

---

## ESSAYS/PERSONAL REFLECTIONS

# Pulling the plug

---

LEWIS M. COHEN, M.D.

Baystate Medical Center, Springfield, Massachusetts

Each year, hundreds of thousands of Americans die following withholding or withdrawal of life-support treatments. This dramatic change in the practice of medicine has quietly taken place and been accompanied by minimal publicity or discussion.

In Western Massachusetts, where my colleagues and I have been studying end-of-life issues of kidney disorders, the change is also clearly evident. A decade ago, less than 1 in 10 deaths of patients maintained with dialysis was preceded by a decision to stop treatment. This past year in New England, dialysis discontinuation preceded 28% of patient deaths. Nationally, 1 in 4 of the 60,000 deaths of individuals with end-stage renal disease followed dialysis termination. Rather than tragic, many of the deaths were transcendent experiences for participants, families, friends, and staff. As such deaths become more widely known, they are likely to be emulated by increasing numbers of people. After nearly 30 years of being a physician, I have come to believe that this medical revolution is both just and correct, but that it also needs to be more actively acknowledged and debated.

In preparation for this article, a group of palliative medicine physicians—experts who repeatedly participate in these situations—were approached to elicit their thoughts and recommendations. These Death Scholars were interviewed last summer, at their annual meeting held in Lake Tahoe, California. They are a diverse group of about 70 medical researchers, academicians, and practitioners, who have received support for their end-of-life endeavors from the billionaire currency investor, George Soros.

Through his parents' deaths, Soros experienced first-hand the different ways that terminal illness can be managed in this country. George Soros is by no means the first person to observe that in America, where youth is extolled as a virtue, growing older is an embarrassment, and dying has come to represent abject failure. Nor is he remarkable in recognizing that medicine's primary focus on curing disease and prolonging life has resulted in an abandonment of the dying. However, Soros is unique in his willingness and ability to donate more than \$30 million to fund the Project on Death in America, a foundation that is seeking to better understand the experience of dying and to help transform the culture surrounding death. An outgrowth of the organization has been the Faculty Scholar's program. The scholars are becoming the spokespersons for the new discipline of palliative medicine. Since 1994, they have been assembling for a week each July, to talk nonstop from 7 in the morning until 10 at night about death, bioethics, terminal symptom management, grief, and other morbid topics.

\*\*\*\*\*

Dr. Tony Bak, an Asian-American oncologist from the University of Washington, agreed to be interviewed while relaxing in the bubbling waters of the hot tub at the Granlibaaken Resort in Lake Tahoe. Like myself, Dr. Bak has been a Death Scholar since 1999, and he wanted to talk about the entrenched resistance to palliative care. What I consider to be a revolution in medical attitudes is, according to Dr. Bak, only just beginning.

"The blessing and curse of cancer treatment," according to this oncologist, "is that there is always one more thing that can be tried." It is not surprising, but "people want to believe that they've tried everything and have no cause to feel regret. . . .

---

Corresponding author: Lewis M. Cohen, Baystate Medical Center, Chestnut Street, S2669, Springfield, MA 01199, USA.  
E-mail: lewis.cohen@bhs.org

Families need to say to themselves later, 'We've left no stone unturned.' It's the Lance Armstrong story that's being internalized—not only did he have a solid tumor, but also brain metastases, and it's not just that he's alive, but he goes on to win the Tour de France three times! How much higher can the bar be set? People are saying, 'Well I don't want to be Lance Armstrong. I just want to live for a few years.' Consequently, patients are pushed to receive second or third or fourth line chemotherapy until they are in a semi-alive, semi-dead state. . . . They get septic, brought to the ICU, and then the question of stopping life-support treatments is finally raised."

According to Dr. Bak, "In oncology, families are socialized into being this rah, rah team—with the doctor as the coach, and the nurse as the trainers. I mean this in a good-natured way, because staff want to support everyone through the toxic chemotherapy stuff. Over an extended period of time, patients repeatedly get such messages as, it is normal to vomit after the first few days of chemo, and it is normal not to want to eat. After a while everyone becomes a little detached from their body. It is almost as if they lose that trust in knowing their own body. So when palliative care specialists arrive on the scene and say, 'We just want to take care of your symptoms,' patients respond, 'What symptoms?'"

His voice begins to rise, as he earnestly says, "I would like to wake people up to the profound socializing process. I wish there would be a way to help them say, 'It's time to write a different story!' The cancer story is try against the odds and if you just search the Internet a little more, if you just find the right doctor, and the right treatment, and the right combination, you'll beat this. It is a shopping metaphor—a consumer's viewpoint—that if you just shop long enough you will find an incredible bargain."

