

# Breast Cancer: Reactions, Choices, Decisions

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Women with breast cancer often experience a predictable set of emotional and psychological reactions to their cancer diagnosis according to recognized influencing factors such as age at the time of diagnosis and stage of life. The time between a breast biopsy and the receipt of the pathology results has been identified by patients as the most stressful period throughout the entire cancer experience. Treatment decisions, until recently, were made solely by physicians while patients assumed passive roles. Increasingly, breast cancer patients want to assume an active role in their treatment decisions and care and are no longer satisfied to be passive observers. More and more women educate themselves about their disease through the Internet, investigating available treatment options, side effects, and in some cases, alternative therapies. This new type of breast cancer patient wants to be cared for by physicians who embrace the patient as part of the team. They appreciate the physician who is not threatened by the educated breast cancer patient and understands that she is ultimately motivated by an attempt to regain some of the control the cancer has taken away from her.

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## “You have breast cancer.”

Of the 175,000 women diagnosed with breast cancer in the United States each year, 3000 live in Louisiana. Ten (10%) percent of these women are cared for by a multi-disciplinary healthcare-team of physicians, nurses, social workers, and technicians at Ochsner Clinic and Ochsner Foundation Hospital. At the time of diagnosis, the majority of these women are over the age of 50 and postmenopausal, but others are in their 30s and 40s and may or may not have a family history of breast cancer. Regardless of their age or life stage, these women share a common diagnosis and are faced with similar challenges of illness and health recovery. Although different women approach the diagnosis of breast cancer in different ways, there is a set of common, predictable, emotional reactions that many will experience during their cancer experience. First and foremost, women diagnosed with breast cancer are scared they are going to die from this disease. Not all women readily admit this. When treating breast cancer patients, physicians have several goals including saving the patient’s life and curing the disease, preventing the spread of

cancer, and preserving as much of the breast as possible. Breast cancer patients share these goals; however, early on in the disease process, patients become acutely aware that breast cancer is a disease that is not confined to the breast. In its broadest sense, breast cancer is a disease that affects every area of a woman’s life and has accompanying emotional, psychological, and sexual issues that are frequently not addressed by healthcare professionals.

During the last 2 decades, dramatic changes have taken place in both the behavior of breast cancer patients and the expectations of physician behavior. The passive, subordinate observer has been replaced by an active, “educated breast cancer patient.” Patients now look for physicians who will embrace the patient as an integral part of the treatment decision-making team; these patients encourage a physician-patient relationship that is built on trust, respect, and two-way communication. Breast cancer patients need and want to be cared for in an emotionally safe and supportive environment through their months of medical treatment.

## Common Reactions to a Breast Cancer Diagnosis

Beginning with the breast biopsy, women report that the time period between the biopsy itself and the availability of pathology results is the most psychologically distressing time period during the entire cancer experience. Anxiety reportedly reaches its highest pitch at the moment biopsy results are actually discussed.

**While waiting for my biopsy results, my son called and asked what I was doing. I told him I was waiting to find out what I was going to do with the rest of my life.**

Once given the cancer diagnosis, the sense of anxiety women feel during the “not knowing” waiting period is quickly replaced by shock, disbelief, and what some describe as a period of temporary physical and mental incapacity when information given beyond the cancer diagnosis simply cannot be heard or processed.

**The moment the malignancy was diagnosed and my doctor said the word “cancer,” my mind went blank. I asked if he was sure the results were mine. I felt paralyzed and frozen with fear.**

The first few weeks following diagnosis have been identified as the most difficult for breast cancer patients to handle. It is a time when women find themselves on an emotional roller coaster crying uncontrollably, and feeling depressed, withdrawn, and angry. Women feel betrayed by their bodies, particularly if they have been doing “the right things.” This period is often combined with an acute “need to know” about the disease, its treatment, and the future. Second only to a woman’s concern over survival are worries about her physical attractiveness following cancer treatment.

**At that moment (awaiting test results), I really didn’t know which was worse: losing a breast to cancer, or wondering, if I did lose it, whether I would ever look chic or attractive again.**

Research by Oktay and Walter studied the reactions of women in different age groups to a breast cancer diagnosis. Although the study obviously cannot be generalized to all women, the findings do provide valuable insights into how some women at various ages are affected by their disease.

