

ELISABETH
KÜBLER-ROSS

Death

THE FINAL STAGE
OF GROWTH

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HUMAN DEVELOPMENT BOOKS:
A SERIES IN APPLIED BEHAVIORAL SCIENCE

Joseph and Laurie Braga, *general editors*
University of Miami Medical School

HUMAN DEVELOPMENT BOOKS is a series designed to bridge the gap between theory and research in the behavioral sciences and practical application by readers. Each book in the series deals with an issue important to the growth and development of human beings, as individuals and in interaction with one another. At a time when the pressures and complexities of the world are making increased demands on people's ability to cope, there is a need for tools that can help individuals take a more active role in solving their own problems and in living life more fully. Such information is not easily found or read by those without previous experience or familiarity with the vocabulary of a particular behavioral field. The books in this series were designed and executed to meet that purpose.

ELISABETH KÜBLER-ROSS is a psychiatrist, a world-renowned leader and authority on death, and the author of *On Death and Dying*, *Questions and Answers on Death and Dying*, and *Coping with Death and Dying*, the latter a series of five cassette tapes available from Ross Medical Associates, Flossmoor, Ill.

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Children and Adults: Activities for Growing Together
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Prayer for Healers

LORD,

Make me an instrument of your health:
where there is sickness,
let me bring cure;
where there is injury,
aid;
where there is suffering,
ease;
where there is sadness,
comfort;
where there is despair,
hope;
where there is death,
acceptance and peace.

GRANT that I may not:
so much seek to be justified,
as to console;
to be obeyed,
as to understand;
to be honored,
as to love. . . .
for it is in giving ourselves
that we heal,
it is in listening
that we comfort,
and in dying
that we are born to eternal life.

Prayer of St Francis

(modified by Charles C. Wise)

Dedicated to—

Manny, Kenneth, and Barbara, whose love makes this work possible, and in memory of my mother, who died on the very day this manuscript was finished, September 12, 1974.

Thanks to Doug McKell for his untiring assistance in putting this manuscript together, to Rosalie Monteleoni, who keeps my spirits up and my office functioning, and the Rubins, whose support continues to flow when I need it most.

Joe and Laurie Braga have not only been the initiators of this book but have spent innumerable hours to “shape” it and have done so with the love that only true friends can put into a task like this.

Foreword

Death is a subject that is evaded, ignored, and denied by our youth-worshipping, progress-oriented society. It is almost as if we have taken on death as just another disease to be conquered. But the fact is that death is inevitable. We will all die; it is only a matter of time. Death is as much a part of human existence, of human growth and development, as being born. It is one of the few things in life we can count on, that we can be assured will occur. Death is not an enemy to be conquered or a prison to be escaped. It is an integral part of our lives that gives meaning to human existence. It sets a limit on our time in this life, urging us on to do something productive with that time as long as it is ours to use.

This, then, is the meaning of *DEATH: the Final Stage of Growth*: All that you are and all that you've done and been is culminated in your death. When you're dying, if you're fortunate enough to have some prior warning (other than that we all have all the time if we come to terms with our finiteness), you get your final chance to grow, to become more truly who you really are, to become more fully human. But you don't need to nor should you wait until death is at your doorstep before you start to really live. If you can begin to see death as an invisible, but friendly, companion on your life's journey—gently reminding you not to wait till tomorrow to do what you mean to do—then you can learn to *live* your life rather than simply passing through it.

Whether you die at a young age or when you are older is less important than whether you have fully lived the years you have had. One person may live more in eighteen years than another does in eighty. By living, we do not mean frantically accumulating a range and quantity of experience valued in fantasy by others. Rather, we mean living each day as if it is the only one you have. We mean finding a sense of peace and strength to deal with life's disappointments and pain while always striving to discover vehicles to make

more accessible, increase, and sustain the joys and delights of life. One such vehicle is learning to focus on some of the things you have learned to tune out—to notice and take joy in the budding of new leaves in the spring, to wonder at the beauty of the sun rising each morning and setting each night, to take comfort in the smile or touch of another person, to watch with amazement the growth of a child, and to share in children's wonderfully "uncomplexed," enthusiastic, and trusting approach to living. To live.

