

*From*

***Advanced Breast Cancer:  
A Guide to Living with Metastatic Disease***

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**Chapter One.**

**Voices of a Forgotten Population**

Although breast cancer has become a topic widely covered in the media, the message is almost always cheerful, emphasizing early detection and the high likelihood of "cure." The reality of metastatic breast cancer is almost never publicly talked about, and considered "too downbeat" by mass media to attract an audience. In this chapter the social context of the disease will be examined, and the ways in which the "politics" of breast cancer isolates people dealing with metastatic and high-risk breast cancer.

Psychological and social factors both play a part in the denial and fear surrounding metastatic disease. Even in the breast cancer community of advocacy and support, there is often a sense of division between those diagnosed with primary disease and those whose disease has recurred. These larger issues—fear, discomfort, isolation, discrimination—create a climate of silence that prevents the real stories of people living with metastatic disease from being told. As the stories in this book unfold, patients and their spouses and partners break this silence, speaking in depth about their lives, their families, their feelings, their hopes and their fears.

**A cheerful message of survivorship**

*Boo! It's October, It's Halloween, It's Breast Cancer Awareness Month. And I'm the bogey-woman who needs to be kept in the closet.*

Karen Caviglia, a breast cancer activist, wrote these words in 1995 for a Massachusetts newsletter a few months before her death.

*Two years ago, sitting in the Memorial Oncology Clinic receiving CMF treatment for breast cancer during October, I was still spinning with the news of my metastasis. It didn't seem that I could get away from breast cancer anywhere—it was a media frenzy. Specifically I remember an enthusiastic TV reporter commenting that Olivia Newton-John had "beat" breast cancer. Since it had only been two years for her*

*and I had gone five and a half years apparently disease-free, I was muttering uncharitably under my breath, "We'll just see what happens. It may not be over yet."*

If you've been feeling angry and left out by the cheerful emphasis on breast cancer survivorship in the media, you are not alone. These days, television specials, magazine articles and books on breast cancer seem to focus exclusively on the importance of early detection and on the process of treatment and recovery in primary breast cancer—that is, the experience of women diagnosed with early stage breast cancer for the first time. The focus is almost always upbeat, the outcome positive.

From watching TV and reading the newspapers, you'd think breast cancer was rarely a fatal disease any more. Throngs of happy survivors sporting pink visors participate in runs and walks around the country each October to benefit various support and research organizations. Not a month goes by without news of some heartening medical "breakthrough" in treatment or diagnosis that on examination usually turns out to be far less promising or novel than it is touted to be.

Thirty years ago, before Betty Ford, Happy Rockefeller and a few other early pioneers of self-disclosure helped to make public revelation of the disease a commonplace occurrence, having breast cancer was perceived as a shameful secret. The name of the disease was spoken only in whispers. The equation in the public's mind was still cancer = death. The disfiguring radical mastectomy was the surgical norm, cobalt radiation treatments left burns and scars, and receiving chemotherapy usually meant the disease was terminal.

Times have changed. More than half of diagnosed women are now considered candidates for breast-conserving surgery, and adjuvant chemotherapy, given following mastectomy or lumpectomy with radiation, has become the standard of care in many cases of primary breast cancer. Radiation is now far less damaging, and there are new, effective drugs to counter the nausea and low blood counts caused by chemotherapy. Scores of women in public positions have admitted having the disease, from Sandra Day O'Connor to Gloria Steinem. Women and men all over the country have banded together in support groups and advocacy organizations. In recent years, the American Cancer Society has developed extensive educational programs on mammography and early detection, and is doing everything it can to promote the notion that breast cancer need not be fatal if discovered early. This message is important and laudable. To reduce the stigma and fear associated with the disease, these public service campaigns have helped the pendulum to swing from the former grim inevitability to a new glib perception of cheerful survivorship.

