

The Human Side
of Cancer

written by

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Chapter One

WHAT IS THE HUMAN SIDE OF CANCER?

I assume that you've picked up this book for the same reasons people come to see me. You may have just found out you have cancer, or you may already be undergoing treatment and feel you've hit a snag. Perhaps you are a survivor wondering whether you're cured or not. Or you are coping with cancer as a chronic disease and feel the need for more support. Maybe you are a fellow traveler on the path, supporting and assisting a loved one with cancer, but feeling the need for help yourself

Whatever your situation, I wish I could sit with you and talk about what's been going on for you and how you've been coping, and help you find the kind of support that's right for you. That's the way I would like to do it. But since that's impossible, I've tried through the chapters of this book to talk with you as I would if you were in my office and we were talking face-to-face about your illness or that of your loved one and about the problems you've had to deal with along the way.

When I see someone for the first time at our counseling center at Memorial Sloan-Kettering Cancer Center in New York, I usually ask a question like this: "How have things been going for you since you got sick?"

Often the response is: "I don't even know where to start."

And I usually say: "Well, let's start with your illness. Tell me about what's happened to YOU."

Then I hear about a "cancer Journey," starting with finding a lump or having a pain that took the person to the doctor, who diagnosed cancer. Or, for others, it's how they were completely surprised by the results of a routine mammogram or colonoscopy or chest X ray that showed cancer. Somewhere along the line, each has heard a version of the words "It's cancer."

Some people come to see me at that moment, right after hearing the news, when they are scared, mixed up, and overwhelmed to the point that they can't take the next step. Others come later, after starting their treatment. They hit a "bump in the road" as they cope with radiation or chemotherapy. A psychological "bump" might be feeling "wired" or scared, not being able to sleep or to concentrate on anything, feeling tired and down in the dumps, or being uncertain about the future.

These feelings lead to questions like these: Can I get through this? Is there a light at the end of the tunnel? Will I have done it all for nothing?

Ironically, some people don't come to see me until their treatment is over. They handled treatment fine because they were in a crisis mode and were doing something to fight the cancer. Now that the treatment is completed, they begin to reflect on what they've been through. The reality sets in, and the nagging question arises that I hear so often: Did I have cancer, or do I have cancer?

Sometimes it's not the person with cancer who comes to see me at all, but a family member or other loved one who finds it painful to watch as the person encounters the curves, valleys, and hills of the cancer journey.

With each of these people, whatever their situation, we talk about how difficult it's been for them to get to where they are now. They often have looked only at their personal shortcomings in meeting the day-to-day crises, seeing only the trees and not the forest. I help them focus on the bigger picture, which so many times reveals how remarkably strong and courageous they have been in the face of one of life's gravest challenges: the threat to life itself.

Together, we look for their inner sources of strength and try to identify their well-honed ways of dealing with adversity that have worked in the past and will likely work again. We review what they know about their cancer and what treatments are out there, and I help them get more information when they need it. We go over their reactions to the diagnosis, their problems with treatment, and their stress as they see family, friends, and coworkers adjusting to the illness of someone close.

Every person brings unique characteristics to dealing with illness: a particular personality, a way of coping, a set of beliefs and values, a way of looking at the world. The goal is to take these qualities into consideration and make sure that they work in favor of the person at each point along the cancer journey. I hope that my suggestions, impartial information, and sharing of what I have learned over many years of clinical work can make your own journey a little easier and keep you from losing hope.

When I first arrived at Memorial Sloan-Kettering in 1977, very little was known about the human side of cancer. Psychosocial research related to cancer was so new it was hardly viewed as a scientific endeavor. But we began to learn about it from the real experts: the patients and their families who were going through the experience. Those of us who shared in this exciting beginning at Memorial Sloan-Kettering felt the joy of "discovery" --of being pioneers--as we identified common threads in what we heard, while recognizing that the experience for each individual was unique.

