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A Patient's Guide to Breast Cancer Care



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This booklet, produced by the Rhode Island Cancer Council, Inc., is a companion guide to the physician version of the Breast Care Algorithm for women with breast cancer.

This guide has been produced to assist women who have a diagnosis of breast cancer. Our intent is to provide practical information about breast cancer treatment in one useful guide. Please take this with you to your doctor's appointment and make sure your doctor fully explains your diagnosis and treatment to you.



Glossary

Adjuvant therapy — treatment used in addition to the main treatment.

Aromatase inhibitors — anti-cancer drug that blocks the effect of estrogen on breast tissue.

Carcinoma — a form of cancer that develops in tissues covering or lining organs of the body, such as skin, uterus, lung or breast.

Chemotherapy — treatment with drugs to destroy cancer cells.

Ductal carcinoma — (DCIS) - cancer cells that start in the milk passages (ducts) but have not penetrated the duct walls into the surrounding tissue.

HER2/neu — Human epidermal growth factor receptor 2; involved in the growth of some cancer cells.

Hormone receptor-positive — the tumor is more likely to grow in an environment with a high amount of a particular hormone, such as estrogen.

Hormone receptor status — cancer cells that have receptors that receive signals from hormones indicating for them to grow.

Lobular carcinoma — (LCIS) - a very early type of breast cancer that develops within the milk-producing glands (lobules) of the breast and does not penetrate through the walls of the lobules.

Lumpectomy — surgery to remove the tumor and a small amount of normal tissue around it.

Mastectomy — surgery to remove part of or the whole breast.

Neoadjuvant therapy — this treatment is given prior to the primary treatment.

Psychosocial support — care that enhances well-being of an individual, increases confidence, and helps social functioning through support groups or individual support.

Sentinel lymph node — the first lymph node to receive lymphatic drainage from a tumor.

Tamoxifen — an anticancer drug that belongs to the category called antiestrogens. It blocks the effects of estrogen in the body.



The Breast Care Algorithm, developed by the Rhode Island Breast Cancer Care Task Force, provides guidance to our physicians on how best to manage breast cancer from the detection of an abnormal breast lump through diagnosis, treatment, and follow-up care for breast cancer. It is a tool for providing up to date, research-based cancer treatment to all Rhode Island women; it can also be used as a teaching device to discuss treatment options with patients.

This Breast Care Algorithm represents the best thinking of Rhode Island's cancer treatment specialists in surgery, medical oncology, radiation oncology, diagnostic radiology, and pathology. Guiding principles involving tumor staging, multidisciplinary consultation, patient access to clinical trials, treatment based upon functional status, psychosocial support, and patient access to complete, understandable information form the backbone of the algorithm. Treatment based upon these guiding principles provides the best outcomes. The women of Rhode Island deserve treatment with the best outcomes!



Guiding Principles

1. All breast cancer patients should have their tumors staged according to the American Joint Commission on Cancer. Biopsy reports should include the size of the tumor, the margins, the grade, the status of lymph nodes, and the hormone receptor markers.
2. All breast cancer patients should have a multidisciplinary consultation including a surgeon, a medical oncologist, a radiation oncologist, and a pathologist. This can be accomplished at a properly convened hospital Tumor Board.
3. All breast cancer patients should be informed of approved clinical trials available for their stage of disease.
4. Treatment decisions should be based upon the patient's overall health and functional status regardless of chronological age.
5. From the beginning of the process, when a suspicion of cancer arises, every patient should have access to complete, comprehensive information in an understandable form and should be offered the services of a patient advocate. Throughout the course of treatment and thereafter, patients should have available sufficient information and psychosocial support to be able to maintain a good quality of life.



Follow-up Care for Breast Cancer Patients

A history and physical examination is recommended every 4-6 months for 5 years; then every 12 months. A mammogram of the treated breast is recommended 6 months post radiation therapy if breast-conserving therapy was done, and, otherwise, every 12 months for both breasts. Women taking Tamoxifen should have a pelvic examination every 12 months if the uterus is present.

If you have had a mastectomy, you still need to have a mammogram of the remaining breast on a regular basis.



Recommended Treatment Options

Ductal Carcinoma — Stage IIIB

Primary treatment: Chemotherapy with or without Tamoxifen. If there is a response from chemotherapy, treatment will follow with total mastectomy and radiation therapy to the chest wall OR lumpectomy with radiation therapy to the breast OR high dose radiation therapy. Surgical removal of the sentinel lymph node and/or other lymph nodes under the arm may be done. Your doctor may suggest Tamoxifen after primary treatment.

Ductal Carcinoma — Stage IV or Recurrence

Primary treatment: Surgical resection if possible. Radiation therapy may be prescribed, if possible. Chemotherapy may also be considered before, during, and after any surgery.



Screening Recommendations

All women in the United States are at risk for breast cancer. Beginning at age 40 all women should undergo a baseline screening mammogram and continue with screening mammograms every 1 to 2 years until 50. At 50, ANNUAL mammography should be continued on a regular basis. A yearly clinical breast exam should be performed by a health professional.

A small percentage of women are at higher risk for breast cancer due to a family history of a mother, sister, or maternal aunt who was diagnosed with premenopausal breast cancer or multiple family members with breast cancer. These individuals should have a yearly clinical breast exam and a yearly screening mammogram beginning ten years before the age of the family member at diagnosis. For example, if your mother was diagnosed with breast cancer at age 42, screening should begin for you at age 32.



