

# Cancer: Fear, Suffering, and the Need for Support

*Marge Whitman*

FEAR, SUFFERING, and a need for support are part of the experience of every person with cancer, but people are often uncomfortable with and shy away from these human emotions, which seem like admissions of weakness. Latter-day Saints in particular often believe that a person with “sufficient faith” shouldn’t fear death, that a “good” doctor can prevent suffering, and that people who need support must not be coping very well. Though we may not always be aware of or voice these attitudes, they become evident as we deal with those with cancer. I know, because I am both a cancer nurse and a nurse with cancer (in remission).

I first learned my blueprint for living with cancer from my mother. Mother was treated for breast cancer and numerous other health problems before she died of cancer of the pancreas when I was twenty-three. She spent her final weeks at home, where I nursed her.

Mother was seen as a pillar of strength by family, friends, co-workers, and clients. Because she was divorced and alone, she worked full time as a beautician to support herself until six weeks before she died. Family members wanted her to quit work as soon as she learned the diagnosis, but she agreed with her doctor’s suggestion that continuing to work would help her feel needed and would delay the role of invalid.

When ward members came to visit her, they reported each time how much she encouraged them. Because she was shy, they hadn’t known until her illness that this little divorcée, who had joined the

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Church only two years before her diagnosis, was so faithful and loving.

Going back to work must have been a burden as well as a blessing for her because customers and co-workers knew that she labored under the weight of a terminal illness. Several of her friends told me they were amazed by her ability to focus on the job, rarely referring to her condition.

For years tension had existed between Mother and a co-worker. This grievance had pervaded their working relationship, and Mother's attempts to reconcile the relationship had failed. However, the way Mother bore her illness, without burdening others or complaining, inspired the woman. A week after Mother stopped work, a large bouquet of white roses arrived at the house from the estranged friend, with a card bearing words of admiration, apology, and love. That prompted a beautiful reunion characterized by forgiveness and tenderness.

I traveled from North Carolina to Oregon to spend Mother's last six weeks with her. She had determined that she could no longer work. When I first arrived, she was dressed and appeared to tolerate some exertion; but almost overnight she had to sit more than stand, then soon lie down more than sit. My role changed from housekeeper to nursing assistant, and, as I now understand, I began to grieve in anticipation of her death.

Among the many things we discussed were her appearance, privacy as the disease progressed, the final hours of dying, the disposition of her worldly goods, and her funeral. She had specific wishes about these issues, but I wanted to reject the idea that she would die. I insisted on talking about how she would make her home with me after my husband finished graduate school and found a job. I talked about how she would see my daughter, her only grandchild at the time, grow to maturity. While she appeared to consider these ideas, she often steered our conversations to heaven and earth and what happens after we die. Mother hoped she would be able to help select her grandchildren before they were born.

One of her sisters had recently died of the same type of cancer, and Mother's decisions about her own last days seemed heavily influenced by what had just happened to her sister. She seemed to take comfort from the idea that she would see her sister shortly. I focused on the present—to give her the care she needed—and continued to deny that I was losing her until she was gone. I regret my stubborn denial that imposed a loneliness only the dying know. Years later when I read Kubler-Ross's works on death and dying, I realized that Mother had tried to talk to me about what she was experiencing and that I had unintentionally refused her that comfort.

As far as I could discern, she was comfortable until the end; and I felt that I had been faithful to her. She had prepared me for the end stages and the funeral during those last weeks and helped me increase my acceptance of her death. These experiences shaped my expectations eighteen years later when my own cancer was diagnosed.

## FEAR

Cancer is frightening. Even as a young woman, I feared it. When my nursing instructors presented the symptoms and risk factors of cancer, I worried about my own health and about how I would be able to deal with cancer personally. I was twenty-four years old when my doctor detected a lump in my breast. I remember clearly the emotion that choked my voice when I called my husband to tell him about the condition—which later proved benign. After that I did everything I could to reduce risk factors for cancer, hoping that my behavior would protect me against the disease. It was not to be.

I will always remember the overwhelmed, powerfully disorganized feeling the diagnosis of cancer generated in me. To the very moment of diagnosis, I was in control of my life, my family, my home, my church responsibilities. At forty, I felt youthful but maturely confident. The information that my condition was malignant turned my planned, predictable world upside down. I focused on the immediate tasks of preparing for a sudden absence from home and family; and with the help of others, I successfully organized that aspect of my illness.

But dealing with the longer-term future and with relationships was much more difficult. I telephoned three friends whose love and encouragement I needed and shared my fears with them. They responded with expressions of love and grief, and the tender cord that connected us gave me the strength to hope.