Our work has spanned two decades during which cancer came "out of the closet," allowing the word cancer finally to be spoken aloud and the diagnosis honestly given in the United States, as compared with many other countries where the diagnosis is still not revealed. Survival from certain cancers has become much more common, and concern for the psychological dimension of patient care has taken on greater importance. Over the past twenty years, we have played a role in the creation of a new subspecialty in cancer (or oncology), which is called psycho-oncology, referring to the psychological issues in cancer. Our work at Memorial and the short history of this field are very much intertwined.

During more than twenty years directing the psychiatry effort at Memorial Sloan-Kettering Cancer Center, I have been listening to patients and their families as they have confronted cancer and struggled to gain a perspective on an unexpected and unwanted intrusion that threatened their own or a loved one's very existence. I have been privileged to witness their remarkable courage and strength. I am grateful for the knowledge and insights that these extraordinary people have shared with me. To have helped some in their Journey through the cancer experience has been an even greater privilege that has more than countered the stresses and challenges of the work.

I began to wonder if the knowledge gained from working with well over a thousand patients and their families could be helpful to others facing cancer. Many of my patients have asked, "Can you tell me what to read to help me cope better and get through this?" That's been hard to answer because there are so many books on coping with cancer. I wondered if I dare add one more to the shelves of bookstores. However, many of those books tout a particular approach and promise that it alone will lead to successful coping. If I have learned anything over the years, it is that there is no single right approach and no simple answer to dealing with the human side of cancer.

Although there are some universals about the cancer experience, particularly the sense of uncertainty people feel, we are each as distinct from one another in our psychological dimension as we are in the pattern of our fingerprints and our DNA. It has always seemed unlikely to me, given this diversity, that there is a single right answer for everybody. I tend to doubt any person who says, "I have the answer for you."

In addition, cancer has been so frightening for so many years that myths and beliefs have developed that add to the fears. Some of these myths include:

- You wanted to have cancer.
- The problems from your difficult childhood caused it.
- Your negative attitude is making the tumor grow faster.

These beliefs are certainly touted by some who support a particular psychological approach. Many people can put these ideas aside, but others cannot. They are harmful, especially to vulnerable people, who are unable to seek their own independent conclusions. There is no scientific basis for these beliefs, which place an unconscionable added burden on patients who already have enough to cope with. My reason for writing this book is to help you and others "sort out" fact from fiction and belief from reality and to help you along your cancer journey. There is much that we do know from our scientific research and clinical experience that can help you gain a better perspective on your own reactions and emotions. It helps to see your emotions in relation to what others have experienced and to read what the experts in the field have learned.

There are two aspects to the human side of cancer: what cancer does psychologically to people and their families, and how emotions and behaviors may influence the risk of getting cancer and its outcome. In this book we explore both questions, providing practical yet scientifically supported information about the range of issues involved in coping with cancer. We try to help you to find your own best way of coping. We also put into perspective what is known, and what is not known, about the role of the mind and emotions both in getting cancer and in surviving it.

Whenever I read a book, I first want to know something about the author so that I can better judge the book's contents and its reliability. For this reason, I feel you have a right to know "where I'm coming from."

From a personal perspective, the journey to psycho-oncology has been both challenging and rewarding. I always wanted to be a doctor, growing up on a farm during the Depression in what was then called the "blackland Bible-totin" area of northeast Texas. I greatly admired the country doctor in our little town of Nevada, Texas, who took care of all generations of a family and knew their strengths and foibles. He treated his patients for their range of health problems, from the physical to the psychological. His tools, beyond understanding and empathy, were limited, for treatment of both mind and body. But he made a difference in people's lives, and I wanted to do something like that, though I had never heard of a woman being a doctor. With remarkable support from my parents and several special teachers, I went to medical school.

