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*“Look to this day, for it is life, . . .
For yesterday is but a dream,
And tomorrow is only a vision.
But today, well lived,
Makes every yesterday a dream of happiness,
And every tomorrow a vision of hope.”*

—Sanskrit proverb

To the Patient

This book has presented concepts, information, and methods that can help give direction to your desire to rehabilitate yourself. Our concept of rehabilitation is one that requires a total approach to the person with cancer—one that addresses both the body and mind with exercise, nutrition, and supportive care, through your efforts as well as those of your health care team.

Only by acquiring specific knowledge can we begin to conceive possible solutions to our complex health problems. To achieve any level of success, you, the patient, must accept responsibility for the role you can play in your medical care. Having made the critical decision that you want to get well, you must believe that it is worth the effort and be willing to make sacrifices and give sufficient attention to the task.

Frequently, coping requires a compromise—to accept what cannot be changed and to proceed from there. A patient who copes can set new, realistic goals. He or she must leave anger and bitterness behind and free up energies to live in the present.

To live in the present, a patient must have hope, because hope is an essential part of the will to live. Hope can come from many sources: from the doctor who shares his or her therapeutic plans with the patient, or from the family members and friends who seek to help. But primarily, hope will come from the patient who is willing to help himself or herself.

The Mind

By knowing yourself, your goals in life, your limits, capacities, and how to compensate for the stresses and trials of daily life, you can accelerate your rehabilitation. Knowing how to keep your “cool,” how to keep your frustration level low, and how to make appropriate use of support systems can make the difference between success and failure in treatment. Psychological

and spiritual aids can help control the disturbances of external mental pressures.

The Body

When you have a disease, there is an accompanying chronic feeling of tiredness, often so subtle that you and your doctor may not recognize it for what it really is.

Expending energy appropriately is paramount, lest the tiredness be compounded and come to characterize daily life. An energy deficit manifests itself in how we feel, emotionally and physically. It can mean the difference between health and illness, misery and happiness. Fortunately, we have an energy reserve upon which to draw. Energy needs may be constant and predictable, yet vary in the ways they are met. The better our mental and physical states, the greater our vitality and energy reserves. The concepts and methods discussed in this book are designed to help you achieve the highest level of functioning possible within the limits of your disease.

Guidelines to Keep in Mind

Adequate Sleep. Your need for sleep will vary, depending in part on your activities and habits (not all people require eight hours of sleep nightly). Prolonged lack of sleep reduces efficiency and the ability to function. How you sleep is important, too. A good night's sleep is "as good as gold." If sleeping pills or tranquilizers are helpful in obtaining an adequate night's rest, they should be used. Resolving any perplexing and annoying emotional problems helps immeasurably. The use of relaxing techniques, meditation, and biofeedback is often invaluable.

Nutrition. Fad nutritional notions and diets should be discouraged. Eating balanced meals, with adequate protein and calories, is vital in helping you to tolerate therapy, fight disease, and gain the strength to return to active life.

Physical Exercise. An active and organized exercise program—with appropriate rest periods—is absolutely essential for maintaining

good physical status. Exercise provides a feeling of well-being, reduces stress, aids relaxation, increases reserve strength, and promotes better sleep. Graduated levels of exercise that add increasing variations as you improve will prevent fatigue and frustration. Nothing is more reassuring than to see and feel self-improvement. Concurrent use of an occupational physical therapy program will help accelerate your recovery.

Sexuality. Your sexuality is still a part of your total being when you have a chronic illness, and it is an area of concern that should not be ignored. If adjustments in your patterns of sexual expression are necessary, communication between you and your partner may enable you to work these out alone. For those who need help, counseling is available.

Relaxation Time. Periods of "trained relaxation," two to three times a day, will help make life more enjoyable. We go through so many changes daily—from hectic stress periods to periods of diversion and relaxation—that we need a tool to help us cope with them. Meditation, biofeedback, and other techniques can relax the mind and reduce stress. Hobbies, sports, and various types of mental or physical games can help maintain energy resources. Allot specific time to "be good to yourself." These times should be private, personal, and inviolate. Don't use your relaxation time as a work period! To do so will only increase mental tension and physical exhaustion.

In short, a person needs to restructure his or her life to succeed in obtaining as full a rehabilitation as possible, no matter what the medical problem is. A person cannot change completely, but habitual daily patterns, even some of life-long duration, can be adjusted and altered by setting reasonable goals and personal priorities, so that time is used both efficiently and constructively. The self-help/self-support programs described in this guide are designed to help you formulate a better recovery program.

