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## Chapter 5 Coping with Cancer

A DIAGNOSIS of cancer is a powerful reminder of the importance of one's health.

This booklet is written for people who are affected by cancer, such as cancer patients themselves, or their family members and friends.

No cancer patients are the same. Although the material in this booklet is intended to be helpful, some sections may not apply to everyone. A few suggested responses might make you feel uncomfortable. Each person has to cope with cancer in his/her own way. What follows is intended to be a general guide.

### EMOTIONAL TURMOIL OF CANCER

Our bodies and minds are not completely separate. It will help keep our bodies strong if we also deal with the emotional turmoil of cancer successfully - a side of cancer that surgery, drugs, and radiation cannot treat.

People with cancer, their friends, and their family members can face intense fears, anxieties, and frustrations. For many of us, these feelings will be new, and the road ahead may appear overwhelming. For everyone, however, it is important to be aware of these feelings and seek ways of coping that fit us best.

Cancer is a major illness, although it is not necessarily fatal. In the U.S., there are 9 million people alive today who have had cancer but have survived. Most of these people are considered cured of their cancers. For others, cancer has become a "chronic condition" somewhat like hypertension, diabetes, or mild heart condition - one that is controlled or managed by life-style changes and/or medication.

Just as others with chronic conditions, periodic health checkups will be part of cancer patients' life long routine. Cancer survivors will, undeniably, be more sensitive to and anxious about minor signs of illness or discomfort. Many will live for years, grow old, and die as they had expected before cancer was diagnosed.

After a diagnosis of cancer, it is hard not to think about dying, but it's even more important to concentrate on living. Remember, a diagnosis is not a death sentence. With advanced medical technology and widespread knowledge of early detection for cancer, its survival rate is relatively high. For some forms of the disease, 9 out of 10 people diagnosed can be considered cured. Of the other types, many will live a long time before dying of the disease. Indeed, there will be many sunrises and sunsets to enjoy. So let us take a look at living - living with cancer and its treatment, but living nonetheless.

### SHARING THE DIAGNOSIS Should You Tell

One question many people ask after diagnosis is, "Should I tell"? Rarely, your answer is no. A family member could be too old, too young, or too emotionally fragile to accept the diagnosis, but people are surprisingly resilient. Most find ways to deal with the reality of illness and the possibility of death. They find the strength to bounce back from

unbearable grief. The diagnosis of cancer hits most of us with a wave of shock, fright, and/or denial. The amount of time each person takes to accept the reality of cancer is different.

Usually, family and close friends learn sooner or later that you have cancer. Most people with cancer find it best to share the diagnosis and to let those closest to them offer their support. Of course, you must find the right timing and use words that you are most comfortable with when you tell your family and friends that you have cancer.

### **When Family Must Decide**

Sometimes family members are the first to learn about the diagnosis. If, as a family member, the decision falls on you, it may be difficult to tell the patient (for example an older parent or grandparent) that they have cancer. However, most people with cancer would say it is best to share the diagnosis. One cancer patient wrote, "Time is so valuable, and there may be things the person would like to accomplish, there are decisions to be made."

Family members also bear great emotional burden during the period of diagnosis. They, too, need the comfort of sharing their feelings. Yet, it is almost impossible to support the rest of the family if you are hiding the diagnosis from the person with cancer. He or she inevitably learns the truth. The consequences can be deep anger, hurt, or bitterness. The patient might believe that no one is being honest about the diagnosis because the cancer is terminal.

### **Somehow Children Know**

Even children sense the truth. Some parents who tried to "spare" their children from knowing later voiced regret at not discussing the truth during the course of the disease. Children have amazing capabilities to understand difficult situations. However, when their normal world is turned upside down and whispered conversations go on behind closed doors, they often imagine situations that are worse than reality. They often feel hurt and confused by what seems to be a lack of attention, unreasonable demands, or expectations placed on them.

The goal in telling the children that someone in the family has cancer is to give them an opportunity to ask questions about the disease and to express their feelings about it. Of course, all of us want to shield our children from pain, but pain that they understand is easier for them to cope with than the pain and fear of the unknown or imagined threats.

### **SHARING FEELINGS**

Sometimes, the whole family suspects the truth before the diagnosis is made. Someone recognizes the symptoms, or the family doctor seems overly concerned. Nonetheless, hearing the words tumor, cancer, or malignant can be devastating. It is often impossible to take in the reality of the diagnosis immediately. We hear it, but somehow we don't believe it. This is normal. People's minds have a vast capacity to absorb information only when they are ready to accept it.

