Caring for the Seriously Ill: 12 Ethical Imperatives for Working with the Dying

“I propose there are some right answers, that there are certain ethical imperatives in working with the dying. I offer you my 12 Ethical Imperatives for working with the dying,” Walter Hunter, MD, said to participants attending the fourth annual Compassionate Care Conference.

Imperative # 1: To serve selflessly our dying brothers and sisters who come into our care.
Whatever material success we doctors have achieved is not of our own design. Society has valued our services and agreed to compensate us well for our efforts on its behalf. Have we lived up to our end of the bargain? I have heard horror stories of how patients and families have been treated by physicians -- not medically treated, but treated simply as human beings -- I see colleagues who appear to be more concerned with personal income, status and time off than with caring for patients -- entire health care systems more focused on “the bottom line.” Is the current assault on physician compensation and autonomy evidence that we have somehow failed to honor our end of the agreement?

Imperative # 2: To meet the real needs of the dying.
What dying patients need first and foremost is a safe environment. They need to know that our care for them is not contingent upon something they do or do not do. They need to know that we care about them as persons worthy of dignity and respect. A physician does not have to personally agree with every decision a patient makes. I have, on more than one occasion, refused a request or even a demand of a patient or family member. But I did not go away. When a patient says they “need” and ask for death, it is because of untreated symptoms or fear of untreatable symptoms, fear of disability, unrecognized emotional, social or spiritual pain. I would not serve that patient well by my meeting that expressed “need” for death, because that expressed “need” is the result of my failing to meet the real needs of the patient.

Imperative # 3: To guide but never lead.
We have great knowledge and must use it wisely. We are called by the dying to be their guides through this final passage. It is the height of arrogance to believe we can somehow lead them through the end of life, step-by-step. We are simply to be guides who provide a sage experience as they explore their final days. I teach all new hospice
staff members that in working with the dying, what is not said is often far more important that what is said.

Imperative # 4: To be honest.  
Nothing can shatter a relationship more quickly and more completely than dishonesty. To be sure, we do not hit people over the head with the truth they are not prepared to hear. That would be cruel. We must rigorously avoid a self-serving deflection of crucial issues and truths in order to “spare” patients and ourselves the pain of honesty. Honesty - tenderly and lovingly kneaded with kindness - will be remembered with appreciation long after the sting of the truth passes.

Imperative # 5: To be gentle and kind.  
There is no doubt that the first casualty to managed care has been time. There is no doubt that our professional lives have become so pressured, so hectic as to reduce us, at times, to machine-like activity, constantly whirring and clicking toward the next task. However, there is no excuse for relegating vulnerable patients to merciless efficiency and then to naively believe that in the process they have been treated.

Imperative # 6: To be joyful.  
Laughter and joy can be a more effective medicine than anything we hope to produce in a laboratory. The joy of medicine was given to me by my patients. I will always remember the day I sat in the bedroom of a hospice patient who was surrounded by his immediate family. For some reason, something someone said, we all started to laugh. It went from the giggles to gut-wrenching laughter, especially the patient. I am not suggesting that we all become a Patch Adams, but joy can suffuse even the most difficult of situations.

Imperative # 7: To be knowledgeable.  
There is so much I don’t know that if I had a lick of sense, I would use my medical diploma to line my kitchen cabinets. The single greatest sin I can commit as a physician is to know not and know not that I know not. To be knowledgeable, I have to be prepared to say “I don’t know.” I must then ask myself, “Do I not know because I’ve never encountered this problem? If so, I must embark on a course of education. If I don’t know and I should know -- I must be humble enough and professional enough to immediately seek a remedy for my deficiency, including calling in a consultant to help. I make a commitment to learn. Working with the dying, we must be prepared to question everything. We think we know -- but do we know for a fact. Much of the current chaos swirling around the treatment of the seriously ill has as its core myths, half-truths, and downright lies.

Imperative # 8: To be courageous.  
Courage is contagious. The defining moments of history have been immortalized
because common men and women inspired others with their courage and together they all accomplished the seemingly impossible. No one and no thing must ever cause us to shirk our duty to a patient who relies on us to fight for him or her. In our private acts of courage, we inspire others who, in turn, will inspire still others to accomplish the seemingly impossible.

