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*Questions and Answers on Death and Dying*

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# On Death and Dying

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## Some Interviews with Terminally Ill Patients

*Death, thy servant, is at my door. He has crossed the unknown sea and brought thy call to my home.*

*The night is dark and my heart is fearful—yet I will take up the lamp, open my gates and bow to him my welcome. It is thy messenger who stands at my door.*

*I will worship him with folded hands, and with tears. I will worship him placing at his feet the treasure of my heart.*

*He will go back with his errand done, leaving a dark shadow on my morning; and in my desolate home only my forlorn self will remain as my last offering to thee.*

Tagore, from *Gitanjali*, LXXXVI

IN PREVIOUS chapters we have tried to outline the reasons for the increasing difficulties patients have in communicating their needs at the time of serious or perhaps fatal illness. We have summarized some of our findings and attempted to describe the methods used to elicit the patient's awareness, problems, concerns, and wishes. It seems helpful to include more random examples of such interviews as they give a better picture of the variety of responses and reactions demonstrated by both the patient and the interviewer. It should be remembered that the patient rarely knew the interviewer; both had met only for a few minutes in order to arrange for the interview.

I have selected one interview of a patient whose mother was visiting at the same time and who volunteered to meet with us in order to share her responses. I think they demonstrate well how different members of a family cope with terminal illness and how, at times, both members have completely different recollections of the same event. Each interview is followed by a brief summary relating the material to statements made in earlier chapters. These original interviews will speak for themselves. They were purposely left unedited and unabbreviated and demonstrate moments when we were perceptive of a patient's implicit or explicit communications and times when we did not react in the most responsive manner. The part that cannot be shared with the reader is the experience that one has during such a dialogue: the many nonverbal communications that go on constantly between patient and physician, physician and chaplain, or patient and chaplain; the sighs, wet eyes, the smiles, gestures with the hands, the empty look, the astonished glance, or the outstretched hands—all communications of significance which often go beyond words.

Though the following interviews were, with a few exceptions, the first meetings we had with these patients, they were in most cases not the only ones. All patients were seen as often as indicated until they died. Many of our patients were able to be discharged home once more, either to die there or to be readmitted to the hospital later on. They asked to be called once in a while when at home, or they called one of the interviewers "to keep in touch." It happened occasionally that a relative would drop in at our office for an informal visit either to gain some insight into a patient's behavior and ask for help and understanding, or to share some memories with us later after the patient's death. We tried to remain as available to them as we were to the patient during hospitalization and thereafter.

The following interviews may be studied in regard to the role the relatives played during these difficult times.

Mrs. S. had been deserted by her husband, who was only indirectly informed by their two small boys of her fatal illness. It was a neighbor and friend who played the most significant role

during her terminal illness though she expected her estranged husband and his second wife to take care of her children after her death.

The seventeen-year-old girl demonstrates the courage of a young person in facing such a crisis. Her interview is followed by one with her mother; both of them speak for themselves.

Mrs. C. felt unable to face her own death because of the many family obligations she had to fulfill. Here again is a good example of the importance of family counseling when sick, dependent, or old people have to be taken care of by the patient.

Mrs. L., who had been the eyes for her visually handicapped husband, uses this role to prove that she can still function, and both husband and wife use partial denial in the time of their crisis.

Mrs. S. was a forty-eight-year old, Protestant woman, mother of two young boys whom she raised alone. She had expressed a wish to talk to someone and we invited her to come to our seminar. She was reluctant and somewhat anxious about coming, but felt greatly relieved after the seminar. On the way to the interviewing room she talked casually about her two boys, and it seemed obvious that they were her biggest concern during this hospitalization.

DOCTOR: Mrs. S., we really know nothing about you except for the minute, you know, we talked with you before. How old are you?

PATIENT: Let's see. Sunday I'll be forty-eight.

DOCTOR: This coming? I'll have to think of it. This is the second time you have been in the hospital? When did you come in the first time?

