

**WHAT TO DO NEXT:**  
**SUGGESTIONS FOR WOMEN NEWLY DIAGNOSED WITH BREAST**  
**CANCER**

Being diagnosed with breast cancer is often frightening and confusing. It is easy to feel lost in a world of unfamiliar medical terms and procedures. Questions about diagnosis, treatment, money, relationships, and quality of life can cause you worry and stress. Sometimes you don't even know where to begin or what questions to ask.

You are not alone in this journey. (This document was written by women who have gone through this experience.) By reading this, you are already taking the first steps toward recovery. The following pages contain ideas and tips that will hopefully make dealing with health care providers, hospitals, and your health easier and less intimidating for you and your loved ones.

The best thing that you can do for yourself now is to **give yourself time to think about your options**. You need not feel rushed into making decisions you are not comfortable with or do not fully understand. You have this time to gather information and make informed decisions. A few weeks most likely will not influence your treatment outcome, but it may make a huge difference in your state of mind. Your diagnosis will be presented to you with a series of choices; what matters is that you make the choices that are right for *you*. The process may seem overwhelming and leave you with a lot of uncertainty. You can ask people you trust to help you make the choices that lie ahead. You and your family or friends can become advocates by doing research and talking to experts. Breast Cancer Action (BCA) is one resource for you during this time.

### **Visits to your Health Care Provider**

**This is a period of time in your life when you may experience miscommunication or confusion.** Visiting health care providers can be one of the most unsettling parts of having cancer. Being prepared for health care provider visits can make you more confident and save a lot of time and frustration. It may seem as though your health care provider is bombarding you with a lot of information. You are being told a lot of information, and you may feel silly or stupid to ask questions or to

admit that you do not understand. It is natural to be less able to grasp new concepts now than you would normally be able to. You may find the following tips helpful in reducing confusion and stress.

- **Remember: This may be a team effort but you are the team leader.** You will be talking with a number of doctors and advocates who will make recommendations for your care. As the patient, you have the final decision.
- Do not be afraid to seek out a **second opinion**. Second opinions are not only available but encouraged by most health care providers in the cancer field. Do not be surprised if you get different opinions from different doctors. In the San Francisco Bay Area, you can call the Regional Cancer Foundation at 415-775-9956 to get a free second opinion. For a directory of multidisciplinary second opinions for anywhere in the country, call the R.A. Bloch Cancer Foundation at 800-433-0464.
- Have a three ring **binder** handy. Use it to collect all your paperwork. (insurance information, laboratory reports, health care provider's notes, hospital forms.)
- Be responsible for retaining copies of all of your **paperwork**; this will save time in the future.
- Get a **pocket calendar** to keep track of all appointments. Keep a list of names and phone numbers in it, as you will be most likely seeing more than one health care provider. This will serve as a handy reference guide to call and verify appointment times.
- **Call ahead** on the day of your appointment to make sure things are running on time. You could save yourself a long wait in the health care provider's office.
- Begin a **list of questions** and keep it in your binder. A sample list of questions is included in this booklet. Do not be afraid to ask these or other questions; health care providers are usually very willing to address any concerns you may have. (If your providers are not, find ones that are.)
- Locate your **insurance policy** and familiarize yourself with the details of your coverage.

- Take **insurance cards** with you to all appointments. Everyone involved in the health care of your breast cancer (health care providers, hospitals, pharmacies, and laboratories) will need them.
- Take along a **tape recorder**, and ask if you can use it. Health care providers will be presenting unfamiliar concepts and using terms that you may not be familiar with. The tape recorder will give you a chance to listen later at your own pace.
- **Another set of ears** can also prove to be helpful. Not only will a loved one help with remembering what your health care provider says, but they may also help curb the anxiety associated with the whole process of the health care provider's visit.
- You may be under the care of more than one physician during and after treatment. Make sure all of your health care providers get **reports** on all provider laboratory visits, x-rays, and tests. Ask your primary care provider to facilitate this, and follow up to be sure that he/she does.
- Try to have your **tests** done at the same facility for the best comparison in the future.
- Don't be afraid to ask for help from your health care provider at any time. It is okay to call on a Sunday afternoon if you are experiencing pain or have a question.
- If possible, leave your **children** at home or with a friend during your health care appointments, such as labs, x-ray, therapy and health care provider's visits. This time is for learning and understanding your illness; the more attention you can give to this experience, the better your health care will be.

### QUESTIONS TO ASK YOUR HEALTH CARE PROVIDER

If your health care provider is not able or willing to answer these questions, you should think about finding another health care provider. Remember to bring a notebook to take notes on what your health care provider says. Having a tape-recorder, and another person to listen to what the health care provider says (and to provide emotional support), can be an enormous help.

