

Living with Mortality: Life Goes On

*Malin Dollinger, M.D., and Bernard Dubrow, M.S.**



We revel in life's beginning, wrestle with its challenges, and take pride in our achievements. We know deep down that we are mortal and that our lives will end some time in the future—the distant future, we hope—but we are not consciously aware of our mortality from day to day.

The media bombard us with flashes of death in stories and graphic pictures of car accidents, plane crashes, murders, and wars, but we block them out in our minds. We feel protected and safe. We can accept the death of war heroes and old people, but reject the idea of its happening to us. We focus on guarding and enjoying our lives and intuitively distance ourselves from thoughts of our mortality.

But what happens when we are jolted by the diagnosis of a possibly fatal illness such as cancer? After recoiling from the shocking news and accepting its reality, how can we cope with this new state of uncertainty? How can we adjust our life-long attitudes and renew our trust in the future? For the first time, we find ourselves in the strange and disruptive situation of having to cope with living and dying at the same time. How can we do it?

The threat of serious illness unleashes a wide range of moods and emotions. We swing back and forth between fear and hope, nostalgia and yearning, sadness and joy, self-affirmation and self-doubt,

confidence that modern medicine offers the prospect of fighting the disease and concern that treatments can fail. Religious people sense God's closeness at times and at other times feel abandoned.

Searching for Answers To avoid confusion and despair, these and other contradictory feelings have to be sorted out, faced squarely, and dealt with.

New social and economic questions also arise. Should you keep trying to fulfill your ambitions, to build and compete? Will telling your friends and coworkers that you have cancer adversely affect your prospects for success? How should you protect your family from financial disaster? How do you emerge from the loneliness that seems to accompany illness and find meaning within your silent universe?

Denial of your illness lessens your capacity to find answers to these and other vital questions. But if you retain control of the illness as much as possible, you will be able to look directly at your own mortality and deal with it.

The Five Stages of Living with Mortality

The process of living with mortality begins when you are first told the diagnosis. A new cancer "victim" develops fear,

*The editors were inspired by the insights and creativity of Bernard Dubrow, M.S. We were very saddened by his passing, in 1997, and wish to acknowledge his lasting contribution.

despair, hope, depression, anxiety, and determination to find answers. It doesn't matter if there is a 50 percent chance of a cure or an 80 percent or a 95 percent. As long as there is even a 5 percent chance that the cancer is *incurable*, the emotional turmoil persists and the need to learn how to go on living in a purposeful way, despite the fear and worry, remains.

Many people diagnosed as having a chronic potentially fatal disease react, think, and behave in similar ways, following a similar pattern. Not everyone will go through all the stages described below. Some will skip one or two or even come back to an earlier stage if a new symptom or other significant event occurs. But it is useful to become aware of these common reactions, whether or not you experience all of them yourself. Understanding these experiences will help you face your own uncertainties and fears and help you put in perspective some of the decisions you will have to make.

When faced with the threat of death or dying, many patients and their families turn for understanding and guidance to the highly regarded work of Dr. Elisabeth Kübler-Ross. She illustrates five stages—denial and isolation, anger, bargaining, depression, and acceptance—that occur during a terminal illness. But the Kübler-Ross model applies to death in the near future of weeks or months. These circumstances may not apply to cancer patients who have been told they have a *potentially* fatal illness and that they *might* die of it, but cannot know when, and, then again, may *not* die of it, but may not know that for years to come. Living with a chronic *potentially* fatal illness associated with a life span measured in years involves responses that differ in many important ways from those described by Dr. Kübler-Ross. A more apt staging might involve disbelief, discovery, redirection, resolution, and emerging victorious.

Understanding the patterns of reaction to a prolonged illness with perhaps years

of remission and a significant chance of being cured will help you put your emotional survival in focus while your doctor concentrates on your physical survival. You will also realize that whatever stage you may be in, you are not alone. Your loved ones will be able to help you go on living. You will renew your confidence and zest in life, deal with fear and worry, discover new value and meaning in your life, achieve gratification, and even attain peace of mind.

Disbelief When the diagnosis of cancer is made, many people first go through a stage of disbelief. You will likely be unprepared for this sudden insult to your normal physical and emotional existence. There may be some denial involved. You may think, "The diagnosis is wrong. . . . It will go away. . . . It can't happen to me." You wish you could make a poor prognosis go away by picking up the phone and saying, "Hello, Heaven, please hold."

