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Leaving no man's land

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I knew that I could not escape myself...
—Eula Bliss, “No man’s land”: American Essays,
Graywolf Press, 2009

Brenda had had a brainstem hemorrhage and survived. But 4 months later, and after 2 weeks of rigorous rehabilitation, this 55-year-old woman was not improving.

A tube fed her and a tracheostomy kept her airway clear. Her arms were spastic and uncontrolled and her legs and feet were rigid and fixed. Her head fell forward without neck support. Saliva pooled in the corner of her mouth and spilled down her chin onto a bib tied to her neck. Her left eye had been temporarily sewn shut to protect the cornea. However, little by little, she had begun to form words that, while garbled, were understandable. After several long and labored conversations, it became evident that she was not only cognitively intact but capable of making decisions. She was “in there,” awake, aware, and afraid.

Her verbal directive, told to her oldest daughter before the hemorrhage, indicated that should she have a catastrophic event and be unlikely to return to independent living, she would not want to live. But amidst a contentious disagreement among family members and an overly optimistic prognosis from her attending physician, Brenda was now stuck in no man’s land.

“What...choices...do...I...have?” she asked.

Brenda was always straightforward, so I was honest and plainspoken and told her the truth. She had 2 paths she could travel: transfer to a nursing home and live out her life there, or withdraw the tube feedings and go to hospice until she died, likely within 2 weeks, perhaps a little longer. Neither path offered hope.

I sat there for a moment, and then, with tears in my eyes, I asked her, “What do you think you want to do?”

She struggled to speak, but amidst coughing and spasms, she asked, “What...would...you...do?” I told her I would not want to live if I was in a similar situation, but I was not sure I would have the courage to withdraw the tube feedings.

“But I think we eventually reach a point where stopping the feedings seems kinder and more humane

than continued existence. We just get tired,” I said. “But I’m not sure you’re there yet.”

She cried and coughed, and moved her right arm like a torn flag flailing in the wind.

“I’m...afraid...to...die,” she said.

She paused, then spoke again. “But...I...don’t...want...to...live...like...this.”

It was clear withdrawing would be difficult, but her existence was intolerable. She could not scratch an itch, comb her hair, brush her teeth, or dress herself—she was a prisoner of everyday life, dependent on someone for everything.

“I...don’t...want...to...live...like...this.” She paused for several seconds, took a deep, wet breath, then said, “This...is...existence...not...life.”

She cried, and strings of thick phlegm stretched from her lips like a spindly spider web.

“But...I’m...afraid...to...stop...the...tube...feedings. I...can’t...do...it.” Brenda became a living ornament, propped in a wheelchair for hours on end. My heart ached for her.

A week passed, and she continued to decline. Finally, with coercion from her youngest daughter, and a threat that insurance would no longer pay for rehabilitation, a decision had to be made. Brenda chose the nursing home path, a path she abhorred, but one that would allow her time to think.

The hospital transferred her the following day. When I visited her a few days later, I was taken aback. I found her sliding out of her wheelchair with the seatbelt lodged tightly under her breasts, her right arm hanging over the armrest with 2 fingers tangled in the spokes of the wheel, and her head angled down and to the side, partially occluding her tracheostomy. Thick, phlegm-like drool dripped from her chin onto her blouse, as a humid cough heralded a likely pneumonia. I was appalled at the care. She did not even look at me. Her spirit was gone—it was clear she had given up. I hung my head as tears welled in my eyes. I began to sob.

“Do you want to stop the tube feedings?” I asked. She did not respond, so I just sat there, offering my presence and holding her hand. She closed her right eye, and with rattled respirations, fell asleep. I kissed her forehead and quietly left.

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A week later, she had had enough, pushed by a dismal existence in a place where the word “home” was a charade, and in part by the unchangeable remnants of a brainstem stroke.

She asked to go to inpatient hospice and discontinue the tube feedings. I marveled at her inner strength, but was dismayed when one sister called it “starvation,” while a brother suggested she would “suffer horribly by not eating or drinking.” Still other family members likened her decision to a “suicidal euthanasia.”

Brenda’s oldest daughter countered the accusations, defending her mother. I reminded the family that it was Brenda’s decision to withdraw the tube feedings, and they needed to honor her wishes, for she was the one existing in a broken body, not them. I also told them it was not starvation or euthanasia, but rather withdrawal of an artificial means of life support similar to a ventilator.

However, I was worried. I was not certain the family could handle seeing Brenda linger and wither away, as one can sometimes do without food or fluid. She was overweight, and her physical changes would likely be more pronounced than someone thinner or overtly cachectic. But in one final show of love for her family, Brenda lapsed into a coma and died 3 days later, sparing them the sight of a shriveling body.

In the end, Brenda reached the point where withdrawal of nutrition and hydration was kinder and more humane than continued existence in a body that was no longer hers. Her brief life as a living figurine in the halls of a nursing home was just too degrading and demeaning. She saw no promise of a future and was suffering terribly, so she chose the only choice she had, a choice that she did not want, but a choice that was arguably necessary and right.

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