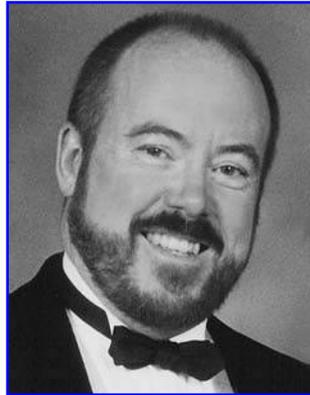


Optimism

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Sometimes, it's better to beg forgiveness than ask permission.

—Grace Hopper

MY FIRST EXPOSURE to hospice care occurred when I was a medical student at the University of Colorado in Denver in the mid-1980s. Ted Rematt, a friend and old Roman Catholic priest volunteered as a chaplain at the Hospice of St. John in the suburb of Lakewood founded in 1977. Over dinner, he described a patient who was a behavior problem. She had a fixed delusion that she was dispossessed royalty from Central Europe and was acting out by throwing dishes because the hospice staff was not treating her in a manner befitting a Grand Duchess. Father Ted visited thrift stores on a weekly basis. He bought a selection of peignoir sets (frilly nightgowns with matching robes trimmed with sequins or caribou) for a few dollars and gave them to her. Her behavior changed dramatically. She was friendly and accommodating and a “good patient” until her death some weeks later. I had no explanation for this. It did not fit the psychiatric syndromes about which I had been learning. I would have done a work up for delirium and prescribed haloperidol or perphenazine; I certainly would not have prescribed a peignoir!

I started my residency in internal medicine at Northwestern Memorial Hospital in Chicago in 1988. Dur-

ing my internship year, I was sometimes called to the inpatient hospice unit to pronounce death or to see a patient for symptom control issues. I was struck by how different the hospice approaches were from the rest of the hospital. The nurses diplomatically suggested changing my IV or IM opioid orders to subcutaneous routes—something I had never heard of. Why didn't my resident tell me about this?! The nurses subtly questioned my orders for checking electrolytes to measure the blood urea nitrogen/creatinine ratio to confirm my clinical suspicion of dehydration. Instead, they suggested I trust my physical examination and be guided by patient/family goals. They suggested the chest radiograph I wanted “tonight” could be done in the morning because the patient wanted to sleep and it would not change management. It seemed deliciously seditious.

My curiosity piqued, I did a month's elective there early in my second year. The hospice medical director, Jamie Von Roenn, let me see patients, develop care plans with the attending physicians and answered my questions. I read Saunders and Sykes' manual on terminal care.¹ I was eager to “try out” what I read. I pored over the drugs to find corollaries in the American phar-

macopeia. I was a kid in a candy store—the attending physicians were delighted to have a house officer interested in seeing their hospice inpatients and supported my suggestions for management. I made rounds 7 days a week because it was so absorbing; the professional reward was intoxicating. I made home visits with the hospice staff and it changed my professional life; I restructured my outpatient clinic at the Veterans Affairs Hospital for the next 2 years because of it.

When I found out that there was a vacant office on the hospice unit for the medical director I moved in, without asking permission! Even as I rotated on other services, I kept my office on the hospice unit, and helped out with signing orders, pronouncing deaths, and doing other little tasks that required a doctor in person. I suspect I am the only internal medicine resident who ever had a private office in the history of Northwestern. I remained in that office through my residency, then my fellowship in hematology/oncology. In later years, I asked the nurses what they thought when I just settled in, like some homeless person. Politely, they never answered the question.

In addition to reading, I wanted to see what others in the palliative care field were doing. I visited the clinical palliative care service at Memorial Sloan-Kettering in New York City (Kathy Foley, Russ Portenoy, and Bill Breitbart) and at the Cleveland Clinic (Declan Walsh). I received an Alfred Stengel travelling scholarship from the American College of Physicians to visit St. Christopher's Hospice in London (Nigel Sykes, consultant), as well as the palliative care services at St. Thomas' Hospital (Geoffrey Hanks, consultant) and the Royal Marsden Hospital (Janet Hardy, consultant).

When I returned to Northwestern in the role of junior faculty member in hematology/oncology, I was confident that I could establish a palliative care consultation service at a general hospital like Northwestern because I had seen what the other leaders were doing, and I thought we could do just as well. Like Dorothy, I had been to Oz, and found out there is no place like home. When I wondered whose additional approval I would need, Sig Weitzman, Chief of Hematology/Oncology, said, "Charles, sometimes it's better to beg forgiveness than ask permission." So, with Jeanne Martinez, manager of the hospice program's promise to provide a nurse from her inpatient budget, and Sig's promise to provide a hematology/oncology fellow each month, I started the service in 1993.

To create initial volume, I decided to turn every referral for hospice care into a palliative care consultation. The response was delight by the attending staff! Only 1 oncologist among 250 referring physicians in 6 years objected by saying he had made a hospice re-

ferral, not asked for a consultation. We often cajoled the hospice social worker or hospice chaplain to see general inpatients if there was a situation the consult service nurse and I could not handle. In off-hours, I sweetly asked hospice nurses to scurry all over the hospital to demonstrate how to put in subcutaneous infusions. Subcutaneous scopolamine drips for secretions, octreotide drips for bowel obstruction, and combination antiemetics for refractory nausea became widespread. We saw patients in the emergency department and the surgical recovery room. We started thinking of the inpatient unit not as a hospice unit, but as an acute palliative care unit where patients didn't have to "sign up" for hospice care before using it. We started taking direct admissions from home who were not enrolled in hospice care. We added two more rooms (all we could add) to the existing 10-bed unit because of the demand. Our home hospice program doubled in census. It all just seemed the right thing to do. As I look back, it all looks impertinent and cheeky!

