PATIENT-CENTERED MEDICINE

A HUMAN EXPERIENCE

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This book is dedicated to our patients,
who have been our greatest teachers.

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FOREWORD

By Andrew Weil, MD

When I was growing up in Philadelphia during the late 1940s and 1950s, our family doctor was a beloved general practitioner who made house calls, knew his patients well, worked hard, and was considered a friend. But, he wrote prescriptions in Latin to keep us in the dark about what they were, and we never questioned them or the treatments he ordered. He was the medical authority—a wise father figure; we were the children for whom he cared.

Medicine in mid-20th-century America was paternalistic and authoritarian, as it still is in many parts of Europe, Latin America, and Asia. But much has changed here in recent years. The Internet has leveled the playing field between doctors and patients, making medical knowledge available to all. The economic catastrophe that has engulfed our nation's healthcare system has weakened the authority of physicians. And the demand for "patient-centered medicine" has become a force to be reckoned with.

I teach and practice integrative medicine, which I believe must be the foundation of healthcare of the future. Integrative medicine insists that patients are not just physical bodies, but also they are mental/emotional beings, spiritual entities, and community members, and those other dimensions of human life must be taken into account to understand health and illness. The reigning biomedical model is obsolete. A new *biopsychosocialspiritual* model of medicine must supersede it. (*Integrative* is a more user-friendly term.)

Integrative medicine also emphasizes the importance of the practitioner–patient relationship in the healing process. Throughout history, in many diverse cultures, that relationship has been held special, even sacred. When a medically trained person sits with a patient and simply allows him or her to tell their story, that alone can initiate a healing response before any treatment is given. Sadly, today's corporatized healthcare does not allow for this. If medical visits are limited to 10 minutes or less, it is unlikely that a productive therapeutic relationship can form.

Patient-Centered Medicine: A Human Experience is a timely and welcome publication. Not only does it define the role of health professionals in the new model of medicine that is coming into being, it gives a great deal of practical advice about the attitudes and skills they should develop to care best for patients. Medical students and doctors in training will find it especially useful. I expect them, as physicians of the future, to lead the much-needed transformation of healthcare.

FOREWORD: PHYSICIAN AS HUMANIST

By Norman Cousins

Written for the first edition of *Medicine as a Human Experience* by David E. Reiser and David H. Rosen

Drs. Reiser and Rosen have written a book filled with compassion and insight not only for patients but also for the singular and often complex young men and women who take upon themselves the healing role. I have been trying in recent years to find out as much as I could about the direction medicine seems to be taking. The authors provide some encouraging answers and point a path toward the resurrection of the principles of integration that are essential. By "integration" I am thinking not of a murky principle but of the need to affirm the importance of the human spirit, dignity, fullness, and hope in the philosophy of medicine.

Few things are more encouraging about modern medicine than the recognition that the psychological and the physiological are part of a totality; psychological and psychiatric problems are not merely aspects of medicine but are central to all medical practice. It is difficult to think of *any* relationship between a doctor and a patient that does not involve psychological and psychiatric competence by the physician. This is a fundamental issue.

Medical training tends to divide most subjects between "soft" and "hard." The hard subjects are defined as, or equated with, science: pathology, pharmacology, biochemistry, biophysics—everything that utilizes facts and numbers in one way or another. The soft subjects involve psychology, patient–doctor relationships, the philosophy of medicine, and the history of medicine.

When some subjects are defined as soft and others as hard, one makes value assignments. The hard is "good" and "dependable." The soft is "weak" and therefore to be disparaged. Yet 15 to 20 years after medical school, what happens? One discovers that the so-called, the supposed "hard" base of medicine breaks up—that the fact base of medicine is vulnerable. All one has to do is to look back over the past 25 years and certainly the past 50 years to see how much of medicine that was considered to be hard and indisputable has been refuted or replaced.

In many respects, the "soft" subjects have greater longevity. The way a doctor listens to a patient, his ability to inspire the patient's confidence, to communicate that which must be communicated in a way that does not destroy hope are things referred to as the "art of medicine." This is what medicine is all about, and this is what endures. As for

science, certainly the scientific aspects of medicine are the foundation, but the "hard" facts keep changing because of the nature of both pure and applied research.

