

Chapter 5

Reactions to Physical Illness
and Hospitalization

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EDITORS' INTRODUCTION

What is it like to be a successful businessman who is secure as a person, competent as an executive, is constantly being looked to for advice and leadership, and then suddenly to find oneself a patient in a coronary care unit? What is it like to feel helpless and totally dependent upon others?

The author delineates the cardinal features of illness. The loss of a sense of indestructibility, the loss of a feeling of connectedness to one's supportive interpersonal networks, the failure of logic when thinking about the disease, and the disappearance of a sense of control over one's life are all central to the experience of illness. The mix differs from patient to patient, but all four features can be found to one degree or another by the physician who observes, listens, and thinks. By means of clinical material and brief vignettes, Cassell brings to life that which the sensitive physician may discern. This chapter provides the physician with much to reflect upon, and a framework upon which to construct the understanding of illness. More than just illustrating a cognitive structure, however, the author illustrates the many ways in which physicians may use their understanding in the service and humanistic care of patients.

It has often been said that all physicians would be better physicians had they experienced hospitalization, a significant illness, or an opera-

tion—a full indoctrination into patienthood. Some physicians have their encounter with “the other end” of the physician-patient relationship. Even if it is as simple as a sigmoidoscopy, barium enema, examination of the genital area, or repeated blood surveys “for some reason,” something can be learned about patienthood. More frightening experiences, such as a lymph node biopsy, often strain the physician-patient’s need to be calm. Major surgical procedures, fever of unknown origin, a small infiltration picked up on a routine chest x-ray, “suspicious” cells in the Pap smear—the list of truly frightening possibilities is endless.

Most upsetting, however, is the experience of either severe or chronic illness. Here the physician may understand something of shattered omnipotence, disconnectedness, illogicality, and feelings of loss of control.

As Cassell brings it all together for the reader, it may become more “real.” Some physicians have the capacity to place themselves in the patient’s situation, others do not. A basic premise of this book is that this capacity can be developed or improved upon in most physicians.

What about the person who has abdominal surgery and has the need to show the surgical scar afterwards? How different it is for the attractive, slender woman who loves her bikinis and is undergoing abdominal hysterectomy! Readers may also reflect on how the patient with a permanent colostomy may feel. How important it is for the physician to take time to explain carefully to the patient not only about the care of the orifice, but also what can be expected in day-to-day functioning, including sexuality, exercise, and “noise.”

Some physicians are uncomfortable in talking about sex, suicide, dying, or any emotional problem. Some even have difficulty discussing excretory processes with patients. It is hoped that the basic attitude throughout this book will enable the physician to talk with patients appropriately regarding all body functions, physical or emotional. Cassell’s vivid way of bringing the reader into the patient’s room with him should be a great aid in their regard.

Recent research on the psychological results of cardiac surgery noted that while 90 percent of the patients who survived showed improvement in physical status, more than one-third developed psychological problems that strongly impaired their functioning. Even those with less serious difficulties appeared to be limited in one or more spheres; they did not return to work, resume normal activities, participate normally in their families, or return to normal sexual function. The surgery had improved the hearts, but apparently had not benefited the patients equally.

All physicians have had similar experiences. A man with a myocardial infarction may return to normal cardiac function. But after going home he may experience numerous symptoms, including sticking chest pains, easy fatigue, and poor exercise tolerance. His wife may complain that he is not the same as before the heart attack and not only because he has lost interest in sex. Such a patient may become more placid, but in any case he may lack his former drives and interests. His symptoms may be attributed to depression, and he may respond to antidepressant agents when they are used in proper dosage for a sufficient period.

Or perhaps he may settle down to a career of illness, and become preoccupied by exaggerated fears and crippling concern about the heart.

Why do these things happen sometimes to patients who have been seriously ill, and why did those patients not get the same benefit from surgery that their hearts did?

Every disease has features that are unique because of the physiology or anatomy of the organs involved. The heart can malfunction as a muscle pump, hydraulic system, or electrical system, and the symptoms of heart disease reflect these malfunctions. As that is true of the heart (or the liver, uterus, muscles, colon, and so on), it is also true of the whole person. When a person becomes ill, there may also occur a distortion of his or her relationship to the body, to other people, to work, and to the other aspects of being a person, a private individual, and a member of society. Such behavioral changes are often as much a part of illness as the disease itself. It follows that when sick patients get better, it is not only the diseased organ system, such as the lungs in pneumonia, that returns to normal, but also those activities that are involved in being a normally functioning person in the day-to-day world. We know much more about what happens when organ systems become diseased and then return to health than what happens when people get ill and return to health. Perhaps such a lack of knowledge was acceptable during an earlier period in medicine. Now, when we can do so much more for terribly complicated diseases, and when patients are less likely to die but may be sick for long periods of time before they recover, our lack of knowledge often hampers our patients in returning to their former selves. With a little more help, they could return to normal functioning. It is as simple as that.

