

## Essay/Personal Reflection

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We cannot change the world by a new plan, project, or idea. We cannot even change other people by our convictions, stories, advice and proposals, but we can offer a space where people are encouraged to disarm themselves, lay aside their occupations and pre-occupations and listen with attention and care to the voices speaking in their center.

-Henri Nouwen, *Reaching Out: Three Movements of the Spiritual Life*

Say it. Say it.

The universe is made of stories,  
not of atoms.

-Muriel Rukeyser, "The Speed of Darkness" from *The Collected Poems of Muriel Rukeyser*

I started working in my father's office in high school. He was a solo family practice physician and it was the early 1980s, so he did just about everything – ingrown toenails to delivering babies to visiting patients at home on what would come to be called hospice. On any given day, he might be at the hospital assisting a surgery, at the office seeing patients, or at home catching a nap after being at the hospital all night delivering a baby.

But what I noticed about my dad was that if there was a bell-curve of life, he seemed to most enjoy his time at either tail of the curve. He loved delivering babies and he loved taking care of seriously ill and dying people. From blood test confirmation to hospital delivery to the first mother–baby visit, it cost \$500. The parents would appear for each prenatal visit with 10 or 20 dollars to slowly nick away at their bill. Because the cost of obstetric medical malpractice insurance became prohibitive, my father retired after 46 years of solo practice chagrined that he never delivered babies of the babies he delivered.

My memory of Christmas at the office was tamales, homemade pies, and so many paper plates, covered in Christmas wrapping paper, loaded with white sugar cookies covered in sprinkles. The gifts did not seem to be a formality, but a genuine gesture of appreciation. And they weren't just limited to Christmas, our cars were repaired, our appliances resurrected in lieu of patient bills more often than I can count.

And, there was the Christmas when Tom was dying. Tom was only 38 years old when he was diagnosed with stage IV lung cancer. With three young children and one on the way, he and his wife Terry were overwhelmed. My dad had been the one to break the bad news and provide the referral to the oncologist and surgeon who would provide some "Hail Mary" treatments. As Terry's belly grew so did Tom's tumors and it wasn't clear who was going to give birth first.

Our family was getting ready to go to Christmas Eve services, which was one of two times a year my dad would step foot in a church. When my dad's pager went off and he announced that he had to go see Tom, you can guess the rest of the story, Tom died on Christmas Day, his new daughter was born a few days later – my dad "caught" her, as he liked to say. And, Tom's family made their way into a new, unwelcome life without him.

What stuck with me about Tom, and why I remember him all these years later, is that after Tom's death, I saw my dad grieve. Really grieve. In all the messy and unpredictable ways we humans navigate the unique cocktail of sadness, helplessness, anger, frustration, and anxiety that is grief. He was, some may have said, excessively devoted to Tom's wife, he seemed to feel an obligation to Tom's children, and on a practical level, I don't think he charged them a single penny for any of their medical care after Tom's death.

Without judging the professional and personal boundary issues that may have surfaced during that time, the imprint left on me was that my father was affected by his patients. He was happy when they beat the odds and saddened when they didn't. He and his patients seemed to have a relationship of sorts, which as his daughter I recognized was alike and different from my own relationship with my father.

Tom summoned forth something from within my father that, as Henri Nouwen says, disarmed and de-robed him in a way. Tom was my father's peer. They both smoked, they both liked fishing, they both were from working-class families, they both had wives and children they were trying to provide for, but Tom got cancer and died and my dad didn't. This affected my dad. Tom's story penetrated any artifice of professional objectivity my dad may have had

and left him open to be wounded when Tom's story ended too soon, and left him open to be wounded again watching Tom's wife and children struggle without Tom's presence.

But babies don't cost \$500 anymore, doctors can't accept a new carburetor instead of money, and they now spend most of their days looking at computer screens, not patients. The profession of medicine has changed. Most medical professionals didn't come to medicine to be transactionalized, corporatized, dehumanized, or micromanagerialized. They came to listen to the stories, after all what is a "history of present illness" but an elaborate story? They came to heal, to promote human flourishing, and to make a few things just a little bit better in a tiny amount of peoples' lives. They came for a front row seat to the beauty and tragedy of human life, to become "clinicians" in the truest sense of the word – from "kline" or one who bows before another – humbled and awed by the beauty, strength, and resilience of the human spirit.