But you can hope—and with good justification—that you have significant time left, whether you are cured or not. The opportunity remains for you to enjoy life's pleasures. Eventually, you are able to accept the idea, "The cancer victim is really me." At that point, you can proceed to the next stage.

Discovery Now you need to know all about the kind of cancer you have. You need some details about its stage and prognosis. You have to find out, to whatever extent is personally meaningful, all that is important to know about the illness. What tests do you need? What treatments are available? Are there alternative treatments? What are the advantages, disadvantages, and risks of each? Where should you go for treatment? Is a second opinion important? What questions should you ask your doctor? You need to do whatever you have to do to be satisfied you're getting the best possible treatment.

One of the main purposes of this book is to help you with this discovery stage. Another pathway to discovery is through a connection with a key physician, sometimes your own physician and sometimes a specialist, with whom you can develop a relationship of confidence and trust. This physician will advise and guide you through the journey ahead.

Besides discovering technical information, you also have to discover your own strengths and weaknesses, your spiritual beliefs, how others can be of help, and who your friends really are. Do your relationships with others need clarification? When you have gathered this essential information and gained understanding of your situation, you are able to redefine and take charge of your life. A new phase of dealing with life begins.

Redirection You need to continue, adapt, or invent a lifestyle and an attitude that let you function physically and emotionally. This is an opportunity to redirect your life in fresh, productive ways.

The method of redirection is an individual choice and depends to a significant extent on how you have dealt with major life problems in the past. Some people need logical, sensible, step-by-step discussions and explanations, with lists of ideas and choices. Others need only minimal consultations with their physicians. Some feel protected and supported by their religious beliefs and make trust in God a major part of their redirection. Some are helped by their relationships with their family, friends, and support groups. There is no single right answer to how we should approach life; there are a number of right answers:

Balancing Worry and Hope The powerful emotions of fear, hope, despair, anger, and guilt released by a serious illness fade with recovery, but anxieties accumulate with a chronic potentially fatal disease. Tensions rise and fall and moods swing in cycles of highs and lows.

You may worry so much that you lose sight of the possibility of optimism. You may also become so hopeful and confident that you lose sight of reality. Your main challenge is how to balance your worry and your hope, integrating both into your day-to-day life without losing sight of either. As you ride this roller coaster of emotion, you should persist in finding the reality of each situation. The struggle is difficult, but great is the reward of finding peace of mind.

Controlling Negative Emotions It's just human nature to believe that if things are going well for us, we must be doing something right. We also tend to believe the opposite: If things aren't going well and some misfortune occurs, we have *not* been doing the right things.

If a construction site collapses or a power plant erupts, we feel the need to mount a thorough investigation to find out why it happened and especially to find and punish whoever was responsible for the disaster. It is not surprising that we sometimes assume personal responsibility for our own illness and single ourselves out as deserving punishment. Explaining illness as a kind of punishment for a tragedy stemming from doing something wrong is, of course, a psychological reaction, a distortion of reality arising from the destructive emotion of guilt.

There is also a reaction called survivor's guilt. By remaining alive when others have died, some survivors dare not feel too confident or reassured for fear of somehow being punished for enjoying good fortune. They may feel that they have survived at the expense of others, although obviously they have not!

The redirection stage can be a time to learn how to lessen the destructive impact of emotional issues. Some people gain support and insight from spouses, family members, or close friends. Sometimes professional help is useful, including

clergy, psychologists, psychiatrists, social workers, and counselors. For some, attending group meetings where feelings can be shared in a comfortable setting can relieve many psychological stresses. This will not abolish all anxiety, but will give expression to the deep emotions—fear, anger, and guilt—that arise during a prolonged life-threatening illness. The first step toward control of negative emotions is recognizing them during this stage of living with mortality.

Affirmation During this stage, some people approach life with renewed enthusiasm, especially if a battle plan has been formulated to conquer the cancer.

You need to find ways to reaffirm your interest in life, in pleasurable activities, in your profession or your hobbies. The role of loved ones and friends is especially important. They have to give you “permission” to share your worries and fears. They can do this by encouraging you to tell them about your problems rather than turning off communication by trying to simply cheer you up. Giving blanket reassurance by saying “Everything will be okay” sends the message that they want to hear only good things. They have to affirm that they are truly interested in you as an individual going through perhaps the most critical time of your life.

