

The Human Side
of Cancer

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Chapter Two

THE TYRANNY OF POSITIVE THINKING

I got really depressed when people said I should think positive. I thought, "If that's what I have to do to survive, I'm never going to make it."

-John, a fifty-two-year-old man with melanoma

People keep telling me to be upbeat. I say, "Screw you. I'll be however I please in dealing with this cancer I've never been upbeat in my life."

-Michael, a forty-five-year-old schoolteacher with recently diagnosed sarcoma

Several years ago, Jane, a forty-nine-year-old woman with breast cancer, came to my office at Memorial Sloan-Kettering Cancer Center in New York City. She had recently completed her treatment, and her doctor had given her a clean bill of health, meaning the doctors had found no evidence of cancer in her body. Indeed, the glow of good health had returned to her cheeks.

But as she entered my office, Jane looked agitated. Her body was tight and tense. As she sat down, I said, "I've heard the good news from your doctor. I hear you're doing well."

"That's what he says," she replied despondently, "but I feel like I'm losing the battle."

Puzzled, I asked her, "What makes you feel that way?" She responded, "Well, my sister gave me a book on how to survive cancer, and it says it's critical to keep a positive attitude. I've tried to stay upbeat through the treatments, but now that they're over, I'm more afraid and worried than ever. I'm sad, and I can't feel positive about anything."

I said, "It must have been hard to stay positive all the time over this past year, because I remember how crummy you felt during those first days after each of your six chemotherapy treatments."

"Yes, it's been hard when I've felt so washed out and tired," she said. "And sometimes I've been so scared and frightened, I wondered if I could get through it. Other times, I've been down and sad and angry that this hit me when I had wanted to do so much for my kids. . . "

"That sounds right on to me I said. "I can't imagine how you could have been positive all through this last year when you had to slog through so many difficult tests and treatments."

Jane started to relax a little. "You mean it's okay, and I haven't kept my cancer from being killed off by chemotherapy because I couldn't do what that book said?"

"No, you haven't," I said with a smile. "You're not superwoman, you know. You're wonderfully human and normal. Most people experience the same reactions you've had at some time."

"Great!" she said. "Because I was thinking that if any more people tell me to think positive, I'm going to slug them."

Jane was echoing a refrain I often hear from people with cancer: the notion that feeling sad, scared, upset, or angry is unacceptable and that emotions can somehow make your tumor grow. And the sense that if the person is not in control on the emotional plane all the time, the battle against the disease will be lost. Of course, patients like Jane didn't come up with this notion on their own. It's everywhere in our culture: in popular books and tabloids on every newsstand, on talk shows, in TV movies.

For most patients, cancer is the most difficult and frightening experience they have ever encountered. AH this hype claiming that if you don't have a positive attitude and that if you get depressed you are making your tumor grow faster invalidates people's natural and understandable reactions to a threat to their lives. That's what I mean by the tyranny of positive thinking. This problem has been brought to me by well-meaning families who say, for example, "You have to help Dad. He's going to die because he isn't positive and he's not trying." On meeting Dad, I see that he clearly is a stoic, a man who copes well in his own quiet way. Maintaining a positive attitude just isn't his style. Insisting that he put on a happy face and cope in a way that would be foreign to him would actually be an added burden; to rob him of a coping mechanism that has worked before seems unfair, even cruel.

Another downside of this tyranny of positive thinking is that Dad may feel guilty for failing his family if his disease should advance and he had been unable to change to a more Pollyanna-like stance.

Another time, I was called by a woman whose husband had died of lung cancer. In her grief, she blamed herself for his death because she had not gotten him to any cancer support groups that could have taught him mind-body techniques, which she believed might have saved him. I tried to reassure her that she had supported him in every way and that these techniques would not likely have carried the day for him in the face of advanced lung cancer.

