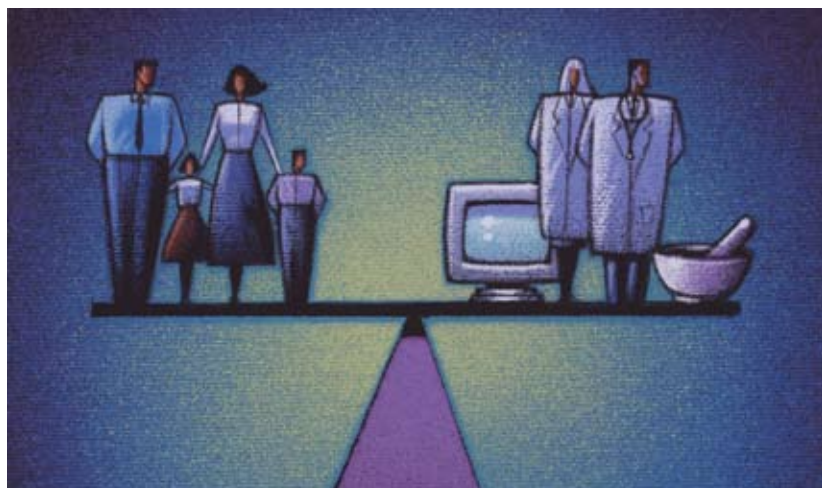


# COMMUNICATION CHALLENGES

## The Family Meeting: Meeting the family where they are

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This was a thankless time: The patient was dying, yet the family wanted “to give him every chance.”

### THE CHALLENGE

“But if he gets through this, then he can try more chemo, right?” Hank’s daughter asked.

We (the palliative care physician; the cancer center social worker; and I, the cancer center nurse) were in the waiting room outside the ICU, meeting with Hank’s family, which consisted of the adult daughter and son and Hank’s two brothers. We had spent the better part of an hour explaining to them how unlikely it was that Hank would be able to breathe on his own and how removing the endotracheal tube would most certainly mean he would stop breathing. His lung cancer had progressed rapidly, growing worse in spite of the chemotherapy. The radiation to his chest had relieved some of his pain and shortness of breath. Hank was only 57 years old, but the cancer was in charge. The disease had spread like wildfire, grabbing hold of his liver and turning him the color

of summer squash. He was in the hospital for pneumonia and shortness of breath.

Before his hospitalization, we’d had “the talk” about code status with him many times. His response had been consistent, “I want to keep fighting.” When his dyspnea turned to respiratory failure, he was intubated and transferred to the ICU, where he was responding minimally. His daughter held the durable power of attorney. We continued the do not resuscitate (DNR) conversation with her. It seemed to us that even untrained observers could look at Hank in the ICU bed and know he was not long for this world. In fact, when I looked at him just before the family meeting, I had had to check the monitor to see if he was still alive.

It didn’t matter what the doctor said or what I said or what the social worker said. The daughter, and by default the rest of the family, was waiting for him to improve. The evidence they presented was, “He’s a fighter. He always has been. If anyone can get better, he is the one.” Inside my mind, I sighed deeply.

When I walked back into the ICU, the nurse caring for Hank asked, “Did you get the consent to make him DNR?”

“Not yet.”

She shook her head. This was a thankless time: The patient was dying, yet the family wanted “to give him every chance.” On the other hand, the ICU nurses were begging us to change his status to do not resuscitate, saying, “I really don’t want to do CPR on that poor guy. It won’t do him any good.”

Palliative care is directed at the relief of suffering. The patient was our primary focus,

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but we had to address the suffering of the family as well. With Hank no longer responsive, we had to listen to the family member he had assigned as his decision maker. His daughter was barely 30 years old. Her burden was already heavy. She had helped care for her father as he went through treatment. She was daughter, chauffeur, cheerleader, mother, sister, and friend all wrapped up in one very sad package. And she was overwhelmed and afraid.

The time line was unclear, but the path Hank was traveling was not. We could try to be hopeful and talk of possibility versus probability, but in truth, he was beyond all that. He might live longer than we could predict, but he could not fight his way back. Hank was relatively young, but no amount of fighting would win this battle and no amount of talking convinced his family of this. They focused on the small details—“Shouldn’t the dried blood around the IV site be fixed?” or “Does he really need the Foley catheter?”—and ignored his more obvious, deteriorating condition.

After 3 days in the ICU, the family finally agreed that he should not be given CPR, but they wanted everything else, reminding us again, “He’s a fighter.” It was progress, just not at the rate we wanted. I hated to see Hank that way. I preferred to remember him walking into radiation oncology for treatment. He would smile shyly as he told the new joke he had each day and was always pleased when I laughed. He had said he wanted to fight, so one had to agree that the family was honoring his wishes. But had he really understood that the end would be

like this? Did the family understand how uncomfortable it is to be intubated? I wondered what else we could have said. The dilemma bothered me on several levels: Were we acceding to the family and, in doing so, adding to Hank’s suffering? What would I do if he were my father? Part of me was sympathetic toward the family, but another part of me was angry.

### THE SOLUTION

This column always strives to resolve the challenge presented, but in this case, the outcome was not what we felt it should be. After meeting with the family day after day, we were forced to accept that reality. As long as the family remained convinced that Hank had some fight left, moving them toward DNR was impossible. I knew that the rocky road ahead of Hank was longer than I wished for him, longer than I wished for his family, and longer than I wished for any of us helping to care for him. We were hijacked by his loved ones and carried along with them as unwilling participants. Eventually, time was on our side. As Hank continued to decline, the long days of waiting and hoping took their own toll on the family. Finally, they agreed that he should be extubated.

Hank lived for 2 more days. When he died, the family seemed surprised. I wish our communication had led to the ending we wanted: for Hank to have been extubated sooner rather than later, for his suffering to have been shorter. Our focus shifted to the family after Hank passed. Ultimately, we could not get the family to meet us partway; instead we met them at the end of the road. We knew the road we were on even though they did not. We knew how long and tortuous it would be. We knew the outcome; indeed we had known it all along. But we had to wait for the family to arrive. We had to meet them where they were. ■

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### Discussion questions

1. What might you have said to the daughter in this situation?
2. Do you know what your hospital’s policy is regarding when to call in the ethics committee? Do you think the ethics committee should have been notified in this case? What if the family had wanted to keep the patient’s resuscitation status full code?