## **The Family Adjusts**

The period following diagnosis is a difficult time of adjustment for family members. Each person has to deal with his or her own feelings while trying to be sensitive to the person who has cancer. Being part of the family doesn't mean you can make people talk about their feelings before they are ready. You need sources of support too. There are ways to encourage openness. Be ready to listen when others are ready to talk, and let your continued presence show your support. But remember, the person with cancer gets to set the timetable.

Sometimes, in trying to support the person with cancer, you may actually cut off his or her attempts to express feelings. Remember that lifting the spirit doesn't mean hiding from the truth. Some family may rush in with assurances that "everything will be all right." When there is really no such assurance, do not deny the reality of the patient's situation. Denial may cause the patient to withdraw, feel deserted, and be left to face an uncertain world alone. Unintentionally, you've abandoned the one you hoped to help and set up patterns that can be difficult to change just when support is important.

### **Finding Hope**

There are ways to find hope during periods of despondency or despair. We all need to remember the individuality of each case. We tend to get caught up with statistics and averages, but no two cancers ever behave exactly the same way. Each individual has different genes and immune system. Their will to live and urge to fight also vary. These cannot be measured on charts or graphs. No one can offer any of us "forever," but there are good prognoses. Despite an increasing number of cancer diagnoses, promising test results and effective treatments can reinforce a positive outlook of life.

### **Listening, Sharing, Being Yourself**

As a family member or a friend of the cancer patient, there are different ways in which you can be important. You can listen to expressions of feeling or act as a sounding board for a discussion of future plans. You can help focus anger or anxiety by helping to explore the specific causes - drug reactions, the job situation, finances, and so forth. This may be what cancer patients need - someone to listen, to react and absorb their outpourings, not necessarily to "do" anything. It is a difficult role, but it can be immensely rewarding.

Many people think they don't know "how to act" around people with cancer. The best you can offer is to be natural, to be yourself. Let your intuition guide you. Do what you can comfortably do; don't try to be someone you are not. This in itself is comforting.

## **COPING WITHIN THE FAMILY Not Everyone Can**

Problems within the family can be the most difficult to handle simply because you cannot escape them at home. Some family members deny the reality of cancer or refuse to discuss it. It is not uncommon to feel isolated or to feel unable to face cancer openly.

In these situations individual counseling or cancer patient groups can provide the needed support and reinforcement. Moreover, these resources provide an outlet for the frustrations you face within the family.

### **Changing Roles**

Families may have difficulty adjusting to the role changes that are sometimes necessary. One husband found it overwhelming to come home from work, prepare dinner, watch over the children's homework, change bedding and dressings and still try to provide companionship and emotional support for his children and sick wife.

On the other hand, the usual head of the household might now be the family's most dependent member. In addition to roles as a wife, a mother, and a caretaker, a woman might have to add a job outside the home for the first time. A spouse who used to share the load can become the sole breadwinner and homemaker.

These changes can cause great disturbance in the ways family members interact. The usual patterns disappear. Parents might look to children for emotional support at a time when the children themselves need it the most. Teenagers might have to take over major household responsibilities. Young children can revert to infantile behavior as a way of dealing with the impact of cancer on the family as a unit and on themselves as individuals. The sheer weight of responsibility can become insurmountable, destroying normal family associations and consuming time needed for rest and recreation.

### **The Health of the Family**

Performing too many roles at once can endanger emotional wellbeing and the ability to cope. Setting priorities may solve the problem. For example, the cancer patient and/or their caretaker can relax housekeeping standards or learn to prepare simpler meals. Perhaps the children can take on a few more household chores than they have been handling.

If a simple solution is not enough, consider getting outside help. Some agencies might provide trained homemakers. Let someone who can be objective help sort out necessary tasks from those that can go undone. The financial cost of professional services needs to be weighed against the emotional and physical cost of shouldering the load alone.

### **Support from the Family**

The desire to "do something" is common for those whose family member or dear friend has cancer. There is nothing anyone can do to change the course of cancer, so they may do everything they can for the patient. Sometimes, doing everything is the worst course to follow.

People with cancer still have the same needs and often the same capabilities as they did before. If they are physically able, they need to participate in their normal range of activities and responsibilities. Helplessness, or worse, an unnecessary feeling of helplessness, is one of the great woes of the person with cancer.

