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.

A Woman's Chances of Breast Cancer Increases With Age	
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	1out of 8
Source: Feuer E.I. Wun I.M. DEVCAN: Probability of	

Source: Feuer, EJ, Wun LM. DEVCAN: Probability of Developing or Dying of Cancer. Version 4.0. Bethesda MD: National Cancer Institute. 1999.

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

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.)

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

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.

Overall Survival Rate		
After 5 years	85%	
After 10 years	71%	
After 15 years	57%	
After 20 years	52%	
Source: American Cancer Society		

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, conveyer 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 <u>not</u> 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

imagine making the trip right after surgery. I prefer a smaller, more "patient-friendly," easily accessed facility.

Mastectomy and Reconstruction

The bi-lateral mastectomy was performed on Monday, September 24, 2001. Tissue expanders were placed under the pectoral muscles. A tissue expander is a temporary device that enables the body to grow extra skin for use in reconstructing the breast permanently. Once in place, the expander is gradually filled with saline through a small valve placed under the skin near the armpit. This requires weekly visits to the surgeon. When the tissue has stretched sufficiently, the expander is removed and a permanent implant is then inserted beneath the chest muscle.

There are risks and complications associated with any surgery. In my case, because the initial lumpectomy took so much of the breast tissue, there was insufficient blood supply to the surgery site thereby causing infection, fever, hematoma, and tissue death. Roger monitored my condition closely. I learned that he is not a risk taker. Two weeks after the mastectomy, when he examined the tissue, he said, "No, this isn't going to work. I don't want to take any chances that the infection will spread. You'll need to go back into surgery; I've got to cut that dead tissue out." I'd already developed a fever.

Roger advised Peggy, the office administrator, that he needed an operating room the next day. He said it couldn't wait; it was an emergency. I sat by Peggy's desk as she pleaded with the O.R. staff who were obviously protesting the short notice. But she remained ever so patient in spite of their ill treatment of her. Peggy orchestrates the synergy of the practice-a practical extension of Roger's holistic treatment philosophy that values each patient as an individual. Peggy treats each patient as though he/she was the only patient.

Two weeks after the mastectomy, I found myself back in the hospital for another surgery-this time to remove the failed tissue. Recovery from that point on went quite well. I resumed my weekly visits for the saline injections. The appointments were brief in duration (15 minutes at most) wherein Roger would do a quick "systems check." "How's it going?" followed by a few "one-liners". He'd inject the anesthetic, then the saline, and the appointment was over. His relentlessly dry sense of humor would crack me up and I'd leave smiling.

Reconstruction is long and drawn out. At times, I felt as though it would never be over and I worried about the finished product. Each week I'd ask Roger the same questions: "Is it going to look okay? Am I ever going to look normal? Will I be happy with the results? His reply was never bland. He'd say something like: "You have no idea!" or "I'll settle for nothing less than ecstatic!" I trusted him and needed his reassurance. The questions were the same each week and so was the response. Reassurance from someone you trust is a source of hope when you're fearful about losing your femininity.

One day when I asked the inevitable question: "Roger, am I going to look good again? Is it going to be okay?" He finished applying the surgical tape, then looked up at me and said, quietly, "Beverly, you ask me that question every week." Just as quietly, I answered, "I need to hear the answer every week." He knew immediately what it was that I needed from him. No one else could give me that and, proud as I am, I found myself asking for it each week. There was never a long discussion. I called it, "Reassurance –in-a minute." (Sort of like a local news station's "sports-in-a-minute.")

Roger's sense of humor made the process a lot easier. I remember the first time he removed the surgical drains. (They had been in place for a month and were uncomfortable and awkward to maneuver with my clothing.) He held the tubes where they entered my chest in a "ready" position. When he signaled "Ready?" I asked, "Is this going to hurt?" He quipped, "Not me!," as he quickly and unceremoniously pulled them out. Roger never "talked down" to me or coddled me. I despise being treated like a fragile victim. We've been partners throughout this lengthy journey and I will always be grateful to him for the process as well as the final product. His work is superb even before the end result. The scars were healing quickly even a week after the surgeries. There has never been a question; I selected the very best surgeon.

