

CHAPTER III

First Stage: Denial and Isolation

Man barricades against himself.

TAGORE,
from *Stray Birds*, LXXIX

Among the over two hundred dying patients we have interviewed, most reacted to the awareness of a terminal illness at first with the statement, "No, not me, it cannot be true." This *initial denial* was as true for those patients who were told outright at the beginning of their illness as it was true for those who were not told explicitly and who came to this conclusion on their own a bit later on. One of our patients described a long and expensive ritual, as she called it, to support her denial. She was convinced that the X-rays were "mixed up"; she asked for reassurance that her pathology report could not possibly be back so soon and that another patient's report must have been marked with her name. When none of this could be confirmed, she quickly asked to leave the hospital, looking for another physician in the vain hope "to get a better explanation for my troubles." This patient went "shopping around" for many doctors, some of whom gave her reassuring answers, others of whom confirmed the previous

suspicion. Whether confirmed or not, she reacted in the same manner; she asked for examination and reexamination, partially knowing that the original diagnosis was correct, but also seeking further evaluations in the hope that the first conclusion was indeed an error, at the same time keeping in contact with a physician in order to have help available "at all times" as she said.

This anxious denial following the presentation of a diagnosis is more typical of the patient who is informed prematurely or abruptly by someone who does not know the patient well or does it quickly "to get it over with" without taking the patient's readiness into consideration. Denial, at least partial denial, is used by almost all patients, not only during the first stages of illness or following confrontation, but also later on from time to time. Who was it who said, "We cannot look at the sun all the time, we cannot face death all the time"? These patients can consider the possibility of their own death for a while but then have to put this consideration away in order to pursue life.

I emphasize this strongly since I regard it a healthy way of dealing with the uncomfortable and painful situation with which some of these patients have to live for a long time. Denial functions as a buffer after unexpected shocking news, allows the patient to collect himself and, with time, mobilize other, less radical defenses. This does not mean, however, that the same patient later on will not be willing or even happy and relieved if he can sit and talk with someone about his impending death. Such a dialogue will and must take place at the convenience of the patient, when he (not the listener!) is ready to face it. The dialogue also has to be terminated when the patient can no longer face the facts and resumes his previous denial. It is irrelevant when this dialogue takes place. We are often accused of talking with very sick patients about death when the doctor feels—very rightfully so—that they are not dying. I favor talking about death and dying with patients long before it actually happens if the patient indicates that he wants to. A healthier, stronger individual can deal with it better and is less frightened by oncoming death when it is still "miles away" than when it "is right in front of the door," as one of our patients put it so appropriately. It is

also easier for the family to discuss such matters in times of relative health and well-being and arrange for financial security for the children and others while the head of the household is still functioning. To postpone such talks is often not in the service of the patient but serves our own defensiveness.

Denial is usually a temporary defense and will soon be replaced by partial acceptance. Maintained denial does not always bring increased distress if it holds out until the end, which I still consider a rarity. Among our two hundred terminally ill patients, I have encountered only three who attempted to deny its approach to the very last. Two of these women talked about dying briefly but only referred to it as "an inevitable nuisance which hopefully comes during sleep" and said "I hope it comes without pain." After these statements they resumed their previous denial of their illness.

The third patient, also a middle-aged spinster, apparently had used denial during most of her life. She had a visible, large ulcerative type of cancer of the breast but refused treatment until briefly before she died. She had great faith in Christian Science and held onto this belief to the last day. In spite of her denial, one part of her must have faced the reality of her illness since she did finally accept hospitalization and at least some of the treatments offered to her. When I visited her prior to planned surgery, she referred to the operation as "cutting part of the wound out so it can heal better." She also made it clear that she wished only to know details regarding her hospitalization "which have nothing to do with my wound." Repeated visits made it obvious that she feared any communications from staff members, who might possibly break down her denial, i.e., talk about her advanced cancer. As she grew weaker, her make-up became more grotesque. Originally rather discreetly applied red lipstick and rouge, the makeup became brighter and redder until she resembled a clown. Her clothing became equally brighter and more colorful as her end approached. During the last few days she avoided looking in a mirror, but continued to apply the masquerade in an attempt to cover up her increasing depression and her rapidly deteriorating condition.

rating looks. When asked if there was anything we could do for her, she replied, "Come tomorrow." She did not say, "Leave me alone," or "Don't bother me," but left the possibility open that tomorrow might be the day that her defenses would not hold up any longer, thus making help mandatory. Her last statement was, "I guess I cannot make it anymore." She died less than an hour later.

Most patients do not use denial so extensively. They may briefly talk about the reality of their situation, and suddenly indicate their inability to look at it realistically any longer. How do we know, then, when a patient does not wish to face it anymore? He may talk about relevant issues as far as his life is concerned, he may share some important fantasies about death itself or life after death (a denial in itself), only to change the topic after a few minutes, almost contradicting what he said earlier. Listening to him at this point may seem like listening to a patient with a minor ailment, nothing as serious as a life-threatening condition. This is when we try to pick up the cues and acknowledge (to ourselves) that this is the moment at which the patient prefers to look at brighter, more cheery things. We then allow the patient to daydream about happier things, no matter how improbable they may be. (We have had several patients who daydreamed about seemingly impossible situations which—much to our surprise—became true.) What I am trying to emphasize is that the need for denial exists in every patient at times, at the very beginning of a serious illness more so than towards the end of life. Later on the need comes and goes, and the sensitive and perceptive listener will acknowledge this and allow the patient his defenses without making him aware of the contradictions. It is much later, usually, that the patient uses isolation more than denial. He can then talk about his health and his illness, his mortality and his immortality as if they were twin brothers permitted to exist side by side, thus facing death and still maintaining hope.

In summary, then, the patient's first reaction may be a temporary state of shock from which he recuperates gradually. When his initial feeling of numbness begins to disappear and he can

collect himself again, man's usual response is "No, it cannot be me." Since in our unconscious mind we are all immortal, it is almost inconceivable for us to acknowledge that we too have to face death. Depending very much on how a patient is told, how much time he has to gradually acknowledge the inevitable happening, and how he has been prepared throughout life to cope with stressful situations, he will gradually drop his denial and use less radical defense mechanisms.

We have also found that many of our patients have used denial when faced with hospital staff members who had to use this form of coping for their own reasons. Such patients can be quite elective in choosing different people among family members or staff with whom they discuss matters of their illness or impending death while pretending to get well with those who cannot tolerate the thought of their demise. It is possible that this is the reason for the discrepancy of opinions in regard of the patient's needs to know about a fatal illness.

The following brief case description of Mrs. K. is an example of a patient who used massive denial for an extended period of time and shows our management of her from the time of admission until her death several months later.

Mrs. K. was a twenty-eight-year-old white Catholic woman, mother of two preschool children. She was hospitalized with a terminal liver disease. A very careful diet and daily laboratory measurement were mandatory to keep her alive.

We were told that two days before her admission to the hospital, she visited the medical clinic and was told that there was no hope for a recovery. The family reported that the patient "fell apart" until a neighbor reassured her that there was always some hope, encouraging her to attend a tabernacle where many people had been healed. The patient then asked her priest for support but was told not to go to a faith healer.