PATIENT: In April.

DOCTOR: What did you come in for?

PATIENT: This tumor, on my chest.

DOCTOR: What kind of a tumor?

PATIENT: Well, now that I really can't tell you. You see, I don't know enough about this disease to know one kind from another.

DOCTOR: What do you think it is? How were you told what you have?

PATIENT: Well, you see when I went to the hospital they took a biopsy, and then about two days later my family doctor came in and said that the results came back and that it was malignant. But actually the name of what kind it was I don't—

DOCTOR: But they told you it was malignant.

PATIENT: Yes.

DOCTOR: When was that?

PATIENT: That was in, oh, that must have been in the last part of March.

DOCTOR: Of this year? So until this year you were healthy?

PATIENT: No, no. You see, I have an arrested case of TB, so I have spent months in the sanitarium, at one time or another.

DOCTOR: I see. Where, in Colorado? Where did you go to the sanitarium?

PATIENT: In Illinois.

DOCTOR: So, you have had a lot of illness in your life.

PATIENT: Yes.

DOCTOR: Are you kind of almost used to hospitals?

PATIENT: No. I don't think you ever get used to them.

DOCTOR: And then, how did this illness start? What brought you to the hospital? Can you tell us about the beginning of this illness?

PATIENT: I had this little lump. It was like, oh, like maybe a blackhead or something, you know. Right here. And it kept getting larger, and painful and, ah, I don't think I'm any different than anyone else, I didn't want to go to a doctor and kept putting it off, until finally I realized it was getting worse and worse and I had to go and see someone. Well, a few months before that my family doctor that I've had for years passed away. And I didn't know who to go to. Naturally, I mean, I don't have a husband, I was married for twenty-two years and my husband decided there was someone else he wanted. So it was just the boys and I, and I felt that they needed me. I think probably that's one reason why I thought that if there was something very serious the matter, why, well, I kept saying it just couldn't be. I have to be home with the boys. That was the main reason that I put it off. Well, and then when I did go it was getting very large and so painful I

couldn't stand it, stand the pain any longer. And when I went to the family doctor, why, he just said that he couldn't do anything there in the office. I would have to go to the hospital. And so, I went. I think four or five days later I was admitted to the hospital and— I also had a tumor on one ovary.

DOCTOR: At the same time? This was found?

PATIENT: Yes. And I think he intended to do something about that also while I was there, and then when he took the biopsy of this and he came back, it was a malignant one and naturally he wouldn't do anything else. And so he said he could do nothing more for me there, I would have to make up my mind where I wanted to go.

DOCTOR: Meaning to which hospital?

PATIENT: Yes.

DOCTOR: And then you picked this hospital?

PATIENT: Yes.

DOCTOR: How come you picked this hospital?

PATIENT: Well, we have a friend who was a patient here at one time. I know him through my insurance, and he couldn't speak high enough of it and the doctors and the nurses. He said the doctors are specialists and you'll get wonderful care.

DOCTOR: Are you?

PATIENT: Yes.

DOCTOR: I'd be curious how you took this, when it was told to you that you had a malignancy. How did you take it after postponing, postponing to hear the truth. Or to hear the fact, you know, out of your needs to be home and take care of your children. How did you take it when it finally had to be said?

PATIENT: When I first heard it I went all to pieces.

DOCTOR: How?

PATIENT: Emotionally.

DOCTOR: Depressed, crying?

PATIENT: Ah ha. I always thought that I couldn't have anything like that. Then when I realized how serious it was I thought it's something I have to accept, going all to pieces will solve nothing, and I suppose the sooner I can go to someone who can help me the better it will be.

DOCTOR: Did you share this with your children?

PATIENT: Yes. I told them both. I mean, ah, I don't know really how much they really do understand. I mean they know it's something that's very serious but as far as how much they understand I don't know.

CHAPLAIN: How about the rest of your family. Did you share this with any others? Do you have any others?

