Section Editor
Anne W. McCammon,
MD, FAAN

No man's land

Paul Rousseau, MD

Correspondence to
Dr. Rousseau:
palliatiivedoctor@aol.com

"Dr. Rousseau, please tell us what you think. They want to insert a tracheostomy and feeding tube. Mom never wanted that."

A distraught daughter wanted to know my thoughts on Brenda, her 55-year-old mother now 5 days post-brainstem hemorrhage. But this was the daughter of a close friend who was asking my opinion—I was not there as a consultant. Her mother was reportedly awake and opening her eyes, but unable to breathe without a ventilator. It was too early to provide any prognosis, but per the family, the attending intensivist was optimistic.

"Mom never completed a Living Will, but she always told me if she couldn't live independently, she didn't want to live—that wasn't quality of life to her."

She paused and looked at her family. "Dr. Rousseau, I think we need to honor her wishes and withdraw the ventilator and let her die."

However, the younger daughter wanted to wait and see how much her mother improved, and if that meant inserting a tracheostomy and feeding tube (PEG), that's what she wanted. Brenda's 5 siblings weren't sure what to do at first, but after hearing the optimistic words of the intensivist, also leaned toward time, a tracheostomy, and a PEG.

I went to visit Brenda and spoke with the nurse prior to entering her room.

"In 20 years of neuro nursing, I've seen some brainstem hemorrhages do really well. She's one of them. She's nodding her head to questions, and moving her extremities. Ethically, I couldn't withdraw her from the ventilator, I just couldn't."

When I entered Brenda's room, like anyone confronting a similar situation, I was taken aback. This once vibrant woman lay bedbound, an endotracheal tube protruding from her mouth, intravenous lines snaking from bruised arms, a urinary bag hanging on the side of the bed, compression supports circling her legs, and the ever-present whooshing of the ventilator and beeping of the heart monitor filling the silence. I called her name, and she halfway opened her eyes. I asked her to move her arms and legs, and to squeeze my hand, and she did. I was encouraged—never mind the movements were hesitant and

uncertain. But she tired quickly, and slowly closed her eyes, so I bid her goodbye and returned to the waiting area.

The family asked my thoughts, and I told them for a brainstem hemorrhage, she was doing remarkably well, although I had not seen her MRI and had not spoken to the attending physician. I was also not a neuro-intensivist. At this point, 5 siblings and the youngest daughter wanted to proceed with the tracheostomy and PEG—the oldest daughter was the lone dissenter. I told them that a tracheostomy and feeding tube were not unreasonable, considering how well she seemed to be doing. I also told them that if she did not significantly improve over the next 2 to 4 weeks, or became worse, life-sustaining therapy could, and should, be withdrawn. But I also cautioned that withdrawal is fraught with emotional stress and accusations of moral and ethical wrongdoing, particularly when there is disagreement among family members. I asked that they put their differences aside and carefully consider the benefits and burdens of the procedures, as well as Brenda's recounted verbal directive, before proceeding. But as I looked at their faces, I feared my words had only muddled the decisional waters.

Saying that, I full well expected her to stay in the hospital, at least for the next week or so, and suggested they request a palliative care consult, the sooner the better. They needed impartial and unbiased guidance, not a family friend who, while a palliative care physician, was battling a measure of subjectivity. I told them palliative care could meet with all of the family and develop realistic goals of care, so everyone could voice their opinion, and no one would feel marginalized.

I excused myself so the family could talk and returned to see Brenda, and this time, after briefly assessing her mental status and explaining what a tracheostomy was, asked if she would want one. She nodded yes. A while later I asked again, and again she nodded yes. Still, I wasn't certain her cognition could grasp the gravity of her situation and allow her to make a truly informed decision.

I then spoke with the attending physician, who was very positive. She related that she expected

Listen to Dr. Rousseau read this story, available on the iPad® and Android™ devices.

Brenda to recover significantly, and strongly recommended a tracheostomy and PEG. In fact, she stated Brenda also indicated to her that she wanted a tracheostomy. And like the nurse, she was resolute in her beliefs: "Ethically, I can't withdraw the ventilator."

The oldest daughter, disturbed by what she perceived as a violation of her mother's wishes, became angry and abdicated lone decision-making to her younger sister. The tracheostomy and PEG were completed the next day, and 1 day later she was transferred to a long-term acute care hospital with a goal of weaning her from the ventilator, and then transferring her to a rehabilitation facility. I was surprised and bewildered by the hurried approach and hasty discharge. Regrettably, there was no palliative care consult, and there would be none.

