



Breast Cancer Options **Resource Guide**

An Informational Guide to Resources & Services
in the Hudson Valley and Surrounding Areas.

*Giving you the information you need to
make informed health choices.*

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The contents of this booklet are not meant to constitute medical advice or replace the care of a qualified physician or other care provider. For more recent updates on this material, please visit www.BreastCancerOptions.org or request our weekly news updates.

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FORWARD: **BREAST CANCER OPTIONS**

Breast Cancer Options, Inc. began as the Mid Hudson Options Project, Inc. in 1998. It was started by a group of breast cancer survivors and their supporters interested in receiving services and information that were not available in the Hudson Valley area. The organization incorporated in December 2000 and got a DBA(Doing Business As) as Breast Cancer Options in 2002. We are now legally Breast Cancer Options, Inc. To date, Breast Cancer Options has directly assisted several thousand people with breast cancer related concerns.

We serve six counties of the Hudson Valley:
Ulster, Dutchess, Columbia, Greene, Orange and Sullivan.

WE WELCOME CALLS & EMAILS AND PROVIDE INFORMATION NO MATTER WHERE YOU LIVE.

Our ultimate goal is to end the breast cancer epidemic through legislation, education and public awareness. We provide support and help create the positive effects of activism, by reaching out to breast cancer survivors, families in our community and anyone whose lives have been touched by this disease. We would like to see increased efforts focused on prevention of this disease, if not for us, then for our daughters, our sons, and their children.

Our Mission

To educate breast cancer patients about effective treatment options, to advocate for and support informed patient choice and to promote public awareness regarding cancer risk reduction.

Our Programs and Services

- **Peer Facilitated Support Groups:** Peer-led support groups are in each of the six counties we serve. They meet once a month. The facilitators must go through a special training and are monitored by a social worker. Funded by a grant from the Dyson Foundation. Check our website: <http://www.breastcanceroptions.org>
- **Acupuncture Clinics:** 5 free sessions for women going through breast cancer treatment or suffering from treatment side effects. Call for all locations and to receive clinic paperwork. Funded by a grant from the Miles of Hope Breast Cancer Foundation
- **The Companion/Advocates Program:** We provide specially trained Breast Cancer Survivors to accompany women or men diagnosed with breast cancer, or facing a possible breast cancer diagnosis, to initial visits with their surgeon and/or oncologist. A cancer diagnosis is one of life's most terrifying moments and many patients and their families find it difficult to remember and process all of the information they receive at these first visits.

A trained Companion Advocate can provide emotional support and an objective viewpoint during and after a visit, ensuring that important questions are asked and answered. They can help in reviewing what was discussed, so that no points are missed and can contribute the invaluable experience of someone who has walked this road before.

- **Camp Lightheart for the children of breast cancer survivors:** A free sleepover camp for children from 8-15 who have a parent with breast cancer. Campers are in a nurturing and fun-loving environment with a trained staff sensitive to their situation. The main task of the staff is to find the right balance between just having fun and providing relief for the kids. Held each August at Omega Institute in Rhinebeck NY.
- **Telephone and e-mail consultations:** A reliable resource for confidential answers to questions and for referrals for additional information or services

- **Complementary Medicine Conference:** A yearly conference, focusing on prevention, risk reduction and evidence-based complementary treatment modalities is held in the spring each year. The conference features internationally known keynote speakers who are expert in the fields of traditional medicine, complementary medicine, and risk reduction and prevention strategies. Sessions are geared to help cancer survivors and anyone interested in reducing risk to learn about tools to use for a better quality of life.
- **E-mail Updates:** “BCO News” is sent out one to two times a week to breast cancer survivors and those who are supporting loved ones with cancer. The subject matter is varied and well rounded, ranging from the latest medical breakthroughs, research updates, and environmental links to cancer and scientific information on complementary adjuncts. The newsletter is intended for educational purposes only. It does not advocate particular treatment options. It does, however, make information available that might otherwise be difficult to obtain and may enhance one’s ability to make informed choices. Please sign up on our website.
- **Website:** Our website, www.BreastCancerOptions.org provides research information on treatment options for those with breast cancer, information on the environment and breast cancer, as well as being a clearing house for reliable information.
- **The Healthy Lifestyles Support Series:** This is an ongoing series that looks at ways we can make small and easy lifestyle changes in our daily lives for optimum health. The evidence points to the benefits of “anti cancer” diets, exercise, managing stress, and other mind/body methods, and shows that they can impact many diseases including cancer and greatly improve the quality of one’s life. These are held throughout the community and will be listed in our Events Calendar section of our website.
- **Breast Cancer Forums:** Breast Cancer Options holds breast cancer informational forums in the community dealing with the latest information about conventional medicine, complementary medicine, and risk reduction. We address common myths about breast cancer.
- **Discount Vitamin Club:** Log into our *Discount Vitamin Club* page on our website and you will receive 25% off 500 different high-quality vitamins. Breast Cancer Options receives a donation from the company.