Even a bedridden patient is probably still able to discuss treatment options, financial arrangements, and the children's school problems. As difficult as it may be, the rest of the family must make effort to preserve as much as possible the patient's usual role within the family.

The least you can do is to keep the patient informed of necessary decisions. You can help the seriously ill patient ward off feelings of helplessness or abandonment if you continue to share your activities, goals, and dreams as before.

### **Help for the Children**

Children may have difficulty coping with cancer in a parent. Mom or Dad may be away from the house - in a hospital that may be hundreds of miles from home - or home in bed, in obvious discomfort, and perhaps visibly altered in appearance.

In the face of such disturbance, children are often asked to behave exceptionally well also: to play quietly, to perform extra tasks, or to be understanding of others' moods beyond the maturity of their years. Children may resent lost attention. Some fear the loss of their parent or begin to imagine their own death. Some children, formerly independent, now become anxious about leaving home and their parents. Disciplinary problems can arise if children attempt to command the attention they feel they are missing.

It may help if a favorite relative or a family friend can devote extra time and attention to the children, who do need comfort and reassurance, affection, guidance, and discipline. Trips to the zoo are important, but so is regular help with homework and someone to attend the basketball awards banquet. If your efforts to provide support and security fail, professional counseling for children, or children and parents together may be necessary and should not be overlooked.

### **SELF-IMAGE When Treatment Brings You Down**

Cancer treatment is nearly always aggressive. Surgery can be disfiguring. Radiation or drug treatment may be prescribed following surgery to ensure that no hidden, microscopic cancer cells are left to travel to other parts of the body. Treatment can extend over weeks or months, and its side effects can include nausea, hair loss, fatigue, cramps, skin burn, or weight changes. It is not unusual for the treatment to cause more illness or discomfort than the initial disease. The cancer patient has to contend with emotional reactions to such treatment and side effects. It is difficult to convince yourself that you are recovering when you feel absolutely rotten. It is hard to be optimistic when you feel worse now than at the time of diagnosis. The schedule of radiation or drug treatments may seem endless. You are convinced that there never was a day when you didn't feel awful and there never will be a time when you will feel normal - if only you could remember how normal feels.

Some even interpret these physical reactions to treatment as signs that the cancer is returning. This is rarely the case, although it may be necessary to remind yourself of this fact again and again. Do not hesitate to share such anxieties with your doctor.

A return to the hospital setting for outpatient treatment causes anxiety for some cancer patients. Researchers studied a group of women undergoing radiation therapy following breast cancer surgery. They found that the women felt better psychologically immediately after leaving the hospital after surgery than they did once follow up treatment began. It can be unsettling, indeed, to return again and again to the hospital or physician's office, places which may have come to represent the most frightening aspects of cancer.

You can try to plan special activities for the days when you feel well and brace yourself for the days when you feel awful. It's helpful to others and easier for you if you inform people around you that treatment may cause shifts in moods. You can let them know matter-of-factly that you will have up days and down days.

The known is usually easier to cope with than the unknown. It is important to be familiar with each treatment's side effects and their causes. Not only does knowledge reduce fear, but some side effects can be eliminated (or at least eased) through treatment changes, medication or changes in diet.

### **Body Images**

Each of us develops our self-image over the years. We may not be completely satisfied with that image, but usually we are comfortable with it when we are with someone we love. This helps us feel sexually attractive to our partner. Disfigurement, hair loss, nausea, radiation burns, and even fatigue can destroy your good feelings about your physical appearance. If you now believe you are unattractive, you might anticipate rejection and avoid physical contact with your partner. It is good to remember that in most cases your partner is more concerned about your wellbeing than his or her own. The overriding reactions probably begin with, "Will treatment succeed?" "How can I show my love and support?" And, only finally, "What about sex?"

In reality, your partner may be afraid to appear overly eager and therefore insensitive. So it may be up to you to show a desire for physical contact and to let it be known whether you are interested in sexual intimacy as well as other expressions of affection- hugging, caressing, and kissing.

Keep in mind that it's not only your body that makes you "sexy." There are also intangible qualities that your partner finds you attractive: a sense of humor, intellect, a certain sweetness, great common sense, special talents, or loving devotion - we all know what qualities we have other than our physical appearance that make us special. If you feel you have lost some of your special qualities along with a breast, leg, or prostate gland, counseling may help you change that perspective.

