

A PIECE OF MY MIND

Our Best Judgment

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"I told them no ventilator. Your thoughts?"

As a palliative medicine physician for almost 30 years, I have discussed such questions with thousands of patients and their families.

This however was a text message from my brother, hospitalized more than 100 miles away in our hometown. It was early evening. I was walking through the aisles of a supermarket, not an ideal scenario for a thoughtful and deliberate response. Les was being transferred to the intensive care unit (ICU) shortly after being admitted with what we had just learned was COVID-19.

It was the hospital where I'd previously practiced for more than 3 decades, helped to establish a hospice and palliative medicine program, and chaired the ethics committee for 20 years. Visualizing his room, the halls, the elevator, and the ICU room into which he was being transferred was easy. Realizing what it meant for a sibling 12 years my senior, with many medical risk factors, made answering his question much more difficult.

I texted back: "Would consider a trial period of a week or so, but it's your call. Love you whatever you choose."

The linchpin for my brother's successful transition was the intensivist who made a clear prediction and offered a strong recommendation based on a patient's stated preferences and values.

Even with all my training, experience, and focus on end-of-life decisions, I felt helpless and uncertain. For years, my brother had made clear to loved ones that he would not want to be on life support and fed artificially for any prolonged period. He had witnessed protracted deaths in friends and family and wanted none of it.

Les had been dealing with chronic respiratory problems that had begun to limit his activity. I knew he had seen a pulmonologist and was placed on steroid and bronchodilator inhalers, but that was about it. No supplemental oxygen was needed nor had he ever been hospitalized. Perhaps he could get through this. And what did "prolonged" mean anyways?

Les was not the most cautious individual as the pandemic roared ahead in early 2021. A devout Catholic, he attended mass and received communion twice a week with his best friend throughout the pandemic. But breakfast inside a cramped restaurant also twice a week afterward seemed to be tempting fate. Nonetheless, Les was garrulous to the extreme and a friend to all he met. Social isolation was unthinkable. "If I die, I die. I've had a great life." As a palliative

care physician I kind of got the point that he was not willing to trade the quality of a "great life" for more time on this earth.

So I knew his wishes as did his wife who was his first designated surrogate with me appropriately second. And I knew he had had some pulmonary issues but none of the particulars. Even with that knowledge and my years of clinical experience, 100 miles away I felt helpless to confidently advise him.

Sleep was not restful that night with plans to make coverage arrangements in the morning and return to my hometown. At 6 AM, the intensivist called with an update. Having worked with him for years I knew to trust what he told me: "It's looking pretty bad. He will probably not last the day." When I asked about a trial of mechanical ventilation, he expressed a high degree of certainty of Les eventually needing a tracheotomy and gastrostomy based on his review of the imaging, laboratory studies, and physical examination. The intensivist's certainty was enough. My sister-in-law was deferring in part to me, and I could defer to my brother based on his prior expressed wishes and the intensivist's clarity in communicating: "I would not do this based on what I've seen, Skip. I think we should keep him comfortable." Two hours later, on my drive home, a call reinforcing this decision came from the infectious diseases consultant from outside of his ICU room.

Les died within 24 hours of admission. In retrospect it appears that he had contracted COVID-19 at least a week prior and came through the emergency department doors just as the inflammatory response engaged his damaged lungs and probably too late for the steroids that were administered to help.

But our family's grief was greatly attenuated by the excellent care he received:

- Within 18 hours of admission both the critical care team and infectious disease consultant told our family what to expect.
- Les's desire for no CPR (cardiopulmonary resuscitation) nor prolonged intubation could be honored because it had been discussed in advance of his hospitalization with his doctors and loved ones.
- Based on his wishes, the medical team recommended that he transition to "comfort care only."
- His wife and son were allowed to visit and stay for the duration.
- A chaplain arrived at the bedside while my brother was still awake and prayed with him.
- The chaplain found a priest who could not enter the room to bring communion, but Les' son, a lay minister, could share the Eucharist with my brother and his wife. That was extremely important to all of them.

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Section Editor: Preeti Malani, MD, MSJ, Associate Editor.

- With the assistance of his wife and son, Les was able to video chat with all his children and grandchildren the morning of the day he died.

- Palliative care subsequently made 3 visits to titrate medications for comfort.

- As death approached, Les was kept very comfortable by an experienced ICU nurse. As the disease raged through his lungs, she carefully titrated midazolam and hydromorphone as needed. He appeared to be sleeping peacefully for a couple of hours until he died with wife and son holding his hands.

All of this in less than 24 hours.

The family described the experience as peaceful and spiritual. Yes, they are grieving but without guilt, without anger, and with a sense of closure for them and for me as well.

We recognize our good fortune given the suffering COVID-19 has imposed on hundreds of thousands of patients and families with loved ones dying alone, with so much uncertainty about outcomes. Our hearts ache for them. We must ask why not them? Why can't all deaths, COVID-related or not, be this peaceful and without guilt for the survivors?

The linchpin for my brother's successful transition was the intensivist who made a clear prediction and offered a strong recommendation based on a patient's stated preferences and values. We were rescued by a physician who acted as a physician should. I could not see my brother nor his labs nor his imaging studies. I had not cared for hundreds of patients with COVID-19 in the ICU. I could not be objective. Thank goodness this physician and his colleagues did not passively offer a menu of options as I've seen so often in joint meetings among specialists and families. These sessions become cringe-worthy as I witness pain and guilt seep into the words and expressions of family members forced to make decisions where the medical reality provides only one realistic alternative. If I could not have made a menu choice, how can we expect

families without a medical background to proceed without very firm and clear guidance? Some physicians fear later second-guessing or recrimination and thus avoid putting themselves out there even when asked: "What would you do?"

Strong recommendations from physicians do not preclude partnerships with patients and families. A purely paternalistic approach would forego discussion and simply allow the clinician to decide. Physicians who make strong recommendations in partnership with patients and families are not acting with paternalism. Instead, they are acting as doctors should by putting patients' values first and then putting those values into the appropriate medical context for families. But this partnership is always unequal. It was even for me, a physician with years of experience caring for seriously ill patients, trying to help my brother's family without the specific skill, knowledge, and experience held by that capable intensivist.

For some clinical dilemmas, truly balanced medical alternatives exist. These decisions need to be based on patient preferences we have not yet divined. Incumbent on us is the responsibility to elicit the patient's wishes, priorities, and principles. We then must translate those into the medical reality, make clear recommendations based on that reality, and operationalize them as best we can. We must try to do so with at least a sense of humility and of the patient as an individual who is loved and appreciated. When even tragic realities are faced with honesty, clarity, kindness, and compassion, present and future pain can be at least in part alleviated. I am at peace with our decisions and Les' death because of these compassionate and capable professionals who spoke and acted decisively.

We have far to go as a health care system in providing the kind of support received by my brother and his family as we confronted his ultimately fatal illness. But it begins with clinicians acting as professionals exercising their best judgment, helping us to see down the road to decide how to proceed.

Published Online: September 16, 2021.
doi:10.1001/jama.2021.16348

Additional Contributions: I thank my sister-in-law for letting me share my brother's story and the

many professionals who helped him achieve a dignified death.

Conflict of Interest Disclosures: None reported.