

BREAST CANCER RESOURCE GUIDE

CAROLE AND RAY NEAG COMPREHENSIVE CANCER CENTER



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HEALTH

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NATIONAL ACCREDITATION PROGRAM
FOR BREAST CENTERS
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Personalized Care for your new Breast Cancer Diagnosis

We are thankful that you have chosen the Breast Cancer Program at UConn Health to receive your care. We have experts in all specialties to draw from, to assist you with prevention, diagnosis, treatment, survivorship, exercise, dietary information, complementary medicine, clinical trials and more. Like this guide, your care will be personalized so that you receive the most appropriate therapies for your diagnosis and general medical health. We intend to provide you with comprehensive support, to enable you to make this journey with information and understanding.

Personalized medicine occurs at all levels. It is based upon understanding each patient and his or her wishes and level of physical and emotional functioning. It is specific to breast size, tumor type, and available standard and experimental therapies. Most importantly, it depends on the goals of each patient.

Our goal is to personalize the care you receive, starting with this guide. We hope you will provide us feedback on how well this works for you.

Sincerely,

A handwritten signature in black ink that reads "Susan Tannenbaum". The signature is fluid and cursive, with a long horizontal line extending from the end.

Susan Tannenbaum, M.D.

Director of the Clinical and Translational Breast Program

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My Health Care Team

Medical Oncologist: _____

Contact Information: _____

Counselor / Therapist: _____

Contact Information: _____

Radiation Oncologist: _____

Contact Information: _____

Nutritionist / Dietitian: _____

Contact Information: _____

Surgeon / Surgical Oncologist: _____

Contact Information: _____

Pharmacist: _____

Pharmacy: _____

Contact Information: _____

Plastic / Reconstructive Surgeon: _____

Contact Information: _____

OTHER TEAM MEMBERS:

Name: _____

Specialty: _____

Contact Information: _____

Primary Care Doctor: _____

Contact Information: _____

Name: _____

Specialty: _____

Contact Information: _____

Oncology Nurse: _____

Contact Information: _____

Oncology Social Worker: _____

Contact Information: _____

Name: _____

Specialty: _____

Contact Information: _____

Breast Cancer Basics

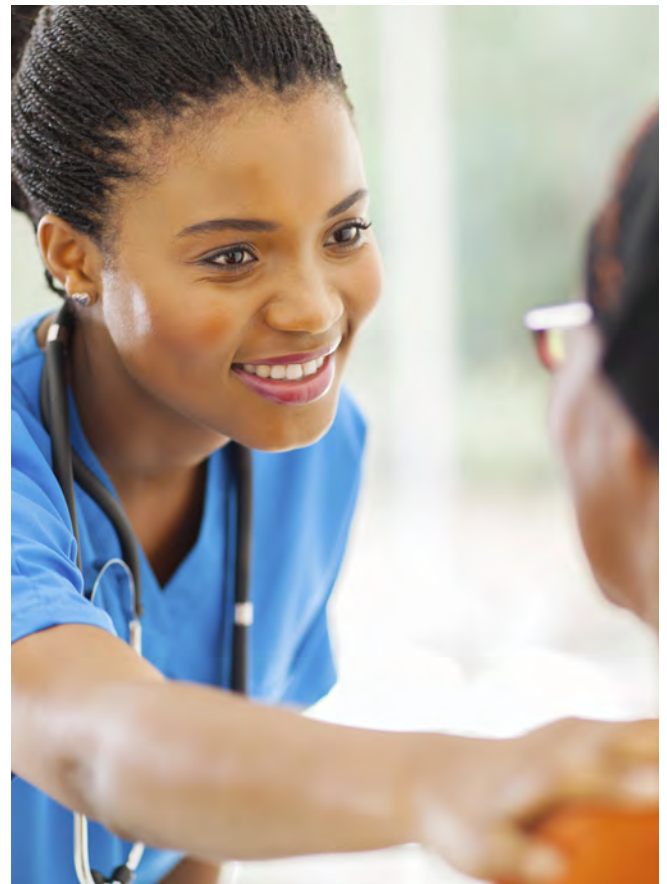
The breast is mostly made up of fatty tissue. Within this tissue is a network of lobes, which are made up of small, tube-like structures called lobules that contain milk glands. Tiny ducts connect the glands, lobules, and lobes, carrying the milk from the lobes to the nipple, located in the middle of the areola (darker area that surrounds the nipple). Blood and lymph vessels also run throughout the breast. Blood nourishes the cells, and the lymphatic system drains bodily waste products. The lymph vessels connect to lymph nodes, which are tiny, bean-shaped organs that help fight infection.

Breast cancer development

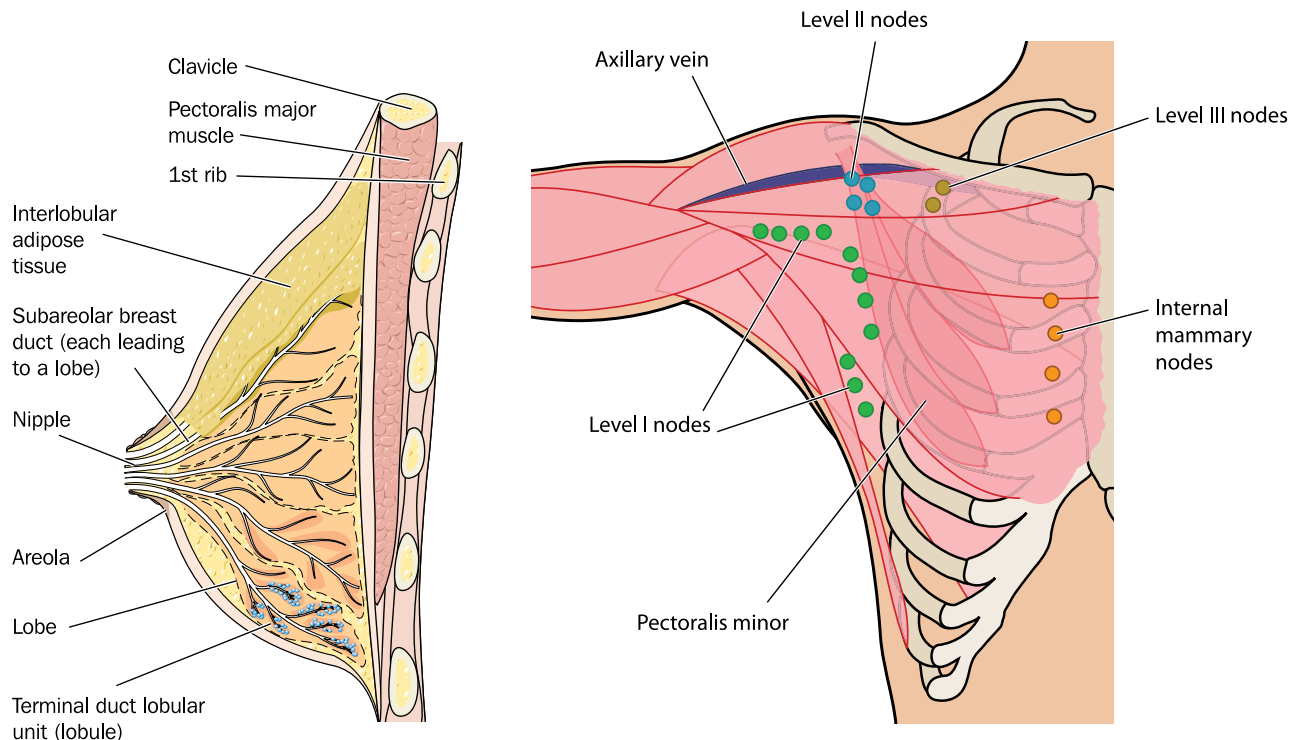
In the United States, breast cancer is the most common cancer diagnosed in women (excluding skin cancer). Men may also develop breast cancer, but less than 1% of all people with breast cancer are men. Breast cancer begins when healthy cells in the breast change and grow uncontrollably, forming a mass called a tumor. A tumor can be benign (noncancerous) or malignant (cancerous). A benign tumor does not spread to other parts of the body and is rarely life-threatening. A malignant tumor, on the other hand, can spread beyond where it began to other parts of the body.

Most breast cancers start in the ducts, but some begin in the lobules. Almost 75% of all breast cancers begin in the cells lining the milk ducts and are called ductal carcinomas. Cancer that begins in the lobules is called lobular carcinoma. The difference between ductal and lobular cancer is determined by the pathologist (a doctor who specializes in interpreting laboratory tests and evaluating cells, tissues, and organs to diagnose disease) after examining a piece of the tumor removed during a biopsy.

If the disease has spread outside the duct or lobule and into the surrounding tissue, it is called invasive or infiltration ductal or lobular carcinoma. Cancer that is located only in the duct or lobule is called in situ, meaning “in place.” Most in situ breast cancers are ductal carcinoma in situ (DCIS). Currently, oncologists recommend surgery to remove DCIS to help prevent the cancer from becoming an invasive breast cancer and spreading to other parts of the breast or the body. Radiation therapy and hormonal therapy may also be recommended for DCIS.



Female breast



Medical illustrations for many types of cancer are available at www.cancer.net.

Lobular carcinoma in situ (LCIS) is not considered cancer and is usually monitored by the doctor. LCIS in one breast is a risk factor for developing invasive breast cancer in both breasts.

Other less common types of breast cancer include medullary, mucinous, tubular, metaplastic, and papillary breast cancer, as well as other even rarer types. Inflammatory breast cancer is a faster growing type of cancer that accounts for about 1% to 5% of all breast cancers. It may be misdiagnosed as a breast infection because there is often swelling of the breast and redness of the breast skin that starts suddenly. Paget's disease is a type of cancer that begins in the ducts of the nipple. The skin often appears scaly and may be itchy. Although it is usually in situ, it can also be invasive cancer. These rarer types of breast cancer are not covered in this guide, but information about them can be found at www.cancer.net/cancer-types.

Breast cancer spread

As a cancerous breast tumor grows, cancer cells may break away and be carried to other parts of the body by the bloodstream or lymphatic system. During this process, known as metastasis, the cancer cells grow and develop into new tumors. One of the first places breast cancer usually spreads is to the regional lymph nodes.

Breast cancer can also spread farther away from the breast to other parts of the body, such as the bones, lungs, and liver. Less commonly, breast cancer may spread to the brain. However, even if the cancer spreads, it is still named for the area where it began. For example, if breast cancer spreads to the lungs, it is called metastatic breast cancer, not lung cancer. No matter the size, location, whether the cancer has spread, or how far it has spread, breast cancer can be treated and/or managed.

Welcome to the Neag Comprehensive Cancer Center Breast Nurse Navigator Program.

The Breast Nurse Navigator Program provides a support system for the patient and her family at this difficult time and collaborates with each patient's medical team to oversee and expedite the quality and pace of care. As a certified oncology nurse with years of experience in both the surgical and medical aspects of oncology, I specialize in diseases of the breast. I am here to guide and support you during your cancer treatment. In addition, I will help you to:

- Navigate through the UConn Health care system with ease
- Answer your questions
- Understand the information about your diagnosis and treatments
- Make connections with our interdisciplinary care team based on your needs

Feel free to contact me any time on our Breast Referral phone at 860.480.1981. I look forward to speaking with you.

Sincerely,

Molly Tsipouras RN, BSN, OCN, CPBN-IC
263 Farmington Avenue
Farmington, CT, 06034
860.480.1981
mtsipouras@uchc.edu



Primary Role as a Breast Nurse Navigator:

- Initiate communication with patients upon learning they have a suspicious mammogram or a positive finding.
- Collaborate with members of the patient's medical team.
- Support physicians and their office staff in the comprehensive care of breast cancer patients, including consultation regarding resources and services.
- Educate patient and family about specific cancer diagnoses and treatment options and how to handle side effects of treatment.
- Guide breast health patients through the health care system by assisting with access issues and helping them arrive prepared to ask the right questions.
- Act as clinicians, care coordinators, educators and counselors for patients and families.
- Improve patient outcomes through education, support and monitoring.
- Coordinate care with other health care providers such as nutritionists, social workers, clergy and counselors.
- Coordinate and facilitate Tumor Board meetings with medical staff.
- Connect patients to community and social support services.
- Facilitate patient interaction and communication with health care staff and providers to get questions answered.
- Provide breast health education to individuals and groups.
- Provide a learning library for patients that includes language-specific materials.
- Assist breast health patients in finding ways to pay for their breast health care.
- Help patients find balance during cancer treatment.
- Help patients learn about image enhancement.



Making the Diagnosis

You may find it useful at this point in your care to use the “My Medical and Lifestyle History” form at the end of this chapter to record your information. Try to fill in as much as possible before your appointment. You might also ask your doctor to write a few notes on the last page of that long form, and to mark your lump location on Figure B.

You will have one or more tests that will help your health care team determine what kind of breast cancer you have. Descriptions of possible tests follow. Some tests, such as a mammogram or ultrasound, look at your breast tissue from outside of your body. Other tests, such as biopsies, take a small sample of your breast tissue or fluid to look at your cells under a microscope.

Accurate diagnosis is critical to effective treatment. Your health care team will take great care to diagnose exactly the type of breast cancer you have. That’s because the choice of treatment depends on the characteristics of the tumor, how far it has progressed (“stage”) and more.

After your diagnostic tests have been performed, you will probably see a surgeon. Be sure to bring to your appointment the results of all of the diagnostic tests you have had, including films and written reports.



Test Descriptions

Mammogram: A mammogram is a low-dose digital 2D radiograph (X-ray) of the breast with computer assisted detection (CAD). Some studies have shown CAD to have the potential to increase the sensitivity of screening mammography. With CAD, a computer marks areas of interest on the mammogram in order to call them to the attention of the radiologist who is reading the image. In the absence of such marks, these areas might be overlooked.

Tomosynthesis: Also currently available is 3D mammography in conjunction with 2D mammography/CAD: this is called tomosynthesis. Health care providers should strongly consider recommending tomosynthesis for women with heterogeneously and extremely dense breasts. Tomosynthesis has a lower “call back” rate and has a higher specificity for breast cancer when compared with 2D mammography.

Ultrasound: A test in which sound waves are used to create a picture of the inside of your breast. A technician moves a handheld device over the outside of the breast. The device transmits information about the contents of a lump and whether these contents are solid or liquid. The test is painless and is usually very quick. This is typically used when the patient is younger than 30 or when a mammogram has been inconclusive.

MRI (magnetic resonance imaging): This scan is highly sensitive and may over-detect changes in breast tissue. It does, however, provide useful information when it is used along with other tests, such as mammogram and ultrasound, especially when those tests have been inconclusive. Among those for whom this test may be useful are women who have dense breasts or those who have an increased risk of breast cancer because of family or personal history. If your situation requires you to have an MRI, be sure to have it at a facility that can also perform MRI-guided biopsies (see biopsy descriptions next). That way, you can have a suspicious area biopsied at the same time you have the MRI.