This is not false; it is merely simplistic. Clearly, it is reassuring to women terrified of breast cancer to know that so many do recover. The hope is that this new optimism encourages women to be less afraid to examine their breasts, and to seek screening for early detection, when the treatment is most likely to be curative. And newly diagnosed women clearly take great comfort in the longevity and vigor of long term survivors.

But the nasty secret that inspired those whispers in the past hasn't changed one bit: women are still dying of this disease, and in huge numbers. Breast cancer remains the most

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common cancer in women, and the leading cause of death for women between the ages of 40 and 55. In 1997, the National Alliance of Breast Cancer Organizations (NABCO) estimates that 43,900 American women will die of the disease.

Yet it is the disease-free survivors we hear from the vast majority of the time. What of the tens of thousands of women whose breast cancer comes back each year, who face a much more grim prognosis? Where are their voices? Who speaks for them? Who speaks for you? Karen Caviglia struggled to break this silence in a letter she wrote to the Breast Cancer List:

*As we approach Survivor's Day—I myself have invitations to four celebrations—I'm prepared to deal with an onslaught of the Pollyannas. Once upon a time I too thought that my breast cancer was a blessing in disguise—but then it metastasized. Talk about struggling to accept. Well now I'm very positive day to day—it's easy when I'm not in pain—and I'm determined to live as long and as well as I can, but my doctors say I'm incurable so I accept that sooner or late, and certainly sooner than I want, it's gonna get me. And please don't talk to me about getting hit by a bus or that mortality is 100%.*

Rosalind Kleban, a social worker at Memorial Sloan-Kettering Cancer Center in New York City who leads a support group for metastatic breast cancer patients, became acutely aware of the impact of Breast Cancer Awareness Month on the women she works with:

*During October, when we are inundated and flooded with stories, one of the women in my group said that she had a question, and you could see that she was not comfortable raising it. She was somewhat embarrassed, didn't know if it was foolish to ask. Her question was: "Are we survivors?" When she said that, all the other women in the room turned away or put their heads down. It was a question that touched them, embarrassed them, something that they had struggled with, too. I asked her what she meant by that. She said, "Well, all you hear about are survivors. I don't know if I am a survivor. I'm alive. But I don't feel like they do. Somehow, they are victorious. I am not victorious."*

It is a story Kleban has heard repeatedly from her patients with metastatic disease, a sense of stigma that she herself has come to feel passionately about.

*They are the forgotten population, shunted aside because they have blown it. They have failed. These other people have won the battle. They're the people we applaud, whom we put on television to talk about breast cancer. Women with metastatic breast cancer connote a failure of the system, of medical knowledge and science, which, clearly, the system doesn't feel good about. The view is that once you have metastatic disease, it's a death sentence, and that it's really over.*

Even at one of the most prestigious cancer treatment and research centers in the United States, these ambivalent feelings about metastatic disease are evident, Kleban admits.

*In trying to help support the primary people, we do keep it quiet. We say, "You're going to be fine." I myself will say that, in order to promote hope. On Wednesday in our metastatic group, one of the women was saying, "Well, it happens even here." In the chemotherapy unit, on the desk where patients check in, there is a flyer that talks about the adjuvant group (for primary breast cancer patients) that meets every Thursday at one o'clock. There's no mention of the metastatic group. I'm afraid of scaring the others. The metastatic group is listed in our brochure, however. To be very honest, I am more comfortable with that. It's folded. You have to look to find it.*

The universal symbol of breast cancer awareness in recent years has been the pink ribbon, appropriated from the ubiquitous AIDS red ribbon. Breast cancer activists frequently object to this symbol. "This is not a pastel-colored disease, and little strips of cloth will not end the epidemic."<sup>1</sup> wrote Barbara Brenner, Executive Director of Breast Cancer Action of San Francisco. Of all the pink ribbon pins made over the last several years, only one manages to convey the dual reality that breast cancer patients really face, and it is that of the Ottawa based Breast Cancer Action group, that uses an upside-down pink ribbon, in the shape of a teardrop, the pink lined with black.

