

By Bernard Lown

Notes taken by DJ Elpern

On December 3 and 4, 2013, the Lown Institute hosted an extraordinary conference. The notes taken there will be posted elsewhere. A copy of Bernard Lown's book, The Lost Art of Healing, was given to every registrant. I read this book when it came out in 1996 and went back to review my underlinings and marginalia. My transcriptions follow:

Medicine's profound crisis, I believe, is only partially related to ballooning costs, for the problem is far deeper than economics. In my view, the basic reason is that medicine has lost its way, if not its soul. An unwritten covenant between doctor and patient, hallowed over several millennia, is being broken.

A doctor establishes credentials as a caring practitioner during the very first visit by listening attentively.

My philosophic outlook has been shaped by many elements: foreign birth, a Jewish heritage with a rabbinic tradition, a love of books, and above all, a continuing romance with medicine. Maimonides prayed, "May I never forget that the patient is a fellow creature in pain. May I never consider him merely a vessel of disease."

Chapter 1.

Practicing the art of medicine requires not only expert knowledge of disease but an appreciation of the intimate details of a patient's emotional life usually presumed to be within the province of the psychiatrist. The need for complex involvement with patients is never alluded to in medical texts or mentioned during medical training. To succeed in healing, a doctor must be trained, above all else, to listen. Attentive listening as itself therapeutic for one encounters many fine details. Few great books expose the human condition more clearly than the patient who has permitted one to look deeply into his or her eyes.

I am persuaded that a majority of prescriptions intended to alleviate chief complaints are largely irrelevant. This may be a reason so many prescribed drugs prove ineffectual and is no doubt a major factor in medical costs. A patient with an unaddressed problem keep searching for an answer and goes medicine-shopping.

Doctors focus on the chief complaint primarily because medical schools do not train students in the art of listening.

History taking is always improved when another member of the family, especially a spouse, is present.

The pity of medical practice is that takes a lifetime to gain the clinical wisdom that enables a doctor to comprehend the essential medical problem with an economy of discourse.

Chapter 3

If listening is so important, what is the doctor listening for? Fundamentally the aim is to understand the medical problem as well as the person behind the symptoms. The latter is what usually needs clarification. During history taking, the doctor begins to know the patient as a human being.

Chapter 5

The denaturing of human values begins in medical school. In my mind it is a grievous error to start the study of medicine with the dissection of a cadaver. This is the beginning of a four-year intensive indoctrination aimed at instilling scientific competence, with little time or effort being devoted to honing interpersonal relations or in the cultured cultivation of caring. The young physician is therefore neither interested nor trained in the art of listening. Later, powerful economic factors undermine a readiness to listen. Presenting a grim scenario fosters acquiescence and avoids time-consuming explanations.

The disquieting aspect of this training is that many doctors are barely aware that they have become docile healthcare merchants. Doctors have been trained since medical school days to romance with technology. Their education emphasizes that the most effective way to help the patient is by means of a comprehensive workup beginning with and guided by history. (*the EMR makes this even worse- DJE*) Invariably, history-taking is given short shrift as the patient is shuttled to a multiplicity of specialists and subjected to a gamut of procedures. This type of medical practice is nearly universally accepted as the highest scientific and moral standard.

Another factor shaping the practice of medicine is the belief by both patients and physicians that anything broken must be fixed. Elderly patients often present numerous symptoms that would prove tolerable if they were reassured of their harmlessness. The chase to diagnose the incurable, to treat the untreatable, to prognosticate the unpredictable, not only is a form of hubris but opens a Pandora's box with dangerous consequences.

Doctors are as much as product of a technological consumer culture as anyone, and their tendencies to rely on technology are further enhanced by the distorted emphasis on making the diagnosis a treasure hunt for the outlandish and the esoteric.

Whatever the explanation, there is absolutely no justification for assaulting patients with language that cowers and disempowers. A patient must never be compelled by fear into difficult choices. If there is to be a partnership in medicine, the senior partner has to be the patient who must not be deflected from having the decisive word.

Chapter 6

Although a doctor's words can injure, they have a far greater potential for healing. The healing process demands more than science; it requires mobilizing patients' positive expectations and stimulating faith in the physician's ministrations. I know few remedies more powerful than a carefully chosen word. Patients crave caring which is dispensed largely with words. Talk, which can be therapeutic, is one of the under-rated tools in the physicians armamentarium. (*Note: this is similar to Michael Balint's concept of the doctor as drug.*)

I heard Doctor Levine worry that the golden age of medicine was about to pass, as concern for a patient was being displaced by preoccupation with the disease.

Faith and optimism have life-giving qualities. Hippocrates, the father of medicine, said, "For some patients though conscious that their position is perilous recover their health simply through their contentment with the physician." That comes from trust, which the doctor promotes by conveying optimism. Certainly promoting optimism is critical to good doctoring and is a significant aspect of the art of healing. I have never tried to frighten a patient or paint a grim scenario.

