

201st Annual Oration

Socrates, Einstein &
The Worcester District
Medical Society

DELIVERED TO MEMBERS & DISTINGUISHED
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By H. Brownell Wheeler, M.D.

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The topic of death and dying has concerned the Worcester District Medical Society for many years. The skull and crossbones – traditional symbols of death—were the center of our official seal from 1820 to 1991—171 years! This 201st Annual Oration will deal with issues surrounding the care of dying patients.

Mainly I would like to tell you some true stories of patients who have taught me something about death and dying. But first, I would like to remind you of a famous story from antiquity.

In 399 B.C., a 70-year-old man was put on trial for his life. The charge was that he did not believe in the gods and that his ideas were corrupting the youth of the city. The city was Athens, and the man was Socrates.

Socrates argued that he had not corrupted the youth, but that Athens itself was corrupt. He angered his jurors, and he was sentenced to die by drinking poison hemlock. His final words to the jury were recorded by Plato, in part, he said: "... death is one of two things. Either it is a dreamless sleep from which the sleeper does not wake, in which case it is a permanent relief from the troubles of the world. Or else, as some say, there is a relocation of the consciousness to another realm, and perhaps the chance to question those who have died before, in which case what greater blessing can there be? It is time to depart. For me, to die. For you, to live. But which of us is going to a better state is known only to God."

His friends were with him when he drank the poison. This scene was visualized by the famous French painter Jean Louis David in a famous painting that hangs in the Metropolitan Museum in New York. In the painting, Socrates is not nearly as downcast as his followers. He seems almost defiant, as he reaches for the cup of poison, and he points upward as though to heaven. As the end drew near, Socrates turned to his closest follower, Crito, and said, "I owe a cock to Asclepius... Will you pay the debt?" "The debt shall be paid..." said Crito.

Socrates then pulled the sheet up over his face. A few moments later there was a slight movement of his body. Crito pulled back the sheet. Socrates' eyes were staring blankly. Crito closed his eyelids.

The moment of death holds a morbid fascination for most of us. Last words seem very important. And when the dying person is perhaps the wisest man in history, his last words seem particularly important. But what do those strange last words of Socrates really mean? "I owe a cock to Aesclepius... Will you pay the debt?"

In order to understand, one needs to know the customs of ancient Athens. In closing, I will share with you what scholars have concluded Socrates saw as the true meaning of his own death. But first, I would like to tell you how I became interested in this whole topic of end-of-life care.

Last February, I stepped down as Chief of Surgery at the University of Massachusetts Medical Center. At 66, it seemed the right thing to do. Without so many committee meetings to go to, or so much paperwork to do, I wanted to create some new professional challenges for myself that wouldn't compete in any way with the new Chief, or with my surgical colleagues. Some aspects of my new role relate to research and teaching and administration of research funds from private industry, but I also wanted to do something related to patient care.

It occurred to me that the greatest suffering I have seen as a surgeon has been in patients for whom surgery has nothing to offer. When in fact all our science and all our technology had nothing to offer. And particularly when the patient was dying.

On many, many occasions I have seen Surgical ICU patients totally de-humanized, barely recognizable as people. Usually comatose. Almost always on respirators. Faces often bloated and eyes shut from over-aggressive fluid resuscitation. Arms swollen and bruised from an endless succession of IV's and venepunctures. Almost always with nasogastric tubes, and frequently lots of other tubes as well.

I have seen sad-faced family members standing around, barely able to recognize their loved ones and totally unable to communicate with them. I have often thought to myself: "No one should die like this! Something went wrong. Somehow we ought to have achieved a kinder, more humane outcome for this patient and this family."

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And so I decided last April to seek realistic methods to improve the care of dying patients. It was not a project which anyone else at UMass was competing to take on. However, I quickly realized that more appropriate care for dying patients was a very hot public topic. The daily papers have been full of articles on the subject the last few months. (The Boston Globe even editorialized about the need to provide better care for the dying.) The hottest single topic has been physician-assisted suicide. A physician-assisted suicide bill is currently on file in the Massachusetts legislature. A law against physician-assisted suicide in the State of Washington was found unconstitutional by the Ninth U.S. Circuit Court of Appeals, thereby invalidating 32 other state laws as well. There was a counterpart case with a similar ruling in the Sixth U.S. Circuit Court of Appeals. The Supreme Court has been compelled to review the issue. Feature articles about the case appeared in the *New York Times*, *The Boston Globe* and the *Telegram & Gazette*.

The AMA was urged to support physician-assisted suicide, but instead came down in favor of improving the care of dying patients as a way to eliminate the need. The Worcester Telegram recently reported the story of one local patient with a truly tragic degree of disability who obtained legal permission not to be fed and so to starve himself to death. His case was somewhat reminiscent of the death of Nancy Beth Cruzan, a now-famous victim of a tragic automobile accident which left her in a persistent vegetative state at the age of 25. Her family fought a long legal battle to stop her life support. Nevertheless, she was kept alive for nearly eight years while her case went all the way to the Supreme Court. Finally, Nancy Beth Cruzan was allowed to die. The family felt that she had really died at the time of the original injury but that she had not been allowed to rest in peace by our laws and by our healthcare system. They were grateful for her death.

Books that deal with death and dying are best sellers. *Embraced by the Light*, a sensationalized account of a near-death experience has been on the *New York Times*' best seller list for well over two years. A more esoteric volume, *The Tibetan Book of Living and Dying*, by Sogyal Rinpoche, was also a *New York Times*' best seller. It maintains that only by confronting and conquering the fear of death can we learn how to live more fully. Shep Nuland, a surgeon and medical historian at Yale whom some of you know, has written a book entitled *How We Die*. It graphically describes the most common ways of dying. It has received a great deal of publicity, has sold well, and even won The National Book Award for Non-Fiction. Many of us know Bernie Lown, a well-known cardiologist in Boston and co-founder of IPPNW, on behalf of which he accepted the Nobel Peace Prize a few years ago. Bernie's new book, *The Lost Art of Healing*, talks a lot about death. In it, he describes most hospital deaths quite bluntly as "...the perpetration of a technologic obscenity."