In the clamor for competing needs, every public message takes on a political cast. Advocacy groups, when they emphasize the mortality figures in an attempt to impress officials with the urgency of this public health problem, know full well they strike a delicate balance between alarmism and complacency. Officials from the cancer establishment tell us that breast cancer is hardly the epidemic activists claim it to be, and that the alarming increase in breast cancer incidence over the past 30 years (from one in fourteen in 1960 to one in eight today) is mostly the result of better screening picking up the disease years earlier. They speak of the innovations in treatment that save lives, of promising new drugs and ever-more aggressive treatments. Breast cancer activists, skeptical of profiteering by the cancer "industry," remind us that the death rate from breast cancer has remained constant over the years, that the promise of microbiology and genetic research has yet to be realized, and that treatments still consist of "slash, burn and poison," to use the oft-repeated characterization of surgery, radiation treatment and chemotherapy.

### **Denial, fear and popular perceptions**

But the problem extends far beyond any individual disease, and stiffens the invisible resistance that works against the abilities of advocacy groups to rally supporters—especially those representing people who may die of their illnesses. American society does not deal well with life-threatening diseases of any kind, preferring to gloss over the realities, just as it idealizes those who are struggling with them, and the nature of those struggles.

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In the first paragraph of her essay Illness as Metaphor, writer and breast cancer survivor Susan Sontag speaks of serious illness as the “night side of life” and “that other country,” a foreign terrain to be explored by each of us, eventually.<sup>2</sup> This strikingly self-evident fact is largely ignored. Most people live their lives as if no such event will come to pass, and are utterly shocked when it does. Thus, a disease considered incurable seems particularly to inspire silence and denial. Consequently, without a supportive group or community of some kind, people dealing with metastatic cancer of any kind are likely to find little in their daily lives to provide any reflection of their altered reality—and this despite that fact that cancer strikes one in three, and is certainly a commonplace occurrence.

As a culture, Americans live in a perpetual state of denial of personal mortality. This is true despite—or perhaps because of, for this surely deadens people to real pathos—the violence of our popular entertainment and the barrage of catastrophes that perpetually assault us through our media news. This is not likely to change. Social scientists say that cultural avoidance of the personal impact and meaning of serious illness derives from individual psychological tendencies. The emerging research suggests that unwarranted optimism and even denial may be an innate protective mechanism.

“Normal people believe to an unrealistic degree that the future holds a bounty of good things and few bad things,” claims psychologist Shelley Taylor in her book, Positive Illusions, “Depressed people are actually realists, having lost the positive biases that normally shelter people from the harsher side of reality.”<sup>3</sup>

“Patterns emerge from the scientific evidence that would seem to indicate that, just as individuals and families deceive themselves, so do larger groups of people, so do whole societies,” psychologist Daniel Goleman writes. “If there is a lesson to be drawn from the new research, it is the urgent need for compelling antidotes to self-deception. The more we understand how natural a part self-deceit plays in mental life, the more we can admit the almost gravitational pull toward putting out of mind unpleasant facts.”

On a large scale, denial can even become the enemy of a democracy, which depends on the free flow of information. “Censorship,” Goleman continues, “seems the social equivalent of a defense mechanism. Now that cognitive psychology is showing how easily our civilization can be put at risk by burying our awareness of painful truths, we may come to cherish truth and insight, more than ever before, as the purest of goods.”<sup>4</sup>

Philip Slater, in his influential social commentary The Pursuit of Loneliness, examined our tendency, as Americans, to hide away from view that which is difficult, and he gave it a memorable name: “the Toilet Assumption—the notion that unwanted matter, unwanted difficulties, unwanted complexities and obstacles will disappear if they’re removed from our field of vision.”<sup>5</sup>

Beyond the cliché-ridden language of popular culture, there’s precious little written about the real experience of life-threatening illness. Arthur Frank, a medical sociologist who suffered a heart attack at 39, then was diagnosed with testicular cancer a year later, offered one explanation of why we find it so difficult to articulate this aspect of our lives, even to those we expect to

understand it most—our doctors. Illness is the total experience of living with the disease, he reminds us. Yet it is only the physical facts of disease, and not the illness, that medicine deals with.