Just as a heart or a liver can malfunction in only so many ways, the psychological changes that accompany illness are also limited, and can be described in an orderly and useful manner. The big difference is that our language for describing disease is more precise than the language for describing the "disorders of person" that accompany illness. For the former, we have objective measurements, while for people, our terms are subjective and thus seem "softer" and less real. To put it another way, sick people, no matter what the cause of their sickness, have certain characteristics that are different from those of people who are well. These characteristics are not chance or random events, but are definable, diagnosable, and relatively constant in occurrence. For this reason, the apparently illogical or difficult behavior of the sick is not at all illogical, but is the result of internal and external forces acting on the sick person. The physician must often manipulate these forces to return the patient to health in the same way drugs or other modalities are used to return a diseased part to health.

THE CHARACTERISTICS OF ILLNESS

Sick people suffer a disconnection from their usual world, a loss of their sense of indestructibility (omnipotence), a loss of the competence and completeness of their reasoning, and a loss of control over themselves and their world. These features, which will be explored in depth, are illness. When they are absent, no matter what the state of the body's integrity, illness is *not present*. Similarly,

when one, another, or all these features (arising in the course of disease or for some other reason) are present to whatever extent, then illness continues, again without regard to the body's state of integrity. Furthermore, the effect of each or all of the features of illness on the patient is dependent upon the patient's personality, surrounding social forces, and the nature of the disease or situation that causes them. The features of illness will be discussed separately, but they are inevitably intertwined. For example, problems of reasoning interfere with the perception of the disease process and social relations, and thus reinforce or diminish the force of those features. Similarly, the boundaries among physical, emotional, and social contributions to the illness are also blurred. Keeping these regions separate, while a necessary task in writing about the sick, may interfere with understanding both the patient and the illness.

The Loss of Connection

What I am going to discuss is best illustrated by the cases of actual patients.

You would have no difficulty guessing what disease Wallace Black has. Sitting up in his bed, he looks somewhat like a white-haired, partly bald, and plucked turkey, because of the wasting of his face, neck, and shoulder girdle. That muscle wasting, which is not quite the cachexia of terminal malignancy, in addition to obvious ascites, is the hallmark of late-stage cirrhosis with portal hypertension. He has been in the hospital for almost 3 weeks. The first 10 days were occupied by diagnostic studies, and in the last week or so a good diuresis has been obtained. The present difficulty is not ridding him of more ascites, but rather that he insists on going home in a few days. Since he is finally making progress, that would be an error. He has offered the usual justification about the bad food and how he would rest better at home. But the real reason is that he is having trouble keeping his business going from the hospital room. While it is often true that a patient's business does suffer during illness, and that should not be dismissed lightly, such is not the case here. Mr. Black is 70 years old and in good financial condition. He has told me that he is a self-made man who has had little education, and that he has been very successful as a broker. Almost no visit to his room goes by without some reference to an important person who just called, or to some business situation in which he alone was able to solve the problem. Mr. Black prides himself on his work and on his social connections, and there lies our difficulty. While he is sick and in a hospital bed, Mr. Black cannot be the person he knows and admires. He knows who he is in part by his relationships to other people and to the world of his business. When he is cut off from those associations he ceases to exist, at least on one level, and that is profoundly disturbing to him.

We are all connected to the world by our relationships with other people and our place in the social scheme. To some, as to Wallace Black, that connection is more important than it is to others; but our interaction with others is vital to the maintenance of our person. In sickness, all these things change. As illness deepens, patients become more and more withdrawn from their usual world, their previous interests, friends, and even their families. We can learn how important this characteristic feature of illness is to our patients by observing how they defend themselves against its effects. (Indeed, that is true of all the characteristics of illness.) It is difficult, if not impractical, to ask patients whether they feel

disconnected. They may not know themselves, or be able to verbalize it in that way. But by watching their behavior in the hospital (Mr. Black is always on the telephone), seeing the visitors, and listening to the small talk, we can construct a picture of what is important to the patient. Mr. Black lives near my home, and in the weeks preceding his admission, I would occasionally see him going toward his office. He walked slowly, with 15 liters of ascites sticking out in front of his wasted frame, but he was erect, impeccably dressed, and a figure of respect. I know what effort that continued presence must have cost.

