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Early Stage Breast Cancer: A Patient and Doctor Dialogue

Q: What type of tumor do I have? What does "invasive" mean?

A: A "tumor" is an abnormal growth that can be "benign" or "malignant." Benign breast tumors do not threaten life and do not spread to other parts of the body. Malignant breast tumors are cancers that may threaten life and may spread to other parts of the body. A malignant tumor that grows into surrounding tissues is called "invasive." Invasive tumors are more likely to spread to other parts of the body than non-invasive tumors.

Q: What does "lobular" mean? What does "ductal" mean? What does it mean for my treatment?

A: Each breast is composed of up to 20 sections called "lobes." Each lobe is made up of many smaller "lobules," where milk is made. Lobes and lobules are connected by small tubes called "ducts" that can carry milk to the nipple.

Lobular carcinoma in situ (LCIS) is a benign tumor that consists of abnormal cells in the lining of a lobule. Even though "carcinoma" refers to cancer, LCIS is not a cancer and there is no evidence that the abnormal cells of LCIS will spread like cancer. Instead, having LCIS means that a woman has an increased risk of developing breast cancer in either breast. Despite the increased risk, most women with LCIS will never get breast cancer. No treatment is necessary and surgery is not usually recommended for LCIS. Occasionally women with LCIS choose bilateral mastectomy as a preventive measure, but most surgeons consider this inappropriate. Some women choose to take tamoxifen to decrease the likelihood of breast cancer. LCIS is sometimes called "Stage 0" breast cancer, but that is not really accurate because it is not really cancer.

Ductal carcinoma in situ (DCIS) is made up of abnormal cells in the lining of a duct. It is a non-invasive malignant tumor, and is also called intraductal carcinoma. The abnormal cells have not spread beyond the duct and have not invaded the surrounding breast tissue. However, DCIS can progress and become invasive. There is no official recommended surgical treatment for DCIS, although a national Consensus Conference held in Philadelphia in 1999 concluded that "most women with DCIS" are eligible for breast-conserving surgery and that less than one in four require mastectomy. The addition of radiation therapy helps prevent recurrence of DCIS and the development of invasive breast cancer. If the DCIS is spread out or is in more than one location, some women will choose to undergo a mastectomy. In the treatment of DCIS, underarm lymph nodes usually are not removed with either breast-conserving surgery or mastectomy. Tamoxifen is sometimes used in combination with one of these two surgical treatment options.

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DCIS is sometimes called Stage 0 breast cancer because it is not invasive.

Q: What is an "early stage" breast cancer?

A: Invasive breast cancer is categorized as Stage I, II, III, or IV. Stages I and II are considered "early stage" invasive breast cancer and generally refer to smaller tumors that have not yet spread to distant parts of the body.

After the health professional explains surgical options, such as breast-conserving surgery (often called lumpectomy) with radiation, modified radical mastectomy, or simple mastectomy, these are the questions most patients will want to ask.

Q: What's my chance of surviving this cancer with each treatment?

A: Most women who are newly diagnosed with early-stage breast cancer have a choice: breast-conserving surgery (such as lumpectomy) or a mastectomy (also called a modified radical mastectomy). The decision is not between your breast and your life. Women with early-stage breast cancer who undergo breast-conserving surgery with radiation therapy live just as long as those who undergo mastectomy. Life expectancy is the same regardless of which choice a woman makes.

When the patient is told that the survival rate for lumpectomy with radiation is the same as for mastectomy, some women may be surprised or skeptical.

Q: Why would any woman pick mastectomy if the survival rate is the same?

A: Thanks to early detection, between 70 and 75 percent of women diagnosed with breast cancer today are possible candidates for lumpectomy or other breast-conserving surgery. Yet, half of these women undergo mastectomies instead. Some of those women are making a well-informed choice. Some do not know that they have a choice. And, because of the costs of health care, some cannot afford to make the choice they would prefer.

Unfortunately, cost sometimes prevents women from choosing breast-conserving surgery. Lumpectomy followed by radiation costs more in the short-term than mastectomy, and some insurance plans do not cover all the expenses of the lumpectomy or the radiation therapy. Reconstruction of the breast after mastectomy adds to the cost, but the law requires that insurance covers that expense. Despite the slightly higher cost of lumpectomy and radiation, that choice is actually less expensive if you look at costs for the five years after the initial diagnosis. Lumpectomy preserves the breast and there are few additional costs when the radiation treatment is completed, whereas breast reconstruction after a mastectomy may require several surgeries that add to the cost over time. This information may help women who are concerned about cost to decide what is best for them.