To this point, my husband Dale had been immersed in the challenges of raising funds for and administering a professional school; he had relied on me to handle our home and family, freeing him to focus on his career. We had recently allowed ourselves to be distanced by these demands and had hoped that the future would allow us time to restore our former closeness. The diagnosis of cancer dramatically cut through that optimism. Tearfully we clung to each other, not just at the first, but with great tenderness for weeks and years after. Our priorities were suddenly boldly clear. I did not want to lose him; he did not want to lose me. In a heroic effort and with the support of wonderful colleagues, he was able both to give me the most

sensitive support imaginable and effectively act as a caring professional.

The experience that offered me the greatest strength occurred the night my breast cancer was diagnosed. My husband was out of town, so my seven children and I worked to organize ourselves for my hospital admission scheduled the next morning. Some of the older children were mature enough to put aside their own immediate fears and help get the younger ones to bed. Exhausted, we all fell asleep quickly. I awoke in the quiet of the night to the sound of a gentle rain, sat up, and turned on the light. As I listened to the rain, the short scriptural verse "Jesus wept" flowed into my mind. In that instant, I felt completely assured of Jesus' love and compassion for me—as if the rain were tears of sorrow, shed for the trial my family and I were facing. From that moment throughout the course of my treatment, I felt sure of his love and of my personal worth to him. I was freed from the feeling that God was punishing me that I might otherwise have carried. It is common for cancer patients to hear the cruel notion that God has offered the experience for their benefit: "God loves you so he is sending this nightmare called cancer to try you." I would like every individual to have the reassurance that earthly sorrows are not handed out to try the weak or test the strong, as well-meaning people sometimes suggest.

I also reject suggestions that a victim's lifestyle has caused the cancer. Such advice is often accompanied by the suggestion of a specific diet or dietary supplement, often with a certain smugness as if the giver were party to special knowledge that would prevent or cure the disease. The very real fears induced by the diagnosis of cancer are not assuaged by simple explanations of cause or easy schemes of treatment. At this time, we simply do not know the cause of cancer. Risk factors associated with some types of cancer have been identified, but the cause remains elusive. Fear is an emotional response to the disease's dangers. But learning the characteristics of a particular cancer and the available services and supports can help mitigate this fear. Knowledge gives power to protect and improve one's lifestyle while managing the disease. People who truly want to help will consider first the feelings of the person with cancer, will set aside theories not accepted by the medical mainstream, and be willing to share the victim's grief and hopes.

#### SUFFERING

To talk openly about one's suffering is taboo in this day of anesthetics and relaxation techniques. We have been sold a view of a mod-

ern life without pain: painless childbirth, painless payments, painless relationships. However, this painless state remains elusive. It does not take much experience as the recipient or provider of medical treatment to learn that some things hurt. Adults with well-practiced self-control may be able to dismiss some of the pain that comes with the disease and its treatment; but when usual coping mechanisms are overcome, these individuals too find that pain is undeniably real and trying.

Pain can often be obscured with medication, but sometimes the costs or risks of painkilling drugs are considered too great. Therefore most diagnostic or short surgical procedures are done with local anesthesia which may not obscure pain entirely. Unfortunately, some health providers may increase suffering when they are rough, hurried, indifferent, or ignorant of the pain they cause. I was impressed and amused by the honest forthrightness of a night nurse who introduced herself to me by saying, "Hi! I have three services to offer: cold, hurt, and embarrass."

When the Savior was on the cross, he cried out from the depths of his suffering, "Why hast thou forsaken me?" To be ignored or treated indifferently increases the impact of physical pain. The loving companionship of a friend or family member significantly alleviates suffering as is demonstrated by the calming presence of husbands in delivery rooms. Women left to the care of impersonal professionals consider this suffering much greater than those who receive loving companionship and support.

When Joseph Smith faced surgery on his leg without anesthesia, he promised cooperation if his father would hold him in his arms. People need assistance to concentrate fully on something other than the painful experience. Slow, deep breathing or soothing sounds like the "white noise" of water falling or wind blowing through trees seem to help some people. I have supported many people through biopsies and suturing by insisting they look directly at me and listen to me as I talk softly but reassuringly to them. I tell them, "You are handling this situation very well and you can maintain control because I will stay with you and help you." One of the most trying aspects of nursing, in this time when nursing personnel are in short supply and medicine strives toward "efficiency," is the limited opportunity to support people who are suffering.

A doctor or nurse can be alienating as well as supportive. I found it very stressful to receive treatment from one physician who seemed to dislike me personally. I felt that he did not approve of my values and was indifferent to my personal needs. Changing to a different doctor was awkward for me, but the change provided greatly improved care

and emotional support. If circumstances had prevented my making a change, I would have needed other advocates to help me achieve a sense of dignity in that relationship.

The suffering that comes from cancer, like the fear, is emotional as well as physical. Social isolation, changes in lifestyle, feelings of rejection, and altered image also cause suffering. While suffering cannot be entirely eliminated, accurate information, empathy, and advocacy for the person who faces cancer can help diminish it.