Dr. Bak's excitement shifts to concern and he quietly remarks, "I do not know how to reverse that . . . but people need to pay attention to their own bodies, and there is a certain knowledge of one's own body that they could trust. You shouldn't go against your gut. So when the doctor says, 'We can do this additional thing or could do that extra procedure.' . . . People need more confidence to speak up when they know that their body is really changing and dying. Families need to be armed with information as to what they can realistically expect, such as when there is only a very small chance of benefit. In most cases, ICU nurses and doctors have a very good idea as to how much medical intervention constitutes a reasonable try. There are discrete events, such as when staff begin talking about ste-

roids or the nurses are putting on a levofed drip—it's really getting to be enough."

Swirling bubbles forgotten, he says, "The other thing I wish I could give people is the knowledge that there is a different kind of story that you can write . . . and it involves envisioning a better kind of death for yourself or your loved one. I wish there was a scrap book of great examples to show them, so they would know that they can expand their own horizons of possibilities. For instance, in our bone marrow unit, we had a kid from Taiwan who was dying. Once this was clear, the family took over his room and decorated it with traditional paintings, dressed him in brocaded costume, and covered the bed with presents. They put roles of cash in his hands, because these things were what he would need in the next world. This was their show. The nurses, who have otherwise seen it all, were given a stunning demonstration of how a family can transform a dehumanizing situation. While this example seems somewhat exotic, we need more illustrations of the very good deaths."

\*\*\*\*\*

It was at the point when Dr. Bak was describing the family from Taiwan that we turned to the woman along side of him in the hot tub and asked if our conversation might be disturbing her or her two children—who otherwise appeared to be contentedly splashing. With a gracious smile, she introduced herself as a member of the newest cohort of Faculty Scholars, explained that she was a trauma surgeon, and that her children were accustomed to hearing such discussions at the dinner table. Dr. Ann Mosenthal later contributed her own thoughts on this subject.

Following one of the conference presentations, Dr. Mosenthal began sketching out some of the complexities she encounters stopping life-support treatment in the course of her role as a trauma surgeon and director of a surgical ICU. She is based at New Jersey Medical School in Newark, where there is a Level I trauma center. In contrast with the elderly, chronically ill, and deteriorating patients one ordinarily thinks about when discussing cessation of life-prolonging treatment, her practice usually involves otherwise healthy, young, predominantly black men and women who sustain severe traumatic injuries during motor vehicle accidents. Unlike the oncologists, surgical intensivists like Dr. Mosenthal do not have time to form a relationship with their patients before hard decisions need to be made. Most of her patients are unconscious at admission, and communication largely occurs with their shocked and emotionally numb families.

For Dr. Mosenthal, palliative care starts with determining who is dying and who is not. She then has “to weigh what is the benefit of this life support with what is the burden, and what is the risk, and then decide what would this person want.” She finds it helpful to keep in mind that “Even though we start something, there is no intervention that we cannot stop tomorrow. Therapeutic decisions do not have to be final.” While she is comfortable withdrawing or withholding treatment, her group of seven trauma critical care physicians vary in their attitudes, and “there are a couple that take more prodding.”

She spoke about some of the pressures that are unique to surgeons. Chief among these are hospital mortality statistics, which in some places are carefully scrutinized. According to Dr. Mosenthal, “A surgeon who does coronary artery bypass grafts will be compared to other surgeons who perform these operations, and hospitals will be compared to other medical centers, with the ‘standings’ sometimes published in the newspapers. If you get patients out of the hospital—even on a ventilator to a nursing home—that’s alive and not dead. Same for transplants; if a patient goes away alive and not dead, that makes a big difference. In those situations, there is a substantive pressure not to withdraw life support, and it is compounded by the macho thing in surgery, where death is a failure. There is always a strong sense that if your patient dies, you did something wrong. It is particularly strong if you operated on the patient. Stopping life support means that you are wimping out.”

Is there a strategy for families in this situation? The best idea is for them “to sit down with the surgeon and be very clear that this is not what the person would have wanted. Make it explicit that you are not going to sue for stopping treatment, but that you are not going to tolerate having the patient’s preferences ignored.”