*Physicians are generally polite about answering questions, but to ask a question one must already imagine the terms of an answer. My questions end up being phrased in disease terms, but what I really want to know is how to live with illness. The help I want is not a matter of answering questions but of witnessing attempts to live in certain ways. I do not want my questions answered; I want my experiences shared. But the stress and multiple demands on physicians and nurses too often push such sharing outside the boundaries of “professional” activity.<sup>6</sup>*

The ensuing silence, this lack of “illness talk,” affects both public and private life. On the rare occasions advanced breast cancer does find its way into the media, it is to show an optimistic and valiant veteran of high dose chemotherapy, convinced that the treatment has saved her life. Or a soft-focused lens will be turned on some sad elegy about a noble, uncomplaining (deceased) cancer “victim,” often a celebrity.

Those who, while mortally ill, project courage, selflessness and transcendence, keeping their inner struggles private, usually provide the prettied-up images we see. Inevitably, both the courageous and the saintly model turn into expectations in the minds of ordinary people—just one more chance for you to feel you don’t quite measure up. In your own day to day life with metastatic breast cancer, it’s not quite so simple; all kinds of complicated and messy feelings intrude.

In real lives, along with precious moments of peace and transcendence, there is also pain and anger and a terrible sadness. In real lives, terror and self-doubt keep daily company with courage. In real lives, family support is given by human beings, by husbands who are tired and frightened too, by children who withdraw into themselves, whose schoolwork suffers. In real lives, despite the love and support, there is still, at times, a wrenching loneliness, and the fear of becoming dependent and burdensome on those you love.

In real lives, the boredom and dehumanization of hours and days spent in hospitals and laboratories and doctors offices swallows time and energies. In real lives, waiting becomes the constant, a training in patience and perseverance that comes in just two flavors: tedium and anxiety. The tedium involves the endless waiting for appointments, for insurance payments, for your records to find their way into the right hands, for all the health care bureaucracy to grind in its slow and inefficient way. The anxiety occurs as you wait for a painful procedure to begin or to end, and to see what the scans and tumor markers will show this time, to find out whether this or that combination of drugs has worked to slow or stop disease progression, and if it has, for how long.

Even with the best, most compassionate medical care, there are bound to be times you feel out of control, at the mercy of tests and divergent medical opinions, times when you despise the weariness and sickness of constant treatment, and are overcome with the fear of what lies ahead, as you struggle to keep some measure of hope, and live with your disease as best you can.

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In the real lives of people with metastatic breast cancer, all these feelings are commonplace, yet rarely shared with others.

Most older Americans recall a post-war era bright with medical miracles. Whole generations grew up expecting the steady advancement of medical progress in every field. If men could walk on the moon, fulfilling Kennedy's promise, surely victory in Nixon's "war on cancer," declared thirty years ago, did not seem beyond reach. But for metastatic breast cancer patients today, those ideals now seem painfully naïve.

Our culture still looks back with nostalgia to these simpler, more optimistic times. Mass media, in response to these widely felt longings, strives to reduce complex information into easily digestible "feel good" soundbites and churn out dramatic "breakthrough" stories. Thus, a newly renamed tumor marker test becomes, in the hands of network news, an innovation of great promise. The discovery of the P53 oncogene, implicated in the wild cellular growth of some tumors, holds out exciting new hope for women with familial breast cancer. On investigation these claims turn out to be premature. The real story is always far more ambiguous.

