

## Breast Cancer: Facing Recurrence

Finding out that breast cancer has recurred or spread beyond the breast is always a terrible blow. Almost all breast cancer patients know already that this means their prognosis, which may have been good, is no longer nearly as hopeful. Unless they've known others with metastatic breast cancer, they may even assume that a recurrence signifies imminent death. It takes time, accurate information, and support to work through these early reactions.

### Getting the bad news

This was how Pam Hiebert, diagnosed with Stage IV breast cancer, described her emotional response to getting the news about her bone metastasis from her surgeon.

*It seemed so bizarre, for she kept repeating, "We have ways of treating this." All I heard were the numbers, 35 percent chance of being alive in two years. Now I realize statistics are only a crude picture, like little stick figures made up to represent a class of people someone else can look at and line up. I remember at one point getting really angry at this surgeon for not having a solution, and I blurted out, "I don't want to hear this. I'll just have to find some people who can tell me better things."*

"People go through various stages in their attempt to adjust to a serious illness," writes psychologist Margaret Backman. Drawing on studies in the literature on coping and adaptation to illness, Dr. Backman describes the responses of one of her patients as typical of what many people experience at this time: "Following the diagnosis, there was a period of shock, of disbelief, an inability to face the reality of what was happening. She felt like an outsider, looking in at the scene. Emotions were cut off, isolated from what was happening around her. There was a sense of cognitive dissonance, a temporary dissociation of the self from the body and from feelings, expressed numbly as 'This can't be happening to me.'"

### Rivers of tears

According to Dr. Backman, the initial stage of shock and disbelief tends to give way to a period of grief and sometimes despair within a day or two. Again describing a patient of hers, newly diagnosed with serious ill-

ness, she writes: "Feelings of anger alternating with hopelessness and deep depression affected her eating and sleeping. She was emotionally flooded with disturbing and persistent thoughts of what was to be: thoughts of self, family, friends, job, upcoming treatments, prognosis. The future appeared bleak, as if there were no way out."

After her first metastasis was found in the bone of her hip, Lisann Charland experienced many of these same strong emotions.

*The "Why me, Lord?" questions came back over and over again in my mind. Where did I go wrong? What could I have done to prevent this? The guilt and helpless feelings left me crying rivers of tears. Poor Buddy cried along with me and felt helpless and angry at what was happening again to me. I wanted to run away to my family—I needed my mommy. I had not even told my mom and dad of the recurrence. After the crying sessions, I begged Buddy for a divorce. I felt doomed and did not want to be a burden to him. He had been a wonderful husband throughout all the obstacles sent our way. He deserved better than that. He would not hear of my divorce request and encouraged me to keep my spirits up. He was staying with me for better or for worse. We lived on coffee only for two days.*

It is normal to experience a sense of numbness, unreality, and disbelief when you first hear the bad news. This is the psyche's way of protecting itself. These feelings are often followed by deep grief, anger, and even despair for a time. It's important to get loving emotional support, if you can. Having someone with you and holding you, perhaps sharing in these strong emotions, is what helps most. While you are absorbing the bad news, it may be difficult to think clearly and make sense of the information you need to help decide about treatment. If you allow yourself time to express the normal feelings of grief and anger and get the emotional support you need, you will feel calmer later on, when it is time to talk to the doctor, research your treatment, and make decisions.

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### The dubious future

“It has been assumed that recurrence is more distressing, disabling, and discouraging than the shock of the first diagnosis of cancer,” wrote Dr. William Worden, a psychiatrist who teaches at Harvard Medical School and practices at the University of Massachusetts Medical Center. Worden studied the experience of patients with several kinds of recurrent cancers, breast cancer being one, and compared his 102 subjects with newly diagnosed patients from an earlier study.

*Surprisingly, there was a sizable group of recurrent patients (30 percent) who found the experience less traumatic than their original diagnosis. These were patients who were less surprised by the recurrence, who had not let themselves believe that they were cured, and who, in some respect, were living under the proverbial Sword of Damocles.*

Lucie Bergmann-Shuster had suspected recurrence for a long time and experienced the confirmation of her fears, when it came, as a kind of relief. As she awaited the surgery that would give definitive word about whether the mass on her ovary found in the scans was a recurrence of her breast cancer, she was already beginning to prepare herself and her husband for what might lie ahead.