Imperative # 9: To be strong.
Strength has a resolute spirit that stands in spite of overwhelming obstacles. We can become a source of strength to our patients and their families. They can draw strength from us. If we are willing to hold their disappointments, their fears, their guilt, not succumbing to desperation, even when that is all the patient and family see at that moment. We become an example of strength, which ultimately helps the patients and families develop their own strength.

Imperative # 10: To be weak.
To jump into the unknown is to know that our weakness will be exposed. To care for the dying requires we be prepared to take a blind leap of faith into the unknown. In doing so, we must be prepared to allow our weaknesses and vulnerabilities to become part of the encounter. If I find the sting of tears behind my eyes, am I less of a physician if my patient sees those tears? In my own vulnerabilities, I may just find the answers I seek for my patient.

Imperative # 11: To be authentically human in our encounters with patients and families.
To be effective, I must be willing and able to throw off the protection of the white coat and be fully human at the bedside. So often I hear professionals say that they just wouldn’t know what to say to a patient who is dying. But isn’t all human interaction fraught with the possibility of saying or doing the wrong thing? If fear of saying the wrong thing is to govern our actions, how do we manage in our daily lives? To care for the dying, we must embrace our humanity. Indeed, we must have embraced our own mortality, if we are to be effective. I cannot attend well a patient who faces the reality of death, if I haven’t faced my own mortality -- that I too will face the hour of my death.

Imperative # 12: To recognize and believe in the Supremacy of Spirit.
Our personal religious convictions -- or lack thereof -- must never cloud our awe at the great miracle of the spiritual realities that come breaking forth as patients approach death. We must be prepared to help patients and families address the great spiritual questions of life: Who am I? Why am I here? What have I accomplished? Do I need forgiveness? Do I need to forgive? Am I loved? Have I loved well? We must ensure that patients are as physically comfortable as we can make them, but beyond
that, we must become witnesses and even partners in their journey through the intangibles of life -- here we respect the spiritual nature of our own humanity.

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Wesley Smith Publishes New Book: Culture of Death

In his compelling new book, Culture of Death, Wesley J. Smith steps boldly into the heart of battle over the American conscience. This noted author demonstrates how an obscure cadre of intellectuals -- bioethicists -- has suddenly gained the upper hand in American courts and legislatures and, consequently, over each of our lives. While most Americans believe all people are created equally valuable, prominent bioethicists now claim the value of each human life can be traded off in complex cost-benefit ratios. Incredibly, members of the bioethics elite have quietly convinced many of our judges, hospital administrators, and doctors that some human lives have relatively less value, and therefore have less right to equal protection. Culture of Death is a clarion call to defend the fragile, yet enduring principle upon which this great country is based -- that all people are created inherently and equally valuable. Culture of Death is a book any American should buy, read and discuss with family, friends and neighbors. It is a call to action.

The book will be in bookstores by January, 2001 or by Dec. 15th direct from the publisher, Encounter Books. You can order by calling: 1-800-786-3839 or e-mailing: Judy@encounterbooks.com. Identify yourself as a recipient of PCC Newsletter to receive your 20% discount ($19.15 plus $1.15 for shipping).

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MAINE VOTERS REJECT ASSISTED SUICIDE

330,671 people said “No” to assisted suicide in the state of Maine, defeating a 1.6 million dollar campaign to legalize doctor assisted suicide. The Citizens Against the Dangers of Assisted Suicide campaign was out spent by $642,526, money that was funneled into Maine from out of state by euthanasia activists.

The American Medical Association (AMA) applauded the defeat of the Maine assisted suicide referendum. Dr. Randolph D. Smoak, AMA president said, “The AMA is pleased that Maine voters have endorsed physicians’ fundamental obligation ‘to do no harm’ by defeating a flawed ballot initiative that would have turned healers away from their primary purpose,” he said.
Since the state of Oregon legalized assisted suicide, 14 other states have passed or stiffened laws that ban assisted suicide, while twenty four others retain current bans against the practice. Four states have now voted down assisted suicide, leaving Oregon farther out on a limb. “We are so grateful to the citizens campaign for this huge victory in Maine,” said Dr. Hamilton, president of Physicians for Compassionate Care. “Their efforts, and the efforts of the Maine Medical Association and Maine Hospital Association, which clearly and forthrightly stood against assisted suicide, won another victory for ethical medical practice. Maine has joined California, Washington and Michigan in defending the principle that all human life is equally valuable, including the lives of the seriously ill,” Hamilton said.

