DANIELLE OFRI

Living Will

"Living Will" is a fine example of the type of essay that follows a narrative arc as the author describes the process of moving from one state of mind to another, usually from a moral or intellectual dilemma to resolution and insight. Such essays often involve an epiphany. *The Irish novelist James Joyce first used this ancient religious term in a modern literary sense to describe the sudden flash of recognition or the unexpected illumination that can transform our understanding. "Living Will" takes us inside today's medical profession—with its awesome technological capability—and confronts one of medicine's major issues: Why are severely ill and depressed patients who have lost the will to live kept alive at such an enormous cost of time, expense, and professional effort?*

Danielle Ofri, MD, PhD, is the author of Singular Intimacies: Becoming a Doctor at Bellevue (2003), Incidental Findings: Lessons from My Patients in the Art of Medicine (2005), Medicine in Translation: Journeys with My Patients (2010), *and* What Doctors Feel: How Emotions Affect the Practice of Medicine (2013). *Ofri is editor in chief and cofounder of the* Bellevue Literary Review *and associate chief editor of an award-winning medical textbook,* The Bellevue Guide to Outpatient Medicine. *Her stories have appeared in both literary and medical journals as well as in several anthologies. A frequent contributor to* The New York Times, *she is an attending physician at Bellevue Hospital and on the faculty of New York University School of Medicine. "Living Will" originally appeared in* The Missouri Review *and was selected by Susan Orlean for* The Best American Essays 2005.

Wilbur Reston was already in the intensive care unit of the tiny Florida hospital when I arrived at two-thirty A.M. I had been

doing a series of temp jobs after having completed my medical residency at New York City's Bellevue Hospital and now found myself in a small town on the Gulf Coast. The breathing tube in Mr. Reston's throat and his heavy sedation precluded formal introductions. But there was a typewritten summary of his medical history that his wife had left with the nurses: a two-page, single-spaced account that chronicled the rebellion and demise of each organ in this sixty-one-year-old white man. He had survived three heart attacks and seven strokes. One kidney had been removed. He suffered from diabetes, high blood pressure, and congestive heart failure. He had emphysema, glaucoma, severe migraines, and arthritis. His medical history included pancreatitis, diverticulitis, pyelonephritis, sinusitis, cholelithiasis, tinnitus, and ankylosing spondylitis. The typed paper also mentioned gastroesophageal reflux, vertigo, and depression. I quickly glanced over to the man hooked up to the ventilator to verify that he was indeed alive.

His wife had told the ER physicians that he'd stopped taking his water pills several days ago. Eventually he could no longer breathe. He possessed a living will stating that he did not want any life-sustaining procedures. In the ER, however, he had apparently agreed to be intubated. It had taken an enormous amount of sedation to get the breathing tube in, and then his blood pressure bottomed out. He was now unconscious in the ICU, on multiple pressor medications to support his blood pressure and augment his weak heart. In Bellevue terminology, he was a "train wreck."

Mr. Reston had been admitted to East General Hospital at two A.M. My colleagues in the small private practice where I was working had instructed me *never* to go to the hospital in the middle of the night. "Give your orders over the phone and see the patient in the morning," they advised. But I was still too new at this kind of medicine to be that confident; I had to at least lay eyes on the patient before I could decide on any medical orders.

I couldn't take a history from Mr. Reston, since he was at present unarousable because of all the sedation. My physical exam was brief. Mainly I plowed through the typed medical summary, converting it into a concise admission note. I handed my admitting orders to the nurse, and then there was nothing for me to do. In this small community hospital, the nurses were used to, and entirely comfortable with, working without any doctors around. How unlike Bellevue, where interns and residents roamed the halls twenty-four hours a day, deeply and intricately involved in the minutiae of medical care. Here the nurses took most of the doctors' orders over the phone and did everything themselves: drew blood, inserted IVs, did EKGs, obtained blood and urine

cultures, sent patients for X-rays, followed up on test results, and so on. The doctors, with their busy private practices, usually visited once a day, either very early in the morning or late, after their office hours. The emphasis was on remembering to sign verbal orders within twenty-four hours. Not surprisingly, the head nurse was taken aback and almost alarmed when I showed up in the middle of the night for Mr. Reston's admission.