What are the issues for a white, female surgeon in treating a population that is mostly black and socioeconomically disadvantaged? The answer is that “one must appreciate that African-Americans have different preferences regarding end-of-life issues. My black families are more likely to refuse DNR orders and want everything done. Race, gender, and economics combine to sometimes form an insurmountable barrier. Some of these families convey that they are not satisfied unless they have a white male physician in charge, who will be an authority figure telling them that everything possible has been done.” In such situations, Dr. Mosenthal turns to the help of the black hospital chaplain.

\*\*\*\*\*

Dr. Tom Prendergast, a pulmonary and critical care physician and Associate Professor of Medicine and Anesthesiology at Dartmouth Medical School, has withdrawn life-support treatment in the ICU from “dozens if not hundreds of people over the last 13 years.” During a conference break, we sit in the shade of a redwood tree, along with Dr. Judith Nelson, the Associate Director of the Medical Intensive Care Unit at Mount Sinai School of Medicine in New York. Dr. Prendergast bears a resemblance to the actor Ed Harris, while Dr. Nelson looks like a young and serious Ann Bancroft. Many intensive care units are split between surgeons and medical physicians, and Drs. Prendergast and Nelson are Dr. Mosenthal’s medical counterparts.

Dr. Nelson is a detail person, and she wants to clarify the subject, remarking, “It is important to define withdrawal, because it includes a lot of different interventions. An intervention that may be life supporting for one individual may not be life supporting to another individual. There are interventions that are clearly regarded to be life supporting by most people, like mechanical ventilation or dialysis. There are a series of other interventions, like providing antibiotics, fluids, or nutritional support, that may not be regarded as such by the public, but stop them and the patient dies. Pulling the plug usually refers to the ventilator, but other things also lead to death.”

The conversation switches to anecdotes of excessively long ICU stays, such as that of the 81-year-old man who has been hospitalized for the past 11 months and spent the last 3 weeks in critical care. What began as a hip fracture turned into an endless series of complications and continuous deterioration. His ICU stay was prompted by an aspiration pneumonia, renal failure, and a fungal infection that spread in the blood. He had not been interactive or conscious for a period of months, but his son was unmarried and had lived with him for his entire life. The son had no other important people in his life, and could not say goodbye to his father. The fact that they were fabulously wealthy and could afford private nursing around the clock made it somewhat easier for the hospital to care for him, but there was no escaping that it would be unprecedented for a patient with these problems to recover and return home.

Dr. Prendergast is a thoughtful man who makes no unnecessary movement, and maintains unbroken eye contact. He remarks that “when there is a family member who cannot let go, it is usually for a selfish reason—not necessarily a conscious selfish reason—but they cannot let go and they have lost

the ability to participate in making the decision on the basis of the patient's preferences."

He describes how cases like these wear down the treatment team, who can only hope that time will alleviate the situation. Such cases make staff more aware of the negative aspects of what even comatose patients experience—the degrading elements of some treatments and procedures, the lack of privacy, the mental and the physical suffering.

According to Dr. Prendergast, "It may be helpful for the lay public to understand that our culture doesn't deal with death particularly well, and that bad things happen to very nice people. The one almost universal aspect of every death that I've been involved with is that it just doesn't seem to be the right time today . . . not today. People may want a peaceful death, but they don't want it now."

Dr. Nelson suggests that if the hospitalization goals begin to get blurry, families should request a staff meeting involving "all of the primary players, the ICU staff, surgeons, nurses, perhaps the family physician, and pastoral care. There may be some resistance to it, but families are going to get the most information and help everyone arrive at a decision that is harmonious and consistent with the wishes of the patient. Be sure to ask the team for their long-term view as to what is going to happen to this individual. For instance, our patients that fail to be extubated from ventilators in the ICU are sent to a special respiratory care unit. Data demonstrate that 70% of those people are going to be dead within a year after they enter that unit, and most of the remainder are still going to require nursing home facilities. I'm not sure that this gets discussed, and it should be!"

Dr. Prendergast adds, "In the ICU, there ought to be an ongoing discussion about the patient's status and prognosis that includes the likelihood of getting better—with getting better being defined as being discharged from the unit, leaving the hospital, and living independently. Unfortunately, the usual model that I see is the zero-sum approach, which is that we treat, treat, treat, treat, and then we decide its not going to work, and now we switch gears and transition to a palliative care approach. Someone said, it's like you're on a train that's going 90 miles an hour and there is a guy standing on the tracks in front of it who shouts, 'stop.' You can't do that, or at least you better be prepared for a lot of confusion and unhappiness. Families require an ICU doctor who starts by saying, 'Forty percent of our patients die given this clinical situation, and everyday we'll have ongoing discussions about whether it looks like she is getting better or worse, and at some point we may come to a consensus. And what we need from you is some sort of idea as to

what your expectations are and what the patient's expectations are. Everyday we will review that in a formal or informal way. Usually what happens is the patient will make the decision for us. She will get better or worse."