Flash forward 10 days. Brenda was now 19 days posthemorrhage, the ventilator had been weaned, and plans were being made for transfer to a rehabilitation facility. She had spastic movements of both upper extremities, early contractures in her right hand, and minimal but purposeful movement of her legs. She had likely lost peripheral vision, had nystagmus, could not speak, and appeared a long, long way from caring for herself, and, in my opinion, would likely never be able to care for herself. The initial improvement after her stroke was now stationary, if not a little worse, save removal of the ventilator and increased alertness. Four days later I visited again, and not much had changed. The same 7 days later. She nodded her head appropriately to questions and appeared to have good cognition, but that was it. I feared she was "in there," trapped in a mind that was awake and aware, but with a body that eluded her control. How terrified she must have been.

As I sat there, she raised her spastic right arm, the arm erratically waving like a windblown flag until it hit her forehead, then fell to her side. Then she coughed a cough of rattling phlegm, her face reddened from the effort, as her eyes danced a nystagmic dance and drool ran down her cheek. How demeaning this must have been to her. Tears came to my eyes. I paused, hung my head, and rubbed her hand. I then asked a question for which I knew the answer.

I asked if she wanted to live like this—she nodded no. I asked again—she nodded no.

I left sickened and hurting for this woman padlocked in a world of the infirm and the invalid. Sending her home with hospice would have been the best thing, but the family couldn't agree. In fact, they couldn't even agree that she had decision-making capacity, even though she nodded her head appropriately in response to questions. The only hope, albeit a small one, was that she would regain her speech and verbalize exactly what she wanted, or the family would come to an amicable consensus, honor her verbal directive, and let her die.

As I waited for the elevator, I saw the attending physician and asked his thoughts. He told me, "We're past withdrawing therapy, past letting her die." I asked his prognosis for recovery—he couldn't, or wouldn't, give one.

"She's going to a rehab facility," he said. "There's no going back. It's too late."

"What do you mean it's too late?" I asked.

"What I mean is we can't withdraw her tube feedings; it wouldn't be ethical." And with that, he walked away.

But he could have withdrawn the tube feedings. In fact, it's not only ethical to withdraw artificial nutrition, it's a guaranteed right under the Patient Self-Determination Act of 1990. But I knew there was an additional concern festering beneath the surface—the "s" word: starvation. There were some quietly arguing that withdrawing tube feedings was tantamount to death through starvation. And while Brenda would admittedly die from a lack of nutrition and hydration (absent an acute medical event), withdrawal of artificial nutrition is generally considered the same as withdrawal of a ventilator: both are extraordinary life support measures that sustain a life that would not ordinarily be sustainable. But for now, the arguments were irrelevant—the tube feedings would continue.

I entered the elevator, alone with my thoughts. Brenda was lost in a broken, sickly body, going where she never wanted to go. But even worse, she was lost in a no man's land, alone in a living coffin, unable to talk and unable to do, quietly longing for a hastened death.

Neurology[®]

No man's land

Paul Rousseau

Neurology 2016;86;1459-1460

DOI 10.1212/WNL.0000000000002565

This information is current as of April 11, 2016

Updated Information & Services

including high resolution figures, can be found at:
<http://n.neurology.org/content/86/15/1459.full>

Subspecialty Collections

This article, along with others on similar topics, appears in the following collection(s):

All Ethics in Neurology/Legal issues

http://n.neurology.org/cgi/collection/all_ethics_in_neurology_legal_issues

Intracerebral hemorrhage

http://n.neurology.org/cgi/collection/intracerebral_hemorrhage

Palliative care

http://n.neurology.org/cgi/collection/palliative_care

Professional conduct and ethics

http://n.neurology.org/cgi/collection/professional_conduct_and_ethics

Permissions & Licensing

Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:

http://www.neurology.org/about/about_the_journal#permissions

Reprints

Information about ordering reprints can be found online:

<http://n.neurology.org/subscribers/advertise>

Neurology® is the official journal of the American Academy of Neurology. Published continuously since 1951, it is now a weekly with 48 issues per year. Copyright © 2016 American Academy of Neurology. All rights reserved. Print ISSN: 0028-3878. Online ISSN: 1526-632X.