Some years ago I asked a Soviet physician from Siberia what the essence of doctoring was. She responded simply: "Every time a doctor sees a patient, the patient should feel better as a result."

Chapter 7

A physician committed to healing cannot focus exclusively on a patient's chief complaint and diseased organs but must attend to the stressful aspects of the patient's life as well. This alerts the physician that the doctor is interested in him or her as a person, not in the immediate problem.

Generally the most critical areas arise from work or family conflicts. If these are ignored, a chronic disease cannot be effectively addressed, whatever its anatomic location.

Treating differs from healing. The former deals with a malfunctioning organ system the latter with a distressed human being.

Chapter 8

A doctor owes it to a patient to be precise and affirmative. Yet a doctor who approaches the power of the word is aware that in some cases certainty may just tip the scale and relieve the patient's pain or other symptoms when all else has failed.

My many years of medical practice have convinced me that if the patient perceives that the doctor is motivated exclusively by concern for his or her well-being, the patient's trust is rarely diminished, even when the doctor turns out to have been wrong. On number of occasions when

I promised a cure that did not come about, the patients were almost apologetic as though they had failed me by not living up to my expectations.

300 years ago the great English physician Thomas Sydenham mused that "The arrival of a clown exercises more beneficial influence upon the health of the town than 20 asses loaded with drugs." (*Cf Patch Adams work*)

A doctor must be an embodiment of optimism. It has been my conviction that a physician should always search out a ray of light even under the darkest circumstances.

My aim in relating these stories is not only to emphasize the value of optimism and of communicating certainty, but the fact that medicine still requires navigating through largely uncharted waters. Many think that since they are living in the age of science, much of the guesswork is taken out of the practice of medicine.

Effective patient management requires appreciation of the art of healing, in which one is guided by experience, by the recall of a similar case, and by the exercise of common sense. A sense of humility, too, is an asset, for any prescription or advice has a substantial measure of conjecture.

The doctor, loyal to his or her calling craves certainty while immersed in doubt. Yet doubt cannot delay the urgency to treat and the necessity to heal. The essence of true professionalism is to act even when the state of knowledge is inadequate.

Chapter 9

In our modern epoch, the growing intimacy between medicine and science promotes an illusion that they are identical. It leads doctors to trivialize the importance of bedside manner, fosters neglect of comprehensive history taking, and diminishes the investment of self in promoting humane interactions with patients. The focus shifts from healing to curing as though these were adversarial rather than complimentary systems.

For patients, the scientific revolution enhances expectations of instant cure for whatever the sickness. Health concerns grow. For many these have become their paramount preoccupation and a major subject of conversation. The media are full of medical news and employ correspondents exclusively devoted to health matters. The health complex has become this nation's largest industry and greatest single drain on social resources. While people are healthier and live much longer than in the past, their tolerance with discomfort has diminished as their fears of sickness has mounted. This relates in no small measure to American's exposure to around-the-clock medical hype. (see Arthur Barsky's book: *Worried Sick: America's Troubled Quest for Wellness*)

Why do people increasingly seek out alternative therapists in preference to primary care physicians? Probably because orthodox medicine does not provide relief for whatever ails or troubles them. At present, about 25% of patients who visit an American doctor are successfully

treated. The other 75% have problems that scientific medicine finds difficult to resolve. After being shuffled among a bevy specialists and subjected to costly and invasive technologies, many patients, frustrated, turn away from conventional medicine.

In my own practice as a highly specialized cardiologist, the problems of more than half of my patients do not relate to their heart conditions but to the stresses of living. I have learned that few patients search for all alternative therapies when physicians focus on healing as well as using the powerful scientific tools at their disposal. Healing and improving the patient's well-being frequently requires imagination and devising approaches that assuage discomfort or relieve a complaint. Sometimes the doctor may have to resort to unconventional techniques in order to improve the patient's well-being. These are not taught in medical school but are discovered through clinical experience and sanctioned by common sense.

The Chinese have reported on cases of addiction to acupuncture needling. Such addicted individuals experienced withdrawal-type symptoms, suffering from lassitude, nausea, abdominal pain and headaches when acupuncture was stopped. The symptoms were promptly relieved when acupuncture was resumed, suggesting that acupuncture stimulated the brain to produce such potentially addicting neurotransmitters like endorphins or enkephalins.

A doctor partakes of two cultures, the dominant one that of science, the second that of the art of healing which is indispensable for the full success of the science. In time, the domain of science will no doubt extend to include within its province more of what ails human beings. However, it will never displace the art. There will always remain ample space for alternative therapies that find their roots in traditions other than science. The fundamental reality is that the soul is not encompassed by the brain. Medicine cannot abandon the healing of aching souls without diminishing its reverence for the human condition.