It was now nearly four A.M. as I drove back to the hotel in my rental car. The main roads of the town were deserted. I rolled down the windows and was quickly enveloped in humid, orange-scented fog. Stretches of flat, boring landscape were broken up periodically by strip malls. Neighborhoods of low-slung, white stucco houses were dotted with pickup trucks and palm trees. The smell of blossoms had not been fully eradicated by the burgeoning construction industry.

Southwest Florida was nothing like West Palm Beach, which I had assumed represented all of Florida. This area was rural, with acres of fields farmed by itinerant workers, mostly from Central America. I had just returned from Guatemala, so I was eager to practice my Spanish, but in the private practice where I worked, I rarely had the opportunity, except for the time when I was called upon to explain to a Honduran fruit picker that we couldn't treat his high blood pressure because he didn't have medical insurance. The hospital emergency room had called me when he'd shown up there needing prescriptions, and I'd said sure, send him over right now. When he arrived at the office, however, the practice manager informed me that we could not treat patients without insurance except for medical emergencies. Since I was the only one in the office who spoke passable Spanish, the duty of telling him fell to me. My verb-conjugating ability floundered, and my pronouns disagreed with their antecedents. My vocabulary in Spanish—and in English for that matter—had never included such phrases as "We cannot take care of you. You must go to a different doctor." I suddenly longed for Bellevue, for the chaos of the emergency room there, with its bubbling tumult of languages, ethnicities, colors, and socioeconomic classes, and its assumption that everybody received medical care regardless of ability to pay.

But aside from that one incident, the office was a pleasant place to work. Three doctors had started this practice several years ago, and they were now extremely successful. They had built an impressive clientele of devoted patients, mainly older but many middle-aged. They had equipped their office with a tiny pharmacy and a stress-test machine, and had arranged for weekly visits from an

ultrasound technician, who performed all their sonograms. They'd even opened a small gym next door, in which they sponsored exercise classes for the elderly and rehab classes for their patients with emphysema. The doctors were in their forties, looking for ways to cut down on hours and enter semi-retirement. They were more than happy to hand over a third of the office patients and one hundred percent of the inpatient hospital duties. They gladly acceded to my request for paid prep time so that I could read patients' charts in advance of their appointments, all in a comfortable office with an experienced, full-time nurse to assist me. It was the lap of luxury. Within a week they offered me a permanent, full-time position with a salary that was four times what I'd earned as a resident for half the working hours, plus a share in the practice.

The patients were pleasant and apparently particularly happy to have a woman doctor, something new to that practice. And for the first time in *my* life, medicine was not a struggle: I could practice the best medicine I wanted without having to fight for anything. Coming from the trenches of Bellevue, where medicine felt almost like warfare, I found the ease of practicing good medicine almost disconcerting. I couldn't deny that the job offer was tempting.

But I could never leave Manhattan—certainly not to live in such a tiny town.

The town was a speck on the map in southwest Florida that no one I knew had ever heard of. The pace was unhurried, and the locals were unceasingly friendly and helpful, traits that were sometimes unsettling to a native New Yorker. Overly polite strangers made me suspicious, though everyone assured me that this was the normal style in the South. There was no place to get sushi, but the two-room library across the street from my office did stock Spanish-lesson tapes, and I was able to study a semester's worth of grammar on my way to work each day. Much to my dismay and disbelief, the library did not subscribe to the *New York Times*. A very weak consolation was the *Wall Street Journal*—only available, however, the following day.