ATTITUDES ABOUT GETTING CANCER: BLAMING THE VICTIM

The additional negative consequences of these particular beliefs and myths about cancer lead to another phenomenon: blaming the person for getting cancer. Accusing questions, such as "Why did you need to get cancer?" or "You must have wanted to have cancer" suggest that the patient must have willed it to happen.

Helen, a young woman with cancer, said to me with great sadness. "I feel as if I have been victimized twice: once because I have a brain tumor for which there is no known cause and a second time because I am blamed, that it's my fault. It just isn't fair."

The late Barbara Boggs Sigmund, who was the mayor of Princeton, New Jersey, became furious at the suggestion that she was somehow to blame for her eye cancer (ocular melanoma) and its spread. In a New York Times op-ed piece (Figure 1) she expressed her rage at self-help books that presumed that "I had caused my own cancer" out of a "lack of self-love, need to be ill, or the wish to die, and that consequently, it was up to me to cure it." Ms. Sigmund repudiated the theory that "cancer cells are internalized anger gone on a field trip all over our bodies" or that "rah-rah-sis-boom-bah, I can beat the odds if I only learn to love myself enough."

I want to set the record straight right up front and give you the most up-to-date information from research studies regarding the role of the mind in causing cancer. It's not your fault that you have cancer. For most cancers, the cause is far from clear, and your psyche did not play a role in your developing it. You surely didn't "want it"! As we learn more about cancer prevention, we are learning about habits and behaviors that do increase cancer risk. But aside from cigarette smoking and lung cancer (see Chapter 12), the results are far from definitive concerning the causes of most cancers.

How did this phenomenon of blaming the patient for the disease come about? It undoubtedly is related to the fact that cancer has been a mystery for so long, as to both cause and cure. When we know little about something, we become even more frightened by it and develop myths to try to explain it and put it in some tolerable perspective. Cancer isn't the first disease to be saddled with myths. Until a cure for tuberculosis using antibiotics was found in the 1940s, it was said that people with certain personality traits developed tuberculosis and that stress or an emotional weakness led to contracting it. Such ideas disappeared as science established that tuberculosis was caused by a bacterial infection and drugs became available to cure it.

I saw some of the first patients with AIDS in New York in the early 1980s. In those early years, fears among the public were high because we didn't know the cause and we didn't know how the disease was transmitted. Many people were terrified until the virus was identified and the blood supply for transfusions was made safe. Panic diminished when scientists identified the highest risk to be from exposure to bodily fluids containing the AIDS virus, through either contaminated needles or sexual contact.

Similarly, as we know more about the causes of cancer and as more types of cancer become curable, the myths surrounding it become less powerful. Increasingly, we depend more on valid scientific information and less on long-held beliefs.

When misfortune strikes, it is a natural human tendency to search for a reason. The ready explanation is often "he must have brought it on himself." This reaction is similar to the response when someone is mugged. People say, "What were you doing in that neighborhood, at night, anyway?" Blaming the victim lets us say, "It can't happen to me." This response is a part of a bigger psychological picture: the need to attribute a cause to any catastrophic event, whether an earthquake or an illness. By blaming the victim, we get a false sense of security that we can prevent events that are beyond our control. We seek to make sense of something that surely makes no sense at all.

The fact is we can't always prevent cancer. Susan Sontag makes the strong point in *Illness as Metaphor*: illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

So it makes no sense to blame the person who is ill. Being ill makes one feel alone enough, and being blamed adds to a feeling of distance and isolation, of somehow being "different" from others in a way we've never experienced before. As Robert, a young man with Hodgkin's disease, put it, "I'm not Robert anymore. Now I'm Robert with cancer. I feel alone with it." You may have encountered the blaming response from friends and family members. If so, I advise you to tell them, "I know you have my best interests at heart. But it's not helpful to tell me that I had something to do with my getting cancer. And it's not realistic to expect me to be positive twenty-four hours a day."