### **The real story about metastatic breast cancer**

Lost in the hype about questionable new treatments, and in focus on screening and primary care, are the lives and experiences of those living with metastatic breast cancer, which are far more diverse and vital than is generally supposed. A 1995 study sponsored by the National Alliance of Breast Cancer Organizations (NABCO) surveyed 200 women with metastatic breast cancer and their caregivers. Most of those surveyed "believe the public sees these women as being near death—with little or no time to live." But this simply isn't the case. Fully 20 percent of newly diagnosed metastatic breast cancer patients live five years or more.

"Prevailing public perception," according to the study, has it "that advanced or metastatic breast cancer is an immediate death sentence—often perpetuated through inaccurate media portrayals." But the survey overwhelmingly refutes this image, with "74 percent of respondents reporting that women with breast cancer are, in fact, not limited in normal daily routine." Amy S. Langer, Executive Director of NABCO, concludes that "Many patients with metastatic breast cancer are able to manage their illness as a chronic disease, and maintain an active and satisfying work, family and personal life for several years."<sup>7</sup>

Yet their lives are often dominated by the fact of their illness. Like many of the women interviewed for this book, PJ Hagler dismissed cancer from her mind after her initial diagnosis back in 1984. She no longer consulted an oncologist. But six years later, extensive lung metastases were found, and six years after that, tumors in her liver. Recently, undergoing a difficult course of treatments, PJ felt frustrated and sad that some of her friends and family members seemed unable to understand the reality she was forced to live with.

*They think it's not healthy for me to put so much focus on cancer. How do you do that? They don't seem to have an answer for that. For some reason Taxol and other chemo and being bald, sick, tired, and in unreal pain seems to keep my mind focused on cancer from the moment I wake until I take the last of my pills and go to bed at night. I have lived with cancer for twelve years and good Lord willing I would like to live another twelve years, at least. But every day I do live, I live with cancer.*

Jenilu Schoolman, diagnosed with a liver recurrence three years after her mastectomy, was initially told she had only months to live. Defying all predictions, she underwent treatment and entered an extended remission that lasted nearly eight years. This was new territory for her.

*Frankly, remission is an awkward place because I am not busy dying. In fact, beyond the normal wear and tear of aging, I now look and feel as well as I did before I became ill. But I have not been able to go ahead with my life simply as though nothing had happened.*

These two women at different stages of their disease—one struggling with the constant reminder of treatment side-effects, the other with the ambiguities of remission—had something in common: their lives had been permanently changed, and they both keenly felt the absence of stories documenting experiences like their own. When she looked, Jenilu found virtually nothing had been written for people in this “uncharted land,” as she called her life in remission—so she set out to write her own story, “Within Measured Boundaries.” Such a record might help others discover an echo of their own lives, she reasoned, or offer an uncomprehending family member or friend a sense of what it is like to live with metastatic disease.

## **Where are the resources?**

In 1989, when my own breast cancer was diagnosed, the burgeoning of resources for breast cancer patients was just beginning in the United States. Eight years later, the latest guide from the National Alliance of Breast Cancer Organizations<sup>8</sup> lists fully 22 pages of resources for patients, including books, pamphlets, videotapes, businesses, magazines, service organizations, as well as some 350 support and advocacy groups around the country. The half page that is headed “Metastatic Breast Cancer/Recurrence,” however, lists three resources for pain control, two sources of hospice information, one reference to advance directives and living wills, and a pamphlet from the National Cancer Institute, written for all cancer patients, entitled “When Cancer Recurs: Meeting the Challenge Again.”<sup>9</sup>

Should this come as a surprise? Societal reactions only reflect personal, individual responses, writ large. Before you became ill, like most people, you probably were uneasy with the realities of life-threatening illness. You may have found yourself tongue-tied and lapsed into awkward silence at the bedside of someone you love. Maybe you felt compelled to keep up a facade of false cheer during strained hospital visits. Or maybe you even avoided seeing your very ill friends, sending cards and flowers from a distance, especially at the end of their lives.

