What happens when a patient says, 'Doc, help me die'

By E. Wes Ely

Updated 1149 GMT (1949 HKT) March 20, 2018

(CNN)"But can't you help me die, Doc?"

My 54-year-old patient was alone in the intensive care unit, with no family or friends in his life. He slumped in his bed, gasping, staring up at me. Admitted with lung fibrosis and pneumonia, he had scars and infection aggressively replacing his airways, despite our best treatments.

As a newly minted doctor years ago, my mind was usually occupied with beeps and buzzers providing me technical information to help calculate choices about patients' care. Having developed gray hair over many years at the bedside, my first priority is now more straightforward: to hear the voices of the vulnerable people looking up at me from their bed. That is what I try to do as a physician, including, of course, what they tell me in the silences.

I pulled a chair next to his bed so we could talk at eye level. His face was blank. "I want euthanasia. I'm going to die soon, so what's the point of living longer? I'm just wasted space."

I felt nauseated. The illegality of euthanasia was not what ran through my mind. Instead I thought about how Paul had lost his sense of personhood. I thought about how I had chosen to become a doctor in the first place.

Caregiving is a partnership

I chose medicine as my calling after

I chose medicine as my calling after a childhood spent in the Deep South: Shreveport, Louisiana. My mother taught English there after my father, an engineer, had left her for another woman. I remember it was so hot that my siblings and I would fry eggs on the sidewalk. No joke. On most days, we'd walk to a nearby bayou and catch baby alligators for fun and fill up coolers with crawfish for dinner. That last part is important because we had no money at all. Dad wouldn't pay anything to Mom, who didn't make much as a teacher. So I started working at the farm of a man who wanted to marry my mother. I worked 14-hour days from about five in the morning doing square bales of hay until seven at night picking vegetables and running the country store.

While I cherish those years and the formation that grueling work provided, I was determined to do something different with my life. Mom told me that Dad had loved math and science, and she taught literature. So I figured it must come naturally for me to split the difference and do something with people, science and the arts. To me, that meant medicine.

Dr. Wes Ely assessing a patient in the Medical Intensive Care Unit at

Vanderbilt.

I remember our first big assignment in sixth grade was to write a research paper on what we would be when we grew up. I rode my beat-up bicycle to the local library and began reading about how to become a physician: What was the process and what would it all mean? I walked out of the library that day having spent most of my time reading a long medical essay about truth. The author insisted that to be a physician, one has constantly to seek truth about the patient's diagnosis, the best treatment, and the best way to serve each and every person. What I learned from the essay was that truth doesn't change depending on our ability to stomach it. As I progressed through Jesuit high school and Tulane, this became a common theme in my pursuit of a life as a doctor: "Wrong is wrong even if everybody is wrong. Right is right even if nobody is right." Numerous people are credited with some version of this quote, from actors to philosophers to theologians. That sense of truth drove my study and training and my realization that each person's life has value beyond measure.

I knew long before I met Paul that I couldn't kill another person just because he or she wanted me to, but I still had to find a way to respond to Paul's request to die.

'Just don't abandon me'

My response came in parts over my days with him. First, I explained that, as his physician, I wanted to be with him through the dying process. I told him that I considered us to be in a mutual covenant. We both had a degree of autonomy that had to be respected, but I would never intentionally harm him. "Paul, our covenant includes my limiting your suffering," I said. "You are the best judge of when you need more meds for pain, anxiety and breathing. All of us will work day and night to end your distress, but we won't deliberately end your life."

With our eyes locked, Paul gave his instruction: "Just don't abandon me." And we sat there, as partners.

As a physician, there is no better place to be. Perhaps especially amid the uncertainty, we must learn to partner with each person in the bonds of this two-way relationship. He in need of help and me in need of helping.

Paul was receiving excellent palliative care for his physical symptoms, but it wasn't enough. It never is. Emotional isolation and despair can cast a shadow darker than disease. Physicians fail our patients on a human level. We forget that our patients are more than the sum of their medical conditions, so I asked Paul about other types of therapy — art, music, spirituality, pets, sunshine — that might help him.

'He who has a "why" to live can bear almost any "how"'

"I want my music. Can you get me the soundtrack for 'Lord of the Rings'?" Within minutes we had the songs playing in his room, and his demeanor changed from desolate to alert and engaged. "I love music. It's always been a motivator, but now ... I don't know." He shifted in his bed. "My goals are gone."

Nietzsche's words came to my mind, "He who has a 'why' to live can bear almost any 'how.'"

Viktor Frankl, as a physician-survivor of Auschwitz, used Nietzsche's quote four times in his crucial analysis, "Man's Search for Meaning." I think this book should be required reading for medical students.