The disconnection of illness is not only social. It may take place over the entire spectrum of being. We exist to the extent that we are connected. Some of the connections are physical, such as the senses, postural reflexes, and proprioception. Even the tearing eyes and the loss of sense of smell that accompany a cold may be disruptive to some. Patching one eye for 24 hours is often associated with irritation, nervousness, difficulty concentrating or coping—disruptions of normal thought and function, despite the fact that sight remains in the other eye. The loss of balance or true vertigo is also profoundly upsetting past the degree of purely functional loss, which is why patients with this sickness may be helped by small doses of phenothiazines in addition to antimotion sickness medication.

Patients are not used to calling these disruptions *symptoms*. They simply do not feel like their usual selves, and when asked about it will point to the eye, ear, or other malfunctioning organ. However, universal recognition of the profound disconnection that can occur is part of the dread of blindness. The losses of connection that accompany interference with the senses are poorly understood when each sensory modality is seen as standing only for itself, like the individual ropes that hold a boat to its dock. Think instead of the empathy one feels for the deaf Beethoven, who has to be turned around so that he can see the audience acclaim the Ninth Symphony. Has he lost only his hearing?

In order not only to understand their behavior better but also to reduce their discomfort, it is necessary for us to know that patients are reacting not only to the physical symptoms or disease, but to the disconnection itself. Further, since patients may not know why they are irritable, depressed, anxious, fearful, angry, or whatever, they may react to their own seemingly inexplicable behavior by externalizing the source or projecting blame for their feelings onto others. That is why we hear Mr. Black complain about the food and cite the behavior of the nurses and house staff as the reason he must go home. Or, he may say to me that I never explain what is wrong with him, just after I have finished answering his questions in detail. He does not know why he feels the disquiet that he does, and must seek some outside reason for it. Often, the patient's distress will subside as a result of just being reassured that it is normal to feel irritable when, for example, vision is acutely impaired. On occasions, it may be necessary to stress the other ways in which the patient is concerned. The doctor should never simply brush aside patients' concerns about business, work, or social relations as being unimportant, no matter how serious the disease, because to do so is to brush aside the importance of the people themselves. Think how badly you would feel if, because you were ill, you were unable to hold up your part of the duty schedule or do your

part of the work, or see patients who had been given appointments. When patients have as little insight as Mr. Black does, explanations may be useless. Then one must balance the danger that the disconnection poses against the need for further hospitalization.

But what threat is posed by something like disconnection? First, it is not too strong to say that anything that threatens the integrity of self, self-concept, or the patient's ability to function as an intact person endangers the patient's physical well-being. *Physical integrity cannot withstand the dissolution of the social personality.* The most extreme example of this is the phenomenon of voodoo death, where the individual is cut off from the group. Friends and relatives share the victim's belief that he or she is doomed. The community withdraws, and on every occasion and by every action suggests to the victim that he or she is indeed dead. Torn from family and social ties and excluded from all the functions and activities through which self-awareness is experienced, the victim yields, and in time dies.

Many of us have seen patients who, when cut off from their world, family, friends, and social ties, simply give up and die from diseases for which recovery might otherwise have been expected. Furthermore, there is increasing evidence that the phenomenon of "giving up"—when the person experiences a sense of helplessness, hopelessness, and deprivation of love or support—may antedate the onset of important organic disease. More commonly, we see an apathetic or depressed patient lying limply in a hospital bed, or we see a patient who will not take medications, refuses diagnostic studies, or insists on leaving the hospital even when obvious danger is involved. The irritation of the staff and its counterarguments merely increase the patient's sense of isolation and disconnection from others, and thus heighten the problem.

