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**AMAZONIAN WOMEN:
A MULTI-VOICED NARRATIVE ON SURVIVING BREAST CANCER**

by

Melissa Bowles

Thesis submitted in partial fulfillment
of the requirements for the degree

of

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Introduction: Why I Am Worried About Breasts

When my mother was diagnosed with breast cancer in May of 2003, I immediately turned to journal writing and to reading to try and make sense of what was happening in my family. I searched websites for causes of breast cancer and ways to prevent it, I read literary women's memoirs, and I wrote a great deal about the way that I was feeling: scared, guilty, angry, broken. As a reader and a writer I needed to somehow intellectualize all of the things I was feeling. This writing project is a product of that initial response and of my subsequent research and experience.

This text first addresses the ways in which traditional breast cancer treatments and the medical system fail women. Breast cancer has affected women for millennia. One of the earliest medical texts ever discovered describes a female suffering from a growth on her breast that eventually killed her. The document is dated to the Egyptian Pyramid Age—between 3000 and 2500 BC (Kasper 28). In the ensuing 5,000 years, with the growing numbers of breast cancer patients, breast cancer has finally become visible to the public and it has also become more curable. There are more than two million breast cancer survivors in the United States today (National Breast Cancer Foundation). But science and medicine could still do more to prevent breast cancer by addressing societal issues such as pollution, radiation, and food quality.

Next, the paper addresses some feminist health care issues recently brought to light by Dr. Susan Love and other feminist health care activists—specifically the symbolism of breasts and the ways that breast cancer affects women as women. The emphasis that American society places on breasts as sexual objects leads many women to subject themselves to dangerous breast reconstruction surgeries following mastectomy. This is another problem that needs to be addressed at a societal level instead of as a personal problem. If we were to value women outside

of their sexuality or appearance, perhaps breast cancer survivors would not risk their already fragile health to rebuild breasts. Many feminist breast cancer activists take on the role of women warriors, fighting with their words to separate the loss of a breast from the perceived loss of femininity and loss of sexuality that are associated with breast cancer. A breast is, after all, just a breast. It does not contain a woman's sexuality and her sexual value or femininity cannot be lost with a mastectomy.

The third and perhaps most personal section of the paper is at work to create a place for daughters in the fight against breast cancer. As the daughter of a breast cancer survivor, I am especially interested in the difficult space that women like me occupy. Studies done among the daughters of breast cancer patients show dangerous levels of guilt, depression, and anxiety in women whose mothers have had breast cancer. I use my journal entries to illustrate some of those negative feelings and the way that writing helped me to work through them during my mother's illness and treatments. I also address breast cancer as a hereditary disease. This is a major concern for me because my great-grandmother, grandmother, and mother have all had breast cancer. I initially felt doomed to follow in their footsteps and started separating myself from my breasts, with the idea that I was bound to be *literally* separated from them eventually. Luckily, my mother does not carry the BRCA1 or 2 gene mutation that would give me an 80% chance of having breast cancer someday. My risk hovers around 30%, which is psychologically much more manageable.

The paper finally addresses writing as a way of healing, citing research from experts on the subject and using my journal entries to show the healing effects of writing. I focus on three main reasons for writing to heal: personal healing, creating a healing community, and writing to

restore wholeness to a wounded or ill person's body and mind. I close the paper with a series of journal entries that represent my journey from a wounded person to a more whole person.

This paper, as a whole, illustrates my argument that writing can heal survivors. From the beginning to the end, it marks the work of a survivor. It healed me.

I. Breast Cancer Treatment (Or Ways in Which the Medical Establishment Fails Women)

In the 1890s Dr. William Stewart Halsted "perfected" the procedure that he had been practicing on indigent women in charity hospitals. Halsted became known as the father of the radical mastectomy, which was the "gold standard" of treatment for breast cancer patients for the next seventy-five years (Leopold 51). By removing all breast tissue, surrounding skin, pectoral muscles, and axillary lymph nodes, Halsted saved 12% of his patients. One of the first-ever post-surgery surveys revealed that only a handful of mastectomy patients lived for ten years after their surgery. Most were bent over and crippled for life from the loss of their pectoral muscles (56). So why was the procedure hailed as a "cure"? For years doctors had been unable to offer any kind of treatment for breast cancer, aside from salves to apply to the affected region, which usually proved completely ineffective. The surgery was a positive action to be taken against an aggressive disease that saved some lives that would have otherwise been lost. Unfortunately, it failed to save many and disfigured most.

Another troubling aspect of the radical mastectomy was the change that it brought about in doctor/patient relations. The prevalence of a surgical "cure" placed predominantly male doctors and their female patients in a grossly inequitable relationship. The surgeon played the role of "conquering hero" while the female patient lay inert and helpless under anesthesia—completely under his control (61). This relationship reflects stereotypical male and female roles,

with males as aggressive “hero” figures and females as victims. Not surprisingly, Halsted is viewed as a brilliant example of a surgeon and glorified for his triumphs over a dangerous (female) disease. His patients, however, knew him as a cold, harsh man with a terrible bedside manner. He was addicted to cocaine and often behaved irrationally in his private life (59). Not exactly a heroic figure, he was disliked and feared by most of his patients. But without any other options, women with breast cancer turned to his “radical” new cure.

Today, mastectomy is still the most widely used form of treatment for breast cancer. The prevalence of surgery serves to turn attention away from prevention with its focus on detection and subsequent treatments. Dr. Susan Ferguson writes in the book Breast Cancer: Society Shapes an Epidemic that “as more of human experience becomes medicalized . . . physicians enjoy increased control over people’s lives” (51). The inequality between physician and patient marks gender and class inequality and often keeps the female patient silent and ignorant of any alternatives to surgery.

December 22, 2003

I told Mom that she must be glad that she’s a nurse so that she can understand all of the treatments and the procedures that they are doing to her. When I watched her in the hospital immediately following her mastectomy I was amazed at her assertiveness, telling the nurse’s aide what to do, what she wanted, and exactly how to treat her. She told me that she is glad that she has the requisite knowledge. When she saw her mother go through the same thing, Grandma was much more hesitant, scared, and upset. Most of us have no idea what doctors and nurses are talking about. And they use that to infantilize patients. It’s not fair.

Visiting my mother in the hospital after her mastectomy frightened me—not for her so much as for myself. When I was in junior high I often walked over to the hospital in Preston and met her at her office for a ride home. Sometimes I had to wait awhile before she was ready to go. I loved the smell of the hospital. It was so clean and antiseptic smelling. It smelled like Mom's work clothes. But visiting her as a patient was another story altogether. She had so many machines surrounding her and tubes entering her body. It was reassuring, once we started talking, to hear her page the nurse's aide and ask for a new IV. And then she directed the girl as to how to insert it. *That* was the mother I knew. Not the "patient" lying in the bed at the mercy of a surgeon and his staff, but the "director" and "teacher" with agency and power. Although many women who enter the medical system as patients are hushed and diminutive, my mother was not going to be one of those. I fear for myself, however. Although I have no trouble being assertive, I don't know anything about medicine or hospital practices. If I find myself in the patient position some day, I will need my mother there to tell the nurses and doctors what to do. I need her strength and expertise, just like my grandmother did. I need her to be there.

The usual treatment for breast cancer is brutal. Dr. Susan Love describes the treatment regime of mastectomy, radiation and chemotherapy as "slash, burn, then poison" (356). The usually lengthy treatment plan can rob a woman of her most identifiably feminine characteristics. Mastectomy takes a breast, or sometimes both breasts. Radiation is almost always a daily treatment and takes a woman away from her family and may make her too tired to fill her accustomed roles. Chemotherapy often takes a woman's hair and also her health. All of the treatments are extremely harsh and take a great toll on the body. But most people, when faced

with life-threatening disease, choose anything that will lengthen the lifespan. Most will offer up their whole selves to finding a treatment that will cause the spread of cancer to abate.

The poison of chemotherapy is especially physically taxing. There are many different chemotherapy treatment plans that oncologists give to their patients. And every patient reacts differently. Some are constantly nauseated. Some lose their hair. Some lose their appetites while others gain weight. Juliet Wittman expresses her chagrin at all of the cancer treatments following surgery: "It's astonishing, once you've fallen into the land of the sick, the odd, offhandedly insulting things they can do to you" (210). Illness can sometimes have a kind of dignity, but it can also embarrass a patient with the way it renders the body weaker and more helpless.