According to the Maine, Bangor Daily News, one of the TV advertisements credited with changing some of the voters minds on the issue of assisted suicide featured Dr. Thomas Reardon of Oregon, past president of the AMA. The advertisement showed a patient being wheeled into a room of gowned and masked ER doctors with Dr. Reardon saying: “After taking this medication some patients in Oregon had complications so disturbing that family members called 911.”

The case Dr. Reardon was referring to was that of a man, who, after completing the paperwork for assisted suicide and taking the overdose was revived at a Portland Oregon hospital after his family called 911 for help when things went bad with the suicide attempt. The assisted suicide movement in Maine attempted to cast doubts on the existence of this case and attempted get the ad pulled off the air. The ad was not pulled. However, Oregon’s Gov. John Kitzhaber, according to Michael O’D. Moore of the Bangor Daily News, “took the unusual step of recording an ad to denounce the Maine advertising campaign.” According to transcripts of the ad, the Governor stated, “There are no complications with assisted suicide in Oregon, not one.”

It comes as no surprise that the Governor of Oregon joined with assisted suicide advocates in Maine, since he did so in Oregon. What is surprising is that Dr. John Kitzhaber would say there were “no complications.” Of course, there have been complications. There are complications with any procedure. The 911 call was just one example. The 911 case was reported and discussed during a December 1999 lecture at Portland Community College delivered by a Portland, Oregon attorney who was familiar with the details of the failed assisted suicide. Her description was documented at the time of her lecture. According to Cynthia Barrett, the elder law attorney who discussed the case, the family of the Oregon man called 911 for help after he took the prescribed assisted suicide overdose due to symptoms the family couldn’t handle.

According to the Maine news, Maine Medical Association’s executive vice president, Gordon Smith, MD, said the Citizens campaign was vindicated and that the data
would reflect badly on Oregon’s Governor, John Kitzhaber, who was once an emergency room physician.

PCC Backs Continued AMA Support of Pain Relief Bill

The Pain Relief Promotion Act (PRPA) has majority and bipartisan support in both the US House and Senate. However, open debate of the bill was hindered by Senator Ron Wyden, D-Or. Because of Wyden’s interference, the bill was attached to an end-of-the-year spending bill. Its fate remains unknown at press time.

The PRPA protects doctors and patients by clarifying in federal law for the first time that aggressive pain management is appropriate medical care even if in rare instances it might increase the likelihood of a patient's death. It states that assisted suicide is not a legitimate use of federally controlled substances. It promotes improved education and research in pain relief and palliative care. And it provides for grants of $5,000,000 per year for five years. All physician concerns have been addressed and specific wording introduced to reassure doctors that the PRPA grants no new authority to the DEA and does not shift the existing balance between state and federal authorities in regulating the practice of medicine. The American Medical Association’s support of the PRPA has been repeatedly reaffirmed.

Misleading claims that the PRPA might have a so-called "chilling effect" on prescribing pain medicine are shown to be entirely spurious using empirical data updated this year. DEA data show that per capita prescription of morphine has increased dramatically when states have passed similar laws. Ten states have passed such laws since 1992 followed by an average increase in morphine use of over 50%. Clearly, there is no "chilling effect" here.

Dr. William Petty, PCC vice-president recently represented PCC at the AMA House of Delegates meeting in Florida to express support of the AMA’s continued endorsement of the PRPA. Dr. Robert Saxer, a PCC member in Florida, helped organize testimony from Florida doctors for that same meeting. The AMA overwhelmingly voted to continue supporting the PRPA.

Recent Publication:
Suicide is a major public health problem in the United States. Psychiatric disorders that feature or lead to suicidal ideation may be overlooked in the primary care setting because patients are reluctant to broach the subject. In this article, Dr. Hamilton describes how physicians can open a dialogue with patients so that those who need treatment receive it before they resort to suicide.

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