### **Rebuilding Mind and Body**

Time, along with demonstrations of love, understanding, and affection by your partner and family should help you work through feelings about your changed body image. In addition, some find that physical activities improve their sense of being when they are in touch with their bodies.

People who take on a challenging activity that moves them beyond a disability - skiing for amputees for example - find that it can provide a whole new sense of self-worth. "Can you believe, I have more pride in this ragged body than I did when it was all there?" asked a tennis ace, who took up the game after his colostomy.

Poetry, music, painting, furniture building, sewing, and reading provide creative growth of which you can be equally proud. Acquiring new interests and talents can also help strengthening personal image.

### **What Spouses Can Do**

Spouses of cancer patients can be affected by disfigurement or debilitation of their loved ones caused by cancer treatment. You expect to see beyond these physical changes and appreciate the person within, the one who more than ever needs your love and physical reassurance of that love. Nonetheless, you might find yourself responding negatively, unable to provide that support. You might feel awkward about physical contact because you think your partner is not ready for it and that you will be judged as being insensitive.

It helps to remember that touching, holding, hugging, and caressing are ways to express the acceptance and caring that are so important to the person with cancer. More than words, they show love and express your belief in the patient's continued desirability as a physical being.

If barriers begin to grow, perhaps a professional counselor can help you work out your reactions toward the patient, the disease, or your feelings that too much of the responsibility has been placed upon your shoulders. Make sure you are doing whatever you can to reestablish bonds of closeness and caring.

### **When Friends Don't Call**

Lost friendships are one of the real heartbreaks cancer patients face. Friends do not call for a variety of reasons. They might not know how to respond to a change in your appearance or just don't know what to say to you. Their absence does not necessarily mean they no longer care about you. If you believe discomfort rather than fear is keeping a particular friend from visiting, you might try a phone call to dissolve the barrier.

Examine carefully whether friends shun you or whether you have withdrawn from your usual social contacts to protect your own feelings. You can neither enlighten nor draw comfort from an empty room. If possible, the best place to be is out in the world with other people.

### **Fighting Loneliness**

Regardless of what you do, your friends might desert you. Circumstances might have left you alone before cancer struck. This is an awful loneliness, difficult for anyone to endure. There are no easy answers or pat solutions. The mutual support of other people with cancer might provide some solace and comfort. There are probably others in your community who need your companionship as much as you need theirs. Search for

cancer support groups in your community to make new friends who understand what you are going through.

Being housebound needs not deprive you of visits from others who would like to share some quiet moments or some deeply felt sorrow with someone who will understand. A physician, social worker, visiting nurse, or member of the clergy should be able to help you contact another cancer patient who could use the company.

### **Staying Involved**

When you have cancer, you need responsibilities, diversions, outings, and companionship just as before. As long as you are able, you should go to work, take the kids to the zoo, play cards with friends, or go on a trip. Try to remember that responsible pursuits keep life meaningful, and recreation keeps it stimulating. You need activities that give you a sense of purpose and those that provide enjoyment.

"Doing," it might be pointed out, is not the same as overdoing. Try to recognize your limitations as well as your capabilities. Fatigue can bring on crushing despair, and many people have found that a safeguard as simple as adequate rest fends off depression. Exhaustion weakens our physical and emotional defenses.

### **THE YEARS AFTER**

Cancer is not something anyone forgets. Anxieties remain as active treatment ceases and the waiting stage begins. A cold or a cramp may be cause for panic. As 6-month or annual check-ups approach, you swing between hope and anxiety. As you wait for the mystical 5-year or 10-year point, you might feel more anxious rather than more secure. These are feelings all cancer patients share. No one expects you to forget that you have had cancer or that it might recur. Each patient must seek his/her own ways to cope with the underlying insecurity of not knowing his or her true state of health. The best prescription seems to be a combination of challenging responsibilities requiring a full range of skills, activities that seek to fill the needs of others, and a generous dash of playfulness and laughter.

You still might have moments when you feel as if you lived perched on the edge of a cliff. These moments can come up anytime, but they will be fewer and farther apart if you filled your mind with thoughts other than cancer.

Cancer might take away your belief that tomorrow stretches forever. In exchange, you are granted the vision that each day is precious, a gift to be spent wisely and richly. No one can take that away.

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