The private practice was affiliated with East General, an eighty-eight-bed community hospital. I'd never seen a hospital that small. Eighty-eight beds was one floor at Bellevue, and Bellevue sported twenty-one floors. East General Hospital reminded me of my elementary school—spread out over two wings, each only two stories high. The elevator seemed redundant. Some of the services that I was used to from Bellevue, like twenty-four-hour-a-day access to cardiac catheterization and hemodialysis, were not available, but

there were other advantages. With a maximum census of eighty-eight patients, there was never any waiting time for anything I ordered. Stress tests, sonograms, CT scans, pulmonary consults, social-work requests—I had only to jot a request in the chart and it would be completed by the end of the day. The staff was small, but everyone seemed competent and extremely friendly. Within a week even the housekeepers were greeting me by name, and the phone operators recognized my voice when I called.

The following morning Mr. Reston was awake but extremely uncomfortable. He had tried to pull out his breathing tube several times, so the nurses had tied his arms down. I apologized to him for the wrist restraints and explained that I would try to get the tube out as soon as possible. I was self-conscious about my words because Wilbur Reston's body was sentient. He heard and understood everything I said, but the tube and the restraints prevented him from speaking or even gesturing; my awkward reassurances met with no response. I spent the morning in the ICU weaning Mr. Reston off the ventilator and draining fluid from his lungs. When the nurses were rolling him over to change the sheets, he managed to dislodge his own breathing tube and set himself free.

There is an entire scientific literature on the most appropriate time to extubate a patient, based on pulmonary function tests, blood gas values, and chest X-ray findings. But the Bellevue ICU's wisdom was that a patient was ready to be extubated when he or she reached over and yanked the damn tube out. Mr. Reston proved this to be true, since enough fluid had been removed from his lungs that he was able to breathe, if a bit huskily, without the tube. His condition was still tenuous, though, and he was too exhausted from his ordeal to talk much; I waited a while for his wife to arrive, but she never showed up.

Thirty-six hours after his admission I was finally able to actually "meet" Mr. Reston. He was a burly fellow who looked surprisingly robust for a patient with such a thick medical record. I would have expected a shriveled old man, but he had beefy arms and a hefty belly. There was a tattoo of an alligator on his left biceps. The ICU bed sagged slightly under his weight whenever he shifted or turned.

Mr. Reston's face was pulled low on his neck by meaty jowls, and dark bags weighed his eyes down. He had lived his entire life in this small town on the west coast of Florida. He was a veteran of the Korean War, with a specialty in artillery. After the war he'd worked as a police officer and spent some time training guard dogs.

His voice was surprisingly soft and somewhat morose. In slow, deliberate phrases he described a lifetime of progressively declining health. His arthritic pains and severe headaches seemed to have taken a greater toll on him than his many strokes and heart attacks. He was confined to his house, unable even to walk down the driveway to retrieve his mail.

Did he have any hobbies? He heaved a melancholic sigh. "I fancied myself a carpenter. I built miniature furniture for dollhouses. Always used the best wood."

I imagined this bearlike man hunched over delicate divans and bedroom sets.

"Can't do it anymore. My hands." He threw up his gnarled, arthritic paws for inspection.

"I also collect Civil War memorabilia. Once found a belt buckle from the second battle of Bull Run," he said with a puff of pride. "They had it in the museum for a while." But his recollection of his former glory was brief. "My wife thinks it's a stupid hobby," he said.

What about depression? "I've never *not* been depressed," he sighed ruefully. "Ever since college, I suppose." His records showed that he'd been treated at the VA psychiatric clinic with both psychotherapy and antidepressant medications for more than twenty years. His only daughter had died of a brain tumor the year before. His mother and sister had both died in the past five years. So had his dog.

Had he ever attempted suicide? "I'm handy with guns, you know. I have at least five in the house," he said dryly. "Different models. Always keep a loaded one at my bedside."

Did he ever use it? "Well, I stuck the barrel in my mouth. Didn't pull the trigger, though. Too messy. Just stopped taking my pills."

I had an image of Mr. Reston sitting on the side of his bed, shoulders sagging, cradling the gun in his hand. Perhaps he'd raised the gun to his head several times, each time not able to bring it close enough. But then he'd take a quick, dry swallow and, squinting, slide the gun into his mouth. I imagined that he might be startled at how comforting the gun felt in his mouth. But then that very comfort would make him shudder, and he'd rip the gun out, stuff it back into the nightstand drawer, and slam the drawer shut.