How many of us here tonight have been inadvertently guilty of the "perpetration of a technologic obscenity"? I have...many times. It is so easy to get rapped! We think we are offering patients their only chance to live, but we overlook the high human cost of the predictable failure. Most doctors make this mistake from time to time. Sometimes they are pushed by desperate patients or families or by fears of medicolegal liability.

Our medical journals are full of the same topic. Even my latest Harvard Medical Alumni Bulletin is devoted to end-of-life care. Since most of this presentation will be patient stories, I will cite only one article from the medical literature. One year ago, the *JAMA* reported the outcome of a four-year, \$28 million study by the Robert Wood Johnson Foundation to study care of critically ill and dying patients. These patients were so ill that they had only a 50 percent chance of surviving. The objective of the study was to improve decision making and achieve a better outcome for these seriously ill and dying patients. The guiding principle was that decision making for patients with life-threatening illness should be shaped by informed patient preferences and likely outcomes of care. None of us would quibble with that principle, but the fact is that it usually isn't followed.

"SUPPORT" is an acronym, standing for the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. The study was carried out at five major medical centers, including Boston's Beth Israel, Duke and UCLA---Some of the finest hospitals in the country. During the first two years, over 4,000 patients were studied and the outcome of their care was documented. Accurate methods were developed for predicting mortality and shortcomings of care were identified. After an attempt was made to improve the shortcomings of care, a second study was carried out to see if in fact there had been any improvement.

In Phase 1, 70 percent of the time there was no discussion between patients, families and doctors about the patient's preferences for CPR or life support. Furthermore, even when patients had a clear preference of not wanting to undergo CPR or advanced life support, most of the time the physician did not know it. Unfortunately, the study also showed that even when physicians did know the patient's preference, often it was not followed. Many patients had prolonged suffering in an Intensive Care Unit. Furthermore, half of the patients experienced moderate to severe pain at least half of the time within their last few days. Most of the patients wanted to die at home. However, all of these patients died in the hospital, despite their wishes.

Apart from the human cost, there was an enormous financial cost. Almost all patients had some form of health insurance. Nevertheless, nearly one-third of families used up all or most of the family's savings in paying the bills incurred by these dying patients. Considering these dismal results, the physicians identified two problems. The first was that they often were not sure that patients were going to die and so they prolonged aggressive treatment. So the Johnson Foundation developed the most accurate prognostic models known and provided this information to the physicians. Many times the probability of survival was less than one percent.

The other problem was that physicians said they simply did not have enough time to communicate adequately, particularly with family members. So the Johnson Foundation paid specially trained nurses to carry out this function and to make contacts between physicians

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and patients and families. Despite the intervention, Phase 2 showed no improvement over Phase 1. The final conclusions were as follows: Too often patients die alone in pain attached to machines. Our healthcare system doesn't know when or how to stop. This study gave doctors the tools that experts said would work but they didn't. Our society has a vision of living well. We need a vision of what it means to live well while dying.

Let's make this personal. If the SUPPORT study is typical, and if nothing is done to improve the problem, you or the person sitting on your right will die in severe pain, which could be relieved, but won't be. You will probably die in a hospital ICU on life support, but you would probably much rather die at home. Unless you have a healthcare proxy and have made your wishes plain to your relatives and your physicians, you will probably die only after a futile and highly undignified full resuscitation attempt which Bernie Lown might well describe as "... the perpetration of a technologic obscenity"...with you as the totally helpless, totally undignified star of the show! Shouldn't we all be interested in improving this outlook? For our patients, as well as ourselves?

There has been a lot of publicity as to how to achieve a so-called "good death." This is the front page of a special supplement of the *Boston Sunday Globe* last summer, pointing out the great benefits of hospice care. Many studies have shown that hospice care is highly beneficial, but that it is also grossly underutilized. Patients are often referred much too late to benefit. The recent death of Cardinal Bernardin has been considered as the model for a "good death," based on a realistic acceptance of the medical situation, religious faith and supportive care.

Major medical organizations have become alarmed about poor care of the dying. Especially in view of what is now thought to be fairly common, but still covert physician-and nurse-assisted suicide or even euthanasia, as recently implied in a survey of ICU nurses published in *The New England Journal of Medicine*. The AMA believes this is a reflection of grossly inadequate patient care and has formed a Coalition to Improve End of Life Care. The American Board of Internal Medicine has recently specified core competencies in palliative care which they believe all doctors should have in order to be board-certified. Other medical organizations have drafted position papers on withdrawal of life support and on the appropriateness of feeding and other types of life support in patients with incurable illness. The Institute of Medicine has identified end-of-life care as a pressing national problem and commissioned a major study.

Twenty major medical foundations have indicated they will fund projects to improve end-of-life care. The Robert Wood Johnson Foundation spent \$28 million on a single study. And an entirely new organization has been set up solely to fund projects related to improving management of dying patients. It is called the Project on Death in America, and it has been funded by a billionaire speculator named George Soros.

Why did this man give millions of dollars to create the Project on Death in America? It is an interesting story, and I'd like to share it with you. Much of my information comes from a speech George Soros gave himself at Columbia Presbyterian Medical Center and the rest from a long Article in *The New Yorker* about a year ago.

Soros was a young Jewish teenager in Budapest during World War II. His father forged false identity papers and hid the family. Soros saw other Jews lined up on the banks of the Danube and gunned down so that their bodies would fall into the river and be swept down stream. He could not comprehend how civilized people could commit such atrocities. Later, when the Germans were driven out by the Russians, the behavior of the Communist Army was almost as brutal as the Nazis'.

But Soros came to realize that neither the Nazis nor the Communists thought that their treatment of others was morally wrong. They had a totally different set of moral assumptions.

To Soros, their assumptions were terribly wrong, and they led to terrible consequences. He began to see history as simply the inevitable consequence of the underlying assumptions held by different societies. These assumptions were often wrong, even though they were strongly held, and wrong assumptions led to war and oppression.