By December 2001, Roger made the decision that the expanders weren't going to yield the results that we wanted. He recommended another procedure called the "Latissimus Dorsi Myocutaneous Flap Breast Reconstruction." We talked about it at length and he provided me with a 4-page written description of the procedure. I agreed with his assessment and set the surgery date for January 23, 2002. It was a 5-½ hour operation that required a 4-day hospital stay. Briefly, the latissimus dorsi muscles, located at the bottom of the shoulder blades, are transferred through a tunnel in the armpits to the chest area where they are used to reconstruct the breast. (This procedure replaces the skin that is removed during the mastectomy.) In my case, he would also use a small implant under the muscle. The result was two incisions placed transversely across the back, which were fading quickly even one month post-op. Healing and recovery were smooth aside from the normal discomforts surrounding such a procedure.

Breast Cancer and The Dance of Denial

In the beginning, I never said the word "Cancer." I would call it anything else, everything else—but never "cancer." In response to inquiries, I would insist that it was so early stage that it really wasn't cancer. I hung onto words like "borderline." Still, I would tell others that the 3 areas were the size of a "dot" made by a pencil on a piece of paper. I said, "If they were any smaller, they wouldn't be there." As my audience nodded in agreement, my anxiety would subside and my denial was once again placated.

The subject rarely came up during my visits with Roger. However, when I did make reference to it, I'd engage in my familiar "denial dance." During one particular visit, the subject of my breast cancer came up as I signed papers to participate in a research study for "breast cancer patients" who opted for "silicone/gel implants." In response to the question on the form, "When was your breast cancer diagnosed?," I looked at Roger and said, "But, Roger, I really didn't have breast cancer." He put down his pen, looked at me and stated quietly, but decisively, "Beverly, you did have breast cancer." I didn't answer him; I needed time to process his revelation-as though it was the first time I had heard it.

As I drove away, the impact of his words took hold and remained with me until I got home. I remember, I hung up my keys, dropped my bags and went straight to my medical dictionary. There, on pages 271 and 272 of Dorland's Illustrated Medical Dictionary was the proof: carcinoma: a malignant new growth made up of epithelial cells tending to infiltrate the surrounding tissues and give rise to metastases." Insitu: a neoplastic entity wherein the tumor cells are confined to the epithelium of origin, without invasion of the basement membrane..also called "cancer in situ" and "pre-invasive cancer." I lingered on the words: malignant, tending to infiltrate, metastases, and tumor.

The absurdity of my "denial" occurred to me as I realized that my medical insurance company had never so much as questioned any of the surgeries from mastectomy to reconstruction. They just continued to pay. That alone should have knocked me out of my fog. I heard myself laugh out loud at my self-deception.

Early on as friends and colleagues learned of my diagnosis, they sent videos and reading material about breast cancer. As well-intentioned as it was, it all remained in a pile on a shelf. At times, I was oblivious to it; at other times I was resentful and angry at it as though it was "lying in wait" for me.

It wasn't until two weeks after the reconstruction that I began reading about cancer. The internet proved to be a rich source of information from screening and diagnosis to treatment and reconstructive surgery. (The internet address I logged onto was imagines.com/breast health/statistics. asp) I bought several books on cancer to add to my trove of literature on trauma, grief and loss, survival, and resilience.

While we have many similarities as human beings, as an eclectic therapist, I have always believed that each of us is unique. That is how I approach my practice of therapy. In the words of famed psychotherapist, Milton H. Erikson, M.D., "I invent a new theory and a new approach for each individual." Many writers posit that all cancer patients and trauma survivors experience a series of stages and reactions that follow a particular pattern. I had never subscribed to those theories before my breast cancer and I certainly don't believe that now. While I believe that we share certain similarities, as human beings, I don't believe that we all respond the same way. My experiences are uniquely mine and my reactions are as well.

While it's natural to compare yourself to other breast cancer patients; remember, we're all different. What is comforting to one person may not be comforting to another. For instance, "support groups" are a great source of solace to some survivors. While other survivors may not be oriented towards the "group" experience.