I loved all of medicine and taking care of patients. But in my internship, I found that listening to people's stories of how they became ill and how they were dealing with their illness was more interesting to me than caring for the physical aspects of their heart trouble or high blood pressure. It was compelling to observe many people with the same illness and similar symptoms and to note the striking differences in their emotional reactions. The reactions ranged from quiet, effective coping in some to a sense of panic and helplessness in others. Making my rounds from room to room, I noticed that some were consumed by fear and sadness--I could hear the fear in their voices and see the terror in their eyes-

while others with the same illness seemed optimistic and hopeful about the future. Sometimes people were so upset that they were simply unable to go through the treatments they needed to be cured. I wondered why one person coped so well, while another had such a hard time. What factors led to these very different responses to the same illness? And how could one help those having trouble coping? I became keenly interested then in understanding how people faced the crisis of an illness that threatened their life and the factors that seemed to influence good or poor coping. The pursuit of this interest led me eventually to my work in the field of cancer.

Wanting to understand people's adjustment to illness led me to seek training in psychiatry. Following my residency in psychiatry, in 1956, I met and married a brilliant young oncologist, James Holland. Jim was in the vanguard of doctors who at the time were developing combinations of chemotherapy drugs that drastically changed the outlook for children with acute lymphocytic leukemia from universally fatal to frequently curable. It was an exciting time in cancer medicine as new, effective drugs appeared each year, and the future for cure of cancer looked bright with the prospect of combining surgery, radiation, and chemotherapy. In the early years of our marriage, I mainly stayed at home in Buffalo and took care of our five young children. I would listen to Jim and his colleagues, who often came to dinner, discuss the new treatments for leukemia and the side effects patients had to tolerate to achieve the long-term goal of cure.

Our children began to wonder if there was any world other than that of patients and medicine.

As these Pioneer doctors and investigators tried new drugs with patients, they measured and recorded every physical side effect and toxicity the new agents caused. Those long discussions over dinner of the troubling side effects would lead to my asking, "But how do the patients feel about all this?" At that time, virtually no one queried the patients about how they were doing because the focus was on changing the dismal outlook all of them faced. Little was known about and little was done to help with the human side of cancer. One patient, Dan, described the situation very well: "They have measured everything but my thoughts and mind. Somehow, my mental attitude, the stress, the anguish should be analyzed and studied the same as my physical condition."

I felt that Dan had put his finger on the problem. If we could measure what our patients were feeling psychologically, we would be able to add that information to the overall assessment of side effects and toxicity. This approach would give us much valuable information, not only about the physical but also about the human effects of a new treatment. That information could then be shared with patients contemplating taking the treatment.

Over the past twenty years, that very thing has happened. I have been privileged to be part of some of the earliest studies that began to seek patients' own reports

of their quality of life and level of functioning, not relying only on what the doctors observed. It took a long time for Dan's plaintive observation of the need for measuring his mind and thoughts to be put into practice, but it has happened. And this shift has improved the care of patients by incorporating their concerns and experience, especially as to their pain and distress.

Up until the 1970s, the word cancer traditionally was rarely spoken to the patient. Medical schools taught that it was cruel for a doctor to tell patients their diagnosis of cancer (although the family was always informed), since to give the diagnosis would take away all hope, it being tantamount to a death sentence. Since the 1970s, the trend has completely reversed. The decade of the 1970s saw the appearance of women's, patients', and consumers' rights. The post-Vietnam restructuring of American society gave greater attention (and legal sanction) to informing people of their diagnosis and treatment options and to allowing them to make an informed choice of treatment. Today, almost all patients in the United States are told their diagnosis and possible treatments. In some states, legal mandates have been imposed regarding information about particular procedures. For example, some states require that women with early breast cancer be informed of the option to have a lumpectomy and radiation instead of a mastectomy.

Many other countries still cling to the belief that the diagnosis should be withheld from the patient. However, the trend toward openness is becoming more widespread as people the world over become better informed.

