Death is not optional. Even in Marin. Talking to patients about their options at end of life is part of a physician’s commitment to excellent care. It is not a question of whether our patients will die. They will. Nor is it about whether they want to die. They don’t. It is about providing good medical care to people in their final years.

When I hung my shingle in Point Reyes 17 years ago, I thought the Hippocratic Oath meant I would keep people from dying. So long as I knew how to discuss when to have a colonoscopy and the risks and benefits of Lipitor, I figured I could safely “do no harm.” But when I met my patients, I discovered only some of them had high cholesterol, and even fewer, colon cancer. Yet, all of them would eventually die. It struck me then: I was a full-fledged physician with no training in the one thing that would affect every single one of my patients.

Of course, in medical school I saw people die. I stared in fright at their grieving families, then at the body in the morgue and finally at a daunting crowd of physicians in Grand Rounds. We all wanted to know how the death could have been prevented—what we had missed, or worse, done wrong. Certainly, no one suggested how the death might have gone better. Nor did it occur to me that this person might have preferred to die somewhere else, accompanied by someone he or she actually knew. Honestly, in my exposure to death during training, I was most aware of wanting to be somewhere else myself.

For this reason, those first few years in practice were the most humbling in all my training. In particular, the education I received from Hospice of Marin (now Hospice by the Bay) provided the biggest lessons. I don’t recall exactly how I started referring patients. It was likely someone else’s idea, perhaps a desperate family member or an experienced caregiver. But before long, I found myself with a handful of patients who, in addition to my care, had a transdisciplinary hospice team visit them at home. This close surveillance ensured early symptom management, medication compliance, family support and patient-centered education. The team members knew what to expect, what to say and what to do. With both chagrin and excitement, I saw excellent end-of-life care for the first time.

More humbling though was that a substantial number of my patients were actually discharged from hospice alive. The team’s good old-fashioned medical care seemed to lengthen prognoses, in some cases beyond six months (the hospice benefit cutoff). Ironically, my patients flourished with end-of-life care. Furthermore, when I gave my “graduating” patients the good news that they didn’t need hospice...
anymore, they begged for the team to keep coming. These patients had initially feared hospice, thinking it would hasten death with drugs like morphine. Yet now they were enjoying better quality and quantity of life and, at this rate, could not imagine letting go of the hospice benefit.

Sheepishly, I began studying hospice care in earnest. I discovered studies that show that patients on hospice, regardless of diagnosis, live weeks to months longer than patients without hospice. In addition, they rate their quality of life higher, spend less of their last six months in the hospital, have fewer invasive procedures and cost less to insurance providers. Fifteen to 20% of patients are discharged from hospice alive (and improved) because of the attentive medical care from the transdisciplinary team. Hospice is a Medicare and Medicaid benefit and is also covered by most medical insurance plans. At Hospice by the Bay, services are provided regardless of insurance coverage, citizenship, housing, caregivers or code status.

A free service that allows patients to live longer and better? Why had I not heard about this before? I was now prepared to refer everyone who was eligible.

Then came the final discomfiting jolt to my ego. One of my patients, a man in his 50s with cardiomyopathy, died while considering participating in a heart surgery study. He was survived by a wife and son. Privately, I had known he was dying. I hadn’t known when it would be, but he was short of breath at rest despite medical therapy, and he was not getting better. The surgical trial showed modest benefits for a fraction of the patients enrolled, so whether or not they accepted him, my patient had had a good chance of dying from heart disease within the next six months. But even if I had thought of referring him to hospice, I didn’t want to get in the way of his hope. I believed, and still do, that he would have preferred not knowing his prognosis.

His wife found him at home after a long day at work. She dialed 911 and then me. When I arrived, I spent the first 10 minutes of my visit convincing the police that a forensic investigation was not necessary. His wife heard me tell them that the death was expected. Through tears, she cursed all doctors across the United States who had failed her husband. More than not fixing him, they lamented, they had not told her the truth. Had she known he was dying she would have taken time off work to be with him. She didn’t say it, but I too was guilty of protecting her from the truth. Later that week, their son returned from college and came to my office. Like his mother, he was careful not to blame me directly, but he also felt robbed. I was pleased that Hospice by the Bay had a community bereavement program to which I could refer them both; they had so much to process.

Of course, I had my own feelings to reckon with too. I knew I was not responsible for his death, yet I felt I should have said something earlier. Was hope for an improbable cure more important than a
family’s opportunity for closure? Could they have had both? Could I have offered the support of hospice without sabotaging my patient’s quest for life?

Unable to sleep that night, I reread the Hippocratic Oath. Interestingly, it does not say “Do no harm.” That is a myth. Rather, it includes the following promises:

1. I will not be ashamed to say “I know not.”
2. I will avoid those twin traps of over-treatment and therapeutic nihilism.
3. I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being.

Around that time, coincidentally, I bought a new car, the first one I had ever owned with airbags. When I signed the paperwork, I imagined commuting to my office, taking trips with my family, and driving to home visits all over West Marin. I was thinking of where my new car would take me, not about airbags. I wasn’t planning to crash, and if asked, I would have said I was not “ready” to crash. The airbags were just tucked into my new car, inconspicuous, just in case.

Perhaps sleep deprivation played a role, but something about that Greek covenant and my automobile’s safety features triggered an overnight change in the way I practiced medicine. I discovered I could follow the Hippocratic directions while allowing my patients to dream about where they are going rather than about crashing. I could have frank conversations about the hospice benefit and wholeheartedly foster hope. Offering hospice was like slipping those airbags into the dashboard, just in case death is not optional. I did not ask whether the patient was ready for the conversation; I asked whether he was eligible. And when a patient’s prognosis flirted below a year, I touted hospice for what it was: a team of experts that knows more about death than any of us is expected or wants to know. A team that can help navigate end of life. Just in case.

In medical school, I committed not just to treat people, but to treat them well, as human beings. As humbling as it had been for me as a young doctor to admit “I know not,” I learned to provide the best care at end of life.

Here’s what I wish I had said six months before my patient died:

On paper, you meet the criteria for the hospice benefit. This means a team of experts can come to your home and help you manage your symptoms, get your affairs in order, and provide tools for you and your family to process the incremental losses that come with an illness like yours. If you decide to do the heart surgery, you can come off hospice with no penalty. But if you don’t, hospice will provide better care than I can alone because they are a phone call away anytime, day or night. I will remain your doctor, and they will keep me abreast of what is going on without your having to come to the office, which I know is getting harder and harder. And if you aren’t sure you want a bunch of people coming into your house, remember you don’t have to meet the team all at once, just at your convenience. And they are as much for your wife and son as for you. I think it is a good idea to do this now, when you are doing well, because the better the hospice team knows you, the better they do their job. And if you get your heart surgery—when you get your heart surgery—should something go wrong, hospice can sweep back in, already aware of who you are and what your goals are. Just as you might hire experts to help with your taxes, to educate your son in college, or even to train your dog, hospice is the expert for this part of your medical care. And to be honest, I wish all my patients could have this service. It is just plain good medicine.


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References