Chapter 10

A careful history, a thorough physical examination and a few simple routine tests provide about 85% of the basic information required for a correct diagnosis. Ref...

Incompetence accounts for an infinitesimal percentage of the mistakes that lead to human suffering and loss of life. In my view, most mistakes are caused by well-trained physicians who bypass careful history taking, indulge in rampant use of technology, and thereby injure far more patients than incompetent doctors do. Regrettably, the focus of criticism is on the outrageous case, not on the less newsworthy but more serious problem caused by the current culture of medicine.

Even more disability and death results from the excessive prescription drugs, from polypharmacy and from drug interactions and from the inappropriate use of technology. Neither surgery nor invasive procedures cause a fraction of the damage that is done with

pharmaceuticals. Rarely a week passes without my encountering one or more patients suffering from adverse drug reactions.

On average doctors spend 2.9% of their gross income on malpractice insurance just a shade over the 2.3% they spend on their professional car upkeep. It is the insurance companies more than the victims of malpractice who are collecting the loot; for example in 1991 malpractice policies earned them \$1.5 billion in profits.

While doctors are generally terrified of being sued, the surge of defensive medicine has a subconscious motivation. The fear of malpractices has grown as a rationalization for lucrative procedures, especially invasive ones. The higher the litigation frenzy, the higher the income of physicians. The case of the Swan – Ganz line is an illustration. There was a time when nearly half the patients having an anterior transmural myocardial infarction had these lines inserted. In my view, the procedure offered little if any useful information that could not be obtained by a far simpler, less traumatic and less costly approach, namely examining the patient.

Patients who sue doctors or hospitals consistently say at the prime reason is a perceived lack of caring. Another reason is the impression that a doctor was unavailable when needed or abandoned them. Still another common answer is that a doctor ignored the patient's concerns and failed to consider his or her perspective. It appears that litigation resulted more from miscommunication than the malpractice per se.

It requires intense determination driven by a high concentration of anger to take legal action. The long and frustrating process requires an enormous investment of time and emotional energies. Furthermore in most instances the judgment is against the plaintiff.

When the doctor-patient relationship is poor, failure of the promised outcome, a seemingly exorbitant medical bill, or a complication from a drug or procedure sets the litigation wheels in motion. This mad dynamic has the inevitability of a self-fulfilling prophecy. The patient has little compunction about litigating against an indifferent stranger.

Once an error has been committed, how should a doctor explain it to the patient? Doctors receive no instruction in medical school or thereafter on how to cope with error.

Keeping quiet and hoping the error passes unnoticed is the worst policy. Adverse outcomes must be anticipated, addressed and apologized for. Physician withdrawal behind a professional mien is interpreted as a lack of caring and fosters a patient's sense of abandonment. Acknowledging error is powerful and humbling stuff.

Shakespeare, in *Winters Tale*, wrote "Be plainer with me – let me know thy trespass by its true visage." An injured patient expects the same thing. Admitting error and offering a deeply felt apology clears the air. I am not aware of a case where apology led to litigation, and I have also known such forthrightness to bond doctor and patient in a closer relationship of trust and friendship.

When practice is time-intensive rather than technology-intensive and focused on the primacy of caring there need to be little worry about litigation.

Many errors that lead to malpractice litigation could be mitigated just by listening to the patient.

I return to my central thesis. Our healthcare system is breaking down because the medical profession has been shifting its focus away from healing, which begins with listening to the patient. The reasons for this shift include a romance with mindless technology, which is embraced in large measure as a means for maximizing income. Since it is uneconomic to spend much time with patients, diagnosis is performed by exclusion, which opens floodgates for endless tests and procedures. Malpractice suits should be viewed as mere pustules on the physiognomy of a sick health care system. They are not what ails medicine in the United States, they are the consequence. The medical care system will not be cured until the patient once again become central to the doctor's agenda.

Chapter 12.

I continue to be troubled by the ways in which doctors rationalize treatments that are not only without merit but draconian punishment to boot.

Doctors had and still have little appreciation that churning emotions derange the functioning of every organ in the body be it heart or intestine (or skin). While anatomy, physiology, and biochemistry were revered, psychiatry has been peripheralized and was merely tolerated. The adverse consequences of enforced bed rest, predominately emotional, we're misperceived and largely ignored.

Curiously, I have received invitations to lecture on every subject I have researched except chair treatment for acute heart attack. While the impact of this work was substantial and profoundly changed the treatment of coronary thrombosis, the study has rarely if ever been cited in the medical literature. Yet in the number of lives saved was a significant medical breakthrough.