The Dissociative Defense

Some survivors of adverse life events (myself one of them) employ a kind of cognitive-emotional prioritizing that result in a temporary compartmentalization of emotions. I believe it is a healthy, adaptive partnership wherein cognition takes primacy over affect so as to allow the individual to make important decisions regarding the crisis at hand. While some may consider this a "dissociative" response (in a negative sense), I believe that it follows the information-processing model of Louis Jolyon West (1967) who defined dissociation as "a psychophysiological process whereby information-incoming, stored, or outgoing-is actively deflected from integration with its usual or expected associations" (p. 890). (West, L.J. (1967). Dissociative reaction. In A.M. Freedman and H.I. Kaplan (Eds.), Comprehensive Textbook of Psychiatry, second edition. Baltimore, Williams and Wilkins.) Pgs.885-899.

This survival mechanism performs three major tasks, which serve adaptive functions:

- (1) Automotization of behavioral responses inspite of psychologically overwhelming material/life events;
- (2) Compartmentalization of affect;
- (3) A distancing from the enormity of the event on the sense of "self." (Extrapolated from Putnam pgs. 59-75)

Whether the reader believes in a dissociative continuum or dissociative types (the latter of which was the formulation of Pierre Janet), it is a debate that continues on to this day. Janet (1901) postulated that dissociation was an unconscious defensive psychological function that reduces anxiety and psychic conflict. In modern times, however, Ludwig (1983) revised Janet's theory by proposing that "dissociation serves adaptive and defensive purposes." (Putnam, pgs. 67,68, 71, 75, 76.) Subscribing to the dissociative continuum school of thought, this method of defense becomes problematic only in as much as it impairs an individual socially, personally, or occupationally.

As I looked back at my life, I realized that I have utilized this cognitive-emotional prioritizing in response to crisis. In effect, I instinctively "handle" the emergency first as a function of my "cognitive" self. When the crisis stage has passed, I assess and process the event emotionally-although not all at once. For example, after my fourth surgery, the reconstruction, I began the process of "reflection" whereby I studied the emotional impact of my breast cancer and experienced the feelings of "loss." Although I felt sad, it did not interfere with my ability to appreciate how my cancer had affected my worldview. While psychological theories are wonderful things, they do not keep the facts from emerging. The fact is, human beings are quite competent at survival even though they are unaware of the theories that dictate behavior. Attempts at postulating discrete stages in the human experience do us little good and may even cause harm to some. As a matter of fact, our species existed long before the psychological theories that explain our existence.

The impact of any crisis can vary substantially from one person to another. For me, breast cancer was and is "a bump in the road." We give the crisis its complexion. Our subjective appraisal of an event determines how distressing the event turns out to be. In the words of poet Percy Bysshe Shelley: "Grief is a matter of relativity; the sorrow should be estimated by its proportion to the sorrower; a gash is as painful to one as an amputation is to another."

Unfortunately, psychology has focused its study on human pathology, not human resilience. Noted Psychologist and author Norman Garmezy wrote, "We have directed our energies to the study of patterns of maladaptation and incompetence. Our mental health practitioners and researchers are predisposed by interest, investment, and training in seeing deviance, psychopathology, and weakness wherever they look. Psychology has ignored the countless numbers of survivors who not only endure, but triumph over life's most crushing blows. The assumptions that victims will be relugated to a life of anxiety, irritability and depression paints a cloudy picture of man's capacity to overcome incredible odds. What separates the survivors and thrivers from the casualties?"

"Blessed is she who overcometh; not she who walloweth in it."

Beverly Anderson

Breast Cancer and Sexuality

"In American society, the female breasts have a special erotic allure and symbolize sexuality, femininity, and attractiveness. Prominent attention is devoted to the breasts in clothing styles, men's magazines, advertising, television, and cinema. As the bigbreasted female has become an almost universal sex symbol – the image used to promote everything from car sales to X-rated films – men and women have been bombarded on a daily basis with the not very subtle suggestion that a woman with large breasts has a definite sexual advantage." (Masters & Johnson on Sex and Human Loving, 1988, pgs. 39 &40)

It is this fascination with the female breasts that have led thousands of women to seek to improve their attractiveness by falling prey to the claims of advertisements for products that will enlarge their breasts. Even today infomercials taut the effectiveness of a pill that will increase breast size and self-esteem. Ultimately, many women opt for breast augmentation surgery to acquire larger breasts and an enhanced self-image.