On Saturday, the day after the clinic visit, the patient went to this faith healer and "immediately felt wonderful." She was found in a trance on Sunday by her mother-in-law, while the husband was out at work and the small children were left alone

without being fed or otherwise attended to. The husband and mother-in-law brought her to the hospital and left before the physician was able to talk to them.

The patient asked for the hospital chaplain "to tell him of the good news." When he entered her room she welcomed him in an exalted mood: "Oh, Father, it was wonderful. I have been healed. I am going to show the doctors that God will heal me. I am all well now." She expressed her sorrow that "even my own church did not understand how God works," referring to the priest's advice not to visit the tabernacle.

The patient was a problem for the physicians since she denied her illness almost completely and became quite unreliable in regard to her food intake. She occasionally stuffed herself to a degree that she became comatose; at times she followed the orders obediently. For this reason a psychiatric consultation was requested.

When we saw the patient she was inappropriately cheerful, laughed and giggled, and reassured us that she was completely well. She went around the ward visiting patients and staff, attempting to collect money for a gift for one of the staff physicians in whom she had immense faith, which seemed to indicate at least a partial awareness of her present condition. She was a difficult management problem as she was unreliable about her diet and medications and "did not behave like a patient." Her belief in her well-being was unshakable and she insisted on hearing it confirmed.

A discussion with the husband revealed a rather simple, unemotional man who seriously believed that his wife was better off living a short time at home with the children rather than having her suffering prolonged by long hospitalizations, endless costs, and all the ups and downs of her chronic illness. He had little empathy with her and separated his feelings quite effectively from the context of his thoughts. He matter-of-factly related the impossibility of having a stable home environment, with him working nights and the children living out during the week. Listening to him and placing ourselves into his position, we were able to appreciate that he could deal with his present life situation

only in this detached manner. We were unable to relate some of her needs to him, in the hope that his empathy might diminish her needs for such denial, thus rendering her more amenable to effective treatment. He left the interview as if he had completed a compulsory task, obviously unable to change his attitude.

Mrs. K. was visited by us at regular intervals. She appreciated our chats, which dealt with daily happenings and inquiries about her needs. She became gradually weaker and—for a couple of weeks—just dozed and held our hand, and did not speak much. After this she became increasingly confused, was disoriented, and had delusions of a beautiful bedroom filled with fragrant flowers brought to her by her husband. When she became more clear, we tried to help her with arts and crafts to make the time go by a bit faster. She had spent much of her past weeks alone in a room, with the double doors closed, and few staff people dropped in since there was so little they felt they could do. The staff rationalized their own avoidance by such remarks as, "She is too confused to know" and "I would not know what to say to her, she has such crazy ideas."

As she felt this isolation and increasing loneliness, she was often observed to take the telephone off the hook, "just to hear a voice."

When she was put on a protein-free diet she became very hungry and lost much weight. She would sit on her bed, holding the little bags of sugar between her fingers and say, "This sugar is finally going to kill me." I sat with her, and when she held my hand she said, "You have such warm hands. I hope you are going to be with me when I get colder and colder." She smiled knowingly. She knew and I knew that at this moment she had dropped her denial. She was able to think and talk about her own death and she asked for just a little comfort of companionship and a final stage without too much hunger. We did not exchange more than the abovementioned words; we just sat silently for a while, and when I left she asked if I would be sure to return and bring that wonderful or (occupational therapist) girl with me, who helped her make some leatherwork for her family "so they have something to remember me by."

Hospital personnel, whether they are physicians, nurses, social workers, or chaplains, don't know what they miss when they avoid such patients. If one is interested in human behavior, in the adaptations and defenses that human beings have to use in order to cope with such stresses, this is the place to learn about it. If they sit and listen, and repeat their visits if the patient does not feel like talking on the first or second encounter, the patient will soon develop a feeling of confidence that here is a person who cares, who is available, who sticks around.

When they are ready to talk, they will open up and share their loneliness, sometimes with words, sometimes with little gestures or nonverbal communications. In the case of Mrs. K. we never attempted to break her denial, we never contradicted her when she assured us of her well-being. We just reinforced that she had to take her medication and stick to her diet if she wanted to return home to her children. There were days when she stuffed herself with forbidden foods, only to suffer twice as much the next days. This was intolerable and we told her so. This was part of reality that we could not deny with her. So, in a way, implicitly, we told her that she was critically sick. Explicitly, we did not do it because it was obvious that she was unable to tolerate the truth at that stage of her illness. It was much later, after having gone through stages of semicomatose stupor and extreme withdrawal, and stages of confusion with delusions of her husband's tender loving care expressed in the flowers, that she developed the strength to look at the reality of her situation and was able to ask for more palatable food and final companionship, which she sensed was not forthcoming from her family.

Looking back at this long and meaningful relationship, I am sure that it was possible only because she sensed that we respected her wish to deny her illness as long as possible. We never became judgmental no matter how much of a management problem she presented. (Granted, that was much easier for us as we were a diet or around her all day long from one frustrating experience to another.) We continued our visits even during the times when

she was totally irrational and could neither recall our face nor the professional role we played. In the long run it is the persistent nurturing role of the therapist who has dealt with his or her own death complex sufficiently that helps the patient overcome the anxiety and fear of his impending death. Mrs. K. asked for two people during her final days in the hospital; one was the therapist with whom she exchanged few if any words at the time, occasionally just holding hands and expressing less and less concern about food, pain, or discomfort. The other person was the occupational therapist who helped her forget the reality for a while and allowed her to function as a creative, productive woman, making objects which she would leave for her family—maybe as little signs of immortality.

I use this example to show that we do not always state explicitly that the patient is actually terminally ill. We attempt to elicit the patients' needs first, try to become aware of their strengths and weaknesses, and look for overt or hidden communications to determine how much a patient wants to face reality at a given moment. This patient, in many ways exceptional, made it quite clear from the very beginning that denial was essential in order for her to remain sane. Though many staff people regarded her as clearly psychotic, testing showed her sense of reality was intact in spite of the manifestations to the contrary. We learned from it that she was not able to accept her family's need to see her dead "the sooner the better," she was unable to acknowledge her own end when she had just started to enjoy her small children, and she desperately grasped at the reinforcement by the faith healer who assured her of excellent health.

Another part of her was, however, quite aware of her illness. She did not fight to leave the hospital; in fact, she made herself quite comfortable there. She surrounded herself with many familiar items as if she was to stay for a long time. (She never left the hospital.) She also accepted our limit-setting. She ate what she was asked to eat, with a few exceptions when she went overboard. She later acknowledged that she was unable to exist with so many restrictions and that the suffering was worse than death itself. One may regard the episodes of excessive overeating of

forbidden foods as a form of suicide attempt, in that they would have brought about a rapid demise if the staff had not interfered so vigorously.