Then he'd be left staring at the pill bottles lined up on that nightstand, loaded with promises of good health. He'd finger them, recalling what ill each was meant to cure. And cure they did. And then what?

I envisioned him opening that drawer again and, with the crook of his clublike arm, sweeping the bottles in, their hard plastic clattering against the gun as they came to rest at the bottom. He'd sink his head into his hands, forgetting to shut the nightstand drawer.

What about his wife, I asked. "She's busy with that volunteer work. She don't have time for me and all my pills," he said sadly. An uneasy silence settled in. I could see moisture accumulating at the edges of his soulful eyes, "We haven't shared a bed in fifteen years," he whispered.

His voice was plaintive but resigned. "Why should I live this life? I can't walk, my wife don't speak to me, I can't do nothing. What's the point?" He fixed his mournful gaze upon me. "*You* tell *me*."

It was both a plea and a demand. His simple statement had caused the space between us to evaporate, and I suddenly felt naked. Without my clinical armor to shield me, I was just one human facing another, squinting before the raw question. What *was* the point? What were the reasons for him to go on living?

I struggled to come up with one. Mr. Reston's body had withered sufficiently to keep him in perpetual pain but not enough to let him die. He had no friends; his wife was estranged. His daughter, mother, and sister had died and abandoned him. He was too weak to walk out of his house. He could no longer do any of the things that brought him pleasure. Why should he want to live? I could see why he had stopped taking his pills.

I didn't have an answer for him, but the law dictated what I had to do: actively suicidal patients must be prevented from harming themselves.

Like all good emergencies, this one occurred late on a Friday afternoon. Unlike Bellevue, there was no residency program in psychiatry to supply immediate consultations. There were several psychiatrists in the community, but they were busy with their private practices during the day and rarely made after-hours calls. But the staff of this tiny hospital was resourceful and helpful. They got me in touch with the local mental health agency, which was able to dispatch a psychiatric nurse practitioner. She agreed with my concerns and helped the nursing staff arrange a round-the-clock "suicide watch" over Mr. Reston. I could have Mr. Reston transferred to a psychiatric hospital once his medical condition stabilized if I felt he was still in danger of hurting himself. The nurse practitioner explained the procedures to invoke the Baker Act, the state legislation that allowed involuntary psychiatric commitment in such circumstances.

Over that weekend Mr. Reston's medical condition slowly improved, but his mood did not. Why should it? I thought. What did he have to look forward to? As much as I tried, I could not bring myself to utter flimsy platitudes about the value of life and how things would be better tomorrow. They weren't going to get better—he knew it and I knew it. Although he was clearly depressed, Mr. Reston was perfectly lucid. Despite his many strokes, his mind seemed to be working just fine. He could do all the tasks in the mental status exam: spell "world" backward, count down from one hundred by sevens, name the president, interpret the proverb "A rolling stone gathers no moss."

Although Mr. Reston seemed to have a reasonably realistic grasp on his situation, I wasn't so sure I had a grasp on mine. Doctors aren't supposed to agree with their patients who say they want to kill themselves, but I found myself overwhelmed by the utterly dismal facts of Mr. Reston's situation. Whom did Mr. Reston have left to live for? Even his dog had died.

I tried to imagine pacing the blank landscape of an empty life. How could I survive if every source of pleasure was denied? How could I live if the flavors, colors, and textures that made life palatable were flattened into a monochrome gray? If I were Mr. Reston, I might have pulled that trigger.

To complicate matters, he was in a rather unique medical situation. Although he had multitudes of medical problems, he was not yet terminally ill. He had a long list of diseases, but none was close to killing him. He was sick enough to be miserable but not sick enough to die. He was still able to eat, care for himself, and communicate with others. There were plenty of services and options for people on the verge of death, but Mr. Reston was not sick enough to qualify. His body, honed from years in the military and police force, was holding on too tenaciously. It left him stranded, strung too far from the shores of either health or death. Mr. Reston had severe physical pain, apparently unresponsive to various treatments, but more important, he was being eaten away by psychic pain.