A diagnosis of "breast cancer" will undoubtedly bring about emotional changes. For the woman faced with mastectomy and reconstruction (maybe chemotherapy and/or radiation), the stressors are both generalized and specific. During the weeks or months before surgery she maybe faced with enormous concerns related to body image and self-esteem. The accompanying fears and anxieties are not conducive to the pursuit of erotic matters. Moreover, the lengthy recuperation periods between surgeries are marked with physical pain, discomfort, embarrassment, and uncertainty. Chronic fatigue during the recovery is also not uncommon as well as feelings of unattractiveness after she loses her breasts. Even a hysterectomy does not affect one's outward appearance.

The amount of support on the part of a woman's partner plays a vital role in reestablishing a comfortable sex life after mastectomy and reconstruction. A woman's precancer self-image and self-esteem are also important determinants in her recovery.

For me, breast size had never been a concern since I had been a D+ cup since puberty. In fact, I took special care to select clothing that minimized my breast size because fitted clothing would bring unwanted attention. Nonetheless, the thought of losing my breasts did not appeal to me either. I was especially disappointed to learn that my nipples and areolas would be amputated along with my breasts. (Yes, amputated.) However, the alternative-living in constant fear that cancer was growing inside of me-made the decision easier. While I knew that my reconstructed breasts would never compare to my natural breasts, I began to think of the positives besides living "cancer-free." I could buy clothing that I'd never dreamed of wearing. Since reconstructed breasts don't sag, I reasoned I wouldn't have to consider "breast lift" surgery sometime in the future. Having a sense of humor helped me a lot; although some people were a bit put off by it. I had to remind myself that this cancer was "about me," not anyone else and I was determined to

say and do the things that were helpful to me. Everyone else would just have to "deal with it."

For instance, while I was being prepared for the "reconstructive surgery" in January 2002, I gave the following cartoon to Dr. Friedman. He loved it!

(Humor is a wonderful aid to healing as long as it's not carried to an extreme.) Goofy, slapstick comedy is a real favorite of mine. I treated myself to comedy television and avoided movies, books, and television whose content was tragic. My cancer and the real-life tragedies of my clients were enough for me to handle.

Thank God for my family, friends and clients who were such good sports. One day after the mastectomy I called my sister Sheila who had been keeping up with my progress almost daily. "Sheila," I said, "I really need to get something off my chest." With deep concern in her voice, she queried me: "What is it, Bev?" I retorted with a howl, "Oh my God. I forgot. I don't have a chest!" My poor sister was horrified. "Bev," she pleaded solicitously, "That's sick. I can't believe you said that." All I could do was laugh and laugh. Laughter is good medicine. It has a wonderful effect on body chemistry.

I am a very happy person by nature and I tend not to dwell on sadness. However, I seek to control what I <u>can</u> control. For those things that I cannot control, I find ways to make myself feel better. For instance, there were four months following the mastectomy when I was flat-chested. Looking at my profile in the mirror was a real shock that even <u>I</u> was not prepared for. It took a while for me not to do a "double take" when I caught a glimpse of myself as I passed by a mirror or store window. My efforts to purchase thick, padded bras were fruitless because the mastectomy sites were too painful to withstand the pressure. After countless tries and lots of money, I resigned myself to wearing bulky sweaters until well after the reconstruction.

In summary, my breasts have never dictated my sexuality. Therefore, the impact of my breast cancer has not altered who I am as a woman or my self-esteem. My sexuality is an important part of who I I am; but it's not all that I am. However, I became a "frequent buyer" at "Victoria's Secret," a chain of well known lingerie shops. They have an endless array of fitted camisoles to wear under pajamas or shirts. I bought pretty lounging wear that made me feel "trendy;" whereas, before my surgeries, I'd wear sweat pants. So, while I couldn't have complete control, I found a way to compensate for my distressed circumstances.