### SUPPORT

For persons reared to value emotional self-sufficiency, the acceptance of support from others may imply personal inadequacy. To the contrary, I think drawing on offers of support is the wise use of every healing resource available for the benefit of oneself and loved ones.

I suppose it is symptomatic of our society that strangers seek each other out to form a social network. Although friendships often develop in support groups, exchanging information for coping and management of the disease is the real purpose.

Not long after my own treatment for cancer started, I was asked to serve on a steering committee to organize a support group for breast cancer patients. I willingly attended the planning meetings because I knew there were many individuals “less fortunate than I” who needed this type of support. Driving to the first meeting, I said to myself, “I am so tired, and I can’t handle more ‘support’ relationships than I have now; I’d really rather not go. But these elderly ladies could probably use a dose of positive attitude.” I sat in the circle, far from the starting point of those introducing themselves, and listened as one by one the women told of their own experiences. The circle was so large that we had to conclude the evening before my turn came—but long after my own awakening. As I listened, I heard these women expressing my own thoughts. For the first time, I allowed myself to admit how I was feeling.

When friends and family had asked me almost daily how I was feeling and getting along, I would reassuringly answer, “Oh, I am just fine,” for fear I would worry them. And when feeling relatively well, I did not want to even discuss cancer. Denial of my illness had been one of my strongest coping mechanisms.

Often cancer patients and their families are so busy coping with lifestyle changes that they do not deal with their own fears. To face the fears alone may be overwhelmingly painful. Honest, open discussion is possible in the company of others who have gone through the pain and share the experience. As I became more involved in my support

group, I came to see it as a place where I could express myself openly without having to protect my family and friends from my fears and feelings.

It was a full nine months after my initial diagnosis and surgery, in a support group meeting, that I first allowed the realization that I probably still had cancer—that I was not cured. Until then I had clung to my surgeon's reassurance that no tumor remained after the operation; but in the presence of supportive fellow travelers, I could finally admit to myself what the chemotherapy doctor had been telling me: there was a good probability that I still had microscopically detectable cancer with the biological potential to spread.

A friend who was objective about cancer's seriousness and the necessity to treat it aggressively also helped me to persevere. Sometimes I could persuade my family that I should stop treatments; but when I would tell my friend this, she would camp at my door, her arms loaded with supportive books and articles, and persuade me to finish my treatments. She refused to be swayed by my distraught appeals. She thought there were apparent solutions to every problem. My chemotherapy often left me too sick to care for my precious, active two-year-old son. "Just put him in day care," she would say. "I'm getting weaker and can't burden my family," I would complain. "Arrange for someone to stay with you when you are sick," she would counter. Her solutions were obvious. My family and I had been too upset to find them.

We were also fortunate to have an excellent LDS social services marriage and family counselor available to help us deal with personal and family problems. I explored with him how I could respond to others' inquiries and concern. Undue attention made me uncomfortable, but I also did not want to conceal the fact that I was having some severe challenges. His professional skills were an enormous help.

Shortly after I realized I had cancer, I began to write about what I was feeling and learning in order to share with my family and friends how blessed I felt and to offer hope of safe passage to other cancer patients. Since then I have met several cancer patients who likewise wanted to write or record their experience in order to encourage others.

I can think of three reasons why cancer patients feel compelled to write about the experience. First, our survival is being challenged, perhaps for the first time, and we use our coping skills as never before. We want to "pull out all the stops" and marshal our total energy to fight a mortal enemy. When we have had time to recover from the initial shock, we want to describe the methods we used to keep our world intact. For example, during treatment I could not satisfy my appetite for scriptures. In a few days, I found I had read and reread

the first half of the Book of Mormon. Many of the things I wrote bear witness to the sustaining power of the scriptures.

Second, writing is a form of firmly setting goals. If I record an idea that I believe will be helpful, then I am determined to prove it helpful. I was convinced that small acts of faith were necessary for healing, so I committed myself in writing to daily prayer and scripture study. If I had written that a spiritual odyssey were necessary to healing, I might have planned a trip to the temple for the purpose of healing. Writing is a mirror to help identify and focus needs and strengths.

Third, writing satisfies the need to nurture. Serious illness saps the active energy required for service at home and in most organized activities. Writing, on the other hand, provides even the bedridden a small opportunity to serve others.

My exposure to cancer, as both caregiver and patient, has taught me about fear, suffering, and the need for support. During my time as a nurse, I have seen patients conquer difficult challenges by persevering and by participating in support groups. From my mother I learned to carry on as normally as possible and to have faith in rational prospects for the future. My own illness has shown me that faith in God accompanied by personal efforts to sustain myself and others provides a good quality of life. Perhaps my experience and my realistic optimism can help another hoping and searching for safe passage.