*The memories of my mother's death nearly a year prior comforted me with the knowledge that dying was not such a terrible and frightening affair at all, especially with the aid of a hospice provider. My husband and I would talk about my end stages, and he offered to stay with me, possibly taking a leave of absence from work for the duration of the terminal portion....It occurred to me that neither my husband nor hired help would be able to continue the upkeep of the garden. Similarly, our house with its three bedrooms was excessive for the one survivor, my husband....I proposed that we sell our home...then move into a two-bedroom condo. Part of the downsizing would be selling off the antiques....Whatever loss I would perceive would lighten the future burden for him, and that gave me release.*

As women and their families emerge from the haze of unreality and numb shock and move through the initial grief and anger, they often begin to experience a sense of great urgency. Although it is rarely the case, death seems imminent. Not knowing if treatment will be effective in bringing about a complete or at least a partial remission, people feel a deep imperative to prepare and plan for what they fear lies ahead. Often, in retrospect, these plans seem irrational or precipitous, but at the time, they fulfill a real need for mastery, and reflect the presence of a heightened sense of mortality.

For Jenilu Schoolman, time was suddenly foreshortened, and she felt a tremendous pressure to complete whatever was undone.

*In the next few weeks, my behavior mirrored my thoughts as I dashed about making sure my will was in order; making funeral arrangements, trying to make sense of my rather messy financial affairs....I had so many decisions to make; most of them felt bizarre. What music did I want at my memorial service? Where did I want such a service? Who would do the service? What did I want done with my remains? I became compulsive at anticipating my family's needs and tried to dream up solutions only to realize more fully that my death meant I would have no part in helping those I love....As I tried to prepare myself to die, I tried to prepare my family to go on living. I picked and froze enough raspberries and blueberries to last two years. I made and froze a year's worth of coffee cakes, thinking they'd be useful when people visited after I died, never dreaming I'd be alive to eat them myself.*

### Where do I start? What do I do first?

Most of us, when faced with a personal crisis, medical or otherwise, find our way through it as best we can. Social scientists, studying how people respond in these circumstances, have found that some situations make coping much more difficult and that those who cope successfully tend to use certain common strategies.

Harvard psychiatrist William Worden's study of coping showed that stressors associated with high levels of

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emotional turmoil were: degree of sickness (including symptoms, disability, and confinement); lack of emotional support; presence of concurrent concerns unrelated to illness; pessimism and fears about death; lack of spirituality; and relative youth. All of these stressors were significantly correlated, he found, with self-blame. “This self-blame is interesting,” Worden commented, “in light of current popular literature that espouses the need to take responsibility for the condition of one’s health, whether good or bad.”

Worden also found that neither elapsed time since primary diagnosis nor prognosis for recovery had much to do with how hopeful patients felt. If anything, patients who went long periods of time before recurrence, who were most likely to have considered themselves cured, were among the most hopeful, contrary to his initial hypothesis.

In looking at how people coped, Worden found certain factors that helped a great deal: knowledge of the medical system and how to negotiate it, understanding of cancer treatments and side effects, and familiarity with the extent—and availability—of a support system. “Support continues to be an important mediator of distress,” Worden observed, “and the support systems for recurrent patients had already been tested at the time of their original diagnosis. By the time the cancer recurred, these patients knew with some degree of certainty what support would be available.”

As the first force of the emotional impact of the diagnosis begins to lessen, most people newly diagnosed with recurrence feel an intense and urgent need to do something, to take some sort of concerted action. Uppermost in their minds, of course, are questions about treatment, prognosis, and selecting the best medical team. At the same time, as they go through the often maddening hurry-up-and-wait process of testing, consulting, and seeking opinions on treatment, they are also reaching out to others for emotional support and embarking on a search for meaning.

Reaching out for support can take many forms. Often it can mean seeking out new sources. Disappointed with the response of their friends, and sensing a need for

more emotional support, as well as for information, Glenn Clabo subscribed to the Breast Cancer Discussion List on the Internet.

*I received an onslaught of welcome messages and a very warm welcome feeling. I think that this day was the day that made me realize that we weren't alone and that I needed people's help. I learned that I could just state my feelings much better through written words than I could verbally.*

If they are fortunate enough to have a close and resilient relationship, couples reach out for one another, experiencing an intimacy deepened by crisis.