My breast cancer taught me many things, not the least of which was "patience." Learning to "let go" and trust the process was another important lesson. Healing is not an event. Healing is a journey with many stops along the way. Some stops are for replenishment; other stops are for repairs.

Lessons in Surviving & Thriving

"Life is filled with experiences that push our repertoire of thinking, feeling, and behaving. We are expected to learn and grow from the events that initiate our coping responses, with the implication that coping is part of the very essence of the human change process. Thus, coping is not only basic for survival, but it also relates to the quality and the ensuing constructive meaning of our own lives. Indeed, a fulfilling life is a tale about coping that works and works well.

Snyder, C.R. & Dinoff, Beth L., <u>Coping: The Psychology of What Works,</u> Coping: Where Have You Been? Oxford University Press, New York, 1999, pg. 5

If you are to survive this process in a meaningful way; that is, to move beyond your cancer on to the next stage in your life, it is absolutely imperative that you take charge of your illness, your treatment, and your recovery. In order for you to do this successfully, you will need to embrace this task as you would embrace any challenge.

The following is a list of suggestions to help you through your recovery. Some of them may require that you change your way of thinking. You might be surprised by how resilient and adaptable you really are!

1. "Attitude" is everything. You become that which you think about most. By your thoughts and words, <u>you</u> are creating your life. If you see yourself as a victim, you'll be one. Subsequently, your body will secrete "fear" hormones that may hinder your healing and recovery. Negative emotions can lead to frustration, fear, anger and depression. This creates negative responses in the body and may drain your coping resources. Positive expectations lead to "action-oriented" behaviors that increase the probability of a positive outcome. Moreover, many researchers believe that a hopeful

attitude may lead to physical changes in the body that improve its immune system.

- 2. **Be about "action."** Take charge of your medical care and take responsibility for your healing. Are you a fighter or do you give up with the least little bit of resistance? Fighting to live <u>is</u> living. Remember, <u>you</u> are the most important factor in your healing, not your doctors. Find the best medical care. Research the newest possible treatment options. Share the healing task with your doctor. Above all, make a commitment to "do" it. I decided to fight and took my best shot.
- 3. Hope is the thing with feathers
 That perches in the soul,
 And sings the tune without the words,
 And never stops at all.

Emily Dickinson

"Hope" is number "one." Develop the belief that we are never given a task that we can't handle. Everything you need is there; just go for it. Learn from other survivors. Realize that you have the disease; it doesn't have you. You will maximize a positive outcome by getting the most skilled, learned physician, by maintaining a strong will to live, and by recognizing all the things you have to live for. I decided that I had too many things to do in my life to entertain the idea of a "life threatening" disease taking over. Focus on your strengths and abilities, not on your vulnerabilities. Set goals regarding the good things that will result from overcoming one of life's toughest battles. Ask yourself, "What positive result can I make out of this adversity?" With that belief, you'll find something good.

When life gives you lemons, make lemonade. Remember life is a "do-it-to-yourself" program. Embrace each day and live in the moment. Don't waste precious time worrying about the past or obsessing about the future. Yesterday's a "canceled" check; learn from it-don't dwell on it. The only "sure thing" we have is "today." Don't dwell on "why" this has happened to you; it's an exercise in futility. Instead, focus your energies on healing and recovery.

4. Rely on your support system throughout the process from diagnosis to recovery. It is a well-established fact that people who have a strong support network recover better than those who do not. The benefits of social support can be practical and material as well as emotional. Practical and material support can take several forms but is essentially made up of direct help with everyday affairs in the aftermath of surgery and between treatments. The drain of surgery followed by the need for the body to heal itself and mobilize its defenses against infection is enormous, to say the least. Household chores, concerns about childcare, and other daily tasks can be overwhelming to a person whose resources are depleted from surgery. Make certain you have someone who can take charge of your medication schedule. If you are taking pain medication, chances are that your memory will be affected. Monitoring my own medication after the mastectomy met with disastrous results. I often couldn't remember what pill I had taken and after I finished the antibiotic, I failed to read on the bottle that two refills had been prescribed. Subsequently, I developed an

infection.

