

# Life After Breast Cancer: Surviving & Thriving

by Beverly J. Anderson, Ph.D.

*I am not an optimist, because I am not sure that everything ends well. Nor am I a pessimist, because I am not sure that everything ends badly. I just carry hope in my heart. Hope is a feeling that life and work have a meaning. You either have it or you don't, regardless of the state of the world that surrounds you.*

*Life without hope is an empty, boring, and useless life. I cannot imagine that I could strive for something if I did not carry hope in me. I am thankful to God for this gift. It is as big a gift as life itself.*  
*Vaclav Havel, Czech playwright  
 and President*

Dear Reader:

Chances are that if you are reading this, either you or someone close to you has been diagnosed with breast cancer or is at a high risk for developing it. My experiences with breast cancer, mastectomy, and reconstruction have taught me how little guidance and coordinated care exists for women diagnosed with this disease. I've decided to share my story with the hope that someone will benefit from my year and one-half triumph over breast cancer.

## Important Breast Cancer Statistics

According to the World Health Organization, breast cancer is the second leading cause of cancer deaths in women today (after lung cancer) and is the most common cancer among women, excluding nonmelanoma skin cancers. Worldwide, more than 1.2 million people will be diagnosed with breast cancer this year. The American cancer Society projected that in 2001 approximately 192,200 new cases of invasive breast cancer (stages I-IV) would be diagnosed among women in the United States. Another 46,400 women would be diagnosed with ductal carcinoma in situ (DCIS), the earliest form of breast cancer. DCIS is confined to the milk ducts and is non-invasive. An estimated 40,600 deaths will occur from breast cancer in the United States. However, overall breast cancer deaths declined between 1992 and 1996 due to earlier detection and more effective treatments.

## Incidence By Age

Like me, many women make the mistake of thinking that the absence of known risk factors for breast cancer eliminates their chances for developing the disease. One oncologist told me that most women who die from breast cancer had very low risk factors. So don't be fooled into thinking that low risk factors protect you from breast cancer.

<b>A Woman's Chances of Breast Cancer Increases With Age</b>	
By age 30	1 out of 2,212
By age 40	1 out of 235
By age 50	1 out of 54
By age 60	1 out of 23
By age 70	1 out of 14
By age 80	1 out of 10
Ever	1 out of 8
<i>Source: Feuer, EJ, Wun LM. DEVCAN: Probability of Developing or Dying of Cancer. Version 4.0. Bethesda MD: National Cancer Institute. 1999.</i>	

<b>Five Year Survival Rate By Age</b>	
Younger than 45	81%
Age 45-64	85%
Ages 65 and older	86%
<i>Source: American Cancer Society</i>	

## Staging and Survival Rates

“Staging” refers to the process used to measure the size and location of a patient’s cancer. Breast cancer stages range from Stage 0 (very early form of cancer) to Stage IV (advanced metastatic breast cancer). The five-year survival rate for breast cancer (below) is calculated based on averages. (e.g. individual tumor characteristics, state of health, genetics.)

<b>State</b>	<b>5-Year Relative Survival Rate</b>
0	100%
I	98%
IIA	88%
IIB	76%
IIIA	56%
IIIB	49%
IV	16%
<i>Source: American Cancer Society</i>	

## Overall Survival Rate

Breast cancer survival continues to decline after five years. Survival rates after five years depends on the stage; early stage breast cancers are associated with a higher survival rate.

<b>Overall Survival Rate</b>	
After 5 years	85%
After 10 years	71%
After 15 years	57%
After 20 years	52%
<i>Source: American Cancer Society</i>	

## The Key to Survival

The American Cancer Society states that early detection and treatment is the key to survival. Beginning at age 40, all women should have an annual screening mammogram.

## My Story

My story begins in early December 2000. I woke up one morning and decided I needed to get a mammogram. I hadn’t had one since 1992 and each year since then my gynecologist, Dr. Nicolae

Filipescue, would argue with me about the necessity for screening. I've known him since 1982 when I moved to Washington, D.C. He's the kind of person you want for your doctor. A perfectionist at heart, Dr. Nic examines and investigates every symptom and doesn't let up until he has a diagnosis. He delivered my last two children, both high-risk pregnancies. How many doctors will sit by your bedside through 18 hours of labor? He did. Nonetheless, I argued with him: "Nic", I'd say, "I have no risk factors. No one in my family has ever had cancer. I don't smoke or drink. I've been on whole foods and vitamins since age 25." He'd shake his head and hand me the prescription for the mammogram anyway. It would remain in my purse until it was so tattered and torn that I'd eventually throw it away.

"Denial" is a strange phenomenon. As a police and trauma psychologist, I should know better. But I've always been so proud of my good health that I lived my life by my own personal fable: cancer will never be a part of my life. Believing that life is a "do-it-to-yourself" program, I have made it my business to take control whenever I could, especially in matters of my health. The importance of "control" was one of three lessons for survival that I learned in the orphanage where I grew up in Fall Rivers, Massachusetts. (The other two lessons were: never back down from a fight and always maintain your place in the packing order.)