An important lesson that I have learned is that many medical practices are not soundly-based. They are sustained, as is true for other human pursuits by and inertia supported by fashion, custom, and the word of authority. The security provided by a long held belief system, even when poorly founded, is a strong impediment to progress. General acceptance of a practice becomes the proof of its validity, although it lacks all other merit. Claude Bernard stated that the innovators talent is "seeing what everybody has seen, and thinking what nobody has thought." Once a new paradigm takes hold, its acceptance is extraordinarily rapid and one finds few who claim to have adhered to a discarded method. This was succinctly captured by Schopenhauer who maintained that all truth passes through three stages: first is ridiculed; second it is violently opposed; and finally it is accepted as being self – evident.

(this reminds me of a quote I first heard the medical school. All new drugs go through three stages. First it's a panacea. Next, it's a poison. Finally it's pedestrian.)

Chapter 14.

Even though the revolutionary innovation of DC defibrillation and cardioversion were first employed at the PBBH, I could not interest the administration in building a CCU. I tried to persuade the distinguished chief of medicine, Dr. George Thorn but while he endorsed the idea, he thought it unlikely that the Board of Trustees waterproof, as the Brigham was planning to build a whole new hospital in the next few years and had no money for the project in any case.

At times impetuosity is rewarded. Within a week I brought lidocaine to the bedside without turning for permission to the F food and D drug administration. Which would have delayed it's clinically used for years. I sent a memorandum to the staff instructing that all patients were to be given lidocaine coronary care unit. I tried to persuade the distinguished chief of medicine, Dr. George Thorne, but while he endorsed the idea, he thought it unlikely that the Board of Trustees would approve, as the Brigham was planning to build a whole new hospital in the next few years and had no money for this project in any case.

When the coronary care unit in the PBBH was opened in January 1965, I put an end to the circus atmosphere that prevailed in other CCUs when a cardiac arrest occurred.

As surgeons are in variably loud, boisterous and threatening, a sign was posted on the CCU door: surgeons do not enter unless consulted. The unit was designed to maximize privacy well permitting direct contact with the nursing station, that is patients could see the nurses and vice versa.

At times impetuosity is rewarded. Within the week I brought lidocaine to the bedside without turning for permission to the FDA, which would have delayed it's clinically use for years. I sent a memorandum to the staff instructing that all patients were to be given lidocaine if on arrival at the CCU they exhibited extrasystoles. From the dog experiments I extrapolated the human dose on a weight basis. Now this seems foolhardy, since there was no reason to surmise that dogs metabolized and excreted lidocaine identical to humans. Fortunately what we have seen in dogs was replicated in patients. To this day the guidelines for using lidocaine clinically remain essentially the same.

In retrospect it is evident, although I failed to appreciate it at the time, that we were on the threshold of a new age medicine, when the excitement resided in the application of novel technologies more than in caring for individual patients. For some victims of a heart attack this was an entirely new ballgame, as one patient brought home to me when he asked rhetorically, "What's the big deal about having a heart attack? It provided me a healthy rest for about a week, I wouldn't mind having another in five years."

Of course, every silver lining has its cloud. Every advance exacts a cost. Medicine grew even more depersonalized. Technology took precedence and patients became secondary. A paradox of my life and its ultimate irony is that my research work facilitated that which I utterly deplore.

Lown Ch 15

Despite the many scientific advances the elixir of youth remains an unrealizable dream. I hasten to acknowledge that despite substantial progress, the toll of sudden death continues largely undiminished. In a significant measure this is due to a scarcity of social resources for solving the sudden-death problem when our national security appeared in jeopardy, we mobilized unprecedented intellectual talent and allocated unlimited fiscal resources for a Manhattan project. In the past decade as many as 4 million Americans have died from a preventable electrical accident of the heart, but no such undertaking is in sight. While AIDS research garners a deserved \$200,000 per victim annually, during the last decade the US government has allocated approximately \$25 per victim for sudden cardiac death Research. The reason for this disparate investment is that sudden-death has no constituency with political clout, except perhaps in the hereafter.

I am convinced of the indispensability of scientific medicine and advanced technology to effect doctoring. From the vantage point of a clinical researcher, I have come to realize that caring without science is well-intentioned kindness, but not medicine. On the other hand, science without caring empties medicine of healing and negates the great potential of an ancient profession. The two complement and are essential to the art of doctoring.

Ch 16

"Life protracted is protracted well," bemoaned Samuel Johnson. In Johnson's time the medical profession could do little to assuage the discomfort of aging to enhance the quality of life, and today, despite the many scientific advances, the elixir of youth remains in on realizable dream.

Shylock's plea in the merchants of Venice with a few minor changes is quite contemporary: "I am old. Has not an old person eyes? Princes get rest" (when dealing with the elderly it is important to recognize that foremost, that does not come in one swoop; instead, it involves a slow separation from oneself in the diminishing ability of the five senses to reach out and connect with the outside world. I constantly encounter what Ronald Blyth Hartcourt called "the stunning contradiction between the lively mind in the senescent buddy in which it is and trapped. We grow unrecognizable to ourselves and embarrassed by our appearance. Our very presence seems to demand an apology."

