Another Word for It

In April of 2010, my 82-year-old father committed suicide. I mean that in the best possible sense. The event was so elegant, so charitable, as to beg the question of whether or not suicide is the right word. If suicide is the act of killing oneself intentionally, then it's wide of the mark. There was no action involved. He simply stopped eating and drinking.

He had ALS. Lou Gehrig's Disease.

Dad had nothing to say about the afterlife except that he didn't believe in it. He accepted the aging process, and didn't seem to fear death. It was hard to say why. After he died though, my mother gave me a manuscript that he had written before I was born, and it revealed thoughts I hadn't been aware of.

Dad had participated in the American Mount Everest Expedition in 1963, studying the dynamics of the group under stress. Once back, he wrote his experience of the climb as a story for young readers – kids of about 12 or so. In it, he described his response to the death of the team's youngest member, Jake Breitenbach, who was crushed while trying to map a route through the Khumbu icefall. While the event was shocking, and forced the team to reflect and reconsider over several days, my father wrote: "That one light should go out here did not seem so surprising or wrong as it does at home, where all the forces seem to be under control and life seems so safe. In the mountains I felt clearly that human life is just one among many other things going on in the world, and that it is in constant struggle with many other things and that it sometimes must lose the struggle."

It's hard to imagine that his philosophical approach wasn't linked to these early feelings. I've never met someone so philosophical. "I'm old enough," he said to Ron Hoffman, the indefatigable founder of Compassionate Care ALS, who came by frequently in the last months of Dad's life to drop off donations of equipment and to speak his support for ways to live with the paralyzing disease. Ron generously kept delivering things that would make it easier for Mum and the hospice nurses to move Dad around, but no harnesses or transfer aids could wipe away the crystal clarity of this statement, written even before his diagnosis: "I've lived long enough and feel no need to cling to a life from which many of the functions that make for quality have been removed. My condition would not have to be terminal to make me want to have an end to it."

So that was it. And that had always been it.

Less than a year before his death, my parents moved from their house in Maryland to a retirement community in Massachusetts. I spent a few weeks helping them pack, and found myself in the back room by the washing machine with Dad, filling and labeling boxes with 50 years of slides, and discussing the use of helium in assisted suicide. He had a video about it on a shelf. I don't recall that he asked me what I thought about the helium option; he just told me he was thinking about it. It was attractive because filling the plastic bag over your head with helium prevents the panic that accompanies suffocation, and also because the direct cause of death is difficult to trace if the bag and gas canister are disposed of before the death is reported. It was unattractive because you couldn't do it alone. Depending on your condition you might be able to manage the equipment before death, but someone would have to get rid of it. He didn't like the idea of involving us more than necessary. He was still thinking.

Before they got in the car on the day they left for Massachusetts, my mother took my brother and me into the empty kitchen. Her eyes were full of tears, but she wasn't desperate. "He's probably going to do this," she said. "I don't know how he's going to do it, or when, but he's probably going to. Just so you know." My brother and I nodded at her. We knew.

Dad was able to drive all the way to their new home, where there were no stairs to negotiate and all the hallways had handrails, but a few months later they narrowly avoided a car accident when he couldn't lift his foot off the accelerator. He declined very quickly from the Charles Eames armchair to the Barcalounger, from the Zimmer frame to the electric wheelchair. His voice on the phone became more and more slurred. He couldn't swallow easily, trying to clear the phlegm in his chest made him gag, and defecation was a nightmare. I flew over at Christmas with my fiancé, so they could meet. I flew back over in March. That was when Dad had my brother and me watch a video of a man, terminally ill with cancer, who makes the choice to end his life through fasting. It was a beautiful video, and a terrible moment. Dad had made his decision. He was just worried about one thing.

As a psychologist, Dad spent his professional time trying to make sense of things. He wasn't assertive, and his modest nature had him seeing both sides of a lot of human issues. This meant that he could imagine people seeing his choice to fast to death as wimping out. He expressed this concern a lot. It was amazing to me that he thought there were only a couple of ways to see his decision, i.e. wimpy or courageous. We were overwhelmed by how many friends were struck by his courage. There was only one person who kept up an active dialogue with him about how he could stay alive for longer, and that was Ron Hoffman. It was Ron's business to get people with ALS the resources they needed – the right commode, the right shower chair, the right foam supports, the right oxygen therapy. He didn't want someone to feel like they couldn't go on living just because they hadn't been offered the special harness that could get them in and out of bed. Dad didn't want to disappoint Ron, but it was precisely because he was at the stage of needing equipment for every single activity of every single day that he made his decision.