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There is so much to say at these times—and yet it is still so difficult to speak about what is painful and frightening. So hard to acknowledge the feelings.

Caren Buffum, having exhausted treatments for her liver metastases, recognized this:

*Most people who have not had to deal with these issues either want to believe the best for me (so they don't want to hear from my "I think the end is near" side) or they see me as dead already so they have these unbearable looks of pity on their faces.*

So did Glenn Clabo, whose wife Barb's disease had already spread at the time of her initial diagnosis with Stage IV breast cancer:

*I find myself wondering why our closest friends are rejecting us and our needs at a time when we need them the most. How can people, so called long time friends, pull away from those that they have claimed to love and cherish?*

Once sensitized, evidence of discomfort and denial about metastatic breast cancer seems to be everywhere. Lucie Bergmann-Shuster, whose breast cancer metastasized after twelve years, describes running an errand near her home in San Jose, California.

*The post office had a little flyer sitting on the counter for the breast cancer awareness stamp. The flyer has three personal accounts of women and supports each with a very positive note. "With education, awareness and the support of family and friends, breast cancer is no longer the death sentence it once was," the pamphlet says. "They get treatment, and they go on with their lives....The survival rate is improving daily....Breast cancer...it's a fact of life...not an end to life." Nowhere in this flyer does it mention the tens of thousands of women who die of the disease. While the pamphlet tells no lies, it certainly distorts the truth. To me it is soft peddling this monster that is still claiming far too many lives.*

### Division in the breast cancer ranks

Now that these resources are more widely available, women with breast cancer often join support groups or advocacy organizations following their diagnosis, appreciating the support, information and camaraderie this offers. But having metastatic disease may make you begin to feel estranged from other breast cancer survivors who have not had a recurrence. What is happening to you is, of course, particularly frightening for them. You may find yourself instinctively pulling back, and censoring what you say, for fear of upsetting them. Their concern for themselves and the fear your situation creates in them may interfere with their ability to give you the support you need, at least until you and they can talk openly about it.

What makes this particularly poignant is that these are likely to be the same women who understood so well how you felt when your healthy friends could not, when you were first diagnosed. However understandable these reactions are, it still hurts to feel this distance. Some support groups disintegrate under this stress. Others manage to survive, however, and benefit

from the experience of confronting the reality of the disease, a reality that will become a part of any group of breast cancer patients who continue to know one another over a span of years.

Social worker Roz Kleban tells this story:

*One young woman joined a post-treatment group I was leading. She recurred after three or four sessions, seven months after her adjuvant treatment had ended. She came to the group dressed to the nines for this meeting. "I know all of you are afraid of recurrences," she said. "And I just want you to know that it's much, much, much, worse than you can ever imagine. I'm your worst nightmare."*

*The response to her from another young woman in the group was magnificent: "You are not my worst nightmare. A recurrence is, indeed, my worst nightmare, and I'm sorry it happened to you. My fear is that when I recur, I am just going to fall apart emotionally and be so desperate, and make it worse on myself, my husband, my children. But looking at you somehow encourages me, because as horrible as you're telling me you feel—and I do appreciate that—look at you, you're dressed, you're put together. It's clear to me that you're coping: you got up in the morning, put your clothes on, you're going to work tomorrow. You're letting me know it's possible to do it."*

Still, dread begets dread, and interferes with rational thought. We play games with numbers in our heads. If American women as a whole read the one-in-eight or one-in-nine lifetime incidence figures and are filled with apprehension, it is even more true that the more than a million American women who already have been diagnosed with breast cancer dread recurrence more, fearing and obsessing about the statistics they are given. Prepared for pessimism by losses already incurred, they know intimately what it is like to lose against favorable odds. And the odds, as it turns out, aren't all that favorable anyway.