Biopsy: This is a procedure that removes cells from the body so they can be examined and analyzed by a pathologist. There are several types of biopsies. Which one(s) you have will depend on your specific condition.

MRI-guided biopsy: The interventional radiologist uses magnetic resonance imaging to pinpoint the exact location of the abnormality and perform a minimally invasive procedure to extract a sample of the suspicious cells.

Core needle biopsy: This test is typically used when clumps appear on ultrasound or mammogram results, but are too small to feel by hand. This is usually done with local anesthesia. Once the breast is numbed, the doctor uses either stereotactic or ultrasound technology to guide a needle to the abnormal area and take tissue samples. This needle acts like the puncher that's used to pierce ears. Several passes are usually done to make sure that enough tissue is collected for pathology testing.

Needle localized excisional biopsy: This test is also used when clumps appear on ultrasound or mammogram results, but are too small to feel by hand. In the X-ray department, your breast will be cleaned and numbed with a local anesthetic. The radiologist will use a mammogram or ultrasound to guide a wire to the clump. Once the wire is in place, you will return to the operating room where a surgeon will use the wire as a guide to surgically remove the abnormal tissue.

Fine needle aspiration: A thin needle is used to draw cells from the lump. If the lump is a cyst that has a lot of fluid, your doctor might drain (aspirate) that fluid through the needle. This is usually done with a local anesthesia. This type of biopsy has limitations, since it can obtain so few cells. It can diagnose cancer, but provides little additional information about it.

Sentinel node biopsy: This minor surgery is usually performed on an outpatient basis using general anesthesia. The procedure begins with the injection of a radiotracer material and/or blue dye into the area around the breast tumor. The first one to three lymph nodes to receive the dye are removed and tested to determine whether cancer cells are spreading from the tumor to the lymph system. This procedure should be performed only by a specially trained and experienced surgeon.

Each test evaluates the tissue obtained for something different. Feel free to ask your doctor or nurse why a particular test is being conducted on you.



Understanding Your Pathology Report

After examination, testing and, in some cases, surgical removal of the tumor, your health care team will know a great deal more about your cancer. This information will appear on your pathology report. The findings that appear on the pathology report will help you and your health care team decide on the best course of treatment.

The next few paragraphs will help you better understand the information you will see on the pathology report.

Where It Is

Breast tumors may begin in the cells of either the “lobules,” the structures that produce milk, or the “ducts,” the structures that carry milk from the lobules to the nipple.

Noninvasive or Invasive

Breast cancer is first identified as either noninvasive or invasive. Noninvasive (in situ) cancer is one that doesn’t seem to be growing into surrounding tissue. About one in seven breast cancers is noninvasive.

Noninvasive

There are two main kinds of noninvasive cancers:

- **Ductal carcinoma in situ (DCIS)** – This type of cancer is in the breast ducts. It may become invasive if not treated.
- **Lobular carcinoma in situ (LCIS)** – Confined to the lobules of the breast, LCIS is not a “true” cancer. It is a warning sign that an invasive cancer may occur in the future in either breast. About one in three LCIS tumors becomes invasive.

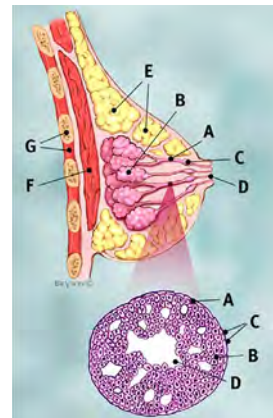
For more information on DCIS see

<http://imaginis.com/breasthealth/dcis.asp>
<http://breastcancer.about.com/cs/dcis>

For more information on LCIS see

<http://imaginis.com/breasthealth/lcis.asp>
<http://www.breastcancer.org>

Ductal Carcinoma In Situ (DCIS)



Normal breast with noninvasive ductal carcinoma in situ (DCIS) in an enlarged cross-section of the duct.

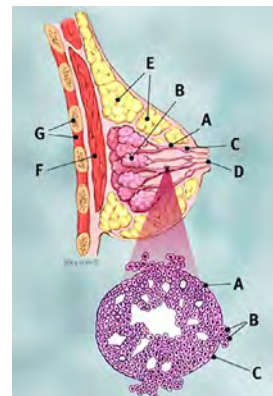
Breast profile:

- A. Ducts
- B. Lobules
- C. Dilated section of duct to hold milk
- D. Nipple
- E. Fat
- F. Pectoralis major muscle
- G. Chest wall/rib cage

Enlargement:

- A. Normal duct cells
- B. Ductal cancer cells
- C. Basement membrane
- D. Lumen (center of duct)

Invasive Ductal Carcinoma (IDC)



Normal breast with invasive ductal carcinoma (IDC) in an enlarged cross-section of the duct

Breast profile:

- A. Ducts
- B. Lobules
- C. Dilated section of duct to hold milk
- D. Nipple
- E. Fat
- F. Pectoralis major muscle
- G. Chest wall/rib cage

Enlargement

- A. Normal duct cell
- B. Ductal cancer cells breaking through the basement membrane
- C. Basement membrane

Illustrations courtesy of breastcancer.org

Invasive

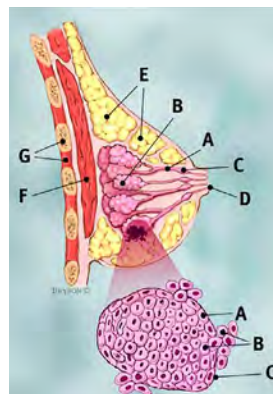
Invasive cancers are those that grow outside the ducts or lobules where they begin. Invasive cancers are sometimes call “infiltrating” cancers. There are two main types of invasive breast cancers:

- **Invasive ductal carcinoma** – This type begins in the ducts, but grows into the surrounding normal tissue inside the breast. It is the most common form of invasive cancer, representing about 70 percent of all cases. Depending on how the cells of this cancer appear under the microscope, your report may describe them in different ways. For example:
 - Tubular cancer cells look like tubes
 - Medullary cancer looks like brain tissue
 - Mucinous cancer produces mucous
 - Papillary cancer has cells that form finger-like projections
- **Invasive lobular carcinoma** – This starts inside the lobules, but grows into the surrounding normal tissue inside the breast. It is the second most common type, representing about 10 percent of breast cancer cases.

For more information about invasive breast cancer

see: <http://www.breastcancer.org>

Invasive Lobular Carcinoma (ILC)



Normal breast with invasive lobular carcinoma (ILC) in an enlarged cross-section of the lobule.

Breast profile:

- A. Ducts
- B. Lobules
- C. Dilated section of duct to hold milk
- D. Nipple
- E. Fat
- F. Pectoralis major muscle
- G. Chest wall/rib cage

Enlargement:

- A. Normal cells
- B. Lobular cancer cells breaking through the basement membrane
- C. Basement membrane

Illustration courtesy of breastcancer.org

Uncommon Forms of Breast Cancer

In addition to the types of cancer mentioned before, there are some rare forms of breast cancer. These include inflammatory breast cancer (IBC), cystosarcoma phylloides, Paget's disease and angiosarcoma.

Inflammatory Breast Cancer (IBC)

Inflammatory breast cancer (IBC) is a somewhat rare form, accounting for 1 percent to 4 percent of all breast cancers.

IBC is an advanced and aggressive breast cancer that travels through the lymphovascular system, causing blockage of the lymph vessels in the skin over the breast. This results in the breast having a red and swollen appearance. The skin may develop a thick, pitted appearance that resembles an orange peel and is referred to as "peau d'orange."

While IBC can occur at any age, the average age of those diagnosed is under the age of 45. It is important to note that not all breast cancer presents itself in the form of a lump.

Symptoms of IBC include:

- Redness of the skin, such as a "rash" or sunburned appearance
- Nipple flattening or retraction
- Thickening or hardening of the skin
- Dimpling or pitted appearance
- Skin feels warm
- Increase in breast size, swelling
- Possible tenderness in the breast

If you notice these symptoms, report them to a doctor immediately. Inflammatory breast cancer is considered the most aggressive form of breast cancer, and immediate treatment is needed after diagnosis.

IBC is difficult to detect on a mammogram because the cancer does not typically form a lump that is easily seen with the standard technology available. Diagnosis will likely result from a biopsy.

Current treatment usually involves initial chemotherapy to stop the cancer from spreading and to reduce the mass. Additional treatments depend on

the extent of the cancer and its response to initial chemotherapy, but these treatments usually involve surgery, radiation, and perhaps additional chemotherapy.

IBC information provided by Susan Asci



The "Grade" of the Cancer

Experts use the term "grade" to describe how different the cancer cells are from normal cells. Your report may say the cancer is:

- **Grade 1** – Cells are well-differentiated. That is, they look a lot like normal cells. These are usually slow-growing.
- **Grade 2** – Cells are moderately differentiated. They do not look like normal cells. They grow faster than normal cells.
- **Grade 3** – Cells are poorly differentiated. That is, they do not look at all like normal cells. They are usually fast-growing.

The Size of the Cancer

The medical community measures cancers in centimeters (cm). A centimeter is roughly one-third of an inch. The size helps your health care team determine the “stage” of the cancer (see below).

Margin

When the breast cancer is surgically removed, the surgeon’s goal is to remove the entire tumor and leave no cancer cells behind. So he/she removes an extra “margin” of normal tissue along with the cancer. The pathologist examines this margin carefully to determine if it is free of cancer cells. On your pathology report, the margin may be described in one of several ways:

- **Negative or clean** – No cancer cells are seen at the edge of the tissue. This usually means no additional surgery is needed.
- **Positive** – Cancer cells are seen right at the edge of the tissue. Additional surgery may be needed.
- **Close** – Cancer cells are close to the edge of the tissue. Additional surgery may be needed.

Lymphatic or Vascular Invasion

A network of blood vessels (vascular structures) and lymph channels carry fluids to and from breast tissue and other parts of the body. If cancer cells are found in these fluid channels, there is an increased risk that the cancer may return. Your pathology report will indicate whether lymphatic or vascular invasion is:

- **Present** – Cancer cells have been found; or
- **Absent** – Cancer cells have not been found.

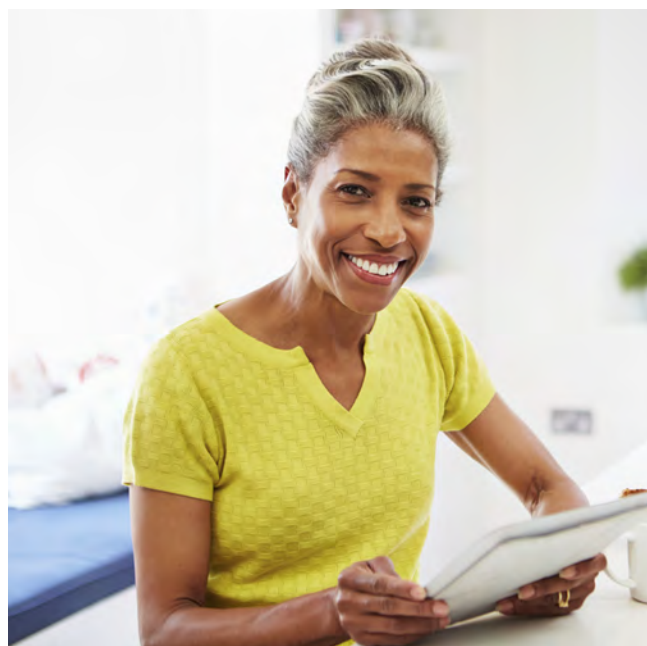
Estrogen Receptor (ER) and Progesterone Receptor (PR)

These tests reflect whether a cancer responds to a woman’s hormones. They give your health care team information about the likelihood that the cancer will respond to a form of treatment called hormonal manipulation. You may see one of these terms on your report:

- **ER-positive** – The cells have receptors for the hormone estrogen.
- **ER-negative** – The cells do not have receptors for estrogen.
- **PR-positive** – The cells have receptors for the hormone progesterone.
- **PR-negative** – The cells do not have receptors for the hormone progesterone.

The report will also tell you the number of cells that have receptors. This may be expressed in one of two ways:

- **As a percentage** – You will see a number between 0 percent (none has receptors) and 100 percent (all have receptors); or
- **As a number between 0 and 3** – “0” indicates no receptors; “1+” indicates a small number of receptors; “2+” indicates a medium number of receptors; and “3+” indicates a large number of receptors.



HER-2/NEU

HER-2/NEU is a receptor on the surface of cells. It regulates cell growth. Cancers with too many HER-2 receptors tend to grow quickly and not respond well to hormone therapy. However, newer treatments that specifically target HER-2 are proving very effective. Your pathology report will indicate your HER-2 status. It may be:

- **Positive;**
- **Negative;** or
- **Borderline.**

Lymph Node Involvement

Lymph nodes are located under your arm. They are filters along the lymph channels that carry lymph fluid from the breast back to the bloodstream. The pathologist will examine the lymph nodes removed along with the breast tissue to see if cancer cells are present in them. Your report may indicate that lymph nodes are:

- **Negative** – No cancer cells are seen in the lymph nodes; or
- **Positive** – Cancer cells are seen in the lymph nodes.



Staging

After the tests are done and the lab reports have determined what kind of breast cancer you have, your doctor will “stage” the tumor. The purpose of staging the tumor is to help determine your prospects for recovery and the best treatments for the stage of your disease. The stage tells how large your tumor is and how far the cancer has spread.

Three letters are used in the staging of breast cancer:

- **“T”** – Stands for tumor characteristics, including tumor size and any involvement of skin or the chest wall behind the breast.
- **“N”** – Stands for lymph nodes. It indicates how far the cancer has traveled through the lymph nodes that drain the breast region. Lymph nodes are found under your arm and at other sites.
- **“M”** – Stands for metastasis, that is, whether cancer cells have traveled (metastasized) beyond your breast and lymph node regions.

Staging is complicated and should be discussed with your oncologist.

For a fact sheet on breast cancer staging, see
<http://www.cancer.gov/cancertopics/factsheet/Detection/staging>

Also see:

<http://imaginis.com/breasthealth/staging.asp>

<http://www.breastcancer.org/symptoms/diagnosis/staging.jsp>

Additional Resources

American Cancer Society

www.cancer.org

American Society of Clinical Oncology

www.cancer.net

Breast Cancer Network of Strength (formerly the Y-ME Breast Cancer Organization)

www.networkofstrength.org

Genetics

If you've been diagnosed with breast cancer, you may want to know more about the biology of the disease. If there are other people with breast cancer in your family, you may wonder if your cancer is hereditary and whether your children or other relatives may also be at heightened risk. This section of the guide contains information that will help you better understand what is known so far about the connection between genes and breast cancer. It will also explain the role a genetic counselor may play in your evaluation and management plan.