Up through the 1950s and 1960s, cancer carried a stigma for the patient and the family, partly owing to the poor survival rate, enforcing a silence on all concerned. Cancer was called the Big C, because the word itself was still so scary. A taxi driver once refused to drive me to Memorial saying, "No ma'am, that place is for the Big C. I drive all the way around it." Many patients felt guilty for bringing the shame of cancer on the family. This cultural silence and stigma limited the opportunity for people even to talk with one other about their illness.

Fanny Rosenow, who became a stalwart volunteer for the American Cancer Society in New York, told me of her experience. In the early 1950s, she and her friend Teresa Lasser had radical mastectomies for breast cancer at the same time. They talked with each other and shared their feelings, but they recognized that most other women had no one with whom to talk about their surgery. Sitting at Fanny's kitchen table, the women decided they would try to reach other women to provide a forum in which women could feel free to talk about having breast cancer. Both women were socially prominent New Yorkers, and Ms. Rosenow felt that a notice in the New York Times was the best way to announce such a meeting for women with breast cancer. When she called the Times, she was put through to the society editor. Her request to place an ad to announce a meeting about breast cancer for women was followed by a long pause. "I'm sorry, Ms. Rosenow, but the Times cannot publish the word breast or the word cancer

Perhaps you could say there will be a meeting about diseases of the chest wall." Ms. Rosenow hung up in disgust. However, the women persisted, and their devoted efforts resulted in what is widely known as Reach to Recovery, a worldwide support program for women with breast cancer, administered today through the American Cancer Society.

As our five children got older and I returned to work, I felt that cancer provided the ideal setting for me to study people's reactions to illness. Cancer is made up of diseases that occur at all stages of life and in all parts of the world, where attitudes are vastly different. Cancer may be cured, become chronic, or lead to death. To understand how people in these different situations cope could be a basis for helping people cope better with the uncertainty of a life-threatening illness. This interest led me to do research at Roswell Park Cancer Institute in Buffalo and then at Montefiore Hospital in the Bronx, when our family moved to New York.

I came to Memorial Sloan-Kettering in 1977 to begin the first full-time psychiatric service in a cancer research hospital. When I first joined the staff at Memorial, many of the oncologists, couldn't understand why they might need someone from psychiatry, because "these people are really sick." My colleague, Dr. Mary Jane Massie, a psychiatrist, and I initially shared a small office that had in it a card table and two chairs. But we spent most of our time on the medical floors talking to patients, families, nurses, and social workers and making rounds with the medical teams. The patients were our teachers, sharing their experiences and exploring with us the personal meaning that cancer had in their lives. We learned how to identify those who were distressed, who needed support and help. We began to understand what the common problems were and how to help people deal with them. The human side of cancer began to be more actively addressed in our cancer center.

In this book we talk about the "human effects" of cancer as opposed to the "physical effects" of cancer, which the oncologists and their staff must treat. It is often not recognized that these human effects are part of every encounter with every doctor and every staff member, irrespective of the stage of the illness or the treatments. It is central to all care, yet it is often unceremoniously relegated to the low-priority category of "I don't have time to deal with that today." But individuals and their families confronting cancer grapple with these human issues every day and want them to be addressed. Some are psychological, some are social, and some are existential or spiritual.

The succeeding chapters of this book outline these issues. Chapter 2 deals with the myths and beliefs about cancer, and Chapter 3 presents the current state of knowledge about the mind-body connection and cancer.

A diagnosis of cancer raises existential questions like "Why me?" But what immediately comes to mind for most people is "My God, I could die of this," a

thought most healthy people have never or rarely entertained, which is the subject of Chapter 4.

Once a diagnosis of cancer has been made, the need to become a partner with your doctor is critical. A positive doctor-patient relationship can make the cancer treatment-and the whole cancer experience-ininitely easier, as discussed in Chapter 5.

Chapter 6, on coping, gives the needed guidelines on effective ways to cope and when to seek help.

The psychological effects of different treatments and how to deal with them are described in Chapter 7. Initial treatment is given with cure as the goal, and the focus is on tolerating the stresses and problems you have to go through to get the cure. This chapter offers help on how to get through your treatment in the best possible way.