Regardless of the treatments offered and the immediate results of those treatments, medical professionals are very hesitant to say that cancer is "cured." A bone scan may be "clean" and a patient may be in "remission," but there is no such thing as completely "cured" as the medical establishment sees it. Once a woman has had breast cancer the chances for a recurrence are high: anywhere from 30-70%. This isn't to say that the situation is hopeless. Many women survive mastectomy, chemotherapy, radiation, and other treatments and live well into old age without another hint of breast cancer. But approximately 40,000 women in the U.S. die of breast cancer every year (National BC Foundation).

June 30, 2003

Mom's hair has started to fall out after just two weeks of chemotherapy. It will probably be gone by the end of the week. It's distressing for me to think about. I can't imagine what it's like for her. To brush your hair and find great chunks of it left behind, to leave the shower drain

full of hair—it makes me shiver. This poison that they are shooting into my mom's veins is heinous stuff.

Chemotherapy was the most difficult part of my mother's treatment to watch. She was violently ill every week on the day after the poison was shot into her body. She spent those Wednesdays "hibernating" in her parents' basement trying to sleep or listen to music or just somehow escape the reality of her illness. An infection control specialist by occupation, she was extremely concerned that her immune system would fail her. She had her cat vaccinated and dewormed. She took vitamins and supplements to boost her white cell count. And somehow she got through it. The first time I saw her without her hair she was wearing a red, white, and blue bandanna on her head. It was the 4th of July. I was shocked, but tried hard not to show my dismay. It was worse when I saw her head without the scarf. I can't imagine how she truly felt about the whole thing. In retrospect, she told me that she was far too sick to care much about what she looked like. At Christmas time, when her treatment was all over and I was shopping with my dad for some new clothes for her as Christmas gifts, he wanted to find something very feminine. He said, with something glistening in his eyes, that she was beginning to feel well enough to be concerned about her appearance. She longed for a restored sense of beauty and femininity to go along with her returning health.

Cancer, in general, is difficult to understand. The medical establishment doesn't even claim to understand it. New causes or remedies appear in print weekly. Only a few things are sure. Cancer happens when a natural process—cell division—becomes abnormal. Why? There are too many possible causes to name. And there are many causes that may not have been discovered yet. A high fat diet, alcohol consumption, using oral contraceptives, age at menarche,

age at menopause, age at children's births, fertility drugs, breast feeding, radiation exposure, pollution, and genetics, are just a few of the known contributing causes of breast cancer (Kelly 136). And although numerous things are known to "contribute" to the onset of breast cancer, there is no way to pinpoint exactly why any particular woman may be afflicted with the disease. However, in a search for some rational explanation, women often try to find a reason. Often the shock of learning that she has cancer causes a woman to review her life, wondering what it was that she did wrong in order to bring this curse on herself. Too often, she blames herself for the disease.

Wittman wonders in this excerpt from her book Breast Cancer Journal: A Century of Petals what she might have done to create breast cancer in herself. At different points in her journal she blames herself for the disease—a common trope among breast cancer patients:

I had been running the risk factors for breast cancer over and over in my mind through the night. I had had my first child late. Bad. But perhaps a little better than never having had a child at all. I had nursed Anna for a long time. Good. Perhaps. My first menstruation had been neither particularly early nor particularly late. Late would have been best. I was perhaps a smidgen overweight—and the weight was concentrated in my midsection rather than on my buttocks or thighs. Bad. Were my breasts particularly dense—another negative? I had no idea (9).

This focus on the self and finding a way to explain the disease by analyzing one's own behavior can be extremely dangerous for women. Often, the messages that women receive from both the medical establishment and from popular media about breast cancer place the responsibility directly on their own shoulders for their disease. In a study of breast cancer in popular women's magazines from 1913-1996, the researchers found no mention of the social, environmental, political, or economic issues that inform the causes of breast cancer. Instead, the articles focused exclusively on personal fault as the cause of breast cancer (Kasper 304). With

breast cancer fast becoming a national epidemic, perhaps it should be addressed as the social issue that it is instead of merely a personal problem.

Many of the actual causes of breast cancer are societal. Janette Sherman, M.D. lists four basic categories for breast cancer causes in her book Life's Delicate Balance. The four categories are: chemical carcinogens, ionization radiation, endocrine disrupters, and genetic interactions. Of those four, "genetic interactions" is the only one that is not preventable by changing the way we care for the earth. And, Dr. Sherman adds, only 5-10% of all breast cancers are truly genetic (13). Sherman places blame for the breast cancer epidemic on synthetic estrogens found in plastics, food treatments (like pesticides and growth treatments), and in certain drugs such as antidepressants and antihistamines (15). She says, "If we consider that the 'traditional' risk factors [age at menarche, menopause, childbirth, etc.] account for perhaps 30% of breast cancers, we are left with the fact that more than 70% of women who develop breast cancer have none of the 'traditional' risk factors linked to breast cancer 'risk.' When we understand this, we can stop blaming women" (26). Instead of blaming victims for having breast cancer, perhaps we should address the actual causes of breast cancer that can easily affect us all. It is time to stop blaming women for their disease.

Breast cancer, a woman's disease, is perhaps the only disease where a patient is made to feel culpable for her own disease in a general, non-specific way. Lung cancer patients may be able to target a specific behavior that has caused their disease. Liver cancer patients may as well. But breast cancer patients are blamed and then left to figure out on their own what they might have done to make themselves ill. One public health announcement circulated in the 1950s urged women to conduct breast self-examinations with the legend, "'Cancer' is written on many a death certificate when 'suicide' would be far nearer the truth" (Leopold 172). Women are

charged with detecting breast cancer in themselves. If they fail to catch it early in its development, their health and their families' well-being is in great danger. Women who conduct monthly self-examinations and have yearly mammograms are praised for caring for their health and preserving their lives and a sense of normalcy for their husbands and children. Women diagnosed with breast cancer may not be explicitly told that they have failed, but they often feel that way. The emphasis on early detection and breast self-examination rather than on prevention shifts the burden of guilt from the physician to the patient herself (176).

May 17, 2003

Mom is so healthy. She may be 43, but she looks much younger. She has done everything right: early childbearing, nursing four children, healthy diet, regular exercise, no alcohol intake, healthy weight, late menarche. How could she have breast cancer? She keeps asking herself these questions. I don't know if she'll ever find an answer.

It was difficult for me to see my own mother engaging in the "victim blaming" that I was beginning to read about in my research for this project. She was certain that by pushing herself too hard and trying to do too much she had worn her body out and allowed the disease in. Her hair dresser, Tamara, has had breast cancer twice—once in her early forties and then again in her early sixties. In a conversation that Tamara and Mom had, Tamara expressed her own feelings of responsibility for her disease. Stress, she said, was as bad for the body as smoking cigarettes and equally deadly. I tended to blame my mother's disease on faulty genes, but she often blamed herself. Once diagnosed, she let a lot of things go. She took a leave of absence from her work at the hospital, cut back on her church responsibilities, and attended school board meetings only when she felt like it. Even now, she is not quite so busy as she used to be. She is more focused

on living today, right now, and not becoming too busy to enjoy the moment. So maybe the blame she placed on herself for breast cancer has led to something good. She argues that patients *should* take responsibility for their own health. The current health movement demanding power for the patient also demands that the patient take responsibility for his or her health. But there are so many variables that are completely out of a woman's control when it comes to breast cancer. Any number of things may be causing 182,000 women to get breast cancer every year. And it's not their fault.

Besides being held responsible for their own disease, many women feel responsible for protecting their families from the disease. In breast cancer memoirs when women write about diagnosis, they often write about the way this will affect their family. Nurturing the family is so inculcated into the female psyche; it is often the first articulated thought. Many women who have daughters feel guilty after their diagnosis, knowing that their illness puts their daughters in a high-risk group for cancer. Laurie Tarkan interviewed many breast cancer survivors who are also mothers to see how they reacted upon learning that they had breast cancer:

Mothers worry about their daughters getting breast cancer and having to endure the emotional and physical hardship of the disease. They also feel bad that their daughters now have to live with the fear, that their lives can no longer be as carefree as they had been before cancer. They are saddened to see in their daughters the loss of innocence, the loss of that sense of invulnerability that young people have (114).

Along with mourning their own loss of health and perhaps a breast, mothers with breast cancer mourn prematurely for their children who may have the disease in the future. This sense of responsibility creates a sense of guilt that is dangerous to an already distressed psyche. As if the fear of death and disease was not enough, these women mourn for unborn generations.

May 15, 2003

Last night I listened to my mom tell me that she has breast cancer. I knew it might happen some day. My great-grandma and my grandma on Mom's side have had it. It's an unbroken line from mother to daughter to daughter. Mom is already worried about me. Do I need genetic counseling? I need to see a gynecologist. I need to start monthly self-examinations and have a mammogram at 35. These are all of the things that Mom said to me moments after telling me that she is ill. None of that seems really important right now, though. What's important is that SHE is sick.