Lisann Charland reached out broadly for support.

*I started by notifying my out-of-town family and friends that the disease had recurred. The support and encouragement I got from both near and far away was unbelievable. My Buddy was a rock. I knew he hurt just as much as I did throughout this whole nightmare. I felt blessed and lucky to have him and all the family and friends in this great time of need. My sister and brothers were devastated. My in-laws were wonderful, as usual. My employer advised me I could work whenever I wanted. Everyone was very supportive and offered to help me in any way I needed....With fellow workers, I wanted them to know directly from me, not from whispering around the edges....Some would make a point to come in and just give me a hug or to tell me they were praying for me. This was a support group—certainly not a group who had “been there,” but a group that really was concerned.*

At the time of her primary diagnosis, Barbara had sought support from her church. Church elders had joined her in prayer at her bedside before a second biopsy and hailed the benign results as a miracle. As a single mother and sole support of her three children, she had prayed then that she would live long enough for her youngest, then five years old, to reach age eighteen.

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*Everyone knew of this prayer. When my son turned eighteen, we all rejoiced, and I have thanked God ever since for allowing this to happen. I taught Sunday school for the next eleven years. When the cancer recurred, my youngest was twenty-five. Although I was absolutely crushed with the news, one of my first thoughts was that I had lived seven years past the time I had prayed for and I was determined to live. If I beat this thing before, I know there's a good chance I can again.*

For Pam Hiebert, the diagnosis of recurrence provoked an existential crisis and then a spiritual awakening.

*On the day the surgeon said "metastasis," I experienced the lowest and most frighteningly intense Thursday night I have ever felt in my entire life. I stood at the living room window and stared out onto the street below for hours. I groped desperately for understanding. I remember trying to rationalize, thinking how people with AIDS were actually worse off than me. I remember thinking about all the people who have lived on this earth and how everyone eventually died. I remember the beginnings of my own awareness that I would also die. It was at this darkest hour of my life that I found spirit. She rose in me like a mother protecting her young. It was in this darkest hour that I began to formulate my own battle. I let go of what I had been holding and began to plan how I would die—but die a warrior's death—I would lay claim to this diagnosis, and I would launch war. I would die a death befitting a warrior, an amazon, a goddess of fire and sword. I would name my dying and lay claim to its process. I mentally moved through a spirit world of basic survival.*

After an ultrasound test confirmed that there was a mass on her ovary, Lucie Bergmann-Shuster and her husband, Cy, decided nevertheless to continue their plans for Thanksgiving at Yosemite National Park with friends. The surgeon's appointment would be on Monday.

During a long, boring stretch of road well known as a hunting ground for hawks, Cy and Lucie were keeping an eye out for birds of prey.

*Suddenly, a hawk dived at our windshield, veering off a few feet before impact. It sent chills down our spines and no sooner did our suddenly jangled beings recover than yet another bird of prey crossed the windshield again only a few feet away from the moving car. It was as though the two flight patterns were making a sign of a cross in our path. My husband and I looked at each other in amazement, and I said, "I think the spirit world is trying to tell us something." After a long silence, I said to Cy, "I think that perhaps the hawks are my spirit beings after all. Why else would they come so close to me at this loaded and uncertain time in my life?"...We all got to go for a hike in Big Trees to look at the majestic sequoias. The ancient, giant trees allow for a serenity and peaceful acceptance of timelessness within a world of decay while heralding new growth in musty, pine-scented peat. Both of us savored the greater calm and let it carry us through to the Monday doctor appointment.*

For each of these people, this was the beginning of an ongoing adjustment process that included a search for meaning within the experience, as well as an attempt to regain mastery over the recurrence and over life in general. All of these people moved past the shock and grief of diagnosis to do something to regain the control they had lost, or to seek a deeper contact with others or with their own sources of personal meaning. By doing so, each took a first step in the direction of coping and acceptance.

This fact sheet was adapted from *Advanced Breast Cancer: A Guide to Living with Metastatic Disease*, 2nd Edition, by Musa Mayer, copyright 1998 by Patient-Centered Guides. For more information, call **800-998-9938** or see [www.patientcenters.com](http://www.patientcenters.com).