For women diagnosed with breast cancer in their 20s, the attention that a breast cancer diagnosis brings from family members and friends can be enormously smothering. A growing desire for independence, coupled with dreams of career and family, are replaced by a much less predictable future. Effects of radiation and chemotherapy on fertility become of paramount concern for those women who desire children. They wonder if pregnancy will be a future option following cancer treatment. Single women may fear a cancer diagnosis followed by breast surgery will leave them less attractive or desirable to a potential future spouse. Women in their 20s, as well as those in their 30s and 40s, are out of sync with the expected natural process of illness and possible death.

Women in their 30s who have postponed starting a family to pursue a career sometimes question and regret their decision when faced with an uncertain fertility future. Some women in this age group feel even more cheated by the onset of an early menopause, brought on by drug or hormone therapy, than they do by the potential loss of a breast. Others worry about the effects cancer therapy will have on their sexual activity. Women with young children have concerns about how and when to discuss the cancer diagnosis with them. This is a time when people struggle with a view of the world as just and fair and challenge assumptions about the way life ought to be. Oktay and Walter’s research found that the breast cancer experience intensified the struggle to let go of this view emotionally.

Women in their 40s are often at their peaks in terms of family responsibilities and productivity. All things being equal, a breast cancer diagnosis leaves a gap in the functioning of the family that is difficult to fill. This is also the time of life when women are beginning to deal with wrinkles and sagging skin. They often find that breast cancer forces an even closer look at their body image, which can result in excessive attention to physical appearance. This is also frequently a time when children are growing up and moving out of the house and maturing marriages are adjusting to change. Women with children often wonder if their “bad seed” has been passed to the next generation. Marriages can also be affected: while the cancer experience brings some couples closer together, the stress of illness can amplify weaknesses in a relationship. A woman in her 40s may want the attention of her children, but if her children are teenagers, who have difficult developmental and psychosocial priorities, she may be disappointed.

Women who have experienced breast cancer in their 50s, 60s, and older are often already familiar with loss. They may have lost a parent, spouse, or partner, retired from work, or grown distant from their children. Some women are challenged by having to learn to relate to their adult children differently. Many women in this stage of life worry both about the possible loss of a breast and the potential loss of independence. Women are socialized to care for others. They are not used to being nurtured or asking for help. Some women struggle when they realize they cannot do it alone and must ask for help.

For some women, asking for help may be uncomfortable and cause internal conflict. Fear of dying, feeling betrayed by one's body, a loss of femininity, and concern with a potential alteration in sexual attractiveness and function are other commonly shared concerns among this age group.

For all women, regardless of age, concerns about medical bills arise at some point. Even those with health insurance often feel overwhelmed by the sheer number, complexity, and variety of medical bills they receive.

## Choices, Decisions, Partnership, and Expectations

Once the shock of the breast cancer diagnosis has registered, clinically related choices and decisions take center stage. Nearly all women feel confused by the difficult treatment decisions they must make. Indeed, the choices can seem overwhelming. While women appreciate the broad selection of available therapies, they also can feel perplexed and frustrated by the number of treatment options offered. Women with breast cancer must make decisions including where to seek care, which physician(s) to choose, whether to seek a second opinion(s), whether to have a lumpectomy or mastectomy, reconstruction now or later, and where to turn for emotional support. The media contributes to this multi-factorial dimension by informing and updating the public about scientific breakthroughs on breast cancer treatment—that may or may not be immediately available or applicable.

The relationship a woman establishes with her physician(s) is critically important to her breast cancer treatment. Although there are no definitive models for the ideal patient/physician relationship, some general guiding principles have emerged. One of the first questions a woman must answer early on in her breast cancer experience is how involved she wants to be in her treatment decisions. Until the last decade, most women accepted a passive, subordinate role during cancer treatment. Patients gave themselves up to their physicians unconditionally, and physicians made all treatment decisions, often with limited