Although I did begin to worry about my own breast health after my mother told me about her disease, I was not nearly so worried as she seemed. She asked me to *please* see a gynecologist right away for a breast exam. She felt badly that I had to deal with the fear of disease in myself because of her own disease. I suppose that's just a motherly thing to do—to worry about your children—but it seemed out of place at the moment when she told me that she had cancer. I wanted her to be more selfish and to worry only about herself so that she could get well, but that's just not the way she is. We were both scared that she wouldn't be there for the important events coming up in my life—college graduation, perhaps marriage, childbirth, career. But she was worried about *my breasts* as well.

Of the 182,000 women diagnosed with breast cancer in 2003 about 43,300 died. That is nearly 25%. Breast cancer is the leading cause of death in women between the ages of 40 and 55. The good news, however, is that there are over two million breast cancer survivors alive in the United States today (National BC Foundation). The women who catch their cancers early have up to a 95% chance for disease-free survival. There are some powerful voices speaking out for a

greater focus on prevention rather than simply detection and treatment. The corporations who sponsor breast cancer awareness month and other awareness- and fund-raising events are beginning to see the importance of preventing breast cancer rather than treating it (Kasper 78). Female gynecologists, breast cancer survivors, and feminist health care leaders are beginning to make their voices heard, but we have miles to go yet.

"I don't know what we have to do to make President Bush wake up and do something about breast cancer. Maybe we should march topless to the White House."

Susan M. Love, M.D. at a speech in Salt Lake City, 1990

The focus of breast cancer research needs to be changed from detection and treatment to prevention. Someday women may be spared both the disease and the harsh medical treatments that have affected them, their mothers, and their grandmothers for thousands of years. But the only way that can be made possible is by addressing the societal ills that cause breast cancer instead of focusing on personal behaviors that have little or no effect on its development and growth.

II. Breast Cancer as a Woman's Disease: Social Pressures and Stigma

Because breast cancer is primarily a women's disease, its victims are subject to some conditions that victims of other cancers are not. Women are held responsible for detecting breast cancer in themselves by the litany of "early detection is the best form of prevention" campaigns. Their most feminine features—breasts—are examined, poked, prodded, and often removed by male doctors who potentially can't empathize with their loss because they are male. Mastectomy,

radiation and chemotherapy all rob a woman some of her most feminine assets as they wreak havoc on her body and her health while trying to preserve her life.

May 22, 2003

It is difficult to imagine myself as a member of the clan of one-breasted women, but I am. I feel completely initiated today on my twenty-first birthday. I went to see my mother this afternoon, just hours after her mastectomy. She looked great. Grandma, Aunt Sandy, and Aunt Roxane were there. I only wept when they all sang "Happy Birthday" to me. Yeah. Happy birthday. Why did this have to happen?

My mom said that losing a breast was not as distressing to her as losing her immune system to chemotherapy. She was much more concerned about that than she was about her breast itself. She rationalized that perhaps it was because her breasts had never been her favorite physical feature. My grandmother, however, was devastated by the loss of both breasts at age 70. Every woman reacts differently. Breasts are imbued with so much cultural meaning and sexual significance, it is difficult to imagine that losing one or both could be easy. Ferguson says that in order to combat breast cancer more effectively, "women's social status needs to be separated from the cultural valuation and objectification of their bodies" (83). In other words, we need to see past the breasts to the woman.

Breasts are everywhere. They are in magazines and on television. They are at the gym, in class, at work. They are in the library and at the theatre. They are in the lingerie department and the "ActiveWear" department at the mall. Breasts symbolize women's roles. They are both sexually inviting and maternally comforting.

Breast cancer is everywhere. Statistics are in the newspaper, on the internet. Survivors are on "Oprah" and in your neighborhood. Prevention methods are on television: "Eat more fiber." "Drink less alcohol." "Get yearly mammograms—early detection is the best form of prevention." "Exercise." Breast cancer research is funded by the government and by private corporations. Women wear pink ribbons all through November.

Although breasts and breast cancer seem all-pervasive in the United States, their constant presence doesn't lessen the shock that occurs when you or someone close to you is diagnosed with breast cancer. When disease strikes most people enter the first stage of grieving—shock and denial. Breast cancer is even harder to believe in than many other serious diseases because most women show no symptoms except for perhaps a very small lump in the breast tissue. Most don't become ill until treatment starts, which further promotes disbelief in a disease that was unseen until the now loathed and feared breast is removed.

Women's concerns about mastectomy are numerous. They worry about losing a part of themselves or even their femininity. A professional photographer, Amelia Davis, began taking nude or topless pictures of women who had had mastectomies. She asked them to write about their experience, or if they were illiterate she wrote what they dictated. One woman, the author's mother, said that the important thing is to "save our lives, not our looks" (14). Another, Charlotte, found it impossible to look at herself after her mastectomy and so went back for breast reconstruction. Now she has two very large, scarred breasts but she is happy with them. Another woman, Marge, has a beautiful slim body with one very large, round breast, and a deep, snaking scar on the other side. She has isolated herself from the world now because she "no longer mirrors the image society expects" (27). The breasts are a symbol of fertility, nurturance, and sexuality, and to lose that symbol is undoubtedly traumatic. Women facing mastectomy worry

about their partner's reaction to the physical change that will take place. They worry about their children, their siblings, their parents. Over 10% of mastectomies are immediately followed by breast reconstruction (Kasper 53). So many women feel that they cannot be themselves without that symbol of womanhood on their chests.

There are many different ways that breast reconstruction can be done. Some procedures use silicone implants (which the FDA has recently deemed extremely hazardous), some use saline (also problematic), and some recent advances in reconstructive surgery have made it possible to use a woman's own flesh to create a new breast. All of these procedures require multiple surgeries and are initiated immediately after the mastectomy while the patient is still under anesthesia. They have multiple risks and consequences. But some women will never feel "whole" without a breast on the chest. In Jennie Nash's humorously (sort of) titled book, The Victoria's Secret Catalog Never Stops Coming and Other Lessons I Learned From Breast Cancer, she writes about the sadness that she felt for her own "mutilated" breast after a lumpectomy to remove a cancerous tumor. She writes about the Victoria's Secret catalog arriving in her mailbox each month, "You can't ignore the images of beautiful breasts that pervade our society and you can't stop your own breast from being damaged" (83). She chose reconstructive surgery after her lumpectomy, but complications from the second procedure lengthened her hospital stay. Eventually the wound became infected and her hospital stay stretched into weeks. Unfortunately, the emphasis placed on breasts by American society might make it difficult for a woman or for her partner to value a body that is one-breasted and therefore "different" from the perceived norm. But if that "different" body makes a woman endanger her health with subsequent surgeries, then our society's view of breasts should be reexamined.

January 12, 2004

This book is breaking my heart. It's called Staying Alive: A Family Memoir, but so far no one in the family is "staying alive." Three sisters and three of their daughters have all died of breast cancer. And they were all under forty when their disease was first diagnosed. If this were fiction it would be awfully melodramatic, but it's nonfiction. And now Janet, the author, has decided to have a bilateral prophylactic mastectomy. And she's choosing reconstruction after. I can't believe this. Hasn't she seen that breasts are dangerous? Why is she choosing to get new ones? Everything went wrong with Janet's implants. Now one sits high on her chest while the other points out to the side. Why would you choose that? The triumphant picture that I think she wants to paint at the end—in her bikini on the beach—is just sad.

Perhaps the best memoir that I read, this book ended very unsatisfactorily for me. At first I really related to the author—she had a family history of breast cancer, watched her mother suffer from the disease, and was deathly afraid of having it herself. So right before she reached her mother's age at diagnosis she had a prophylactic mastectomy. But then she got breast cancer in the remaining 10% of breast tissue that remained underneath her implanted breasts. And she had to endure the same regime of treatment that her mother had, plus the added worries of dealing with silicone breast implants. I was so angry that Janet, to whom I now felt so close, chose to have her breasts reconstructed. Surely she, who had watched her aunts, her mother, and three of her cousins die of breast cancer, could recognize the fact that women can exist apart from their breasts. Couldn't she find another defining feature in herself? Breast reconstruction, with all of its associated risks, negates the value of a breastless body. Janet had seen breastless bodies and she loved and valued them. I wish that she could value her own.