To the Family and Friends

There are many resources for patients with cancer, but probably the greatest allies to the physician are you, the close family and friends of the patient, who are available to help when the need arises; you offer a reserve that cannot be found in any other resource. Your continued love and compassion give hope and courage to the patient.

We all need love. The person who is ill is particularly vulnerable to the feelings of being alone and abandoned. Thus, the importance of your understanding of the patient cannot be overestimated. Without your support, the patient's recovery process may be prolonged.

Illness, incapacity, and the threat of death are difficult subjects for a patient and his or her family and friends to discuss together. You may want to talk to each other but be hindered because you want to protect one another, or because you do not wish to face the truth yourselves. The inability to communicate can occur with all people at any time, but it is usually heightened under conditions of stress.

Families and friends faced with the life-threatening illness of a loved one have the dual problem of trying to control their own fears and anxieties while giving support to the patient. They may spend their time wondering how to ease the patient's emotional suffering, while the patient is busy worrying about the despair of those he or she loves. Each is searching for the most tactful way to deal with the other.

Our experience with patients has shown, however, that a deliberate policy of candor and openness will create an atmosphere that is beneficial to all concerned. It can remove the burden of secrecy and open the door for the alleviation of apprehensions. Candor may not be easily achieved, for often people are not in the habit of speaking about their deepest concerns. Even those who have established close relationships may become fainthearted

in the presence of cancer and the threat of death. To achieve openness and to maintain it under stress is part of the challenge of living with cancer—for both the patient and the patient's family and friends.

Hearing what the others are experiencing is never as devastating as what the imagination can conjure up. Fears and frustrations should be talked about as they arise, rather than being left to fester until they become too frightening to mention, or until a habit of withholding evolves into inevitable isolation. Confronting each other's fears, therefore, becomes a means of keeping those fears under control. Candor will allow relationships to operate in a new realm, in which despair can be minimized or set aside and enjoyment and pleasure can resume their rightful places.

Candor between a patient and his or her family and friends includes recognizing one another's needs as well as one another's fears. Family and friends need to give, to feel they are doing something practical to hasten the patient's recovery, whether at home or in the hospital.

The separation caused by hospitalization is particularly traumatic to the family. They leave the hospital each evening and worry about whether their loved one will ever again lead a normal life, or whether he or she will even leave the hospital. Feeling powerless, they need to give of themselves. Fortunately there are many practical services a patient's family and friends can perform while the patient is in the hospital—services such as feeding, walking, turning, and massaging. These, along with the offer of special foods, a favorite pillow, or a comforting hand, become the routine of the daily hospital visit, giving solace to the family and friends as well as to the patient.

When the patient is critically ill, it is not unusual for at least one family member to be in attendance around the clock. This may mean sleeping in a chair beside the patient's

bed. To obtain up-to-date information on the patient's condition, relatives may rearrange their schedules so as to be present when the doctor makes rounds or a particularly helpful nurse is on duty.

When the patient is at home, functioning well, there are still many opportunities for family and friends to give emotional and practical support. One need only consider what the cancer patient must sometimes be feeling: anxiety about a visit to the doctor, wondering whether a new problem will be discovered or a new treatment recommended, dreading the side effects from the day's treatment, and concern about lack of transportation to and from the doctor's office. A family member or friend can offer a ride or go with the patient on the bus. If everyone is working and cannot be with the patient during the day, there is still the evening, when the side effects of therapy may have to be endured. Patient, family, and friends all benefit from any means by which love and encouragement can be expressed.

To be realistic, however, not everyone is able to be open, loving, or supportive in crisis. Even stable relationships may be severely threatened by the pressures of long-term illness. Latent problems may emerge, and anger or guilt may surface in sudden attacks or recriminations, or in indifferent or overly solicitous behavior. The exhaustion and frustration of constant worry and care may break even the most loyal supporter. Family and friends must be reminded that they need time to themselves and moments of rest if they are to keep emotionally and physically fit. Calling on other friends or relatives for assistance can provide a respite from the responsibilities and worries of constant caring.