You can see the way he was weighing up the value of his life in a statement he wrote as he was preparing for the end (preparing us, that is, not himself): "I'm happy with my life as I lived it: I've passed my 82nd birthday and my 46th wedding anniversary with as fine a wife and lover as anyone could want, I've watched my two children grow into wonderful, productive adults and give me 5 grandchildren, I've loved and been loved, admired and been admired, achieved a few things and experienced a lot, and I can survey the whole with rich feelings of contentment and satisfaction." Surveying the future, he had this to say: "What I want to avoid is unnecessary and prolonged suffering purely for the sake of prolonging life regardless of its quality." He looked at the bills he received for all the tests and procedures he had undergone, and shook his head in dismay. Medicare would pay for them, sure. But that was precisely why he felt the pain. I'd call Dad very much a JFK Democrat, and I believe he maintained his connection to the values of that era. Allow people to live the way they see fit. Do what you can for your country. It was abhorrent to him that the American taxpayer was to be saddled with maintaining the meager delineations of the last years of his life. So, setting the past and the future side by side, in much the same sensible way that he had compared purchase options in his exhaustive research of any used car or new fridge, he made the choice that satisfied his logic: not to allow the last months of his life to be so completely unlike his life as to eclipse it.

"Here's how I want you to remember me," he said when he could still talk intelligibly, handing me a photo of him in his 50s, grinning in a top hat. It's funny, because that photo doesn't really remind me of him. He had a great sense of humor, but he wasn't a goofball. He was modest. He played beautiful jazz piano and trombone. He spent the bulk of his career, after early days of clinical psychology and teaching, in the Office of Naval Research, administering grant money for research in the behavioral sciences. He

wasn't happy working there, particularly as the presidential administrations became more conservative and grant money for the soft sciences was harder and harder to come by. But he kept playing jazz and taking photos during the evenings and weekends, and when he retired, wrote a biography of the jazz pianist Art Tatum. *The Washington Post*'s Jonathan Yardley said of it, "Among the spate of jazz biographies that have been inflicted upon us in recent years, *Too Marvelous for Words* stands out from the crowd."

I know that my father was deeply depressed at times in his life. I know that he questioned his musicianship and wished he'd been able to sell more photos. He wrote drafts of two more books – one a historical look at why mountaineers climb, one a biography of Timothy Leary. He didn't find a publisher for the first, and Robert Greenfield pipped him to the post on the second. But when he wasn't feeling frustrated, he found great pleasure in both big events and poignant moments, and these piled up and outweighed the advantages of staying alive for the sake of it. When he could no longer play the piano, when he could no longer hold a camera or a conversation, what then were his struggles to chew, swallow and breathe in aid of?

For my mother, disagreeing with his choice was never an option, but while she would not be required to participate actively in his death, her support was making it possible. He couldn't do it without her. "I feel that I'm your executioner," she told him. "No," he said. "You are my hope."

Dad stopped eating and drinking on April 16th, 2010. When my fiancé and I arrived from Singapore on the night of the fourth day of his fast, he was sitting up in his chair in the living room. He looked gorgeous. A nurse's aid was coming in every day to bathe him, so his hair was clean and his beard snowy. His cords and turtleneck looked great on his lanky frame. At that moment, he was still very Dad.

His sister arrived as well, and stayed in a nearby apartment with my fiancé and me. My brother stayed in the apartment with Mum, in case she needed help in the night.

It was sunny during the days, and for the first few we were able to take him out to a nearby pond and sit and chat while he dozed in the sun. When he was visibly much weaker, we moved him to the hospital bed that fit into the bay window in the living room. He could no longer reach for the swab that kept his mouth moistened, so we took turns swabbing his mouth and putting lip salve on his lips. The hospice nurse showed us how to administer syringes of palliative medicine under his tongue, both for breathing problems and for anxiety. He looked out the window. He listened to jazz. He winked at us. For the first few nights we looked at selections from the slides he'd been taking since the 1950s, literally making his life pass before his eyes. Many times on those evenings, he was the one who was able to put to rest a lot of questions about who was who in the photos, and where they were.

Photos of him during those days, and even from the few months before the decision, show a man who had already started leaving his life. We kept taking them, in different groupings, outside by the pond, inside gathered around his chair. Looking back on it, I can't really think why. His body had been telling the story of his death for over a year, but when his face started joining in, he had reached the point of no return. It's much too hard to look at those photos now, but it did help to look into his eyes during those moments. They made it clear that he was fighting to stay with us, and just needed our permission to push off.

One of the things I was really glad the hospice people told us was that dying people can act in ways you've never seen. It's not something I've heard talked about much. It makes sense, of course, but not the sense I thought it made. I could easily imagine that my dad might become fretful over his decision, or morose, or angry, but Ron told me to be prepared because he might suddenly try to do something like pinch my mother's bum. He couldn't say exactly what he'd do, just that he would most likely do something. And he did. He became fixated on needing to pee.