But how can we be sure that Mr. Black's complaints about the food and the staff are not the issue, that indeed he is suffering from disconnection and isolation from the people and environmental props that help maintain his integrity of self? As with any other diagnosis, the first thing needed is a high index of suspicion, and the next is listening for the clues. Mr. Black insists that he is going home this weekend—as a matter of fact, on Friday. I cannot, in conscience, discharge him on Friday, but I think I could on Sunday. We talk back and forth for a while, and I ask him why those 2 days are so important. He says, "Doc, I need those 2 days to rest up." Now I know. Rest up? Rest up for what? I turn to his wife and say, "Charlotte, Wallace is going to work on Monday, isn't he?" And that turns out to be the case. He has been working on a deal by telephone, and the papers will be signed Monday. Perhaps they could be signed in a hospital room, but that would not serve the purpose. Wallace Black does not need the money, but he does need the setting and the people around him to tell him that he is Wallace Black. And to him and to many others who are sick, hospitalized, and disconnected from their world, that is more important than merely being alive. We will try to work out something that can meet both objectives: diuresis and improvement of hepatic function, as well as the restoration of his person.

Disconnection may occur rapidly, as in such acute emergencies as

myocardial infarction or severe trauma. Suddenly the patient is among people who, well meaning as they may be, are nevertheless strangers. While the patient is lying on a stretcher in a hallway or being moved like an object from place to place, the sense of isolation is heightened. It is also worsened by the lack of privacy in intensive care units, where even the markers of individuality that are usually found in hospital rooms—family pictures, get-well cards, or what-have-you—are absent. It is very common for patients in these circumstances to try to identify for the strange doctor some connection, common acquaintance, or place that connects them. The small talk made while waiting can be used to establish such ties and relationships, thus diminishing the patient's stress. In those settings, there is no such thing as meaningless conversation. It can always be used to serve a purpose. In emergency situations, few needs are as important and as simple to satisfy as making patients feel that they are known.

In chronic diseases or long-term illness, the withdrawal from the world may be gradual. Connection to friends and associates may be replaced slowly by new friendships and relationships that are drawn from within the world of illness. The patient may be alternately frightened by the perception of withdrawal, or disinterested as the horizon shrinks. Leaving the outside world, the sick person begins increasingly to build a new reality that is shared exclusively with the other sick. In the beginning, friends and family may have abandoned the patient, but now the sick person actively begins to reject those from the outside. Even the relationship with a spouse or children may change radically, as everything becomes oriented around the illness. This phenomenon has been compared to the social consequences of aging, with illness producing the social equivalence of premature aging. Thus, in a sense, sickness spreads into the family, causes disruptions, and causes relationships to change in ways of which the members may not be aware. As one must learn to deal with the disconnection of the patient, so must the needs of the family be tended. Once again, from the patient's point of view, these changes may be seen as originating in others and as being directed toward the ill person, rather than, as is often the case, starting with the patient's behavior. Psychotherapeutic intervention may be desirable to diminish the impact of the patient's withdrawal on the family and on the patient. *But it may be an error to attempt to reconnect the patient to his or her former world, since the reality of the illness and its physical and social impact often cannot be overcome.* The new world of the chronically ill exists because it allows patients to reconstitute a self, a sense of their own persons that is appropriate to their new circumstances. In former times the tuberculosis sanatorium, which was described so well by Thomas Mann in *The Magic Mountain*, was an example of the society of the sick. *The Magic Mountain* is worth reading, if only for its superb insight into that society. Today, kidney dialysis and transplant units provide better examples. It is interesting how many patient associations have arisen, associations such as Ostomy Associations, Reach for Life, or Run for Your Life groups that serve the purpose of reconnecting the sick to the world of the well through the mediation of others in the same situation.

The fact that the dissolution of the social personality is often the basic

element in the *suffering* of a patient cannot be overemphasized. The sick will tolerate, or even adapt to chronic pain, dyspnea, weakness, or other symptoms without considering themselves to be suffering. If you ask those patients whether they are suffering, they will say that they have pain (or whatever), but are not suffering. But if they perceive themselves as losing their connection to their group—friends, family, or peers—then they will consider themselves to be suffering.

