

A Profound Lesson for the Living

by LOUDON WAINWRIGHT



The viewing room on the dark side of the one-way glass was full 10 minutes before the patient came, and those who couldn't find chairs sat on tables, along ledges of the shaded windows or leaned against the walls. Several of the visitors wore long white hospital coats, and there were nurses in starched caps, but perhaps half of the 50 men and women were dressed in ordinary street clothes. There was little talk, and when the word arrived that she was coming, the silence was immediate. The door was closed, leaving the room on the other side of the glass, the room where *she* would appear, the only source of light. When she did come, erect, alert and graceful with her long hair brushed to shining, dressed in a fresh, soft blouse and tweed slacks instead of the dressing gown they had

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Unseen behind a one-way glass, a Chicago seminar on dying hears a very ill patient (center) discuss her case with Chaplain Carl Nighswonger and Dr. Elisabeth Kübler-Ross.

Photographed by
LEONARD McCOMBE



This young patient, 22, agreed to talk to the seminar after discovering only a month ago that she has leukemia. She also discussed with calm and courage her family, her treatment in the hospital and her views on death.

'You have to play the odds'

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expected, a gasp jumped through the watchers. They had been told she would be young, but her bearing and beauty were shocking beyond that and flew against the truth—accepted by all these professionals who dealt with more obvious forms of it daily—that she was terribly ill.

That was precisely why the patient was there—for that reason and because she had been willing to come to this seminar at the University of Chicago's Billings Hospital and tell the group how she felt about her illness (which she had learned about only two weeks earlier). In almost a light voice she described a conversation she had had with one of her doctors about it. The doctor had told her a story about a movie he'd seen in which a man escaped a tank by jumping in a narrow ditch just before it crushed him. She said: "We were talking about playing the odds. He said you have to play the odds no matter how small they are. The percentage of people that live with leukemia," she continued with a little laugh, "well, it's not a percent, it's a fraction of a percent that go on for years, and he said, 'You have to play the odds.' Well, it cheered me up. It did."

She spoke about her family and the boyfriend she planned to marry in June ("He's very cheerful, he doesn't believe it"). To her interviewers, a chaplain and a psychiatrist seated with her on the bright side of the glass, she talked also a bit about God. "When I was little," she began, "I always believed in God. I still want to . . . but I don't know. Sometimes if I talk to somebody, and we talk about not believing in God, I'll sort of look up and think—well, you know—don't believe me. I'm just kidding if You're there."

Protected from visual contact with her audience by the darkness of the window-wall, she spoke with candor and composure. In reply to a question about the sort of help she would most like when she was in the hospital, she said with determination and a strange quality of near-gaiety: "Oh, just come in and tell me when you find out about somebody that wasn't supposed to make it—and they did."

Her mixture of laughter and tears at this remark was not unusual for the seminar. All the patients at these meetings every week speak from the intensely private and painful view of sufferers from illnesses which most often are fatal. In an entirely real sense, the patients

are teachers—through their own experience—about the end of life. The clarity, courage and dignity they show in descriptions of their changing attitudes and feelings as they move toward final acceptance arouse profound empathy among the medical students, social workers, nurses and aides, chaplains and student chaplains who sit in the dark room and watch. It is very much as if, while watching the others come to an understanding with death, they begin to move toward understandings of their own.

The seminars at Billings were begun more than four years ago by Elisabeth Kübler-Ross, a psychiatrist trained at the University of Zurich who spent a year as a country doctor in Switzerland before coming to the U.S.

Asked for help by Chicago theological students who wanted to do a study on the ultimate human crisis of facing death, Dr. Ross began with the notion that the best sources would be people in that crisis. Searching the hospital (she was a member of the staff and also of the University of Chicago faculty) for subjects who would be willing to talk, she im-

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mediately ran into difficulty with doctors and other hospital workers. Many were astonished that she would even want to speak to terminally ill patients; others wanted to protect their patients from what they were certain would be the dangerous effects of frank and penetrating conversations. But when Dr. Ross finally was allowed to approach a patient about an interview, the man welcomed the opportunity, and in the years since only three of more than 200 subjects have refused the invitation to speak to the seminar. In that time, too, the antipathy of other professionals to her approach has dropped greatly. Patients are now regularly referred to her group, and Dr. Ross has written a book (*On Death and Dying*, Macmillan, \$6.95) based largely on the conversations and findings from the seminars.

The reasons the patients are so willing to talk seem easy enough to understand. The loneliness of hospital life for the very sick, the particular isolation of pain, both are broken by the chance to speak to sympathetic listeners, and the real possibility that one's efforts will eventually help other suffering people is

powerful motivation for those who fight to stave off the end of their own usefulness.

The basic findings of Dr. Ross and her seminar are that the very ill proceed through five emotional stages along the way to death. The first of these is denial, and at this point, which often occurs following the person's initial awareness of his sickness, the patient is unwilling or even unable to accept the real nature of his predicament. The stage following this—when physical indications such as loss of weight or increasing pain make further denial impossible—is anger. Here the patient, enraged at his illness, may become angry with his family or his doctor, berate the nurses, insist on continuous attention and never find it satisfactory, and generally behave in ways that may provoke in return the anger of his targets.