To rejoice at the opportunity of experiencing each new day is to prepare for one's ultimate acceptance of death. For it is those who have not really lived—who have left issues unsettled, dreams unfulfilled, hopes shattered, and who have let the real things in life (loving and being loved by others, contributing in a positive way to other people's happiness and welfare, finding out what things are *really you*) pass them by—who are most reluctant to die. It is never too late to start living and growing. This is the message delivered each year in Dickens's "Christmas Carol"—even old Scrooge, who has spent years pursuing a life without love or meaning, is able through his willing it, to change the road he's on. Growing is the human way of living, and death is the final stage in the development of human beings. For life to be valued every day, not simply near to the time of anticipated death, one's own inevitable death must be faced and accepted. We must allow death to provide a context for our lives, for in it lies the meaning of life and the key to our growth.

Think about your own death. How much time and energy have you put into examining your feelings, beliefs, hopes, and fears about the end of your life? What if you were told you had a limited time to live? Would it change the way you're presently conducting your life? Are there things you would feel an urgency to do before you died? Are you afraid of dying? Of death? Can you identify the sources of your fears? Consider the death of someone you love. What would you talk about to a loved one who was dying? How would you spend your time together? Are you prepared to cope with all the legal details of the death of a relative? Have you talked with your family about death and dying? Are there things, emotional and practical, that you would feel a need to work out with your parents, children, siblings before your own death or theirs? Whatever the things are that would make your life more personally meaningful before you die—do them now, because you *are* going to die; and you may not have the time or energy when you get your final notice.

In this book, Dr. Elisabeth Kübler-Ross has gathered a spectrum of

views on the subject of death and dying that will guide you in your search for the meaning of life and death. Whether you are a dying patient; a relative, friend, or loved one of someone who is dying; a member of one of the helping professions involved with terminal patients; or simply a person who desires to learn to live more fully through better understanding death's meaning, this book will provide insights that should help you find peace in life and death.

From her sharing of her own life experiences that have provided her with the direction and strength necessary to open our eyes and hearts to the realities of death and dying; to discussions of the issue from the points of view of ministers and rabbis, doctors, nurses, funeral directors, and sociologists; to presentation of other cultures' views of death and dying; to the sharing of feelings of persons dying or experiencing the death of someone they love, the author has assembled and integrated a collection of perspectives on death and dying that should stimulate both your thoughts and feelings about the subject. Whoever you are and whatever your stage of growth, you'll find something here to light your way on life's journey.

None of us knows what awaits us after this life. But you will hear the thoughts, beliefs, and hopes of other cultures and of individuals within our culture. You will be able to observe the growth of one woman as she shares her experiences of the death of her only son. You will learn how some have found ways to work through their grief over a loved one's death and see the ways that you can help yourself and others in this process. You will learn what factors make a difference in how a person faces death, and gain insight into the type of personality characteristics that predict acceptance of that fate. And you will see how all these things can be applied in your day-to-day life now, even if you have another fifty years on this earth.

But it is not enough simply to intellectualize about the subject of death and dying. You must go beyond the words and become involved in the feelings those words evoke for you. As you read, it is important that you become aware of and examine your own emotional reactions to the accounts that are presented. Then stop to think about those feelings as they relate to your dealing with (1) the death of others—friends, family, or dying patients you serve as a member of the helping profession, (2) your own death, and (3) the way you are living your life.

Because of the courage and love for humanity that Elisabeth Ross has shown in bringing to wide public awareness the much avoided

subject of death and dying, we are all being given an unparalleled opportunity—to discover life's true meaning through coming to terms with death's place in the spectrum of human development, and thus to learn to use our gift of life as happily and productively as possible. If you face a problem, whether you are able to solve it or not, you will grow. Death is a problem in our society. We urge you to accept the challenge and opportunity available to you now of dealing with this problem, of facing it squarely. You will grow through the experience.

JOSEPH L. BRAGA

LAURIE D. BRAGA

General Editors

Preface: A Journey into the Realm of Death and Growth

At the time when this book is published, ten years will have passed since my first interview of a young dying patient in Colorado, in front of a group of medical students.

This was by no means planned or preconceived, and no one at that time had the slightest idea that this kind of "Death and Dying Seminar" would become known nationwide and be copied throughout the country and abroad. Being a foreigner, I never dreamed of writing a book on this topic; I simply tried to do a good job as a new instructor in psychiatry. Coming from Europe, I was impressed by the lack of understanding and real appreciation of psychiatry among medical students. I must admit that many of the teachers were just plain boring and simply repeated the contents of psychiatric textbooks to the young medical students who would have been better off reading the original texts themselves. Others flooded the students with terminology which made no sense to them, and so they either switched off the teacher's voice or dozed through the lectures.