Another reason why women choose mastectomies is because they do not want to undergo radiation therapy or are unable to arrange radiation treatments. Radiation therapy is usually an outpatient procedure performed over

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a period of at least 5 weeks, and some women are not able to make that commitment. Some women live far away from radiation facilities, or can't afford to take the time for daily treatments. Others may have health conditions such as lupus or heart disease that prevent them from undergoing radiation. Since radiation reduces the chances of recurrence for women choosing lumpectomy, it is important that patients and their doctors consider the required time commitment to radiation therapy before deciding which surgical procedure is best for them.

Fear is another reason why some women choose mastectomy. Some women are afraid of radiation therapy. Radiation therapy does cause side effects, but they are usually mild—like fatigue or skin irritation. Only very infrequently does radiation therapy induce more severe side effects.

Fear of recurrence of breast cancer is another reason why some women prefer a mastectomy to a lumpectomy. Some women assume that breast cancer won't return if the breast is removed. However, women may have a recurrence on the chest wall where the breast was removed because some breast tissue remains even following a mastectomy. For women who choose breast-conserving surgery with radiation, research clearly shows that radiation reduces recurrence for most women with early-stage breast cancer. The risk of cancer returning in the same breast is very low. After 12 years, only one out of approximately 10 women will have had a recurrence of cancer in the same breast. Most importantly, even if breast cancer does recur in the same breast, that does not reduce the woman's chances for a healthy recovery. However, a recurrence could require additional surgery, and a woman may decide to have a mastectomy at that time.

Many women want to make the surgical choice that will enable them to "get it over with and get on with my life." Many of these women choose mastectomies, in order to avoid the several weeks of radiation that is required for lumpectomy patients. However, even mastectomy patients may find that recovery takes longer than expected. Lymph nodes are removed with both lumpectomy and mastectomy, and the pain from arm swelling that can result may last a long time and be debilitating. If chosen, breast reconstruction after mastectomy often requires multiple additional surgeries and significant recovery time. Breast implant manufacturers have informed the FDA that one in four patients whose breasts were reconstructed with implants have at least one additional surgery within three years. For women undergoing TRAM flaps and other reconstruction procedures, the pain from surgery can last for months.

Q: You say that the survival rate does not differ "significantly" between lumpectomy with radiation and mastectomy. But, if there is a tiny percentage difference in outcome, how many women does that represent? Isn't it significant to those women?

A: "Statistically insignificant" means that any difference could have occurred by chance, and not necessarily because one

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treatment is better than another. It does not mean the difference is small—it means it is not known whether the difference (however large or small) is related to the treatment or if it occurred by chance. It is necessary to conduct studies of thousands of breast cancer patients to determine whether small differences are "real" or occurred by chance. The studies that have been conducted seem to indicate that survival rates really are the same for women with early-stage breast cancer, regardless of the type of surgery.

Q: Does the decision about what kind of surgery to have affect whether I need chemotherapy?

A: Chemotherapy is not recommended for most women with early stage breast cancer. If chemotherapy is recommended, it can improve survival and decrease the risk of breast cancer recurrence. There are several different kinds of chemotherapy, and it is sometimes used in combination with tamoxifen. Chemotherapy is usually given after surgery, but there are exceptions. For example, a woman with Stage III breast cancer may undergo chemotherapy before surgery to shrink a tumor so that she can undergo breast-conserving surgery.

Q: I have breast cancer in my family. Should I choose the more aggressive treatment? Should I undergo surgery to prevent breast cancer?

A: Most women who have breast cancer in their families will never get breast cancer themselves—even if a mother or sister has died of breast cancer. In fact, even a woman with the mutated gene for breast cancer may never get breast cancer, even though her risk is much greater than other women with "breast cancer in their families" who don't have the mutated gene.

A family history of breast cancer increases your risk of breast cancer, but it is not necessary to choose more aggressive treatment or more radical surgery just because you have a family member with breast cancer. Research shows that a strong family history of breast cancer does not affect local recurrence rates or overall survival among women who undergo breast-conserving surgery. So family history should not influence your choice of either mastectomy or breast-conserving surgery.

Women diagnosed with breast cancer who have a family history of breast cancer are at increased risk of getting breast cancer in their healthy breast. Sometimes these women decide to have the other removed to prevent cancer in the future. Occasionally, women with several close relatives with breast cancer decide to have both their breasts removed as a preventive measure, even if they have never been diagnosed with breast cancer. Removing one or two healthy breasts reduces the risk of future breast cancer, but it does not eliminate the risk completely. The disadvantage is that the surgery will be unnecessary for most women who choose it, because most women who have a breast removed as a preventive measure would never have gotten breast cancer even if the breast (or breasts) were not removed.

Instead of surgery, there are other strategies that can prevent breast cancer, and it is advisable to obtain a second

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professional opinion before deciding to undergo a mastectomy to prevent, rather than treat, breast cancer.

Q: What are the chances of the cancer coming back if I get a lumpectomy with radiation? If it comes back, is it likely to be invasive? If I decide on a lumpectomy/radiation, how can you be sure there are no other "spots" in the breast? Wouldn't a mastectomy eliminate that possibility?