Allow yourself to lean on others for the help you need. Healing and recovery should be your only job after surgery. I find that women are entirely too proud when it comes to accepting help. The "superwoman complex" has no place in the healing process. My need for self-sufficiency and control really impeded the healing process. Accept the fact that after a mastectomy, the body needs to be immobile, especially with respect to the drains that are placed near the surgical sites. I discovered the hard way that "activity" increases the fluid build-up, which means that the drains must stay in place longer. They're uncomfortable and cumbersome. The doctor's instructions were: "Limit your activity." This was not specific enough for me, so allow me to translate what this means: **Don't** do laundry; **don't** cook; **don't** vacuum; **don't** dust furniture. In short, **don't** do anything but rest. Practical help can also take the form of friends and family running errands and bringing meals.

Social support includes emotional support both direct and indirect. Surrounding oneself with friends and family can really improve one's emotional state. Feeling cared for and comforted by loved ones is healing in itself. My daughter, Cortney and 16 month old grandson, Nathan, came to stay with me after the reconstructive surgery in January. Inspite of the fact that the surgery was longer than the mastectomy and involved several incisions, their presence made it seem so much less painful. Cortney took charge of the house and me. Little Nathan was a continuous source of joy and comfort. Just the words, "Hi, Mimi," were enough to make me smile. A positive mindset and positive emotions go a long way in the healing and recovery cycle.

- 5. **Respect the enormity of what has happened to you.** It's okay to cry. It's okay to be afraid. It's natural to experience a whole range of emotions-that's the essence of the human experience. Reach out to your support system and talk about your feelings. That's why it's called the "talking cure."
- 6. **Decide that something good will come out of this adversity.** No matter what setbacks may occur, and I experienced several, find a reason why it's good. For instance, two weeks after the mastectomy, a large patch of tissue on my right breast and a smaller patch on my left breast became necrotic, which required another surgery to remove the dead skin. This meant that I would need to undergo a third surgery to transplant new skin to the area. The "latismus dorsi mycutanues flap" is a 5-hour procedure whereby a section of skin, muscle, and fat is transplanted from the back to the chest area. What could possibly be good about this? I discovered that the extra role of skin directly above my waistline and below my shoulderblades would be removed along with the muscle. That was definitely a good thing!
- 7. **Cultivate persistence and perseverance.** There were times during the recuperation when looking at the long-range future was impossible. I focused my energy on getting through just the smallest increment of time-sometimes five minutes seemed like forever. But I refused to let it overcome me. Instead, I would reach out to someone and there was always someone around when I was in need. Psychologist James Pennebaker's study of more than 2000 people who had suffered trauma revealed that those who did not discuss their experiences developed more illnesses of

various sorts. Survivors were healthier when they confided in someone about the event. People who keep their anguish to themselves tend to develop more symptoms and suffer more pain than those who share their feelings. His research coincided with other studies that the potential physical damage of internal stress can be mitigated simply by unburdening oneself of pent-up fears and anxieties.

Dr. David McClelland, a Harvard University psychologist, discovered that people in crisis who keep their feelings to themselves tend to release hormones that lower their bodies' immune system's resistance to disease. Hebew University psychiatrist Gerald Caplan found that when stress is high, people without emotional support suffer as much as ten times the incidence of physical and psychological problems experienced by those who have a support system. People facing a major life crisis do much better with the benefit of human contact and human involvement. Strong family support is a critical factor in healing and recovery. (Winning Life's Toughest Battles; Roots of Human Resilience, Dr. Julius Segal, McGraw-Hill Book Company, N.Y., 1986, pgs. 18,19.)

This was no surprise to me since I hear it from my clients almost daily. They tell me that after talking about their problems, they feel as though a great burden has been lifted off their shoulders. "Coping with life becomes so much easier," they say.

8. "Who, then, can so softly bind up the wound of another as he who has felt the same wound himself?"