To teach psychiatry under a distinguished and admired professor* was a challenge to me, and I searched for ways to keep my students awake and interested during the two-hour lecture assignment. Determined not to speak about psychiatric disease entities, the thought occurred to me that death and dying would be an interesting topic with which all students eventually had to come to grips. I desperately searched for literature, but there was little to be found. I finally put my first lecture together, a compilation of rituals and customs in other cultures, a way to cope with death from the American Indians to modern Western man. In order to bring this to a clinical and more relevant level I followed the lecture with an interview of a 16-year-old girl suffering from acute leukemia and I asked some medical students to sit and question her with me. The patient did most of the talking;

* Dr. Sydney Margolin, Denver

the students were frightened, nervous, stiff, or very academic—displaying more anxiety than the dying girl.

Much to my relief none of the students fell asleep. They sat quietly and remained absorbed in their own thoughts and feelings about the mystery of death—which they were to face as future physicians (though this did not dawn on them until the moment of that young girl's sharing).

Much later, in Chicago, where these seminars became a weekly occurrence, another medical student so wisely described what she had never noticed in all the years of her training: "In all my experiences as a medical student in the dramatic and desperate resuscitations, I can hardly recall seeing a dead person. Part of it is the result, no doubt, of my own desire to have as little to do as possible with corpses. However, part of it is also due to the remarkable disappearing act that occurs as the body is cleverly whisked out of sight. In all the hours, day and night, that I have spent in this hospital, I have never caught a glimpse of any point of the procession, from the exit of the cart from the patient's room to its destination, be it morgue or hearse."

For many years I continued to ask terminal patients to be our teachers. They volunteered for this and were quite aware that many students would watch and hear them. For the sake of more privacy we sat behind a two-way mirror, seen and heard by physicians, nurses, clergy, social workers and others concerned with the dying patient. Some observers could hardly tolerate the anxiety these interviews stimulated in them; others sat in awe and admiration of the courage and openness of these patients. I don't think any of the hundreds of students who sat and listened were untouched. Old memories surfaced, accompanied by a new awareness of their own fears as something to be understood and not judged. We all grew in many ways, most importantly perhaps in an appreciation of life itself.

One of my most sensitive students recalled some of these memories: "I remembered G., one of my best friends. I was twenty when G. was hospitalized for a check-up. He meant a lot to me, especially during my teenage years. I guess, like all teenagers, I felt that my parents did not understand me, but somehow G. always did. . . . I met him in church as an altar boy. As I grew older he seemed to be the only person I could really talk to."

This student later described how he was studying music, how a critical illness left him alive but without a voice to sing, and how it was G. who encouraged him never to give up. He regained his voice again, only to be faced with another tragedy: "G. was hospitalized the next

fall for a biopsy. It was cancer. The doctor told him that he may have six months to live. I called on him at home regularly in the months that followed, and gradually the truth started to sink in. He became thinner and weaker and finally was confined to bed, a skeleton with white hair. I could not take it anymore and left. I never again saw him alive. He died several weeks later. Even in death he remembered me. He knew that as a junior member of the choir I would never get to sing Presentor's aria, and he requested in his funeral instructions that I sing it at his funeral. His funeral was a festival. People he had helped at one time or another came from all over the hemisphere. I could not believe that one man could become so involved with so many people. And I guess I have never forgiven myself for deserting him during those last weeks."

The student who wrote these memories a few years ago is now one of the most helpful ministers I know for those who are critically ill or bereaved. It is through such losses and with the help of caring and teaching people that we can face death rather than avoid it.