The Role of Genes

Every cell in our bodies contains genes, tiny units of information that are passed along to us by our parents. Each of us inherits two copies of each gene. Each cell in our body has 20,000 to 40,000 genes. Genes direct the growth and development of our cells, and therefore of our bodies as a whole. In addition, most of our physical characteristics, such as the color of our eyes and skin, how tall we are and our blood type, are influenced by genes to some extent.

An alteration or "mutation" in a gene is like a typographical error. When this genetic alteration

is in a gene that controls cell growth, the "error" may enable cells to grow out of control.

All cancers involve genetic alterations in a cell. The genetic alteration causes the cell to transform into a cancer cell that can eventually multiply and become a tumor.

Genetic alterations that lead to cancer may develop in isolated cells during an individual's lifetime. These are called "acquired" or "sporadic" alterations. They are not passed on to future generations.

Other genetic alterations are hereditary. That is, the alteration is already present in all of our cells when we are born and can be inherited by our children when the alteration is passed on in the sperm or egg.

Hereditary Cancer

Certain families have multiple members affected with cancer because of a specific inherited gene mutation. Individuals in these families may have a significantly increased risk of developing cancer. Only a small percentage (5 to 10 percent) of breast cancers can be traced to hereditary mutations.

When cancer occurs in one or more close relatives, we may begin to suspect that it is not by chance. So



it is prudent to look into whether these occurrences might be hereditary. We will be more likely to suspect it is hereditary if the cancers are the same type (breast cancer, for example) or a particular combination of cancers (such as breast and ovarian cancers).

Gene Mutations That Cause Hereditary Breast Cancer

While only a small percentage of breast cancers are hereditary, the majority of them are due to hereditary mutations in two particular genes: BRCA1 and BRCA2. The abbreviations stand for breast cancer gene 1 and breast cancer gene 2. An even smaller percentage are due to other hereditary gene mutations. For example, gene mutations in PTEN are associated with Cowden's syndrome, and gene mutations in p53 are associated with Li-Fraumeni syndrome.

The BRCA1 and BRCA2 genes are examples of tumor suppressor genes. The role of tumor suppressor genes is to slow down cell division, repair DNA mistakes, and tell cells when to die naturally. We all possess these genes, having inherited one copy of each from each of our parents. Those of us who inherit an altered form of one of these genes are at higher risk of developing breast or ovarian cancer. The mutations in these genes may interfere with a cell's ability to put the brakes on its growth. Without the brakes, cells may grow out of control and begin the process of developing a tumor.

For more information about the role of cells and genes, visit www.cancer.org and enter the search term, "tumor suppressor genes."

Hereditary Breast and Ovarian Cancer

Mutations in the BRCA1 and BRCA2 genes increase the risk of developing both breast cancer and ovarian cancer. The medical community has identified risk factors that tend to indicate the presence of a BRCA mutation in a family.

Signs of hereditary breast-ovarian cancer syndrome in a family include, but are not limited to:

- Breast cancer at age 50 or younger.
- Breast cancer in both breasts in a woman, when the first cancer occurred under 50.



- At least one family member with breast cancer under age 50 and one with ovarian cancer on the same side of the family, or breast and ovarian cancer in the same individual.
- Breast cancer in men.
- Ashkenazi Jewish heritage.
- Three or more close relatives on the same side of the family with breast or ovarian cancers and one of these cancers: prostate cancer, pancreatic cancer or melanoma.

Source: www.facingourrisk.org, the website of FORCE (Facing Our Risk of Cancer Empowered)

It is important to know your family's health history, because it may help you and your health care team determine whether you have a hereditary risk for breast cancer.

Discovering Your Family's Health History

Families differ in how much information they know about the health of their relatives. Information about your closest relatives (parents, children, brothers and sisters, aunts and uncles, and grandparents) has the most impact on your cancer risk. If you don't know whether your relatives had cancer, you can speak with your health care provider to determine the specific information that might be the most use-

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ful. They can guide you to obtaining this information from numerous sources, including death certificates or the medical records from the hospitals where relatives were treated. Death certificates are public records and, while not perfect, usually list the cause of death. To get information about obtaining a copy of a death certificate, contact the city or town clerk in the community where your relative died or the Connecticut Department of Public Health's State Office of Vital Records (www.ct.gov/dph or 860-509-7700).



Medical records are kept for varying lengths of time by different health care facilities. If you know the name of the hospital where your ancestor was treated, call the facility and ask how to obtain records. Make sure to get the name of the contact person you spoke with. Then write to the hospital's medical records department to request a copy of your relative's medical record and explain how you are related to that person. The executor of a relative's estate is often a good resource for requesting

records. Be mindful that the records department may ask for a death certificate that documents the fact that the relative is deceased. This may seem like a lot of red tape, but the procedures are designed to protect the privacy of an individual's medical record.

Under revised privacy rules put in place by the federal government in April 2003, you can still access protected health information for treatment purposes. Known as "continuity of care," this rule allows a health care provider to disclose a decedent's health information, without authorization, to the health care provider treating the surviving relative. The executor of an estate may also obtain the information or authorize its disclosure.

You can get information on how to access deceased relatives' health records at www.hhs.gov/ocr/hipaa/, the website of the U.S. Department of Health and Human Services' HIPAA program. At this site, click on "Answers to Your Frequently Asked Questions." When the search engine appears, type in "obtain medical records deceased." The first answer reviews how to access these records.

A cancer-genetic counselor (described below) can also advise you on methods for discovering your family health history.

Adopted?

If you're adopted, you can petition the court to release your birth record, or you can contact the Connecticut Adoption Registry (through the Connecticut Department of Children and Families) to see if your birth parent has registered to release information.

Genetic Counseling

If you are concerned about whether you have an inherited form of cancer, you may want to seek help from a genetic counselor. Genetic counselors are health professionals with advanced degrees and experience in medical genetics and counseling. When seeking to understand the genetics of breast cancer, you will want to select a genetic counselor with special expertise in cancer genetics. This professional can help you assess your risk of cancer

and the likelihood that the cancers in your family are inherited. In addition, you will receive a personalized explanation of the benefits and limits of any available genetic testing.

For assistance in finding a cancer genetic counselor in your area, ask your doctor or nurse or visit www.nsgc.org, the website of the National Society of Genetic Counselors.



What Genetic Counseling Involves

Genetic counseling begins with a discussion of your concerns and involves a detailed look at your family history. The genetic counselor asks questions about your relatives to obtain information about their current ages, their ages at death and whether they had cancer. It is important to record the type and location of cancer they had and at what age they developed cancer. You may be asked to bring in medical records and pathology reports for people in your family who had or have cancer, because these records often provide more detailed information.

In the course of a genetic counseling visit, the counselor will provide more information about genetics and inherited cancer. You will also discuss cancer screening recommendations for the type of cancer you may be at risk of developing, based on your

family history. In families with inherited susceptibility to cancer, cancer screening is often started at an earlier age and done more frequently than usual. You might feel overwhelmed by the volume and the details. Ask questions, take notes, and ask your counselor how you can find answers to questions that you think of after you leave. Take time to review any printed material or reports the counselor gives you.

For additional information, visit the websites listed at the end of this chapter or consult your local librarian.

Genetic Testing

If it appears that your family may have an inherited cancer susceptibility, your counselor will discuss with you the pros and cons of genetic testing. Genetic tests for hereditary breast and ovarian cancer are performed on blood in order to find genetic disorders.

Because inherited cancer susceptibility accounts for about 5 to 10 percent of breast cancers, genetic testing is usually offered to individuals who have a reasonable chance of having an altered cancer susceptibility gene. Genetic tests are available for some breast cancer susceptibility genes, including BRCA1, BRCA2, PTEN and p53. Your genetic counselor will determine which test is most appropriate for your specific situation. Here are some questions to ask:

- Which specific mutations or genes will be analyzed?
- What are the potential risks, benefits and limitations of testing?
- How will my privacy be protected?
- Does insurance cover the test?
- How much of my blood will be taken?
- What will happen to the blood sample after testing is done?
- How can I obtain more information about my hereditary breast cancer risk?
- Who can I call for more information?

Informed Consent

If you decide to have genetic testing, you'll be asked to sign a consent form that gives your permission to have your blood drawn and analyzed. The form may include many of the following points:

Implications of a Positive Test - If testing reveals that you have an altered cancer susceptibility gene, that means you have an increased chance (or risk) of developing cancer. Risk is sometimes a difficult concept to grasp. Ask your cancer genetic counselor as many questions as necessary to understand this idea. And remember that a genetic test result helps determine only some aspects of development of cancer in the future. Risks apply to groups of people, and statistics can't predict what will happen to one person. A higher risk does mean that something is more likely to happen, but it doesn't mean that it will happen.

For example: the BRCA1 gene, if altered, causes a predisposition to breast and ovarian cancer. The likelihood that a woman with an altered BRCA1 gene will develop breast cancer is from 50 percent to 85 percent in her lifetime. While this is higher than the 11 percent risk faced by the average woman in

the U.S., these numbers mean that some women with altered BRCA1 genes will not get breast cancer even though they carry a mutation.

Another important fact to understand is that altered cancer susceptibility genes cause an increased risk of specific cancers — not all cancers. While women who have BRCA1 alterations have increased risks of breast and ovarian cancer, they do not, according to today's research, have a significantly greater risk of developing other cancers, such as leukemia, lymphoma or cervical cancer, than someone who does not have a BRCA1 alteration.

What to Do if You Test Positive - If testing shows that you have an altered cancer susceptibility gene, talk with your genetic counselor and other health care providers about what it means. Next — and most importantly — make sure you know the options available to you for management as well as the recommended screening for cancer. You will most likely receive a written report about these recommendations from the genetic counselor. Most cancer susceptibility genes predispose individuals to specific types of cancers in specific organs of the body. Cancer monitoring should focus on those organs because, while cancer might not be preventable, treatment is most effective when it is caught early.



Reducing Your Risks – Some individuals with inherited predispositions to cancer who want to reduce their risk might choose to undergo prophylactic or risk-reducing surgery. (See *Chapters seven and eight for more information about risk-reducing strategies.*) Prophylactic surgery is the removal of healthy (non-cancerous) tissue before cancer develops. Prophylactic surgery, however, doesn't guarantee that cancer won't develop. For example, a woman who has an altered BRCA gene (and a high chance of getting breast cancer) may consider having her breasts removed (mastectomy) before a cancer develops. Prophylactic mastectomy, however, doesn't completely eliminate the possibility of developing breast cancer, because it is impossible to remove every single breast cell from a person's chest. These are issues to discuss with your health care providers, because a remaining risk for cancer may depend on a number of factors that are unique to you.

Prophylactic surgery affects a person's body, mind and feelings. If you are considering this option, work with health care providers, family, and friends who can understand these different areas. Professionals who can help include your surgeon, plastic surgeon, oncologist, genetic counselor, nurse, mental health counselor and spiritual advisor.

Health Insurance Considerations – Many people are concerned about experiencing genetic discrimination if they test positive for cancer susceptibility. Genetic discrimination is the use of genetic testing results by insurers or employers in an adverse way. However, on May 21, 2008, President Bush signed the Federal Genetic Information Nondiscrimination Act, or GINA. This legislation prohibits employers and health insurers from penalizing people without a cancer diagnosis for disease.

Risks Revealed by Genetic Testing – It is important to note that life insurance and disability insurance companies may consider genetic information when making decisions regarding coverage. In addition, the Affordable Care Act prohibits insurance discrimination due to a preexisting condition.



Genetic Testing: The Choice is Yours – Talk with your genetic counselor and team of health care providers about whether you want to find out if you have an altered cancer susceptibility gene. If you seem to be at risk of hereditary cancer, you should be closely monitored by medical professionals and screened frequently for cancer, even if you don't choose to have genetic testing. Your health care providers can give you specific screening recommendations based on your personal and family history.

Most people who choose to be tested deal quite well with this new knowledge if they have gone through an appropriate process of evaluation and preparation for testing.

Panel Testing – Advances in genetic testing now allow testing for many of the inherited breast cancer susceptibility genes at one time. It is important to ask questions about the type of genetic testing you will undergo, how long it will take to get results, and how many genes are being analyzed.

Sharing Information – Most people share their results with their families, because it helps family members better manage their own risks.

If you have an altered cancer susceptibility gene, consider how you want to share this information with your family. Ask your genetics or mental health counselor for advice on how to share such information. Most studies have shown that women share their genetic test results with their family members.

What to Do if You Test Negative – You may test negative for a known hereditary mutation even though your family may seem to have many people with cancer. Remember that not all cancer is inherited. You may want to keep in contact with the genetic counselor on a regular basis. Future research in the area of genetics may uncover other hereditary mutations for which you'd want to be tested. The program may also have research opportunities: you might want to ask if they suit your particular situation. As newer technologies emerge, additional knowledge has pointed to other moderate-risk genes that increase breast cancer predisposition. Ask about whether additional testing may have a role for you or your family.

What to Do if Your Test Shows a Variant of Uncertain Significance – Occasionally a DNA test will identify a genetic change that is not well defined. It may take months, or years, for the variant to be reclassified as a harmless DNA change, or as a positive result with associated cancer risks. If your results show a variant of uncertain significance, it is important to keep in contact with your genetic counselor on a yearly basis.

Additional Resources

FORCE

www.facingourrisk.org

FORCE (Facing Our Risk of Cancer Empowered) provides information and initiatives to improve the lives of individuals and families affected by hereditary breast and ovarian cancer.

Bright Pink

www.brightpink.org

Bright Pink provides information and support to women, especially women under 40.

Connecticut Department of Public Health:

<http://www.ct.gov/dph/site/default.asp>

National Society of Genetic Counselors:

<http://nsgc.org/p/cm/ld/fid=164>

National Cancer Institute:

<http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA>

UConn Hereditary Cancer Program:

<http://humangenetics.uhc.edu/hereditary/>



Local Surgical Treatment



Lumpectomy

A lumpectomy is the removal of the tumor with a rim of surrounding normal tissue. This tissue is examined by a pathologist, using a microscope, to see the extent of the cancer cells. If the cancer cells involve the edge of the tissue removed, a follow-up surgical procedure may be required to achieve a “clean margin,” a partial or segmental mastectomy or quadrantectomy is a lumpectomy in which a margin of surrounding breast tissue is removed.

Lumpectomy is generally followed by radiation therapy (five days a week for four to six weeks in most women) to decrease the chance of the cancer reappearing in the breast.