That point was central in the case of Annette Landy, a 53-year-old woman with increasingly severe chronic obstructive pulmonary disease. Despite severely compromised pulmonary function, she managed to go shopping occasionally, visit friends, or even go to the movies from time to time. She seemed to have adapted well to her considerable disability. Then office visits began to become too difficult for her, and it was evident that her pulmonary function had decreased even further. However, repeat studies, while dreadful, were not worse than previously. She felt, and I concurred, that going out of her apartment had become too difficult, so an oxygen "walker" at home was arranged for her. I was troubled because, despite her taciturn manner and no objective evidence of worsened disease, she seemed sicker. Within a week of my return from vacation, she reported increased cough, phlegm, and dyspnea. I admitted her to the hospital. Her pO₂ on admission was 50mm of Hg. There was little evidence of infection. What had precipitated her respiratory failure? While examining her I noticed shiny, brownish, palm-sized patches about both knees. They came from resting her hands on her knees while urinating—30 to 40 times, day and night! Urinary frequency started about the time I perceived her as worsening, before she could no longer leave the apartment. She urinated so often because she was afraid she would be incontinent. Indeed, that had happened on several occasions. Respiratory failure was probably precipitated by exhaustion. However, both the urinary symptom and her lack of desire to leave her apartment occurred when she began to feel that it was simply too difficult to keep up appearances any longer. She said, "I just decided I didn't give a damn anymore and I didn't care anymore what anyone thought." A devastating idea for someone as well bred and ladylike as this patient—the equivalent of deserting a lifelong mode of behavior and interaction with the world. As in all instances, it is the meaning of the behavior to the patient that counts, not what others believe.

Cystometrics were normal. First desire to void occurred at 15 ml, but her bladder capacity was 350 ml. There was evidence of mild trigonitis, but infection was not present.

In the hospital, with indwelling catheter, adequate rest, increased bronchodilators, and steroids, she began to feel much better. Even though she felt better and was optimistic about going home (although, as usual, slightly apprehensive in anticipation of discharge), her arterial blood gases at discharge were not appreciably better than on admission (although her steroid requirement was increased). Her pulmonary function was marginal at best, and the probability of early death had not diminished. Yet the patient returned home better in her eyes and in mine. What had treatment accomplished aside from teaching her to control the desire to void? She was again one of us, a part of her social group and no longer alone.

It is sad but inevitable when patients die from diseases that we cannot control, but it is an absolutely unnecessary tragedy when the same patients die

alone and disconnected from their social world, like a sailor fallen overboard at night.

One other facet of the disconnection of the sick is symbolized historically by Hansen's disease. Here, the sufferer is not only ill, but a threat to the healthy. Venereal diseases are often seen in the same light, even when treatment is simple. With these and other infectious diseases, the bond of the patient to the group is disrupted by the patient's fear of causing sickness in others, which would be a deep breach of social convention. Sometimes one must temper the zeal of hospital epidemiologists when they isolate patients for questionable reasons. The fact of isolation can be an added stress for a patient and should not be done without good reason and without active and continued reassurance.

The tie of the sick to their world, then, may be menaced by the effects of the disease on them or by the danger of their disease to others. Thus, the loss of connection that happens in illness can occur at any or all the places where we connect to our world: physically, as with the sensory disturbances; emotionally, in our connection to those close to us; or socially, where we are connected to the wider world. The physician must be aware of these losses of connection and their danger to the patient's well-being. Dealing with them may mean simple reassurance in conjunction with other treatment, as in the case of the patient who loses vision temporarily, or may be one of the most important aspects of treatment, as with the patient whose ventilatory failure I just described.

The Loss of the Sense of Omnipotence

The next patient, Mr. Fred Bortman, came up from the cardiac care unit a few days ago. He was admitted with a typical history of myocardial infarction, which had been confirmed by the evolution of his electrocardiograms and enzymes. His chest pain subsided rapidly, with no evidence of failure or important arrhythmia. He is 48 years old, white, and a relatively successful middle-level manager for a large corporation; my "typical" patient with a myocardial infarction. He appears healthy, and that is part of the problem in caring for him. In his behavior and in his reaction to the heart attack, he demonstrates another feature of illness, the loss of the sense of omnipotence—a failure of the person's belief in his or her own indestructibility. In health, we take our bodies for granted. Even when one does not like his or her body, its intactness and readiness to go and do are prized. The fact that the world can be a dangerous place that threatens injury or death is known to everyone, but that knowledge is no match for the sense of omnipotence that denies the possibility of bodily damage or death. If there were no sense of omnipotence, who would cross a busy street? Certainly no one would ride a motorcycle. Some individuals have a more strongly developed sense of omnipotence than others, and they are frequently described as fearless, while others who are more fearful have a sense of omnipotence that seems less protective. All physicians have patients who are racked by body fears; every symptom seems to them the ticking of a time bomb.

That was not Fred Bortman's problem. He worked and acted as though nothing could happen to him. But it did. When I see him now, he is talking as if

nothing has happened. He tells me that he is not sure that he had a heart attack; he feels fine now. He never felt better. The chest pain that made him call me was not that bad. When I remind him of how severe his pain seemed to be on admission, he tells me that he was "overreacting."

