

# Life ABC

**Life** **A**fter early **B**reast **C**ancer

*Improving Your Chance of Staying Cancer Free*



Executive Summary | [Life After early Breast Cancer: Science, Perceptions & Communication Surrounding Risk of Recurrence](#) | May 2005



SOCIETY FOR  
WOMEN'S HEALTH RESEARCH

## Life After early Breast Cancer:

## Science, Perceptions & Communication Surrounding Risk of Recurrence

### EXECUTIVE SUMMARY\*

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### Life After early Breast Cancer

*Improving Your Chance of Staying Cancer Free*

Every three minutes, a woman in the United States is diagnosed with breast cancer. One person dies of the disease every 14 minutes. While advances in breast cancer treatment have increased the likelihood of survival, there is still a significant risk that breast cancer will come back – or recur – in some patients. But, there are steps a woman can take to improve her chance of remaining cancer free.

The *Life ABC Report: Science, Perceptions and Communication Surrounding Risk of Recurrence*, is part of *Life After early Breast Cancer: Improving Your Chance of Staying Cancer Free (Life ABC)*, a nationwide public education campaign conducted by the Society for Women's Health Research.\*\* The report explores the way women with early breast cancer perceive overall risk of breast cancer recurrence and how the complexities of communicating about this risk between women and health care professionals may contribute to these perceptions.

To prepare this report, the Society conducted a thorough review of the scientific literature about the recurrence of early breast cancer and risk communication. The Society also commissioned the Roper Organization/NOP World to conduct a comprehensive survey of 300 women with early breast cancer.\*\*\*

## Understanding Early Breast Cancer

The term “early breast cancer” refers to breast cancer in stages 0, I and II at the time of diagnosis. With stage 0, the cancer is non-invasive, meaning it has not spread to surrounding normal tissue (sometimes called carcinoma in-situ). In stage I cancer, the tumor is two centimeters in size or smaller and has not spread outside the breast. And, in stage II, either:

- There is no tumor in the breast, but cancer is found in the axillary lymph nodes (nodes under the arms); or,
- The tumor is two centimeters or smaller *and* has spread to the axillary lymph nodes; or,
- The tumor is two-to-five centimeters *and* has spread to the axillary lymph nodes; or,
- The tumor is larger than five centimeters *and* has not spread to the axillary lymph nodes or,
- The number of lymph nodes involved with cancer is not more than three.

In early breast cancer, the tumor is usually removed by surgery. However, undetectable microscopic deposits of the disease may sometimes remain behind. After several years or even decades, these deposits may result in the cancer coming back, a phenomenon called “recurrence.” Health care professionals use a number of factors to predict a woman’s risk of recurrence, including but not limited to: whether the tumor has spread to the lymph nodes (known as node-positive breast cancer), tumor size at diagnosis, how the cancer cells look under a microscope (histological grade), if hormone receptors in the tumor are positive or negative, and whether the tumor is positive or negative for the growth-promoting protein HER2/*neu*.

When health care professionals consider a woman with breast cancer to be at either high or medium risk for recurrence, they typically suggest that following surgery to remove the tumor, the patient receive additional treatment with medication that may include hormonal therapy, such as tamoxifen. Therapy during this post-surgery period is commonly referred to as “adjuvant” therapy or treatment. Research suggests that some women who are considered at low risk for recurrence may also benefit from additional therapy after surgery. This research shows that additional therapy helps reduce risk of recurrence and improves overall survival for some women with breast cancer.

## Risk of Recurrence in Early Breast Cancer

Current approaches to treating early breast cancer, including adjuvant therapy, have indeed improved survival and reduced recurrence. However, the risk of recurrence may be underestimated by some women, but overestimated by others.

While the risk of recurrence does diminish somewhat over time, ongoing risk has been observed in many studies, some of them involving tens of thousands of women with breast cancer. In fact, some of the women who experienced recurrence after five years in these studies had previously been considered “low risk” – for example, their cancer had not spread to the lymph nodes at the time of their initial diagnosis, or their estrogen receptor status was positive. In one of these studies, a substantial number of recurrences occurred more than five years post-treatment.