These matters Reiser and Rosen clearly grasp, and their book is an attempt to integrate "soft" and "hard," "science" and "art"—in short, to be truly scientific in the best sense of the term. Many textbooks have already been written that aspire to present students with a unifying view of patients and the practice of medicine. In this regard, *Medicine as a Human Experience* is not unique. What makes it unique, in my view, is the spirit its words embody, the attitude its pages communicate. The authors understand, and repeatedly demonstrate in this book, that the patient–physician relationship is a powerful, sometimes mysterious, frequently healing interaction *between human beings*. At the core of this interaction is communication.

Five years ago, I accepted an invitation to teach literature and philosophy to medical students at the University of California, Los Angeles, and to study problems in patient–physician relationships from the standpoint of patients. I also wanted to pursue research in a field of deep interest to me, the biochemistry of the emotions.

I thought I would have to brace myself for all the shocks that go with a new career, but I quickly discovered that physicians and writers have at least one thing in common: Communication is an important part of their trade. In journalism you live or die by your ability to use words. In health care the words a physician uses have a profound effect on the well-being of the patient. A doctor's words can be gate-openers or gate-slammers: They can open the way to recovery, or they can make a patient dependent, tremulous, fearful, resistant. The right words can potentiate a patient, mobilize the will to live, and set the stage for heroic response. The wrong words can produce despair and defeat or impair the usefulness of whatever treatment is prescribed. The wrong words can complicate the healing environment, which is no less central in the care of the patients than the factual knowledge that forms the basis of treatment.

Being able to diagnose correctly is one good test of medical competence. Being able to tell the patient what he or she has to know is another (and, as the authors later explain, both are essential skills of a "competent" physician). Now, I recognize the problems involved for the physician in proper communication. There is not only the problem of language itself—how to use words that do not confuse or mislead. There are also the professional problems—the obligation of the physician to inform the patient, the difficulties caused by the fact that patients vary in their ability to deal with the truth, the ease with which poor communication with the patient can spill over into tangled relationships and even malpractice suits.

Let me hover over some of these problems.

First of all, proper communication is one of the most difficult undertakings on earth. The older I get, the more I am forced to recognize that many or even most failures and break-downs have their origin in faulty communication. Whether we are talking the predicaments of human beings or the confrontations of nations, the inability of people to convey intention and meaning has been one of the prime causes of confusion and violence over the centuries. On a small but accessible level, you need go no further than the administration of hospital affairs to see how many errors, some of them serious, proceed out of faulty communications. Consider the wrong medications in the intravenous bottle, or the wrong pills, or the wrong quantities, or the hospital attendant

who misinterprets instructions intended for one patient and applies them to another. Not infrequently, that attendant can fault ambiguous communications: the orders just were not clear enough.

Imprecision in communications, it goes without saying, is not confined to the medical profession. It is in the air. In the business world, blurred or faulty use of language represents the biggest single problem and single largest expense confronting any organization.

In my own contacts with patients, I have been made aware of the frequency with which they seem frightened or confused or immobilized as the result of their medical encounters. I allow for the possibility that their reactions may be the result of their own failures in understanding, but I am nevertheless struck with the fact that the relationship between patient and physician is often impaired because of sloppy communications.

Now we come to an entirely different problem. Even when the physician's message *is* clearly delivered and clearly understood, its effect may run counter to the well-being of the patient. Patients are not equally adept in their ability to handle the truth. Some may even be exposed to iatrogenic hazards if they are confronted at point-blank range with the fact of extreme illness.

One of the residents at UCLA spoke to me about a conference with a patient and the family, during which they were all expecting the attending doctor's verdict after a biopsy. The oncologist came in the room; the family was seated. He sat down, spread his hands, and said, "Well, I've got to let you have it." He said, "Your kidneys have crapped out." He said, "Your liver is crapped out. As a matter of fact, he said, "Everything is crapped out. That's the way it is." And he left.

Truth is the fashion these days. No one wants to stand against the truth. We all want the truth. But there are some problems here. The issue, it seems to me, is not do you tell the truth, but first do you really know the truth? Does any doctor really know enough to make a pronouncement of doom? Yes, he knows the basis of the evidence and on the basis of the averages that this patient may live just 3 or 4 months, but he is diagnosing an average—he is not really diagnosing a patient. No one knows enough about a human being to make a precise pronouncement of doom, and yet such pronouncements are made all the time. A good habit to get into is to ask yourself: Do you really know the truth in the first place?

Second, how do you deliver the truth? Do you deliver it as though you have a truckload of bricks to unload on a patient, or is a certain sensitivity called for? Do you deliver it in a way that crushes the patient's hope? Or could you find some way of allowing that patient to stay alive psychologically?