Caring for the aged requires less reliance on drugs and more of a focus on rearranging the furniture of life. Holding out hope that life will continue functions to encourage is a patient to persevere. Setting objectives, searching for anniversaries, graduations, all help the patient maintain a hold on life. The doctor probes for such events even as a coral diver plummets to great depths searching for a pearl.

The doctor when motivated by goodness and love for patients, cannot lie but does not always have to tell the whole truth.

Many of my older patients are overwhelmed with loneliness. By the time they reach the mid-80s most of their contemporaries are gone. Some patients imprison themselves in their own homes, but being alone speeds aging and further enfeebls. Absence of socialization dulls faculties, impairs speech, and shrouds waking hours with morbid **caprice**? apprehensions. The elderly do not fear death as much as the long act of dying, the bumpy road to final dissolution.

I am persuaded that loneliness incubates hypochondriasis. Furthermore, our culture medicalize age as through growing old were a disease. The conversation among the elderly is consistently focused on disease and spiced with anecdotes of the woe befallen those who have ignored early signs for trivial symptoms.

Many elderly people are willingly entrapped in the burgeoning medical- industrial complex. Visits to doctors, like shopping, combat loneliness. For people who have nowhere else to go and are tired of looking at the same four walls. Connecting with the health industry is a way of socializing. Shuttling from specialist to specialist fills up time in addition to providing the gratification of having someone listen attentively to one's problems.

Although I encounter elderly patients who continue to be charged with life, they are the exception. The buffeting of life has left the majority **involted** in spirit and morbid in outlook, the future trajectory is only downward.

On sex.

Society takes a dim view of sex among the elderly as ridiculous, laughable, unclean, even perverse.

The physician is witness to a wide panorama of the human condition. Sexuality in the aging is invariably tintured with sadness.

On humor.

In our youth-fixated culture old age is regarded as the dreary dénouement to life. The elderly if not to be ignored are to be humored and trivialized. They have little to teach that is relevant to our recent times. I have learned the contrary people. People who have reached right old age with intact faculties are commonly a source of great insight and instruction.

A patient conveyed the sense of an old Jewish proverb, "A man should go on living, if only to satisfy his curiosity." Parenthetically, there is a fine book of Jewish proverbs. It is by Hanan Ayalti.

On healing.

The aged patient brings an abundance of historic baggage. In a brief visit, only the essential contours and binding elements can be grasped, and even this takes more time than is generally available. The first visit is critical and I therefore spend an hour or more with the patient, until I can perceive the human being behind the medical complaints. Even then my imagination has to churn disparate facts to make a coherent story. It is much guesswork.

On the aging doctor.

Now that I have passed the milestone of my 70 birthday, the subject of the elderly physician fills me with trepidation. In the words of the Czech writer Milan Kundera, "there is a certain part of all of us that lives outside of time. Perhaps we become aware of our age only at exceptional moments, and most of the time we are ageless.

Still, other times, I am convinced that I'm just reaching the apogee of my medical skills. Despite all the shortcomings, my doctoring has improved and I am a lot more helpful to my patients. My judgment is sounder, I have greater clarity in anticipating the patient's outcome, a honed sensitivity to unspoken problems, and more empathic faculty. The older I get the less I rush to judgment. The less I rush, the older my patients get.

I am persuaded that as we age we may fail in knowledge but gain in wisdom.

Reaching a diagnostic conclusion is a process of sifting through extensive experience. The brain forms and algorithm and searches for like cases in the **emerging gestalt is increasingly relied upon.**

It takes a doctor nearly a lifetime to clear from his or her system the tendency, ingrained during medical education, to focus on remote and rare oddities; to think of zebras when hearing beats; to cease being on an ego trip; to stop dreading being wrong.

With age you learn to sort out and understand that the common is what we most commonly encounter. The majority of human afflictions are self-limited; they are aggravated by the patients' imagining the **worst and I consistently ameliorated or cured find unstinting and unequivocating reassurance from the physician. As I grow older, I listen differently, I hear more of the unspeaking spoken text. Facts and data slip by so rapidly, I begin to wonder, "Why invest time to inquire these gossamers?"**

So what is medical wisdom all about? It is the capacity to comprehend a clinical problem exists **morning**, not in an organ, but any human being. The doctor, as healer, searches for this skill above all others, all of his or her professional life.

Ch 17

Death and dying

While the public expects them to address the question of death sagely, doctors are no more profound or insightful about this subject than anyone else. Experience with death does not lend wisdom to physicians any more than to undertakers. To explore life's meaning with death's mysteries we can learn more from poets, philosophers, theologians.

