A Guide for Women who have been Recently Diagnosed with Cancer of the Breast

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When a woman first learns that she has breast cancer, it is usually such a shock that she finds it difficult to take in any more information. The idea for this booklet came from hundreds of women who had recently been diagnosed with breast cancer. They asked for written information that they could read and digest at home, that could give them a chance to think about what questions to ask when they return to see their physician.

We wrote this booklet to give you that chance, and hope it alleviates some of your anxiety.

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Breast Cancer

Learning that you have **cancer** is frightening to everyone. But the diagnosis of **breast cancer** is in a category by itself in terms of the fear and anxiety it creates in the women it affects.

In this brochure we hope to dispel some of the myths about breast cancer, and to help women cope with the disease.

It is important to know that:

. . . the diagnosis is in no way a death sentence,

. . . in most cases early diagnosis and treatment leads to normal life expectancy,

. . . breast preservation is the norm.

This brochure attempts to unravel the complexities of staging and treatment of the disease to allow women to make rational decisions about their care.

Discovering Breast Cancer

An abnormal mammogram, finding a new lump, or a nipple discharge can lead to discovery of breast cancer.

Diagnosis

Diagnosis is confirmed by removing tissue from the lump or the suspicious area seen on a mammogram. There are several methods available.

If there is a ***palpable lump*** (a lump that can be felt), the next step is usually a ***needle core biopsy***. This technique may be possible even if the area is not palpable but is visible on ultrasound. A needle core biopsy avoids a formal operation since it can be performed by a radiologist in the x-ray area with a local anesthetic. Without a formal surgical procedure, the provider can establish the diagnosis, and the patient and provider can then discuss the treatment plan.

If the suspicious area can only be **open surgical biopsy** . In this procedure the radiologist ***localizes*** (locates) the area with a thin marker needle guided by mammogram, so the surgeon can remove the marked area in question.

The area removed is so tiny that most women say this is not a very painful procedure. In fact, most women are given a prescription for a small amount of pain medication to take after the procedure, and most report that they don't need it all. The procedure does not deform the breast, although there may be some temporary black and blue discoloration. It usually takes 48-72 hours to get the result of the biopsy.

What's the difference?

Needle localization requires open surgical biopsy to remove the tissue, while a needle core biopsy actually takes multiple small samples of tissue for diagnosis, using ultrasound for guidance of the biopsy site.

Although both procedures establish the diagnosis of malignancy, needle localization and open biopsy may provide more initial information. In many cases, the cancer may be completely removed and its characteristics better defined than is possible with a needle core biopsy.

QUESTION: I have been told that I have breast cancer. What does that mean? Are all breast cancers the same?

ANSWER: For the purpose of discussion we will divide breast cancer into two types, invasive and noninvasive. Noninvasive cancers are also known as DCIS, or ***ductal carcinoma in situ***.

Almost all breast cancers begin in the mammary ducts. When malignant

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(cancer) cells spread or invade breast tissue outside the ducts, we call this ***invasive*** cancer. The implication is that the malignant cells can not only invade surrounding breast tissue, but ultimately can also spread (metastasize) elsewhere in the body.

Non-invasive cancer (DCIS) has not spread beyond the mammary duct where it started. By definition, it also has not spread beyond the breast (metastasized). However, if not removed, DCIS does have the potential to become invasive. From a practical viewpoint, it should be treated as a very early form of invasive cancer.

These two types of breast cancer are treated differently, primarily because DCIS, by definition, has not spread to other parts of the body.

The biopsy usually tells which of the two types of cancer you have.

Treatment of Ductal carcinoma in situ

Ductal carcinoma in situ (DCIS)

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small amount of tissue from the suspected cancer. It is a convenient method of establishing the diagnosis, but the area in question must either be visible on ultrasound or palpable by the physician.

Another type of biopsy is ***open surgical biopsy***, performed in the operating room under anesthesia. This technique is used to remove the entire area in question or when the area can't be palpated or seen on ultrasound.

QUESTION: My doctor used the term *axillary dissection*. What does that mean?

ANSWER: Axillary dissection is the surgical removal of some of the lymph glands from the underarm, on the same side as the breast that has the malignancy. The procedure is done in conjunction with lumpectomy, or as part of a modified mastectomy if that is the choice of the patient and caregivers.

Axillary dissection requires general anesthesia. Patients usually spend one or two nights at MGH or MIT Medical's Inpatient Service. Most patients report some discomfort from the surgery but are up and around and eating normally the morning after the operation. A small catheter drain is usually removed 24 to 48 hours after the surgery.

The operation is designed to remove an area that has definite anatomic boundaries and contains between 6 and 15 lymph glands – only a small portion of the total number of glands in the area. If mastectomy is chosen rather than breast preservation, axillary dissection is done as a part of the mastectomy operation.

QUESTION: What is sentinel node biopsy?

ANSWER: Sentinel node biopsy is an ongoing experimental technique of trying to identify the first (or "sentinel") lymph node, and making a diagnosis after removing just that one node. There are two techniques for identifying the sentinel node, and both techniques are usually used. One involves injecting a dye, and seeing which lymph node is the first to receive the dye. The other uses a radioactive injection, and following the trail of the injection by using a counter or wand.

Since this technique is still experimental, it is usually followed by removal of the typical 6-15 nodes.

Mastectomy Or Breast Preservation?

In most cases women can choose breast preservation rather than mastectomy. The decision to preserve the breast requires that in addition to lumpectomy the patient must undergo postoperative radiation therapy, to reduce the possibility of another cancer.