ATTITUDES AND SURVIVING CANCER

The same attitudes that are at work in blaming you for having caused the cancer in the first place are often also applied in explaining why you are cured or not. Attitudes and personality, by affecting your behavior, do often lead to your getting an early diagnosis of cancer. This alone is a key factor in cure. For example, if you are the type of person who has a proper respect for staying healthy, you go to the doctor for regular checkups or when troubling symptoms develop, you cooperate with your doctor and follow advice carefully, and by so doing you are apt to discover a cancer at an early stage, should it develop. We know a lot about the ways that our personality and emotions lead us to engage in habits or behaviors that increase our risk of getting cancer. Good examples are smoking and lung cancer, and sunburn and malignant melanoma.

We also know a lot about how attitudes and emotions can affect our endocrine and immune systems as we respond to stress. However, it is less clear whether attitudes and emotions, by themselves, can change an internal process to make an impact on tumor growth or the body's response to it. We don't know whether the blips in hormone and immune levels due to stress have any connection to cancer at all or, should there be any such connection, how it works.

Indeed, research in the new field of psychoneuroimmunology--exploring connections between the brain, the hormonal (endocrine) system, and the immune system--has given us an exciting picture of the body's responses to stress. It is known that different types of stress, ranging from taking medical school exams to going through a divorce, affect both hormones and the immune system. The evidence linking stress and risk of heart disease is quite strong. Stress exerts its effect through the nervous system, which in turn affects heart rate, blood pressure, and hormones. But whether this is so for cancer is far less clear. Nevertheless, people today have many questions, based on what they've read and what their friends tell them about cancer and the mind. And people make a lot of mistakes and premature assumptions on the basis of incomplete research. They think, for instance, that if the stress of divorce affects immune function, then it follows that "my divorce must have caused my cancer." This kind of extrapolation, which is without scientific evidence, leads to many false assumptions and conclusions. In Chapter 3, we attempt to separate facts as we know them now from the hype and plain misinformation surrounding the mind-body-cancer connection.

It is common for people who have survived cancer to look back on the experience and attribute their survival to their positive thinking, discounting the fact that they also sought medical help early and had the best-known treatment for their cancer. This belief not only provides an explanation for their cure from cancer, but also buffers fears that it will come back. "If I licked it once with this attitude, then I can keep it from coming back the same way." This belief is reassuring and provides a way of coping with the normal fears people have about the cancer returning. A good attitude surely leads to the best and most logical approach to getting cancer successfully treated. But I have also known people with positive attitudes, who sought early diagnosis and treatment, and who simply weren't as fortunate. I have seen patients who had no belief in the mind-body connection and who discounted the importance of their attitude completely, yet they survived.

Ernie, a lawyer who was absolutely negative about every aspect of his diagnosis and treatment of lymphoma, was convinced from Day 1 that he would not survive. He explained that he usually saw the dark side of things and the glass as half-empty. Although he stuck faithfully to his chemotherapy treatment, no amount of encouragement or "good" results on his medical tests could persuade him he was doing well. He would say over and over again, "Dr. Holland, I'm not going to make it." It's now been eighteen years since his treatment; he's been cancer free ever since. He's still going strong and is still as much a pessimist as ever. Ernie is an example of how attitude is not the whole story in surviving cancer.

My view is that if a positive attitude comes naturally to you, fine. Some people are optimistic, confident, and outgoing in virtually every situation. Your attitude toward illness reflects your attitude toward life in general and your handling of day-to-day stresses and hassles. There is no way you will see that the glass is half-empty if you are certain that it is half-full. And the converse is true: If you see the glass as half-empty, I can't convince you that it is half-full. It is not easy to change people's ingrained attitudes and patterns of coping.