In the women's magazines, it is common to see figures of 80 to 90% survival, and even higher. According to the American Cancer Society, "The overall five-year survival rate for breast cancer is approximately 83%. The rate can be as high as 96% if the cancer is detected early, before it has spread to other parts of the body." Sounds positive, doesn't it? That is, until you realize it is not disease-free survival they are talking about, and until you examine how the numbers change over time. The ACS report continues: "In spite of this advance, some breast cancers, even localized ones, will recur after five years. The overall 10-year breast cancer survival rate is 65%, and after 15 years, the rate is 56%." <sup>10</sup>

These figures make it clear that breast cancer can, and does, recur many years after the original diagnosis. There is never a time when those diagnosed with the disease can rule out the possibility of recurrence. Once metastasized, breast cancer is no longer considered a curable disease, but a chronic condition that will sooner or later result in death for all but two or three percent of the women with this diagnosis. Of course, as humorists and sages often point out, life itself is an incurable condition.

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### What this means to you

If you feel isolated, judged or discriminated against as a person with metastatic disease, being aware of these larger issues may just help you to identify what's going on. If your friends or family members ask how you are, but don't seem to want to know the answer, if they change the subject or say, "But you're fine now, aren't you?" rather than listening to you, you can know that it is their fear talking. It doesn't excuse such behavior, but it makes it easier not to take it personally.

What can you do about it? Speak frankly, take action as needed and seek out others who understand your feelings. Telling your story and hearing the stories of others, whether in a support group or elsewhere, can provide surprising help and real comfort—but it's not an easy thing to do. Many women discover a sense of healing and purpose in advocacy efforts, working with others to advance legislation relating to breast cancer, secure increased funding for research, and raise public awareness. Speaking publicly, or even privately, about any illness that is rarely cured, where length of survival is extraordinarily variable, where medicine too frequently defaults on its promise of life-saving treatments, means confronting others with what they'd rather not think about. It means being mindful of walking the thin edge between preserving hope and facing reality, between optimism and truth-telling, between challenge and acceptance. This balancing act is what all metastatic breast cancer patients and their families, caregivers and physicians face every day.

From this dynamic relationship comes this book's dualistic original title:  Holding Tight, Letting Go . Holding tight to those you love, to integrity, courage, to what matters most to you, to the promise of remission and even cure, to life itself. Letting go of your illusions of control, of immortality, of health and youth and beauty—and of the guaranteed future. Letting go of regrets and expectations, into the present moment in which you live, into your final moments and the mystery beyond.

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### NOTES:

<sup>1</sup> Brenner, Barbara, "Let them lick stamps," Breast Cancer Action Newsletter #37, August/September 1996. Pg. 2.

<sup>2</sup> Sontag, Susan, Illness As Metaphor, and AIDS and Its Metaphors, Doubleday: New York 1990, Pg. 3.

<sup>3</sup> Taylor, Shelley Positive Illusions: Creative Self-Deception and the Healthy Mind, New York: Basic Books, 1989.

<sup>4</sup> Goleman, Daniel "Insights into Self Deception," The New York Times Magazine, May 12, 1985, Pg. 36.

<sup>5</sup> Slater, Philip The Pursuit of Loneliness :American Culture at the Breaking Point, Beacon Press: Boston, 1976, Pg. 19.

<sup>6</sup> Frank, Arthur At the Will of the Body: Reflections on Illness Houghton-Mifflin, New York, 1991, p. 13

<sup>7</sup> "NABCO Survey Challenges Public Perception About Metastatic Breast Cancer," PR Newswire, October 19, 1995, Thursday

<sup>8</sup> Breast Cancer Resource List: 1999/97 Edition, p. 16. National Alliance of Breast Cancer Organizations (NABCO) 9 East 37<sup>th</sup> Street, 10<sup>th</sup> Floor, New York, NY 10016 (212) 719-0154 Single copies \$3.00.

<sup>9</sup> "When Cancer Recurs: Meeting the Challenge Again," 1992 National Cancer Institute, publication 93-2709.

<sup>10</sup> American Cancer Society Website, at <http://www.cancer.org>.