Nonetheless, I scheduled the mammogram because of a gnawing feeling that told me I should. One week after the screening, I wasn't surprised when the radiologist requested that I return for more detailed diagnostic films. Three areas of microcalcifications were found on my right breast. Although 90% of microcalcifications are harmless, 10% of cases are associated with breast cancer. The results of the second mammogram indicated that there were three growths associated with the microcalcifications.

Dr. Nic referred me to a general surgeon who was a member of a very large surgical practice. Although I liked him and he came with the highest of recommendations, I felt like I was on a conveyor belt; the atmosphere of the office was cold and impersonal. I was just one patient among hundreds of nameless faces all in need of medical care.

While surgical skills and excellent credentials are important, the atmosphere of the medical office and the demeanor of its personnel make a crucial difference as patients experience the emotional roller coaster ride of a cancer diagnosis. I didn't expect the world to stop rotating on its axis because I had cancer, but being treated like a faceless body in need of surgery was not a part of my plan, either. After studying my films, the surgeon gave me two options—a needle biopsy or a lumpectomy. He recommended the lumpectomy because he didn't like the irregular pattern of one of the growths. I knew little about this procedure aside from the fact that the surgeon would cut out the tumors. There was a breakdown in the system because I was taken by surprise the day of the surgery.

Prior to the surgery, I was taken to the radiology department where they inserted three needles into the three lesions in my right breast. Attached to the needles were wires that were placed at the site of the lesions to guide the surgeon. Dye was injected into these sites to further identify the abnormal tissue. I don't like surprises and felt angry that no one had prepared me for this very painful procedure. Once again, conveyor belt medicine; get them in and get them out but not before you get all the insurance information and a signature to guarantee payment.

With 3 wires protruding from my breast, I was wheeled to a corridor outside of the operating room to await my turn on the conveyor belt of mass medicine. I lay there alone, angry, wounded, shaken and in pain. The surgery itself was uneventful and the excised tissue was sent to pathology for diagnosis. I left the hospital that day feeling violated, as though some of my dignity had been taken away.

A few weeks after the surgery, I called the surgeon's office for the pathology results and to schedule a post-op visit. The nurse told me that everything was "normal." I exhaled loudly. Great! Since I was feeling so good I almost canceled the follow-up visit but something told me to go anyway. The nurse had given me false information. The surgeon explained that the tissue was not normal. He used the term "extensive atypical hyperplasia", and recommended that I return in 6 months for a mammogram. Atypical hyperplasia is a dangerous increase in the number of breast cells; a sign that breast cancer may develop.

I felt uneasy with his recommendation and telephoned Dr. Nic. I heard the concern in his voice as he instructed me to have the tissue slides sent to the Armed Forces Institute of Pathology (AFIP). He explained that they have an excellent "Breast Cancer" department. It's their specialty. (General hospital pathologists examine all kinds of slides, not just breast tissue) It took three separate calls to the surgical practice before they finally got around to sending my slides to the AFIP. My operated breast was painful and noticeably smaller than my left breast. It looked deformed. However, I knew the surgeon had done the right thing in removing the cancer.

Four weeks later, I called for the AFIP results. The nurse faxed the report to me. Of all the words on the two pages, what jumped out at me was "carcinoma insitu." That meant cancer. I was stunned; I could feel the tears filling my eyes. What did this mean? What was I going to do? Did they get it all? I called to speak with the surgeon who had operated. Yes, "carcinoma insitu" means early stage cancer. He couldn't tell me what to do so he referred me to an oncologist and a medical doctor who specialized in cancer radiation treatment.

The oncologist was cordial and, like the surgeon, non-committal and reluctant to make recommendations. My repeated requests for guidance were met with vague answers or computer printouts with risk factors for breast cancer. I thought, "Damn it! Just give me your medical opinion! I've got a brain; I'll make my own decision." I thought to myself, "Are doctors so afraid of liability or do they just not care?" The only exceptions were Dr. Nic and Susan Pearce, M.D., the radiologist/oncologist at Fairfax Inova.

When I asked Dr. Nic, "Is it possible for there to be additional carcinoma insitu cells in my breast even after the lumpectomy?" He replied without hesitation, "Yes, of course it is." He spoke with me whenever I needed to ask questions.

I then scheduled a consultation with Susan Pearce, M.D. of the Fairfax Inova Cancer Center in Fairfax, Virginia. Walking out of the elevator, the reception desk was directly in front of me. However, my eyes were drawn to the large sign that read, "Cancer Center." Over to the right was a waiting area that looked like most every hospital waiting area except for one thing: in addition to the chairs, was a tiny children's table and chairs with toys and books. I thought, "Even children get cancer." I felt myself feeling out of place and uncomfortable. When I told the receptionist that I was there to meet with Dr. Pearce, she answered, "Please have a seat in the patient lounge while I call Dr. Pearce." Before I realized what I was saying, I heard the words, "Oh, I'm not a patient; I'm just here for a meeting." And rather than sit down, I remained standing near the elevator. I just could not bring myself to be identified as a cancer patient. (I had also refused to participate in the annual "Race for the Cure" walk in Washington, D.C. with a colleague whose sister and mother had both undergone mastectomies. I was not ready emotionally to accept that I had cancer.)