It may be said that the physician has no choice but to convey the facts flat out, that the danger of malpractice suits is such that the physician is forced to tell the patient the worst in unmistakable terms. At least, if the worst should happen, the physician cannot be accused of failing to prepare the patient—a failure for which he could be held legally accountable.

The essential question, perhaps, is whether the hard facts and nothing but the hard facts are always necessary or useful. Now, if the reason for the hard facts is the doctor's fear of legal reprisal, then we have to ask ourselves if there is a conflict of interests

between the patient's need for treatment and the physician's need for legal protection. Consider the case of the San Francisco patient who had a biopsy of a lump in her breast and who telephoned the oncologist 3 days later asking about the result. She was told that such serious matters were never discussed over the telephone but that she would be informed in due course. She was. She was informed by *certified* letter. The letter was completely unambiguous. It said in the tersest language that she had a malignancy. There was certainly no failure here in communication, but there was certainly little regard for the effect that communication in this form would produce. With a registered receipt in his possession, the physician could protect himself against any possible accusation later that he had failed to make an accurate diagnosis. The woman was not so much told as notified, not so much instructed as sentenced.

Is it reasonable to ask if insensitive reference to the worst helps to bring on the worst? To what extent does the *unvarnished* recital of a negative prognosis have the effect of a hex? Physicians are obligated to use all the science at their command—chemotherapy, radiation, surgery—in an attempt to reverse or slow down a malignancy. For the same reason, the wise physician calls up his humanity to potentiate and motivate the patient. The mood and attitude of the physician as well as that of the patient are potent factors affecting treatment. For that reason alone, the physician should try to avoid a situation in which either one leaves an encounter in sheer terror and defeat.

In my current position, I have a chance to see patients at the request of doctors: patients who have given up and who need emotional support. The most difficult thing in dealing with these patients is not the illness but the psychology it engenders. Nothing is more inevitable in serious illness than the panic that accompanies it. Panic is the intense fire of disease. Panic is a disease by itself. Panic makes biochemical changes in the body. What happens when the doctor communicates with a patient in a way that intensifies that panic? Perhaps it might have been better in some instances not to have gone to the doctor at all.

The authors of this book draw for you a clear picture of the way panic and stress can throw the entire endocrine system into disarray. It is no accident that disease frequently and suddenly becomes intensified as the diagnosis is pronounced. The way a patient receives a diagnosis can have a profound effect on the course of the disease. This does not mean that the truth must be deferred or denied. It is a matter of attaching as much importance to the manner and style of communication as to any other aspect of medical care.

We are accustomed to thinking of iatrogenic problems in terms of the wrong medication, or mistaken surgery, or harm done in diagnostic procedures. But there are also psychological iatrogenic situations—what happens after a patient is sent into an emotional tailspin with physiological consequences as the result of the exchange with a physician?

Everything we have said so far points to this question: Is it possible to communicate negative information in a way that is received by the patient as a challenge rather than as a death sentence?

I believe it is. As the authors of this book repeatedly demonstrate, understanding how patients are affected by serious illness, as well as what illness they happen to have, paves the way for communicating without crippling.

Throughout the book, an attitude is evidenced that is conducive to treatment and recovery. The authors do not minimize the seriousness of a patient's condition. What they do, instead, is to put their emphasis on healing as a partnership. They describe what it is that modern medical science has to offer, what it is that the patient has to offer, and finally what the physician as a human being has to offer. They talk about the patient's resources and, equally important, about the resources of the healer.

We make a great mistake if we think that in a serious or terminal illness victory is represented only by some miracle that reverses the illness—some beautiful remission—and that defeat is represented only by death. An illness is similar to existence inside the concentration camps. There are many victories short of escape, many victories short of cure, and many defeats that are not marked by death. Even though we cannot expect ultimate victory, our existence is enriched or impoverished by the interim victories or failures within our reach.

A young boy says, "It was wonderful when mother opened her eyes and recognized me." Another patient is able to turn over in bed by himself, and yet another patient is able to hold out her hand. These are the moments that are made possible by the physician as humanist, the physician who does not equate healing with some rigid and narrow definition of biomedical cure, the physician who appreciates the importance in medicine of such imponderables as hope, dignity, courage, and yes, love.

I am reminded of one of the doctors at Encino Hospital, who had a judge as a patient. The judge was willing himself to die. The family was bereaved not just because of his impending death but because his character had changed so drastically under circumstances of extreme adversity.

