



Surviving End-of-Life Care

Lisa Marie Mellor, MD

(Fam Med. 2018;50(1):67-8.)

doi: 10.22454/FamMed.2018.683394

Listen to my colleagues preparing a seminar for our family medicine residents entitled “Navigating End-of-Life Care.” I experience a flood of emotions. I had always been a strong proponent of “no extraordinary measures” and “pull that plug” at the end of life, especially if the patient was brain dead. I have ordered many terminal extubations, and signed many “allow natural death” and “do not resuscitate” orders. My own deep fear of being brain dead and mechanical ventilator-dependent often fueled my convictions. However, since my own near-death end-of-life experience 3 years ago, I have significantly conflicted emotions about this topic.

There was no identifiable precipitant. I was practicing family medicine as a faculty physician in a residency practice. I developed a rare rheumatologic condition, and was treated with powerful immunosuppressants. One day, a seemingly minor respiratory infection rapidly developed into respiratory failure requiring intubation. This cascaded into acute respiratory distress syndrome (ARDS), multi-organ system failure and finally, severe encephalopathy. For a month, I was an intubated mess with no brain function. My prognosis was hopelessly poor. Many specialists caring for me were leaning toward terminal extubation. My own family members, knowing how I felt about extraordinary

measures, were murmuring to my physician that I might not like all of the extreme measures that were being performed, given the hopelessness of the situation. But the family physician managing my case was not ready to give up because of my young age (47) and the unknown etiology of my encephalopathy. In fact, she tempered the grim reality of the situation with just enough hope to keep my family from withdrawing life support while she pursued any and all treatment avenues for my rare encephalopathy, rheumatologic disorders, ARDS, and renal failure. She followed treatment recommendations from the most current journals to the most obscure. Finally, having exhausted all the recommendations from the literature and with nothing left to try, the encephalopathy miraculously began to slowly resolve.

It was later determined that I had posterior reversible encephalopathy syndrome (PRES). I got off the ventilator. I was paralyzed from the neck down and pretty confused—but I was alive! I spent 3 months at a rehab hospital and slowly learned to use my limbs again. My brain gradually recovered. Although I have large memory gaps, I can now think and function with only a few leftover physical deficits. I take 22 medications per day just to stay alive. My medications serve as a daily reminder of my experience, keeping me

grounded and grateful. Now back to work full-time as a faculty physician, I just recertified my American Board of Family Medicine exam with a very strong score!

It’s interesting when I run into the specialists who cared for me during my hospital stay. We talk, and they all say that I am a miracle. It is interesting to me that I think I can tell those who wanted to terminally extubate me. They look vaguely uncomfortable. But I don’t blame them for wanting to withdraw life support. Maybe I would have “pulled the plug” on a patient in my condition, too.

I feel conflicted and guilty when I discuss end-of-life care with my learners. The part of me that is a physician can list off the pros and cons of performing extraordinary measures, or of withdrawing care for each of our critically-ill patients. I am able to be clinically rational, and I seem perfectly reasonable to my colleagues. I confidently discuss comfort care, hospice care, and withdrawal of life support. The part of me that is a miracle patient is not so sure. It is easy to withdraw life support on an 88-year-old with metastatic cancer. What about someone closer to my age—a 48-year-old? What about a 60-year-old? How bad

From the Rutgers University Robert Wood Johnson Medical School, CentraState Family Medicine Residency, Freehold, NJ.

does the cancer have to be? Is any case really “hopeless”? All of my old, easy answers are not so easy when I think how close I came to being dead, and how extraordinary measures kept me alive. And there are so many lingering questions! What if my physician had given in to all the specialists who wanted to terminally extubate me? What if I had been some random patient instead of a friend and fellow physician? Would I be dead right now?

So now my family wants me to get a will and an advanced directive. My deep belief in “no extraordinary measures” and “pull the plug” is not so clear any more, as my 20 years of clinical experience and teaching collide with my own improbable existence. How do I decide on advanced directives when all my old ideas have been demolished by personal experience? It literally pains me to choose “any and all extraordinary measures” on my own advanced directive because I often advise my patients to choose the opposite and “Allow Natural Death”. I fear the scenario where I end up

a “vegetable on a vent”, but what if lightning strikes twice and I end up in the same situation again? I would certainly want the same chance to come back from the brink again.

Ruminating on these questions can be all-consuming. When it comes to end-of-life care, there are no easy answers. Physicians are not omniscient, and the end of life is precarious and unpredictable. Each case needs to be assessed individually. Careful consideration of the pros and cons of extraordinary measures and the situation of the particular patient is of paramount importance. We must remember that my own case is an example of the kind of miracle that keeps us practicing medicine and fighting at the end of life. The ambivalence that I endure is also part of that miracle.

When I come back to reality, my colleagues are still constructing their end-of-life seminar. I listen to them describe how to make these complex decisions in theoretical terms, using logical algorithms. I smile. I think I’ll skip the seminar.

ACKNOWLEDGMENTS: I would like to thank John Clabby, PhD for his constant support as I wrote this essay, and Maria F. Ciminelli, MD for saving my life.

CORRESPONDENCE: Address correspondence to Dr Mellor, 1001 West Main St, Suite B, Freehold, NJ 07728. 732-890-0667.