## Death and dying

## by Lucy Bregman in the May 23, 2001 issue

Life Lessons by Elisabeth Kübler-Ross

For those of us who associate Elisabeth Kübler-Ross with the death awareness movement she initiated 30 years ago, her subsequent work and writings are a puzzle and a disappointment. Why did she abandon the communal world of research and clinical work to assume the isolated position of a death-and-dying guru? This move was accompanied by a spiritual perspective that many consider eccentric at best and profoundly misguided and denial-oriented at worst. The aspect of her work that has remained alive for people is her description of the "five stages of dying," a model for coming to terms with loss which seems applicable to just about any kind of loss.

Today professionals such as those in the Association for Death Education and Counseling (ADEC) deny that anyone dies or grieves "in five stages," and ignore Kübler-Ross's later work on such topics as near-death experiences. Her latest book will be no exception; it is easy to categorize as a New Age inspirational potboiler, uncritically filled with rhetoric from the 1970s human potential movement.

Are the professionals correct? Is Kübler-Ross ignored because she deserves to be? I recently reread *On Death and Dying* (1969), the book which brought her fame, and found it remarkably fine. But what makes it fine is not primarily the "five stages" theory, but the many perspectives and voices Kübler-Ross presents. The Freudian beginning insists that our unconscious minds find our own deaths "inconceivable," although the point of the book is to show that true acceptance of death is indeed possible, even amid the dehumanizing milieu of a large research hospital. Though the patients interviewed for the book are long dead, they speak memorably through these pages. They do not confirm that there are a neat five steps on the way to the acceptance of death. Rather, they stammer and contradict themselves and the interviewer. Their continued vitality as they move closer and closer to death is what makes them real to us.

The book's underlying plot pits Kübler-Ross, the champion of the dying and their families, against powerful doctors. Recognizing fear and denial in herself and others, she works to change hospitals and American society. The book is awash in nostalgia for a lost rural past when death was "a natural part of life." It is also marked by an antiwar ethos that makes the military imagery used by hospitals to describe their combat with death look as warped and misguided as America's involvement in Vietnam.

Perhaps it is a tragedy that the changes Kübler-Ross worked for more than 30 years ago have not occurred. Bill Moyers's recent PBS documentary on the plight of the dying, *On Our Own Terms*, makes one wonder why so much remains as it was in 1969. Or perhaps the original critique, with its vision of death as psychologically "acceptable," was itself so flawed that it's no surprise things have not moved in the direction that Kübler-Ross and many others had hoped they would.

But *On Death and Dying* did help to start a movement and a popular language in which the very phrase "death and dying" became a catchword. College courses, workshops, sections in bookstores and endless writings by counselors, pastoral caregivers, American Buddhists, freelance inspirational authors and others rely on Kübler-Ross's model of dying as a process of coming to terms with loss. Hospice care and the rise of such professional specialties as "grief counselor" have professionalized this movement, but its breadth and importance are also revealed in the proliferation of autobiographies whose major plots concern life-threatening illness, dying and bereavement.

Kübler-Ross has framed for us what the experience of dying is about and how to respond to it. Categories such as "denial," "anger," "depression" and "acceptance" are the dominant organizers of such contemporary inspirational literature as books of meditations for those facing death. Add "forgiveness" and "surrender," which were not in the original 1969 book but are included in *Life Lessons*, and we have a kind of basic core of topics constituting a "spirituality" of the death awareness movement. The ADEC professionals, now focused on cultural construction, narrative and a relational vision of identity, may slowly have moved away from this original framework, but many still are rooted in it.

*Life Lessons* both assumes and proclaims some specific beliefs about self, society and ultimate reality. According to Kübler-Ross, there is a "core self," a real and eternal "you," who is not identified with actions, social roles or history. Happiness is

its natural state. This self is good and pure but always learning; its experience is to be seen as "lessons." Because it learns from its mistakes, "guilt feelings" about the past are burdensome and unnecessary. Kübler-Ross believes that "the world is set up to work; it is coded in a way that brings us to our lessons. . . . There is a reason for every experience, even if we don't see it."

Culture, history, groups, classes, neighborhoods and communities do not matter. "Relationships" do, but these exist for the sake of the self's development. Finally, emotions such as anger or depression are the immediate experiences of the self. Their objects don't matter, and there are no cognitive categories needed to explain their meaning. Everything is basically just a feeling.

These beliefs may go back to the "New Thought" movement about which William James wrote in his 1902 *Varieties of Religious Experience*. Some derive from the Christianity of 19th-century "domestic piety," an ongoing popular tradition on which authors of inspirational literature continue to draw. They are certainly not bound to the experiences of dying, recovering and bereaved persons, as Kübler-Ross and David Kessler want us to believe; they are "over-beliefs," not experience-based conclusions. Indeed, the stories of sick and dying people in *Life Lessons* are bare snippets told to confirm these core beliefs, very unlike the in-depth interviews of *On Death and Dying*.

The professionals of ADEC are right to have moved away from these ideas. They have seen the importance of public structures, institutions and financial arrangements for ordering people's experiences. They know that justice issues cannot be excluded from any attempt to better the situation of the dying in America. And the leaders of the death awareness movement are deeply conscious that loss, disjunction and the particularities of culture and history are what their work is about. These do not smoothly lend themselves to "healthy-mindedness." Strikingly, however, little or no Christian imagery or critique guides this movement past the limits of the original Kübler-Ross framework. Christian critiques of American individualism and narcissism and of the central images of death as "natural" and "loss" have not penetrated here.

Karl Rahner's theology of death's "darkness" can help us begin such a critique. Even without the traditional juridical language of "death as punishment for sin," Rahner's theology includes the recognition that death is a destructive, not a neutral, force. It can be seen as natural, it can be accepted, but it marks us in ways that the death awareness movement has never quite been able to articulate.

But we could also start with a careful reading of the psalms. Although the psalmists acknowledge that the Lord rewards the righteous, the psalmists complain and lament. They recognize that life does not work the way Kübler-Ross claims it does. Moreover, to speak realistically of forgiveness means to take guilt and fault seriously; to categorize our misdeeds simply as mistakes or learning experiences won't do.

Though Kübler-Ross's education metaphor echoes some of the psalms, when the psalms speak of lessons they speak of experiences that require effort and whose parameters and purpose are very different from that of developing one's core self and reaching some private fulfillment. Because the possibilities of success and failure are part of all education, honesty, justice and courage are intrinsic to this imagery. When we pray the psalms, we join our voices to those of past sufferers. Kübler-Ross realized this when she first set out on her journey. Her latest book makes one wish again that she had not deserted this path.