In a way, then, this patient showed a fluctuation between an almost total denial of her illness and a repeated attempt to bring about her death. Rejected by her family, often overlooked or ignored by the hospital personnel, she became a pitiful figure, a disheveled-looking young woman who sat desperately lonely on the edge of her bed, clutching the telephone to hear a sound. She found temporary refuge in delusions of beauty, flowers, and loving care which she could not obtain in real life. She did not have a sound religious background to help her through this crisis and required weeks and months of often silent companionship to help her finally accept her death without suicide and without psychosis.

Our own reactions to this young woman were manifold. At first there was utter disbelief. How could she pretend to be so healthy when she was so limited in her food intake? How was she able to stay in the hospital and undergo all those tests if she was really convinced of her well-being? We soon realized that she was unable to hear such questions and proceeded to get to know her better by talking about less painful things. That she was young and cheerful, that she had small children and a nonsupportive family contributed much to our attempts to help her in spite of her prolonged denial. We allowed her to deny as much as was necessary for her survival and remained available to her during her whole hospitalization.

When the staff contributed to her isolation, we tended to be angry at them and made it a routine to keep the door open, only to find it closed again on our next visit. As we became more familiar with her peculiarities, they appeared less strange to us and began to make more sense, adding to our difficulties in appreciating the nurses' needs to avoid her. Towards the end it became a personal matter, a feeling of sharing a foreign language with someone who was unable to communicate with others.

There is no question that we got deeply involved with this patient, beyond the usual involvement of hospital personnel. In trying to understand the reasons for this involvement, we also

have to add that some of it was an expression of our frustration at being unable to have the family play a more helpful role for this pathetic patient. Our anger expressed itself perhaps in our taking on the role of the comforting visitor which we expected the husband to be. And—who knows—perhaps this need to extend ourselves under such circumstances was an expression of an unconscious wish that we may not be rejected one day if fate should have something similar in store for us. After all, she was a young woman with two small children—in retrospect I am beginning to wonder if I was not a bit too ready to support her denial.

This shows the need to examine more closely our own reactions when working with patients as they will always be reflected in the patient's behavior and can contribute a great deal to his well-being or detriment. If we are willing to take an honest look at ourselves, it can help us in our own growth and maturity. No work is better suited for this than the dealing with very sick, old, or dying patients.

CHAPTER IV

Second Stage: Anger

We read the world wrong and say that it deceives us.

TAGORE,
from *Stray Birds*, LXXV

If our first reaction to catastrophic news is, "No, it's not true, no, it cannot involve me," this has to give way to a new reaction, when it finally dawns on us: "Oh, yes, it is me, it was not a mistake." Fortunately or unfortunately very few patients are able to maintain a make-believe world in which they are healthy and well until they die.

When the first stage of denial cannot be maintained any longer, it is replaced by feelings of anger, rage, envy, and resentment. The logical next question becomes: "Why me?" As one of our patients, Dr. G., put it, "I suppose most anybody in my position would look at somebody else and say, 'Well, why couldn't it have been him?' and this has crossed my mind several times. . . . An old man whom I have known ever since I was a little kid came down the street. He was eighty-two years old, and he is of no earthly use as far as we mortals can tell. He's rheumatic, he's a cripple, he's dirty, just not the type of a person you would like to be. And

the thought hit me strongly, now why couldn't it have been old George instead of me?" (extract from interview of Dr. G.).

In contrast to the stage of denial, this stage of anger is very difficult to cope with from the point of view of family and staff. The reason for this is the fact that this anger is displaced in all directions and projected onto the environment at times almost at random. The doctors are just no good, they don't know what tests to require and what diet to prescribe. They keep the patients too long in the hospital or don't respect their wishes in regards to special privileges. They allow a miserably sick roommate to be brought into their room when they pay so much money for some privacy and rest, etc. The nurses are even more often a target of their anger. Whatever they touch is not right. The moment they have left the room, the bell rings. The light is on the very minute they start their report for the next shifts of nurses. When they do shake the pillows and straighten out the bed, they are blamed for never leaving the patients alone. When they do leave the patients alone, the light goes on with the request to have the bed arranged more comfortably. The visiting family is received with little cheerfulness and anticipation, which makes the encounter a painful event. They then either respond with grief and tears, guilt or shame, or avoid future visits, which only increases the patient's discomfort and anger.

The problem here is that few people place themselves in the patient's position and wonder where this anger might come from. Maybe we too would be angry if all our life activities were interrupted so prematurely; if all the buildings we started were to go unfinished, to be completed by someone else; if we had put some hard-earned money aside to enjoy a few years of rest and enjoyment, for travel and pursuing hobbies, only to be confronted with the fact that "this is not for me." What else would we do with our anger, but let it out on the people who are most likely to enjoy all these things? People who rush busily around only to remind us that we cannot even stand on our two feet anymore. People who order unpleasant tests and prolonged hospitalization with all its limitations, restrictions, and costs, while at the end of the day they can go home and enjoy life. People who

tell us to lie still so that the infusion or transfusion does not have to be restarted, when we feel like jumping out of our skin to be doing something in order to know that we are still functioning on some level!

Wherever the patient looks at this time, he will find grievances. He may put the television on only to find a group of young jolly people doing some of the modern dances which irritates him when every move of his is painful or limited. He may see a movie western in which people are shot in cold blood with different onlookers continuing to drink their beer. He will compare them with his family or the attending staff. He may listen to the news full of reports of destruction, war, fires, and tragedies—far away from him, unconcerned about the fight and plight of an individual who will soon be forgotten. So this patient makes sure that he is not forgotten. He will raise his voice, he will make demands, he will complain and ask to be given attention, perhaps as the last loud cry, "I am alive, don't forget that. You can hear my voice, I am not dead yet!"

A patient who is respected and understood, who is given attention and a little time, will soon lower his voice and reduce his angry demands. He will know that he is a valuable human being, cared for, allowed to function at the highest possible level as long as he can. He will be listened to without the need for a temper tantrum, he will be visited without ringing the bell every so often because dropping in on him is not a necessary duty but a pleasure.

The tragedy is perhaps that we do not think of the reasons for patients' anger and take it personally, when it has originally nothing or little to do with the people who become the target of the anger. As the staff or family reacts personally to this anger, however, they respond with increasing anger on their part, only feeding into the patient's hostile behavior. They may use avoidance and shorten the visits on the rounds or they may get into unnecessary arguments by defending their stand, not knowing that the issue is often totally irrelevant.

An example of a rational anger provoked by the reaction of a nurse was the case of Mr. X. He had been flat in bed for several

months and had just been allowed to come off the respirator for a few hours during the daytime. He had led a life of many activities and had taken it hard to be so utterly restricted. He was quite aware that his days were numbered, and his greatest wish was to be moved into different positions (he was paralyzed to his neck). He begged the nurse never to put the siderails up as it reminded him of being in a casket. The nurse, who was very hostile to this patient, agreed that she would leave them down at all times. This private duty nurse was very angry when she was disturbed in her reading, and she knew that he would keep quiet as long as she fulfilled this wish.