Re: death in America. A Frenchwoman told me, "Americans are the only people who think that death is an option." In my mind the paramount factor is hospitalization of the dying with the pervasive idea that death is somehow indecent and to be avoided at all cost. This is a precept to which physicians contribute mightily. Medical school and hospital training prepared doctors to become journeyman in science and managers of complex biotechnologies. Little of the art of doctoring is imparted and doctors are taught little about dealing with the dying patient. From the beginning, a young doctor is conditioned to view death as the mark of failure, the ultimate sacrilege in the temple of science. The paradigm that all problems are solvable is doomed to fail in the face of nature's immutable law of death.

Patients and doctors believe that the biotechnical revolution enables one to prolong the act of dying interminably. This near-godly potential is a source of hubris for the doctor and inspires patients with unreal and and realizable expectations.

The physician deals with cold facts in making therapeutic decisions, rarely considering what genuinely matters to the individual patient. From my own observation, doctors have a penchant to emphasize the successes and down play the possible aggravation that may make one's remaining days a veritable living hell. With emphasis on a possible cure, the patient grasps at the slimmest statistic. Generally what is offered is not a cure but a brief remission, at times so short as to be meaningless. (This reminds me of Ivan Illich's Medical Nemesis).

In my experience, oncologists are the worst practitioners of intervention at whatever the human cost. They have never refused to treat any of my patients. When death is the inevitable result of a chronic and incurable disease, it is often kinder not to impede it with heroic measures but to manage its approach with common sense and compassion.

To sustain life against its will is both in enormously costly and extraordinarily profitable. A substantial percentage of the hospital's revenues derives from prolonging the act of dying. Ironically, death constitutes the most lucrative part of the healthcare business and end of life expenditures are disproportionately large for example, approximately one third of Medicare disbursements each year are for the 6% of beneficiaries who die in that year. The healthcare

system is structured to torment the elderly, not because of intrinsic malevolence but because it is a program based on reimbursement rather than what is best for the individual patient.

The pornography of death derives largely from an amalgam of five factors: a technology that makes it possible to prolong life almost indefinitely, a medical profession that has declared war against death, a hospital that has vested interests in extending the usually futile battle, a patient who is ignorant of his or her rights and conditioned to suffer, and a public that has been led to expect only victory for the medical profession.

For those who subscribe to conspiracy theories, there appears to be one huge conspiracy in American society in favor of slow dying. The bottom line is that scientific medicine has lengthened and improved life, but by the same token, worsened death.

In patients who died of illness, the underlying disease shapes the course of dying.

What I have learned during my years of caring for dying patients is that the quality of one's life helps to determine the course of final passage. What is most important are close and affectionate relations with other people, particularly family members. To have a storehouse of fond memories and family present in the final hours eases the trials and tribulations of dying. Those who have given the most to others generally have the easiest time in dying. As the Talmud has taught, "A person possesses what he gives away."

Modern medicine shapes the contemporary mode of dying in which doctors make each patient another battleground in their unceasing struggle against death.

I believe that the image of the physician has been tarnished by the way doctors approach the act of dying. A vast apparatus is deployed to service death instead of life. Biotechnology defines the rules of the road, with the possible determining the necessary and the doctor follows these absurd rules rather than focusing on the well-being of the patient. The madness of the system is illustrated by my mother's death. (this is reminiscent of what Illich writes about in *Medical Nemesis*).

The Roman philosopher Lucius Seneca commented, "Death is sometimes a punishment, often a gift, and to many a favor." My mother in her final year began to welcome death as a favor. (the story of his mother's death on pages 278 and following is very poignant.)

Even though Lown was a world-famous cardiologist his "carefully laid plans for allowing his mother a humane ending to a well lived life were short-circuited by a sick robotized system that wages mindless battles against death. My mother was beyond pain, her death was peaceful and dignified. While she was spared suffering, the indignity was inflicted in the living room. The memory of her death invokes pain and tears but I weep more for what is happening to my profession.

What follows is the story of his relationship with a 74-year-old retired businessman in hospital for his sixth heart attack.

We chatted about trivia and reminisced about our long relationship. I felt a stab of remorse and guilt as he commented, "There are advantages to dying. I get to spend a good deal of time with my doctor." He fell asleep and passed away peacefully on the following hour.

Immediately thereafter I have assembled the entire medical staff and asked why no one else had come to provide comfort for this dying man. "Had we decided to balloon pump him or called the shock team or considered him a candidate for bypass, you would have been hopping around the bed." 10 people, young doctors and nurses clearly pained, stood with heads bowed.

I kept intoning, like a priest in a hushed church, that life is robbed of meaning when human beings avoid confronting the inexorable certainty of death. For those of us in the healing profession, our failure to accept death as life's ultimate destination made a mockery of our vaunted humanitarian commitment. We continually assaulted patients who should have been allowed to die peaceably because we saw death as a professional failure. We put technology between us and our patients, to spare us the grief of failing, to confront our own mortality.

He goes on to describe a dignified death at the end of a fulfilled life. Norman Cousins wrote, "what I have learned is that the tragedy of life is not death but what dies inside us while we live."