We do not have difficulty identifying his reaction to the heart attack as denial. Indeed, the conversation is reminiscent of many similar interactions with men who have had heart attacks. (Women behave this way less often.) The threat that illness poses to the sense of omnipotence must be met, and denial is one of the most common defenses. A sense of omnipotence, of indestructibility, is essential to *normal* functioning, just as the normal person must feel connected to others and to the social world. Just as the heart muscle heals, so, too, must the sense of omnipotence regenerate. There are, however, some ways of reconstitution that are better than others. The degree of denial displayed by Mr. Bortman is going to get in the way of his return to health.

What this patient is doing is not unusual. I am sometimes awestruck by the power of denial in the face of the most dire symptoms. Patients will occasionally alter their entire life-style to avoid the activity that produces the symptom. Denial is often the mechanism that keeps patients from going to a physician in the first place. Further, denial may be selective—present for one symptom or disease, but not for another. A 58-year-old woman came because of episodic abdominal pain, which was quite typical of gall bladder disease. No other complaints were offered. During physical examination, I was shocked to discover a large fungating carcinoma of the left breast. She said, "To tell the truth, I forgot all about that." Her sister had died of breast cancer (the patient also had cholecystitis).

Angina pectoris and dyspnea are examples of symptoms that are so distressing, not only in themselves but for the meaning they convey about the vulnerability of the body, that patients may go to great lengths to deny their existence. History taking from someone you are sure has angina can be difficult, because occasionally the patient denies not only the symptoms, but also any activity that might produce the symptom. For the same reason, exercise programs for rehabilitation in cardiac or pulmonary diseases have the difficulty that the therapeutic regimen produces symptoms of these diseases, thus constantly reminding the patient of the disease.

On occasion, a patient may report a worsening of symptoms when there is no objective evidence that the disease has worsened. What has happened is that previous denial has failed, and the patient perceives now what was concealed previously.

Symptoms of central nervous system disease are more shattering than most others. Difficulties in speech or memory, hallucinations, and interference with thoughts may strike at the sense of oneself as a person. They are person symptoms rather than body symptoms. In the same manner, disturbances of thought or perception may make patients feel that they are losing their sanity. The same worry about losing their sanity may disturb patients with organic symptoms of disease, such as myalgias, arthralgias, weakness, or fatigability, when physicians do not believe what the patient reports. The patients are first distressed at

the failures of their bodies and then, when they are not believed by physicians, they begin to doubt their own perceptions. Patients with insidious onset of, for example, thyroid disease, myasthenia gravis, or multiple sclerosis, will often report such occurrences as part of the very distress of their illnesses.

The sense of omnipotence is protected by denial even in the language that patients use to describe their symptoms or disease. During a second-year class on interviewing, the demonstration interviewer asked the patient (who was unknown to him) what his problem was. The patient said, in almost so many words, "acute lymphoblastic leukemia." The interviewer never quite recovered, but the patient then proceeded to give the stunned class a lecture on his own inevitably fatal disease. After he left, we all wondered how he could be so calm and self-assured despite his fate. After we had listened to the recording of the interview, the mechanism became clear. All the symptoms and signs of disease were preceded by impersonal pronouns. For example, "you get these spots on your skin" or "one gets bleeding from the gums" or, referring to patients with leukemia, "they often feel weak and listless." On the other hand, all manifestations of health were preceded by personal pronouns, as in "I worked hard all fall" or "we went sleigh riding in the country in February" or "I expect to go home next week." It was as though his internal conception of self was still healthy and intact.