The medico-legal issues were clear: a suicidal patient is prevented from committing suicide, even against his will, period. But the shades of gray needled me. My patient didn't want his life, and I wasn't sure it was ethical to force him to continue living it.

These issues plagued me for the remainder of the week. Ashamed to reveal my heresies to anyone, I secretly toyed with my doubts, picking at them as one does a loose tooth, perversely finding pleasure in its pain. What if I let him go

home to his household of loaded guns? What if I discharged him, knowing full well that he'd stop taking his life-saving medicines? What if I turned my head and let him kill himself, as he so desperately wanted to do? There are those who say that all suicidal thoughts are products of depression, but Mr. Reston had been assiduously treated with medications and psychotherapy for decades. Perhaps he was being entirely rational. Who was I to stand in his way?

Then the toothache would burrow down to the raw nerve: What kind of evil doctor was I to even *consider* not protecting my patient from his violent tendencies? How could I be so negligent?

As I drove back and forth to work each day, this dilemma nagged at me. Lulled by the bland landscape, my mind would wander from the Spanish vocabulary coming from the car's tape deck to Mr. Reston languishing in his bare hospital room. Could there ever be any happiness for him? What if I found him a new hobby, one that he could manage with his disabilities? Stamp collecting—that wouldn't require much mobility. But probably his fingers couldn't manipulate the fragile paper stamps. Maybe he could take up painting. Large, easy brushes with hefty tubs of paint—he could manage that. Perhaps there was an artist waiting inside his weary body.

Traffic was stopped as a cumbersome tractor-trailer backed out of a construction site, attempting to turn around. A grove of orange trees had just been plowed, probably for a new strip mall. The trailer was open on top, and I could see the stacks of shimmering steel girders. The driver backed up a few feet, and then the trailer swung in the opposite direction, blocking his turn. The workers on the road waved their hands, shouting contradictory instructions: "Pull back a bit." "Swing to the right." "Turn your wheels on a sharp left." The driver edged forward and back, craning his neck out the window, then up toward his rearview mirror, as he tried to extricate himself from the tight spot. The steel girders flashed in the sunlight each time he changed angles. The smell of fresh, damp earth blended with the intoxicating sweetness of the orange blossoms, something I'd never smelled in New York City.

The metallic clanking and the competing shouts, along with the glare of the sunlight and the overpowering fragrance, made me feel heady and somewhat faint. I leaned my head into the steering wheel, and suddenly I saw the hole in Mr. Reston's armor: he had let himself be intubated. This man, who possessed a living will

explicitly refusing all life-sustaining procedures, had *voluntarily* allowed a breathing tube to thrust air into his drowning lungs. He had reached for a life preserver.

I picked my head back up, feeling the murkiness begin to clear. Despite all of Wilbur Reston's misgivings and doubts, a desire to live had somehow percolated through.

As I leaned back in my seat, I wondered how that had come to pass. Was it simply the life-grabbing instinct that springs forward in such moments of near doom? Or was it truly evidence of Mr. Reston's ambivalence, of a desire to be saved and cared for?

Clearly, I had no way to know—I doubted if he himself would even know—but it seemed to me that Mr. Reston had given himself permission for a second chance. Now that he had done so, I had the opportunity, perhaps even the obligation, to allow that chance to flourish. If this second chance wasn't nourished, there probably wouldn't be a third. As if to confirm my realization, the tractor-trailer veered to the left and finally pulled itself out of its trap. The traffic snarl cleared, and I jammed on the accelerator, flying down the road with the breath of orange blossoms sweeping against my face.

When his medical condition stabilized, Mr. Reston was involuntarily committed to a VA psychiatric facility. He didn't protest when I informed him. He just nodded his head, his baggy jowls bobbing. During his entire stay, I'd never once met his wife; her occasional visits never seemed to coincide with mine.