In her breast cancer memoir, The Cancer Journals, Audre Lorde writes, "Strength can lie at the core of this experience, acknowledged and examined" (9). Lorde titled the last section of her book "Breast Cancer: Power vs. Prosthesis." She sees a prosthetic breast as a danger to breast cancer survivors because it covers up "battle wounds" and promotes silence and invisibility (60). Lorde calls mastectomy wounds "honorable wounds" and covering them up in an attempt to pretend that breast cancer never happened prevents education about breast cancer. But the prosthesis itself isn't the real issue. The important thing is for women who have had an experience with breast cancer is to talk about it, as it is happening and after it is over (if it ever truly ends).

The focus on prosthetics and reconstructive surgery illuminates the importance that American society places on breasts. Beginning in the 1940s, shortly after World War II, surgical breast augmentation became a real possibility for thousands of women. Since then, hundreds of thousands of women in the United States have undergone dangerous surgeries to enhance their (non-diseased) breasts with silicone or saline implants (Leopold 178). Images seen daily on television and in print media reinforce the idea that breasts—big ones—are necessary in order to attract a partner, to feel like a real woman, and to enhance both appearance and lifestyle. This idea is especially dangerous for breast cancer patients, whose breasts have been diagnosed as "abnormal." In a society that equates breasts with female desirability and attractiveness, the loss of a breast can mean the loss of those qualities as well. Our society's concept of "wholeness" is one of a perfect, unattainable body.

February 9, 2004

“Tamara said that she thinks we should dye my hair brown, go dark. But I just don’t think I can do it. I’ve always been blonde. So why should that change?”

What if you can’t even recognize yourself? How can a disease change your self-concept and the way that you see yourself in the mirror every morning? That is just not fair. I have often wished that I had my mother’s bone structure. She has beautiful, strong features—not at all like my soft, round ones. But she’s right when she says that without the softening effects of hair, those model-like features look stark and sort of over-exposed. Her hair is coming back darker and curlier. This is hardly the mother I knew nine months ago.

It’s difficult to see my mother hate her body or her image. I ache for her dissatisfaction. My grandpa, her father, thinks that she is beautiful and tells her so constantly. He thinks her new hairdo is amazing and perfect and wonderful. Mom thinks it looks weird. I suppose it doesn’t help that on her first day of work *sans wig* one woman—whom she has known for about 20 years—at first didn’t recognize her and then burst into tears when she did. What kind of reaction is that? I worry about my mother’s concept of herself. I try to tell her that I think she’s beautiful, but unfortunately she’s like me—we don’t believe words like that sometimes. Not when the mirror tells us something different.

Women use a lot of war and battle imagery to write about cancer treatments. It is a “fight for life” or a “battle for health.” This vocabulary was originally assigned to diseases by male surgeons, cast in the role of conquering heroes (Leopold 59). That language of war has been adopted by many women, including feminist health reformists. There are multiple parallels between women’s search for political empowerment and their position as breast cancer

(Amazon) warriors. Audre Lorde adopts a political agenda in her breast cancer memoir. Her political voice speaks out against carcinogens in the environment and in produce that we buy. Her feminist voice speaks out against the constructs used to silence women. She calls her mastectomy scars “battle wounds” and her bout with cancer a “battle” (59). Her political agendas are based on the experience she gained fighting cancer and she proclaims her intent to continue as a warrior of words.

In Refuge: An Unnatural History of Family and Place, Terry Tempest Williams

juxtaposes her mother’s battle with cancer with the slow deterioration of the Great Salt Lake and the bird refuge she loves. Williams adopts a political stance against nuclear testing and the legacy of cancer that it has given her family. In the epilogue, titled “The Clan of One-Breasted Women,” Williams dreams of a protest involving women singing a song from their Shoshone grandmothers:

| | |
|-----------------------|------------------------------------|
| <i>Ah ne nah, nah</i> | Consider the rabbits |
| <i>nin nah nah--</i> | How gently they walk on the earth— |
| <i>ah ne nah, nah</i> | Consider the rabbits |
| <i>nin nah nah--</i> | How gently they walk on the earth— |
| <i>Nyaga mutzi</i> | We remember them |
| <i>oh ne nay--</i> | We can walk gently also— |
| <i>Nyaga mutzi</i> | We remember them |
| <i>oh ne nay--</i> | We can walk gently also— (287). |

Williams uses her experience and the history of her family’s illnesses—including her mother’s breast cancer—to propel her to “an act of civil disobedience”: participation in a protest against nuclear testing in “a gesture on behalf of the Clan of One-Breasted Women” (290). When interrogated by a police officer about the pen and paper tucked in her boot, Williams calls them “weapons.” The voice she gained by telling her mother’s story is a powerful battle cry calling women to arms with the weapons that they have access to. The name of the epilogue, “The Clan of One-Breasted Women,” refers to the Amazon warriors who cut off their right breasts, lived

without men, and fought valiantly to protect themselves. Williams situates herself within that tradition of female warriors by the words that she uses.

May 17, 2003

Mom told me tonight that she learned that the Amazon women cut off their right breasts in order to improve their archery skills. "So," she said with an optimistic smile in her eyes, "I'm going to be an Amazon woman. They were warriors. And I'm in a battle now. I'm going to fight this. I'm not going to let cancer beat me."

At first I resisted battle imagery in breast cancer writing. War is violent, masculine territory and I didn't want to associate myself with it in any sense. But as I saw how women appropriated the language for themselves, I realized the forcefulness that it holds. Audre Lorde, Terry Tempest Williams, and my mother are all very strong women whom I admire. And they all feel as though breast cancer leads a woman to fight for her life and also teaches her how to fight on larger, political battle fields. Now I recognize that my mother's breast cancer—her battle—has helped me learn to fight a political fight. This, my breast cancer manifesto, proves my newfound political voice. We have all become Amazon women, warriors of words, and we will fight on.

III. A Place for Daughters

May 30, 2003

Mom postponed her mastectomy so that she would not miss Robert's high school graduation ceremony. As a member of the school board, she sat there on the stand at the front of

the high school gym. She was beautiful in a royal blue suit and a corsage. She is the only woman on the board, and stood out among the older men around her in their drab suits of black and blue. She gave Robert his diploma and a hug. And so, because the surgery was postponed, the day it was scheduled for was my birthday. My twenty-first.

Yes, I was angry. I tried so hard to repress the anger and hurt that I felt about Mom scheduling her life-altering surgery on my birthday, but it came out in my journal writing. In front of my family I acted the adult part that I felt they expected of me, the oldest child who had always seemed older than her years. But inside I felt like a little girl who has just been told that she will not be having pink strawberry ice cream at her birthday party. I was mad! It was not fair! Why did Robert still get to have his special day, but mine would be ruined? May 22nd would never be my birthday again, it would just be the anniversary of Mom's mastectomy. The guilt that I felt over these resentful feelings was intense. I couldn't let anyone know how I was feeling. So outwardly I was all daughterly concern and selflessness. But inside I ached with anger and hurt.

When daughters of breast cancer patients talk about their experience, they often recall their mother's disease striking at an important life milestone. Several women who tell their stories in Tarkan's book My Mother's Breast tell stories of a mother's disease disrupting a big event: "I was in the midst of planning a wedding", ". . .seven months pregnant with my first child", "my first major presentation at a big national conference", "a few days before my college graduation." Breast cancer often strikes just when a daughter is beginning to make it on her own, to carve a niche for herself in the world of adults.

The daughter of a breast cancer patient often suffers from a heavy burden of guilt and of anxiety. Because many daughters identify so closely with their mothers, a daughter will often immediately believe that since her mother has breast cancer she must be destined to have the disease as well. Although it is natural for a daughter to be concerned about her own health when she learns that her mother has breast cancer, she may feel guilty for worrying about herself when her mother is ill and her family, most likely, needs her to step up to a difficult task and help bear the load. In the foreword to My Mother's Breast, Dr. Kathryn M. Kash writes that "Women at increased risk for breast cancer, because of their family histories, are often emotionally distressed and unable to express the wide range of emotions they feel about their relative's cancer. . . Women whose mothers developed breast cancer often suffer the greatest" (i). Kash also states that daughters of breast cancer patients often overestimate their own risk for the disease and 27% have levels of anxiety and depression consistent with a need for psychological counseling (ii). Daughters of breast cancer patients see their mothers' struggle with the disease and often observe the effects of the disease and the treatments firsthand. Seeing the illness progress can be frightening. It can also be difficult to understand what is happening and why it is happening. Most breast cancer patients are relatively healthy when their cancer is discovered but the treatments may make women very ill. Watching a healthy mother descend into illness can be confusing and heartbreaking.