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PART ONE: MAKING DECISIONS

I've Been Diagnosed With Cancer...What Do I Do?

Carol Robin, Hope Nemiroff

The importance of making informed decisions

A breast cancer diagnosis often brings treatment decisions that can be confusing and frightening. Should I choose surgery or something less invasive? Is this procedure right for me? Should I "watch and wait" and defer a decision for now? Should I have this test? What are the chances that this treatment will work for me? How will it make me feel? How will it change my life?

The treatment that is best for one person may not be what is best for another who is in exactly the same situation. The decision that best serves a particular person often depends on their own preferences and values. Take time to make your decision. Know yourself. Know the type of lifestyle you live and the values that you hold dear, and make your decision based on those values. Make sure that you understand all of your options and that all of your questions get asked and are answered.

Making decisions can be difficult because:

- There is more than one choice.
- Each choice has good points (pros) and bad points (cons).
- There is no "correct" choice.
- What you choose depends on what is important to you.

Informed people feel better about the decision process. Their decisions are more likely to match up with their preferences, values and concerns. These people are more likely to stick with the regimens the treatment requires, and they often end up rating their health after treatment as better.

What should I do first?

Breast cancer feels urgent but most people diagnosed with breast cancer (regardless of the stage of their breast cancer) can safely take a few weeks to:

1. FIRST OF ALL...BREATHE

Give yourself time and space to take it in and explore how best to proceed. It's natural to want to deal with it immediately, but breast cancer is usually not an emergency. Your treatment and your experience will be greatly improved by taking a reasonable amount of time to understand your particular condition and the treatment options you have. Most tumors have been growing for years when they are discovered. A few days or weeks is not very significant to the tumor growth, but can make all the difference in finding the treatments that are best for you. Ask your doctor if you can spend a few weeks thinking about your choices.

2. GATHER INFORMATION AND ASK QUESTIONS

Talk to your doctor and get all the information you can. Ask your doctor *which* choices you need to make *when*. You don't need to decide everything at once. However one choice may affect other choices for your care.

It's very helpful to write down your questions, and to bring someone with you to support you and take notes for you. If you can't talk comfortably with your doctor it is okay to change doctors and find one you feel comfortable with. Everyone on your healthcare team should be supportive of you and receptive to open discussion of your unique situation and options.

Be sure to find out exactly what kind of cancer you have, and what stage it is so you can research your particular type of cancer. Find out what tests were used to arrive at the diagnosis, and what further tests are planned to confirm it. Use the resources in the Breast Cancer Resource Guide to help you understand your condition and your different treatment options. When your doctor tells you your treatment options, ask if these are your **only** choices.

If you're not comfortable looking up information online, or by phone, ask a friend or family member to

research it for you until you understand the information and get the answers you need.

3. GET SECOND OPINIONS

It's always wise to get a second opinion on what type your cancer is, and how it should be treated. After you get a pathology second opinion, you should get second opinions about your treatment options. That will give you more information and help you choose a course of care. A second opinion is particularly important if your cancer was discovered by a doctor without much experience in dealing with your type of cancer. New developments in cancer treatment are happening so fast that it's practically impossible for every doctor to be aware of all the most up-to-date ways to deal with the disease. The best doctor to see is one who has had many years experience in treating your type of cancer.

*Studies have shown that one in five cancers are incorrectly diagnosed or staged.
In one study, more than half of the women interviewed had not been told
all their surgical options at their first surgical consultation.*

Get a second opinion *outside* the first doctor's medical practice or cancer center. Often doctors who work together don't like to disagree with each other. No reputable physician will question your right to a second opinion. Remember, you are creating a healthcare team to help you. Your health is the primary objective. You have a right to support and open communication from all your healthcare providers.

When you go for a second opinion, take your current doctor's diagnosis and treatment plan with you, along with your pathology report. Take all related test results, tissue slides, x-rays and/or other imaging you have undergone so they will not need to be redone. The doctor should review your medical records and automatically reevaluate your diagnosis to make sure that it's an accurate second opinion.

