

**The medical profession must do better when it comes to palliative care and hospice. Sadly, patients and their families are often unprepared for the final stages of the dying process. As a result, many wait too long before utilizing hospice and palliative services, which can result in loved ones dying poorly or in a way they would not have wanted. We must be more willing to talk about death to ensure that patients receive the very best care at the end of life.**

**Assisted suicide or euthanasia is not the answer. It comes with too great a risk of abuse and coercion. As Dr. Daniela Lamas points out, *the real answer is that doctors and the medical field, as a whole, must do better.***

## **When the Hospice Care System Fails**

By DANIELA J. LAMAS, M.D. *nytimes.com*

Your father was gasping for breath. The hospice care providers had not yet trained you in how to respond. So you called 911.

Let me start with an apology.

When I saw that your 90-year-old father was in our emergency department, after being resuscitated while on home hospice, I assumed that I understood what had happened. As a critical care doctor, I have cared for *patients whose families have changed their minds at the last minute, grasping on to impossible hopes rather than face the reality of death.*

On the phone with the E.D. physician, I sighed. "Family?" I asked.

"Must have reversed the D.N.R." - the do-not-resuscitate order that is standard for a patient on hospice care. "They're on the way," she said.

I told her I'd head down. I was fairly sure that nothing was going to change. But before we took this patient to the intensive care unit, tethered to machines he had never wanted, I wanted to begin to talk with you.

There your father was. He was so pale. A ventilator breathed for him. His body, wasted by cancer, flopped like a rag doll. I touched his fingers and they were cool, vessels clamped down by the medicines keeping his blood pressure from plummeting. I imagined caring for him in the I.C.U., trying not to hurt him even more.

You came in crying, your brother and a sister trailing behind. It was summer and you wore a flowered skirt, your brother in a T-shirt that said something happy about Hawaii. I walked up to you, introduced myself. I'm sure you don't remember my name.

The social worker pointed us to a small meeting room down the hall. It must have doubled as an exam room and there were not enough chairs for all of us, so I sat down on a stretcher.

*Your father had come home just the day before from the last in a long series of hospital stays for incurable cancer,* you told me, weak but awake, with plans to begin hospice care at home. He had been able to talk to you and he seemed happy to be back in his own bed. He took little sips of juice.

The hospice team had stopped by as planned, to introduce themselves to your family and to begin the mountains of required paperwork. *They explained that they'd return the next day to talk more about what would happen as your father grew sicker, to teach you about how to use the meds that would treat his pain and to sign an advance directive so that he would not end up back in the hospital. They didn't want to overload you with too much on that one day.*

*But in the morning, before anyone from hospice had come back,* your father's breathing grew short. You did not yet have the tools to react when he started to gasp. You tried to do the right thing. First you called hospice. But as you waited on the line, your father stopped breathing altogether. Your brother

panicked, yelled for you to call 911. This is what life had trained you to do in event of an emergency, and so you called. You were so scared.

Over the phone, they coached your brother through the chest compressions. He did exactly as they said, and then he felt a crunch. At first he did not know what it could be but then he realized his father's ribs were breaking. He asked if he was doing something wrong and the 911 operator said it was O.K., that he should continue, that sometimes ribs break. It meant that he was doing a good job, that his hands were strong.

He was still doing chest compressions when the emergency medical team arrived. They restarted your father's heart with shocks of electricity, slid down the breathing tube. If it had been just a few hours later, he might have had a signed form at his home telling them not to do those things.

In the E.R., you took in a sharp breath, surprised, when I mentioned the tube. In the flurry of activity, you must not have seen them doing this.

"He's not breathing on his own?" you asked.

"No," I said.

You were quiet for a moment, we all were. But when you spoke your voice was certain. "He would never want that," you told me. "He wanted to be at home with us. He didn't want to die, but he never wanted to be kept alive by machines."

I shifted on the stretcher. Then I explained to you that although I worked in the I.C.U., your father didn't have to come up there. We could take out his breathing tube down there in the E.D. Your father would have wanted a chaplain, you told me, and so we could call one. It would not be the chaplain he knew, the one that might have been able to come to your home, but it would be the best that we could do. He would pass quickly, I said. We would make sure that he was comfortable.

You all nodded. It had happened so quickly. You never expected to end up here.

"I'm so sorry," I told you.

Those words felt so small, but I wasn't sure what else to say. *I know that even in the best of circumstances, dying at home demands an incredible amount of family members, more than they expect, and surely more than doctors like me ever realize. I simply have no idea what it must feel like to be at home watching a person you love take his last breaths. Sometimes that reality is untenable. I'm not sure it's even possible to fully ready yourself for this. Of course people get scared and plans fail.*

*But we didn't even give you a chance to make it work. We could have made sure you filled out an advance directive before you left the hospital, but we didn't. You trusted us to make a safe plan for your father, but you were left to watch him struggle without knowing how to help. You hadn't yet learned that you could have given him medications to ease his breathing, to keep him calm. You didn't have time to realize that calling 911 would start a cascade of interventions that your father had never wanted.*

And now, your brother will always remember the feeling of his father's ribs breaking under his hands. You will always remember the fear you felt when you saw your father gasp for air. You will know that he died in our E.R., behind a curtain, in a room that was not his own.

My apology can't take away those memories. But I can hope that when you look back on your father's death, you will also see this: You did everything you could. *We're the ones who must do better.*

**\*Comment:**

*A very familiar story to us in Hospice Care,.. receiving a referral a day before patient's demise. M.Yoong*