I journaled extensively throughout my mother's diagnosis, surgery, and subsequent treatments. My journal entries reflect the guilt, anxiety and heartbreak that Kash found in her study of the daughters of breast cancer patients.

May 22, 2003

Why did Mom think it was OK to miss my 21st birthday but not Robert's graduation? She rescheduled for him but she couldn't avoid my day. Am I supposed to be an adult now? Because I still don't feel like one. I had plans for tonight. I was supposed to go out with friends. But I am at home with my little brothers and my dad, praying for my mom to be all right. This is my 21st birthday. I am 21. I am of legal age to drink and do whatever else adults do. But if this is adulthood I hate it. I hate the fact that I just bought my own birthday dinner (Chinese takeout) and brought it home for my family to eat. I hate the fact that my mom is in the hospital instead of being here to take care of me and wish me happy birthday. And I hate feeling so childish and petty. I mean, she's sick. She had to have this operation. I shouldn't be so selfish and mean and awful. I am the only daughter. I am the oldest child. I should step up and take care of things while she is ill. That is my responsibility.

The guilt and anxiety I suffered between learning of Mom's disease and the day of her surgery were some of the most intense emotions I have ever felt. I was the last in the family to find out that she had breast cancer because I was away on a trip when she found out. That made me angry because I felt that the stakes were higher for me than for my brothers. They would never get breast cancer, but I might. I also felt guilty for not being there for my mother when she found out that she had breast cancer. We've always been close and shared important milestones of any kind. And I felt awful for missing this one. But the worst guilt came from the resentment I felt towards my mother the day of my birthday/her mastectomy. After visiting her in the hospital, I just felt sorry for myself. I should have been mourning her loss, but I was only pitying myself.

July 2, 2003

Yesterday after work I went home to lie on my bed and not think about anything. Jer came and found me lying there and asked about my graduate school applications. Slow tears welled up and trickled down. I wasn't angry—I had no reason to be—I was just sad. That was the third time such a thing has happened this week—these inexplicable tears. I had no answer when he asked me what was wrong. I met Lisa yesterday, a therapist at the campus counseling center. I hate her. She said that I can't let my sadness and grief over my mother's illness keep me from living my normal life. Normal life? What the hell is a normal life? My mother has cancer.

At the suggestion of a friend, I visited the university's counseling center. The counselor I spoke with there was difficult for me to relate to. She denigrated my grief, telling me that just "feeling sad" is not a good reason for putting off real life. She told me about the way that she felt when her father had cancer and told me to put on a happy face. After this unsatisfying experience, I cancelled my follow-up appointment. The daughters of breast cancer patients are in a unique position. Because they identify so closely with their mothers, as they grieve the loss of a mother's breast or health they are also grieving for the possibility of their own future losses. The grief and pain are doubled.

May 16, 2003

I didn't know that Great-Grandma Neeley had breast cancer. Why didn't someone tell me that? Dad says that he noticed her post-mastectomy asymmetry. I didn't. Maybe it's because I was only seven when she died. But I should know this! Is saying "BREAST" that embarrassing? Breast, breast, breast. What's the big mystery in that? Nearly half of the people in the world have them. I do. Grandma doesn't any more. My mother is losing one of hers. Will I?

My great-grandmother died when I was in elementary school. I vividly remember visiting her house and going back to the "play room" to dress dolls and have tea parties. I remember her Strawberry Shortcake cookie jar with frosted animal-shaped cookies in it and I remember her always walking out to the car with us and calling out, "Come again!" as we left. But I do not remember any mention of cancer, breasts, or disease. When my grandmother had breast cancer I finally learned that her mother had had it as well. The silence in my family on the subject of breast cancer still puzzles me. With the several cases, shouldn't it be a topic for discussion at least in women's circles in the family? Some of my cousins and I should probably be thinking about our futures and the real possibility that we could someday have breast cancer as well.

June 11, 2003

Yesterday afternoon when I found free hours I went to my parents' home. My mom said she gets energy from me. I feel good when I'm there, as though I could give and give, but then when I leave I feel so empty. Last night I cried myself to sleep. I don't think that I'm doing enough for my family, but I don't know what else to do.

Often the people surrounding an ill person experience a sense of powerlessness. I felt as though I couldn't do anything to help my mother, although I desperately wanted to. I was living away from home, but visited at least twice a week to clean and help out in any way I could, but when I left I felt guilty once again for not being there all of the time. One day one of my mother's friends visited me at work. She said that my mother seemed upset, and attributed this to the fact that the house was not as clean as usual. This "friend" offered to pay me to clean the house weekly and keep the money a secret from my mother. I stared at her in shock. I was visiting my mother and cleaning the house every week. Her intrusion implied that she thought I

was not doing enough—or at least that’s the way I interpreted it in my delicate state of mind. I’m ashamed to say that I was so angry at this woman, I have barely spoken to her since.

June 26, 2003

All I want to do is sleep. I tried getting interested in my music again, practicing the piano and guitar. I still have a long list of books to read this summer as well as a list of things to do to prepare myself for graduate school. But I just want sleep. My heart hurts. Praying has become difficult. I don’t want to see or talk to anyone, least of all my brothers. They act like nothing is happening in our family. If my own siblings can’t understand the way I feel, who can?

Perhaps it is because my brothers are all teenagers that they have a difficult time talking about their mothers’ breasts. There have been only a handful of times when any of the three of them have talked to me about breast cancer or about Mom’s case in particular. This has left me with no one to talk to about it but my mother. And I don’t think that Robert, Justin, or Nicholas talk to anyone about it at all. Perhaps it is because they are boys on the cusp of manhood. Men in my family are what you might call stoic. They don’t talk much about the things that bother them. They belong to the masculine, Western tradition of “rugged individualism” and they believe whole-heartedly in self-sufficiency and fighting things out on your own. My brothers can’t talk about breast cancer because of a culturally mandated silence that prohibits talking about breasts and talking about things you don’t understand and can’t fix. They are (almost) men. They are strong. And since they can’t do anything about Mom’s disease they, like so much of society, will pretend that it isn’t real.

June 1, 2003

I guess I'm jealous of Mom's friends. I've never had girlfriends like hers. Sharon, Jan, Joyce and Mom make up "The Club," which has existed since I was a preteen. Mom is the youngest, at 43, and Joyce the oldest, at 63. They do outdoorsy things together—camping, hiking, boating, skiing—and they also sit around and talk a lot. After the mastectomy, Joyce came up with some brilliant plan of how to make Mom well again. She planned a secret ritual that would take place in the mountains, near the lake where Jan camps every summer. I was imagining naked dancing by the fire, but I should have known better. Joyce had built little boats. Each of the four women put a candle in her boat, lit it, and placed it on the water and then watched them bob away together. The boats kept clustering and gathering as they floated away.

Soon after the "intervention" I wrote about in this journal entry I went home for the day and found my mom playing the piano. She was playing and singing a simple song from the Disney movie Pete's Dragon—"Candle on the Water." She told me about what she and her friends had done and I thought it was a beautiful image that Joyce had arranged for my mother. The support that "The Club" lent Mom throughout her treatments was amazing. They often brought food, they called, and they left her alone when she needed to be alone. Women seem to be very talented at taking care of each other and being true friends. It's a real gift.

Immediately following my mother's diagnosis I began searching different websites about breast cancer in order to understand what my mom was facing and what my risk might be. I wanted facts. I started reading women's memoirs, trying to find out how they had survived breast cancer. I wanted to know whether or not my mother and I were going to survive and how we were going to do it. I also started writing extensively in my journal, trying to make sense of what

was happening, driven by a desire to express what I was feeling. Some of my feelings were socially prohibited—it didn't seem appropriate to be angry at my mother or to hate my therapist, but in my journal I could express those feelings. That journaling led me to more reading to understand and writing to record. By journaling, I was able to revise my mother's illness and my response into a narrative that I could handle. By reading other women's memoirs I recognized a community of survivors that gave me hope for my mother's survival. And by putting those things together in this paper, I began to feel whole again.

IV. Writing as Healing

December 24, 2003

I love Christmas. I love the lights and the music and the food and everything about it. And I love being with my family again. Grandma and Grandpa Bowles and Grandma and Grandpa Hansen were at our house tonight for dinner. Mom talked for a moment about the past seven months and how wonderful everyone has been. She thanked all of us for the contributions that we've made and she thanked me for the research and the writing that I have done about breast cancer. I didn't know that she valued this project like I do. But I'm glad.