There is an excellent chance that your second opinion will mirror your first opinion with regard to diagnosis and treatment recommendations. If so, you can move forward with treatment, confident that you are doing the right thing.

If the second opinion does not concur with the first, you are faced with the dilemma of opting for a third opinion, or returning to your original doctor and requesting that he or she engage in a constructive dialogue with the doctor who rendered the conflicting opinion. It's possible that after they share the reasons for their opposing opinions, they will find common ground and agree on the best course of action for you.

The important thing is that you must be able to trust and believe in the persons charged with your care, so that you can focus your energies on getting better and moving ahead with your life.

You can get second opinions from a:

- breast surgeon
- pathologist
- radiation oncologist
- medical oncologist

*A recent patient guidelines brochure developed by the NCI and the ACS strongly recommends a 2nd opinion for pathology review of the slides, **particularly for ductal carcinoma in situ** and other noninvasive lesions for which the error rate on review may be as high as 35%.*

A second opinion may make the difference between a diagnosis of benign hyperplasia vs. an in situ carcinoma and the need for re-excision, radiation therapy and/or chemotherapy. Second opinions can also help by confirming a diagnosis and providing reassurance that the patient is making a reasonable choice.

4. EXPLORE THE DIFFERENT TREATMENT OPTIONS

Your treatment options include surgery, chemotherapy, radiation, hormonal therapy and complementary medicine therapies.

If all the doctors you've consulted with agree on a particular course of treatment, and you feel comfortable with it, your decision should be fairly easy. When there's a difference of opinion, the doctors involved should talk together to explore their points of view and develop a clear recommendation. If the doctors cannot resolve their conflicting viewpoints, a third opinion may be in order.

Sometimes, you may be presented with more than one appropriate treatment plan. For example, in certain cases there may be a nearly equal chance of recovery with a mastectomy (removal of the entire breast) or with a lumpectomy plus adjuvant therapy (removal of the tumor only, followed by radiation or chemotherapy). In a case like this, your doctor can give you a thorough discussion of the pros and cons of each alternative and an informed opinion, but only you can make the final decision about which treatment feels right to you.

You may also have a very personal choice to make if your doctor has told you that you are eligible to receive an investigational therapy. Investigational therapies represent the most recently developed ways to treat particular cancers. They are given to patients whose conditions meet specific criteria in carefully regulated tests called clinical trials. Many people eligible for a clinical trial are also good candidates for a standard therapy such as radiation or chemotherapy, and so must make a carefully considered choice in consultation with their doctors.

With any treatment, be sure your doctor clearly explains to you the pros and cons, including how the treatments will affect your body, your overall health and your lifestyle. The best treatment plan for you will be the one that is most compatible with your belief system, your emotional needs and your lifestyle. Your doctor's advice should be based on the best medical research but should also take into consideration your individual needs. New medical research is always giving us new information. The decision should be based on the latest medical evidence.

Once a decision on your type of treatment is made, you still have to determine where you will be treated and who will treat you. You may well end up being treated by one of your diagnosing physicians. But the "where and who" decision depends largely on the type of care you need. If you've been told that you have a rare form of cancer that requires highly sophisticated equipment to give you the best chance for a cure, you may need to stay at a National Cancer Institute-designated cancer center. (People living far away from such a hospital may be able to take advantage of the travel and lodging assistance available through special programs.)

Most cancer cases, however, can be treated successfully at a local hospital, provided it has the right facilities. However, surgery for breast cancer should be done by a breast surgeon who knows all the latest techniques.

A study from 2003 Annals of Surgical Oncology showed that treatment by a specialist resulted in a 33% reduction in the risk of death at 5 years. A 2006 study from England adds to concerns about surgeons who only perform occasional breast cancer operations and the study found a strong link between the volume of procedures a hospital carried out and the readmission rate for further surgery.

Since the doctors you choose will be crucial members of your healthcare team, whenever possible choose doctors with whom you feel safe and comfortable with, both in terms of their medical expertise, and their sensitivity to your needs.

Once you find out all the particulars on the type of cancer you have, get hard copies of all your records and tests that were used to arrive at your diagnosis.

5. GET THE SUPPORT YOU NEED

Your healthcare team should also include people and/or organizations that provide the various kinds of support you may need while treating breast cancer. These can range from emotional support in the form of support groups or private counseling, to assistance with keeping your life and household

functioning smoothly. While family members and friends can be a tremendous help, sometimes people who are not emotionally involved can offer a different type of support.