His role as Mr. Y.'s doctor was to diminish symptoms, not improve cardiac function to the limits that science and technology permitted, but constantly to devise ways to enhance his comfort, and impart optimism to his caregivers. I look back with pride at having been able to exercise both the art and science. A doctor has the power to make a dignified death possible for many patients.

Reflecting on a life of dealing with death and dying, I am persuaded that death's anguish is, in no small measure, man-made. It is a product of western culture, which denies death its due and foolishly allocates mammoth resources to prolong the tormenting act of dying. This is a contemporary phenomenon. It is difficult to foresee any change in hospital structure or in physician thinking that will humanize institutional death. The economics of dying are too great, and doctors too deeply fixated on improving their power over death for the system to yield readily to what is socially appropriate. Furthermore, the romance of saving a life, even when it is an exercise in futility, will not be easily abandoned by youthful house staff who are the ultimate guardians of the hospitalized patients.

Any melioration of the problem has to face up to the fact that the contemporary hospital functions most efficiently when patients are infantilized and disempowered. There can be no dignity to death when the patient lacks control over the vital decisions concerning how to die. Death with dignity is meaningless when life has been robbed of it. To change our cultural

approach will require the deinstitutionalization of dying, a prerequisite being that hospitals no longer serve as a place to die.

Studies of hospice deaths contravene the notion that dying has to be an ugly and miserable end of life. Dr. Loring Conant, medical director of the Hospices of Cambridge, has estimated that "well over 60% of people in hospices have good deaths with their symptoms addressed appropriately, allowing for patients and significant others, friends or family, to achieve closure that may not have been fully identified up to that time." According to Conant, the good death has three elements. The first is the palliation of symptoms and alleviation of suffering, which have become increasingly possible by growing scientific understanding of pain and the introduction of new and powerful analgesic drugs as well as by innovative drug delivery systems. The second involves helping the family to come to terms with the death of a loved one. Finally there must be an effort to discuss vexing matters and bring to the surface concealed problems, perhaps never hitherto addressed. Even if such conversations remain uncompleted, the mere beginning is therapeutic. Lessening the burden of such unresolved issues frequently enables control of intractable pain.

12 days before his death, the brilliant physician—essayist Lewis Thomas was interviewed by New York Times correspondent Roger Rosenblatt. Thomas said, "When death was regarded as a metaphysical event, it commanded a kind of respect. Today when the process is long protracted it seems as evidence of failure. A dying patient is a kind of freak. It is the most unacceptable of all abnormalities, an offense against nature itself....In a sense quite new to our culture, we have become ashamed of death, and we try to hide ourselves away from it. It is, in our way of thinking, a failure...There is really no such thing as the agony of dying. I'm quite sure that pain is shut off at the moment of death...Something happens when the body is about to go. Peptide hormones are released by cells in the hypothalamus and pituitary glands. Endorphins attach themselves to the cells responsible for feeling pain...On the whole...I believe in the kindness of nature at the time of death.

Chapter 18

Despite more than 45 years and medicine, I feel like a student struggling through a tough curriculum at a demanding university. My teachers are not august scholars but the patients I encountered daily. Many instruct me about the manifestation or progress of a disease. Some provide understanding of the ups and downs of fickle fortune or the bad hand dealt by an indifferent fate. A number inform me about the ineluctable tragedies that effect nearly everyone's life. A small group of patients, like closely passing comets, have permanently altered the trajectory of my life, the powerful gravitational field of their personalities displacing my own traverse into a new orbit.

My most endearing memories are of illnesses that posed impossible challenges, the resulting intense human interactions and the enduring friendships wrought thereby. Such experiences have stretched me to the outermost limits and taught me that knowledge of the human condition is not to be derived from books but from intimate engagement with other human beings. No

book knowledge equals what one may glean from patients who have permitted a doctor to look deeply into their eyes.

Chapter 19 The Art of Being a Patient

Getting Doctors to Listen

At present, scientific medicine, even in a narrower sense, lacks precise solutions to the most chronic ailments such as arthritis, heart disease, neurodegenerative disorders, most cancers, etc. In the absence of a cure, these diseases require management, usually over a lifetime. The only available medical approach is to assuage symptoms, to slow, and where possible, halt a downward course, to help the patient maintain a positive outlook, and to prevent the disease from taking charge of his or her life. (In other words, *to cure sometimes, to relieve often, to comfort always.*)

Unreal expectations heighten dissatisfaction for many who find that their conditions are not diagnosable, yet, in my experience, the vast majority of symptoms lack exact explanations. The medical community has partially resolved this problem by devising a host of meaningless diagnostic labels that mask ignorance rather than illuminate an underlying cause.

In the doctors Doctor's Dilemma, George Bernard Shaw generalized that "All professions are conspiracies against the laity."