After World War II, the Soros family fled to England. Soros graduated from the London School of Economics and went to work on Wall Street. He began to wonder if financial markets are also based on underlying assumptions, and if some of those assumptions might also be wrong, no matter how strongly held. He felt that if he were clever enough to figure out which underlying assumptions were wrong, he could hedge his investments in such a way as to capitalize on the erroneous assumptions of others. He was spectacularly successful. Wealthy investors flocked to him. He created huge so-called "hedge funds." In time he became a multi-billionaire.

Soros' father developed a progressive and ultimately fatal illness. I think it was cancer, but Soros doesn't say. He underwent surgery and had what was thought to be the best of medical care. But his suffering was intense, and so was that of his family. When he died, there had never been any discussion between him and his family about the fact that he was dying. There had been no reconciliation of the family's emotional baggage. There had been no gratitude expressed for his saving their lives during World War II.

The Soros family became bitter about the circumstances of their father's death. The wife said that she was never going to go through anything similar. She joined the Hemlock Society and laid in a stock of barbiturates so that she could commit suicide whenever she wished.

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Soros was deeply troubled. He started reading books about death and dying, including this and other books by Elizabeth-Ross which indicated that the dying process can become a time of acceptance, a time of personal growth and a time of family healing, despite the fact that it is also a time of loss. He concluded that the suffering he and his father and their family had all endured was due in large part to wrong assumptions held by the medical profession about how to care for dying patients.

Soros wondered why he had been so unwilling to think or talk about his father's impending death. He decided that it was because of his own assumption that death was the end of everything, the absolute and irrevocable annihilation of consciousness. And yet he had learned from his reading that there are many other assumptions about death, and that in fact most people throughout history have assumed that one's consciousness does survive death.

Like Socrates, Soros concluded that there was no way to prove or disprove assumptions about death. But somewhat to his own surprise, he found comfort simply from the thought that annihilation of one's consciousness at death is only an assumption. And that the assumption may be wrong, just like many other wrong assumptions that he had seen held strongly in the worlds of finance or politics.

About this time his mother became seriously ill. Remembering the Hemlock Society, he worried that she might commit suicide. So he said, "Mother, I know you have pills hidden somewhere in the house, and I suspect that you may want to use them. I respect your right to make that decision. But please let us know first so that we can at least say goodbye."

His mother replied that she was not considering suicide, that in fact she was having unusually rich and meaningful experiences with her family despite, and perhaps even because of her illness. However, she said it was a comfort to know that the pills were there if she needed them.

She talked openly about her impending death. Family wounds were healed. The family became much closer. Each day seemed precious. But she continued to deteriorate.

Not long after that, Soros was sitting by his mother's bedside, holding her hand, when she suddenly had a vision that she was walking up to the gates of heaven. She even let loose of his hand, saying that she did not want to take him with her. Soon after, she lapsed into a coma and later she died.

The mother's death was a cathartic, even uplifting experience for the Soros family, though the father's death had left them angry and depressed. In thinking about what made the difference, Soros concluded, "...We have created a medical culture that is so intent on curing disease and prolonging life that it fails to provide support in that inevitable phase of life—death. Advances in high technology interventions have contributed to this weakness in our medical system, deluding doctors and patients alike into believing that the inevitable can be delayed almost indefinitely...By focusing exclusively on conquering disease and prolonging life, doctors abandon the dying..."

And so Soros founded the Project on Death in America in order to improve the management of dying patients.

George Soros learned to take a critical look at underlying assumptions. His story made me take another look at my own assumptions about the role of a physician in the care of patients with life-threatening illness. I started my career with the strong assumption that the paramount role of a surgeon such as myself was to save the life of the patient – at almost any cost. When surgery could not save the patient, and when all the tools of science and technology were useless, I assumed that the patient was no longer my responsibility. I also assumed that I had nothing much to offer the patient apart from my scientific knowledge and my surgical skill. Now I believe that these assumptions were wrong, or at best only half-truths.

Take the assumption of preserving life at almost any cost. Let me illustrate with a case history. A few years ago, one of our vascular residents said to me, "I learned more from one of your patients than from any other patient all year, but you will never guess which patient it was."

He then reminded me of a patient that I had all but forgotten, a 75-year-old man who arrived in the ER late one night with a ruptured abdominal aneurysm. We had been called in advance and the patient was in shock, so we had called in an OR team and an anesthesiologist who were ready and waiting in the OR.

The patient was accompanied in the ambulance by his physician and a nurse. The nurse was the patient's daughter, and the physician was a longtime family friend.

I asked my resident to take the patient straight to the OR, while I got a quick medical history from the physician. It went something like this:

"Is he otherwise in good health?"

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“Not really. He’s on dialysis three times a week, and that made him refuse an elective operation for the aneurysm six months ago.”

“Why is he on dialysis?”

“He has multiple myeloma and his kidneys are gone.”

“What’s the prognosis on the myeloma?”

“The oncologist says about three to six months.”

“What’s his quality of life?”

“Not great. He hates dialysis and he has bone pain from the myeloma. He doesn’t eat well and he’s losing weight. He also requires blood transfusions for anemia from time to time.”

I could hardly believe this litany of medical problems! Hearing it, I became less and less interested in surgical heroics, despite the fact that we had called in the OR team and were all set to go.

So I said, “Let’s think through what may happen if we operate. First of all, he may not make it through the surgery. If he does survive, he will certainly be in for an extremely rocky course in the ICU. He will undoubtedly be on the ventilator for a long time, not to mention dialysis. He is a prime candidate for sepsis and multi-organ failure. He will most likely never make it out of the ICU, but he may have a long drawn out course which will be quite distressing to him and his family. If by some miracle he survives the postop period, he will die of his cancer in a few months anyway. Do you think that if he understood all this, he would want us to operate?”

“What’s the alternative?”

“If we don’t operate, he will probably die quietly sometime within the next few hours. But he will never go through a long drawn-out ICU stay or a progressive downhill course from his cancer.”

By this time the patient’s wife had arrived and was listening intently. The daughter turned to the mother and said, “What do you think Dad would want?”