Chapter 8 outlines the most common types of cancers and specific psychosocial issues related to each of them.

The good news is that psychological and social support to bolster you and your family is now increasingly available, as described in Chapter 9. Many programs are tailored for the needs of those who are newly diagnosed, are in treatment, are survivors, or are receiving palliative care (treatment to ensure comfort, both physical and psychological, for the patient and family). These programs have repeatedly been shown to improve quality of life. Counseling and psychotherapy are now more widely available, in hospitals and in the community, for those who need individualized psychological help. For severe distress, a psychiatrist might determine whether a medication is needed, in addition to providing counseling, to reduce anxiety, sleeplessness, and depression, which make it difficult to function. The human side, after long neglect, is finally getting the attention it deserves. We call these approaches "medicine that doesn't come in a bottle," and they are discussed in Chapter 9.

Chapter 10 looks at alternative and complementary therapies, which people increasingly are adding to their conventional cancer treatments.

Chapter 11 is concerned with the survivors of cancer, who carry emotional baggage from the experience. It is easier today, in the still relatively new climate of open conversation about cancer, to be a survivor. Cancer survivors want to know how to stay healthy, how to avoid recurrence and the development of a new cancer.

Chapter 12 gives the guidelines for a healthy lifestyle and for proper screening to ensure early detection. As a survivor, you also want to be certain that family members are protected by good health habits and practices.

Unfortunately, not everyone with cancer will survive. Chapters 13 through 16 bear on matters of importance if the cancer progresses. Chapter 13 explains the new phenomenon of seeing cancer as a chronic illness. Today, palliative and terminal care for patients with advanced disease is an aspect of care whose importance is increasingly recognized throughout the country.

The search for meaning in life after cancer is the theme of Chapter 14. We call this search "the last taboo" because of our society's avoidance of talking about ultimate questions like the meaning of life and death.

Chapter 15 discusses the important issues faced by family members and other loved ones who are caring for an ill person.

Finally, Chapter 16 addresses the nature and facets of bereavement and attempts to help answer the question "How do I go on?"

The human side of cancer is all-encompassing; it's about you, your surroundings, and your experience of the illness. It's based on the kind of person you are; the meaning you attach to illness; the specifics of your illness in terms of its stages, symptoms, and treatment; social attitudes; and the availability of support from others. The mix of your particular circumstances influences the human side, along with basic issues such as whether the disease is localized or has spread, whether people are around to help you, your age, and whether or not you have a strong philosophical belief system. It has been a rewarding personal journey for me to develop a deeper understanding of the challenges people with cancer and their families face and to appreciate how they manage them so well. This book attempts to share with you this collective wisdom.

If you or a loved one has cancer, particularly if you have recently received the diagnosis, your mind is probably filled with questions and feelings that need to be brought into perspective. Questions like "Will I die of this?" "How will I ever get through this?" or "What can I do to improve my chances of cure and survival?" are normal and to be expected. I hope to answer them in this book.

Similarly, many people who have cancer describe a range of emotions-worry, fear, sadness, anger-that may be intense at times. These are all normal and expected responses to a major crisis. Feeling this way doesn't mean that you are mentally ill or lacking in emotional "stamina." Sometimes these feelings become painfully difficult and interfere with your ability to cope with the illness and carry on with your life. It is important that you know of this range of normal reactions as well as the red flags that indicate you might need some help in handling your feelings. Being seriously depressed and anxious are the most common examples. The good news is that most emotional symptoms are treatable. You can face the reality of cancer much better when complicating psychological problems are reduced.

In this age, with its explosion of information, confusing reports about the role of attitudes, emotions, stress, and personality in cancer can place an added burden on you if you have cancer. We want to relieve this burden by providing reliable information about these matters and by helping you find the best sources and types of psychological support. In so doing, we hope to help you manage the human side of cancer.