During my last visit to Mr. X., I saw that this usually dignified man was furious. He said over and over again to his nurse, "You lied to me," staring at her in angry disbelief. I asked him the reason for this outburst. He tried to tell me that she had put the siderails up as soon as he asked to be put in an upright position so that he could put his legs out of bed "once more." This communication was interrupted several times by the nurse, who, equally angry, stated her side of the story, namely, that she had to put the siderails up in order to get help to fulfill his demands. A loud argument ensued during which the nurse's anger was perhaps best expressed in her statement: "If I had left them down, you would have fallen out of bed and cracked your head open." If we look at this incident again in an attempt to understand the reactions rather than to judge them, we must realize that this nurse also used avoidance by sitting in a corner reading paperbacks and "at all costs" tried to keep the patient quiet. She was deeply uncomfortable in taking care of a terminally ill patient and never faced him voluntarily or attempted to have a dialogue with him. She did her "duty" by sitting in the same room, but emotionally she was as far detached from him as possible. This was the only way this woman was able to do this job. She wished him dead ("crack your head open") and made explicit demands on him to lie still and quiet on his back (as if he were already in a casket). She was indignant when he asked to be moved, which for him was a sign of still being alive and which she wanted to deny. She was obviously so terrified by the closeness of death that she

had to defend herself against it with avoidance and isolation. Her wish to have him quiet and not move only reinforced the patient's fear of immobility and death. He was deprived of communication, lonely and isolated as well as utterly helpless in his agony and increasing anger. When his last demand was met with an initially increased restriction (the symbolic locking him up with the siderails raised), his previously unexpressed rage gave way to this unfortunate incident. If the nurse had not felt so guilty about her own destructive wishes, she probably would have been less defensive and argumentative, thus preventing the incident from happening in the first place and allowing the patient to express his feelings and to die a bit more comfortably a few hours later.

I use these examples to emphasize the importance of our tolerance of the patient's rational or irrational anger. Needless to say, we can do this only if we are not afraid and therefore not so defensive. We have to learn to listen to our patients and at times even to accept some irrational anger, knowing that the relief in expressing it will help them toward a better acceptance of the final hours. We can do this only when we have faced our own fears of death, our own destructive wishes, and have become aware of our own defenses which may interfere with our patient care.

Another problem patient is the man who has been in control all his life and who reacts with rage and anger when he is forced to give up these controls. I am reminded of Mr. O. who was hospitalized with Hodgkin's disease which, he claimed, was caused by his poor eating habits. He was a rich and successful businessman who had never had any problems in eating, and had never been obliged to diet to lose weight. His account was totally unrealistic, yet he insisted that he, and only he, caused "this weakness." This denial was maintained in spite of the radiotherapy and his superior knowledge and intelligence. He claimed that it was in his hands to get up and walk out of the hospital the moment he made up his mind to eat more.

His wife came one day to my office with tears in her eyes. It was hard for her to bear it any longer, she said. He had always been a tyrant and kept strict control over his business and his

standing that you do need once in a while to be free of pain, just for somebody to relax.

This interview shows clearly the need that this patient had. She was full of anger and resentment, which seemed to originate in her early childhood. She was one of ten children and felt as an outsider within the family. While the other siblings enjoyed sitting home doing embroidery and pleasing mother, she appears to have been more like her father, reaching out, wishing to go places. This was equated as not pleasing Mama. She appeared to have compromised her needs to be different from her siblings, to have her own identity, and to be the good girl that Mama wanted by becoming a nun. It was only in her late thirties when she became ill and more demanding that it became increasingly more difficult to remain "the good girl." Part of her resentment of the nuns was a repetition of her resentment of her mother and siblings, their lack of acceptance of her, a repetition of her earlier feelings of rejection. Rather than understanding the origin of her anger and resentment, people in the environment reacted to it personally and began to reject her even more in reality. She was able to compensate for this increasing isolation only by visiting other sick people and making demands for them—thus gratifying their needs (which were really her own) and at the same time expressing her dissatisfaction and blame for the lack of care. It was this hostile demand which alienated the nursing staff, understandably, and which gave her a more acceptable rationalization for her own hostility.

In the interview, several needs were met. She was allowed to be herself, hostile and demanding without judgment and personal feelings about it. She was understood rather than judged. She was also allowed to ventilate some of her rage. Once she was able to relieve this burden, she was able to show another side of her, namely one of a warm woman, capable of love, insight, and affection. She obviously loved this Jewish man and gave him credit for finding the real meaning of her religion. He opened a door for many hours of introspection and finally made it possible for her to find an intrinsic rather than an extrinsic belief in God.

Toward the end of the interview she asked to have more opportunity to speak up like this. She paraphrased this, again angrily, in form of asking for a pain pill. We continued our visits and were surprised to hear that she had stopped visiting other dying patients and was more amenable to the staff. As she became less irritable to the nurses, they visited her more often and finally asked for a meeting with us "to understand her better." What a difference this made!

In one of my last visits to her, she looked once more at me and finally asked me something that I was never asked before, namely, to read her a chapter from the Bible. She was quite weak by then and just put her head back, telling me which pages to read, which ones to omit.

I did not enjoy this assignment as I found it somewhat peculiar and beyond the usual things I was asked to do. I would have felt much more comfortable had she asked me for a backrub, emptying a nightstool, or something like that. I also remembered, however, that I had told her we would attempt to fulfill needs, and it seemed somewhat cheap to call the hospital chaplain when her need seemed urgent at that very moment. I recall the dreaded thought that some of my colleagues might come in and laugh at my new role, and I was relieved that nobody entered her room during this "session."

I read the chapters, not really knowing what I had read. She had her eyes closed and I could not even elicit her own reactions. At the end I asked her if this was her last acting-out or if there was something else behind it that I did not understand. It was the only time that I heard a hearty laughter from her, filled with appreciation and humor. She said that it was both, but the main purpose was really a good one. It was not only her last testing of me but was at the same time her last message to me, which she hoped I would remember after she had long gone....

A few days later, she visited me, fully dressed, in my office to bid farewell. She looked cheerful, almost happy. She was no longer the angry nun who alienated everybody, but a woman who had found some peace if not acceptance and who was on her way home, where she died soon thereafter.

Many of us still remember her, not for the difficulties she had caused, but for the lessons she had taught many of us. And so, in her last months of her life, she became what she wanted to be so badly, different from the others, yet still loved and accepted.

CHAPTER V

Third Stage: Bargaining

*The woodcutter's axe begged for its handle from the tree.
The tree gave it.*

TAGORE,
from *Stray Birds*, LXXI

The third stage, the stage of bargaining, is less well known but equally helpful to the patient, though only for brief periods of time. If we have been unable to face the sad facts in the first period and have been angry at people and God in the second phase, maybe we can succeed in entering into some sort of an agreement which may postpone the inevitable happening: "If God has decided to take us from this earth and he did not respond to my angry pleas, he may be more favorable if I ask nicely." We are all familiar with this reaction when we observe our children first demanding, then asking for a favor. They may not accept our "No" when they want to spend a night in a friend's house. They may be angry and stamp their foot. They may lock themselves in their bedroom and temporarily express their anger by rejecting us. But they will also have second thoughts. They may consider another approach. They will come out eventually, vol-

unteer to do some tasks around the house, which under normal circumstances we never succeeded in getting them to do, and then tell us, "If I am very good all week and wash the dishes every evening, then will you let me go?" There is a slight chance naturally that we will accept the bargain and the child will get what was previously denied.