A: Approximately one of every ten patients who are treated with lumpectomy and radiation therapy will have a recurrence of breast cancer in the same breast within 12 years. Recurrence in the same breast usually requires additional surgery, but does not affect chances of survival compared to mastectomy. However, fear of recurrence of breast cancer is the reason why many women prefer a mastectomy to a lumpectomy. It seems rather obvious that you can't get cancer in your breast if your breast is removed. However, women who have undergone a mastectomy can still experience a recurrence on the chest wall where the breast was removed. Recurrence on the chest wall following a mastectomy is slightly less likely than recurrence in the same breast following a lumpectomy and radiation.

As we explained earlier, recurrence of cancer in the other breast or elsewhere in the body does not differ between mastectomy patients and lumpectomy patients.

Q: What does "margin" mean?

A: In a lumpectomy, the surgeon removes the cancer (the "lump") and a narrow area of normal breast tissue surrounding the lump (the "margin"). The goal is to obtain "clean margins"—breast tissue around the tumor that is completely free of cancer.

Q: I have heard that some tumors are "estrogen receptor-positive?" What does that mean? If my tumor is estrogen receptor-positive, should that make a difference in my treatment?

A: Some breast cancers are sensitive to the female hormone, estrogen, and are called "estrogen receptor-positive." The drug tamoxifen interferes with estrogen and when breast cancer cells are sensitive to estrogen, tamoxifen can inhibit their growth.

Studies have shown that tamoxifen improves the chances of survival and helps prevent recurrence of breast cancer, if the cancer cells are estrogen receptor-positive. Tamoxifen is not an effective treatment for breast cancer that is estrogen receptor-negative, and therefore should not be taken for those cancers. Tamoxifen may have unpleasant side effects that are similar to menopause, such as hot flashes, vaginal dryness, irregular periods, and weight gain. Tamoxifen also slightly increases the risk of uterine cancer and blood clots. Studies suggest that Tamoxifen should not be taken for more than five years

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Q: If I choose a lumpectomy, how much of my breast has to be taken out? Will it affect the look of my breast? What will the scar look like?

A: Breast-conserving surgery is also known as lumpectomy, partial mastectomy, segmental mastectomy, or quadrantectomy. These surgeries remove the cancer but leave most of the breast intact. In a lumpectomy, the surgeon removes the cancer and some normal breast tissue surrounding the lump in order to obtain "margins" around the tumor that are free of cancer. The other types of breast-conserving surgery remove a somewhat larger area of the healthy breast. The appearance of the breast will depend on the size of the breast compared to the size of the cancer and the amount of healthy breast tissue that is removed. The appearance of the scar depends on the type of surgery and the location of the cancer.

Q: What will my breast look like after lumpectomy/radiation? I hear it gets hard.

A: Depending on the size of the cancer and the margins, and a woman's response to radiation, a breast may look almost identical after a lumpectomy, or it may look quite different. Radiation can cause a skin condition that looks like sunburn. This usually fades, but in some women it never goes away completely. It is also true that some women find that radiation makes their breast feel hard or firm. Again, this may last just a few months, or longer. However, firm or hard breasts are even more common among women who have implants after a mastectomy.

Q: I thought that radiation can cause cancer. Will it increase my risk for other cancers?

A: Radiation therapy has improved greatly through the years, and the doses are much lower than they used to be. The bottom line is that women who have radiation therapy after lumpectomy are less likely to have a cancer recurrence in the same breast, and they live just as long as women who undergo mastectomy without radiation. There are exceptions: women who are pregnant do not undergo radiation treatment because it is dangerous to the fetus, and radiation can be harmful to women who have certain diseases, such as lupus.

Q: Can I have a mastectomy without removing the nipple?

A: Most surgeons recommend removal of the nipple because cancer cells can grow there. Although rarely done, it is possible to undergo a subcutaneous mastectomy, and save the nipple, if the cancer is not located near the nipple. A subcutaneous mastectomy is more likely than a total mastectomy to leave breast cells behind that could become cancerous. Neither the nipple nor the breast will have the same sensations after a mastectomy that they do before a mastectomy, because the nerves are cut.

Q: What are the side effects of both surgical treatments? What's the worst case scenario?

A: When considering what kind of surgery to have, it is important to know that there are potential side effects common to all surgical procedures. Any surgical procedure carries a risk of infection, poor wound healing, bleeding, or a

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reaction to the anesthesia. Also, pain and tenderness in the affected area is common, usually in the short-term. Because nerves may be injured or cut during surgery, most women will experience numbness and tingling in the chest, underarm, shoulder, and/or upper arm. Women who undergo lumpectomy usually find that these changes in sensation improve over 1 or 2 years, but may never completely resolve.