Another helpful tool is to try visualizing what is being explained to you. Ask the doctor to show you an illustration to help you grasp where the cancer is, how tests will be performed, and how treatment will proceed. You can also use this illustration to help explain things to your family.

Also, try and verbalize what you heard. Repeat to the doctor what you thought he or she said. This provides an opportunity to clear up any communication problems.



## **Doctors**

Q: Is the doctor **board certified**? For the doctor's education, training, certification, and years in practice, you can either ask the doctor directly, call his or her office, call your local medical society or osteopathic medical association. You can also call your state board of medical examiners, or look in the Directory of Medical Specialists (in public libraries). You can quickly find out if a doctor is board certified by calling 866-ASK-ABMS (275-2267), or through the ABMS website at [www.abms.org](http://www.abms.org) and then click on "Who's Certified." Verification is also available in the Official ABMS Directory of Board Certified Medical Specialties, published annually. The Directory can be found in many medical and public libraries. Written verification is available by contacting the individual specialty board in the physician's field of practice.

Q: What **specialized training** has the doctor had in treating the type of cancer you have? During the past 12 months, **how many patients has the doctor treated** with cancers similar to yours?

Q: When is the doctor normally in his or her office (days and hours of the day)?

Q: How can you reach the doctor during evenings and weekends?



## **Biopsies**

Q: What **type of biopsy** do you recommend?

-Incisional: part of the tumor is cut out and looked at under a microscope

-Excisional: the tumor is removed totally

-Needle: a needle is used to extract either fluid or tissue for microscopic analysis. This is also called “aspiration biopsy,” and can usually be done as an outpatient with a local or minimal anesthetic.

Q: What is a sentinel node biopsy? Are you qualified to do it? Do you recommend it? Why or why not?

Q: What, specifically, did my biopsy show? Ask the doctor for a copy of your pathology report.

Q: If there is a malignancy, **how much time can I take** to make up my mind on what type of treatment to have?

Q: Are you recommending **axillary node dissection** for me? Why or why not?

Q: Has cancer **spread** beyond the original site?

Q: What **stage** is the cancer in? How was this determined?

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### **Further Tests**

Q: Are there any specific instructions to follow before or after the test?

Q: **How long** will I be there? Will I be able to drive myself home?

Q: What are the **risks** in taking the tests? What are the most likely complications?

Q: Does my insurance company have to **approve the test** before it is done?

Q: Will the test hurt? How long before I can resume my usual activities?

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## Treatment Options

Q: What are my **treatment options**, considering the type and extent of my cancer, my age, and my lifestyle?

Q: What is the **goal** of the treatment?

*Possible goals:*

~ Control growth of tumor

~ Cure or eradicate the disease

~ Increase comfort level (reduce pain, stimulate appetite, increase energy)

Q: Can you arrange for me to **talk with someone** who has been treated for this kind of cancer?

Q: **What type of doctors** will be involved in treating me? This team of doctors may consist of a medical oncologist, a surgeon, a radiation oncologist (sometimes referred to as a radiation therapist), and oncology nurses, social workers, pharmacists, dieticians, and rehabilitative specialists.

Q: Which treatments will provide me with the best chance of long-term survival and the highest quality of life?

Q: How do non-conventional treatments differ from standard medical treatments?

Q: How can I find out about non-conventional treatments?

*For each treatment option:*

Q: Please **explain** what the treatment is. (Consider getting an illustration from the doctor.)

Q: What are the short-term and long-term **risks**?

Q: What are the treatment **side effects**, and what can I do to lessen or prevent these? (medication, nutritional support, exercise)

Q: Do I need to restrict my **diet or fluid intake**?

Q: Will my treatment make me prone to **infections**? If so, what type of symptoms should I look for?

Q: What problems should I report to you?

Q: Will the treatment hurt or be uncomfortable? If so, how can I lessen or prevent this discomfort?

Q: How long will I be in this treatment (weeks or months)? And how often?

Q: If I take this treatment, what will my **quality of life** be like during and after treatment? How will it affect my ability to work or to perform other activities that are necessary and important to me?

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## **Surgery**

Q: Why do you feel surgery is necessary for me? Are there any **non-surgical alternatives**?

Q: Is there a **less invasive** way to do this surgery?

Q: Please explain the surgery. Can you show me a diagram or illustration to help me to understand it better?

Q: Which surgery do you think is better for me: Lumpectomy or mastectomy?