A young social worker described for us her reasons for wanting to attend the Death and Dying seminars. She had worked for years with the elderly and never became comfortable in this work until she attended the seminars and listened to what our patients had to say: "One of the main reasons why many of us avoid any talk of death is the awful and unbearable feeling that there is nothing we can say or do to comfort the patient. I had a similar problem in working with many aged and infirm clients in the past years. I always felt that old age and sickness was so devastating, that although I wanted to communicate hope to them, I only communicated despair. It seemed to me that the problem of illness and death was so insolvable and therefore these people could not be helped. . . . I think that this seminar has helped me to see that life did not have to end in mental and physical agony. Just listening to Mr. N. (one of our interviewed patients) describe the death of his father-in-law as an almost beautiful event, and then seeing Mr. N. himself coping so well with his own approaching death gave me a feeling that it really is possible to resolve the crisis of dying in a dignified way. In working with any patient, there must be a goal toward which you both are striving and some belief that movement to resolution or comfort is possible. It seems to me from observations of the interviews that listening itself is a comfort to these patients. I think another great help a social worker can give is to the family of the dying patient—not so much in the way stressed by so much of the casework literature (homemaker, financial aid, etc.)

but in helping them to relate better to the patient. Mr. N. wanted to talk about his illness to his wife and she to him. But they were each afraid to cause the other pain and did not know how much the other knew. With reassurance from the staff, Mrs. N. was able to broach the subject with her husband, and they were then able to share and to be a source of comfort to each other—instead of each suffering alone. This seminar has certainly helped me to realize this—that people need not suffer alone when they are dying. It is possible to help them share their feelings and in this way find some relief and peace.”

Many of our patients passed from a stage of shock and disbelief to the ever-recurring question “Why me?” Many of our dying young people tried to find a meaning in their suffering. Victor Frankl has written: “Let us now consider what we can do if a patient asks what is the meaning of his life. I doubt whether a doctor can answer this question in general terms. For the meaning of life differs from man to man, from day to day, and from hour to hour. What matters therefore, is not the meaning of life in general, but rather the specific meaning of a person’s life at a given moment.”

Later on he clarifies something that perhaps each one of us should realize more often: “As each situation in life represents a challenge to man and presents a problem for him to solve, the question of the meaning of life may actually be reversed. Ultimately, man should not ask what the meaning of his life is, but rather must recognize that it is he who is asked. In a word, each man is questioned by life; and he can only answer to life by answering for his own life; to life he can only respond by being responsible.”

Having seen hundreds of terminal patients grow through the crisis of their illness, becoming responsible for their own life, one wonders if Frankl himself would ever have reached this high level of wisdom and understanding, compassion and richness if he had not had the experience of facing death a thousand times in the death camps of World War II!

A young minister, who was looking forward to his clinical counseling duties with mixed-emotions, summed up his feelings after the Death and Dying seminar, a course he had signed up for as a preparatory step:

I consider this opportunity a totally new experience for me and one that I anticipate with a mixture of excitement, curiosity and dread. I will take five “rules” with me into this experience, “rules” that I know will change as I experience my self in relation to them:

Number 1: Concentrate on the dying patient not as a case history, but as a part of a one-to-one relationship. This attitude requires disciplines which are new to me. First, I must try to be myself. If the dying patient repulses me, for whatever reason, I must face up to that repulsion. I also must let the other person be himself, without projecting my own feelings of repulsion or hostility. Since he really is a human being, I suspect that he needs the same type of love and care that I do.

Number 2: Honor the sanctity of the human being. Just as I have "secret" values, fears, joys, so does he. His God, Christ, and Value-system have been hard-won over a life-time of curiosity, struggle, and hope, as have mine. My faith is that when we talk to each other about ourselves, we will find something in common. And the commonality is that "wondrous ingredient" that allows people to share their lives. That sharing is the realization of our humanness.

Number 3: Honoring the sanctity of the individual forces the counselor to let the patient "tell him" how he feels. The minister must, in this situation, "let the patient be." This simple rule does not imply granting all of the patient's demands and jumping whenever the patient wants the counselor to jump. If the counselor is honest, he will face his bias and accept it as his personality rather than apologize for it and try to hide it. The belief that "I know what's best for the patient" is not true. The patient knows best.

Number 4: I must continually ask myself "What kind of a promise am I making to this patient and to myself? If I can "realize" that I am trying to save this person's life or to make him happy in an unendurable situation, then I believe that I am typically human and hopefully can stop trying to attempt both. If I can learn to understand my own feelings of frustration, rage, and disappointment, then I believe I have the capacity to handle these feelings in a constructive manner. It is in this realization that human wisdom lies.

Number 5: My fifth and last rule, the rule that covers all four others, is expressed in the Alcoholics Anonymous Prayer:

God grant me the serenity to accept the things I cannot change,
the courage to change the things I can,
And the wisdom to know the difference.