We turn to medicine to repair what essentially are tears in the social fabric wrought by violence, economic oppression, class ostracism, racism, sexism, and a host of other factors. Most doctors do not have the time, patience, training, or incentives to become involved in these societal quagmires and their inattention leads patients to shop around for a quick fix. Unless they encounter an empathic physician who helps assuage symptoms, focuses on the potential source of the problem, and teaches them how to endure life's constraints, these troubled people increasingly turn to alternative medicine, with many falling prey to charlatans.

The chronically ill patient should question the doctor, not with the intent of mastering the rudiments of physiology or biochemistry of an illness but to gain clarity in coping with a chronic problem that requires highly personalized answers. The doctor should be able to answer the following six questions:

1. Are the symptoms from a precisely understood medical entity for which a definitive cure exists?
2. If the disease is not curable, can symptoms nonetheless be relieved?
3. If a disease is life-threatening, what is the approximate life expectancy?
4. If not life-threatening, is the disease likely to plateau or progress? If so, over what time frame?
5. Are there attendant complications and how are these to be mitigated, or better still, prevented? If that is a possibility, at what compromise in living?

6. Will change in one's lifestyle make a substantial difference in outcome in relation to well-being and survival?

The doctor may not be able to provide exact answers, but even approximations are valuable.

If a patient is ready to be helped, even a little, and grateful for the marginal, it enhances the doctor's commitment to fostering a relationship between equals. Only such a relationship, bonded by understanding and respect, can deepen into a true healing partnership. This encourages, in the words of Lewis Thomas, "the capacity for affection," the essential element for healing.

Defining individual medical and human problems requires time, but in a counterproductive effort to contain costs, the doctor is pressured to minimize the time invested with each patient. Giving precedence to profits sacrifices both physician autonomy and the patient's right to know to and to exercise available therapeutic options. It also makes for more expensive healthcare in the long run. In this environment, doctors increasingly become technicians leashed to assembly lines, the aim of which is to maximize patient throughput.

For a patient, to get the most out of the medical system, she should always be accompanied by a significant other or family member, preferably a spouse or an adult child. The other person helps the patient remember what has been discussed, concluded, and prescribed. The presence of a family member or friend gives the patient more courage to question the doctor about the rationale for procedures, tests and the like in this respect a few fundamental questions are always in order.

1. Is the test or procedure necessary to confirm or disprove the diagnosis the doctor has already reached? Or is it merely a preliminary reconnoitering that will require many more such tests?
2. Whatever the findings of the testing, will they alter the way a disease is managed?
3. Finally, how expensive are the tests and will they be reimbursed by insurance?

In today's technology driven healthcare system, a patient cannot passively accept a doctor's decisions. A full partnership is the objective but with rights, responsibilities for both the patient as well as the doctor.

Choosing a Doctor

A few small clues can help to decide whether a doctor is one with whom a patient can be comfortable, can grow to respect, and in time learn to trust on matters of life and death.

1. When meeting a doctor, does he or she shake hands? This gesture is a small first sign that the doctor wants to reach out to the patient.
2. Punctuality should be a serious determinant of a physician's human qualities for it fundamentally signals respect for another person. Respect for patients' time is a significant indicator of the qualities required for a partnership and healing. True emergencies are rarely the cause for a doctor's habitual lateness.

3. One also has to look askance at a doctor who allows an interview to be interrupted by telephone calls. I have forbidden my secretary to interrupt me except for a dire emergency.
4. A doctor's disposition and demeanor, to my mind, should be a decisively important factor in selecting a physician. The doctor should radiate affirmation and optimism.
5. Another important factor is whether the doctor is ready and able to listen.

(Personally, I find these suggestions a bit simplistic and naïve. They probably work well for a doctor like Dr. Lown who sees the very rich and gives them the time they expect and are paying for. In a busy office that takes walk-in and emergency patients and accepts the poor and poorly-insured, running on time is not always possible. In addition, if another doctor calls with a patient-related question, it is often preferable to take that doctor's call rather than call him or her back when it's convenient for you to do so. Of course, if one is discussing sensitive material with the patient a call should not be taken. DJE)

In the final analysis, one searches for a physician with whom one feels comfortable in describing complaints, without worrying about being subjected, as a result, to numerous procedures; a doctor for whom the patient is never a statistic; a doctor who does not recommend measures that compromise life in order to prolong life; someone who neither exaggerates the hazards of minor illness nor is overwhelmed by major ones; and above all else, a fellow human being whose concern for patients is actuated by the joy of serving, regarding it as an incomparable privilege.

(The last part of this chapter is a bit facile and naïve. Still, it is a good guide for patients and trainees. One needs to keep in mind that Dr. Lown was a doctor for the privileged and the rich. He had the luxury of spending open-ended time with his patients and most likely had assistants and junior doctors to pick up his slack. This is not the reality for a doctor in the trenches. Nonetheless, most of the recommendations are right-on. DJE)