Lumpectomy is not an option for all women with breast cancer. Factors that generally preclude lumpectomy include:

1. The breast is small and the tumor is very large.
Or the tumor extends so far within the breast that a clean, or clear margin cannot be achieved.
2. There is more than one tumor in the breast.
3. Other medical conditions, including pregnancy, present the woman from having radiation therapy.

Some women may have the option to try to shrink the tumor with chemotherapy prior to surgery so they are able to have a lumpectomy.

In addition, some women may opt for mastectomy, with or without reconstruction, for personal reasons.

Surgery for the Axillary Lymph Node

The lymph nodes under the arm nearest the breast are known as the axillary lymph nodes. It is extremely important to know if cancer cells have left the breast and spread to those nodes. That is why the standard treatment since the 1980s has been the axillary lymph node dissection, and more recently, a sentinel node biopsy.

Sentinel Node Biopsy

Of particular interest to doctors is the sentinel node. It is thought that cancer cells may invade it first as lymph flows from the breast through it to the other lymph nodes.

Sentinel node biopsy is the preferred method of evaluation of lymph node spread that may not be obvious through a clinical exam.



For invasive cancer, or large, non-invasive cancers, sentinel node biopsy is recommended so that the lymph nodes can be evaluated. This minor surgery is usually performed on an outpatient basis using general anesthesia.

The procedure begins with the injection of a radiotracer material and/or blue dye into the area around the breast tumor. The first one to three lymph nodes to receive the dye are removed and tested by a pathologist to determine whether

cancer cells are spreading from the tumor or lymph system. This procedure should be performed only by a specially trained and experienced surgeon.

Women having a lumpectomy and radiation therapy who have a smaller tumor and no more than two sentinel lymph nodes with cancer may avoid a full axillary lymph node dissection, which helps reduce the risk of side effects and does not decrease survival.

With a full lymph node dissection, 10 to 30 of the approximately 40 lymph nodes under the arm are removed. Those nodes are studied under a microscope to determine if breast cancer cells are present. After the nodes are removed, the patient usually leaves the hospital with a drain in place for a few days and has minimal discomfort.

Side Effects of Lymph Node Removal

After the lymph nodes are removed, you may experience numbness of the armpit and upper inner arm skin. Another, less common side effect is lymphedema (swelling of the arm).

There are ways to help prevent or reduce the effects of lymphedema. If you are experiencing swelling, tightness or pain in your arm, you should tell your doctor or nurse immediately. This can happen immediately after axillary dissection (removal of underarm lymph nodes) or years later.

Mastectomy

A mastectomy is removal of the entire breast and, possibly, adjacent tissue. Patients undergoing mastectomy are anesthetized during the procedure. They may go home soon after the operation or they may remain in the hospital for a few days. However, if they opt to have breast reconstruction done at the same time as the mastectomy that may extend their hospital stay.

If you have a mastectomy you may feel pain that usually improves in a few weeks. The pain can be treated with medication. Drains are usually placed that will remain for a few weeks.

You may experience some stiffness in the area of the surgery. It is also possible that fluid will build up in the area, increasing the possibility of infection.

Women who undergo mastectomy can also experience some long-term side effects: loss of feeling or sensation is common. Tenderness usually gets better in a few weeks. Loss of feeling, on the other hand, can last for an extended period.

No one undergoing mastectomy should expect an immediate recovery. The process of getting back to “normal” can take weeks or even months.



Post-Mastectomy Reconstruction

Reconstruction procedures are generally not considered “treatment” for breast cancer. Rather, they are procedures to restore “normal” appearance after a mastectomy. While many women choose to undergo breast reconstruction, many others decide it is not for them. If your treatment choice includes mastectomy, you may also want to find out about your options for breast reconstruction.

If you know you will definitely have a mastectomy and will want to have reconstruction, it is important that you consult with a plastic surgeon before your mastectomy. In some cases, you can have reconstruction performed at the time of the mastectomy. In others, this might not be advisable.

If you do decide that you would prefer breast reconstruction, make sure you talk with a plastic surgeon who is board-certified and a member of the American Society of Plastic Surgeons. You can visit the society’s website at www.plasticsurgery.org or call 800-635-0635 for a list of board-certified surgeons in your area.

Prostheses

In the event that you are unable or choose not to undergo breast reconstruction, you might want to consider using an external breast prosthesis. This is an artificial breast form that you can attach to your body or place in your bra, lingerie, or swimwear. There are many companies – locally, regionally, and nationally – that carry a variety of breast prostheses or forms.

When you begin to look for a breast form, you will quickly discover that they come in a variety of shapes. These variations are designed to accommodate the different needs and shapes of the women who will wear them. Prostheses also come in different weights. A professional prosthesis fitter will be able to help you choose the correct shape in order to distribute weight evenly against your body for anatomical fit and alignment. The silicone breast forms are available in light, medium, and dark skin tones.

If you choose to use a prosthesis, you will find that there are surgical support bras available in attractive, feminine styles to fit most sizes. In addition, bras purchased in department stores can be customized to accommodate your prosthesis – as can other clothing, such as bathing suits and lingerie.

Some helpful hints when shopping for a prosthesis:

- Make sure your physician fills out a prescription for your prosthesis so that costs may be covered by your insurance. It is a good idea to check with your insurance provider regarding coverage.
- Look for a prosthesis when you have plenty of time to evaluate which breast form suits your needs. Most times it is best for you to make an appointment with a professional, certified fitter so that you can get the personal attention you need and deserve.
- Bring someone with you who will be supportive and honest about how the breast form looks on you. You may want to take a t-shirt or light sweater with you to see how the breast form fits under different types of clothing.
- Do not feel that you have to make an instant decision when choosing a breast prosthesis. You will have it for some time, and it is important that you are comfortable with your choice.

Rehabilitation

Following surgery for breast cancer, you will likely experience some pain or discomfort in the breast area, possibly accompanied by numbness or tingling in the arm. You may also have discomfort under your arm where the lymph nodes were removed.

This discomfort can take several forms. You may experience pain that radiates down the arm, or you may feel as though “pins and needles” are sticking you. Additionally, your arm may feel numb. Pain from the incision usually takes about a week to ten days to subside, and the sensations will improve as your arm mobility is restored.

There are exercises that you can do to relieve your discomfort and restore your range of arm movement. Ask your doctor about recommended therapies and when you can begin exercises. You should not lift anything heavy or begin any exercises until your doctor has given you the permission to do so. You will meet with a physical therapist who specializes in lymphedema. The therapist will review the exercises and know what symptoms to look for.



Questions to Ask the Doctor about Surgery

- Am I a candidate for a lumpectomy? Why or why not?
- If I have a lumpectomy, will my breast differ in size and shape compared to my other breast?
- If I have a lumpectomy, will I be able to breastfeed if I have a child in the future?
- Do I need to have a mastectomy? If so, would you recommend immediate breast reconstruction (plastic surgery)? What are the advantages and disadvantages?
- Do the lymph nodes under my arm need to be removed? Do you recommend a sentinel lymph node biopsy? If not, do you recommend an axillary lymph node dissection instead?
- Will I need to be admitted to a hospital for this operation? If so, how long will I need to stay in the hospital?
- Am I at risk for developing lymphedema? If so, how can we reduce this risk?
- Where will the scar be, and what will it look like?
- What kind of pain will I be in after surgery? What can be done to manage this pain?
- Will my arm be affected by surgery? If so, for how long? Will I need physical therapy?

Radiation Treatment

Radiation therapy uses precisely directed and calibrated x-rays in an attempt to eliminate cancer cells that may remain after surgical removal of a breast tumor. Radiation is most commonly used after limited breast surgery (lumpectomy). In selected cases it may be recommended to treat the chest wall after total removal of the breast (mastectomy). There may be indications in certain patients to consider treatment of the lymph nodes under the arm (axilla) and the collarbone (supraclavicular area).

Whole breast radiation has been the standard technique used after lumpectomy for over 30 years and it has a proven long-term track record for efficacy and safety. It involves daily treatment, Monday-Friday, generally for a total of three to six weeks. This treatment course often includes a lumpectomy boost treatment which is given daily over the last one or two weeks of the treatment course. The radiation boost is directed only to the lumpectomy area and spares the other areas of the breast continued treatment.

Recent data indicates that a shorter overall radiation course of 3 to 4.5 weeks (hypofractionation) is a reasonable alternative to the traditional 6-week treatment program for many patients.

Some patients may benefit from being treated in a prone position (lying on stomach) as opposed to the more standard supine position (lying on back). In certain instances this technique may allow lower chest wall, lung and heart radiation exposure.

Common side effects of treatment observed during the radiation course include fatigue, skin and nipple redness and breast irritation. Before the initiation of treatment planning, your radiation oncologist will have a thorough discussion with you concerning the possible acute effects of the radiation as well as potential long-term issues.

Partial breast irradiation (PBI) is an alternative technique that involves the use of a radioactive source placed in the lumpectomy cavity as an alternative to whole breast radiation. A plastic catheter is placed in the lumpectomy cavity by your surgeon at the time of the breast tumor removal.



PBI involves twice a day treatment over about a week. The catheter exits the skin and must remain in place during the entire treatment course. The technique does spare some of the breast tissue from exposure to radiation, but PBI is still considered investigational by some physicians until more data about long-term efficacy and toxicity become available.

There is concern that sparing portions of the breast from radiation exposure may lead to a higher rate of tumor recurrence in the breast. Many patients have been enrolled in clinical trials involving PBI, so in time we may have more information on who might best benefit from this technique as a radiation option.

Preparing for Radiation Treatment

In order to fully inform you of the benefits and side effects of radiotherapy, you will have a consultation with a radiation oncologist who will be in charge of your care if you choose to proceed with radiation treatments.

A treatment planning session, called a simulation, will be scheduled as the next step. This simulation process involves positioning your body on the treatment table to assure optimal geometry for treatment as well as reproducibility of your body position for the subsequent treatments. Three small permanent marks (tattoos) will be placed on your skin as a guide for accurate delivery of the radiation during your daily treatments. A CT scan of the breast area will be performed to provide an accurate three-dimensional representation of your breast anatomy, as well as heart and lung tissue. The radiation plan will be formulated to minimize treatment of your normal tissues.

This advanced technology allows your physician to work with the physics staff to produce a radiation plan that limits side effects. When you initiate treatment your physician and the nursing staff will advise you on proper skin care.



Systemic Therapy

Surgery and radiation treat the cancer found in the breast and local lymph nodes. Unfortunately, the cancer can spread beyond the local area. This spread is often minute and cannot be seen by any studies or found in a blood test. In order to eliminate these small deposits, systemic therapies are utilized. This is called adjuvant therapy. Sometimes your treating physicians may choose to initiate this therapy even before surgery. This is called neoadjuvant therapy.

Adjuvant systemic therapies include chemotherapy, anti-estrogen therapy, and/or biologic therapy. The choice of one or more of these depends on the characteristics of each person's own breast cancer.

The tailoring of treatment to individual patients is a goal for all providers. Clearly, "one treatment does not fit all," but deciding who needs which systemic treatments can be complicated. Your physician and care team will consider issues such as the size of your tumor, the presence of positive lymph nodes, the tumor grade and receptor status as well as more personalized characteristics of your cancer, the expression of certain genes that may drive its growth and spread.



The Oncotype DX is a test created for women with estrogen-positive breast cancer that looks at a gene pattern in a patient's own breast cancer. A score is generated from which therapy with anti-estrogens, chemotherapy or both can then be recommended. This test has reduced the use of chemotherapy on women who would not benefit from it. This is not a test for all women with breast cancer, but your doctor may mention it or you may want to ask more about it.

Because these drugs may hurt normal cells, you may experience some side effects. Some side effects include loss of energy and fatigue, hair loss, nausea and vomiting, infection and bleeding. Many of these are either prevented or well-managed with supportive treatments.

Chemotherapy

Chemotherapy for breast cancer is one or more drug(s) given through an intravenous line or taken by mouth in pill form. Patients receiving chemotherapy for breast cancer most often do so as an outpatient, either in the outpatient department of a hospital or at a doctor's private office.

Chemotherapy attacks cells, especially those that reproduce rapidly, such as cancer cells. As a treatment that is dispersed to the whole body, the chemotherapy drugs can't be selective about which cells are attacked. Normal cells, particularly those growing quickly like the mother cells of our blood cells and those found in our mouth and digestive tract, can also be affected by these drugs.

Blood Counts

Your doctor will monitor your blood cells during chemotherapy through a laboratory test called a complete blood count (CBC). The test checks the levels of your red blood cells, white blood cells and platelets. It helps the doctor gauge how much chemo you can tolerate at that particular time.

Red blood cells carry oxygen throughout your body. A reduction of those cells can cause fatigue. When your red cell count is too low, you may also have difficulty breathing or feel dizzy when you stand up quickly. Red blood cells live from three to four months in your body, so the effects of chemotherapy are likely to be minimal on this part of your blood.

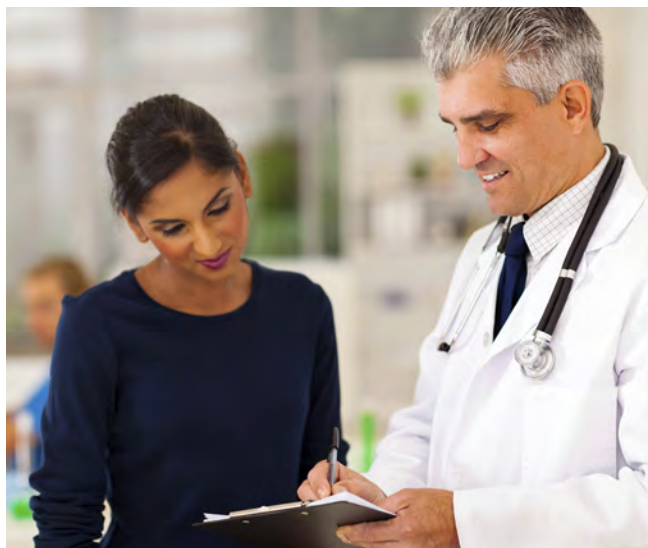
Still, if you have symptoms, tell your oncology nurse.

White blood cells are responsible for fighting infections. After you receive chemotherapy, the number of white cells in your blood may be low, making you susceptible to infections. When that happens, it's important for you to:

- Stay away from people who have colds, flu, or other infections.
- Keep your skin warm, dry, and clean, and take care of cuts or breaks in your skin by washing them thoroughly.
- Tell your nurse or doctor if you catch a cold or other infection.
- Check with your doctor about eating fresh fruits with rinds, such as melons or cantaloupe.