“You know what he would want.”

“He wouldn’t want the surgery.”

“Yes.”

I said, “Let’s see if we can talk to him.” And I went up to the OR. The patient could barely open his eyes, but he still seemed to understand what I was saying. I tried to explain the situation honestly but kindly. I also volunteered that if I were in his place. I might take my chances without the operation. When I asked if he wanted the surgery, he faintly, but very definitely, shook his head “no.”

So we transferred him from the OR suite to a quiet private room with the lights dimmed. By this time he had a transfusion dripping. I slowed down its rate, but I left it dripping. I left the wife and daughter alone with the patient and went home to bed. My resident stayed the night. He told me later that about 4 a.m. the patient opened his eyes and seemed more alert. There was some brief, but meaningful communication with the wife and daughter. Then the patient closed his eyes. The wife and daughter sat on each side of his bed, holding his hands, until he just stopped breathing. It was all very peaceful, and his family was by his side. There had been no “perpetration of a technologic obscenity.”

The resident was convinced that he had learned an important lesson.

Mr. B was an extreme case. But the issue of when life-saving surgery is really appropriate comes up in less extreme circumstances as well. Some years ago, a very wise man refused surgery for this abdominal aneurysm, even though he had none of the overwhelming medical problems of Mr. B. He was perhaps the greatest scientist of the twentieth century. His name was Albert Einstein. He was 79 years old.

Einstein entered the Princeton Infirmary on Friday, April 15, 1955 with severe abdominal pain from an aortic aneurysm. A prominent vascular surgeon from New York urged emergency surgery, but Einstein refused. His condition stabilized and even improved to the extent that on Sunday he asked for his notepad so he could work. However, shortly after midnight, the aneurysm burst and he expired immediately.

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I don't know why Einstein refused surgery. Perhaps because aortic surgery was relatively new in the mid-1950s. More likely, he simply felt that his life was drawing to a close, and perhaps a ruptured aneurysm was a better way to die than some others. One month earlier, after the death of a longtime friend, he had written "...now he has preceded me briefly in bidding farewell to this strange world. This signified nothing. For us believing physicists the distinction between past, present, and future is only an illusion, even if a stubborn one." He had written previously, "To think with fear of the end of one's life is pretty general with human beings. It is one of the means nature uses to conserve the life of the species. Approached rationally, that fear is the most unjustified of all fears..."

When my grandfather was 91, he went into complete heart block with a pulse rate of 28. I was called and said to take him immediately to the nearest hospital that could insert a pacemaker. But my grandfather refused to go! Three days later, he died. I was frustrated by his needless death, which could have been easily prevented by a minor procedure. And he had been alert and able to look after himself!

At the funeral, I reflected on the fact that my grandfather had been a farmer all his life, and he could no longer do the farm work he loved. He had been married twice, one wife dying of TB and the other of cancer. Now he lived all alone on his farm, except for itinerant tenants who helped out with household chores. At 91, he could only look forward to being 92, or 93, or 94, and becoming progressively more infirm. I ended up deciding that my grandfather, an Eastern Kentucky hill farmer, had more common sense than his Harvard-educated doctor grandson.

It is short-sighted to assume that our paramount role as doctors is to save life at any cost. We have to put life and death into a broader perspective. Above all, we have to respect the patient's right to make his or her own decision. Patients may know far better than we what is the right decision for them. And they have the legal and moral right to do so.

When patients think through their own treatment decisions in advance, and when they document their decisions in writing, it helps to insure that their wishes will be followed. It also relieves the family and the physician from the burden of deciding for them.

Last March, I went to Nashville to visit my mother. She was living by herself in an apartment. We had a particularly good visit. She was upbeat, as always. She enjoyed going out to dinner at a restaurant with me, and she seemed generally quite happy. She still enjoyed her club meetings, and her occasional small trips, although she did complain of forgetfulness. She was nearly 92.

My mother was a lovely and proud lady, quite conscious of her appearance and her personal dignity. People usually thought she was 20 years younger than her true age.

She said quite spontaneously and without any regret whatsoever that she felt the time had come for her to die. In a very matter-of-fact way, she stated that death was to be expected at her age. She seemed comfortable with the idea. She did not relish the prospect of going into a nursing home some day, or becoming dependent on others in any way.

One week later, back in Worcester, I got a call from my brother, who is a pediatrician in Nashville. He told me that my mother had had a heart attack. She was in the coronary care unit and had gone into left ventricular failure. My brother had been informed that she would be intubated and put on a respirator. He had said to the critical care specialist that my mother most emphatically did not want to be intubated and put on a respirator. They had discussed the matter several times. Furthermore, she had a durable healthcare power of attorney, and he was her agent. Before the critical care team would back off from intervening in what they correctly regarded as a life-threatening situation, my brother was required to bring in the written document to prove the point, despite the fact that he had been on that hospital's staff for 30 years and had served as their Chief of Pediatrics!

My mother lapsed into a coma. Her breathing became more labored. With my brother at her bedside, she went into Cheyne-stokes respiration and finally just stopped breathing. He and I are both convinced that that is just what she wanted. She was a proud lady who did not want to die on a respirator and who felt that her life had reached its natural end. She would be thankful that she died before being overtaken by the indignities that so often accompany a life that has gone on for too long.

I apologize for the personal nature of this story. The point is simply that I know from personal experience the importance of having an advance directive that is readily available and legally enforceable. It takes the burden off family members or physicians to decide, and it insures that your wishes will be followed—provided that someone will speak up for you. And it is important to execute such a document before the crisis comes! Otherwise, it may be too late. In the SUPPORT study, 40 percent of patients were not able to discuss their preferences in the hospital, whereas 83 percent of them could have done so only two weeks earlier.

As physicians, we should help our patients make end-of-life decisions that are appropriate for them. And we should advise them about documenting their wishes through advance directives. Massachusetts recognizes only healthcare proxies as legal instruments. We should all have one. However, you should be sure to discuss your wishes with your healthcare proxy and be sure that you are both in agreement.