PATIENT: I have a fellow, a friend that I've been going with for about five years. He's a very nice person and he has been very good to me. And he's been good to the boys, I mean, since I've had to be away from the boys he has been overseeing them, seeing that someone was there with them to get their meals at night, to be with them. I mean that they aren't entirely alone, you know, entirely on their own. Of course, the older boy, probably he would be responsible enough but he is still a minor, I feel, until he is twenty-one.

CHAPLAIN: You feel more comfortable with somebody there.

PATIENT: Yes. And then I have a neighbor there. It's more like a duplex, she lives in the other half of the house. And she's in and out every day. And she's been helping me with my housework at home, between those two months that I was home. She took care of me, you know, she'd give me my baths and see that I had a meal to eat. She's a very wonderful person. She's a very religious person, you know, in her own faith, and she has done just an awful lot for me.

DOCTOR: What faith does she have?

PATIENT: I don't know whether I really know what church she does go to.

CHAPLAIN: Protestant?

PATIENT: Yes.

CHAPLAIN: Do you have other family or is this—

PATIENT: I have a brother who lives here.

CHAPLAIN: But he's not as close as—

PATIENT: We haven't been too close, no. I feel that in the short time that I've known her, she's really the closest one I have. I mean, I can talk to her and she talks to me, which makes me feel better.

DOCTOR: Um hm. You are lucky.

PATIENT: She's wonderful. I've just never known anyone like her.

Nearly every day I get a card or a few lines in the mail from her. It might be silly, it might be serious, but, I mean, I even look forward to just hearing from her.

DOCTOR: Just that somebody cares.

PATIENT: Yes.

DOCTOR: How long ago did your husband leave you?

PATIENT: In September of '59.

DOCTOR: '59. Then did you have tuberculosis?

PATIENT: The first time was in 1946. I lost my little girl. She was two and a half years old. And at that time my husband was in the service. She got very sick and we took her to a specialist in the hospital. And, ah, the hardest thing was that I couldn't see her while she was there. And she went into a coma and she never did come out of it. They asked if it would be all right to perform an autopsy, and I said yes, perhaps it might help someone else someday. So they performed an autopsy, and she had what they call military TB. That was in the bloodstream. And when my husband went in the service, my father came to live with me. And so afterward we all had checkups and my father had quite a large cavity in one lung, and I had just a small amount of trouble. So he and I both went into the sanitarium at that time. And I was there about three months, the only medication I had to have was bedrest and shots. I didn't have to have any surgery. And then, well, on through the years, I was there before and after each one of the boys was born. And I haven't been there now as a patient since after the youngest boy was born in '53.

DOCTOR: Your girl was your first child?

PATIENT: Yes.

DOCTOR: And the only girl you had. That must have been quite something. How did you recover from that?

PATIENT: Well, it was very hard.

DOCTOR: What gave you strength?

PATIENT: Prayer, probably, more than anything. She and I were, I mean, she was all I had for all that time. She was three months old when my husband left. She was just, well, I really lived for her, you know. And I didn't think I could accept but I did.

DOCTOR: And now since your husband left it's the boys that you live for.

PATIENT: Yes.

DOCTOR: That must make it very hard. And now does your religion or prayers or what help you to take care of all the times when you have the blues or you feel depressed about your illness?

PATIENT: Prayers I think are the main thing.

DOCTOR: Do you ever think or talk with anybody in terms of how it's going to be if you would die of this disease or— You don't think about these things?

PATIENT: Well, ah, I haven't too much, no. Other than this lady friend of mine, she will talk with me you know about how serious it is and things that, ah, other than her I haven't talked with anyone.

CHAPLAIN: Does your priest come to see you or do you attend church?

PATIENT: Well, I did go to church before. You know, I hadn't been feeling well for months, even before I came in here. And I hadn't been too good at going to church. But—

CHAPLAIN: Does the priest come to see you?