Thomas Jefferson

Help others. To survive meaningfully, we must move beyond our own pain and minister to the pain of others. If we turn inward, consumed with our illness, we risk becoming professional victims. Helping others is actually the best thing we can do to help ourselves. Reach out to other breast cancer survivors. Communicating with fellow survivors helps us to recognize that others who have similar problems have managed to survive. Discovering that we are not unique in our suffering is a source of comfort. There is "hope" when we find others who are thriving after adversity. I've learned this from police officers who have been involved in deadly shootings and from parents who have experienced the loss of a child. They learned from communicating with other survivors that their reactions are natural responses to catastrophic life events. By reaching out to others rather than isolating and withdrawing into ourselves, we are actually "doing" something to control our fate. It is this sense of personal control that will enable us to overcome life's greatest adversities.

9. Share your story

"For reasons we are just beginning to understand, sharing one's story through writing promotes good physical and mental health."

Joshua M. Smyth & James W. Pennebaker

In "Coping: The Psychology of What Works," Smyth and Pennebaker offer two major treatment approaches, relaxation techniques and "talk" therapies, as having

proven beneficial effects on health. Relaxation techniques encompass hypnosis, biofeedback, meditation, yoga, and relaxation training. Consistent use of these modalities enhances mood, assists in the body's immune defense, and improves physical health.

Translating emotions into words brings about remarkable results. "Journaling" (putting one's thoughts and deep emotions into writing) has emerged as a powerful therapeutic tool.

In the past ten years, more than two dozen studies from laboratories around the world have confirmed the findings that subjects who wrote about their traumas and stresses drastically reduced their doctors visits and enjoyed improvements in overall health.

To evaluate the effects of writing, researchers assessed the subject's quality of life through the following measures:

- (a) health reports and visits to health care providers;
- (b) mood and well-being measures;
- (c) employment and academic functioning;
- (d) immunological outcomes; and
- (e) short-term effects (i.e. pre-post-writing changes)

Whether subjects were asked to write about current stressors or past traumas, the beneficial effects were similar even six months after the study. Pennebaker, Kiecolt-Glaser, and Glasser conducted studies examining the effects of written disclosure on the immune system. The results showed improved immune function and improved liver enzyme function. Long-term benefits in mood was also found in subjects who wrote about their traumas. The value of writing about traumatic events has been studied in groups of differing educational levels, in various languages and multiple cultures. In the U.S., the writing technique has produced similar beneficial effects for advanced degreed professionals and maximum-security prisoners with little education. Moreover, the writing technique has consistently produced positive results among French-speaking Belgians, Spanish-speaking residents of Mexico City, multiple samples of adults and students in The Netherlands, and medical students in New Zealand.

However, in patients suffering from severe depression and posttraumatic stress disorder, the benefits of writing may not be realized, especially in the absence of therapy. Moreover, the use of written disclosure in other "at-risk" or psychiatric patients should not be done without caution.

Several investigators have begun to use this technique with individuals suffering with chronic illness. Lumley and colleagues found that their subjects suffered less depression and enjoyed improved physical function than subjects who wrote about neutral topics. These experimental results have also been replicated in studies of patients with rheumatoid arthritis and asthma.

I found the writing technique to be particularly useful in my recovery and recommend the following guidelines developed by Smyth and Pennebaker:

- 1. Find a quiet location where you will not be disturbed by the phone or other noises.
- 2. Allow 30-40 keep minutes each day for writing. Leave the last ten minutes or so for reading what you have written. Don't be surprised by your emotions.
- 3. Write for three or four days (consecutively, if you can.)
- 4. Explore your deepest thoughts and feelings about your cancer, and what it means to you.
- 5. Relate your battle with cancer to other experiences in your life, your childhood, your relationships, who you are, who you would like to be, people you have known who have gotten cancer, plans you have for the future.
- 6. Write continuously without regard for spelling, grammar, or punctuation.
- 7. Remember, the writing is for you, not anyone else.
- 8. Explore both the positives and negatives of your cancer experience.
- 9. Integrate your thoughts and feelings into a narrative as opposed to simply reporting the facts.
- 10. Tell your doctor or therapist that you are interested in this technique and report back to them if you've found it helpful. I found the writing technique most helpful after my surgeries during recuperation.