I needed more physicians, so I dragooned Martha Twaddle, medical director for Hospice of the North Shore, Mike Preodor and Mike Marshke, medical directors for Horizon Hospice, and Kathy Neely to help me staff the consultation service and inpatient unit so I would not always be on service. One morning, I asked them all to a breakfast meeting and declared that we were the palliative medicine faculty for Northwestern University and also boldly predicted that we would soon be part of a recognized specialty in the United States just like in the United Kingdom.

In 1995, Laurel Herbst, then president of the American Academy of Hospice Physicians, built on initial work of Andy Billings at Massachusetts General Hospital and appointed a committee, for which I raised my hand, to establish a certification process. Our first examination was offered in 1996. Ten years later, after serving as Chairman of the American Board of Hospice and Palliative Medicine for 3 of those years, formal recognition was achieved. The years in between were filled with the important work of developing an examination process and helping leaders in medicine to understand that our field met the criteria for subspecialty status. When we started, we were told that formal recognition would come in 10–30 years, if it came at all. In other words, we went as fast as we could. I never had less confidence than at that rather impertinent breakfast meeting in Chicago.

The greatest challenges in my career were more administrative than medical. Management skills are primarily taught by apprenticeship and social acculturation, not unlike clinical skills. I am very grateful for the administrators who had the patience and time to explain the system, help me learn from my mistakes,

and prevent me from making more in the future. I will never forget my first high-level meeting with senior hospital leadership in my new role as medical director where I asked when I could expect a decision. I might as well have passed flatus. I have since learned to ask “what should the next steps be.” I still find management to be the most challenging area, in part because health care is structured in such a way that physicians are relatively excluded from administrative circles. It is not unlike the feeling when caring for a patient and family of a different culture—you miss so much of the communication because it is culturally based. The single most helpful insight I learned was that Robert Buckman’s six-step approach to breaking bad news works for any important meeting. I start by asking what the person understands, what he expects, and what she is hoping for. Just as in patient care, I withhold my opinions until I feel confident I understand the perspective of the person with whom I am speaking. I suppress the urge to talk, just because I am nervous. In addition, just like in clinical care, silence is a powerful communication tool.

My interest, now, is in fostering the next generation. At San Diego Hospice & Palliative Care, where I enjoy the exalted title of Provost, I am excited to see the same enthusiasm in our fellows that I felt when I was at a similar stage. I see it in the residents, medical students, nursing students, social work students and bereavement counseling interns. I love watching their sense of wonder, their indignation at not having been taught this field as part of their core training, their frustration with initial efforts that don’t match their aspirations, their confidence as they strive to be independent in working with the team for challenging patients and families, the patience of the hospice staff as they shape yet more learners. When I look in their eyes, the future seems bright, indeed. Similarly, I see a bright future from working with authors who submit their work to the *Journal of Palliative Medicine* for publication.

The generalizable themes from these stories are enthusiasm and dogged determination. It surprises many when I say I never had a big strategic plan for my career or the field; it all just seemed obvious . . . like reaching out for something that is in plain view. Early on, I was strongly influenced by one of William Osler’s essays where he quoted Thomas Carlisle, “He who goes furthest focuses on the work of the day.”² If it was good enough for Osler, who transformed American medicine, it would work for me.

One error I avoided, I think, is to feel apologetic about my interest in palliative care, as if it were somehow a less noble or valuable branch of medicine than fields like nephrology or cardiology. If one feels like one is second class, I think that is the way one is treated. In

contrast, I continue to be convinced that our field has nothing to be embarrassed or apologetic about. The biology, pathophysiology, pharmacology, sociology, and mythology of medicine are as complex and interesting as in other subspecialties. It has seemed to me that the enthusiasm I feel makes it compelling to others. I think my pedigree with a basic science doctorate in biochemistry as well as subspecialty training in oncology, my gender, my willingness to always dress in coat and tie, and writing my consultation notes with a fountain pen helped me project that kind of confidence in the early days. The official recognition of our subspecialty should give that sense of confidence to others. Our field is as important, but not more important, than the other subspecialties of medicine. I think I have avoided the militant stridency that I have observed in some. Medicine values collegiality. My experience in the diplomatic process for formal recognition of the field has confirmed this opinion. People treat you with the same respect you hold for yourself. A gay civil rights slogan, now a household phrase for any previously hidden or unrecognized issue, works as well for us as it did in previous generations: “We’re out and we’re proud.”

The next phase for our field will, perhaps, be more challenging in that the “newness” and the campaign for recognition are over. Now comes the challenge of working within the larger framework of health care and institutionalizing our achievements. The scientific data about change are clear—sustaining change is much harder than initiating it. So, following the advice of Carlisle, let us all turn to doing the next steps that appear to be needed; federal funding for fellowship training and institutionalized clinical services. Do not look too far into the future, just do what needs to be done today. Sometimes, it’s better to push ahead and beg forgiveness rather than wait for permission.

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