Most women who have lumpectomy with radiation will still have sensation in the breast, whereas women who have had a mastectomy with reconstruction—either with implants or her own tissue—will not have much (or perhaps any) sensation in their breast mounds, because the nerves to the breast skin have been cut. And, although nipples can be reconstructed, they will not have sensation.

Removal of lymph nodes under the arms is usually performed with both lumpectomy and mastectomy. This can lead to pain and arm swelling ("lymphedema") in up to 30% of patients.

The side effects of treatment vary for each person. Some people may experience many side effects or complications, others may experience very few. Pain medication, physical therapy, and other strategies can help.

Q: Can I have breast reconstruction at the same time as my mastectomy?

A: Most women can undergo at least part of the breast reconstruction procedure at the same time as their mastectomy. Breast reconstruction can be done later as well. For some kinds of reconstruction, more than one surgery is needed. Different breast reconstruction procedures have various complications that need to be discussed before a decision is made.

Q: With reconstruction, can I change the size of my breasts? Can the plastic surgeon make the other breast match?

A: In many cases, a plastic surgeon can change the size of the breasts. Some plastic surgeons are more skilled than others at making the other breast match. Sometimes, it would be necessary to perform surgery on the healthy breast to help make them match. Usually, reconstruction with a woman's own tissue has a more natural appearance than implants, which tend to be higher and rounder than a natural breast. Women who are seriously considering reconstructive surgery should have a full consultation with the plastic surgeon before having a mastectomy, and can bring a list of questions to ask.

Q: What happens when each treatment ends? How often do I see you?

A: These are questions that each woman should ask, and doctors should be prepared to answer. There are several different kinds of physicians and health professionals that are involved in treatment, and this should be clearly explained to the patient.

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Q: If I have a lumpectomy and I get a recurrence, will I have to have a mastectomy then? Can I have reconstruction after radiation?

A: Most women who have a lumpectomy followed by radiation will not have a recurrence in the same breast. A recurrence in the same breast does not reduce a woman's chance for a healthy recovery. It probably, however, will require surgery, and a woman may decide to have a mastectomy at that time, because radiation is not recommended a second time. Breast reconstruction is possible after radiation but the surgery may be more difficult to perform, and this should be discussed with a plastic surgeon.

Q: These are questions that breast cancer patients commonly ask their doctors. What's your recommendation? What treatment would you recommend if I were your wife/sister/daughter? What do most of your patients in my situation decide?

A: Many doctors will answer these questions honestly. However, a doctor's opinions may be affected by age, training, and other personal influences. For example, research shows that older doctors, male doctors, doctors working in community hospitals, and doctors in the South and Midwest are more likely to recommend mastectomies. Younger doctors, female doctors, doctors working at university medical centers, and doctors working in the Northeast are more likely to recommend lumpectomies.

These differences are probably related to the kind of training a doctor has had. Doctors who were trained within the last 20 years, and work at university-based medical centers, may be more aware of the recent research indicating that lumpectomies are just as safe as mastectomies, and may have received more training on how to perform a lumpectomy. However, there are certainly older doctors and doctors at community hospitals who are very well informed about current treatment options, and well trained to perform them.

It is important for you to feel comfortable discussing your preferences and participating in the decisions about your surgical treatment. Research shows that women are happier if they help make treatment decisions, rather than just following their doctor's recommendations.

Q: Should I get a second opinion?

A: Your cancer treatment involves several important decisions. A second opinion may help you feel more confident of making the decisions that are best for you. Asking for a second opinion is always appropriate, and well-qualified physicians are not offended by it. And, feel free to ask your doctor for copies of your medical records. ■

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For More Information…

To find out more about early stage breast cancer, contact womenshealth.gov at 1-800-994-9662 or the following organizations:

National Research Center for Women & Families
Internet: http://www.center4research.org

Cancer Information Service
Phone: (800) 422-6237
Internet: http://cis.nci.nih.gov/

National Cancer Institute
Phone: (800) 422-6237
Internet: http://cancer.gov/

National Breast Cancer Coalition
Phone: (800) 622-2838
Internet: http://www.natlbcc.org/

National Breast and Cervical Cancer Early Detection Program
Phone number: 1-888-842-6355 (select option 7),
Internet address: http://www.cdc.gov/cancer/nbccedp/index.htm

Susan G. Komen Breast Cancer Foundation
Phone: (800) 462-9273
Internet: http://www.komen.org/

BreastCare
Phone: (501) 661-2000
Internet: http://www.arbreastcare.com/

National "Get A Mammogram: Do It For Yourself, Do It For Your Family" Campaign
(brochures in English, Chinese, Tagalog, and Vietnamese)
National Cancer Institute (NCI)
Phone Number(s): (800) 4-CANCER (800-422-6237)
Internet Address: http://breasthealth.cancer.gov

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