Platelets are blood components responsible for blood clotting. If your platelet count falls with chemotherapy, you may bruise or bleed more easily. Let your health care provider know if this is occurring.

Timetables for chemotherapy treatment are guidelines. Individual schedules will vary, depending on how each person's body tolerates the treatments. The durations of chemotherapy or radiation may be prolonged for some women or not for others. Understanding that this might occur, and allowing for flexibility in scheduling if it occurs, will make the process easier.



Hormonal (Anti-Estrogen) Therapy

Breast cancers are tested for whether they have receptors for the hormones estrogen and progesterone.

If the cancer does have that receptor (results noted on the pathology report), a woman will have a recommendation to take some form of anti-estrogen treatment – either alone or in addition to chemotherapy.

Tamoxifen was the first anti-estrogen drug used in this setting and is still the main drug used for anti-estrogen treatment in premenopausal women. Aromatase inhibitors are now most often used in place of or sequentially with Tamoxifen in postmenopausal patients. Most of these drugs are given orally and are tolerated with few major side effects. The duration of therapy is generally between 5 and 10 years and is determined by the patient and her physician. Occasionally, younger, premenopausal women receive a recommendation to take a monthly injection of something called an LHRH agonist, which makes them postmenopausal and may be more effective than an anti-estrogen alone in preventing their cancer from recurring.

Biologic Therapy

Agents are used to attack specific targets critical to cancer growth and spread. The only such agent currently used in the adjuvant setting is a drug called trastuzumab or Herceptin®. If your tumor cells are HER2-positive (results noted on the pathology report), trastuzumab will be an important drug to consider. An intravenous drug, it is generally given with chemotherapy, then continued alone for a year. In the neoadjuvant setting, a new anti-HER2 drug, pertuzumab, or Perjeta®, is approved and used in conjunction with trastuzumab. The development of new therapies is another indication of the progress being made in treating breast cancer early to prevent recurrence.

Complementary and Integrative Medicine

Information adapted from:
http://www.breastcancer.org/treatment/comp_med

Complementary medicine aims to bring the whole person into harmony – physically, mentally, and emotionally – while conventional medicine does its work. For many people diagnosed with breast cancer, complementary medicine helps to relieve symptoms, ease treatment side effects, and improve quality of life. Complementary therapies are added to or used to “complement” conventional medicine. Complementary medicine can be combined or integrated with conventional medical treatment, and is thus also called “integrative medicine.” Complementary medicine includes a variety of therapeutic techniques that are not part of conventional or regular medicine.

What Is Complementary Medicine?

Complementary medicine is not alternative medicine. Complementary medicine is used with conventional medicine. Alternative medicine is used *instead of* conventional medicine. Adding yoga, tai chi, or massage to your regular treatment plan may help you. But you should never replace any part of your regular treatment (surgery, chemotherapy, radiation, hormonal treatment) with something else. Therefore, Breastcancer.org does not recommend alternative medicine. Conventional medicine has been proven to be safe and effective by numerous scientific studies. Complementary medicine includes techniques such as acupuncture, herbal medicine, massage, support groups, and yoga. Sometimes called holistic medicine, complementary medicine typically addresses how disease affects the whole person: physically, emotionally, spiritually, and





socially. Cancer patients and survivors often use complementary medicine. For example, studies have found that up to 80% of breast cancer survivors have used at least one complementary technique. To help doctors and patients understand which complementary therapies are safe and effective for people diagnosed with breast cancer, the Society for Integrative Oncology released guidelines that make recommendations about more than 80 complementary therapies. Meditation, yoga, and relaxation with imagery are recommended for routine use for common conditions, including anxiety and mood disorders (Grade A). Stress management, yoga, massage, music therapy, energy conservation, and meditation are recommended for stress reduction, anxiety, depression, fatigue, and quality of life (Grade B).

Types of Complementary Techniques

Explore a wide range of complementary therapy techniques — from acupuncture and yoga to prayer, music therapy, and massage at this site:

http://www.breastcancer.org/treatment/comp_med/types

Once you decide that you're ready to try a complementary therapy, the next step is to choose your practitioner with care.

Some, such as acupuncturists or massage therapists, may need to be licensed to practice. This means that the practitioner follows approved treatment standards and has passed a test on the therapy. Others — tai chi, meditation, and hypnosis instructors — are not licensed. It's important to interview a practitioner and make sure you're comfortable with his or her training, experience, and approach to the therapy before you begin treatment. It's also important to find a practitioner with experience working with people affected by breast cancer.

Your doctor may be your best source for finding a reputable practitioner.

Talking to Your Doctor About Complementary Medicine

About two-thirds of all people who use complementary medicine have not talked about these treatments with their cancer doctors. This could be for a number of reasons. Because medical schools didn't offer classes on complementary therapies until relatively recently, you may think that your doctor doesn't know anything about complementary medicine. Or maybe because some complementary therapies seem more spiritual than medicinal, you may think your doctor doesn't need to know about them.

If you would like to try complementary therapies, it's important to talk to your primary doctor about it. Your doctor wants to make sure you get the quality care you deserve. Coordination between all the doctors and practitioners you see helps to make sure you get the best care possible.



How to Talk to Your Doctor

Researchers say (and a Breastcancer.org survey confirmed) that many people don't want to tell their cancer doctors that they are using complementary therapies.

Here are some reasons many people say they can't discuss their use of complementary medicine:

- There's not enough time during the doctor's visit.
- The doctor might not take them seriously.
- The doctor might disapprove.
- The doctor doesn't ask about these treatments, so why should they volunteer any information?
- Their doctor did not study this type of medicine in school.
- They feel they don't know enough to have an in-depth discussion about the therapies.

If you feel that these concerns could keep you from discussing complementary medicine with your doctor, there are things you can do:

- **Ask for more time.** You can alert the nurse or doctor in advance that you'll need a little more time in the appointment to talk about these issues.
- **Be specific.** The more specific you can be about the kind of complementary therapy you're interested in, the easier it will be for your doctor to offer help. For example, if you're interested in acupuncture, make a list of the symptoms you think it will help. Your doctor will be better able to help you figure out if acupuncture would be safe for you and how it can be integrated into your conventional therapies.
- **If your doctor is not familiar with complementary medicine, direct him or her to books, websites, or research on the techniques you want to try.** If patients are interested in a treatment, most doctors want to learn about it so they can provide help and advice. If you can direct your doctor to information sources he or she respects, you'll most likely have a productive discussion about complementary therapies.

How much your doctor knows about complementary medicine may depend on where he or she practices medicine. If you're being treated at an

academic medical center, the cancer doctors there probably have worked with a number of specialists. There may even be a complementary therapy center within the hospital. Your doctor might have colleagues in psychology who offer meditation or colleagues who are pain specialists and do acupuncture.

If your doctor practices at a small hospital that's not connected to a medical school, he or she may not have had the chance to interact with complementary therapy practitioners. But that doesn't mean that he or she doesn't know anything about complementary therapies.

- **Learn about the technique you want to try so you can start the conversation.** The Resource Guide in this section will give you the background that you need to bring up the subject with your doctor.

Preparing for Your Discussion

Once you've made the decision to talk to your doctor about complementary medicine, you can use the talking guide below. This list can help you prepare for the discussion and make an outline of topics to bring up.

1. Do a little homework. Download information on the therapies that interest you from reputable websites, such as Breastcancer.org, the National Center for Complementary and Alternative Medicine (NCCAM), and cancer center sites, such as those listed in our Finding a Complementary Medicine Practitioner section. Write down your questions. Bring the information and questions with you to your appointment. When your doctor asks if you have any questions, choose the top 3 things you want to discuss in your appointment — and make complementary medicine one of those 3 things.

2. Express your point of view. Tell your doctor that you have started to read about complementary therapies or you want to try them. Make it clear that you feel complementary medicine is an important way to help your physical and emotional symptoms, as well as your quality of life. Make statements with “I” in them, such as “I have read a lot about acupuncture and breast cancer, and I feel it may be helpful in my treatment.”

3. Listen to your doctor's response. Give your doctor enough time to respond to your statements. After she or he has spoken, make sure you understand the doctor's point of view.

4. Talk to the nurse about complementary therapies. Nurses may have had more training in complementary medicine. The nurse also can go over the points you have already brought up with the doctor.

5. Ask your doctor if your complementary medicine practitioner can call to discuss your combined care. Your doctor may be concerned that your complementary medicine practitioner has not worked with people who have been diagnosed with breast cancer. Or your doctor may have a question about the practitioner's credentials. A conversation between the two can help ensure you get the quality care you deserve.

6. Restate your commitment to conventional cancer treatment. It's important for your doctor to know that you are committed to continuing your chemotherapy, radiation treatments, or hormonal therapy.

Complementary Medicine Resource Guide

<http://www.integrativeonc.org/index.php/patients>

http://www.breastcancer.org/treatment/comp_med

<http://www.cancer.gov/cancertopics/cam>

<http://www.cancer.org/treatment/treatmentsand-sideeffects/complementaryandalternativemedicine/complementaryandalternativemethodsandcancer/cam-and-cancer-toc>

Infertility and Breast Cancer

While breast cancer itself does not appear to affect fertility in women, cancer treatments pose a variety of reproductive risks, including infertility and premature menopause. Menopause after chemotherapy can be temporary, lasting weeks to many months, or can be permanent. Factors determining which if either occur include the type of drugs used and their dosage, the patient's age and pre-treatment fertility (which is often unknown). If menopause occurs, that means that a woman is no longer able to get pregnant. It also means that body changes will begin to occur in the absence of estrogen produced in the ovaries. These changes may include hot flashes, mood swings, weight gain, hair thinning, muscle and bone discomfort as well as bone loss. These menopausal changes will be discussed in another section. In this section we will focus on ways to reduce infertility and promote successful pregnancies.



Reproductive Options

Most importantly, as best we can tell, pregnancy after cancer does not cause the cancer to recur. Around 70 percent of breast cancers are estrogen receptor positive, and may grow in response to the hormone estrogen. Part of therapy for these cancers is anti-estrogen treatment, which is generally given for 5-10 years. In order to adequately treat patients, there may be a recommendation to delay pregnancy. What are the options to preserve fertility or allow for successful pregnancy?

Recent studies utilizing a medication called an LHRH agonist during chemotherapy, a monthly injection, may help preserve ovarian function and fertility. While on this medicine the body is fooled that it is in menopause and ovulation does not occur. This protects some of the eggs in the ovaries and has been shown to be effective in preserving fertility in some women. You may feel like you are in menopause while on these medicines, with mood swings and hot flashes. In addition, some measures known as in vitro fertilization can be utilized to maintain the highest chance of fertility. To fully understand your choices we recommend two things:

1. Explore the website <http://www.myoncofertility.org> - look under "Patients" and learn about fertility concerns and options. This is a complete resource in Spanish as well as English.
2. Ask your breast care provider (nurse navigator, oncologist, or surgeon) for a referral to a reproductive endocrinologist (fertility expert). These appointments can be expedited and can occur within 24-48 hours.

Feeling Your Best



After you have been diagnosed with breast cancer, your health care team will recommend the course of treatment that is best for you. Treatment can involve surgery, chemotherapy, radiation therapy, oral medication or a combination thereof. These life-saving treatments can also produce unpleasant side effects such as nausea, vomiting, constipation, diarrhea, taste alterations, and mouth sores. In this section, we suggest ways to take good care of yourself on this journey, including advice on healthy eating and ways to address side effects, so that you can feel your best before, during and after treatment.

Eating Well

Making healthy food choices is one of the best things you can do to take care of yourself at this time. Even though many cancer treatments may reduce your appetite, calories and nutrients are essential to keeping up your strength and helping your body recover from cancer. And making appropriate food choices can actually alleviate

some of the side effects of treatment. So, while you may not feel hungry, you still need to eat. Think of food the way you think of medicine – as something you take because it makes you better.

Balancing Calories

Weight gain is commonly seen when being treated for breast cancer as a result of hormonal therapies or early menopause. However, some of the side effects of chemotherapies can also cause loss of appetite and consequently weight. It is important to balance the type of calories you consume and choose from healthy sources. Carbohydrate-containing foods such as fruits, vegetables, and whole grains are good sources of fiber, and provide us with energy. Proteins, such as meat, fish, poultry, nuts, nut butters, and legumes are the building blocks of our bodies and help us heal. Healthy fats, such as those from vegetable sources like oils and nut butters help us to absorb certain vitamins and aid in keep our bodies in good working order.

Here are some suggestions for getting enough to eat, even when your appetite is reduced because of treatment:

- Eat five to six small meals throughout the day, roughly every two to four hours, even if you don't feel particularly hungry.
- Bring healthy snacks wherever you go. Nuts, dried fruits, crackers with peanut butter or cheese, a granola bar, yogurt, hard-boiled eggs, or a banana with peanut butter are good portable snacks. Supplements such as Ensure® Complete or Boost® Plus are healthy meal replacements when the thought of eating or preparing a meal is not feasible.
- If trying to maintain or gain weight, avoid filling, low-calorie foods such as popcorn, lettuce and broth.
- Choose nutrient-rich beverages such as milk, Boost® Plus, Ensure® Complete, or 100 percent fruit juice instead of sodas.
- Sip non-caffeinated fluids throughout the day. A general goal would be approximately two liters per day or about 8 cups unless you have been told by your doctor to restrict fluids. This is particularly important if it is a chemo day or if you are experiencing vomiting or diarrhea.
 - Pay attention to portion sizes if you are watching your weight. Check food labels and package serving sizes.

The Importance of Protein

When the body is stressed by both cancer and cancer treatments, it requires more protein than usual to rebuild. On average, try to take in 70 to 90 grams of protein every day. Three ounces of meat, poultry or fish provide approximately 21 grams of protein. If you don't feel like preparing a meal, having high protein "grab and go" items on hand will help you to reach this goal. These could include hard-boiled eggs, Greek yogurt, cottage cheese, cheese sticks, and lean cold cuts such as sliced turkey.

Healthy Carbohydrates

Eating enough fruits, vegetables, and whole grains can help you keep up your energy – most of our vitamins and minerals are found in this group. They also promote healthy bowel habits. This is especially important during chemotherapy, which can cause either diarrhea or constipation, depending on the drug. On average, a person should consume 25-35 grams of fiber per day. Another bonus is that fiber can help us feel fuller longer if weight maintenance or loss is desired.

Fats

There are two kinds of fat – saturated and unsaturated. Saturated fats come from animals (butter, cheese) and are known to increase risk of heart disease and high cholesterol. Unsaturated fats come from vegetables (olive and other vegetable oils, avocados, nuts) and have been shown to protect your heart and cholesterol. They have equal calories per tablespoon, so if trying to gain weight, focus on the unsaturated fats. If trying to lose weight, eliminating excessive fat from any source is a good thing.