The VA doctors assumed care of Mr. Reston, and I had no more contact. The private practice was busy, and I saw many patients every day. My mind was filled with Shana Elron's brittle diabetes and Henry Shaw's uncontrolled hypertension. There was the couple who lived in Pennsylvania during the summer but spent winters down south, and I was helping them coordinate his prostate cancer treatment between the two locations. I had recommitted myself to Spanish and spent my evenings conjugating verbs. I planned to leave for Mexico as soon as this stint in Florida was over, and I wanted to have the conditional tense under my belt. I had to decide if I wanted to start my trip in Guadalajara and end it in Chiapas, or vice versa. Or maybe just fly straight to Oaxaca and enroll in the Spanish school there. And then there was that shell-beach peninsula set against a tangle of mangroves twenty minutes from my hotel which beckoned me every night after work. I soon forgot about Mr. Reston.

Several weeks later, as my assignment in Florida was drawing to a close, some paperwork concerning Mr. Reston's original hospital admission turned up in my office needing a signature. Wilbur Reston's morose face flickered in my mind, and I thought about his miniature doll furniture. I wished I were still his doctor.

Besides giving himself a second chance, Mr. Reston had granted me the opportunity to tease out some of the more subtle aspects of medicine. He forced me to see beyond his imposing résumé of disease to his simple, hurting human self. The patient is not simply the sum of his illnesses, Wilbur Reston taught me. It is far more—blessedly far more—intricate than that.

After a labyrinth of phone calls through the VA bureaucracy, I finally tracked down his psychiatrist. Mr. Reston had just been discharged a few days ago. The psychiatrist described the long weeks and the laborious effort it had required to get Mr. Reston to take responsibility for simple things like brushing his teeth. By the end, though, he was showing up at the group meetings, even if he rarely spoke. Once in a while he even went to arts and crafts. Mr. Reston did not beome an effusive, energetic person, but according to the psychiatrist he no longer actively expressed the wish to die. That was considered a major success. And once he was no longer suicidal, there was no justification for keeping him involuntarily hospitalized. He could go home to his wife and continue with his regular outpatient therapy.

The psychiatrist commiserated with me over the many painful but immutable realities of Mr. Reston's life. A social worker was trying to help Mr. Reston get a new dog—that was about the only thing they could remedy.

I flew to Mexico the following week. In the end I'd decided to fly directly to Oaxaca for a month of Spanish lessons. Afterward I'd trek to Chiapas to see the Mayan ruins. I plunged into my classes, determined not to speak a word of English for six weeks, if that was possible. I rented a room from a family that spoke no English; I purchased Spanish editions of *Jonathan Livingston Seagull* and *The Little Prince* as my reading material; I tried to minimize my social contacts with the other foreigners in my classes and instead hang out at local cafés.

But I still thought about Wilbur Reston and wondered how he was doing. Those thoughts could only be in English. I imagined that he was sitting alone in his house, his wife at yet another volunteer function, his bones still aching, his weak heart preventing him from even getting the mail. But maybe there was now a puppy

yapping at his feet, freely dispensing and demanding love. When the headaches and joint pains became overwhelming, maybe Mr. Reston would again consider ending his life. But then he might stop and think: Who would feed the puppy?

Reflections and Responses

1. Consider Danielle Ofri's title for her essay. What two meanings does it possess simultaneously? How are these two meanings in opposition to each other? How are both of these meanings relevant to the essay as a whole?

2. What dilemma prompts Ofri's "epiphany"—the realization that her patient actually has the will to live? How and where does this sudden realization occur? In what ways is the specific context in which the epiphany occurs appropriate? How does it help to trigger the sudden insight?

3. Note the number of times that Ofri imagines her patient's life and activities. Why do you think she does this? Reexamine the final paragraph, for example. How would you evaluate this conclusion? How would a reader know whether it's at all accurate? Do you find the conclusion satisfying from a narrative point of view? Explain why or why not. How else might the essay have ended?