The terminally ill patient uses the same maneuvers. He knows, from past experiences, that there is a slim chance that he may be rewarded for good behavior and be granted a wish for special services. His wish is most always an extension of life, followed by the wish for a few days without pain or physical discomfort. A patient who was an opera singer, with a distorting malignancy of her jaw and face who could no longer perform on the stage, asked "to perform just one more time." When she became aware that this was impossible, she gave the most touching performance perhaps of her lifetime. She asked to come to the seminar and to speak in front of the audience, not behind a one-way mirror. She unfolded her life story, her success, and her tragedy in front of the class until a telephone call summoned her to return to her room. Doctor and dentist were ready to pull all her teeth in order to proceed with the radiation treatment. She had asked to sing once more—to us—before she had to hide her face forever.

Another patient was in utmost pain and discomfort, unable to go home because of her dependence on injections for pain relief. She had a son who proceeded with his plans to get married, as the patient had wished. She was very sad to think that she would be unable to attend this big day, for he was her oldest and favorite child. With combined efforts, we were able to teach her self-hypnosis which enabled her to be quite comfortable for several hours. She had made all sorts of promises if she could only live long enough to attend this marriage. The day preceding the wedding she left the hospital as an elegant lady. Nobody would have believed her real condition. She was "the happiest person in the whole world" and looked radiant. I wondered what her reaction would be when the time was up for which she had bargained.

I will never forget the moment when she returned to the hos-

pital. She looked tired and somewhat exhausted and—before I could say hello—said, "Now don't forget I have another son!"

The bargaining is really an attempt to postpone; it has to include a prize offered "for good behavior," it also sets a self-imposed "deadline" (e.g., one more performance, the son's wedding), and it includes an implicit promise that the patient will not ask for more if this one postponement is granted. None of our patients have "kept their promise"; in other words, they are like children who say, "I will never fight my sister again if you let me go." Needless to add, the little boy will fight his sister again, just as the opera singer will try to perform once more. She could not live without further performances and left the hospital before her teeth were extracted. The patient just described was unwilling to face us again unless we acknowledged the fact that she had another son whose wedding she also wanted to witness.

Most bargains are made with God and are usually kept a secret or mentioned between the lines or in a chaplain's private office. In our individual interviews without an audience we have been impressed by the number of patients who promise "a life dedicated to God" or "a life in the service of the church" in exchange for some additional time. Many of our patients also promised to give parts of or their whole body "to science" (if the doctors use their knowledge of science to extend their life).

Psychologically, promises may be associated with quiet guilt, and it would therefore be helpful if such remarks by patients were not just brushed aside by the staff. If a sensitive chaplain or physician elicits such statements, he may well wish to find out if the patient feels indeed guilty for not attending church more regularly or if there are deeper, unconscious hostile wishes which precipitated such guilt. It is for this reason that we found it so helpful to have an interdisciplinary approach in our patient care, as the chaplain often was the first one to hear about such concerns. We then pursued them until the patient was relieved of irrational fears or the wish for punishment because of excessive guilt, which was only enforced by further bargaining and more unkept promises when the "deadline" was past.

CHAPTER VI

Fourth Stage: Depression

The world rushes on over the strings of the lingering heart making the music of sadness.

TAGORE,
from *Stray Birds*, XLIV

When the terminally ill patient can no longer deny his illness, when he is forced to undergo more surgery or hospitalization, when he begins to have more symptoms or becomes weaker and thinner, he cannot smile it off anymore. His numbness or stoicism, his anger and rage will soon be replaced with a sense of great loss. This loss may have many facets: a woman with a breast cancer may react to the loss of her figure; a woman with a cancer of the uterus may feel that she is no longer a woman. Our opera singer responded to the required surgery of her face and the removal of her teeth with shock, dismay, and the deepest depression. But this is only one of the many losses that such a patient has to endure.

With the extensive treatment and hospitalization, financial burdens are added; little luxuries at first and necessities later on may not be afforded anymore. The immense sums that such treatments and hospitalizations cost in recent years have forced

many patients to sell the only possessions they had; they were unable to keep a house which they built for their old age, unable to send a child through college, and unable perhaps to make many dreams come true.

There may be the added loss of a job due to many absences or the inability to function, and mothers and wives may have to become the breadwinners, thus depriving the children of the attention they previously had. When mothers are sick, the little ones may have to be boarded out, adding to the sadness and guilt of the patient.

All these reasons for depressions are well known to everybody who deals with patients. What we often tend to forget, however, is the preparatory grief that the terminally ill patient has to undergo in order to prepare himself for his final separation from this world. If I were to attempt to differentiate these two kinds of depressions, I would regard the first one a reactive depression, the second one a preparatory depression. The first one is different in nature and should be dealt with quite differently from the latter.

An understanding person will have no difficulty in eliciting the cause of the depression and in alleviating some of the unrealistic guilt or shame which often accompanies the depression. A woman who is worried about no longer being a woman can be complimented for some especially feminine feature; she can be reassured that she is still as much a woman as she was before surgery. Breast prosthesis has added much to the breast cancer patient's self-esteem. Social worker, physician, or chaplain may discuss the patient's concerns with the husband in order to obtain his help in supporting the patient's self-esteem. Social workers and chaplains can be of great help during this time in assisting in the reorganization of a household, especially when children or lonely old people are involved for whom eventual placement has to be considered. We are always impressed by how quickly a patient's depression is lifted when these vital issues are taken care of. The interview of Mrs. C. in Chapter X is a good example of a woman who was deeply depressed and felt unable to deal with her own illness and impending death because so many peo-

ple had to be attended to and there seemed to be no help forthcoming. She lost her ability to function in her old role but there was no one to replace her.

The second type of depression is one which does not occur as a result of a past loss but is taking into account impending losses. Our initial reaction to sad people is usually to try to cheer them up, to tell them not to look at things so grimly or so hopelessly. We encourage them to look at the bright side of life, at all the colorful, positive things around them. This is often an expression of our own needs, our own inability to tolerate a long face over any extended period of time. This can be a useful approach when dealing with the first type of depression in terminally ill patients. It will help such a mother to know that the children play quite happily in the neighbor's garden since they stay there while their father is at work. It may help a mother to know that they continue to laugh and joke, go to parties, and bring good report cards home from school—all expressions that they function in spite of mother's absence.

When the depression is a tool to prepare for the impending loss of all the love objects, in order to facilitate the state of acceptance, then encouragements and reassurances are not as meaningful. The patient should not be encouraged to look at the sunny side of things, as this would mean he should not contemplate his impending death. It would be contraindicated to tell him not to be sad, since all of us are tremendously sad when we lose one beloved person. The patient is in the process of losing everything and everybody he loves. If he is allowed to express his sorrow he will find a final acceptance much easier, and he will be grateful to those who can sit with him during this stage of depression without constantly telling him not to be sad. This second type of depression is usually a silent one in contrast to the first type, during which the patient has much to share and requires many verbal interactions and often active interventions on the part of people in many disciplines. In the preparatory grief there is no or little need for words. It is much more a feeling that can be mutually expressed and is often done better with a touch of a hand, a stroking of the hair, or just a silent sitting together. This is the

time when the patient may just ask for a prayer, when he begins to occupy himself with things ahead rather than behind. It is a time when too much interference from visitors who try to cheer him up hinders his emotional preparation rather than enhances it.