Radiation therapy requires treatment visits five to seven days a week for five to six weeks, according to the recommendations of a radiotherapist.

QUESTION: Why choose mastectomy if breast preservation is as effective?

ANSWER: Some local breast cancers are too extensive to remove. This may be due to the actual dimensions of the tumor or because it is associated with a large component of DCIS (ductal carcinoma in situ), suggesting that the disease may be multifocal – arising in more than one location in the same breast.

Also, if the breast is small, disfiguration of the breast can sometimes be obvious after an adequate lumpectomy.

Some women, particularly older women, prefer avoiding the five to six weeks of radiation therapy, which requires daily trips to the hospital, or want to avoid the side effect of this type of treatment: fatigue, skin reddening, radiation exposure, etc. Others may worry that lumpectomy and radiation treatment is not as safe a choice as mastectomy, despite extensive research results to the contrary.

Systemic Therapy: Women with positive lymph nodes.

Chemotherapy, hormonal therapy or both?

The decision about systemic (whole body) therapy is based on whether cancer cells are found in the lymph nodes removed at axillary dissection or during a mastectomy. The lymph nodes act like "sieves" and in most cases are the first line of defense when a cancer tries to spread.

If lymph nodes are involved, systemic therapy is recommended.

• In pre-menopausal women, clinical trials strongly suggest that chemotherapy prevents the recurrence of breast cancer better than hormonal therapy.

• In post-menopausal women, however, the use of hormonal therapy (tamoxifen) is most effective. This is particularly true in patients with tumors that test positive for estrogen receptors. The tamoxifen binds to these receptors and provides some protection against local recurrence in the affected breast and cancer in the opposite breast as well.

QUESTION: What is an oncologist?

ANSWER: Oncologists are physicians who specialize in the study of tumors. Their primary role is recommending and administering systemic therapy. MIT Medical uses oncologists at MGH and at Mount Auburn Hospital.

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Systemic Therapy: **Women with negative lymph nodes.**

In the past, women whose nodes were not involved (node negative) were usually given the option of not undergoing systemic therapy.

Today, however, we know that even women in the most favorable group, those with tumors less than two centimeters in size and negative axillary lymph nodes, still have a 10-20 percent chance of recurrence of their disease over the next 10 years. Unfortunately, there are not yet any accurate predictors of which patients will experience recurrence of cancer. This has led oncologists to be more aggressive in their recommendations to women in general and in particular to women with negative nodes.

QUESTION: I have heard the term *E.R. positive.* What does this mean?

ANSWER: E.R. stands for estrogen receptor. Tumors are routinely tested for these receptors. Tumors that are E.R. positive are more susceptible to hormonal therapy, such as tamoxifen. This is good news, because it means that the tumors are more receptive to treatment and have better prognoses.

QUESTION: What is the typical follow-up like?

ANSWER: Although follow-up is planned for each woman individually, this is a typical follow-up plan:

1. Mammogram once-a-year.
2. For the first two years, examination every three months by the surgeon, the radiotherapist, and oncologist in rotation.
3. For the next three years, examination every six months by the surgeon, the radiotherapist, and oncologist in rotation.
4. From that point on, yearly examinations by your surgeon for breast specific exams and your primary care physician for routine general exams.

Support Services

When faced with the diagnosis of breast cancer, most women feel they need two things: information and support. At MIT Medical we try to meet both these needs in a variety of ways. Your personal physician, surgeon, nurse practitioners, and mental health resource people work together as a team, sharing information to provide the highest standard of coordinated care.

Each woman may need different forms of support, so we provide a variety of support resources to choose from:

• For the past several years an on-campus Cancer Support Group has been meeting regularly. This group is open to any member of the MIT community with a diagnosis of cancer – not just breast cancer. There is no charge for the group, and the meetings are usually coordinated by Dawn Metcalf, LICSW, Social Worker, and Peter Reich, M.D., Chief, Mental Health, both at MIT Medical/ Cambridge, (617) 253-2916. The group meets during the workday to allow people who are on campus to attend. It is specifically dedicated to the support of cancer patients themselves, so it is not open to family members or friends. For more information, call Dawn Metcalf or Peter Reich.

• Individual members of the Cancer Support Group are also available to help newly-diagnosed patients and patients in the process of developing a treatment plan, to talk about their experiences and reactions to their diagnosis, treatment, and outcome.

• Health Education at MIT Medical /Cambridge maintains a comprehensive library of information, resources, and support available in the Boston area. They also have information about on-line resources, prostheses, wigs, and service organizations.

• At times of emotional stress and uncertainty the Mental Health Service can be a valuable resource for patients and families.

• There are social workers who specialize in medical case management, individual support and counseling, and family support and counseling.

• There are also psychologists and psychiatrists and a clinical nurse specialist with expertise in individual and family counseling.

• The staff also have information about benefit programs, family medical leave, and other areas of concern.

Several psychiatrists have a particular interest in women's health. They can:

• meet with individual patients and families,

• consult and coordinate care with other providers, and

• provide short-term treatment.

During treatment for a serious medical illness, a psychiatric consultation about depression and coping skills during treatment can often be helpful and reassuring to patients and families, who wonder if what they are experiencing is normal, and if enough is being done. We recommend that a woman consider a "consultation" appointment to make an initial contact and lay the groundwork for support during treatment.

We hope this information helps you understand how we evaluate, diagnose, and treat breast cancer.

If you have further questions, ask your physician or nurse practitioner.✣

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