What about my old assumption that as doctors we have nothing much to offer our patients when our professional skill can't help? Actually, we can do much more for our patients than we think, and we can do it much more easily than we think.

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Several years ago, an acquaintance of mine, a man in his fifties, was dying of lung cancer on our medical oncology ward. He was a well-know Worcester lawyer, a graduate of Harvard College and Harvard Law School. His wife said I was free to use his name, but I have chosen not to do so. At any rate, I thought I should pay him a visit.

He was emaciated, and obviously extremely ill. He was also upset about a treatment decision that was troubling him a great deal. He had been offered a last ditch round of chemotherapy, even though the previous chemo had been ineffective and had caused him extremely unpleasant side effects. He hated the thought of more chemo. He doubted that he had the strength to survive it. And yet it seemed unthinkable to this strong-welled man just to give up.

I was there as a friend, not as a doctor. I had come simply to listen to whatever he wanted to talk about, not to get involved with his treatment decisions. But he insisted on knowing what I would do if I were in his place. I told him that I was not a medical oncologist, and that my opinion was not at all expert.

However, he still pushed for an answer. Finally, I said that quite honestly I would probably not have another round of chemotherapy. I didn't think there was any reasonable chance that it would cure the cancer, but I was sure that it would cause a lot of distressing symptoms. I tried to lighten the mood a bit by reminding him that George Bernard Shaw once wrote, "Do not try to live forever, you will not succeed." He smiled a bit. He liked Shaw.

Without saying it explicitly, I also left my friend with the impression that I thought it was OK not to fight his cancer any longer, and even OK to die if things got too bad. That in fact dying was probably inevitable, no matter how hard he fought. When I left, he told me how much he had enjoyed our visit and that he hoped I would come back soon.

So the next day I came back. He was delighted to see me. He was in a much better mood. He had decided not to have the chemo, and he was greatly relieved by that decision. He was a proud man, used to being in charge of things, and somehow he felt back in control of his life, even if not much remained of it.

He asked with great interest if I had seen a Bill Moyers program with Joseph Campbell on Channel 2 the night before. The program was about the power of myth. I said that I had seen the program and found it interesting.

He immediately began talking about some of the myths which dealt with death and the afterlife. I was surprised that he didn't just dismiss these myths as simply primitive superstitions. From past discussions I know that he was cynical about religious beliefs, and a bit of an iconoclast. But he was obviously intrigued with all the myths and legends – and religions – which had been built around a belief in life after death. He was particularly impressed by the fact that there were common perceptions which had been shared by many different people at widely separated places and at many different periods of time.

I don't remember saying much of anything. Mainly, I just listened. Before long I left, but I promised to come back again.

A day or two later, I returned. My friend seemed quieter and more withdrawn, but also more at peace. We talked a bit more about the Joseph Campbell program. He was no longer a militant atheist or agnostic. Neither did he express any real personal beliefs. He seemed content simply to think that death was a mystery. But, like George Soros, regarding death as a mystery rather than as his certain annihilation seemed to hold some comfort for him.

The next time I came back, his bed was empty and freshly made with clean sheets. The flowers and cards were gone. I inquired at the nursing station and learned that my friend had passed away quietly. I went back to my office and didn't think much more about it.

A week or two later, I got a letter from his daughter. She was a third-year medical student at Yale. She said that through my talks with her dad, she had learned what it meant to be a real doctor. I was astounded.

Before long, I also heard from the patient's wife about how much my few visits had meant to her husband. Finally, I heard from the son, a Harvard Medical School graduate and a medical resident at Beth Israel, saying how much he had learned about being a physician from my dialogue with his father.

I was pleased to have been helpful, but I was also mystified as to exactly how I had helped. Frankly, I felt like a bit of a fraud. From my point of view, I had done virtually nothing. No surgery. No scientific insight. No technical know-how. I had simply paid a few visits to a dying friend, saying little, and with no conscious message to give. Why were those brief visits so helpful?

I think I have since learned why. Having no medical message to deliver, and going simply as a friend, I was there to listen. I didn't realize at the time what an enormous gift it is to a dying patient simply to have a doctor listen quite intently, and respond honestly and without any judgment. Through our conversations, my friend regained a sense of personal control over his medical care. He was able to say "no" to another round of chemotherapy, and he even became comfortable with the idea that it was all right to stop fighting and simply let go.

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He also found some emotional, and maybe even spiritual comfort at the end. It didn't come from me. It came from somewhere inside him. I had no spiritual message to sell, and I was not there to preach. Instead, I simply listened sympathetically to whatever thoughts were going through his own mind, prompted by a TV program he had heard by chance. Having a doctor whom he respected listen with interest to his own thoughts about dying had brought him real comfort.

I learned from my friend – and from many other patients since – that we can give a lot to our patients simply by being attentive. If we listen to them, really listen, and if we respond openly and honestly, they are often amazingly grateful. We can help them remain in control of their decision making. We can respect their wishes. We can honor their right to refuse treatment that they do not see as being in their best interest. We can let them know that we will not abandon them and we will do whatever we can to keep them comfortable.

What does all this do for us? It gives us deep personal satisfaction. It allows us to be “real doctors.” It helps to restore the “lost art of healing” that Bernie Lown talks about. Murray Brennan, whom some of you know as Chief of Surgery at Memorial Sloan-Kettering in New York, recently told me that the greatest professional satisfaction he gets is going around at the end of the day all by himself, sitting down with each patient, and simply saying, “Tell me how it's going for you.” Usually he doesn't have to say any more. Just the fact that he's there, ready to listen, means an enormous amount to his patients. And he gets a lot of gratitude back in return.

A few years ago, Anatole Broyard, the former editor of the *New York Times Book Review*, was dying of metastatic prostate cancer. He wrote of his experience in *The New York Times Magazine*. Broyard's article is entitled simply: “*Doctor Talk to Me.*” It echoes the silent plea from many patients to many doctors. “To most physicians, my illness is a routine incident in their rounds, while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity. I don't ask him to love me... a sick man (is) at a point where what he wants (most) is (simply) “empathetic witnessing”...i.e., listening, “being there”, understanding, responding to the unspoken plea, “Doctor, talk to me.”