The example of Mr. H. will illustrate the stage of depression which worsened because of the lack of awareness and understanding of this patient's needs on part of those in his environment, especially his immediate family. He illustrates both types of depression as he expressed many regrets for his "failures" when he was well, for lost opportunities while there was still time to be with his family, and sorrow at being unable to provide more for them. His depression paralleled his increasing weakness and inability to function as a man and provider. A chance for additional promising treatment did not cheer him up. Our interviews revealed his readiness to separate himself from this life. He was sad that he was forced to struggle for life when he was ready to prepare himself to die. It is this discrepancy between the patient's wish and readiness and the expectation of those in his environment which causes the greatest grief and turmoil in our patients.

If the members of the helping professions could be made more aware of the discrepancy or conflict between the patient and his environment, they could share their awareness with their patients' families and be of great assistance to them and to the patients. They should know that this type of depression is necessary and beneficial if the patient is to die in a stage of acceptance and peace. Only patients who have been able to work through their anguish and anxieties are able to achieve this stage. If this reassurance could be shared with their families, they too could be spared much unnecessary anguish.

Our first interview with Mr. H. follows:

PATIENT: Do I have to talk very loudly?

DOCTOR: No, that's all right. If we can't hear you then we'll say so. You speak as loud as you can as long as you are comfortable. Mr. H. said if I keep him up psychologically he will be

Mr. H.'s interview is a good example of what we called the "door-opening interview."

He was regarded as a grim, noncommunicating man by the hospital staff, and their prediction was that he would not agree to talking with us. At the beginning of the session, he warned us that he was likely to collapse if he sat for more than five minutes—yet, after a full hour of conversation he had difficulty leaving and felt perfectly all right physically as well as emotionally. He was preoccupied with many personal losses, the most serious one the death of a daughter far away. What grieved him most, however, was the loss of hope. It was related at first as the doctor's presentation of his illness: ". . . they gave me no hope. The doctor himself said that his father had had a similar operation, in the same hospital, with the same surgeon, and that he failed to recover and died within about a year and a half at the same age. And that all I could do was just to wait for the bitter end . . ."

Mr. H. did not give up and admitted himself to another hospital, where hope was offered.

Later in the interview he expresses another sense of hopelessness, namely, his inability to have his wife share some of his interests and values in life. She often made him feel like a failure, he was blamed for the children's lack of achievements, he did not bring enough money home, and he was fully aware that it was too late to satisfy her demands and ever meet her expectations. As he felt weaker and unable to work, looking back at his life, he became even more aware of the discrepancy between her values and his own. The gap seemed to be so great that communication became almost impossible. All this happened to this man during the mourning process for his daughter and reawakened the sadness he experienced after his parents' deaths. As he describes it, we had the feeling that he had so much grief, he was unable to add more sorrow to it—thus leaving the most vital dialogue unspoken, which would have, we hope, given him a sense of peace. In all this depression there was a sense of pride, a feeling of worth in spite of his family's lack of appreciation. So we could not help but wish to be instrumental in a final communication between the patient and his wife.

We finally understood why the hospital staff was unable to tell how much Mr. H. was aware of his illness. He was not thinking of his cancer as much as he was reviewing the meaning of his life and searching for ways to share this with the most significant person—his wife. He was deeply depressed not because of his terminal illness but because he had not finished his own mourning for the dead parents and child. When there is so much pain already, some added pain is not experienced as much as when it hits a healthy pain-free body. Yet we felt that this pain could be eliminated if we could find means to communicate all this to Mrs. H.

The following morning we met with her, a strong, powerful, healthy woman, energetic as he had described. She confirmed almost verbatim what he had said the day before: "Life will go on much the same when he has ceased to be." He was weak, he could not even cut the lawn or else he might faint. Men on the farm were different kind of people, they had muscles and were strong. They worked from sunrise to sundown and he was

not much interested in making money either . . . Yes, she knew he had not long to live, but she was unable to take him home. She had made plans to bring him to a nursing home and she would visit him there . . . Mrs. H. said this all in a tone of a busy woman who had a lot of other things to attend to and could not be bothered. Maybe at that time I felt impatient or had a sense of Mr. H.'s hopelessness, but I repeated in my own words once more the essence of her communications. I summarized briefly that Mr. H. had not fulfilled her expectations, he was not very good in many things really, and would not be mourned when he ceased to be. Looking back at his life, one might wonder if there was anything memorable in it . . .

Mrs. H. suddenly looked at me, and with feeling in her voice she almost yelled: "What do you mean, he was the most honest and the most faithful man in the world . . ."

We sat for another few minutes during which time I shared with her some of the things that we had heard in the interview. Mrs. H. admitted that she had never thought of him in these terms and was quite willing to give him credit for these assets. We returned to the patient's room together and Mrs. H. repeated on her own what we exchanged in our office. I shall not forget the patient's pale face deep in his pillows, the expectant look on his face, the wonderment in his expression at whether we were able to communicate. And then his eyes lit up when he heard his own wife say, ". . . and I told her that you were the most honest and most faithful man in the world, and that's hard to find these days. And on the way home we would pass by the church and pick up some of your church work that was so meaningful to you. It will keep you busy for the next few days . . ."

There was some genuine warmth in her voice when she talked with him and prepared him to leave the hospital. "I shall never forget you as long as I live," he said when I left the room—both of us knowing that this would not be long, but it mattered little at this point.

CHAPTER VII

Fifth Stage: Acceptance

*I have got my leave. Bid me farewell, my brothers!
I bow to you all and take my departure.*

*Here I give back the keys of my door—and I give up
all claims to my house. I only ask for last kind words
from you.*

*We were neighbours for long, but I received more
than I could give. Now the day has dawned and the
lamp that lit my dark corner is out. A summons has
come and I am ready for my journey.*

TAGORE,
from *Gitanjali*, XCIII

If a patient has had enough time (i.e., not a sudden, unexpected death) and has been given some help in working through the previously described stages, he will reach a stage during which he is neither depressed nor angry about his "fate." He will have been able to express his previous feelings, his envy for the living and the healthy, his anger at those who do not have to face their end so soon. He will have mourned the impending loss of so many meaningful people and places and he will contemplate his

coming end with a certain degree of quiet expectation. He will be tired and, in most cases, quite weak. He will also have a need to doze off or to sleep often and in brief intervals, which is different from the need to sleep during the times of depression. This is not a sleep of avoidance or a period of rest to get relief from pain, discomfort, or itching. It is a gradually increasing need to extend the hours of sleep very similar to that of the newborn child but in reverse order. It is not a resigned and hopeless "giving up," a sense of "what's the use" or "I just cannot fight it any longer," though we hear such statements too. (They also indicate the beginning of the end of the struggle, but the latter are not indications of acceptance.)