The sense of omnipotence is like a shield around the integrity of the person; it preserves intactness. The symptoms of illness are the enemy of that intactness, and denial is one of its defenses; the completeness of a person extends past the physical boundaries of the body. A person is also his or her beliefs and ideas, as well as usual activities, habits, and patterns of behavior. That is why sometimes, when you are about to hospitalize someone who has been taken with serious illness suddenly, the person will say, "I can't go to the hospital. I have to go to my exercise class tomorrow." The comment is inappropriate to the seriousness of the situation, but the patient does not seem aware of how silly it sounds. Going to the exercise class is part of the weekly routine. It is not so much the content of the activity that is important—although exercise may play a significant part in the image of self—as it is the loss of part of oneself. Nonetheless, patients are usually aware of the symptoms they deny, but to accept the symptoms would demand a change in self-image, in the sense of self. Thus, if you listen closely, you will hear patients depersonalize their symptoms by doing what the patient with leukemia did—using impersonal words. *The* pain, not *my* pain. A woman with a pulmonary embolus was giving the history of the thrombophlebitis that preceded her present illness and said, "*My left leg*" (the patient's own leg, part of herself) "which is *the bad leg*" (no longer "my leg," but a bad leg that is not part of myself) "from the vascular point of view," (not bad from her point of view but from some outside, abstract position) "had a thrombophlebitis in it." (She did not have thrombophlebitis—a leg had *it*.) She could have said, "I have vascular problems in my left leg and I got thrombophlebitis." You will have to listen very carefully because such impersonal usages are so common that they are difficult to hear as distinct entities. The difficulty in picking up the language attests to the normalcy of the phenomenon. The language distances the patient's intact self

from the phenomenon that threatens the self. Women virtually always refer to their breasts as "my breasts," but when about to have a mastectomy, they will commonly talk about "the breast." More strikingly, after the mastectomy, they usually refer to the remaining healthy breast as "the breast" rather than "my breast." Months after the mastectomy, the healthy breast again becomes "my breast." The fundamental point is that the self, the person as seen by oneself, must be preserved at all costs, and illness threatens that sense of self. Thus, the sense of omnipotence functions to maintain certain aspects of self-image.

Ultimately, as sickness becomes worse, all defenses fail and the patient is forced to acknowledge the body's failure. Previously powerful and now helpless, previously sure and now untrustworthy, the body is seen for what it is: fragile and defenseless against injury.

The problem with denial as a defense against the recognition of illness is that its opposite face is frequently panic. The sick person has refused to accept or even consciously recognize all symptoms of disease, even the trivial, but when illness overwhelms, the patient begins to react with great fear to all the symptoms that had previously been denied. The panic comes not only because of the sudden awareness of illness, but *also because of the loss of the major defense mechanism*. To be both sick and defenseless is terrifying. Denial can cause major problems for a physician. The patient does not accept the facts of the illness, and thus may not take medications, go for needed diagnostic studies, or return for the follow-up. I am sometimes uncertain what to do when a patient behaves in this manner: I know how dangerous it can be to breach the denial forcibly by telling the patient in no uncertain terms what the situation is. I do not want to use stark language that would be avoided with the most stable person. If I use it, the patient will not act, but will be paralyzed with fear by what I said, and that was hardly my original object. Furthermore, by using such straight language I become the enemy (after all, I frightened the patient, not the disease).

In these situations, I try to provide an alternate defense for patients. Overintellectualization is a useful substitute that can be encouraged by long intellectual discussions of the disease or symptom, as though we were talking about someone else's body, and that can point the way to the desired action. In engaging in such discussions, I am employing the same mechanism described above—depersonalizing the body part of symptom by using impersonal pronouns. I might say, "Fluid in a chest like that often comes from the reaction of the chest lining to an inflammation. It is important to find out what the chest wall or the lining is reacting to in order to prevent the lining from making more fluid and compressing the lungs." The fact that what afflicts the lungs afflicts the person is not mentioned.

At other times I let more time pass, when that can be done safely, because I know that sooner or later the patient will be forced by the symptoms to recognize the illness. Panic may follow, but now I am not the one whose bad tidings caused the panic, but rather the one who offers safety.

After Wallace Black, the patient discussed earlier, went home, his diuresis continued. One day he called, weak-voiced, from his bed. His weight that

morning had been 116 pounds. (His weight when leaving the hospital was 126 pounds, and his normal weight about 155 pounds.) He said he was dying—wasting away and dying. I saw him at home. The abdomen was flat, almost free of ascites, but there had been no further muscle wasting. He went on for a while about his pitiful state. He was finally ready to listen as he had not been for all the months of his illness. So frightened was he by the sudden awareness of his condition and by his interpretation of its fatal meaning, that what I had to say about his cirrhosis seemed to be a reprieve. Together, we could plan a realistic therapeutic regime. Fred Bortman is not yet there.

