BREAST CANCER ACTION

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

[Last revised Jan 2013]

Being diagnosed with breast cancer is often frightening and confusing and it is easy to feel lost in a world of unfamiliar medical terms, procedures, and advice. Questions about diagnosis, treatment, finances, relationships, and quality of life can cause you worry and stress. Sometimes you don't know where to begin or even 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 your 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, and 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, but you can ask people you trust to help you make the choices that lie ahead. You and your family or friends can become your best advocates by doing research and talking to experts. Breast Cancer Action (BCAction) is one resource for you during this time.

Visits to your Health Care Provider

Visiting health care providers can be one of the most unsettling parts of having cancer but there are things you can do to avoid miscommunication and minimize confusion. Being prepared for these 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 and you may feel your questions are silly or stupid. 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, but as the patient, the final decision is yours.
- 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 Second Opinion 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.
- Keep a three-ring **binder** to collect all your paperwork. It should include documents with insurance information, laboratory reports, health care provider's notes, hospital forms, etc.
- Be responsible for retaining copies of all of your **paperwork**. It 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 can save yourself long waits 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 treatment and management of your breast cancer (health care providers, hospitals, pharmacies, and laboratories) will need them.
- Take along a **voice recorder** with adequate capacity to record your entire visit, 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. Don't forget to ask for your own copies and keep them in your binder.
- 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 diagnosis, and the more attention you 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 provider. Remember to bring your binder, paper and a pen to take notes on what your health care provider says. Your voice recorder and another person to listen to what the health care provider says (and to provide emotional support) can be an enormous support

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 to 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 information about the doctor's education, training, certification, and years in practice, you can ask the doctor directly, call his or her office, or 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 and then click on "Who's Certified." Verification is also available in the Official ABMS Directory of Board Certified Medical Specialties, which is 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** does the doctor 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 in the doctor's office with a local or minimal anesthetic.

Q: What is a sentinel node biopsy? Is your doctor qualified to do it? Does she/he 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: Is your doctor recommending **axillary node dissection** for me? Why or why not?

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

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

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?

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 it be arranged 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), 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? (i.e., 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)? How often will I be treated?

Q: If I opt for 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?

Surgery

Q: Why does your provider feel surgery is necessary for you? Are there **non-surgical alternatives?**

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

Q: Please explain the surgery. Request a diagram or illustration to help understand it better.

Q: Which surgery does your provider think is better for you, lumpectomy or mastectomy?

Q: What is **lymphedema**? How can you protect yourself from it?

Q: What is **reconstructive surgery**? Can it be done in your case? Can it be arranged for you to be in touch with patients who have gone through it?

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

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

Q: What is this medicine supposed to do?

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

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

Q: Does it matter if you 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 (including vitamins or minerals) you are already taking?

Q: Where can you 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 (accessible at www.canceradvocacy.org/assets/documents/teamwork-resource.pdf)*

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 foods that satisfy you. Freezing meals and preparing snacks ahead of time will come in handy when you are too tired to cook.
- Look for sources of laughter and comfort in movies, television, and uplifting books. Nurture your spirit with nice, long baths, visual art, poetry, decadent desserts, music – whatever sustains you.
- You may want to bring along a book, magazine and/or your digital device with headphones to the waiting room.
- Ask your health care provider about relaxation techniques.
- Consider joining a breast cancer support group. You can call BCAction at 877-2STOPBC for local support groups. Be willing to try a few groups until you find the ones you're comfortable with, if the first one does not feel right. You can often find 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 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 – can help you save time and conserve 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 and 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 very useful.

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 and understanding 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 and what worked for one person might not work for you.

RESOURCES *(also available on our website)*

Books: There are hundreds of books written on breast cancer and many are available from the public library. These are a few good sources of general information that we suggest for newly diagnosed women:

- **Dr. Susan Love's Breast Book** (latest edition) by Susan Love, M.D. and Karen Lindsey
- **Everyone's Guide to Cancer Therapy** edited by Malin Dollinger, M.D., et al.
- **Choices in Healing** by Michael Lerner *(complementary 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.

Websites & Organizations: Keep in mind that not everything you read on the internet is reliable. Below are some well-known and credible websites.