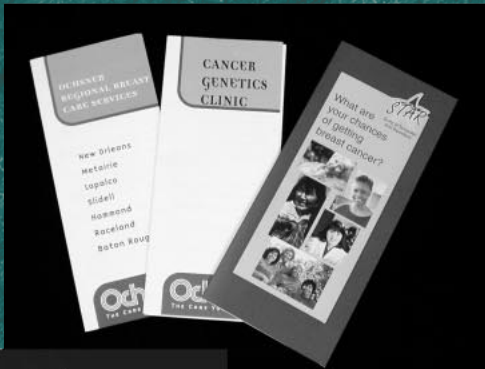
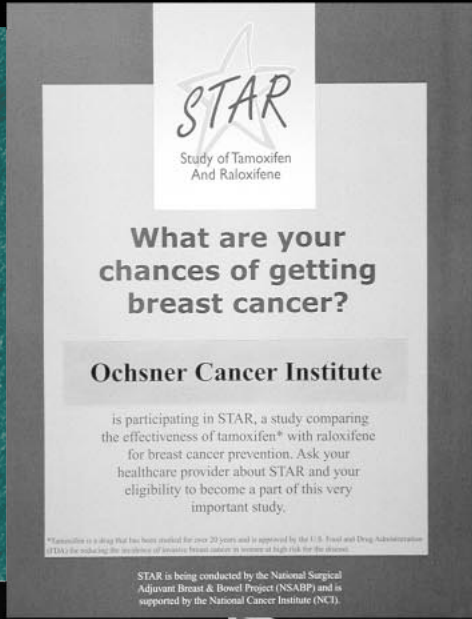
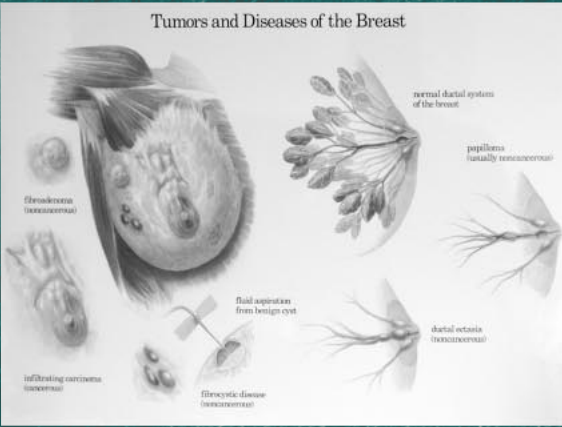
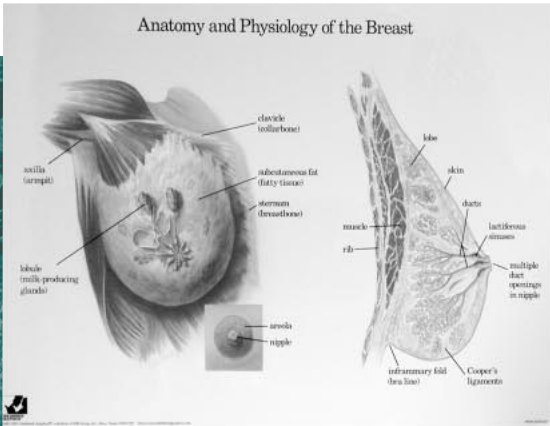
input from the patient. For some women this approach still works. However, as social trends have changed, the passive patient of the 1970s is being replaced by the informed, educated breast cancer patient, who is no longer satisfied to sit on the sidelines of her care while medical decisions are made without her.

This new type of patient desires to remove the obstacle of ignorance and understand her disease, its available treatment options, and the side effects. She searches for breast cancer information in books, journals, and on Internet web sites provided by large breast cancer organizations including the National Cancer Institute, the American Cancer Society, and the Susan G. Komen Foundation. She feels entitled to actively participate in her treatment decisions and understand her treatment plan. She expects an opportunity to ask questions and to receive answers in clear, understandable language (patiently repeated several times if necessary). Studies show that a woman's degree of satisfaction with her outcome has less to do with the results of her treatment and more to do with how much information she had when she made her treatment decisions.

**Know the enemy. Know what you are facing and most of your fears will become manageable. That was the most important thing to me—to educate myself about breast cancer.**

Breast cancer advocacy groups encourage patients to seek a physician who listens when the patient speaks, understands her need to know, and embraces her as part of the treatment team. Today's typical breast cancer patient will likely take the time to find this physician. Patients look for a physician who encourages questions, communication, and the search for information, and, in short, is not threatened by her desire for knowledge and education. Patients applaud the physician who acknowledges and addresses the emotional and psychological issues that accompany breast cancer and recognizes that psychological healing does not parallel physical recovery—it usually takes longer.

**My physicians were taught how to cure, but little about how to care. They learned how to treat my breast cancer, but forgot about the rest of me. My body image changed after my breast was removed. I was depressed. My physicians did not want to talk about it.**



Patient education materials used in Ochsner Breast Care Services.

Patients appreciate the physician who recognizes that the transition from treatment completion to “after-treatment survivorship” is a traumatic adjustment, and, regardless of prognosis, all breast cancer patients live indefinitely with the fear of recurrence. Most importantly, the breast cancer patient thanks the physician who understands that her desire to assume an active role in her treatment decision is her attempt to regain some of the control that cancer has stolen from her.