PATIENT: The priest came to see me when I was in the hospital there at home before I came here. And he was coming down to see me again before I came in, and I guess I just all of a sudden decided to come here, so he didn't get to see me before I came. And then after I was here for about two or three weeks, Father D. came to see me.

CHAPLAIN: Primarily, though, your faith has been nourished by your own private resources at home. Where you haven't had an outlet talking to anyone at church.

PATIENT: No.

CHAPLAIN: But your friend has played this role.

DOCTOR: You sounded like this friend was a relatively new friend.

Did you just move into this duplex or did she just move in?

PATIENT: I've known her for about, oh, maybe a year and a half.

DOCTOR: Is that all? Isn't that wonderful. How did you click in such a short time?

PATIENT: Well, I don't know. It's really rather hard to explain. I

mean she said all her life she always wanted a sister and in talking I said why I always wanted a sister too. I said there were just the two of us, my brother and I, and she said, well, I think we've found each other and I think you have a sister now and so do I. Just to have her walk in the room, she makes you feel, oh, you just feel good like it's home.

DOCTOR: Did you ever have a sister?

PATIENT: No. Just my brother and I.

DOCTOR: You had just one brother. What kind of parents did you have?

PATIENT: Well, my father and mother were divorced when we were very small.

DOCTOR: How small?

PATIENT: I was two and a half and my brother was about three and a half. And we were raised by an aunt and uncle.

DOCTOR: How were they?

PATIENT: They were very wonderful to us.

DOCTOR: Who are your real parents?

PATIENT: My mother is still living. She lives here and my father passed away not too long after he had been sick and been in the sanatorium.

DOCTOR: Your father died of his tuberculosis?

PATIENT: Yes.

DOCTOR: I see. Whom did you feel closer to?

PATIENT: Well, I mean, like my aunt and uncle, they were really my father and mother. I mean, we were with them from the time we were little. And, I mean, they never, they told us they were an aunt and uncle, but I mean they were like parents to us. DOCTOR: There's nothing phony about it. They were honest about it.

PATIENT: Yes, yes.

CHAPLAIN: Are they living?

PATIENT: No. My uncle has been dead for several years. My aunt is still living. She is eighty-five years old.

CHAPLAIN: Does she know about your illness?

PATIENT: Yes.

CHAPLAIN: Do you have much contact with her?

PATIENT: Well, yes I do. I mean she doesn't get out too much, she's not too well. Last year she had arthritis of the spine and she was in the hospital for quite some time. I didn't know whether she would be able to live through that illness or not. She did, and she is doing quite well now. She has her own little place, she lives by herself, takes care of herself which I think is wonderful.

DOCTOR: Eighty-four?

PATIENT: Eighty-five.

DOCTOR: How do you make your living? Were you working?

PATIENT: I worked part-time up until the time I came in here.

DOCTOR: In April?

PATIENT: Yes. But my husband gives us so much a week support

DOCTOR: I see. So you are not dependent on working?

PATIENT: No.

DOCTOR: Your husband has still some contact with you?

PATIENT: Well, he, he sees the boys whenever he wants to and that's always—I always felt whenever he wanted to see them that it was up to him. He lives in the same town as I do.

DOCTOR: Um hm. Is he married again?

PATIENT: Yes, he's married. He was remarried, oh, perhaps a year or so after he left.

DOCTOR: Does he know about your illness?

PATIENT: Yes.

DOCTOR: How much does he know?

PATIENT: Ah, I don't know really, I mean, nothing but perhaps what the boys have told him.

DOCTOR: You don't verbally communicate with him.

PATIENT: No.

DOCTOR: I see. You haven't seen him then personally?

PATIENT: Not to talk to him. I don't—no.

DOCTOR: What kind of parts of your body are involved now with this malignancy?

PATIENT: Well, it's this tumor here and this spot on the liver. And then I had this large tumor on my leg that had eaten most of the bone away and so they inserted that pin in my leg.

DOCTOR: That was in the spring or summer?