Acceptance should not be mistaken for a happy stage. It is almost void of feelings. It is as if the pain had gone, the struggle is over, and there comes a time for "the final rest before the long journey" as one patient phrased it. This is also the time during which the family needs usually more help, understanding, and support than the patient himself. While the dying patient has found some peace and acceptance, his circle of interest diminishes. He wishes to be left alone or at least not stirred up by news and problems of the outside world. Visitors are often not desired and if they come, the patient is no longer in a talkative mood. He often requests limitation on the number of people and prefers short visits. This is the time when the television is off. Our communications then become more nonverbal than verbal. The patient may just make a gesture of the hand to invite us to sit down for a while. He may just hold our hand and ask us to sit in silence. Such moments of silence may be the most meaningful communications for people who are not uncomfortable in the presence of a dying person. We may together listen to the song of a bird from the outside. Our presence may just confirm that we are going to be around until the end. We may just let him know that it is all right to say nothing when the important things are taken care of and it is only a question of time until he can close his eyes forever. It may reassure him that he is not left alone when he is no longer talking and a pressure of the hand, a look, a leaning back in the pillows may say more than many "noisy" words.

A visit in the evening may lend itself best to such an encounter as it is the end of the day both for the visitor and the patient. It is the time when the hospital's page system does not interrupt such a moment, when the nurse does not come in to take the temperature, and the cleaning woman is not mopping the floor—it is this little private moment that can complete the day at the end of the rounds for the physician, when he is not interrupted by anyone. It takes just a little time but it is comforting for the patient to know that he is not forgotten when nothing else can be done for him. It is gratifying for the visitor as well, as it will show him that dying is not such a frightening, horrible thing that so many want to avoid.

There are a few patients who fight to the end, who struggle and keep a hope that makes it almost impossible to reach this stage of acceptance. They are the ones who will say one day, "I just cannot make it anymore," the day they stop fighting, the fight is over. In other words, the harder they struggle to avoid the inevitable death, the more they try to deny it, the more difficult it will be for them to reach this final stage of acceptance with peace and dignity. The family and staff may consider these patients tough and strong, they may encourage the fight for life to the end, and they may implicitly communicate that accepting one's end is regarded as a cowardly giving up, as a deceit or, worse yet, a rejection of the family.

How, then, do we know when a patient is giving up "too early" when we feel that a little fight on his part combined with the help of the medical profession could give him a chance to live longer? How can we differentiate this from the stage of acceptance, when our wish to prolong his life often contradicts his wish to rest and die in peace? If we are unable to differentiate these two stages we do more harm than good to our patients, we will be frustrated in our efforts, and will make his dying a painful last experience. The following case of Mrs. W. is a brief summary of such an event, where this differentiation was not made.

Mrs. W., a married fifty-eight-year-old woman, was hospitalized with a malignancy in her abdomen which gave her much

pain and discomfort. She had been able to face her serious illness with courage and dignity. She complained very rarely and attempted to do as many things as possible by herself. She rejected any offer of help as long as she was able to do it herself and impressed the staff and her family by her cheerfulness and ability to face her impending death with equanimity.

Briefly after her last admission to the hospital she became suddenly depressed. The staff was puzzled about this change and asked for a psychiatric consultation. She was not in her room when we looked for her and a second visit a few hours later found her still absent. We finally found her in the hallway outside of the X-ray room where she lay uncomfortably and obviously in pain on a stretcher. A brief interview revealed that she had undergone two rather lengthy X-ray procedures and had to wait for other pictures to be taken. She was in great discomfort because of a sore on her back, had not had any food or drink for the past several hours, and most uncomfortable of all, needed to go to the bathroom urgently. She related all this in a whispering voice, describing herself as being "just numb from pain." I offered to carry her to the adjacent bathroom. She looked at me—for the first time smiling faintly—and said, "No, I am barefoot, I'd rather wait until I am back in my room. I can go there myself."

This brief remark showed us one of the patient's needs: to care for herself as long as possible, to keep her dignity and independence as long as it was possible. She was enraged that her endurance was tested to the point where she was ready to scream in public, where she was ready to let go of her bowel movements in a hallway, where she was on the verge of crying in front of strangers "who only did their duty."

When we talked with her a few days later under more favorable circumstances, it was obvious that she was increasingly tired and ready to die. She talked about her children briefly, about her husband who would be able to carry on without her. She felt strongly that her life, especially her marriage, had been a good and meaningful one and that there was little left that she could do. She asked to be allowed to die in peace, wished to be

left alone—even asked for less involvement on the part of her husband. She said that the only reason that kept her still alive was her husband's inability to accept the fact that she had to die. She was angry at him for not facing it and for so desperately clinging on to something that she was willing and ready to give up. I translated to her that she wished to detach herself from this world and she nodded gratefully as I left her alone.

In the meantime, unbeknown to the patient and myself, the medical-surgical staff had a meeting which included the husband. While the surgeons believed that another surgical procedure could possibly prolong her life, the husband pleaded with them to do everything in their power to "turn the clock back." It was unacceptable to him to lose his wife. He could not comprehend that she did not have the need to be with him any longer. Her need to detach herself, to make dying easier, was interpreted by him as a rejection which was beyond his comprehension. There was no one there to explain to him that this was a natural process, a progress indeed, a sign perhaps that a dying person has found his peace and is preparing himself to face it alone.

The team decided to operate on the patient the following week. As soon as she was informed of the plans she weakened rapidly. Almost overnight she required double the dose of medication for her pains. She often asked for drugs the moment she was given an injection. She became restless and anxious, often calling for help. She was hardly the patient of a few days before; the dignified lady who could not go to the bathroom because she was not wearing slippers!

Such behavioral changes should make us alert. They are communications of our patients who try to tell us something. It is not always possible for a patient to openly reject a life-prolonging operation, in the face of a pleading, desperate husband and children who hope to have mother home once more. Last but not least, we should not underestimate the patient's own glimpse of hope for a cure in the face of impending death. As outlined earlier, it is not in human nature to accept the finality of death without leaving a door open for some hope. It is

therefore not enough to listen only to the overt verbal communications of our patients.

Mrs. W. had clearly indicated that she wished to be left in peace. She was in much more pain and discomfort after the announcement of the planned surgery. Her anxiety increased as the day of the operation approached. It was not in our authority to cancel the operation. We merely communicated our strong reservations and felt sure that the patient would not tolerate the operation.

Mrs. W. did not have the strength to refuse the operation nor did she die before or during the procedure. She became grossly psychotic in the operating room, expressed ideas of persecution, screamed and carried on until she was returned to her room minutes before the planned surgery was to take place.