It's dangerous to generalize about attitudes and their impact on cancer without more information. The present-day tyranny of positive thinking sometimes victimizes people. If thinking positively works for you, well and good. If it doesn't, use the coping style that's natural to you and has worked in the past. (I discuss different modes of coping in Chapter 6.) Trying to get you to "put on a happy face," to pretend you are feeling confident when in fact you are feeling tremendously fearful and upset, can have a downside. By feigning confidence and ease about your illness and its treatment, you may cut off help and support from others. You may also be hiding anxious and depressed feelings that could be alleviated if you told your doctor how you really feel. Also, this tyranny of positive thinking can inhibit you from getting the help you may need out of fear of disappointing your loved ones or admitting to a personality some people think is fatal. If you are surrounded by "the positive attitude police" ask your doctor, clergy, or therapist to call them off, letting them know that this is an important time for you to be honest about your feelings so that you can get all the help you need. (Or give your or friends this chapter to read.)

It is ironic that many negative, pessimistic people survive cancer, while others who believe positive attitudes will cure it do not. While members of the former group are stunned by their survival, those in the latter group are made to feel guilty or ashamed that they were not "up to" beating an aggressive disease. This is unfair. I do not believe for an instant that people whose cancer progresses have a weaker spirit or character than anyone else.

For many years, whenever I spoke to groups of patients and their families about cancer and the mind, I would cite all the research data suggesting that we couldn't attribute cancer survival totally to personality or positive attitudes. Invariably, someone would come up to me after the talk and say, "Dr. Holland, I heard what you said about the research, and I respect your opinion. But, I don't care about what the research says. I believe in the mind-body connection, and I know I survived because of my attitude." I began to realize that people have strong ideas about these issues that aren't based as much on facts as on deeply held beliefs.

I have come to view beliefs about the mind-body-cancer connection as being similar to beliefs about religion. People who truly believe don't need (or look for) scientific proof of the connection. People who don't believe are equally adamant on the "no connection" side. I have learned from experience that trying to influence strongly held beliefs is exhausting and, more important, successful only once in a blue moon. You believe or you don't. "At probably matters most in the long run is that your view is consoling and

comforting to you. We have a strong obligation to insist that families and medical staff respect each person's beliefs about cancer. People who have cancer should be supported, irrespective of their views, and without fear of criticism or ridicule from those around them.

Clearly, there is a broad spectrum of beliefs regarding the role of the mind and emotions in cancer. Some people believe that emotions are the key factor and that cancer is caused--and, therefore, can be controlled--by the proper emotional makeup and response. Others discard that idea as unscientific and untenable by current scientific standards. Others sit in the middle, believing that how we respond to cancer certainly affects the quality of our lives--and might have an impact on survival.

If you do hold a belief in a mind-body-cancer connection, it is important that you understand that your doctor may not share your view. However, most doctors today are willing to disagree respectfully and do not discourage complementary mind-body therapies that are potentially helpful and not harmful. (A complementary therapy is used in addition to, rather than instead of, standard medical treatment; see Chapter 10.) Most physicians today will say something like this: "I'm not aware of the proof for that. But I encourage you to do anything and everything that helps you feel better, so long as it doesn't interfere with your medical treatment."

Occasionally, a physician might completely discourage you from pursuing a therapy you believe is helping you. It is important to resolve the conflict with your doctor as best you can through open discussion. Even if your doctor does not agree with the approach you've embraced, it is important to be honest about it. For example, if a diet or nutritional regimen you've embarked on has caused you to lose a lot of weight, tell your doctor, because it could interfere with your medical treatment. Most diets suggested today are not extreme, but any that limit protein and calories can reduce your body's ability to tolerate chemotherapy.

Researchers in Toronto, Drs. Brian Doan and Ross Gray, suggest that at one extreme of a continuum of beliefs about the mind and cancer are the persons who see cancer as the enemy and see themselves as the warrior on the white horse who must fight the proverbial dragon, in this case, cancer, like St. George. These are the folks who confidently say, "I'm going to beat this." British researchers Drs. Steven Greer and Maggie Watson, at the Royal Marsden Cancer Institute, called this the "fighting spirit," which ensures that a person uses a head-on, direct approach to dealing with cancer. We know that this is a good way to cope. This active stance is carried a step further in a complementary cancer therapy in which one visualizes the immune system fighting cancer. This approach was developed by Dr. O. Carl Simonton and Stephanie Simonton and popularized in their book *Getting Well Again*.