Foods in Question

Soy products such as tofu and edamame have been shown to be safe to consume even in people with ER-positive breast cancers. However, soy protein isolates, a concentrated form of soy, that have been concentrated into supplements should be avoided. While a serving of tofu or edamame is acceptable, you should not consume soy protein in this highly concentrated form.

<https://www.cancer.org/cancer/news/expertvoices/post/2012/08/02/the-bottom-line-on-soy-and-breast-cancer-risk.aspx>

Ground flaxseed has properties similar to soy. Current research is showing that two to three tablespoons of ground flax is an acceptable addition to a healthy diet, even in women with ER-positive breast cancers.

<https://www.oncologynutrition.org/erfc/hot-topics/flaxseeds-and-breast-cancer/>

Many people are concerned about sugar causing cancer. All carbohydrate-containing foods break down to sugar (or glucose). Glucose is the

primary fuel for every cell in our body. The brain uses glucose almost exclusively for energy. So eliminating fruits, vegetables, and whole grains would not be practical if we want to maintain a healthy diet. However, avoiding foods with simple sugars such as sweets, candy, cakes, etc., is a healthy choice for all of us.

As with any choice, you may feel more comfortable avoiding soy and flaxseed during treatment. If you would like more information, please speak with your registered dietitian or oncologist.

A Word about Water

Everyone needs sufficient water to stay healthy, but for people being treated for cancer, drinking enough water is especially important. The vomiting or diarrhea that may occur as a side effect of treatment can rob the body of fluid and cause dehydration. Take care to replace these fluids by drinking adequate amounts of fluids like water or other clear liquids. Avoid tea, coffee, colas and other beverages containing caffeine, since these draw fluid out of the body. The American Cancer Society recommends drinking eight 8-ounce glasses of water a day.



Weight Control

During treatment for breast cancer is not a good time to try to lose weight. As mentioned before, you do need sufficient calories during this time. However, once your treatment is finished, getting to a healthy weight as soon as possible is very important. Excess weight has been associated with heightened hormone levels, which may play a role in tumor development in some people. Plus, you'll feel better physically and emotionally when you achieve a weight that's right for you. Take care to avoid fast food, "junk" food, sweets and other high-calorie, low-nutrient foods. Watch your portion size, and, with your doctor's approval, increase your level of physical activity.

Treatment Side Effects

The side effects associated with chemotherapy, radiation, and even surgery can be difficult to manage. Nausea, vomiting, diarrhea, constipation, mouth sores, etc., all can prevent you from eating and obtaining enough energy to help you heal and, ultimately, feel better. It is important to ask to speak with the registered dietitian who can give you helpful tips to lessen these potential side effects.



As you go through your breast cancer journey, the nutrition recommendations may change. Ultimately the goal is to keep you healthy, minimize side effects, and send you on your survivorship journey with the tools to maintain a healthy weight and lifestyle.

More Nutrition Information

Our registered dietitian can give you more information about nutrition during and after treatment for breast cancer. You can also find useful information about nutrition and managing side effects on the website of UConn Health's Carole and Ray Neag Comprehensive Cancer Center: http://cancer.uchc.edu/patients_families/programs/nutrition.html.

Other helpful sites are:

www.aicr.org (American Institute for Cancer Research)

www.oncologynutrition.org (Academy of Nutrition and Dietetics' Oncology Practice Group)

www.cancer.org (American Cancer Society)

Benefits of Exercise

Research increasingly suggests that exercise is of great benefit to people during and after cancer treatment. No, you don't have to train for the Olympics! Whatever exercise you can comfortably do - with your doctor's advice, of course - is believed to be beneficial.

The American Cancer Society now holds that exercise is not only safe and possible during cancer treatment, but can improve both physical functioning and quality of life.

For more information on exercise and the cancer patient, visit www.cancer.org and enter "Physical Activity and the Cancer Patient" in the search window. You'll find a list of benefits, advice on exercise safety and cautions, and tips on how to build exercise into your day.

Clinical Trials: Another Treatment Option

A clinical trial could be an option for you. Clinical trials are research studies in which real people participate as volunteers. Clinical research studies (also known as clinical trials) are designed to evaluate health risks and to test new approaches to the diagnosis, treatment and prevention of specific diseases or disorders. These studies play a significant role in the development of new treatments and medications for diseases and conditions.

The goal of research is to find better ways to treat or identify cancer and help cancer patients. Clinical trials test many types of treatment, such as new drugs, new approaches to surgery or radiation therapy, new combinations of treatments, or new methods such as gene therapy. Some clinical trials study the effects of our standard treatments on patient quality of life during and after completion of the treatment. The knowledge that may be gained from this type of work can be of great value to our society.

To ensure the safety of volunteers who enroll in clinical studies, each project must be approved by

an Institutional Review Board (IRB) before it can begin. During the review process, the IRB evaluates the potential risks and benefits associated with the study and decides whether or not to approve it.

Should I Participate in a Clinical Trial?

This is a question only you, those close to you, and your healthcare providers can answer together. Learning you have breast cancer, and deciding what to do about it, is often overwhelming. Clinical trials are the safest and most effective way to study cancer prevention, improve breast cancer diagnosis and treatment, and address the needs of breast cancer survivors. Each trial has a specific set of criteria that determines who is eligible to participate.

Individuals who choose to participate in clinical research studies may do so in hopes of improving their own health or advancing scientific knowledge about the cause, treatment and prevention of disease. The health of millions has been improved because of advances in science and technology, and the willingness of thousands of individuals like you to take part in clinical research.



Am I Eligible for a Clinical Trial?

Your eligibility may be determined by various factors, depending on the nature of the study. If you meet the screening conditions, you will be given an “Informed Consent Form” containing a detailed written description of the project, any risks involved, and your rights as a participant.

If the screening process involves any type of intervention, such as obtaining a blood sample or documenting personal health information, the consent process will be conducted prior to the screening to ensure that you are informed of what will be required of you and of any potential risks to your well-being. By signing and returning the consent form you agree to participate. If you should have second thoughts about participating, or become uncomfortable during the study, you have the right to withdraw at any time without any penalty whatsoever.

Benefits of Participating in a Clinical Trial

Participating in clinical research may have a significant impact on your life. Some people may benefit directly from participating in a study, for example, if a drug being used in the study proves to be effective. Some people may not benefit directly, but their participation may help to advance knowledge that could benefit others in the future.

It is important that you are well-informed and feel confident about your decision. If you have breast cancer, we encourage you to join a clinical trial. Clinical trials offer the chance to try new treatments and possibly benefit from them. Learning a new therapy is better than the standard treatments can open doors to other drugs and procedures that may be even more effective.

Some people worry they will get a placebo instead of an effective treatment in a clinical trial. Your health care provider or the clinical research staff can tell you if there is a placebo in the study. Most



often in a breast cancer treatment clinical trial, you will get either the new treatment or the standard treatment. So, even if you do not get the new drug (or other new therapy), your breast cancer will be treated just as it would if you were not in the trial. You may want to consult with your doctor, family members and the research staff of the project to discuss any concerns you may have.

Is it Safe to Participate in a Clinical Trial?

Clinical research studies conducted at UConn Health are approved according to federal, state and UConn Health guidelines. In fact, no study can even begin before it has been approved by the Institutional Review Board (IRB), which carefully considers the potential risks and benefits of the study before authorizing it. The safety and protection of research subjects participating in these studies are of paramount concern.

If you are interested in participating in a clinical trial, you will be given an informed consent form that



spells out the nature of the study and any risks that are involved and clarifies your rights as a participant. If any kind of intervention is involved in the trial, such as obtaining blood samples or documenting the participant's health history, a careful consent process is conducted before the person actually becomes involved in the study. This ensures that the research participant knows what is expected and any potential risks. Completing and returning the consent form means the person agrees to volunteer. But if the volunteer then has second thoughts, she/he can simply withdraw from the study anytime.

Additionally, UConn Health has a research subject advocate (RSA), whose job is to represent the interests of the volunteers who participate in our studies. The RSA has a number of responsibilities. She/he must provide information to patients and volunteers who are participating in any clinical trial and research where there is a greater than minimal risk. Other responsibilities of the RSA include:

- Assisting investigators to develop data and safety monitoring plans, and helping research advisory committees review those plans;
- Assuring that the Health Center's studies adhere to the IRB-approved protocol and monitoring procedures;
- Ensuring the reporting of any significant problems or conflicts of interest to appropriate local committees and federal agencies; and
- Assuring that UConn Health investigators are appropriately trained and remain current on their regulatory and patient safety responsibilities.

Who Conducts a Clinical Trial?

Each study conducted at UConn Health has a principal investigator (PI) who is the person in charge of the research study. The PI may be one of a number of different kinds of healthcare professionals. He or she will assemble a team of research professionals who will also be involved in managing the study. The majority of the breast oncology research studies are conducted through the Clinical Trials Office (CTO), well-qualified research professionals who successfully help conduct clinical trials at UConn Health.



Some Important Questions to Ask About Clinical Trials

If you are considering participating in a clinical trial, you probably have a lot of questions. Even if you are eligible to participate in a study, you should give it careful thought before deciding to become a participant. While you may benefit in a host of ways from participation, you should also be aware that participating could impact your life in many ways, as well.

It is important for you to make an informed decision. So, you will probably want to consult with your personal physician and members of your family before making a commitment. If you have any concerns about the project, you should also discuss them with the research team working on the research study. Here are some questions you'll want to obtain answers to before making a decision:

- What is the purpose of the study?
- How many people will take part in the study?

- What kinds of tests will be required as part of the study and how often will the tests be done?
- Are there any risks? How likely are they to occur and what will be done to reduce the likelihood of their occurring?
- Am I likely to benefit directly from participating in the study?
- What are the study's potential benefits to other people and to society as a whole?
- What potential advantages does the experimental treatment offer over the current standard of care?
- How long will my participation in the study be required?
- What discomforts, inconveniences or costs will I experience as a participant?
- If I choose not to take part in the study, what other options do I have at this time for treatment?
- Can I withdraw from the study if I experience negative side effects?
- Will this treatment be covered by insurance? If my insurance does not pay for the treatment, who is responsible for the costs?
- Will any of the treatments be free?
- Is there any follow-up care after I leave the study? If so, for how long?

What are your Rights as a Participant?

Signing a consent form and joining a study does not obligate you to remain in a study. In fact, you can leave at any time if you decide, for any reason, that the study is not right for you.

One of your key rights is the right to informed consent. This means that you must be given all the facts about the study before you decide whether to take part.

All volunteers who participate in studies at UConn Health are guaranteed rights that ensure they are treated professionally and respectfully. When you take part in one of our studies you have the right to:

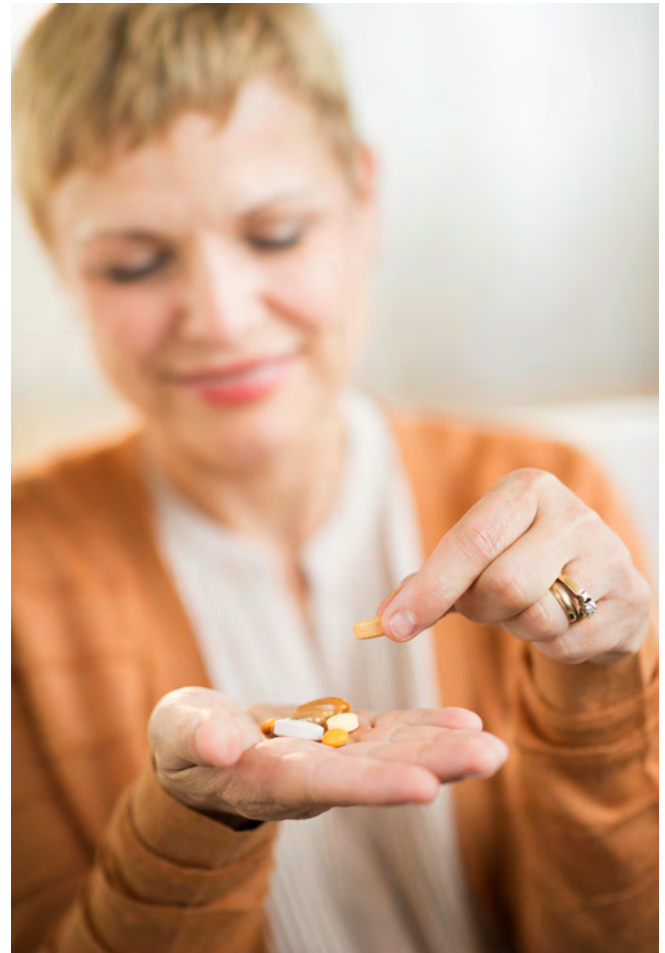
- Be treated with respect.
- Know the risks of participation in the study.
- Know what alternatives are available.
- Withdraw from the study without penalty.

- Make your decision without feeling any pressure from the research staff.
- Know the name, credentials and contact information of the study's principal investigator.
- Know the purpose of the study.
- Know who will have access to your information.
- Know what procedures may be performed and what drugs or medicines may be used.
- Seek additional help or clarification during the informed consent process and at any time during the study.

What are your Responsibilities as a Participant?

All volunteers who participate in studies at UConn Health are expected to comply with the specific requirements of the study. In addition, study participants are expected to adhere to a general set of requirements that apply to all participants. They include:

- Arriving for all scheduled appointments or calling ahead if you are unable to keep an appointment.
- Arranging your own transportation to and from the study site(s).
- Following the directions of the researchers.
- Making sure your contact information is up to date.
- Providing - to the best of your ability - accurate information about your medical history if it is relevant to the study.
- Seeking healthcare for any medical conditions unrelated to the study.
- Asking the researchers to completely answer any questions you may have at any time during the study.
- Informing the research staff of any negative experiences you have while participating in the study.
- Informing the research subject advocate and, if necessary, the Institutional Review Board if you feel your rights as a study subject have been violated.



Types of Clinical Trials

There are four kinds of clinical trials:

- In treatment trials a new treatment (such as a new cancer drug or a new approach to surgery or radiation therapy) is studied.
- In prevention trials the study tests new approaches (such as medicines, vitamins or some other form of dietary supplements) that may lower individuals' risk of cancer. Prevention trials may target people who have never had cancer or focus on preventing a recurrence in people who have had cancer.
- Screening trials focus on ways to detect cancer, especially in the early stages, when it is most treatable.
- And quality of life trials study how best to improve the care and comfort of cancer patients.