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# Ochsner Breast Care Services

## Breast Cancer Screening Services

**Breast Screening Clinic:** A clinical breast examination, breast self-examination instruction, and patient education are provided to help women learn proper examination techniques. Silicone breast models are used to demonstrate the difference between fibrocystic breast tissue and breast cancer lumps. Ochsner New Orleans (504) 842-3936 and Ochsner Baton Rouge (225) 761-5488.

**Cancer Genetics Clinic:** Cancer risk assessment services are available for women with a family history of breast or ovarian cancer who are concerned about their chances of developing either of these cancers. Ochsner New Orleans (504) 842-5275 and Ochsner Baton Rouge (225) 761-5488.

**Screening Mammography:** Ochsner provides multiple breast screening sites for women who are asymptomatic.

Ochsner New Orleans	(504) 842-4111	Ochsner Tangipahoa	(504) 543-3600
Ochsner Metairie	(504) 842-4111	Ochsner Raceland	(504) 537-3211
Ochsner Lapalco	(504) 842-4111	Ochsner Baton Rouge	(225) 761-5999
Ochsner Slidell	(504) 842-4111	(two locations)	

**Diagnostic Mammography and Breast Ultrasound:** Diagnostic breast services are available for women with breast symptoms or an abnormal mammogram. Ochsner New Orleans (504) 842-4111 and Ochsner Baton Rouge (225) 761-5999.

**Stereotactic and Ultrasound Core Biopsy:** Core biopsies of breast lesions are performed by the radiologists in the Breast Imaging Department. Ochsner New Orleans (504) 842-3395.

**Needle Localization:** Needle localization, prior to breast surgery, is performed by the radiologists in the Breast Imaging Department. Ochsner New Orleans (504) 842-3395 and Ochsner Baton Rouge (225) 761-5488.

## Multidisciplinary Breast Cancer Team Services

**Multidisciplinary Breast Oncology Clinic (MBOC):** Cases of women diagnosed with breast cancer are reviewed by the Ochsner multidisciplinary breast cancer team and a treatment plan is developed. During MBOC, the treatment plan is presented, reviewed, and discussed with the patient and family member(s). Ochsner New Orleans (504) 842-6518.

**Stereotactic/Ultrasound Guided Core Biopsy Conference:** Core biopsy cases performed the previous week are reviewed by a radiologist, pathologist, and surgeon. Conference results are communicated to ordering physicians.

**Weekly Breast Cancer Conference:** Selected breast cancer cases are presented, reviewed, and discussed by the multidisciplinary breast cancer team each Friday morning.

# Ochsner Breast Care Services (cont.)

***Ochsner Cancer Institute Research Center.*** The Cancer Institute participates in several national breast cancer clinical trials including sentinel lymph node mapping and brachytherapy clinical trials. The Institute is currently participating in STAR, the second national breast cancer prevention trial comparing raloxifen to tamoxifen. Ochsner New Orleans (504) 842-3708 and Ochsner Baton Rouge (225) 761-5488.

***Manual Lymphedema Drainage (MLD) Treatment Program.*** Ochsner was the first health care institution in New Orleans to offer this innovative approach for the treatment of arm lymphedema following breast cancer surgery. The MLD approach combines massage, compression bandaging, and exercise to reduce swelling, manage edema, and decrease the frequency of cellulitis and lymphangitis. A lymphedema support group meets quarterly to discuss new treatment information. Ochsner New Orleans at Elmwood (504) 842-3750.

## Social/Psychosocial and Patient Education Breast Cancer Services

***Breast Cancer Support and Information Group.*** Monthly meetings, facilitated by oncology social workers and registered nurses, are held for breast cancer patients, family members, and friends to provide new information and updates on breast health and disease and to offer support to women afflicted by the disease.

Ochsner New Orleans (504) 842-3708  
Second Tuesday each month  
2:00 - 3:30 PM or 6:30 PM - 8:00 PM

Ochsner Baton Rouge (225) 761-5488  
First Tuesday each month  
6:30 PM - 8:30 PM

***Look Good, Feel Better.*** A non-medical, cosmetic program, *Look Good, Feel Better* is intended for women undergoing cancer treatment. The program addresses cosmetic problems that women undergoing radiation and chemotherapy may experience.

Ochsner New Orleans (504) 842-3440  
Ochsner Baton Rouge (225) 761-5488

***Ochsner Cancer Resource Center.*** Located in the Hematology/Oncology waiting room on the first floor of the clinic, the recently opened Cancer Resource Center offers computer and Internet access, cancer information, free brochures, and computer print-outs. A health care professional is available to assist patients in their search for information. Ochsner New Orleans (504) 842-3708.