Further Testing

When the screening mammogram and clinical breast exam are negative, your doctor will ask you to return in one year.

If your screening clinical breast exam is positive and the screening mammogram is negative, your doctor will refer you to ultrasound and a surgical consultation. An ultrasound uses sound waves to produce a picture of breast tissue. It can differentiate cysts from tumors and is particularly useful for dense breasts.

If your screening mammogram is questionable, your doctor will refer you for a diagnostic mammogram and/or ultrasound.

If the result of your screening mammogram is abnormal, your doctor will refer you for a diagnostic mammogram, and/or ultrasound, and a surgical consultation.



Recommended Treatment Options

Ductal Carcinoma — Stage I, Stage IIA, Stage IIB

Primary treatment: Lumpectomy OR total mastectomy with or without reconstruction. Surgical removal of the sentinel lymph node and/or other lymph nodes under the arm may be done. Your doctor may suggest *chemotherapy* before your surgery; this is called *neoadjuvant therapy*. You and your doctor may want to consider chemotherapy and/or radiation therapy after your surgery; Tamoxifen and/or aromatase inhibitors may be suggested if hormone receptor-positive or for risk reduction. Chemotherapy and/or radiation therapy after surgery and Tamoxifen are all considered *adjuvant therapy*.

Ductal Carcinoma — Stage IIIA

Primary treatment: Total *mastectomy* with or without delayed reconstruction or lumpectomy for breast preservation. Surgical removal of the sentinel lymph node and/or other lymph nodes under the arm may be done. Hormone receptor status and *HER2/neu* level will be determined if possible. *HER2/neu* is a growth factor receptor involved in causing cells to grow at an accelerated rate. This causes too many copies of the same cell to occur. Chemotherapy and chest wall radiation therapy may also be given as adjuvant or neoadjuvant therapy. Your doctor may also suggest Tamoxifen and/or aromatase inhibitors for risk reduction if hormone receptor-positive or if hormone receptor is unknown .



Recommended Treatment Options

Lobular carcinoma in situ (LCIS) (a pre-invasive cancer)

Primary treatment: Observation OR, in special circumstances, removal of both breasts with or without reconstruction. If treated with observation, your doctor may suggest you take *Tamoxifen* for risk reduction.

Ductal Carcinoma in situ (DCIS) — Stage 0 (a pre-invasive cancer)

Primary treatment: Lumpectomy alone OR lumpectomy with radiation therapy OR mastectomy with or without reconstruction. Surgical removal of the *sentinel lymph node* and/or other lymph nodes under the arm may be done. Your doctor may suggest you take Tamoxifen and/or aromatase inhibitors for 5 years if hormone receptor-positive or for risk reduction. Tamoxifen blocks estrogen from getting to the breast cells; this limits the growth of cells.



What's Next

Breast cancer is a disease that begins in the tissue of the breast. It occurs when the cells that line the ducts and lobules change in appearance and grow abnormally. The most common type of breast cancer, *ductal carcinoma*, begins in the lining of the ducts. Breast cancer beginning in this region makes up about 80% of all cases. Cancer that begins in a lobe region of the breast is known as *lobular carcinoma* and accounts for about 10-15% of all breast cancer cases. Cancer that begins in these areas can spread to other areas of the breast tissue and, possibly, to other parts of the body.

A biopsy or evaluation of a tissue sample that has been removed from the breast will need to be done. Lymph nodes from under the arm may also be removed and examined. All of this provides information as to what type of breast cancer is present and what stage, or how advanced, the cancer is. A biopsy also allows the tumor cells to be compared to normal, healthy breast cells; this will grade the tumor. Once stage, grade, and *hormone receptor status* are known, a treatment plan can be developed.

Italicized words are described in the glossary at the end of this guide.



Staging

The TNM SYSTEM is used to stage breast cancer. Combinations of T, N, and M determine the stage of the cancer for any patient.

T as in T₁, T₂, etc. represents the size of the untreated primary tumor with the number reflecting the size of the actual tumor. This ranges from T₁ to T₄ from very small to large.

N represents lymph nodes in the area of the tumor. N₀ would tell us that there were no nodes in the area that were biopsied that had cancer. N₁, N₂, etc., would refer to specific areas where nodes have cancer.

M refers to metastasis or spreading of the cancer to distant sites in the body. M₀=no spread, M₁=cancer has spread.

The staging of your cancer should be thoroughly discussed with your physician.



Grading

Grade 1 (G_1) refers to well differentiated cells; they look almost like a normal cell.

Grade 2 (G_2) refers to moderately differentiated cells; they look similar, but only slightly different, to a normal cell.

Grade 3 (G_3) refers to poorly differentiated cells; they have little resemblance to a normal cell.

Grade 4 (G_4) is undifferentiated cells; they have no resemblance to a normal cell.

Grade X (G_x) is when the grade cannot be determined or is unknown.

TO BETTER UNDERSTAND THE STAGING AND GRADING OF YOUR BREAST CANCER, REQUEST A COPY OF YOUR PATHOLOGY REPORT FROM YOUR DOCTOR AND HAVE HIM/HER REVIEW THIS WITH YOU.