Q: What is **lymphedema**? How can I protect myself from it?

Q: What is **reconstructive surgery**? Can it be done in my case? Can you put me in touch with patients who have gone through it?

Q: How long does it take to resume normal activities after surgery?

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### **Medications (questions for your doctor, oncology nurse, or pharmacist)**

Q: What is this medicine supposed to do?

Q: How and when will I know whether it is working?

Q: **How often** and **at what times** should it be taken?

Q: Does it matter if I take it on an **empty stomach** or with a meal?

Q: Will this prescription create problems with the other prescription or over-the-counter medicine (or vitamins or minerals) I'm already taking?

Q: Where can I find **printed material** on this drug?

*\* Most of these questions came from the book, Teamwork, The Cancer Patient's Guide to Talking with Your Doctor.*

### **Your Overall Health and Wellness**

While taking care of yourself physically will be your primary focus as you deal with your illness, it is important to nurture your mind and spirit as well. Here are some tips that women have found to be helpful for becoming relaxed and feeling prepared for decision-making and treatment.

- Wear comfortable clothing and shoes.
- Eat something that will make you feel satisfied. Freezing meals and preparing snacks ahead of time will come in handy when you are too tired to cook.

- Look for laughter or comforting entertainment: movies, TV comedy, a nice long bath, books, poetry, a decadent dessert, and music are some ideas.
- You may want to bring along a book, magazine and/or tapes and headphones to the waiting room with you.
- Ask your health care provider about relaxation techniques.
- Consider joining a breast cancer support group. You can call BCA at 1-877-2STOPBC for local support groups. Try out a few support groups if the first one does not feel right. Some areas have specific groups for young women, mothers, women of color, lesbians, etc.

### **Asking for Help**

Having breast cancer is a life-changing experience. This is a good time to reach out to the people in your life and let them reach out to you. **Don't be afraid to ask for help;** you can return the favor later. Even if this is the first time in your life that you have ever asked for help, learning to let go and reach out - or simply letting others in - could save you a lot of time and energy. Often your friends and family will want, and even need, to help you. Letting them do things for you will help them deal with your diagnosis and relieve some of the stress from your life.

Start keeping a list of things that friends can do for you. This is especially helpful when you have small children. Keep this list handy so you can easily assign people jobs. Here are some things that your friends and family can do:

- Provide rides to your health care or any other appointments.
- Help with household needs, such as babysitting, shopping, housecleaning, cooking, and taking care of pets.
- Do research into treatment issues and available resources. Health libraries and online services may be good resources.

### **Educate Yourself**

Breast Cancer Action believes that women can and should educate themselves about their disease. Some women may find that they prefer to have more information than others. In some cases, too much information can be as frustrating as too little. Try to focus on the decisions you need to make now, rather than ones that you may confront in the future. While gathering information is important, there are a lot of materials

available about breast cancer and you may find it difficult to decide what is relevant and what is not. Over time this will become easier as you learn who to trust and where to go for information. Start by learning to understand the basics, and then slowly build on that knowledge so you can make sound decisions about treatment options. **Gather the information that YOU need**, not what someone else thinks you need.

As you do your research, ask friends and family who have gone through a similar experience about what to do next and where to find information. Remember, however, that every person's experience is different. What worked for one person might not work for you.

## **RESOURCES:**

**BOOKS:** There are hundreds of books written on breast cancer. Many are available in the public library. Here are some that we suggest for newly diagnosed women.

--Dr. Susan Love's Breast Book (3<sup>rd</sup> edition) by Susan Love, M.D. and Karen Lindsey

--Everyone's Guide to Cancer Therapy by Dollinger

--Choices in Healing, by Michael Lerner (*a resource on complimentary and alternative cancer treatments*)

--Breast Cancer: What You Should Know (But May Not Be Told) by Steve Austin, N.D., and Cathy Hitchcock, M.S.W.

**Internet:** Beware that not everything you read on the web is reliable. Some well-known and credible websites on breast cancer are:

--**Breast Cancer Action:** [www.bcaction.org](http://www.bcaction.org)

--**Breast Cancer Network (BreastCancer.Net):**

[www.breastcancer.net/bcn.html](http://www.breastcancer.net/bcn.html)

--The National Cancer Institute's **Cancer Information Service (CIS):**

<http://cis.nci.nih.gov/>

--Community Breast Health Project: [www.cbhp.org/](http://www.cbhp.org/)

--Dr. Susan Love, MD, Breast Cancer Foundation: [www.SusanLoveMD.com](http://www.SusanLoveMD.com)

