Last Stand

Category: Stories
written by E. Wesley Ely | July 24, 2015

E. Wesley Ely

The first time I saw Jessa, she lay crumpled in the ICU bed, paralyzed, expressionless and unable to speak. A military veteran, she had fought in Desert Storm, but she now was facing a deadlier and more inexorable foe: amyotrophic lateral sclerosis (ALS), aka Lou Gehrig’s disease.

This disease causes progressive loss of muscle control, and Jessa was unable to speak, eat or breathe on her own. Her only means of communicating was through small facial movements—opening and closing her eyes or mouth, raising her eyebrows.

A dozen people made up her ICU team: three interns, three residents, a pharmacist, a nurse, a respiratory therapist, a social worker, a hospital chaplain and myself—the lead physician, or intensivist.

My intensivist mind, trained to seek solutions, skitters down a patient’s problem list in search of answers. And Jessa’s list was extensive: she needed a feeding tube, IV fluids, diapers and a special bed to prevent bed sores, antibiotics for a newly contracted pneumonia, intermittent sedation to ease anxiety and narcotics for chronic back pain.

But now, listening to the respirator pumping air into Jessa’s lungs and felt her intense cobalt gaze on me, I saw one thing clearly: any concerns about antibiotics or nutrition took second place to a larger question.

“What do we know of Jessa’s wishes about staying on a ventilator, now and in the coming weeks and months?” I asked the team when we stepped outside the room to confer.

“Her chart says that she wanted to be placed on a ventilator when she couldn’t breathe on her own,” said one resident.

“Look how long Stephen Hawking has lived that way,” the nurse chimed in.

“I don’t think we should look at someone else’s life,” another resident burst out, clearly frustrated. “She’s suffering. I’d never want to live like this. She probably didn’t know it would be this way when she requested life support.”

I listened, having no strong opinion of my own as yet.

At that moment, Jessa’s husband Zach walked into the ICU. We shared our concerns about Jessa’s situation and asked him about her wishes.

Calmly, he replied, “Doctors, while it wouldn’t necessarily be my choice, Jessa does want life support so that she can have as much time as possible with me and the people around her. She was raised to believe that all life, however frail, is sacred. It might seem paradoxical, but that was a key reason she joined the military—to defend life and freedom.”

Later that morning, he shared his own wish: “Just make sure Jessa knows that she’s not a burden, and that serving her is our privilege.”

This conversation led to others over the next two weeks, and they sparked what I now see as a transformative period in my growth as a physician and in my understanding of patients like Jessa.

The next day, Zach told us more. “Jessa was born in Germany; she’s bilingual. We’ve been married for twenty-seven years. We have no living children—we had several miscarriages. I’m all the family she has.”

It had been Jessa’s dream to serve as an American soldier. After they married, she enlisted and was deployed to Iraq as a diesel mechanic—one woman among over 1,000 men. “She got caught under a tank once and smashed her head getting out,” Zach recounted. “They flew her to an army hospital in Germany, and she recovered and went back. She’s tough as nails.”

More than twenty years later, he said, she was diagnosed with ALS. “I’ve learned a ton from her about serving without concern for self,” he added. “And now I’m learning even more. The amazing way she adjusts to whatever life throws at her….She’s constantly recalibrating my vision of how to make the most of every moment. Like today, she’s on that breathing machine, and she just smiled at me with her eyes.”

In those few minutes, Zach revealed our silent, nearly motionless patient as a heroic person—someone I admired not only for her technological skills but for her pioneering attitude and resolve. I got an inkling of why she was fiercely holding onto the time she had left.

Still, some team members continued to see her quality of life (or QOL) as unacceptable. More than once, they called it “hellish.”

When I told Zach this, he said, “Jessa once said she believes hell to be the absence of hope, just as cold is the absence of heat and darkness the absence of light. Now that you’re getting to know her, can you see that she doesn’t consider her illness hellish?” He whispered, “She’s surrounded by love.”

These discussions, as difficult as they were, marked a major shift in my understanding. I began to see how often I impose my own QOL standards onto patients—a fundamental clinical error.

Researching the empirical data, I learned that ALS and other “locked-in” patients often rate their QOL as acceptable despite their physical debility. Their focus shifts to less tangible qualities—transcendence, spirituality and security. Pondering this, I realized more and more clearly how, in this particular situation, it was Jessa’s values and perceptions that mattered, not mine.

Our role, I saw, was to dive into the chaos of Jessa’s life and offer her care and comfort despite our inability to cure her.

Over the next week, we worked with our palliative-care team to ease Jessa’s pain, anxiety and delirium (which receded along with her pneumonia).

Every day, I made a point of remembering bioethicist Edmund Pellegrino’s words: “Healing can occur when the patient is dying even when cure is impossible.” With this in mind, I asked Zach if Jessa would enjoy being read to, as our team had done with other patients.

“Doc, she loves poems and the Psalms,” he said immediately. We began to take turns reading to her every day.

On Jessa’s last day with us before she was to leave for a long-term care facility, I chose Edna St. Vincent Millay’s *Sonnet XXX*.

“Love can not fill the thickened lung with breath, nor clean the blood, nor set the fractured bone; yet many a man is making friends with death, even as I speak, for lack of love alone….”

As I read, Jessa’s mouth opened wide, in a smile brighter than any we’d yet seen from her.

The medical student across the bed from me began to cry. “From joy and amazement,” the student later said.

Seeing Jessa’s smile and the student’s tears, I felt my mind stop in its tracks. Time stood still.

Jessa had lifted us above the physical realities of our existence and into something mystical. I can’t explain it, and I almost don’t want to try. Let’s just say that she gave us a private treasure, one that I will always savor as a gift I never expected or deserved.

I squeezed Jessa’s hands, holding her eyes with mine. Finally she looked away and up to the ceiling, and I stood in thought beside her.

Although my team and I loomed over Jessa as she lay in her bed, I knew that in spirit she soared high above us.

About the author:

E. Wesley Ely is a professor of medicine at Vanderbilt University School of Medicine and associate director of aging research for the Tennessee Valley VA Geriatric Research Education and Clinical Centers. He has authored more than 275 peer-reviewed articles. He and his wife, Kim Ely, a surgical pathologist at Vanderbilt, have three lovely daughters. His reflective writing has appeared in the *Wall Street Journal*, *JAMA*, *Annals of Internal Medicine* and elsewhere. “I got into writing as an outgrowth of being raised by a single mom, Diana Ely, who was an English teacher and director of Shakespeare. Without this form of reflective writing, I’d never be able to process the immense gift of being immersed in the lives of countless wonderful patients, each of whom has a unique story and path.”

Story editor:

Diane Guernsey