As with many patients, Paul's story needed unpacking. "Paul, what did you do in life?"

He smiled and shrugged. "I'm a rare beast: a plumber who acts. I do Shakespeare festivals. You know, 'The quality of mercy is not strained.' I've been mulling over that line. Years ago I didn't understand it. I do now.

Mercy should not be forced. It's better as a natural infusion, one person to another."

I described for Paul the many years I spent alongside my single-mom-turned-Shakespeare-director, helping her cue actors. As we talked, I watched his erratic oxygen levels fall and then partially recover, obliging us to take breaks. Sweat would build up on his forehead, and, more than once, I worried that our conversation was too much of a strain. But we were unpacking, and it was essential.

The quality of mercy

That night I asked Christine, a nurse who loves theater, to sit and talk with Paul. Soon their lives were interwoven, too.

"I think I helped Christine," Paul said the next day. "My own illness made me forget that one of my 'things' is seeing when someone is hurting. And Christine is. She came to help me, but it turns out some really personal things in our background are weirdly similar. I told her my way through the worst of it." He paused, his thoughts far away.

It seemed like a good time to return to his previous request. "Paul, you've asked for euthanasia, and you brought up Portia's line from 'Merchant of Venice' about mercy. Can we talk about these things?" He nodded, and closed his eyes.

"We all want to be here with you in your suffering. I want your opinion: I don't think injecting you with a lethal drug would be truly merciful, but it would, in every sense of the word, be 'strained.' It would be a forced and unnatural 'false' mercy. Whenever possible, mercy must also be lifting and healing. I don't want to abandon those key elements in serving you."

His eyes opened wide. "Doc, talking with you and Christine about life's best and worst times has helped." He took a deep breath, and I heard the

whoosh of high-flow oxygen into his nostrils. "Things I confided to Christine are helping her sort through her own struggles. She said she's coming back tonight, and that means the world to me." Then, unwittingly,

Paul paraphrased Nietzsche: "When we met, I was afraid of being a burden and not mattering. Now I feel different. I'm not a believer like others, but I guess I remembered the 'why' to live."

Short of a war zone, there are few settings as raw as an ICU. Yet treasured moments of human transformation come when people like Paul rediscover their "why," even if just for an hour or a day.

'I'm glad I didn't miss this time'

I see many paths toward survival in the ICU, and for non-survivors, myriad paths toward death: sudden, prolonged, stuttering, reluctant, stoical -- and these paths are dynamic, not static.

It is a rare patient who asks me for euthanasia, but it is nearly universal that dying patients seek help with suffering. Sitting on their beds brings me right up against their fears, the greatest of which is usually not intolerable pain.

Lack of control is what bothers people the most, and it drives most requests for euthanasia, which is predominantly a first-world phenomenon. As we have gained more and more ability to dictate so many aspects of our lives, looking ahead in uncertainty has become something people are not willing to tolerate. As a physician, I find this is a very important "teachable moment" for most patients: helping them (and me) to live in the moment. Whitewashed along a wall in the home for destitute and dying in Kolkata, these words of Saint Mother Teresa became emblazoned in my mind, and I recalled them for Paul: "Yesterday is gone. Tomorrow has not yet come. We have only today. Let us begin." He nodded in agreement.

Paul reminded me that the best remedy for angst is human relationship and community.

The problem with assisted suicide and euthanasia for Paul — and for others

— is that it presented him with an illusion of 'cure,' when in reality it would have left him devoid of the healing he received.

And alongside the patient, of course, sits the physician. The problem for me with intentionally administering lethal medications to end the life of another person is that it would rob me as a healer. I would be qualitatively changed. If I were ever to assume that I had authority over life to take it deliberately, it would, for me, create an irrevocable cavern of emptiness. The infinite worth of every person outprices autonomy: What you and I want is less important than who we are.

Obviously, the approach I took with Paul won't be an answer for everyone, yet it is too often left untried. Some will say Paul's story is merely an uplifting anecdote. Nevertheless, I hope to embrace the lessons I learned at his bedside for most of my patients, and I hope my colleagues do the same.

We are sent to heal even when cure is not possible. What we should be trying to heal is often not physical disease or clinical depression, but a person's sense of insignificance and hopelessness, which we cannot heal by eliminating the person.

Paul died a week later. By then he realized his life was of value even with a terminal disease. In fact, the last thing he said to me, between gasps, was: "I'm glad I didn't miss this time. I never saw it coming, Doc. ... In losing my breath, I gained it."

Note: The patient's name and age have been changed for privacy. These conversations reproduce Paul's words as accurately as possible from the

author's memory.