10. **Build a Resilient Lifestyle**

The recipe for a "resilient" personality is described by Frederich Flach, M.D. in his 1988 book entitled: *Resilience: Discovering A New Strength at Times of Stress.* He found that resilient people were "emotional-friendly." That is, they were not afraid to cry, to express anger, or to share their fears and hopes. Dr. Flach identified the attributes of creative people who were particularly resilient in the face of adversity. They include:

- A strong sense of self-esteem
- Independence of thought and action
- The ability to give and take in one's interactions with personal friends, including one or more who serve as confidants
- A high level of personal discipline and a sense of responsibility
- Recognition and development of one's special gifts and talents
- Open-mindedness and receptivity to new ideas
- A willingness to dream
- A wide range of interests
- A keen sense of humor
- Insight into one's own feelings and those of others, and the ability to communicate these in an appropriate manner
- A high tolerance of distress

Focus, a commitment to life and a philosophical framework within which personal
experiences can be interpreted with meaning and hope, even at life's seemingly most
hopeless moments.

While this is a wonderful list of traits, I know few people who meet all the requirements for resilience. Nonetheless, all of us possess some of these qualities in greater or lesser degrees. We have the ability to strengthen our resilient qualities even during periods of stress. The key to resiliency is balance and flexibility. (I had no time in my busy schedule for countless doctor's visits after my diagnosis. However, I soon learned how flexible my time could be and managed to balance both my client schedule and my medical appointments.)

Epilogue

My triumph over breast cancer has brought many gifts. Countless survivors have reported how their lives were changed for the better. They live at a higher level and enjoy life more than ever. They no longer get bogged down by the small things that used to upset them.

Having cancer was an important part of my life. Surviving cancer was an "event." In the words of authors Glenna Halvorson-Boyd and Lisa K. Hunter (both cancer survivors), "I tried to make my survival a nonevent. Surviving cancer is a big deal: a big, wonderful, horrible, important, mundane, crazy, sad, and joyous long-running event. ...forgetting the truth of survival has a terrible cost: all of us lose our connection to who we are and how we feel."

From the very beginning, I knew inherently that my personal battle with cancer would change my life-and it has. It has fortified my belief in people and in myself. It has validated the stubborn optimism I have developed throughout my life. But, most of all, it has enabled me to relate to other victims and other survivors at a whole new level that I'd never known. Although I wouldn't have chosen to have breast cancer, I'm grateful for the human connection of empathy that it has given me. Thank you for sharing in my story. Let me leave you with thoughts about the indomitable human spirit by A. Powell Davies, a Unitarian minister:

"There is a light within each of us that need never entirely go out. We can lose the battles, but not the war. We can go on when our minds tell us that there is no point in going on-because something deep inside tells us we can go on. And we do."

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<u>Medical Questions & Answers- (Dr. Roger Friedman will answer these questions sometime in the near future)</u>

Roger J. Friedman, M.D., P.C.
Aesthetic, Plastic and Reconstructive Surgery
Microvascular Surgery
Laser Surgery

- 1. What is the average length of time from mastectomy to the end of breast reconstruction?
- 2. What types of reconstruction are available? What type of reconstruction is best for me?
- 3. What realistic results can I expect from reconstruction?
- 4. Will the reconstructed breast match my remaining breast? Will it feel like a natural breast?
- 5. Will I have any feeling in my reconstructed breast?
- 6. What complications are possible? Are there any risk factors I should know about?
- 7. Will I need a blood transfusion? What should I do to prepare for my surgery?
- 8. How long is the average recovery time? Will I be in a lot of pain? What can I do to aide the healing process?
- 9. When can I begin an exercise program? When can I return to work?
- 10. How long should I wait to resume sexual activity? Are there precautions I should take with the reconstructed breasts?
- 11. Will the reconstruction interfere with chemotherapy or radiation treatments?
- 12. How long will the implant last and what kind of changes can I expect over time with aging?
- 13. Will fluctuations in my weight affect my reconstructed breast?