## Women’s Perceptions about Recurrence and Desire for Information

A recent Roper survey of 300 women with early breast cancer, who are receiving or who completed treatment, showed that most women with the disease are concerned about their risk of recurrence. Nearly all of the women surveyed, regardless of whether they completed or were still receiving adjuvant hormonal therapy, said they want to learn more about risk of recurrence and do whatever they can to prevent it. According to the survey results:

- 49% of women with early breast cancer who completed adjuvant hormonal therapy and 58% of women who are currently receiving adjuvant hormonal therapy indicated that they “still worry about [their] cancer returning in the future.”
- 95% of women who completed adjuvant hormonal therapy and 95% of women still receiving adjuvant hormonal therapy say they want to learn everything they can about preventing recurrence.

- Also, 84% of women who completed adjuvant hormonal therapy and 87% of women who are still receiving adjuvant hormonal therapy believe that it is “critical” or “very important” that they do everything they can to reduce the risk of their breast cancer returning.

Despite women’s concern about recurrence and their desire for information, the Roper survey found that a significant number of women have not discussed their risk of recurrence, following five years of adjuvant therapy, with their health care professionals.

- Nearly one-quarter of women with early breast cancer who completed adjuvant hormonal therapy and 40% of the women who are still receiving adjuvant hormonal therapy say they have never discussed with their health care professionals their risk of breast cancer coming back once they have completed five years of adjuvant hormonal therapy.

These results clearly demonstrate that women who have been treated for early breast cancer still worry about the chance that their cancer might come back. They recognize the importance of ongoing risk for recurrence but feel they are not currently getting all of the information that they need if they are to make informed decisions with their health care professionals about prevention of breast cancer recurrence. These results also indicate there are gaps in the communication between women and their health care professionals—either providers are not communicating sufficient information or patients are not recalling important communicated information, or both. Clearly there are challenges in the communication process which must be understood and overcome if women with early breast cancer are to make informed decisions.



# RISK COMMUNICATION BETWEEN WOMEN AND THEIR HEALTH CARE PROFESSIONALS: COMMUNICATION STRATEGIES ARE KEY FOR BREAST CANCER TREATMENT

Research about how patients and health care professionals communicate about risk may shed some light and help generate new tools for cancer risk communication in particular. Effectively communicating about cancer risk is fundamentally challenging for both health care professionals and women with breast cancer. Health care professionals may find it difficult to translate risk statistics to the individual because:

- Communicating contradictory or inconclusive information to patients is emotionally difficult if they feel they are giving patients “bad news.”
- Patients may have trouble understanding complicated risk calculations and probabilities.
- Patients may inaccurately interpret the science and develop greater or lesser perceptions of their risk relative to what was communicated.
- Some women may not even want to discuss risk, because it can be frightening or depressing.

Because there are so many subjective elements involved on both sides of the communication process, there can be serious gaps that leave women without the information they need. There is a significant need for more research that will help health care professionals more effectively communicate risk information to their patients in a way that patients can accept and use.

## Steps Women Can Take To Remain Cancer Free

What does all of this mean for women with early breast cancer? The bottom line is that we have come a long way in successfully managing early breast cancer, but some women face the risk of a recurrence. Risk is individual and so is the way we communicate about it. We encourage women to talk to their health care professionals about steps they can take to prevent a recurrence. While there is a critical need for communication and education to ensure women with early breast cancer are doing everything they can to stay healthy and cancer free, here are some tools that women can use now:

- » [Checklist: Taking Steps to be Good to You](#)
- » [Questions to Ask Your Health Care Professional](#)
- » [Additional Breast Cancer Resources and Organizations](#)

\* All material for this executive summary was taken from *Life ABC Report: Science, Perceptions and Communication Surrounding Risk of Recurrence*.

\*\* Supported by Novartis Oncology.

\*\*\* The survey commissioned by the Society and administered by the Roper Organization (as part of NOP World), was conducted between February 18th and March 28th, 2005 via telephone among a national sample of 300 postmenopausal women diagnosed with early breast cancer who met the following criteria:

- Have completed three or more years of adjuvant hormonal therapy (such as tamoxifen) and are still receiving that therapy, or
- Have completed five or more years of adjuvant hormonal therapy (such as tamoxifen) within the past two years.

The sampling error for those currently on therapy is +/-7 percentage points. For those recently completing the therapy, the margin of sampling error is +/-9 percentage points. This survey is subjective and based on the opinions (of the patients who participated). This report interprets their results in the context of other published research.

## TAKING STEPS TO BE GOOD TO YOU

To help prevent breast cancer and recurrence, it is important for all women to maintain a healthy lifestyle. Many factors contribute to breast cancer recurrence; therefore, the risk of recurrence is different for every woman. However, there are steps that all breast cancer patients can take that may increase their chances of remaining cancer free. The following checklist includes some of the important steps that may improve a woman's chance of remaining cancer free.