What all of us hoped for during the first few difficult and lonely years of our Death and Dying seminar is perhaps best summarized in this prayer. Students came from numerous disciplines: Medicine, Nursing, Social Work, Sociology, Philosophy, Theology, and Psychology. Each one of them came for a different reason, I am sure. Some felt truly uncomfortable in their work with dying patients and tried to find ways of understanding their frustrations and anxieties. Others

knew that no exams or tests were given and came out of curiosity. Still others came "not knowing why" but obviously with some unresolved grief or death experiences in their own life. The students were never a problem. They filled the classroom long before the classes started and often continued to discuss the interviews long after I left.

The patients who were asked to serve were no problem either. They were often quite grateful to be "useful," to feel that someone needed them rather than the other way around. When we started to talk they quickly overcame their initial shyness and rather quickly shared with us the fantastic loneliness they felt. Strangers whom we had never met shared their grief, their isolation, their inability to talk about their illness and death with their next-of-kin. They expressed their anger at the physician who did not "level" with them, at the minister who tried to console them with the too often repeated phrase "It is God's will", or at friends and relatives who visited them with the inevitable "Cheer up, it's not so bad." We learned to identify quickly with them and became much more sensitive to their needs and fears than ever before. They taught us a great deal about living and dying, and they appreciated our asking them to be our teachers.

Our main problem was with the physicians. They first ignored the seminar; later they would refuse to give us permission to interview their patients. They often became quite apprehensive or hostile when we approached them. Many colleagues said to me quite indignantly: "You cannot interview this patient. She is not dying. She may even be able to go home once more." It was obvious that they missed the whole point of the seminar. We certainly did not wish to talk to dying patients during the last day of their lives. How could we ever bring families together in the very last moment? How could we help to alleviate the loneliness and fear of our patients when we were not allowed to see them before they were on their actual death bed? How could we teach our students what a patient goes through if we only saw them in their last few days? We could not convey to our colleagues that we are all dying—that we all have to face our finiteness long before we are terminally ill. This is perhaps the greatest lesson we learned from our patients: *LIVE, so you do not have to look back and say: "God, how I have wasted my life."*

Mrs. M. was 71 years old. One of her recurring statements was "If I could only do my life over, and know what I know now, I would do it so differently!" When she enlarged upon this, it came through that her whole life appeared to her as having been mostly wasted. Her life had

been filled with anxiety because of several failures in marriage, several job changes, and many moves. Now in the hospital, looking back at her life, she saw herself without roots, friends, or meaningful relationships, and her fears were magnified by the awareness of her limited life expectancy. In the midst of this emptiness and sorrow came the invitation to our seminar. Someone needed her. We asked her to teach us what she would change, if she were given a second chance. We became involved with her, and she started to trust us and confide in us. We became friends. We began to look forward to our visits with her, and we left enriched and aware that we should live today and not postpone it, lest we die alone. How fortunate that she had a physician who trusted us and who allowed us to visit her before her very last days!

The real change occurred when our seminar became “famous.” For several years I held my Death and Dying seminar almost inconspicuously, not marked in any program, yet always filled with students. It was after it became an accredited course and was publicized by the university’s PR Department that magazines like *TIME* and *LIFE* became curious and visited my classroom. Little did I know that the *LIFE* article was to change thousands of lives, including my own.

It was on a cold and rainy fall day when I interviewed Susan, a lovely girl of twenty-one, who was in our hospital with acute leukemia. She talked openly about her wish not to have a funeral and to donate her body to a medical school. She talked about her fiancé, who appeared to have deserted her when the diagnosis was confirmed (though she still denied that fact), and she also mentioned her awareness that her days were counted.

Deeply impressed by her frankness and lack of fear, I invited her to attend my seminar so that my students could hear and learn from her. Upon entering my classroom she opened the conversation with the statement: “I know my chances are one in a million; today I only wish to talk about this one chance.” Needless to say, we changed the topic of that day’s seminar to “On Life and Living.” We simply asked her what it would be like if she could live. She shared her hopes with us that she could still graduate in June and get married in July: her bargaining was that she would wait for five years to have children in order to be sure that she would live to raise them. Occasionally I realized while listening to her that the *LIFE* magazine people were behind the screen window, watching their one and only Death and Dying seminar. But I had no time to worry about them. I was too involved with Susan, who seemed to have the strength to face her