Denial is by no means present in all patients with myocardial infarction or other serious illness. On occasion, patients appear to be completely aware of the danger of their situation, or the bleakness of their future. Not surprisingly, such awareness is frequently followed by depression. Those patients may appear agitated, apathetic, or merely bland. It is distressingly common to find every emotion that patients evidence labelled as "anxiety" and treated with anti-anxiety agents. In the first place, all emotion does not have to be "treated away," as though it is inappropriate to be sad or depressed after serious illness. Rather, the reasonableness of the response and its reasons should be acknowledged by the doctor. As will be discussed later, the patient is beset by uncertainties about the future, many of which can be put to rest by the doctor in a few minutes of conversation. False optimism is neither desirable nor desired by patients who are alert to their situation—they see through it quickly. But what is necessary is an attempt to elicit the concerns that are *specific* to each patient, followed by information that the patient needs in his or her own terms. Second, sedative drugs may depress the patient further by restricting psychic and physical activity, which may increase the patient's sense of being in a straitjacket.

When speaking with Mr. Bortman, I discovered that his heart attack had occurred one year to the day after his wife died. His relationship with his wife had been extremely close, and he has felt lost since her death. One of his two children fled the home and married unexpectedly two months after her mother's death, and the other daughter left college to come home and care for him. Aside from telling me these facts, he does not want to talk about his wife, the emotional impact of her death, or the possibility that he might be depressed. The anniversary timing of his myocardial infarct is to him "coincidence." Mr. Bortman's denial, then, extends beyond physical illness and into his emotional life. When denial is present in psychological matters, we often speak of a patient as having no insight. But the problems presented in caring for such patients are the same as those presented in other cases of psychological denial. Just as it will be difficult to get Mr. Bortman to accept a program of cardiac rehabilitation, so too are the chances minimal that he will seek needed psychiatric help.

A number of studies have reported the anniversary phenomenon—death or illness occurring on the anniversary of the death of a loved one, who is most commonly a parent or a spouse. The finding is interesting in itself, but it points to something of broader significance: the association of illness in the patient with illness in other family members, who are generally the parents. Patients commonly

tell us that they know that their joint pain is arthritis because their mothers or fathers had arthritis. As I said earlier, the boundaries of a person do not stop at the limits of the body. We often speak of identification with a parent as though the connection to the parent occurred solely in thought. In fact, however, the person may think or behave as though his or her body were a literal extension of the parent's, and display the same physical strengths or weaknesses, or be prone to the same diseases, as the father or mother. (A child may identify with either parent.) We acknowledge this, generally, by inquiring specifically for a family history of heritable disorders. But it is important to go beyond such diseases and inquire whether the patient knows of any diseases or health problems that "run in your family or which are of concern to you because of your family history." Unless specifically asked, patients will often not offer such information because they are unaware of its importance, or even on occasion because they are embarrassed at what they perceive to be a "nonrational" influence on their behavior. On the other hand, the link of their illness to that of a parent may offer comfort. A 49-year-old physician had what he thought was an inexplicably prolonged upper respiratory infection and finally went to see his own doctor. When told that he had hay fever (a diagnosis that should have been obvious to him) he said "But that's impossible, I'm 49." He did not seem satisfied when told that it did not matter how old he was. But then he said, "What's the matter with me, I forgot all about it—my father and sister had hay fever." Now hay fever was acceptable.

While that is a trivial example, more serious situations exist when patients act as though history is prophecy, as though if the parent died of (say) congestive heart failure, it is inevitable that they, too, will die of congestive heart failure. Because of that belief, they may not carry out simple and obviously effective treatment. Since the patient may not be aware, for whatever reason, of the association with the parent's disease, the information must be actively sought. Often merely pointing out the association and showing what can be done for patients to change their future is sufficient to avoid an otherwise fatal outcome—it is often a matter of a few minutes conversation.

Fred Bortman's illness extends to his family. Indeed, he was referred to me by his sister-in-law prior to his heart attack (but he did not call until he developed chest pain) out of her concern for the disruption of the family following the death of his wife. His heart attack has compounded the family problem. The wife on whom he was so dependent is dead, but her place has been taken by the daughter who left college to care for him. With his illness, the burden on the daughter has increased and I suspect that she will have difficulty leaving her father again and resuming her own life and career. Similarly, the flight of the other daughter suggests trouble. I call it flight because the period of mourning for the death of a parent is usually longer than two months; usually families draw together rather than disperse during that period. Furthermore, she married someone whom she had not known prior to her mother's death. This added to my belief that her actions were precipitous. One may speculate about the reasons for her departure and marriage—that she was escaping the burden that ultimately settled on her sister. But those would be speculations that could neither be confirmed nor acted