If a clinical trial is testing a new drug, it will almost certainly progress along a series of phases:

- In Phase I trials, researchers evaluate how new drugs should be administered, how often they should be administered, and what dosage is safe.
- Phase II trials extend the research conducted in Phase I and begin to study how well the new drug actually works. Usually, the focus in Phase II is on a specific type of cancer.
- Phase III trials test a new drug or a combination of drugs or, sometimes, a new surgical procedure by comparing those new therapies to current standards. Phase III trials almost always involve large numbers of participants and many different healthcare facilities.
- Phase IV trials are used to further evaluate the long-term safety and effectiveness of a treatment. These refining trials may take place after a new treatment has been approved for standard care.

What do Clinical Trials Mean for Breast Cancer Patients and Survivors?

For breast cancer patients, participating in a clinical trial could mean studying or comparing many different things, including new drugs; current drugs; new surgical methods; the use of new equipment or devices; better ways to manage side effects; support groups; complementary therapies; and innovative approaches to reducing the likelihood of contracting cancer or experiencing a recurrence.

Clinical trials offer breast cancer patients and survivors a number of opportunities, including:

- Benefiting from new treatments not yet available to patients in general,
- Contributing to an understanding of what works for people who have breast cancer and what may help others with breast cancer in the future, and
- The possibility that a treatment may help one feel better while living with breast cancer.

Can you Learn the Results of a Study?

Many study participants wish to review the results of studies in which they have participated. Once a study is complete, participants are informed of their results and given advice concerning their future medical care. You should be aware that this may not occur for some time after a study is complete, while all research data are being analyzed.

Where can I find Additional Information on Clinical Trials?

You can find additional information by visiting the UConn Health clinical trials resource website available at http://www.uchc.edu/patients/clinical_trials/resources.html.

Resources

UConn Health Clinical Trials Information: http://www.uchc.edu/patients/clinical_trials/volunteers.html

UConn Breast Clinical Trials List: <https://starr.uchc.edu/Study/ConditionDetails.aspx?Condition=32>

National Cancer Institute Clinical Trials Information: <http://www.cancer.gov/clinicaltrials>



Living Beyond a Breast Diagnosis and Treatment into Survivorship



The treatment for your breast cancer diagnosis is done. You've traveled a long road since hearing the words, "it's breast cancer." You are now entering into a new aspect of breast cancer care called Survivorship.

You may feel strong, proud, relieved, and grateful, like a new person, and that it's time to celebrate – or you may feel anxious about treatment ending, fearful of the unknown, alone, or traumatized without the safety net of your frequent visits to your oncology team.

For the majority of you, the side effects from treatment may be minimal if any at all; you will return to your everyday routine and continue with a good quality of life. Some of you will still be experiencing the effects of treatment physically (with fatigue, neuropathy, chemo brain, hot flashes); emotionally (with anxiety, depression, worry, and questions about sexuality and appearance); spiritually (finally asking, why me, what did I do wrong?); and financially (who's going to pay all the medical bills?). Remember this: you matter to us.

Now that your active treatment has ended, your quality of life and long-term survivorship are just as important as the day you were told of your diagnosis. We took you under our wings then: we will not abandon you now. Our goal is to move you beyond curative treatment to what you consider a good quality of life, a new normal.

You may wonder and worry about how and when you will be followed by your breast cancer team for your history of breast cancer. You may ask yourself, are the appointments random? Will they remember me if I am not there as often? Who do I call if I have a question, or begin to panic because I have a cold, headache and cough? The Breast Team follows best practice guidelines that specifically outline the timeline for follow-up care visits and active surveillance. These guidelines are individualized to specifically meet your breast cancer diagnosis and treatment. These visits include a review of your history, physical exam and mammogram or MRI if you still have breast tissue after your original breast cancer surgery. You will be asked about how you are feeling and of any concerns you may have since your last visit to your team. You will have an opportunity to follow up with a visit to a genetic counselor, social worker, physical therapist, dietician, chaplin, or to discuss an issue with the RN breast cancer navigator. It is still very important that you continue with regular GYN exams, especially if you are taking Tamoxifen. In addition, your bone health will be a central part of your surveillance if your treatment can have an impact on it.

As part of our commitment to individualized breast cancer care, we have started a Survivorship Program. About 3-6 months after your surgery, chemotherapy or radiation treatment has been completed (but while you may still be on anti-estrogen therapy), you will be referred for a Survivorship Visit with an APRN. She will review in detail your breast cancer history and treatment as well as your team of health care providers. She will also provide a calendar of follow-up visits. She will review with you any distressing or bothersome symptoms that you are continuing to experience; when to call your breast team or primary care provider; possible long-term side effects you may experience; and assist you in accessing rehabilitation

services you may need to help you feel your best. This is a one-time personalized visit that will last about an hour. Breast cancer survivors who have attended survivorship visits have told us the information on their diagnosis, treatment and follow-up plan was invaluable to them and their families.

You will be provided with a written survivorship treatment summary for your own personal records. A copy will be placed in your cancer center medical record, and provided to your primary care provider or any other healthcare provider you identify to receive a copy. Our goal is to prevent gaps in communication and improve coordination of your care between members of your care team.

Check out these links for more resources:

www.survivorshipatoz.org

www.cancer.net



Survivorship Plan Example: Page 1

UConn Health---EXAMPLE
Neag Comprehensive Cancer Center

Medical Record #

Survivorship Care Plan for Breast Cancer

Prepared by: Nancy D. Baccaro, APRN on 12/2/2014 at Neag Comprehensive Cancer Center, UConn Health

General Information

Patient Name	XXXXXXXXXX
Medical record number	XXXXXXXXXX
Phone (home)	XXXXXXXXXX
Phone (cell)	XXXXXXXXXX
Email	XXXXXXXXXX
Date of birth	XXXXXXXXXX
Age at diagnosis	XXXXXXXXXX
Support contact	XXXXXXXXXX

Care team

Hematologist/oncologist	Susan H. Tannenbaum, MD, 860-679-2100
General/breast surgeon	Peter J. Deckers, MD, 860-679-2100
Radiation oncologist	Robert J. Dowsett, MD, 860-679-3225
Plastic surgeon	
Primary care physician	
OB-GYN	
Nurse/nurse practitioner	Ellen Oliver, RN/Kristi Dubey, RN/Genevieve Dinh, APRN,
Mental health/social worker	Marie Ziello, MSW, LCSW,
Coordination of care	Ellen Oliver, RN/Kristi Dubey, RN/Genevieve Dinh, APRN,
ACS Resource Navigation	860-679-7820
Spiritual Care (Chaplin)	Katy Wilcox, 860-588-0647
Rehabilitation (PT/OT)	Megan Bartos, OTR/L, CLT 860-679-4119
Breast Navigator	Molly Tspouras, RN, OCN, CBPN, IC 860-480-1981

Survivorship Plan Example: Page 2

UConn Health---EXAMPLE
 Neag Comprehensive Cancer Center

Medical Record #

Background Information

Family history	
Genetic testing	
Other health concerns	
Additional comments	

Right breast

Definitive breast surgery	
Sentinel node biopsy	
Axillary dissection	
Lymph nodes	
Tumor type & stage	
Pathologic stage	
Oncotype DX recurrence score	
Estrogen receptor status	
Progesterone receptor status	
HER2 status	

Treatment Plan & Summary

	Pre-treatment	Post-treatment
Comments		

Treatment on clinical trial	
Therapeutic agents	# cycles
	% dose reduction

Biologic therapy	
Pre-operative chemo administered	
Reconstruction	
Radiation therapy	
Growth factor given	
Hospitalization for toxicities	

Survivorship Plan Example: Page 3

UConn Health---EXAMPLE
 Neag Comprehensive Cancer Center

Medical Record #

Neurotoxicity impairing activities	
Disease status at end of treatment	
Endocrine therapy	
Endocrine therapy timing	

Follow-Up Care

UPON SCREENING, THE PATIENT HAS BEEN DETERMINED TO HAVE THE FOLLOWING ISSUE(S):

Patients – Please consult your health care provider for medical advice specific to you before using any medications, supplements, or other products, and before beginning any lifestyle program.

Chief patient concern	Depression (related to life events)
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Surveillance	When/How often	Coordinating provider
Medical history/physical exam: Yrs 1-3	Every 6 months	Drs Tannenbaum alternating with Peter Deckers
Medical history/physical exam: Yrs 4,5	Every 6 months	
Post-treatment mammography	Every year	Dr Peter J. Deckers, MD
MRI	Not needed	
Bone densitometry	Every year	Dr Susan Tannenbaum
Pelvic examination	Every year	Jacquelin Nissen, MD
Genetic counseling referral	Not applicable	
Breast self-examination	Every month	

Preventive care recommendations	Colon cancer screening, Cholesterol monitoring/management, Diabetic screening/management, Diet, Exercise, Hypertension control, Mental health, Smoking cessation, Vaccines, Weight management
Comments on follow-up care	

Survivorship Plan Example: Page 4

UConn Health---EXAMPLE
Neag Comprehensive Cancer Center

Medical Record #

End Notes

Note 1: *Important caution.*

This is a summary document whose purpose is to review the highlights of the cancer chemotherapy treatment plan for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with cancer and adjuvant chemotherapy in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

Your sexual health is important!



Sexual health issues are a major concern for breast cancer survivors and should be addressed throughout your cancer care. Up to 2/3 of all breast cancer survivors will report some type of sexual dysfunction, ranging from painful intercourse to a lack of interest or desire. Unfortunately, surveys have shown that very few women will feel comfortable talking to their provider about these issues because they may feel embarrassed or they worry their provider does not think it is a priority. Your sexual health may be a very important part of your life: if you are having issues, they may impact your relationships at home and overall sense of well-being. The first step is to know that these issues are important and your doctors do want to listen and help. There are many resources available to you, and

your breast cancer team should include a gynecologist, with whom you schedule an annual visit and pelvic exam. Many breast cancer treatments impact hormone levels through chemotherapy, surgical removal of the ovaries, or medications like Lupron that shut down the ovaries. Also, some of the medications you take following treatment for 5 or 10 years (aromatase inhibitors, Tamoxifen) can also impact the vagina and uterus. A lack of estrogen can lead to hot flashes, night sweats, decreased sexual drive and thinning and drying of vaginal tissue. Most women with breast cancer are not able to be on estrogen replacement therapy to treat these symptoms: it is important to discuss your options with your breast team.

Vaginal Dryness (Atrophy) and Pain with Intercourse

The first step is to have a pelvic exam and assessment. Atrophy is a very common cause of painful intercourse: depending on how severe the dryness is, there are a range of options. (See attached sheet on vaginal dryness.) Start with lubricants and daily moisturizers; in some cases a vaginal estrogen pill or cream can be used for a short time to rebuild the tissue. Sometimes the vagina can begin to stick together from dryness and using vaginal dilators can help stretch the tissue out over time.

Sometimes after breast surgery and radiation women can have chronic breast pain. This can impact their sexual health and even lead to pain with intercourse as well. There are specialists in physical therapy who can help you learn techniques and exercises that may help.

Women who have experienced pain with intercourse following breast cancer treatment may be more apprehensive and fearful about future attempts. Sexual health counselors are a great resource to talk with about these fears and give you strategies on how to overcome them.

Decreased Interest and Desire

Your libido will be impacted by a lack of estrogen and some medications. Many antidepressants can also decrease your sex drive. There are currently no approved medications for women that are comparable to 'Viagra' for men, but there are several options being studied currently. It is important to talk to a sexual health counselor and your provider. Depression and anxiety are very common for anyone dealing with cancer and can also impact your overall mood and ability to find pleasure.

Additional Resources:

Suggestions for treatment of vaginal dryness/vaginal atrophy

Moisturizers – Use on a regular basis

- Replens
- Me Again
- Vagisil Feminine Moisturizer
- Feminease
- Senselle
- Moist Again

Lubricants – Use prior to intercourse and in addition to moisturizers

Read the label. If you have sensitive skin do not use the ingredients propylene glycol or chlorhexidine. They can be irritating.

Oil-based – Do not use with condoms or diaphragm, may cause damage or tear

- Elegance Women's Lubricant – Contains natural oils

Water-based – Best for sensitive skin

- Slippery Stuff
- Astroglide
- K-Y Jelly/Liquid

Silicone-based – Ultra moisturizing, does not break down in water, long-lasting

- ID Millennium
- Pjur (Eros)

Organic

- Good Clean Love – 100% vegan, and paraben, glycerin, and petrochemical-free
- Olive oil



Cancer Treatment and Bone Health

Maintaining good bone health is an important aspect of cancer survivorship in both pre- and postmenopausal women. Therapies to treat breast cancer may have significant impact on bone health, with potential for bone loss and fractures. Therefore, it is important for all women undergoing cancer therapies to understand the implications of their treatment.

Chemotherapy may have a direct negative impact on bone metabolism leading to lowering of bone mass in women receiving this treatment. Moreover, in younger premenopausal women, chemotherapy may lead to loss of regular menstrual periods, a major risk factor for bone loss that occurs early in the course of therapy. Therefore, it is critical that women in this category receive adequate counseling about prevention strategies, and consider treatment with medications to slow down or inhibit this bone loss in order to maintain good bone health and prevent future fractures.

Aromatase inhibitors are medications used in the treatment of postmenopausal hormone receptor-positive breast cancer. The major effect of these agents is to lower estrogen levels to almost undetectable values. In doing so, they may compromise bone health in women who are already potentially at higher risk of bone loss due to the menopausal state. A number of large studies in trials in the medical literature demonstrate this finding very clearly. Therefore, it is extremely important that women are educated in prevention as well as treatment options to avoid bone loss which can ultimately lead to fractures that can have a major impact on quality of life.

All women undergoing aromatase inhibitor therapy should have a Bone Mineral Density exam done by DXA technology prior to or upon starting this therapy to assess their risk for fracture. This should be done in a radiology unit that does these examinations routinely, and also has measures in place to assure the high quality of each examination.

Prevention strategies include knowledge of adequate amounts of calcium from food sources as well as supplements, adequate intake of vitamin D, and an understanding of weight-bearing as well as resistance-training activities and exercise. All of these are important for the foundation of any bone health program. Furthermore, medications that can inhibit or slow down the bone breakdown that can occur due to chemotherapy or aromatase inhibitor treatment in women already menopausal, are important to consider.

To fully understand prevention and treatment of osteoporosis in general:

1. Explore the website; <http://www.nof.org> and look under “patient information” to learn more about nutrition, exercise and treatment. It is a complete resource guide.
2. Ask your breast care provider (nurse navigator, oncologist, or surgeon) for a referral to a bone endocrinologist who is experienced in the care and follow-up of breast cancer patients.



Dealing with Fatigue

Fatigue is one of the most common side effects of cancer treatment. In fact, experts say that nearly 90 percent of people receiving chemotherapy and radiation experience fatigue. It can be a serious problem. Debilitating fatigue can cause people to quit their jobs, withdraw from social activities and experience a diminished quality of life. Fatigue among people in treatment for cancer is so common and troublesome that the Neag Comprehensive Cancer Center at UConn Health has established a cancer fatigue clinic to provide treatment and support to patients with cancer-related fatigue and to conduct research on the subject.