By the time this happened, it had been a week since he'd had anything to drink other than the water that dripped down his throat after we swabbed out his mouth (even when he seemed to be sleeping his mouth would reflexively chew on the swab). He also had an adhesive catheter on, so if there were any urine in his bladder he could let go. He was determined to get up, though, and his arms would flail as he tried to sit upright and pull his legs over the side of the bed. We'd have to stand right next to the bed and block his efforts with our bodies, speaking soothingly. Eventually he'd give up and shrug his shoulders in a "Have it your way, asshole" manner that didn't resemble Dad at all.

Every day had some peace, every day had anxious moments. I believe in this case we are fortunate to be a very small family, which meant that we could all be there, and could all find a role to play. We fell into a rotation through a list of tasks and responsibilities, and I would recommend this to any family approaching a similar event. In order not to distress a starving man with the smell of food, we avoided cooking in the apartment as much as possible, and ate in the residence cafeteria or café. One of us would stay with him while the rest of us ate out, and we'd bring them back a sandwich or a salad. We took turns administering his drugs and swabbing his mouth. We took turns reading or singing to him. And we took turns going out for relief – a massage, a walk in the woods, a bike ride. I don't know how people can manage this if they are too numerous, or not in agreement. I shudder to think. But it does seem to me that our family's ability to function smoothly during those days stemmed from my father's having made his values clear to us for many, many years.

If your parents or partners have not been vocal about the end of their lives, I'd say ask. Do it. It's hard. And it's good. My fiancé (now husband) and I did it soon after he met my dad, walking between sunny, snow-covered fields in his native England. I won't forget the conversation, but I'll also insist on having it again, just to see if anything's changed. If his thoughts have shifted I want to know, so I can help him both to live and to die in the way he desires to.

The last real conversation Dad had was with my mother, about four days before he died. She came in from an errand and said, "Hello darling, I'm here," and he said, "I'm not." When she asked him if everything was all right, he said, "Ideal."

On the tenth night, none of us wanted to leave him. It was something we agreed on almost without discussing it. Mum slept in the chair by Dad's bed in the living room, with my brother on the floor. My fiancé and I were in the bedroom on one side of the living room, and my aunt was in the den on the other.

Something woke my mother and brother shortly before six the next morning. Neither of them can say what it was, but both of them went straight to Dad. He wasn't breathing, but he was still warm. He still had color. Mum woke me up, and I went out and felt his warmth as well. My fiancé joined us, and went to wake up my aunt. We all stood around his bed, watching, listening, seeing his skin go pale, relieved that he was no longer struggling to breathe, and overwhelmed by his timing. He had only just died. He had let us all sleep through the night, and everyone we needed to call was awake, or soon to be.

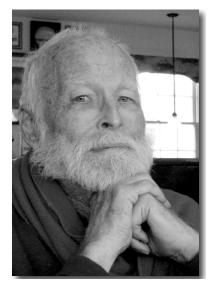
Dad's hospice nurse came and pronounced him dead. When she was gone, my mother invited my aunt and me to join her in washing his body. Again, we easily found our places, with Mum and me on either side and my aunt at his feet. Later, my fiancé noted how we reacted when Dad died. "It was like you all just went, 'Oh!'" he said. And he was right. It was a quiet moment. There was no more ragged breathing, there were no more false alarms. But like everyone else in the world faced with a peaceful loved one lying quietly in bed, I didn't know how to register him as gone. Bathing him helped with that. Mum was washing his face, and I was washing his chest. The center of his chest was a bit scaly, and I wanted it clean and smooth, so I scrubbed a bit, and as I scrubbed his chest hair came out into the washcloth. "Oh," I thought again, differently this time. I rinsed the washcloth and finished washing his chest and arm, more gently. We noticed the livor mortis in his heels and back. My brother and my fiancé

stepped in to help dress him in his most comfortable nightshirt, and we covered him in a quilt made by a friend. Mum called the undertaker.

There's a story attributed to the Chinese philosopher Laozi about some very old men who gather every morning outside their village huts in order to sit and chat. One morning, one of the old men, whose bones are twisted with arthritis, comes out of his hut and sees his shadow thrown onto the wall by the rising sun. "Hey!" he laughingly shouts to his friends, "I look like a chicken!"

When I told this story to my father, well before he was sick himself, he laughed so hard tears came to his eyes. He loved that old man, a perfect, uplifting representation of the Taoist concept of *wu wei*, or non-action. These Chinese words are also variously rendered by Alan Watts in *The Watercourse Way* as not doing anything, not forcing, creating nothingness, acting spontaneously, and flowing with the moment.

I think maybe this, and not suicide, is what Dad committed.



James T. Lester, 1927-2010

My name is Alison Lester, and I am an American writer living in Singapore. I welcome your responses to this essay either on the post of the same title in my blog at <u>www.restroomreflections.com</u> or via email at <u>alison@restroomreflections.com</u>.