*(Education, research and advocacy)*

--National Alliance of Breast Cancer Organizations: [www.nabco.org](http://www.nabco.org)

--National Lymphedema Network: [www.lymphnet.org](http://www.lymphnet.org)

--Oncolink: <http://www.oncolink.org>

--Shared Experiences of Cancer: <http://www.sharedexperience.org/>

*(a website devoted to personal experiences of people with cancer, most of the entries are from women with breast cancer.)*

--Y-ME National Breast Cancer Organization: [www.y-me.org/](http://www.y-me.org/)

### **Support Groups and Contacts:**

It is important to remember that support groups can be very helpful and are not just for women "having trouble" with their diagnosis. **You can call BCA at 1-877-2STOPBC, or email [info@bcaction.org](mailto:info@bcaction.org), to find a support group in your local area.**

### **Throughout the U.S.:**

--Mautner Project for Lesbians with Cancer: (202) 332-5536; [www.mautnerproject.org](http://www.mautnerproject.org)

--National Latina Health Organization: (510) 534-1362; [www.latinahealth.org](http://www.latinahealth.org)

--National Lymphedema Network: (800) 541-3259 *(Quarterly newsletter, education, patient support and research.)*

--National Women's Health Network: (202) 347-1140; [www.womenshealthnetwork.org](http://www.womenshealthnetwork.org)

--National Y-ME: (800) 221-2141; [www.y-me.org](http://www.y-me.org)

*(Referrals to local support groups in your area, as well as peer referral)*

--Patient Advocate Foundation: (800) 532-5274; [www.patientadvocate.org](http://www.patientadvocate.org)  
*(insurance, job retention and/or debt crisis matters relative to diagnosis)*

--Richard & Annette Block Cancer Foundation: (800) 433-0464  
*(free second opinion and peer referral)*

--Telephone Support Groups: Cancer Care: (800) 813-HOPE  
*(a weekly one-hour conference call that is free to participants)*

### **U.S. Government:**

--National Breast and Cervical Cancer Early Detection Program: (888) 842-6355;  
[www.cdc.gov/cancer/nbccedp](http://www.cdc.gov/cancer/nbccedp) *(free or low-cost mammograms)*

--Information on breast cancer/clinical trials sponsored by the National Cancer Institute: 800/4 CANCER (800) 422-6237; [www.cancernet.nci.nih.gov](http://www.cancernet.nci.nih.gov)

--Up-to-date information on many cancers, delivered via fax: CANCERFAX:  
(800) 332-1088; [www.fda.gov](http://www.fda.gov)

--Information on adverse reactions to drug therapy: (800) FDA-1088 (800) 624-2511;  
[www.fda.gov](http://www.fda.gov)

### **In the San Francisco Bay Area:**

--Community Breast Health Project, Palo Alto: (650) 326-6686; [www.cbhp.org/](http://www.cbhp.org/)  
*(Provides information, support, and education to breast cancer patients, their families and friends.)*

--The Wellness Community, Walnut Creek: (925) 933-0107; [www.twc-bayarea.org/](http://www.twc-bayarea.org/)  
*(Free cancer support groups)*

--Women's Cancer Resource Center, Oakland: (510) 420-7900; Toll-free (888)-421-7900

[www.wcrc.org/](http://www.wcrc.org/) (*Library information, referrals, support groups, legal services and one-on-one practical and emotional support; also Latino and Sister-to-Sister African American program*)

--Charlotte Maxwell Complementary Clinic: (510) 601-7660; [www.charlottemaxwell.org](http://www.charlottemaxwell.org)  
(*Free massage and other therapies for low-income women with cancer*)

## **GLOSSARY OF TERMS FOR BREAST CANCER PATIENTS**

Adenocarcinoma: Specific form of breast cancer arising in gland-forming tissue

Alopecia: Hair loss, a common side effect of chemotherapy

Areola: The pigmented area around the nipple

Axillary lymph nodes: glands in the armpit that fight harmful invaders such as bacteria. The presence of breast cancer cells in these lymph nodes generally indicates that cancer is more likely to spread elsewhere in the body.

Axillary lymph node dissection: Surgical removal of lymph nodes in the armpit area

Atypical hyperplasia: Cells that are not abnormal in shape and increased in number

Benign: Not cancerous

Bilateral: Involving both sides, such as both breasts

Biopsy: Removal of tissue, either with a needle or through surgery. This term does not indicate how much tissue will be removed.