She was clearly delusional, had visual hallucinations and paranoid ideas. She looked frightened and bewildered and made no sense in her communications to the staff. Yet, in all this psychotic behavior, there was a degree of awareness and logic that remained impressive. As she was returned to her room, she asked to see me. When I entered the room the following day, she looked at her bewildered husband and then said, "Talk to this man and make him understand." She then turned her back to us, clearly indicating her need to be left alone. I had my first meeting with her husband, who was at a loss for words. He could not understand the "crazy" behavior of his wife who had always been such a dignified lady. It was hard for him to cope with her rapidly deteriorating physical illness, but incomprehensible what our "crazy dialogue" was all about.

Her husband said with tears in his eyes that he was totally puzzled by this unexpected change. He described his marriage as an extremely happy one and his wife's terminal illness as totally unacceptable. He had hopes that the operation would allow them once more to be "as close together as they had been" for the many happy years of their marriage. He was disturbed by his wife's detachment and even more so by her psychotic behavior.

When I asked him about the patient's needs, rather than his own, he sat in silence. He slowly began to realize that he never

listened to her needs but took it for granted that they were the same. He could not comprehend that a patient reaches a point when death comes as a great relief, and that patients die easier if they are allowed and helped to detach themselves slowly from all the meaningful relationships in their life.

We had a long session together. As we talked, things slowly began to clear and came into focus. He gave much anecdotal material to confirm that she had tried to communicate her needs to him, but that he could not hear it because they were opposing his needs. Mr. W. felt obviously relieved when he left and rejected an offer to return with him to the patient's room. He felt more capable of talking with his wife frankly about the outcome of her illness and was almost glad that the operation had to be canceled because of her "resistance" as he called it. His reaction to her psychosis was, "My God, maybe she is stronger than all of us. She sure fooled us. She made it clear she did not want the operation. Maybe the psychosis was the only way out of it without dying before she was ready."

Mrs. W. confirmed a few days later that she was not able to die until she knew that her husband was willing to let go. She wanted him to share some of her feelings rather than "always pretend that I am going to be all right." Her husband did make an attempt to let her talk about it, though it came hard and he "regressed" many times. Once he clung to the hope for radiation, at another time he tried to put pressure on her to come home, promising to hire a private nurse for her care.

During the following two weeks he often came to talk about his wife and his hopes but also about her eventual death. Finally he came to accept the fact that she would become weaker and less able to share the many things that had been so meaningful in their life.

She recovered from her psychotic episode as soon as the operation was permanently canceled and her husband acknowledged the impending death and shared this with her. She had less pain and resumed her role of the dignified lady who continued to do as many things as her physical condition allowed. The medical staff became increasingly sensitive to the subtle expres-

sions to which they responded tactfully, always keeping in mind her most important need: to live to the end with dignity.

Mrs. W. was representative of most of our dying patients, though she was the only one I have seen to resort to such an acute psychotic episode. I am sure that this was a defense, a desperate attempt to prevent a life-prolonging intervention which came too late.

As stated earlier, we have found that those patients do best who have been encouraged to express their rage, to cry in preparatory grief, and to express their fears and fantasies to someone who can quietly sit and listen. We should be aware of the monumental task which is required to achieve this stage of acceptance, leading towards a gradual separation (decathexis) where there is no longer a two-way communication.

We have found two ways of achieving this goal more easily. One kind of patient will achieve it with little if any help from the environment—except a silent understanding and no interference. This is the older patient who feels at the end of his life, who has worked and suffered, raised his children and completed his tasks. He will have found meaning in his life and has a sense of contentment when he looks back at his years of work.

Others, less fortunate ones, may reach a similar state of body and mind when they are given enough time to prepare for their death. They will need more help and understanding from the environment as they struggle through all the previously described stages. We have seen the majority of our patients die in the stage of acceptance, an existence without fear and despair. It is perhaps best compared with what Bettelheim describes about early infancy: "Indeed it was an age when nothing was asked of us and all that we wanted was given. Psychoanalysis views earliest infancy as a time of passivity, an age of primary narcissism when we experience the self as being all."

And so, maybe at the end of our days, when we have worked and given, enjoyed ourselves and suffered, we are going back to the stage that we started out with and the circle of life is closed.

* * *

The following two interviews are examples of husband and wife attempting to reach the stage of acceptance.

Dr. G., a dentist and father of a twenty-four-year-old son, was a deeply religious man. We have used his example in Chapter IV on anger, when the question is raised, "Why me?" and he remembered old George and wondered why that man's life could not be taken instead of his. In spite of the picture of acceptance that he presented during the interview, he also demonstrates the aspect of hope. He was intellectually quite aware of the state of his malignancy and as a professional man realized the slim chances of continuing to work. Yet he was unwilling or unable to consider the closing of his office until briefly before this interview. He maintained an office girl to accept his calls and sustained the hope that the Lord might repeat an incident that happened to him during the war years when he was shot at a close distance and missed "being shot from twenty feet away and the person misses you, you know that there is some other power than the fact that you are a god dodger or whatever."

DOCTOR: Can you tell us how long you have been in the hospital and what reasons brought you here?

PATIENT: Yes. I am a dentist as you probably know and have been practicing for quite a number of years. In the last part of June, I experienced this sudden pain that I realized was unusual and I had X-rays immediately and the 7th of July of this year I was operated on for the first time.

DOCTOR: In 1966?

PATIENT: In 1966, yes. And I realized that there was ninety percent chance that it was malignant but this was a slight consideration on my part since this was my first episode and my first feeling of any kind of pain. I came through the operation in very good shape, recovered remarkably and then had a subsequent bowel blockage and had to go back in for further surgery on the 14th of September. And from the 27th of October I was not happy with my progress. My wife got in touch with a doctor here and we came here. So I have been constantly in treatment since the 27th of October. This covers my hospitalization about as well as I can summarize it.

something to stand on. That's what I really think and I think a happy marriage is based on that.

Dr. G.'s wife gives a good description of the reaction of a close family member to such unexpected news of a malignancy. Her first reaction, shock, followed by a brief denial, "No, it cannot be true." She then attempts to find some meaning in this turmoil and finds solace in the Scriptures, which have always been a source of inspiration for this family. In spite of her apparent acceptance, she too maintains the hope "research is going on" and prays for a miracle. While this change in her family has deepened their religious experiences, it has also allowed her time to become more self-sufficient and independent.

The outstanding feature of this double interview is perhaps again the two different stories we hear about how the patient was told. This is quite typical and has to be understood if we are not to take things at face value.

Dr. G. explains how his son had matured and finally faced up to the responsibility by sharing the bad news with him. He is obviously proud of his son, sees him as a mature, grown-up man, who can take on the responsibilities when he has to leave his rather dependent wife. Mrs. G., on the other hand, insists that it was she who had the courage and strength to tell her husband about the outcome of the operation, not giving her son credit for this difficult task. She contradicted herself later on several occasions so that it seems unlikely that her version was the reality. Nevertheless her wish to have told her husband also says something about her needs. She wishes to be strong, to be able to face it, and to talk about it. She wants to be the one who shares good and bad with her husband and who seeks solace and strength in the Scriptures to accept whatever may come.

A family like this can best be helped by a reassuring physician who communicates that everything will be done that is possible and by an available pastor who visits the patient and his family as often as possible, making use of the resources the family has used in the past.