This stage—which, one hopes, can last a long time—also includes key medical judgments such as the affirmation that the correct physician is in charge of your care and is making the correct decisions about treatment. Sometimes a relapse, a setback, or even an uncertain lab test or X-ray report may disrupt the redirection process. You may suddenly find yourself back in a stage of disbelief or discovery, but you will be better prepared to settle on and handle the course of action required to resolve new questions or problems.

During this stage, you will also usually be forced by circumstances to deal

with physical, emotional, financial, and social effects, whether your illness is considered to be “cured,” is in remission, or requires continued treatment. You must master the techniques of how to get on with your life and enjoy yourself despite problems such as denial of health insurance claims, prejudice in the workplace, and trying to find people with whom you can share your concerns.

You have to learn to retain your independence and to keep the anxieties of illness from suffocating you. Redirection helps shape your life and makes it more productive.

Resolution Finally, the stage of resolution is reached. This may occur if your cancer is cured and you are able to accept this fact and put the experience behind you. It may also occur when you realize that cure is not possible.

If your cancer cannot be cured, this stage is not necessarily associated with a sudden dismal change in attitude or depression, although certainly your spirits and emotions may be at a low ebb. Having known for months or years that someday this time might come, someone who has been dealing productively with his or her illness will have spent time getting renewed enjoyment from life in whatever way possible, perfecting relationships with significant people, and sorting through the issues that he or she finds important. You may have discovered the meaning of life in general and of your life in particular. In some cases, there may even be relief that the long-awaited catastrophe need no longer be feared in the abstract but can be dealt with directly.

You have worked through the complex and progressive emotions that the illness has created in you as well as in those you love. You know that everything possible has been done and are comforted by the fact that you have gained additional time and meaning. You know that if there is

to be a brief period of ending, it will be made as comfortable and as free of suffering as possible. This may mean aggressive medical treatment to relieve symptoms, hospice care when appropriate, or the cessation of active anticancer treatment if that is appropriate.

If the previous three stages have successfully dealt with problems and needs, the fourth stage of living with mortality represents the attainment of peace of mind. It can become a validation that your struggle has been worthwhile and of value to you, your loved ones, and your close friends.

If your cancer is gone, many months or, more often, several years after apparently successful treatment—which can often be complex, difficult, and lengthy—your mind finally allows you to believe that you are cured. You can then reach the stage of resolution by regaining your belief once more that you are a normal person. You finally accept that the hoped-for goal has been achieved. You have a new awareness of the value of life and what in life holds special meaning for you.

Emerging Victorious The miracles of modern medicine have created a new dilemma for millions of people with chronic illnesses such as cancer, heart disease, and stroke. Prolonged illness, especially if potentially fatal, generates anxiety, tension, and worry that may be more troublesome than the illness itself.

Those who have cancer are labeled “cancer patient” and often agree somehow to accept this new identity that has been forced upon them. Loved ones and friends treat you differently—not to mention employers, insurance companies, and everyone else who hears the news that you have cancer.

You want to get on with your life. You want to feel and look normal. Your doctor has told you that you are okay now. But that’s hard to believe when every trip to the doctor’s office, even for a checkup, reawakens old fears. Anxiety will not disappear completely, but thinking about and understanding the emotional stages cancer patients face will help you cope with the awareness of mortality that cancer evokes.

For some of us, the threat of death increases our creative energies. Friends and family can draw closer and long-standing conflicts can be resolved. In spite of, or perhaps because of, the prospect of suffering, life intensifies and takes on added importance. Time is telescoped, and greater sensitivity to the wonders of the world is often gained.

In our society, the prospect of dying makes most people shrink and hide from a significant part of life. But you have to think positively. You have to recognize the potential within each of us even during prolonged illness.

It is unfortunate that our society shuns the thought of dying and turns away from the large segment of the population marked with the stigma of a chronic potentially fatal illness like cancer. We deny the self-worth of millions of capable and active people. We have to learn to recognize that medical technology has greatly extended life by offering effective treatments to people who are seriously ill. Such people are living full lives and deserve full acceptance by society. When a chronic and potentially fatal illness is not dealt with effectively by patients, family, or friends, emotional problems will inevitably mount and social fears will continue to fester. But if the threat to life by disease is accepted, understood, and dealt with, life, not death, will be the winner.