Bone marrow: Tissue that fills the center of bones

BRCA-1 and BRCA-2: normal genes, which can carry a mutation that may increase a person's risk of developing breast cancer

Breast reconstruction: Creation of an artificial breast by a plastic surgeon after mastectomy

Calcification: Small calcium deposits in the breast tissue that can be seen by mammography

Carcinogen: Substance that causes cancer

Carcinoma: Cancer arising in epithelial tissue (outer layer tissue such as skin, glands, and lining of internal organs). Most cancers are carcinomas.

Chemotherapy: Treatment of disease with certain chemicals. The term usually refers to cancer cell killing drugs given for cancer treatment.

Core biopsy: Type of needle biopsy where a small core of tissue is removed from a lump without surgery

Cyst: Fluid-filled sac

Dissection: Surgical removal

Ductal carcinoma in situ: (DCIS) Ductal cancer cells that have not grown outside of their site of origin, sometimes referred to as precancer

Estrogen: Female sex hormone produced by the ovaries, placenta, adrenal glands (glands near the kidney that produce hormones)

Estrogen-receptor-positive (ER+): tumor status indicating sensitivity to hormones. Breast cancer patients with ER+ tumors are often treated with chemical estrogen blockers such as tamoxifen or anastrozole

Fine needle aspiration: Procedure in which a surgeon uses a needle and syringe to remove cells from tissue to determine whether cancer cells are present

Genetic: Relating to genes or inherited characteristics

Hyperplasia: Excessive growth of cells

In situ: In the site of. In regard to cancer, it situ refers to tumors that have not spread past their site of origin.

Invasive cancer: Cancers that are capable of going beyond their site of origin and invading neighboring tissue

Lesion: A point or patch of a disease

Lumpectomy: Surgery to remove a cancerous tumor from the breast and a small rim of normal tissue around it

Lymph nodes: Glands found throughout the body that fight harmful invaders such as bacteria. The presence of cancer cells in lymph nodes adjacent to a primary tumor generally indicates that cancer is more likely to spread elsewhere in the body.

Lymphedema: Swelling of arm that can follow axillary node removal as part of breast cancer surgery. It can be temporary or permanent and occur immediately or any time after

Malignant: Cancerous

Mastectomy: Surgery to remove the breast

Metastasis: Spread of cancer to an organ beyond the location in which it originated

Oncogene: Cancer gene present in the body. These can be activated by carcinogens and cause cells to grow uncontrollably.

Oncology: The study of cancer

Pathologist: Health care provider who specializes in examining tissue and diagnosing disease

Radiation therapy: Treatment with high-energy rays (x-rays) to kill cancer cells

Radical mastectomy: Surgical removal of a breast

Radiologist: An individual specializing in the use of X-rays to diagnose or treat disease

Recurrence: Return of cancer after it seems to have completely disappeared

Remission: Disappearance of detectable disease

Sentinel Node Biopsy: Removal of only one or a few lymph nodes to determine whether breast cancer is likely to spread elsewhere in the body. The sentinel node is the first lymph node to which a tumor drains (and therefore, the most appropriate lymph node to examine for evidence of cancer)

Side effect: Unintentional or undesirable secondary effect of treatment

Staging of Breast Cancer: Stage is determined by the size of the tumor and the presence or absence of cancer cells in lymph nodes and in other parts of the body. Staging is important because it establishes how far the disease has spread, helping doctors to develop a treatment plan.

Stage 1: The tumor is  $\frac{3}{4}$ " or less with no evidence of spread to lymph nodes or distant sites.

Stage 2A: A tumor is less than  $\frac{3}{4}$ " with spreading to lymph nodes, or is a large tumor and no spreading to lymph nodes.

Stage 2B: A tumor is between  $\frac{3}{4}$ " and 2" with spreading to lymph nodes, or is a very large tumor without spreading to lymph nodes.

Stage 3A: A big tumor (over 2") with spreading to lymph nodes or fixation of lymph nodes to one another or other structures.

Stage 3B: If the lymph nodes inside the chest are involved or the tumor extends into the chest wall or involves and ulcerates the skin.

Stage 4: There are distant metastasis (to bone, liver, or lung for example) or skin, and chest wall involvement beyond breast area.

Tamoxifen (Nolvadex®): Drug that blocks hormones from stimulating cell or tumor growth in the breast, reducing the risk of recurrence for women whose breast cancer is receptive to estrogen

Tumor: Abnormal mass of tissue. A tumor can be benign or malignant

Ultrasound: The use of sound waves to obtain images for medical diagnosis

**Definitions taken from our newsletters and from *Dr. Susan Love's Breast Book*, third edition, by Susan Love, M.D., with Karen Lindsey (Perseus, 2000)**