You can call someone from our free Companion/Advocates program for support. We will provide a trained Breast Cancer Survivor to accompany you to initial visits with your surgeons and oncologists. (845/339-4673). You can also call your local hospital to see what support services they offer.

Practitioners such as psychotherapists, counselors, social workers, massage therapists, body workers, yoga or exercise teachers can offer important support. Household help, rides to appointments, home healthcare can help make life more manageable. *See the Resources section for local services*

6. LEARN EFFECTIVE DOCTOR/PATIENT COMMUNICATION TIPS

When consulting a doctor, try to present a detailed, well-organized account of your present symptoms and relevant past history. It may help you to write down what you want to say before going in for your appointment. If there is more than one problem, start with the most important one. If you have a particular concern, bring it up at the beginning of your visit or phone call. If medications are being taken, write down their names and dosages or bring the original bottles to the appointment. Since patients often forget much of what they are told in a doctor's office, taking notes or bringing someone with you might be helpful.

Some physicians are good communicators and others are not. You have the right to receive a clear explanation of the physician's findings and proposed treatment regarding your case. If you feel you are not being addressed with openness and respect, or receiving answers to your questions, don't let it pass.

It is important that feelings of fear, embarrassment, or even resentment do not create a barrier between you and your care provider. Discomfort during an examination is something else the physician wants to know about. If the physician makes a sound or comment that causes concern, ask what it means. Likewise, do not let fear or embarrassment stop you from mentioning a symptom or a problem that is bothering you.

If you have doubts about a diagnosis or treatment plan, voice them. If a particular treatment is objectionable, the physician may be able to suggest an acceptable alternative. If necessary, a consultation with another physician should be requested.

Telephone Tips: Before calling the office, take a moment to organize your thoughts. What is the problem? When did it begin? If there is a pain, does it come and go or is it steady? Does anything bring it on or relieve it? If there is an infection or any other reason to suspect a fever, the temperature should be taken. Try to decide whether the problem is urgent. Before calling, write down a one-sentence description of your problem, your reason for calling, a symptom list, and no more than three questions that you may have.

In a well-run office, the receptionists and nurses are trained to assemble the information needed for a preliminary evaluation. After talking to a receptionist or nurse, if you still believe it is necessary to speak with the physician, *ask*.

When you telephone, have a pad and pencil handy to write down any instructions. Don't depend on memory alone, as it often fails us when we are anxious.

When calling for a prescription refill, know the phone number of the drugstore. The request should be made during the physician's office hours and before you are down to the last pill. That way the physician can review the office record to see whether the medication is still needed, whether the dosage should be changed, and so on.

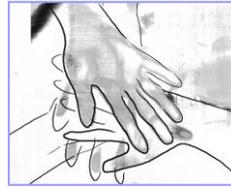
Remember, good medical care should be a partnership between patient and physician.

7. ASK FOR HELP

Don't be afraid to ask for help. Whatever treatment options you choose, it will be easier with some help. Women often have a hard time asking for and accepting help, so we often don't realize what is available to us. Give yourself a break, and give someone else, a friend, relative, co-worker, neighbor or stranger an opportunity to give of themselves. You would do it for them. If you are too overwhelmed to do any of this yourself, you can ask a friend or someone from your local support group to do it for you.

8. BREATHE SOME MORE

In fact, make it a habit to breathe every day, all day. You are alive and you are not alone and healing is always possible.



Getting Organized

Keep a notebook that includes:

1. Copies of all of your medical and lab test reports.
2. Record of the dates of your doctor and health related visits.
3. Co-pay receipts for medical visits and prescriptions.
4. A log of mileage and tolls to and from doctor and health related visits. (a tax deductible expense)
5. Receipts for airfare, meals and lodging related to doctor visits.
6. Names, phone numbers and emails of your doctors and healthcare practitioners.
7. Names, phone numbers and emails of your support team.

Other Records to Maintain:

1. A file of all your medical bills.
2. Copies of the Explanation of Benefits from your insurance company. (Check to make sure that your insurance company paid their part.)
3. Doctor bills that you have crosschecked to make sure that they have been submitted the bill to your insurance company.
4. Bills from all practitioners that are not covered by your insurance company. (You may be able to deduct the expense from your income tax.)

Record of mileage and tolls to and from healthcare professionals who are not covered by your insurance. (You may be able to deduct the expense from your income tax.)