In this day of professional frustration and burnout, perhaps the happiest group of healthcare professionals I have encountered are hospice nurses. By and large, they love their work. And yet every one of their patients is dying. The average survival is only 30 days. And the nurses are sensitive. They grieve the losses. They go to the funerals. But first, they have listened to their patients. They have relieved their symptoms. They have provided emotional support. They have given enormous help when it was needed most. And they get back a great deal in return. By giving, they receive. And they are much happier in their work than many doctors these days.

Contrary to most people's expectations, it is a privilege to work with the dying. You often see extraordinary personal growth and emotional healing in dying patients and their families. You see old wounds healed. You see people come to grips with what their life means. It helps put your own life and your own problems in perspective. Working with dying patients provides a great opportunity to serve, and service to others brings satisfaction. Albert Schweitzer once said to a group of graduates, “I don't know what you will become. But I do know that only those of you will be happy who find a way to serve.”

In surgery, and in most of medical practice, we no longer focus on serving, but on fixing what is broken. There is a big difference. When we can't fix something, we often forget that we can still serve in other ways. We can go beyond being merely a technician or a fixer. We can help bring a broader kind of healing to patients when they need it most. Patients can sometimes be healed even when they can't be cured of their disease.

We can also do a lot to relieve the distressing symptoms of dying patients. There is an art and a science to pain relief that most doctors don't know. Until I started making home visits with hospice nurses, and until I visited the Pain and Palliative Care Service at Memorial Sloan-Kettering, I knew virtually nothing about modern pain relief despite over 30 years of surgical practice.

There are lots of tricks to symptom control in dying patients. Hospice nurses are experts. Most doctors know very little. One of our former medical students told me with frustration that she had only one lecture on pain control in medical school, but many, many teaching sessions dealing with substance abuse. She said, “Is it any wonder that some doctors withhold narcotics from patients dying of cancer for fear of making them drug addicts?” Or that the SUPPORT study showed that half of the patients dying in some of the best hospitals in America died in pain?

Dr. Russell Portenoy, Co-Director of Pain and Palliative Care at Memorial Sloan-Kettering, and one of the country's top experts on pain control, told me that he has never known a cancer patient to become a drug addict, even though many patients on long-term narcotics develop some degree of physical dependency on the drug. He feels that failure to give adequate doses of pain medication to dying patients is cruel. He also feels that most of the troublesome side effects of narcotics are either temporary or can be alleviated rather simply.

The assumptions that patients have about death can affect their emotional response to life-threatening illness. Fearful assumptions can sometimes change dramatically. About 15 years ago, I saw a slightly obese, middle-aged housewife for abdominal pain. She was probably the most nervous patient I have ever seen. Two weeks before, she had been hospitalized elsewhere for severe right upper quadrant pain. An ultrasound showed gallstones and she was scheduled for surgery. However, she had the overpowering premonition

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that she would die if operated on. Nobody could overcome that irrational fear, and she signed out of the hospital against medical advice.

However, she continued to have severe pain. Desperate, she went to the Worcester Public Library, got the Directory of Medical Specialists, and decided that somehow my mini-biography seemed reassuring. She had the feeling that if I did the surgery, perhaps she would live.

I tried to persuade the patient to go back to the surgeon at the other hospital. I told her that I had limited my practice to vascular surgery. Nothing would dissuade her. She was convinced that if I operated on her, she would live. If she went somewhere else, she would die. It was totally irrational, but she was totally convinced. And she was terrified, absolutely terrified by the thought of dying.

Finally, I gave in and operated, although I did not relish caring for this extremely nervous lady. The surgery was completely uneventful. That night, when the senior resident gave me his evening report, he mentioned that although Mrs. T was doing very well, he had heard a couple of skipped beats when he listened to her heart. Recalling her premonition, we decided to monitor her overnight in the ICU as a precaution.

About 2 a.m., Mrs. T had a totally unexpected cardiac arrest. Alarms went off, nurses rushed over and a full code was begun. Happily, the patient was resuscitated. A cardiology fellow put in a temporary pacemaker. After all the excitement was over and the patient had been extubated, somebody finally thought to call me. Everything was now under control and the patient was doing just fine, but I got to the hospital as quickly as I could. Knowing how extremely nervous this lady had been, and how terrified she was of dying, I assumed that after a full code she would be a total basket case.

Nothing could have been further from the truth! She looked as though she had just had 10 grams of inderal IV, or maybe even 10 grams of heroin. She was not just calm, she was blissful. She looked at me, gave a contented sigh, and said, "Dr. Wheeler, I know one thing for sure. I'll never be afraid of dying again."

She then told me that she had watched her resuscitation. It seemed to her that she was floating somewhere up near the ceiling, looking down on the scene. She described all the details, including a nurse who said, "There's been a QRS for 30 seconds."

And then she had found herself somewhere exceptionally beautiful, feeling great love and peace. Relatives long dead welcomed her, but told her that she could not stay.

"I'll never be afraid of death again," she said. The way she said it, and especially the way she looked, I could easily believe it was so. The change in her anxiety level was nothing short of miraculous.

I went off to find someone who could describe the resuscitation to me. It had gone just as the patient described, including the remark, "There's been no QRS for 30 seconds."

She turned out to have an unusual arrhythmia, and she ended up with a permanent pacemaker, but as far as I know she is alive and well today. Her presumably irrational premonition may actually have been correct. If she had been operated on elsewhere, they might not have been as lucky as we were.

I was not greatly surprised by the near-death experience because she was not the first patient of mine to have such an experience. I don't know how to explain the phenomenon, but it is widely recognized. It has been the subject of many books. Some are sensationalized and perhaps not credible. Others are serious studies which deserve serious consideration. Skeptics have tried to explain away the near-death phenomenon, but prospective studies have validated its existence and have also ruled out most of the facile explanations, such as cerebral hypoxia, drug-induced effects or hallucinations. Having observed patients firsthand, all I can say is that the event was certainly a profound emotional experience for them, and happily a very reassuring one with respect to their fear of death.