Tell Your Doctor: Help Is Available

About half of people with cancer-related fatigue also have significant anxiety and depression. The most important thing for patients to do is to tell their oncologists about these problems. Some people have underlying medical problems that contribute to fatigue. These may include thyroid problems or electrolyte imbalances. Your doctor can evaluate you for these and other underlying problems and correct them with medication. Depression, anxiety, pain and insomnia all contribute to fatigue. Your doctor can also prescribe medication and/or counseling to help alleviate these symptoms.

Many people are helped significantly by a therapeutic technique called cognitive-behavioral therapy (CBT). Your doctor or nurse can help you find a therapist skilled in CBT.

The cancer fatigue clinic at UConn Health's Neag Comprehensive Cancer Center is an excellent resource you and your doctor can turn to for help with fatigue, depression, anxiety and insomnia.

Practice Good Habits

Practicing good “sleep hygiene” may also help. Go to bed at the same time each evening, and get up at the same time each day. Avoid alcohol, caffeine or other substances that might disturb your sleep. Make sure your bedroom is dark and that the temperature is comfortable.

Reduce Your Stress

When you're in treatment, it simply may not be possible to maintain the pace of life you had before diagnosis. It's often difficult for women who've always been active and who may be juggling work and family demands to accept the fact that they may have to do a little less for a while. But trying to “do it all” while in treatment is likely to increase the stress you feel, and stress only adds to fatigue. So take some time to set priorities and to let some things go. Don't be afraid to ask others to do a little more. Accept offers of help from family and friends. You'll feel less burdened, and they'll feel good about having a tangible way to show that they care about you.



Staying Active and Healthy Eating

Women living with a prior breast cancer diagnosis number in the millions. The proportion of women who succumb to their cancer is decreasing with early detection and better treatments. Death from cardiovascular disease is now the number one killer. In part due to diagnosis and treatment, it is not uncommon for women to develop other medical issues called comorbidities. These include weight gain, insulin resistance, diabetes, elevated cholesterol and reduced activity. These in turn act to not only increase the incidence of death due to heart and other vascular diseases, but perhaps to increase mortality from the breast cancer as well. One thing that we can control is our ability to exercise and eat well. Below are some recommendations for regular exercise and eating healthier.

Staying Active

As recommended by the American Cancer Society: <http://www.cancer.org/healthy/eathealthygetactive>

Be Physically Active

Adults: Get at least 150 minutes of moderate intensity or 75 minutes of vigorous intensity activity each week (or a combination of these), preferably spread throughout the week.

Limit sedentary behavior such as sitting, lying down, watching TV, and other forms of screen-based entertainment.

Doing some physical activity above usual activities, no matter what one's level of activity, can have many health benefits.



Usual and intentional activities can also be grouped by intensity:

- *Light* intensity activities include activities such as housework, shopping, or gardening.
- *Moderate* intensity activities are those that require effort equal to a brisk walk.
- *Vigorous* intensity activities generally use large muscle groups and result in a faster heart rate, deeper and faster breathing, and sweating.

Examples of moderate and vigorous intensity physical activities:

	Moderate intensity	Vigorous intensity
Exercise and leisure	Walking, dancing, leisurely bicycling, ice and roller skating, horseback riding, canoeing, yoga	Jogging or running, fast bicycling, circuit weight training, aerobic dance, martial arts, jumping rope, swimming
Sports	Volleyball, golfing, softball, baseball, badminton, doubles tennis, downhill skiing	Soccer, field or ice hockey, lacrosse, singles tennis, racquetball, basketball, cross-country skiing
Home activities	Mowing the lawn, general yard and garden maintenance	Digging, carrying and hauling, masonry, carpentry
Workplace activity	Walking and lifting as part of the job (custodial work, farming, auto or machine repair)	Heavy manual labor (forestry, construction, fire fighting)

Tips to reduce sitting time:

- Limit time spent watching TV and using other forms of screen-based entertainment.
- Use a stationary bicycle or treadmill when you do watch TV.
- Use stairs rather than an elevator.
- If you can, walk or bike to your destination.
- Exercise at lunch with your coworkers, family, or friends.
- Take an exercise break at work to stretch or take a quick walk.
- Walk to visit coworkers instead of phoning or sending an e-mail.
- Go dancing with your spouse or friends.
- Plan active vacations rather than only driving trips.
- Wear a pedometer every day and increase your number of daily steps.

Healthy Eating



Nutrition

If you are overweight or have poor eating habits, your risk of developing breast cancer is increased. Here are some simple tips to help get you on the path to a healthier life and reduce your risk.

1. Weight Loss - Being overweight or obese (Body Mass Index of 25.0 or greater), is a primary risk factor for breast cancer, particularly if you are post menopause. While following a diet high in fruits, vegetables and whole grains is not shown to directly prevent breast cancer, it can help you lose the weight and provide your body with the nutrition it needs to fight other types of cancer, diabetes and heart disease.ⁱ

2. Building a Healthy Meal Plan ⁱⁱ

a. Fruits and Vegetables - Half of your plate should be covered with fruits and vegetables. And, the more variety and color, the greater the

nutrition. A general rule of thumb for women is 1 ½ - 2 cups of fruit per day, which can include fresh, frozen, dried or canned fruit. If you drink juice, limit it to 4 ounces per day. Vegetable choices can include green leafy vegetables, legumes such as beans and lentils, yellow and orange squashes, starchy vegetables such as corn and potatoes, and options like cucumbers and avocados. Two to 2 ½ cups of cooked vegetables is a good target. One and a half cups of raw salad is considered equal to ½ cup of cooked vegetables.

b. Grains - These help with weight loss because they contain fiber which keeps you fuller longer. Fiber also has the added benefit of improving constipation. One quarter of your plate should contain grains such as oats, wheat, barley, rice, and corn and products made from these. Choose “whole grains” (check the label on

cereals, breads, pastas, rice and cornmeal products) for at least half of your choices. These contain the most nutrients because they are made with the whole grain. “Refined” products do not contain whole grains and therefore are not as nutritious. New “old” grains such as farro and quinoa can bring added interest, texture and flavors to your meals. The recommended amount for women is 5-6 ounces per day.

c. Lean Protein - This food group provides the building blocks for your body including healthy muscles. Choose mostly from fish, chicken, tofu, beans, peas, nuts, and seeds. Other sources of protein include dairy products like cottage cheese and yogurt, and meat and pork. Choose low-fat dairy and limit beef and pork consumption due to higher saturated fat content. Recommended servings per day for women are 5-5.5 ounces.

d. Dairy - These products are rich in calcium to help build strong bones and teeth, in addition to helping your body operate. Low-fat and no-fat milk, cheese, yogurt, and soy dairy products are good choices. If you have lactose intolerance, there are many lactose-free products to choose from - this helps you get your calcium and other benefits from dairy without intestinal discomfort.

e. Fat - This is an important group that helps us absorb certain vitamins and provides us with some essential nutrients. However, we don't need a lot and should choose fat sources from vegetable oils, nuts, and nut butters for heart-healthy benefits. Fat that is solid at room temperature (saturated fat), such as butter, margarine, lard, bacon fat, etc., is bad for the heart and should be limited. Generally, three to six teaspoons a day will provide essential nutrients. Err on the lower side for weight loss.

f. Water - Keeping up with your water or non-caffeinated fluid intake is as important to your body as the food you eat. If your urine is pale yellow to clear in color, you are drinking enough. Try to drink 48-60 ounces of non-caffeinated fluid per day and focus on most of that being water, if possible.

3. Alcoholic Beverages - Alcohol consumption is a high risk factor for breast cancer occurrence or recurrence. It also has a lot of empty calories that can prevent weight loss. Alcohol should be limited. If you choose to drink, the maximum is one drink per day for women and two drinks per day for men. This means 1 ounce of hard liquor, four ounces of wine, or 12 ounces of beer. ⁱⁱⁱ

Please ask to see our registered dietitian to develop a meal plan that is tailored to your specific needs. You can call the Neag Comprehensive Cancer Center at 860-679-2100 to set up an appointment.

ⁱ <http://www.mayoclinic.org/healthy-living/womens-health/in-depth/breast-cancer-prevention/art-20044676>, accessed 1/8/2015.

ⁱⁱ <http://www.foodpyramid.com/myplate/fruit-food-group/>, accessed 1/8/2015.

ⁱⁱⁱ http://www.nutritioncaremanual.org/client_ed.cfm?ncm_client_ed_id=136, accessed 1/8/2015.



Contact	Phone Number
American Cancer Society (www.cancer.org)	1-800-227-2345
Breast Nurse Navigator at UConn Health	860-480-1981
Cancer Care (www.cancercare.org) In addition to information, Cancer Care offers phone support by trained social workers to help with coping.	1-800-813-4673
Leukemia & Lymphoma Society (www.lls.org)	CT Chapter 203-665-1400 Toll-free 1-800-955-4572
National Cancer Institute (www.cancer.gov)	1-800-4-CANCER

Community Resources for Practical Needs

Cancer Care (www.cancercare.org) For women with cancer, small grants related to child care or transportation.	1-800-813-4673
Connecticut Sports Foundation (www.sportsfoundation.org) Small grants for rent or electric bills of cancer patients.	860-388-0788
Info Line (www.211ct.org) For information regarding specific needs, such as housing, childcare, transportation, and financial concerns.	dial 221
Financial Services Department at UConn Health For assistance with financial or insurance concerns, or to learn how to apply for state insurance and other state programs.	860-679-4120
Oncology Social Worker at UConn Health To explore financial assistance programs, such as Social Security Disability, Supplemental Security Income, or private funding options.	860-679-6577
Your local town social services department may also be able to assist.	

Transportation

American Cancer Society Road to Recovery (volunteers)	1-800-227-2345
Logisticare (for people on Husky C or D)	1-888-248-9895

Contact	Phone Number
Emotional/ Psychological Support	
For individual or family psychotherapy, check your health insurance for a list of behavioral health providers in network.	
The oncology social worker is also a resource to provide guidance in finding psychotherapeutic services.	860-679-6577
The following options are private practices:	
Anxiety Treatment Center (6 Forest Park Dr, Farmington) Specializing in cognitive-behavioral therapy for anxiety and related disorders. (www.ctanxiety.com)	860-269-7813
Connecticut Mental Health (The Exchange, Farmington) Specializing in older adults.	860-677-5570
Connecticut Anxiety and Depression Treatment Center (1031 Farmington Ave, Farmington) Counseling and psychiatry. (www.treatmyanxiety.com)	860-677-2550
Counseling Affiliates (The Exchange, Farmington) Treatment of children, adults, and families.	860-659-2657
Joan Duggan, PsyD (191 Albany Tpke, Canton) Individual adults and couples psychotherapy.	860-322-5394
The following options accept HUSKY insurance:	
Capitol Region Mental Health Center (500 Vine St, Hartford) (Serves towns of Avon, Canton, Farmington, Hartford, Simsbury, and West Hartford)	860-297-0800
Community Health Resources (Programs in Bloomfield, Danielson, Enfield, Hartford, Manchester, Mansfield, Middletown, Norwich, Putnam, Willimantic)	877-884-3571
Community Mental Health Affiliates, Inc. (270 John Downey Dr, New Britain) (Serves towns of Berlin, Bristol, Burlington, Kensington, New Britain, Plainville, Plymouth, and Southington)	860-826-1358
Hospital of Central Connecticut Psychiatry and Behavioral Health (100 Grand St, New Britain)	860-224-5285
InterCommunity Mental Health Group (281 Main St, East Hartford) (Serves towns of East Hartford, Glastonbury, Marlborough, Newington, Rocky Hill, and Wethersfield)	860-569-5900
Psychiatry at UConn Health (10 Talcott Notch, Farmington)	860-679-6703
St. Francis Behavioral Health Services (500 Blue Hills Ave, Hartford)	860-714-2750
Dr. Alejandro Gonzalez-Restrepo Specializing in oncology psychiatry.	800-658-4859

Contact	Phone Number
Cancer Support Groups	
<p>Advanced Prostate Cancer Support Group: Hartford Hospital - Helen & Harry Gray Cancer Center Taylor Conference Room B, 85 Retreat Ave, Hartford Meets one evening a month</p>	860-243-8359
<p>Bladder Support Group: UConn Health Onyuke Dining Room – Main floor near the cafeteria 1st Saturday of each month, 2:00-3:00 pm</p>	Call Kim Hackett at 860-679-7820
<p>Breast Cancer Support Group: Hospital of Central Connecticut Radiation Therapy Waiting Room at 5 Highland St, New Britain 1st and 3rd Wednesday of each month, 5:30-7:00 pm</p>	Call Donna Boehm at 860-224-5900 extension 6307
<p>Breast Cancer Support Group: St. Francis 114 Woodland Street, Hartford For those with a diagnosis of breast cancer within the last 2 years. 2nd Wednesday of each month, 5:15-6:45 pm</p>	Call Janet G. Ragno at 714-4112 to register.
<p>CHES - Support for Breast Cancer Patients: Hartford Hospital - Helen & Harry Gray Cancer Center Taylor Conference Room B, 85 Retreat Ave, Hartford</p>	Register online through www.harthosp.org or call 860-545-3781
<p>Gynecological Cancer Support Group: Hospital of Central Connecticut Dining Room B in main hospital, 100 Grand St, New Britain 2nd Monday of each month, 6:00-7:30 pm</p>	Call Marcia Anderson at 860-224-5299
<p>Living With Cancer – Caregiver Support Group: Hospital of Central Connecticut Lecture Room One in main hospital, 100 Grand St, New Britain 3rd Wednesday of each month, 5:30-7:00 pm</p>	Call Diane DeFronzo at 860-224-5212; or Marcia Anderson at 860-224-5299
<p>Gynecological Cancer Support Group: St. Francis 114 Woodland Street, Hartford 39B Conference Room of the Patient Care Tower 3rd Thursday of each month, 4:00 pm</p>	Call 860-714-7995 or 860-714-7945 for more information.
<p>Look Good...Feel Better</p>	Call the American Cancer Society at 800-227-2345 for more information.
<p>Prostate Cancer Support Group: Hartford Hospital - Helen & Harry Gray Cancer Center Gilman Auditorium, Conklin Building, 85 Retreat Ave, Hartford Meets one evening a month</p>	Call 855-255-6781
<p>CancerCare offers online and telephone support groups for patients with a wide variety of cancers and their caregivers.</p>	Call 800-813-4673 or go to www.cancerca.org/support_groups