Following this is often a stage of "bargaining." Here the patient attempts to stave off the inevitable by striking a bargain for an extension of life or a short period without pain.

Many promises made "to live a life dedicated to God" or to the church, or offers to give the body or parts of it to science, are made with the silent additional clause that the Lord or the doctors must live up to their part of the bargain. Yet the bargaining does little but provide a temporary respite in the progress toward dying.

The next and most difficult stage for the patient is a period of increasing depression in which he realizes what is happening to him, that denial, anger, bargaining are of no real use any longer. At this point of depression the dying quite literally grieve for themselves, for the fact that they are going to be separated from all they have known and loved. Only after this period of grief does the patient usually arrive at the final stage before death, the stage of acceptance. Then, even though the smallest glimmer of hope will remain, he is ready to let go.

The work of Dr. Ross and of her associate in the group, Chaplain Carl Nighswonger, does not consist merely of listening to the patients at the seminars. With the help of students, nurses and other chaplains, they follow



each person through the various stages and offer support appropriate to the patient's need. For example, Dr. Ross attempts to help the dying express their rage at a terminal illness and explains the angry behavior to relatives, who might otherwise withdraw some support in anger or wounded feelings of their own. In dealing with the depression of the very ill, doctors, nurses, families—all of whom occasionally flinch from coping with this pervasive sadness—often tell the patients to cheer up. In the face of the predicament, this is absurd. Dr. Ross is convinced that this depression is, in fact, a sign that the patient is facing the fact of his coming death, and that the right thing is to encourage him to express his grief as a way of natural preparation for the final stage of acceptance. Here, very close to the end, Dr. Ross has found that families and even hospital staff are often confused by the withdrawn composure of these very ill patients. According to her, the fact is that these people have pretty thoroughly sifted through all unfinished business in their minds, need little conversation and require only the touch of companionship or almost silent support to keep them from feeling alone.

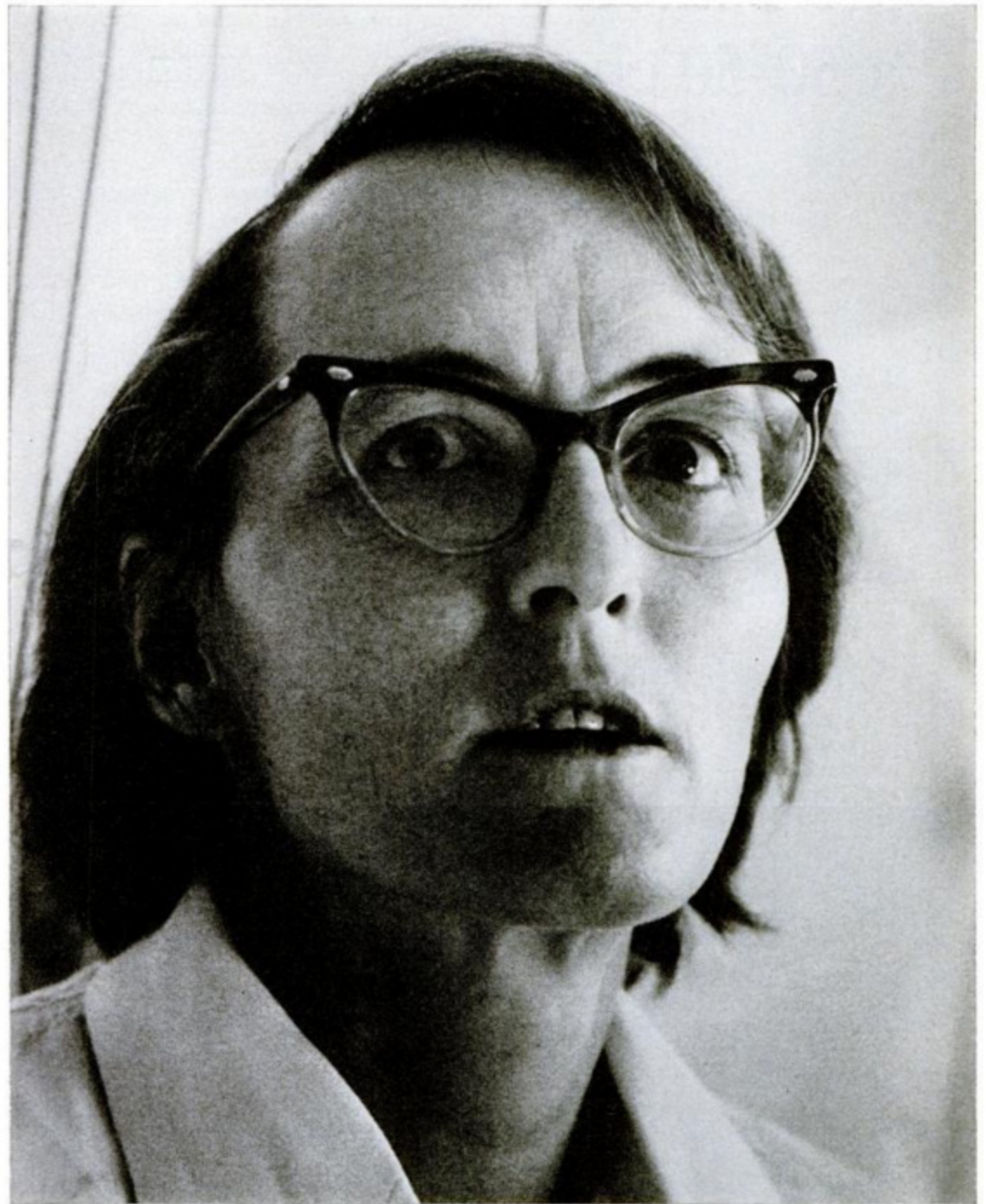
Some indirect findings of the seminar cast important light on American attitudes toward death and dying. Speaking of those attitudes in our society as opposed to others, Dr. Ross says in her book that "Death is viewed as taboo, discussion of it is viewed as morbid, and children are excluded [from being near the dead] with the presumption and the pretext that it would be 'too much' for them. . . . Dying becomes lonely and impersonal because the patient is often taken out of his familiar environment and rushed to an emergency room. . . . He may cry for rest, peace and dignity, but he will get infusions, transfusions, a heart machine, or tracheostomy, if necessary. He may want one single person to stop for one single minute so that he can ask one single question—but he will get a dozen people around the clock, all busily preoccupied with his heart rate, pulse, electrocardiogram or pulmonary functions, his secretions or excretions—but not with him as a human being." Without discounting the need to make every effort to save lives, Dr. Ross goes on to question what she characterizes as "our increasingly mechanical, depersonalized approach." "Is this approach," she asks, "our own way to cope with and repress the anxieties that a terminally and critically ill patient evoke in us?" When she speaks of these, Dr. Ross is referring to anxieties all will recognize: "our lack of omnipotence, our own limits and failures, and last but not least . . . our own mortality."