The practice of medicine has lots of mysteries, if we are open to them. Life itself is an incredible mystery. The human body is an unbelievable mystery. It's true that we've learned a lot about DNA and genes. We're heavily into molecular biology. We know a lot about how the machinery works. We are sometimes pretty smug about our knowledge – but when we step back and take a longer look, what lies behind all the machinery is still an incredible mystery. And so is death.

Einstein once said, "The most beautiful experience we can have is the mysterious. It is the fundamental emotion which stands at the cradle of true art and true science. Whoever does not know it and can no longer wonder, no longer marvel, is as good as dead, and his eyes are dimmed...I am satisfied with the mystery of the eternity of life...."

By now, you may be wondering what all this has to do with the Worcester District Medical Society. Let me get to the point. Our District Society has recognized, as has the American Medical Association that the care of the dying is a major shortcoming of our healthcare system. With the enthusiastic support of the Executive Council, our President, Ed Amaral, has appointed an Ad Hoc Committee to Improve End-of-Life Care. It includes a number of highly respected members of this Society, representatives from all

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three hospital systems. Physicians, surgeons, medical educators, critical care specialists, medical oncologists and family care physicians. George Dunlop, one of our committee members, is a former member of a Presidential Commission on Medical Ethics, as well as a former President of the American College of Surgeons. Lennie Morse is a former President of our Society and also of the Massachusetts Medical Society and a member of the AMA House of Delegates. All of our members were appointed because they had something significant to contribute, and I am proud and honored to serve with them.

Several priorities have been identified.
They include:

1. **More Appropriate clinical decision making near the end of life.** David Kaufman has led this discussion. He is the Director of Critical Care at Saint Vincent. Last year 80 percent of the patients who died in the Critical Care Unit at Saint Vincent Hospital died either after having life support withdrawn or after making a conscious decision not to institute life support. Most of the patients did not die “attached to machines.” This is a remarkable record with respect to appropriate use of life support which our committee would like to see duplicated throughout the region. We would also like to see a more realistic approach to surgery, chemotherapy, and radiotherapy.
2. **More widespread use of healthcare proxies.** Much of our discussion on this topic has been led by Jeff Burl, Chief of Geriatrics at Fallon. A while back, Jeff found that only 4 percent of Senior Plan patients had healthcare proxies. He undertook an aggressive program to increase this percentage. It is now up to 12 percent. He hopes to have 25 percent of Fallon patients with healthcare proxies by the end of this year, and 50 percent by the end of next year! We would like to extend this effort to the community at large.
3. **Better symptom control, especially pain relief.** The committee’s thinking on this topic has been stimulated by Kate Atkinson. Kate is a former hospice nurse. She left that role to enter medical school because of her frustration with the terrible job physicians did in providing pain relief to her patients. We believe inadequate pain control is primarily a function of physician education.
4. **More home and hospice care.** Allen Ward is providing leadership in this area. Allen is the Medical Director of the Hospice of Central Massachusetts and has learned from personal experience how to care for dying patients at home.
5. **Education about palliative care: medical student, resident, practicing physician, patient and the public.** Andy Cohen, Vice Dean for Education at UMass is also on our committee. We look to him to help us develop educational programs at all levels.

You will notice that we have not included physician-assisted suicide as an immediate priority of our committee. We believe that if physicians do an excellent job with all of the priorities listed above, it should be extremely rare for any patient to feel the need to seek physician-assisted suicide. In over 30 years of surgical practice, I never had such a request. Luke Hill, a doctor friend of mine in Exeter, New Hampshire, has been the Medical Director of the Seacoast Hospice for the last 18 years. He tells me that in all that time working with dying patients, he has had only a single request for physician-assisted suicide. So our committee is starting its work with where the greatest need appears to be.

We are just developing our action plans, and we invite your advice and input. Clearly, education of the public is required, as well as education of the profession, and we need the help of the media.

Some of you may have seen this “As I See It” article in the Telegram & Gazette recently by Allen Ward, one of our committee members. Allen makes specific suggestions to patients and their families about how to obtain the benefit from the value of palliative care and hospice care, and how to avoid the need for physician-assisted suicide. His article grew partly out of our committee discussions and specifically mentions the work of our committee. We hope to have other public education articles in the press during the next few months. There will also be talks by committee members in various public forums.

Our committee will be working with Bill Primack and the Education Committee to sponsor a major EME program dealing with end-of-life issues for the late spring or early fall of this year. We will be meeting with Paul Locke and the Editors of the Worcester Medicine about a special issue dealing with care of the dying. We have also debated whether or not to sponsor a pro and con debate about physician-assisted suicide. We welcome your input on that hot topic.

We plan to work with the Medical School to provide committee input about education for end-of-life care to students and residents. We plan to work with the hospitals to increase the use of healthcare proxies. We would also like to include issues related to the care of dying patients in each hospital’s Quality Assurance Program.

We will encourage doctors to make better use of hospice services in order to provide more home care for dying patients. We expect to sponsor a resolution to the Massachusetts Medical Society meeting in May urging other district societies to take the same proactive approach toward management of dying patients that our own society has.

The main purpose of this presentation is to underscore the importance of this whole topic and to enlist your help in improving the care of dying patients in Central Massachusetts. We welcome your ideas, and we invite you to work actively with our committee.

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So what is the final take-away message? Care of the dying in this country is a national disgrace, and one that the public has become increasingly restless about. Neither our society nor our profession deals well with death. Future physicians may well look back on us as having been long on science, but short on common sense, and even inadvertently cruel.

Given the fact that America has the most advanced health care in the world, it is a disgrace to have 50 percent of patients dying in our best hospitals endure severe pain, when appropriate palliative care can relieve that pain in the great majority of patients. It is also a disgrace that most patients die in critical care units on life support machines, when they want to die at home, and when most of them can in fact be managed there. Not to refer someone for home hospice care early enough for them to benefit is heartless.