- Eat a healthy diet and maintain a normal weight**
  - Follow a balanced diet containing the main food groups
    - Servings depend on your age, sex and physical activity
  - Eat whole grain foods such as:
    - whole-wheat flour
    - oatmeal
    - whole cornmeal
    - brown rice
  - Take a daily multivitamin
  - Limit alcohol intake
  - Limit saturated and trans fat intake
- Begin an exercise program, at least three times a week. But be sure to discuss any exercise program with your health care professional before you start. Exercise can include**
  - Walking around the neighborhood
  - Swimming
  - Playing tennis with a friend
  - Joining a gym
  - Taking dance classes
  - Taking the stairs rather than the elevator
  - Parking a little farther away from your destination so you have to walk a little more
- Examine the stresses in your life and find ways to reduce them if possible**
  - Daily meditation or regular exercise can help
  - Taking a yoga or tai chi class can help
- Learn to care for yourself the way you care for others**
- Tap into a support network—whatever you are comfortable with, such as friends, family, spouse/partner, spiritual community, online discussion groups, or others**
- Develop a regular schedule for follow-up office visits with your health care professional**
  - Complete physical examination every 4 to 6 months for the first 5 years following treatment; then every 12 months
  - Annual mammograms
  - Monthly self-examinations of both breasts
  - Annual pelvic exam
- Remain positive during this experience**
  - Measure what you have learned about yourself
- Concentrate on what changes you can make to improve your quality of life**

## QUESTIONS TO ASK YOUR HEALTH CARE PROFESSIONALS

### **About breast cancer risk:**

- In what stage would you classify my breast cancer?
- What is my nodal status, and how does it affect my risk of recurrence?
- Am I estrogen receptor-positive or negative?
- Am I HER2/*neu* positive or negative?
- Can you talk to me about my personal risk of recurrence?

### **About reducing recurrence:**

- What can I do to help prevent a recurrence of my cancer?
- How often should I visit you and for what types of exams (physicals, breast exams, checkups, etc.)?
- What cancer screening tests (e.g., mammography) should I have and how often?
- Should I consult a nutritionist about changes in my diet?
- When can I begin a regular exercise program?

### **About treatment:**

- After I finish my treatment, what kind of follow-up care will I receive? For what length of time?
- What symptoms should I be on the lookout for that might mean that my cancer has returned?
- Will the treatment affect me sexually (reduction in sex drive, ability to have children)?
- Are there any long-term side effects of my treatment of which I should be aware?
- Am I at risk for any other cancers and what can I do to reduce that risk?



## ADDITIONAL BREAST CANCER RESOURCES & ORGANIZATIONS

Additionally, women with early breast cancer should take full advantage of resources available to them outside their health care professional. Following is a list of groups whose mission it is to help women with breast cancer.

Avon Breast Cancer Crusade  
[www.avoncompany.com/women/avoncrusade](http://www.avoncompany.com/women/avoncrusade)

BreastCancer.org  
[www.breastcancer.org](http://www.breastcancer.org)

Breast Cancer Resource Committee, Inc.  
202-463-8040  
[www.bcresource.org](http://www.bcresource.org)

Cancer Care  
800-813-4673  
[www.cancercares.org](http://www.cancercares.org)

Intercultural Cancer Council  
[www.iccnetwork.org/](http://www.iccnetwork.org/)

Living Beyond Breast Cancer  
610-645-4567  
[www.lbbc.org](http://www.lbbc.org)

Men Against Breast Cancer  
866-547-MABC (6222)  
[www.menagainstbreastcancer.org/](http://www.menagainstbreastcancer.org/)

Ribbon of Pink  
[www.ribbonofpink.com](http://www.ribbonofpink.com)

Society for Women's Health Research  
202-223-8224  
[www.womenshealthresearch.org/](http://www.womenshealthresearch.org/)

Susan G. Komen Breast Cancer Foundation  
800-IM-AWARE (800-462-9273)  
[www.breastcancerinfo.com](http://www.breastcancerinfo.com)

The Wellness Community  
888-793-WELL  
[www.thewellnesscommunity.org/default.asp](http://www.thewellnesscommunity.org/default.asp)

Vital Options  
[www.vitaloptions.org/](http://www.vitaloptions.org/)

Y-ME  
800-221-2141  
[www.y-me.org](http://www.y-me.org)