At Mother's Weekend at Utah State University my mother and I attended a memoir writing seminar. She wrote about the day that the pig Nick was raising for the county fair died. She was in the middle of chemotherapy, Justin had just had knee surgery, and Cache Valley was in a drought. But through all of this, she had willed herself to be strong and to be optimistic. But when Nick's fair pig died, she broke. She cried for several days. It was at that moment that she finally allowed herself to grieve over all of the losses she was experiencing. When she shared

that piece of writing with me, we mourned together, once again, for what we had lost—lost innocence, lost health, lost hair, lost breast, lost time. Now as I write this I'm grieving once again, but I'm all right. We've learned, through experience and through other women's shared experiences, that women survive breast cancer. And by writing and sharing her experience, my mother has helped both of us to heal a little bit more. By writing and sharing my experience, I am also helping us to heal.

Arthur Frank writes about the wholeness and power ill people can gain as storytellers. He writes: "As wounded, people may be cared for, but as storytellers they care for others. Their injuries become the source of the potency of their stories. Through their stories, the ill create empathic bonds between themselves and their listeners" (xii). Through telling their stories, ill people change from being "broken" to being healers of others. This gives the storyteller a feeling of importance and usefulness in the world. Throughout my mother's illness I felt powerless and broken. I wanted to somehow help my mother and my family but was unsure as to what I could do. The research and writing that I began to do for this project made me feel as though I was making a positive contribution to my mother's recovery.

Writing can lend a sense of wholeness to the ill or to survivors of amputation in the way that it helps their experience coalesce into a "whole." After major surgery, people often feel fragmented or broken. Audre Lorde writes about the grief she felt over her lost breast following a mastectomy: "I'm so tired of all this, I want to be the person I used to be, the real me. I feel sometimes that it's all a dream and surely I'm about to wake up now" (25). She mourns not only her breast, but a lost identity that vanished with her breast. Through writing, however, Lorde is "possessed by a rage to live" (33) that propels her to action. Although the landscape of her body

is forever changed, she makes the choice to love her body in the form that she now finds it. Writing about her pain in order to heal herself and heal the perceptions of those around her, Lorde finds solace in being of use, just as I used writing to become useful to my mother.

Frank also addresses the way that ill people must recover their voices. Often, upon entering the medical system, patients are silenced. They usually do not know the technical or scientific language that their caretakers use and so are unable to talk to them. Frank says that these "seriously ill people are wounded not just in body but in voice" (xii). He says that they need to become storytellers in order to recover their voices and thereby recover themselves. He calls the confusion and loss of illness "narrative wreckage" and says that stories must repair the damage that illness has done to the person's sense of self (53). "Illness," Frank writes, "is a crisis of self." Especially when a body part is amputated, a patient must redefine herself into her new role as a patient and eventually as a survivor. These crises of identity provide rich material for stories, if the ill person can just find her new voice.

September 5, 2003

How my mother constructs her illness narrative:

To most people who ask she says, "I'm fine" and flashes a smile and they are comforted. "You look fine, you look great," they reply, and she remains a whole person, not an ill person, in their eyes. But, as she said, who would want to go through all of this hell and be unchanged? She is, of course, not really fine. She just wants people to believe her when she says that she is fine. When she speaks to her doctors she tells a medical tale. She knows their language and speaks it fluently. When the surgeon Dr. Weiss tried to talk with her about her emotions, she simply wasn't ready to go there yet. So she offered another smile and an "I'm fine."

It can be difficult to talk about illness with people who are not and have not been ill. Usually they simply want reassurance that nothing is wrong, that soon everything will be back to "normal." Those who are not ill can't understand the way that the ill person feels, regardless of how sympathetic or caring they are. The ways that an ill person can talk about illness are prescribed by a society that usually wants no real details, just an assurance that everything is fine. Anderson and MacCurdy write that "Trauma survivors are usually very careful to protect others from what they know. They keep silences because they fear that others will be broken by what survivors have to tell them" (4). So most ill people construct their narratives very carefully. They are not too specific, too graphic, or too personal. They are trying to protect their listeners. So they take great pains to construct a guarded illness narrative, forced by the medical professionals around them to speak in a clinical sense about their disease and forced by society to share only what is OK to share.

Louise DeSalvo, in Writing as a Way of Healing, argues that writing about a difficult event is a sign to ourselves and to the world that we have chosen hope instead of despair. When we write about trauma or illness we gain mastery over it and take control of our situation. We can do this by altering or fictionalizing the past or by simply relating the past as we remember it and analyzing the feelings that we had then and now (36). Writing about a difficult event can also provide a necessary distance so that we can hold the event in our hands, look at it, and observe the way that we have triumphed over it. The writing and revising process is very similar to the grieving process and both can take us through trauma to reach an acceptable conclusion. The grieving process begins with shock and denial, continues through anger, bargaining, guilt, depression, loneliness, and then finally to acceptance and hope. Writing and revising often

include similar periods of despair and loneliness but build to hopefulness. This writing project has taken me through those stages. Mid-manuscript I was certain that I would never finish the project, but upon nearing the end I feel much more confident in the eventual finished product. By examining my journal entries throughout my mother's illness and treatment, I see growth and healing taking place. Also through the drafts of this writing project, her illness and my response has been revised and rewritten several times. Through writing about the experience, I keep getting closer to the truth of the situation, and that possibility of finding truth heals me.

October 7, 2003

I have labeled myself a breast cancer survivor. Although I have not had the disease, I don't feel that it is untrue to say that I have survived it. I have survived it in my family members and I am surviving even now. For three generations the women in my family have been afflicted with breast cancer in a direct matriarchal line. If the past predicts the future, I am the next in line. I have no choice in the matter. I was helpless as a tiny child when my great-grandmother had the disease, helpless as a teenager when my grandmother had the disease, and now at age 21, on the cusp of adulthood, I am helplessly watching my mother battle for her selfhood and her health while wondering, at the same time, whether or not I may someday face the same battle. But I am discovering that I and other women can gain control over our situation by writing and/or sharing our experiences. Writing is one of the ways that I have survived and am surviving my mother's breast cancer. Also, through reading other women's writing I have learned some of the things that I can do to perhaps prevent breast cancer or at least survive if it does attack my body. Reading the experiences of other women who have had breast cancer has helped me to realize the importance of community, the importance of writing about trauma, and the way that

writing can heal us emotionally and even physically. Seeing the commonalities between different women's stories has acquainted me with the virtual community of survivors that exists. Reading their stories has made me a part of that community. Sharing the experience with others has been an integral part of my healing, making me realize the power of writing in overcoming trauma.

I found myself, in my journal, working to find a new voice and a story that would accommodate my concerns for my mother and for myself. What seemed true to me was not always true for the rest of my family. There are several points on which we disagree. Not everyone may see me as a breast cancer survivor. My mother believes that women are very responsible for protecting themselves from breast cancer and detecting, while I believe that the medical establishment should be more helpful to women. But if my writing is to heal me, I have to write from my perspective and find my own version of the "true" story of breast cancer.

August 30, 2003

So, my first gynecological exam is over. It really wasn't bad. Mom asked me to do it for her, so I couldn't very well refuse. I've been putting it off long enough. I talked to Dr. Kimberly McCulloch about some very personal things today. She taught me how to do a breast self-examination, allayed my fears about a perennially irregular menstrual cycle, and then performed the breast exam. I told her my family history of breast cancer. We talked about genetic screening. Do I really want to know right now whether I might have the BRCA1 or 2 gene mutation? What would that change? The only answer is—I don't know. That's the big, ugly answer to many of my questions.

After visiting the gynecologist at my mother's request I thought a lot about genetic testing. Some of the women I had read about in Laurie Tarkan's My Mother's Breast had opted

for the tests. One of them learned that she carried the gene mutation and then had a prophylactic mastectomy. She chose to have the tests done because she was constantly distraught about breast cancer. She found herself feeling for lumps in public. I vowed to myself to never become that neurotic. I talked to my mom about genetic testing. She said that she would not encourage me to be tested because if the tests were positive, I would be uninsurable for the rest of my life. That was a practical way of looking at it. I found myself obsessed with calculating my risk. With the gene mutation: 80%. Without the gene mutation: 30%. What was causing all of the cancer in my family? Because it's not just breast cancer. There's ovarian cancer, prostate cancer, colon cancer, skin cancer. You name it, we've got it. Cancer was in my family and on my mind. I was almost relieved to learn that my mom had decided to have a genetic screening herself in order to decide whether or not to have her ovaries removed. Maybe we would find some answers in her blood.