Dr. Pearce is a tall, slender, attractive woman in her early forties. She drew pictures and explained the entire process of breast cancer in a way that anyone could understand. Moreover, she answered every question as if she had all day to spend with me. Dr. Pearce told me that I wasn't a candidate for radiation because the cancer was in three sites. When I asked her what course she would take, without hesitating, she answered, "Mastectomy, no question. That would be my decision." She said she would have a mastectomy on the right breast only. However, I knew that I would opt for a bi-lateral mastectomy (both breasts). She also offered to have my slides sent to another breast cancer specialist, Dr. Stuart Schmitt, at the Beth Israel Hospital in Boston. I agreed. (His diagnosis matched the AFIP's; the hospital pathologist had missed the carcinoma insitu.)

With the decision to have a bi-lateral mastectomy made, I began my search for a plastic surgeon. What a disappointment. Of the six plastic surgeons I interviewed, most basically recited the procedure for mastectomy and reconstruction as though reading from a script. They even showed me pictures. It was not promising. They would remove all the skin on the breast, including the nipples and areolas. There wouldn't be much to work with and I'd certainly never be a 34D again. And, my breasts would never look normal. I wanted a plastic surgeon who would work with me as a partner. I wanted to be treated like a person-not just another surgical patient.

I was feeling demoralized and disheartened when I telephoned an attorney friend, Kevin McCarthy, who specializes in medical malpractice. He said, "Bev, I know of an excellent plastic surgeon. He does great work on breast reconstruction. His name is Roger Friedman." I jotted down the name and telephone number. One hour later, between patients, I received a telephone call. The voice on the other end began enthusiastically, "Hi, this is Roger Friedman and I understand you've made a decision to undergo a mastectomy and reconstruction. Let me tell you, we can perform reconstruction with excellent results. There are so many options; it's wonderfully exciting work. Make an appointment and we'll discuss all your options." I hung up the phone and for the first time, I felt that I had connected with a doctor who loved his work. This was too good to be true.

When I arrived for my first appointment, I was greeted at the desk by Cara and Tina, both pretty and very friendly. What a nice feeling; even the energy in the office was warm and inviting; yet very busy. In a short while, a tall attractive man came out to greet me. He extended his hand and said, "Hi, I'm Roger. Let's go back and talk." (Hmm, I mused to myself, this man has a healthy ego. He refers to himself as "Roger," not Dr.)

My initial "gut" reaction to Roger Friedman proved to be my overall impression as I drove home: He's "straight up," direct, very competent and, a good listener with a great sense of humor. I knew I had found "Dr. Right." He had talked to me for well over an hour educating me about mastectomy and options for reconstruction. He showed me pictures of actual reconstructions and explained the "skin-saving" surgical technique that he and general surgeon Glenn Sandler, M.D., were simple mastectomies. But it was his last words before I left that first day that have remained with me throughout several surgeries and a few setbacks: He said, "I promise you that the day you leave, I'll have you looking better than the day you walked in."

## Choosing "Dr. Right"

Mastectomy and reconstruction is a lengthy, multi-stage series of surgeries and adjustments. While "competence" is the primary objective in choosing a surgeon, it's also essential to feel comfortable with your doctor and his staff. Trust your "gut level" feelings when choosing "Dr. Right." These are the criteria that were important to me:

- (1) I wanted a surgeon who specialized in breast reconstruction and was recommended by doctors and other health care professionals.
- (2) While I wished to be treated like a "partner" in making decisions about the surgery, I needed a surgeon who "took charge" and was undaunted by my strong personality. (One surgeon I consulted with agreed to use my nipples and areolas as a skin graft in spite of all the research that contraindicates keeping them.) In response to my request to keep them, Dr. Friedman replied, "Absolutely not." He explained that cancer has recurred in patients whose nipples and areolas were saved. He was adamant that he would neither keep them nor use them as skin grafts.
- (3) I needed a surgeon who would take the time to listen to my concerns, answer my questions, and explain each procedure every step along the way. Roger supplemented his explanations with literature that described each procedure fully.
- (4) It was very important that my surgeon's staff share his traits and philosophies. A friendly, helpful staff sets the tone for any office but is especially needed by patients undergoing multiple surgical procedures.
- (5) Hospital affiliation was also a factor in my final choice of surgeries. One well-known, very competent surgeon was affiliated with a large hospital that was difficult to get to because of traffic problems. His office was located inside the hospital, far away from the parking facilities. It was an "obstacle course" getting from the parking lot to his office and I couldn't

