But what if the profession so many have given their oath to has been bait-and-switched with a substitute? What if the space for story, for healing, for being regularly disarmed by encounters with human vulnerability has been replaced by RVUs, DRGs, ROIs, throughput in the ED? Or, as my dad put it, what if the day-to-day practice of medicine feels less like a healing art, and more like being a "traffic cop on an egg timer?"

This year was my first Father's Day without my dad, and it is hard not only because his heart and lungs gave out fairly quickly (the "waterfall" end-of-life trajectory is great for the dying, but not so great for the grieving), but also because the clinicians we encountered during his 10-day ICU stay seemed to have chosen the ROI track. We were never asked about my dad's healthcare wishes or goals. Instead, we were given reports about what they were going to do *to* my dad. Was it just a coincidence that their treatment plans would have landed my dad in the long-term acute care facility that happened to be the intensivist's side gig? How can we ever know? We had high hopes for the palliative care team. After several days of asking for a family meeting, our experience with palliative care mirrored our interactions with the intensive care team. Again, we were told what they would be doing *to* him without any discussion of my dad's preferences or goals. It was palliative care in name only, absent of any substance that might have helped my dad, and eased our suffering. In the end, my dad was allowed to have comfort care only after the intensivist had sufficiently convinced himself that our family was educated enough to deserve such a radical intervention.

Aside from my own personal disappointment, and frankly rage, about the profound inadequacies of this hopefully small and backward corner of the US healthcare landscape, what would my dad have thought of the care he received from the very system he gave his life to? Not to put a gloss on my dad, one of his initial reactions may have been to blame "Obamacare." But, after that initial jab mostly to irritate the "blue" members of the family, wouldn't he have been disappointed too? On his last morning outside of the hospital, he was at home, having just spent Memorial Day weekend enjoying cocktails and cigars. He woke up short of breath, waited 45 min, called 911, was in critical condition by the time he reached the

ED, agreed to intubation, and 10 days later was dead, his body riddled with tubes, lines, and restraints.

My dad had a high-tech death. Over 30 years ago, my dad's patient Tom had a high-touch death. In Giotto's famous depiction of the death of St. Francis, the beloved saint is surrounded by his community, prayer, love, and peace – but no morphine or Ativan. The ultimate high-touch experience. St. Frank, the modern-day equivalent of St. Francis, dies much like my dad with monitors, strangers, fear, anxiety, and alone in COVID time. Our infatuation with technology, especially medical technology, continues to medicalize and dehumanize one of the most human experiences each of us will eventually have.

Fortunately, today, for the most part we do not have to choose between a high-touch and high-tech. Hospice is widely available throughout the USA and a fully covered benefit of Medicare. Over 90% of US hospitals report the presence of a palliative care program. However, the hospice model of care is best suited, not for the "waterfall," but the "escalator" end-of-life trajectory, which was not the case for my dad. Failing fast, running out of air, what choice did my dad really have but to call 911 and give intubation a try? And, this is the exact point at which the hospital system failed my dad and continues to fail so many others. He was swept up on the conveyor belt of modern medicine. Intensivists, cardiologists, and a cadre of other "ists" seem to have forgotten their role as "kline." Medicalized dying persisted, individual values and priorities be damned.

Much ink has already been spilled admiring the problem that is the modern hospital structure. COVID-19 has brought these gross deficiencies into harsh focus. Brilliant people are working diligently on solutions. But, while we await the transformation of a system that produces the exact results, it was designed to yield, stories like my dad's, and so many others must be told until they are heard and heeded.

Knowing that by the end of my father's medical career he felt like a "traffic cop on an egg timer," it seems a foregone conclusion that my dad would have been unhappy not just with the medical care he received prior to his death, but more so with what his field became during the 50 years he practiced medicine. Desperate to humanize him to the hospital staff while we were unable to be at his bedside due to COVID-19 visitation restrictions, we snuck in details about him in the pauseless, sanitized reports on his EF, FiO<sub>2</sub>, PEEP, and creatinine that were rattled off to us every day. "Did you know he had a t-shirt that said, 'I want to be a burden?'" "Did you get to see the pictures we had put up in his room of his eight grandchildren and the time he went to see *Hamilton*?" In spite of our efforts, we never had the sense that my dad's story was getting through. To the professionals caring for him, he seemed to remain a body of numbers and laboratory values, trending positively then not. The "kline" had no "kline" of his own. The healer had no healer. His story, unlike Tom's, went untold.

### Conflicts of interest

None declared.