nutrition sites. From their website: "The Foundation is dedicated to restoring nutrient-dense foods to the human diet through education, research and activism. It supports a number of movements that contribute to this objective including accurate nutrition instruction, organic and biodynamic farming, pasture-feeding of livestock, community-supported farms, honest and informative labeling, prepared parenting and nurturing therapies."