Not to provide better emotional support for dying patients is also unkind. It usually requires much less than we think. Just taking the time to listen is often all that is required. A house call from a physician is a small miracle to a dying patient.

In late November, I was making a home visit with a hospice nurse. By chance, we saw one of my former vascular patients who was dying of pancreatic cancer. She and her husband were quite excited to see me. We talked candidly about her impending death. There were no tears. They had already gone through their grieving and accepted the inevitable outcome. They just wanted her dying to be as easy as possible. She had very little pain. A long-acting, transdermal patch of fentanyl gave her a constant low level of opiate which was quite effective. Her only real complaint was that eating was often followed by vomiting and abdominal discomfort. I asked if she got hungry. She said "no." I asked why she struggled to eat if she wasn't hungry and if eating bothered her. She seemed relieved to think that she could eat only when she wanted to. She was touchingly grateful for my visit.

One week later, she died. Her husband told me that her death was very peaceful. She stopped eating, and she weakened rapidly. She was peaceful and comfortable and pain-free and glad to be at home. I am grateful that I had the privilege to visit her. I hope and believe it helped her. I know it helped me.

We don't have to serve as a chaplain or share some strong religious faith of our own at such times. In fact, usually it is much better for doctors just to let patients work through such issues on their own, or with a religious counselor of their choice. For some patients, an after-life is a very real and reassuring prospect, the reward for a good life. For others, the concept of heaven seems remote and unlikely. For some, like George Soros or Albert Einstein, there is comfort simply in thinking of death as a mystery.

Is it really our job as physicians to spend our precious and over-committed time with dying patients? Of course it is, if the patients have been our patients! We often have a rapport and a special place with the patient and their family that nobody else can fill. If we remain involved, we provide continuity and reassurance. One of a dying patient's worst fears is the fear of being abandoned by their doctor. We can relieve that fear.

We can give the patient wise advice about what is realistic treatment for their condition. We can help them avoid unnecessary suffering caused by futile, last-ditch treatment. We can help counsel them about the appropriate use of healthcare proxies and advance directives. We can see that their wishes are followed.

Finally, it's hard to deal well with dying patients until you confront your own feelings about death. You can't give comfort to a patient that you don't have yourself. If you're an existentialist, death looks pretty bleak. But many wise people are not existentialists.

This is where we should return to those last words of Socrates. "I owe a cock to Asclepius...Will you pay the debt?"

When Socrates spoke these words, he was literally in the jaws of death. If there was ever a time for a deathbed vision or a prophetic insight, it was then. We'll never know if he had some heavenly vision, like George Soros's mother, or like my nervous patient with the gallstones and the unexpected cardiac arrest, but at least Socrates had an insight into the meaning of death.

In ancient Greece, when a person recovered from a serious illness or injury, it was customary to make a gift to the temple of Asclepius, the god of healing. One customary gift was rooster. The rooster was chosen as a sacrificial animal to the god of healing because it is the symbol of the sunrise. The practice was to sacrifice the rooster with the very first rays of the rising sun. Simultaneously, the doors of the Temple of Asclepius were thrown open so that the first rays of the sun struck the statue of the god within. Asclepius was the son of Apollo, god of the sun.

The conventional interpretation of most scholars is that, face-to-face with death, Socrates saw death as a healing for which he should be grateful, and for which he should accordingly give thanks to the god of healing. Furthermore, they believe that he saw death as the dawn of a new day. A German classics professor wrote about the last words of Socrates as follows: "Scholars were long puzzled as to the meaning of Socrates' strange last words... Today we know what he meant. He might just as well have said: "The sun is rising, the light is coming, let us give thanks."

In other words, death looked to Socrates like the dawn of a new day. From Plato, we know that although Socrates disclaimed any specific knowledge of what happens after death, he clearly favored the theory that, to quote his own words, "...there is a relocation of consciousness to another realm."

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Most Americans do not think of death in such philosophical terms. Instead we regard death as an implacable enemy, the ultimate loss of everything, a fate to be put off at all costs – except perhaps for the extremely elderly or those in intractable pain. This attitude causes a great deal of unnecessary human suffering. It leads to ill-advised surgery, chemotherapy, radiotherapy and life support. It also costs an enormous amount of money.

Not many doctors speak out in public about how they feel about death. One who did was Bert Dunphy, a well-known and well-loved former Boston surgeon. In 1976, he gave a now-classic Annual Oration to the Massachusetts Medical Society entitled “On Caring for the Patient with Cancer.” At my invitation, he repeated that talk in Worcester when he was Visiting Professor of Surgery at UMass. Bert was a graduate of Holy Cross, and we arranged a special joint dinner meeting of the WDMS and the Worcester Division of the American Cancer Society in the Hogan Center at Holy Cross College.

What made it particularly poignant for some in the audience was that they knew Bert himself was a cancer patient, with widely metastatic prostate cancer. What made it even more poignant for a few in the audience was that they knew his wife Nancy also had metastatic breast cancer. So Bert was speaking from deep personal experience, as well as from a lifetime of surgical practice. His now-famous talk was published in *The New England Journal of Medicine*. It concluded. “...death is as natural as birth. Regardless of religious belief when the finality of death arrives, the patient acquires a singular equanimity. Under appropriate circumstances, the anxiety and fear of dying are reduced to a minimum. The role of the physician in accomplishing this goal is unbelievable ...all we need to do is stand up and show the public that we understand.

“Death holds no fearful threat. Living without life is Hell. Death is natural; it may be just; it is often easeful and merciful; it ought always to be dignified. Who knows, it may be Paradise.”

In his new book, Bernie Lown says that patients expect their doctors to know something about death, but that most doctors actually know very little. He feels it is better for patients to turn for comfort to poets or philosophers or theologians. Frankly, I’m not sure that most of them know any more than doctors do. But poets do come up with striking images. One of my own favorite images of death is from the Indian poet, Rabindranath Tagore. He said, “Death is like snuffing out a candle, in the first light of dawn.” Socrates would have agreed, and I suspect that Einstein would have too!

Thank you for your attention and for the honor of giving this 201st Annual Oration.