- **Asian & Pacific Islander American Health Forum:** http://www.apiahf.org/programs/chronic-diseases/api-nationsl-cancer-survivors-network
  Network of cancer survivors, family members, health care providers, researchers, health advocates, community members and organizations concerned about the issue of cancer and survivorship in Asian American, Native Hawaiian and Pacific Islander communities

- **Breast Cancer Action:** www.bcaction.org (877-278-6722 or 415-243-9301)
  Advocacy, education and reliable, unbiased information on breast cancer

- **Black Women's Health Imperative:** http://www.blackwomenshealth.org/moving-beyond-pink-mbphome
  Advocacy and information for the African American community on many health issues

- **Breast Cancer Connections:** www.bcconnections.org (650-326-6686)
  Resource for information, support and services

- **Cancer Care:** www.cancercare.org
  Resources, support, information and education

- **Circulo de Vida**: http://circulodevida.org/ (415-648-9423)
  Information, resources and support for the Spanish-speaking community

- **Dr. Susan Love, MD., Research Foundation:** www.dslrf.org (866-569-0388)
  Education, research and advocacy

- **National Cancer Institute:** www.cancer.gov/cancertopics/types/breast
  Comprehensive breast cancer information

- **National Lymphedema Network:** www.lymphnet.org (415-908-3681)
  Information and guidance for lymphedema patients

- **National Women's Health Network:** www.nwhn.org (202-682-2640)
  Comprehensive information on women's reproductive and sexual health

- **Native American Cancer Research:** http://natamcancer.org/index.html (800-537-8295)
  Focused on conducting and promoting research and training in the cancer continuum to benefit the Native American community

- **Native People's Circle of Hope:** http://www.nativepeoplescoh.org (503-970-8004)
  Education, advocacy and information for the Native American community

- **Oncolink:** www.oncolink.org
  Comprehensive cancer information

- **Redes en Acción:** http://www.redesenaccion.org
  Training and research opportunities for Latino students and researchers, and supporting cancer awareness activities in the Latino community

- **Patient Advocate Foundation**: www.patientadvocate.org (800-532-5274)

Insurance, job retention and/or debt crisis matters relative to diagnosis

- **SHARE: Auto-Ayuda para Mujeres:**
  http://latina.sharecancersupport.org/latinashare/?count=910&lang=es
  Information and support for the Latina community

- **Sisters Network:** www.sistersnetworkinc.org (866-781-1808)
  Services and resources for African American women

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 BCAction at 1-877-278-6722 or email info@bcaction.org to find a support group in your local area.

Organizations Offering Support Programs:

- **Cancer Care**: (800) 813-4673
  www.cancercare.org/support_groups

- **Mautner Project for Lesbians with Cancer**: (866) 628-863
  www.mautnerproject.org/support/client_services.cfm

- **National Lymphedema Network**: (800) 541-3259
  www.lymphnet.org/patients/supportGroups.htm

U.S. Government:

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

- **National Cancer Institute:** www.cancer.gov/ (800) 422-6237
  Information on breast cancer/clinical trials sponsored by the National Cancer Institute

For resources in your area, please call our Information and Resource Hotline at 1.877.2.STOPBC (877-278-6722), email to info@bcaction.org, or visit our website at www.bcaction.org.

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

Aromatase Inhibitors (AIs): Type of hormone therapy for breast cancer patients with estrogen receptor positive breast cancer. AIs decrease the circulating estrogen in a woman's body by preventing the aromatase enzyme from converting androgen (androstenedione and testosterone) into estrogen (estrone and estradiol), which is the principal source of estrogen for postmenopausal women. These drugs should only be prescribed to women who are postmenopausal or who have had an oophorectomy.

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: A condition that occurs when cells become abnormal in number, size, shape, and appearance

Benign: Not cancerous

Bilateral: Involving both sides, such as both breasts

Biopsy: Removal of tissue, either with a needle or through surgery, to determine if a mass is benign or malignant; 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: A 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 pre-cancer

Estrogen: Female sex hormone produced by the ovaries, placenta, and adrenal glands

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: Literally, in the site of; in regard to cancer, in situ refers to tumors that have not spread past their site of origin.

Invasive cancer: Cancer that is capable of going beyond the 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 the 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 surgery.

Malignant: Cancerous

Mastectomy: Surgery to remove the breast

- Partial: A form of breast-conserving therapy in which the part of the breast containing the tumor is removed.
- Radical: Surgical removal of a breast along with the nipple, overlying skin, muscle beneath the breast, and lymph nodes.
- Preventive (aka prophylactic): Can be a total mastectomy with the removal of the entire breast and nipple, or it may be a subcutaneous mastectomy, where the breast is removed but the nipple is left intact.

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

Oncogene: Gene with the potential to cause cancer; 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

Progesterone receptor-positive (PR+): Tumor status indicating sensitivity to progesterone; patients with PR+ tumors are often treated with hormone suppression drugs.

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

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 ¾"or less with no evidence of spread to lymph nodes or distant sites.
- *Stage 2A*: A tumor is less than ¾" with spreading to lymph nodes, or is a large tumor and no spreading to lymph nodes.
- *Stage 2B*: A tumor is between ¾" 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

Triple-negative breast cancer (ER-/PR-/HER2 -): Tumor status indicating a lack of sensitivity to estrogen, progesterone, and Her2; because these cancer cells are not hormone-driven, they will not respond to treatment that blocks the effects or production of these hormones.

Tumor: Abnormal mass of tissue; the 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 Love, S., *Dr. Susan Love's Breast Book* (5th Ed.), Perseus Publishing: MA. 2010., and WebMD.**