Peabody's Corner

Locked In and Locked Out

"... for the secret of the care of the patient is in caring for the patient."
— FWP

Herbert L. Fred, MD, MACP

As a little girl, Helen recited 2 lines in a school drama: "I have *always* been beautiful. It was *you* who could not grasp it." Throughout her life, she jokingly repeated those lines with a wry smile and turned-up nose, usually in response to, "Gee, Mother, you sure look beautiful today."

The fact is, Helen, my mother, really was beautiful, not only in how she looked, but also in how she lived. She never sulked, showed prejudice, or carried a grudge. Whereas my father was a charitable, outgoing, prominent figure in the community, Mother was his quiet, ever-supportive mate who lovingly ceded him the limelight. Her main satisfaction came from nurturing her family. She set high standards with special emphasis on education, discipline, and honesty. When my sister and I fell short, Mother taught us how to do a better job the next time around.

After Dad died, Mother lived alone—200 miles from me and 400 miles from my sister. She enjoyed maintaining her home, dining out with friends, reading novels, traveling, and rooting for her favorite sports team, the Dallas Cowboys. But her biggest pleasure was having my sister and me back home for visits.

When she was 80, Mother took the lead role in a real drama. This time, however, she had no lines. Still, she gave a riveting performance, holding her audience's attention for 11 days and nights. The stage was the hospital where I was Director of Medical Education, and the cast included me, my sister, and the many people involved in her care.

About 3 years earlier, Mother had begun having intermittent trouble speaking—as if she had mush in her mouth. The episodes would come on abruptly, last for a minute or so, then disappear. Although an extensive work-up yielded no cause, Mother knew that the episodes might be signaling an impending stroke, a destiny she dreaded. "When my time comes, I want to go quickly," she would say, often and emphatically. "Don't let me linger or suffer." I took this as her medical directive.

One day, Mother called to say that she missed me and wanted to see me. Because I had a busy schedule and could not leave town easily, she decided to visit me. Waiting at the airport to board the plane, she had one of her spells. But she was bent on making the trip, and she completed it in good spirits.

At the end of our second day together, Mother suddenly couldn't speak. She could only make sounds, and the difficulty did not go away. Terrified, she hugged me tightly, and, for one fleeting moment, was able to say, "I love you." Soon thereafter, she lapsed into a coma.

Several days later, the extent of damage became clear. Serial CT scans had shown evidence of a massive pontine infarction that had irrevocably paralyzed Mother from her eyes down. Even more brutal was her return to consciousness. She was aware of her abject helplessness and could communicate with us only by blinking. She was locked in and we were locked out, and there was no key to that impenetrable door.

Mother's irreparable situation raised questions that I struggled with under intense personal circumstances. What approach is most humane for an elderly woman who was previously independent and, now, with mind intact, will never move or speak again? And what do you say to her when she looks at you?

The medical literature at that time (1985) did not provide me with answers. It said nothing about the emotional devastation and ethical dilemmas peculiar to the locked-in syndrome.

At first, I told Mother that she couldn't speak because of the tube in her throat. I didn't mention her paralysis, fearful that it would increase her own fears. I soon realized, however, that words could not fool her, nor could they hide the totality of her affliction. Consequently, I limited my conversations with her to "I love you" and

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hoped that holding her hand, stroking her brow, and kissing her cheek would make both of us feel better.

I knew that as long as Mother remained conscious, she was experiencing unthinkable mental agony—agony far greater than most individuals ever experience or could ever imagine. She was literally entombed alive. Impelled by her wish not to suffer, and tormented by seeing her suffer, I pleaded to have her senses dulled. Her primary physician discussed the matter with the clergy, hospital administrator, family, and colleagues, and agreed to give Mother relief.

With a morphine drip, Mother lost the horrid awareness of her situation. For that I was thankful. But she also lost all human contact, and I lost her.

We expected her to die soon, but with good skin care, an adequate airway, and water, Mother lived 5 more days—long enough for all of us to second-guess our decisions. Finally, her temperature rose to 109 °F, and she died.

The long ordeal had several positive features. It took place in *my* hospital, which assured Mother the best possible attention and allowed me access to her at all times. It forced my sister and me to keep a vigil, a torturing vigil that enabled us to put aside our differences and gain new love and respect for each other. And it prompted the hospital administrator to tell me that a host of hospital personnel had benefited from seeing another side of me—the tearful, devoted, powerless son, not the clinician in control.

Mostly, however, I'll remember the ordeal as Mother's final gift to me—a gift that broadened my understanding of death and dying. Death can bring happiness as well as sadness, togetherness as well as loneliness, and tranquility as well as turmoil. And the way we die, like the way we live, can teach much and inspire many.

Submissions for Peabody's Corner should 1) focus on the interpersonal aspects of a specific patient–doctor experience; 2) be written in storybook fashion; 3) contain no references; and 4) not exceed 5 double-spaced typescript pages.