Writing can heal people in a personal way by working as a form of "alternative therapy." Its greatest therapeutic quality is what Charles Anderson and Marian MacCurdy call the "dual possibilities of permanence and revision" (7). Healing can take place in both of these ways through writing. The traumatic experience of the writer can be made permanent and available to a broad readership and also to the author. Anderson and MacCurdy write that trauma survivors often have a sense of powerlessness, "taken over by alien experiences we could not anticipate and did not choose. Healing depends upon gaining control over that which has engulfed us" (5). The possibility of revising an experience by shaping and molding it allows the survivor to exert a measure of control over the thing that they feel that they can never control—the past.

In her cancer memoir, Jennie Nash tells the story of the day that she was diagnosed with breast cancer. A writer by profession, upon diagnosis she was possessed by a desire to

immediately tell the story of her illness to everyone that she knew. She says that repeating the news over and over made cancer into a story that she could “retell, reduce, and rebroadcast with a prescribed emotion . . . no longer new and raw” (38). The repeated tellings diffused some of the shock, pain, and despair associated with the disease. The initial grieving stage of shock and denial was very temporary for Nash because she immediately took control of the situation. By revising and retelling her story multiple times—perhaps changing it slightly with each retelling—Nash owned the story. She was empowered by her personal hold on the story. As Anderson and MacCurdy write in *Writing and Healing*, telling one’s story gives it the possibility of both permanence and revision. Nash made her story both permanent and real, and she also revised it into a tale that she could tell.

Alice James, the younger, little known sister of William and Henry James died of breast cancer in 1892. A talented, introspective writer, she relied on writing to ensure that her identity would not be lost after her death. She was an avid journal and letter writer. Alice James’s final diary entry is dated March 4th. She died March 6th. Her long-time partner, Katharine P. Loring, wrote very shortly after James’s death:

All through Saturday the 5th and even in the night, Alice was making sentences. One of the last things she said to me was to make a correction in the sentence of March 4th “moral discords and nervous horrors.” This dictation of March 4th was rushing about in her brain all day, and although she was very weak and it tired her much to dictate, she could not get her head quiet until she had had it written: then she was relieved. (233)

James, throughout her illness, focused on writing as a way of making herself whole again. Her loss of health did not prevent her from writing. As noted by Katharine Loring, until the very end James was intent on leaving her diary whole and in the best possible condition, perhaps with the idea that it might be published in the future. The wholeness that she searched for through writing is a commonly realized benefit of writing as a way of healing.

People can gain a sense of self-efficacy through writing. Often, traumatic events leave a person feeling helpless, like a meaningless pawn in the great scheme of things. Writing and producing something of value may give one a sense of purpose and a feeling of accomplishment. Illness often leaves people—both the patient and the family—feeling helpless and useless. It is often difficult to know how exactly to help a loved one who is struggling with illness, but writing can be both a creative outlet and a work of love.

De Salvo writes that we can use our difficulties in our work to master emotions—like fear and guilt—by representing them in writing. One researcher that DeSalvo cites, James W. Pennebaker, found in his research that students who explored feelings about difficult or traumatic events as they wrote found “a congruence in brain wave activity between the left and right hemispheres, indicating that both emotional and linguistic information was being processed and integrated simultaneously” (23). This integration improves both brain function and the capabilities of the immune system, benefits that persons under stress can definitely use.

Nancy Mairs writes about what she calls “The Literature of Personal Disaster.” She says that in writing the literature of personal disaster, “some may find . . . that they thereby write their way into better behavior than they believed themselves capable of. I am forever publishing brave statements that I must then make good on if I am to be a woman of my word” (127). So besides becoming smarter and healthier, writing about trauma may make us braver. It allows us to see, in retrospect, what we have overcome and therefore what we are capable of in the future.

May 12, 2003

Texas has so many different landscapes—flat plains, green forests, beaches. It's beautiful and varied and so vast. Singing “Amazing Grace” in San Antonio last night was amazing. The

audience was huge and enthusiastic. I drew so much energy from the crowd. This trip is exactly what I need right now. I was so tired of Cache Valley and my roommates and school and even my family. Getting away was wonderful, but I guess now I'm ready to go home. I called Mom this morning to wish her a happy Mother's Day and she just didn't sound well. I'm pretty sure that she was close to tears. All day here in the car I've been worrying about what might be wrong. I hope that Grandpa is all right. Maybe Mom is upset with me. What have I done lately that she may have heard about?

The above journal entry marks the beginning of this writing project. I didn't know it yet, but my mother had just learned that a small lump she had found on her breast a year earlier, deemed harmless by her gynecologist, was in fact a Stage III malignant tumor. It was the last thing that I expected after the phone call, although I knew that something must be wrong in the family. My first guess was that one of my grandparents was ill, probably my maternal grandfather since he's the oldest of all of them. But after I thought about my grandparents being ill I wondered if my mother might be upset with me. At the time, my family didn't approve of some of the "life choices" that I was making and I thought that I might be the cause of her Mother's Day tears. My turn inward, shifting the blame to myself, would carry through for a great deal of her illness, when I would feel guilty for not helping her enough, for not being present for my brothers' sake, and for feeling a great deal of resentment about her illness.

Writing can heal the psychic wounds caused by the guilt experienced by both cancer patients and those that surround them. DeSalvo quotes Alice Walker in Writing as a Way of Healing. Walker says that in Native American cultures,

when you feel sick at heart, sick in soul, you do sand paintings. Or you make a basket. The thing is that you are focused on creating something. And while

you're doing that, there's a kind of spiritual alchemy that happens and you turn that bad feeling into something that becomes a golden light. It's all because you are intensely creating something that is beautiful. And in Native American cultures, by the time you've finished the sand painting, you're well. The point is to heal yourself. (154)

Focusing the energies on something creative draws the mind away from the current sad or depressed state of mind. By writing about a sad or traumatic event, it is possible to change those "bad feelings" into a creative piece of work. And by writing about an event we take control of it and own it.

Marian MacCurdy writes that one of the main benefits of writing about trauma is "the journey [that] will take them ultimately out of themselves and back to a community which can reestablish our common humanity" (198). The fear of death and the many life changes that cancer brings can alienate a person from those close to them and give a person a sense of incurable loneliness. In The Wounded Storyteller Arthur Frank writes about "The Remission Society," made up of those with invisible but often incurable illnesses. They live in a "demilitarized zone between the land of the sick and that of the well" (9). Members of this society can become detached from family and friends who have not experienced the same things that they have experienced. Then, once in "remission," past patients are cut off from the world of the sick in which they have spent their last several months. It is important for people in this situation to find a community of survivors in order to share the experience and feel validated in their concerns and perhaps ongoing fears.

Frank writes about the importance of sharing stories of illness: "The *personal* issue of telling stories about illness is to give voice to the body, so that the changed body can become once again familiar in these stories" (2). One of the important things about writing about disease is to connect with others, to create a virtual community of survivors. After breast cancer

treatments a woman may not even recognize her body because of its vastly altered state. The numerous physical side effects of chemotherapy drastically change the appearance and may alter a woman's feelings about her body. If she finds a community of women with the same concerns, whether that community is local or virtual, she may no longer feel cut off from her normal life.

By reintegrating traumatic events into a narrative of daily life, survivors can find a sense of wholeness. Survivors of illness have a special need for wholeness because of the fragmentation that has occurred through the trauma of their illness. Healthy people don't experience that same need because their bodies are experienced as whole. Mastectomy, for breast cancer patients, is amputation of a body part that holds tremendous symbolic value both for them and for the world that looks at them. Post-mastectomy, women often feel broken, or less than whole. Writing can restore a woman to the person that she was before mastectomy and make her feel whole again.

MacCurdy and Anderson identify three important benefits of writing about trauma. The writer bears witness to her lived experience; writing opens confusion and pain to the possibility of wholeness; and the victim becomes an agent of change, both personally and publicly (16). A person who has been ill often has to take some kind of action in order to make herself whole again. Writing is a way to reclaim that wholeness.

Many women think that if they can only pinpoint the cause of breast cancer in themselves they will be a step closer to being in control. The trouble with disease is that it disrupts ordinary life. It places people in a new role or even a new world. Pinpointing the cause and then pointing a pen at it gives a new patient a sense of knowledge and control that seemed lost. By writing about and naming their disease they gain control over it. Louise DeSalvo writes that "when we face serious or chronic illness, disability, or dying, we are plunged into a terrifying, chaotic place

where nothing seems secure, where the very nature of time changes. . . We can write to . . . restore a sense of meaning and coherence to our lives” (181). Finding a voice and finding a place for oneself is a vital step in recovery, both mental and physical.