While the leaves gently rustle, the two intensivists speak about how comfortable it is to withdraw or withhold life support when a team of medical professionals and the family have reached a consensus that treatment is death prolonging rather than life sustaining. Dr. Nelson comments that "almost no one that I know would want their life prolonged if they could never leave the hospital." According to Dr. Prendergast, "Continued treatment of people against their will and in situations where no one thinks there is any clinical benefit seems absurd. In these cases it is intuitively obvious that withdrawal is an appropriate clinical act." He concludes that "it is almost always possible to maintain comfort through the process of withdrawal. The clinical team can describe to families what to expect, and everyone can be offered an opportunity for a private leave-taking."

\*\*\*\*\*

Dr. David Weissman, a Death Scholar from Milwaukee, brings an important perspective to this topic. He is an oncologist by training, and is now a palliative care consultant and the editor of the *Journal of Palliative Medicine*. As we sit down, he grins and announces, "We use life support long after it has any value."

Physician leadership is a big issue for Dr. Weissman. He does not see doctors exercising what he calls their fiduciary responsibility—to help patients make difficult decisions. Instead, echoing Dr. Prendergast, he says, "What you have is no decisions and default decisions, and far too often the default decision is to treat. There are a variety of forces that can push treatment beyond what anyone really wants. The doctors do not want it, the families do not want it, and the patients do not typically want it. But there is not an appropriate context set, and there is not appropriate leadership. Many physicians turn to families and fall back on, 'Here are the options; what would you like me to do?' As opposed to 'Mrs. Jones, your mother is dying, and I think that it is time to stop.'"

According to Dr. Weissman, "Doctors do not like to prognosticate. They do not want to be wrong—mainly out of concern that people will lose faith in their opinion. They also do not want to face their own mortality."

Advice for the public? "The number one thing that I tell families is find a physician that allows

them to feel comfortable. There should be no question that you cannot ask the doctor. The corollary is that if the doctor is evasive and does not answer you, you need another doctor.”

Further thoughts about the doctor-patient relationship? “I am continually amazed that it does not require a long-term relationship. You sit down with someone you have never known, and 15 minutes later you tell them that they are going to die, and 30 minutes later they are thanking you, and saying, ‘Why didn’t anybody ever say this before and would you please take over my care for the rest of my life?’ The fundamental aspect of medicine is that people want to feel respected. People want to feel that you care about them. If you can demonstrate that you are concerned about them as a human being, a relationship is established that is truly the most important aspect of what we do.”

How can one identify whether someone is dying? “We know a lot more now as to who is going to do badly than people really want to admit. There are tons of data about who is going to survive in the intensive care unit, who is going to do well and who is not. It helps if you look at the medical facts and see where the patient is in the trajectory. The other piece is identifying where the person and the family are psychologically. The person who says, ‘You know, Doc, I have been in the hospital three times and on a ventilator, and each time I have gotten off and I have gone back home and done what I want to do. I want to do that again.’ Well, that person is not dying. The patient who is at the same point physically, but who says, ‘Doc, the next time this happens

forget the machine. I want to stay at home and you should keep me comfortable.’ That person is dying.”

\*\*\*\*\*

Woody Allen has observed, “I’m not afraid of death, as long as I don’t have to be there when it happens.” Listening to the Death Scholars, a group of clinicians who spend their professional lives at death beds, is another way to overcome that fear. What are their take-home messages? There is nothing simple about stopping life-support treatment and accelerating death. In fact, medicine got considerably more complicated when extending life and avoiding death ceased to be its only goals. However, it also became much more relevant. In the same manner that obstetrics changed over the past decade—with the creation of birthing rooms in hospitals, home births, and the use of midwives—so too, end-of-life care is now being transformed. We can look forward to more options, more choices, and more opportunities to finish life in ways that are consistent with how we have lived the balance of those lives. People now have a greater chance of having not only good deaths, but extremely good deaths. After nearly 15 years of studying terminal illness among patients with renal disease, my advice is that the public needs to increase its expectation of what medicine can do to improve how we die. Control is important to many of us, and it is time to become imaginative about what can be accomplished in the last phase of our lives.