



Volume 13  
Issue 2  
2018

## Writing His Own Ending

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I met Lon a week after he had been told that he would die soon. After a year of troubling symptoms—slowing gait, stooping posture, slurring and thickening of his speech—he had finally grown too sleepy and confused for his family to do anything but bring him to the emergency room. Positive-pressure ventilation courtesy of Bilevel Positive Airway Pressure (BiPAP) helped flush the carbon dioxide from his system and cleared his sensorium just in time for him to learn his diagnosis: Amyotrophic Lateral Sclerosis, an unfortunate diagnosis by any standards. But rather than broadcasting its intentions by first weakening the limbs, then progressively overtaking Lon’s ability to speak, swallow, and breathe, this less common bulbar subtype had robbed him of these functions straightaway.

A feeding tube was inserted with what might have been knee-jerk consent, still startled as he was to come face to face with his mortality just past the age of seventy. However, Lon adamantly refused a tracheostomy, even as he grew to require BiPAP for an increasing number of hours each day.

Given the choice between ventilator dependence and transfer to inpatient hospice with removal of the BiPAP and impending death, he chose the latter.

By the time our paths crossed during my hospice and palliative care fellowship, Lon was barely able to speak due to the mask constantly present on his face, in addition to the weakening of his vocal cords. Yet I could imagine his voice as strong and deep. I could see him holding court in a boardroom or at the head of a dinner table, wearing a blazer and loosened tie, even though I had seen him only in a hospital gown. “Harris tweed,” he wrote on a dry erase board by way of greeting when one of my colleagues entered his room wearing exactly that.

Lon had little patience for the process of dying; while he clearly cherished time with his wife and adult children, who set up camp in his room and stocked every corner with snacks, beverages, laptops, even a printer, he asked me every day how much time he had left.

And every day I told him that I didn’t know.

Lon, it turned out, was able to tolerate around-the-clock BiPAP surprisingly well. When the skin on the bridge of his nose grew raw, he tried a different mask that relieved the pressure to his nose and also allowed his glasses to perch on his face so that he could read notes from friends and peruse the daily paper. And so Lon simply went on living.

I learned from the first time I entered his room that Lon could communicate only via messages written on dry erase boards. Meniere’s disease had damaged his hearing even before the ALS wreaked

havoc on his central nerves and impaired his speech. He grew irritated when others conversed around him without transcribing their discussions so that he might follow and take part. The day that I met him, I scrawled a feeble-seeming “Hi” on the board that his family handed me, followed by my name. “I’m going to be your doctor,” I wrote, then turned to him for a cue, unsure just how we might proceed.

I needn’t have worried; Lon took it from there. We grew acquainted. I learned tidbits of his Irish Catholic upbringing and found that we shared a love of poetry. He distributed copies of a salty limerick to each member of the staff. It might have been crude, but for the fact that each was adorned with a personalized message of thanks. Mine read: “Doc, thanks for always being honest.”

It truly was the only thing I could offer. He had little in the way of emotional or spiritual symptoms, other than an honest curiosity about what the future would hold. I talked and wrote through the pathophysiology of the disease with Lon and his family, explaining as clearly as I could that his muscles, especially his diaphragm, would continue to weaken, impeding ventilation, and that carbon dioxide would once again build up in his brain. It would happen despite the use of BiPAP, I told them, though I couldn’t predict how quickly. The only way to truly keep it at bay would be to initiate invasive ventilation via tracheostomy, which Lon adamantly refused.

So we focused on the things that he could do and enjoy. Once he learned that taking nutrition

through his feeding tube would be unlikely to alter the course of his disease, he had no desire to use it. With no significant appetite, and understanding his risk of aspiration, Lon chose instead to take sips of the beverages whose tastes brought him some joy. Coffee: as hot as possible. Smoothies: always mango, always cold. He took visits from family and friends, and during long “talks” with his wife and children, expressed sentiments that they captured by taking photographs of the dry erase boards, preserving his words written in his own hand.

Though he usually greeted me with a list of prepared questions, on some days he seemed to have nothing further to discuss. “Go take care of someone who needs you, Doc,” he wrote one morning with a smile, waving me away. “I’m fine.”

Had he been asked a year or even a month before we met how he would like to spend his final days, I doubt that Lon would have described sitting in bed tethered to a BiPAP machine, communicating with his family by scrawling his every thought and need with a dry erase marker. It hardly sounds like what most of us would call a good death.

But, then, what is a good death? I confess that I entered my fellowship training with the belief that a good death required a code status of DNR/DNI, cessation of all cure-directed treatments, and a sole focus on management of pain and spiritual and emotional symptoms.

I can now appreciate the naïveté—and, frankly, the paternalism—of my earlier beliefs. A good

death, I have learned, is one in which the circumstances adhere as closely as possible to the patient's wishes and goals at that time, whatever they might be. While not all wishes can be brought to fruition, the actions and interventions taken by a family and medical team can and should be informed by the patient's desires, even if the ultimate outcome cannot match what the patient hopes for. I cared for one young boy who declined precipitously after his cancer metastasized and though his parents would have preferred to have him at home, they felt unable to manage the caregiving that would have entailed. The team outfitted his hospital room to mimic the comforts of home, replacing the plain hospital linens with plush bedding patterned with his favorite cartoon characters and adding posters, matching pajamas, and a few toys. Another patient chose to continue receiving intensive inpatient chemotherapy for her widespread disease but put a DNR/DNI order in place because she wanted to avoid transfer to the ICU and invasive, potentially painful, interventions. By contrast, many of my patients have continued to seek cure-oriented therapies and have maintained a status of "full code" even in the face of illnesses that cannot be cured. If a patient truly understands that there is a slim likelihood of recovery, but still prioritizes extending his or her life by every possible minute and knowing that every available intervention has been tried, that, too, can be a good death.

These goals can shift as a disease progresses, as symptoms change, or as patients' understandings of, or feelings about, their illnesses evolve. The

chance to help patients identify what is most important to them and to engage as a team in developing a plan of care consistent with these wishes—even if they are the polar opposite of what I value and would choose for myself—is one of the distinct honors of working in hospice and palliative care. My goal remains to help provide, to the best of my ability, a good death for every patient. Only now I recognize that a good death can take many forms.

The day eventually arrived when Lon’s handwriting began to grow sloppy. In his list of daily questions, inquiries appeared that didn’t make sense and that he couldn’t explain further when one of us drew a question mark in the margins.

“Is it the carbon dioxide?” his children asked guardedly and I nodded. They whispered, but he seemed unperturbed by the conversation taking place around him. This was the progression we had expected to see, only we hadn’t known when it would start and still had no idea how long it would take. We had talked, for a time, about discharging him from the inpatient facility to receive hospice care at home or in a nursing facility, but it was becoming clear that Lon’s time was growing short.

Gradually, Lon grew less and less alert and spent more of each day asleep. His pain didn’t increase, but he, who had once—even in these dire circumstances—been a robust and notable presence, began to wilt away. He used the dry erase boards less, and was not as irritable when people had conversations without translating their spoken words into writing. And while his family contin-

ued to grieve, they also felt great relief that the inpatient hospice facility was where he would stay.

Lon passed away in the early morning hours of St. Patrick's Day with his family by his side. When I arrived later that morning, the funeral home had already collected his remains and his family had packed away all of his belongings and the accoutrements that had made his room feel so much like a home. In their wake, they left a note of gratitude thanking us for the care that Lon had received. It was written, most fittingly, on a dry erase board.

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