The judge had always been a fighter, strong and resolute. Now he was giving up, and all he wanted to do was to die. His family hardly recognized him, but the doctor was wise enough to ponder, "You know, if we can just give this family one week—one week—with the judge as he used to be, not in terms of health, but in terms of the spirit as they have recognized it, it would make a very big difference to them for the rest of their lives.

The next day I was leaving for China, so at the doctor's request I went to the Encino Hospital that night. The judge—a tall man, six feet three inches—was wasting away. He was down to about 90 pounds. He could barely speak. He had been a reader of the *Saturday Review*,* so there was some way for me to reach out to him and have him reach back.

He whispered. He spoke about the magazine and how he had read it all those years, and I said "Dr. Bluming asked me to come and see you because of the family."

He said, "What about the family?" in a high whisper; and I said, "Well, you know, cancer is the most contagious of diseases."

He said, "No, it's not."

I said, "Well, it is contagious in the sense that the grief is the virus, and sometimes the way we die helps to determine what happens to others; and when you look at the records, you find that wives follow husbands within a few months and husbands follow wives—and the inability to handle grief is really a virus."

"You know, your family has always seen you as a great fighter, and now you're going out of character."

He said, "I gotcha."

The next day, when I arrived in Hong Kong, I telephoned the Encino Hospital and talked with Dr. Bluming. He said, "Gosh! Something very strange and wonderful has happened. When they tried to hook the judge up to his intravenous this morning, he said, 'Turn the damn thing off and give me my breakfast the regular way.' I don't know how he got it down—but he did."

The doctor reported, "Two hours later, he asked his wife to come over to play a game of bridge. How they played that game of bridge. I'll never know." The next day, the judge even walked around the room.

When I got back 3 weeks later, I discovered that he had died just 2 days before my return. He not only lived out 1 week, he lived out three—and he did so with spirit. He found his victory, and the family found its victory, in an altered context that was real.

There are victories that are possible, and a physician is responsible for helping us to get the most out of whatever may be possible. In the final analysis, medicine is the science and the art of the possible.

As this volume makes clear, the doctor's job is not just to deal with the ultimates. The doctor's concern is with the intermediates that make up our day-to-day lives. Nothing is more wondrous than the ability of the human spirit to produce profound biochemical, physiological, attitudinal, and behavioral change, even though a cure is not possible. I have been mystified by this and at times ennobled. This, it seems to me, is the great experience within the reach of physicians. The present text offers a path toward that full realization.

Patients need and look for qualities in their doctors that go beyond technical competence. They want reassurance. They want to be looked *after,* not just looked *over.* They want to be listened to. They want to feel that it makes a difference to the physician, a very big difference, whether they live or die. They want to feel that they are in the doctor's thoughts. In short, patients are a vast collection of emotional needs. Yes, psychological counselors are very helpful in this connection, and so are the family and clergy; but the patient turns most of all and first of all to the physician. It is the physician's station that has most to offer in terms of those emotional needs. It is the person of the doctor and the presence of the doctor, just as much as—frequently more than—what the doctor does that create an environment for healing. The physician represents restoration. The physician holds the lifeline. The physician's words and not just his prescriptions are entwined in that lifeline.

This aspect of medicine has not changed in thousands of years. Not all the king's horses and all the king's men—not all the tomography and thallium scanners and two-D echograms and medicinal mood modifiers—can preempt the physician's primary role as the keeper of the keys to the body's own healing system. To the students who read, and more important *understand*, the spirit and the essence of this book, I would say, without hesitation or fear of hyperbole, you are medicine's future. You are also its only hope.

I pray that you will never allow your knowledge to get in the way of your relationship with your patients. I pray that all the technological marvels at your command will

not prevent you from practicing medicine out of a little black bag if you have to. I pray that when you go into a patient's room you will recognize that the main distance is not from the door to the bed, but from the patient's eyes to your own—and that this distance is best traveled when the physician bends low to the patient's fear of loneliness and pain and the overwhelming sense of mortality that comes flooding up out of the unknown, and when the physician's hand on the patient's shoulder or arm is a shelter against darkness.

I pray that, even as you attach the highest value to your science, you will never forget that it works best when it serves your humanity. For, ultimately, it is our respect for the human soul that determines the worth of our science.

* Norman Cousins was an American journalist, author, professor, and world peace advocate. He was editor of the *Saturday Review* magazine for many years.