The Simonton approach encourages patients to visualize their healthy cells fighting the cancer cells. This method is appropriate and satisfying for many people with the fighting spirit. Patients with this personality type derive considerable comfort from visual imagery, relaxation exercises, and hypnosis. These are also people who confront their

problems head-on when well, and they are likely to collaborate vigorously in their treatments when ill.

However, this approach is not for everyone. Many people tend to face a difficult situation by using an outwardly "nonfighting," stoic stance. They may view the role of the mind as less central in the treatment of cancer, except as it involves commitment to the medical treatment. In the past several years, these individuals have often been made to feel that they are failing because they cannot create a warriorlike fighting stance. They may be criticized by relatives for "not trying hard enough." Many people with cancer come to see me or other therapists for help with depressed feelings precisely because they don't fit today's popular model for coping with cancer. They assume that it must be their fault that they're out of step, that there must be something wrong with them. So they come to see me in the hope of getting fixed up and altered into a "healthy, normal" copier. Instead, they're often surprised to discover that I validate their feelings and their own natural way of coping. I learned early on that when a person is in the middle of a crisis related to illness, it is not the time to try to change his or her way of coping. When you are in the "trenches" of cancer treatment, it is best for you to call on the resources you already have. Immediate support is important in the crisis. Helping you find more appropriate and more effective ways to cope can come later (see Chapter 6).

If you wake up every morning and exclaim, "I'm going to beat this thing!" and you practice your imagery exercises, which help you feel powerful "in the face of this tough disease, I would never discourage you from following this "combat-style" approach to your cancer.

But if you wake up and say, "Oh God, I don't know how I will get through this. I just feel so lousy and scared," you likely need some help to cope better. Nevertheless, as of today's knowledge, you are not making your cancer worse.

The bottom line is that there is no generic "one size fits all" coping style for dealing with cancer. If there is one thing we hope to accomplish in this book, it is to make it clear that you are unique, and your tried and true ways of coping (that have worked in past crises) are likely your best bet for dealing with the crises of cancer. I urge family members, friends, and medical professionals to respect and support each person's way of coping.

If you are a "nonbeliever" in the mind-body connection and cancer, it may reassure you to know that the scientific base is not firmly established for such a connection in cancer beyond the important role the mind plays in getting us to the proper medical treatment and maintaining a healthy lifestyle. We really don't know whether psychological or emotional factors play a role in extending life by some as yet not understood mechanism, but the factor is likely to be small in relation to the total picture.

We do have overwhelming proof, however, that how you cope with your illness can improve your overall quality of life. This will clearly lead you to get the best medical results because of a better working relationship with your doctors and your willingness to

complete your full course of treatment, which in turn leads to a better outcome from your treatment.

Taking a middle position on this mind-body-cancer subject has not been easy because of the way the "believers" and "nonbelievers" feel so strongly one way or the other. Over the years, some of my colleagues in cancer medicine have viewed me as an advocate of "soft science" regarding mind-body-cancer interactions. At the same time, proponents of mind-body techniques have considered me to be a conservative spokesperson for the medical establishment, lacking the ability to accept their premises without proof.

In all honesty, I am entirely comfortable with my place in the middle of the road, holding an open mind. On the one hand, I firmly believe in the value of scientific research. I would never tell you that a particular technique has been proved effective when, to my mind, the data to support it are not yet there. On the other hand, I encourage you to pursue approaches, proved or not, that help you to feel better, as long as the approach is not harmful and as long as you continue the medical treatment recommended by your physician. Complementary approaches are popular today, and they permit you to feel more in control by personally contributing to the treatment.

You need to find your own comfort level with the mind-body-cancer connection, based on your temperament, your natural way of coping, and your belief system. That approach should be respected by your family, your doctor, and others who support you through the cancer experience.