The seminars have led Dr. Ross to the conviction that most very sick people want to know about their illness. Often, in fact, they know how sick they are even if they have not been told, but they want hope to be held out no matter what the diagnosis. Dr. Ross feels

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During seminar, students, many of whom related strongly to the patient their own age, listen reflectively as she speaks of her plans.

A remarkable doctor and her special patients



Dr. Elisabeth Kübler-Ross hopes that the seminar technique of teaching professionals about aspects of death and dying will spread to other institutions. The poised and serene-looking woman at left, now deceased, spoke before the seminar. She was in the stage of peaceful acceptance of her terminal illness when she permitted this photograph to be made as part of a film of the interview produced for showing in hospitals by the Network for Continuing Medical Education.

'Nobody tells me I have a 50-50 chance'

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that it is a serious error to indicate to a patient a specific number of months or years a disease may run.

In the case of the girl with leukemia who so moved a recent seminar, this mistake was made. "The doctor said the average is two to three years," the girl told the group. "I was sort of disappointed that he'd said that. Now my friends will call and say they heard on the news that there's been a breakthrough and that makes me real happy. . . . There are [some in the hospital] that I don't even want to talk to about it anymore. When I talk to them, I talk like I'm going to be around 10 years from now, and they don't seem to cheer me on. . . . If 100 people come in and tell me that they know somebody who died after they had it for a year, and one person comes in and tells me they know somebody who's had it for 10, that one person can erase all the others."

Though this intelligent and courageous young woman is quite aware of the nature of her illness, her conversation shows traces of denial of her full predicament. Speaking of the marriage she plans next summer after she and her fiancé graduate from college, she said: "We weren't planning to have children right away anyway. So we'll just wait for five years. . . ."

And there was anger and depression about her illness, too, when she talked about a hos-

pital roommate who had just had breast surgery that the doctors believed was successful. "This lady," the girl said, "used to sit around and cry all the time. She asked the doctors all the time whether she was going to make it, and I heard them tell her every day that she was going to make it, that they'd removed all the cancer and that her chances for a normal life were excellent. . . . I really sympathize with her because I know psychologically what she was going through. It was a big blow to her."

"But every day she'd cry, even three days after they told her she'd live to be 100. I couldn't take that. I'd get up and walk out. I don't think it was because I felt sorry for her. Maybe I would sit there and feel sorry for myself. You know, nobody's coming in and telling me I have a 50-50 chance."

"That was the only time I really got depressed. I'd run out in the hall and cry. Nobody understood. The nurses would tell me, 'Well, you know, she's going through a big psychological thing,' and I'd say, 'What about me?' I used to think I'd give her my breasts, you know. I want to live."

When Dr. Ross gently brought the conversation to a close, she thanked the girl for coming. The girl's lovely smile framed her enthusiastic reply. "Oh," she said, "any time." ■



A student nurse, a family therapist, a student chaplain and one of the Billings Hospital nurses are deeply moved as they listen to the patient.