Children of cancer patients often need special understanding. Absence of a parent during hospitalization and the parent's fatigue following treatment may cause children to feel neglected and lost. Children may also feel they caused the illness; this misconcep-

tion must be corrected quickly. Reassurance from other family members is important for children to realize they are still loved. Adolescents are particularly vulnerable to stress, as they may be asked to assume a supportive role, to approximate an adult partner or spouse. If this responsibility is beyond the adolescent's capabilities, he or she may rebel by not making hospital visits or by excessive drinking or drug use. Adolescents are adults—up to a point—but they still require the reassurance and comfort routinely given to younger children.

Lengthy illness can also break the most courageous of patients. When a person has fought long and hard against cancer, losing and regaining hope many times, and then realizes that the battle is not to be won, he or she may, at times, experience rage or depression that will focus on the nearest available person—the patient's spouse or significant other, child, parent, friend, or the nurse on duty. This anger usually manifests itself as irritation over trivial matters that normally would not even concern the patient. The person under attack needs to understand that this is not a rejection, but a cry of anguish.

In addition to anger and depression, a patient must also endure the endless boredom of being ill, as well as the fear of being a burden when he or she really wants and needs special attention. Ironically, the people from whom this attention is demanded may be suffering from the same tedium or from feelings of inadequacy and guilt for being unable to relieve the suffering. They may not be able to cope with the reality in which the patient is imprisoned. The result may be a gradual diminishing of attention and care by the family, and increased bitterness and fear of isolation for the patient.

No one should be blamed for the ways he or she responds to the crisis of a long-term illness or the threat of change and loss. Some people and some relationships grow stronger, experiencing new depths of love, respect,

and understanding; some waver, yet hold together; and some collapse.

The most important thing that family and friends can do for a patient is to be supportive, give encouragement, and do everything possible to promote his or her recovery. However, it is vital that they do not err on the side of being overly solicitous, because this deprives the patient of the accomplishments that can give a sense of independence, purpose, and self-esteem, and concrete proof of progress in returning to a normal life.

The purpose of life is to live. The goal of the physician who treats cancer patients is not only to administer medical therapy but also to help them live as normally as possible while undergoing treatment. There is a widespread belief that a diagnosis of cancer is an automatic death sentence. This is not true. Today, 60 percent of all cancer patients are cured; the majority of those who are not cured are leading active, productive lives with the same odds and life expectancy as people who live with other chronic diseases.

Of course, a cure for cancer is not just around the corner. No single breakthrough will produce all the answers; the answers will come one by one, just as they have until now. Nevertheless, as of 1996, more than fourteen types of cancer were curable when diagnosed at an advanced stage. New forms of cancer will continue to be added to this list, because new discoveries are constantly being made and known techniques perfected. New methods of giving radiation therapy, new chemotherapeutic drugs and combinations of drugs, and the use of adjuvant chemotherapy, hormonal therapy, and experimental therapies—such as immunotherapy and hyperthermia—all give hope for the future.

In spite of the promise of these medical advances, though, living with cancer is an anxious, fearful time. Undergoing therapy and experiencing the side effects of treatment involve compromise. This compromise consists of accepting what has happened and at

the same time being willing to fight for your life. But no matter how well informed you become about current therapies and available treatment alternatives, you will still feel a loss of control over your fate because you must trust the judgment of cancer specialists and pray for good luck. It is not unusual to be full of hope one day and full of gloom the next.

Sometimes we are able to survive a current crisis because of the way we coped with a crisis in the past. We acquire resilience; we learn how tough we really are and develop confidence in our ability to endure. By turning to these inner resources and to the resources offered by members of the medical team, a cancer patient will have the best chance of maintaining a good quality of life while living with cancer. Attention to nutrition and muscle strength can have marked physical and emotional benefits for the patient. Knowledgeable, sensitive nurses and physicians can assuage fear and offer reassurance as well as good medical care. Medical social workers can help with insurance problems, or arrange for home care or participation in a discussion group. Every patient should be aware of these services.

Thus, help is available from people in many professions who understand your needs. These needs can also be met by other cancer patients who have formed support groups. We are here to help each other. How you live with cancer is your choice.

All cancer patients must live with their disease. The decision of how to approach the problem is individual. With the proper support from family, friends, and the medical team, and with their own inner resources of courage and hope, cancer patients can continue to live a meaningful life.

Choose life—only that and always, and at whatever risk. To let life leak out, to let it wear away by the mere passage of time, to withhold giving it and spreading it, is to choose nothing.

—Sister Helen Kelley