Writing and sharing stories of illness can also provide a healing community. Linda Dackman writes in the preface to her book, Upfront: Sex and the Post-Mastectomy Woman, that she wrote the book to provide information for other breast cancer patients and survivors, so that her experience might make their own easier. She writes, “I have also written this book for me. Writing is one way of looking back in an effort to both chronicle and understand. This process has meant not just writing, but talking with other women about their experience as a way of comprehending and informing my own” (xv). In order to overcome the loneliness that is often associated with disease, breasts and breast cancer need to be demystified. Although a great change has taken place in the last fifty years, breast cancer is still not talked about in healing or regenerative ways. There are “support groups” for survivors, but they often don’t address the most necessary concerns about breast cancer. Dackman wrote her book because she could not find any books or any people who would address sexual concerns for the post-mastectomy woman. This seems like a very basic concern for a woman who is going to lose a breast, but her need was not met. Many women who write breast cancer memoirs write in order to help not only themselves, but other women who find themselves as part of the breast cancer community.

Other women write about their breast cancer experience in order to pursue a sort of political activism. Audre Lorde wrote in order to “transform silence into language and action” (18) and encourages other breast cancer survivors to do the same. Her text serves as a rallying cry to women to take control of their cancer experience and be proud of their mastectomy “battle wounds.” Amelia Davis took pictures of post-mastectomy women for the same reason—to make

a statement against silence on the topic of breast cancer. She writes in the introduction: "The images remind us of the female spirit's resilience and ring the bell calling all of us to unite in the circle of women . . . The ties that join us are stronger than the cancers that try to pull us away from each other" (xi). Davis seeks to draw women into a community of survivors and supporters by seeing the true "face" of breast cancer. Jennie Nash is explicit about her desire to heal others through her breast cancer story. She says that most of us can't do a great deal to find a breast cancer cure. Some people can write a check or invest themselves in fundraising efforts and some very talented people may have the scientific and medical ability to work on a cure. But the rest of us, Nash says, need to tell our stories:

What we can do is tell our story. Stories help. Stories heal. Your story might be the very thing that saves someone's life or helps them get through the night. It might be the only thing that brings you a measure of peace . . . It might not be a cure, but it's a truth, and it can make a difference. (13)

Nash's argument is that women need to hear the stories of others and we can be of service to each other by joining the community and raising our voices.

Writing and talking about an experience like breast cancer makes the speaker and the readers or listeners part of a community. No one has to feel alone with the experience when it is openly shared and discussed. This is important for women, says Nancy Mairs in Voice Lessons: On Becoming a (Woman) Writer. She writes that women should lend each other the "courage to say the next hard thing, without fear of ridicule or expulsion if she strays across the borders of good taste, good sense, or good judgment demarcated by a tradition she has had no part in forming" (25). After losing a part of oneself, it is important to find a place and a group of people who can restore your sense of self and of wholeness. Mairs writes that women should do this for each other by valuing and sharing each others' writing and promoting a sense of community among women writers.

February 6, 2004

Today Mom and I went cross-country skiing. This is something that she absolutely loves. It was my first time and she was so excited to share it with me. I have seen quite a change in my mother over the last ten months. A physical change, of course, but that's not the significant thing. She already looks wonderful and will soon show no outward traces of the disease that tried to control her life for a year. But I see this difference in her spirit. She is more serene. She is less often distressed. She cares more for herself and is taking time to do things that she loves—and not that she feels obligated to do. This is the third time that she has been skiing this week. I can see the rehabilitative effects it is having. These are not physical effects. Her spirit is regenerated when she is here, outdoors, with people she loves, doing something she loves to do.

Hopefully the breast cancer chapter of my mother's life is over. Chemotherapy is over, radiation is over. Her hair is growing back, she has chosen a breast prosthesis, she has returned to work and to most of her usual activities. I am moving on with my life. I will start graduate school in the fall, a new chapter for me. I'm no longer obsessed about calculating my breast cancer risk or checking for lumps. It's been almost a year since Mom's diagnosis. In another four years, she'll be officially "in remission." I'm not too worried about having breast cancer, myself. I've already survived it. And I'm still here.

Creating this text has brought my life and my writing together. Marian MacCurdy says that "the separation of text and life is artificial" (195). Bringing text and life together has been frightening at times, but it feels real rather than contrived. All of the texts that I have read about breast cancer—memoirs, books on prevention, websites built to calculate personal risk,

cookbooks—intersect in me with my personal experience of breast cancer in my family. The only way to be honest to myself and my experience was to include all of those voices that I have learned from along with my own personal, sometimes confused, journal voice and with my academic voice. Bringing all of this information together and writing about it has healed me as it has given me a voice to use as a weapon as I join the ranks of Amazonian women. We are warriors of words. We are survivors.

Works Cited

- Anderson, Charles M. and Marian M. MacCurdy. Writing and Healing: Toward an Informed Practice. Urbana, Ill: National Council of Teachers of English, 2000.
- Dackman, Linda. Up Front: Sex and the Post-Mastectomy Woman. New York: Viking, 1990.
- Davis, Amelia. The First Look. Chicago: University of Illinois Press, 2000.
- DeSalvo, Louise. Writing as a Way of Healing: How Telling Our Stories Transforms Our Lives. Boston: Beacon Press, 1999.
- Frank, Arthur. The Wounded Storyteller: Body, Illness and Ethics. Chicago: The University of Chicago Press, 1995.
- James, Alice. The Diary of Alice James. Ed. Leon Edel. Boston: Northeastern University Press, 1999.
- Kasper, Anne S. and Susan J. Ferguson. Breast Cancer: Society Shapes an Epidemic. New York: Palgrave, 2000.
- Kelly, Patricia T., Ph.D. Assess Your True Risk of Breast Cancer. New York: Henry Holt and Company, 2000.
- Leopold, Ellen. A Darker Ribbon: Breast Cancer, Women, and their Doctors in the Twentieth Century. Boston: Beacon Press, 1999.
- Lorde, Audre. The Cancer Journals. San Francisco: Aunt Lute Books, 1980.
- Love, Susan M., M.D. Dr. Susan Love's Breast Book. Cambridge: Perseus Publishing, 2000.
- Mairs, Nancy. Voice Lessons: On Becoming a (Woman) Writer. Boston: Beacon Press, 1994.
- Nash, Jennie. The Victoria's Secret Catalog Never Stops Coming: And Other Lessons I Learned From Breast Cancer. New York: Scribner, 2001.
- National Breast Cancer Foundation: Help for Today . . . Hope for Tomorrow. 2003. September 12, 2003. <http://www.nationalbreastcancer.org/>.
- Reibstein, Janet. Staying Alive: A Family Memoir. New York: Bloomsbury, 2003.
- Sherman, Janette D., M.D. Life's Delicate Balance: Causes and Prevention of Breast Cancer. New York: Taylor and Francis, 2000.
- Tarkan, Laurie. My Mother's Breast: Daughters Face Their Mothers' Cancer. Dallas: Taylor Publishing Company, 1999.

Williams, Terry Tempest. Refuge. New York: Vintage Books, 1991.

Wittman, Juliet. Breast Cancer Journal: A Century of Petals. Golden, CO: Fulcrum Publishing, 1993.

Works Consulted

Belenky, Mary Field, Blythe McVicker Clinchy, et al. Women's Ways of Knowing. New York: Basic Books, 1986.

Breast Cancer.org: A Nonprofit Organization for Breast Cancer Education. September 8, 2003. September 12, 2003. <http://www.breastcancer.org/>.

Halverstadt, Amy and Andrea Leonard. Essential Exercises for Breast Cancer Survivors. Boston: The Harvard Common Press, 2000.

Hinson, Raelia J. Held by an Angel's Wings. Lafayette, LA: Vital Issues Press, 1998.

Lee, John R, M.D., David Zava, Ph.D. and Virginia Hopkins. What Your Doctor May Not Tell You About Breast Cancer. New York: Warner Books, 2002.

Magee, Elaine, MPH, RD. Tell Me What to Eat to Help Prevent Breast Cancer: Nutrition You Can Live With. Franklin Lakes, NJ: Career Press, 2000.

Olson, James Stuart. Bathsheba's Breast: Women, Cancer and History. Baltimore: The Johns Hopkins University Press, 2002.

Ratner, Elaine. The Feisty Woman's Breast Cancer Book. Alameda, CA: Hunter House Publishers, 1999.

Sinor, Jennifer. "Inscribing Ordinary Trauma in the Diary of a Military Child." Biography 26 (2003): 405-415.

Strouse, Jean. Alice James, a Biography. Boston: Houghton Mifflin Company, 1980.

Tompkins, Jane. "Me and My Shadow." Feminisms: An Anthology of Literary Theory And Criticism. New Brunswick, NJ: Rutgers University Press, 1991. 1079-1092.