



2019 Hope Babette Tang Humanism in Healthcare Essay Contest

First Place Medical Student Essay: The Healing Yellow Raincoat

April Butler

“Home is wherever I’m with you,” a patient wrote on a marker board to his daughter. He lay in a hospital bed thin and frail, with the sound of his ventilator whirring in the background, a wash cloth hanging in his mouth to soak up saliva, a fentanyl patch tucked behind his ear. Out of his entire body, he could only use his right hand. In a few hours, he would be taken off his ventilator and placed on a morphine pump. His daughter held his hand with tears in her eyes. This is amyotrophic lateral sclerosis (ALS).

He received his diagnosis less than two years before. A positive person by nature, he was never angry or bitter about his diagnosis. He could not change it. He felt blessed with the privilege of foresight to be able to cherish every moment with his daughter. They spent every second they could together. They built furniture for her new apartment where she would be attending school. They scoured eBay looking for new rocks to add to his extensive rock collection. As his muscles grew weaker, his daughter drove home to open the heavy packages and show him his new beauties. They picked March flowers in the middle of February together and took silly pictures while they enjoyed an unseasonably warm winter day. That was their relationship—bright beauty blooming when it did not make sense. He was adamant that she continue to follow her dreams, and she vowed to spend as much time as she could with him.

He quickly declined later that year. His bulbar onset ALS worsened his prognosis, and the effects the disease were taking on his respiratory muscles were evident. They discussed the options together, and he elected to have a tracheostomy performed. His daughter remembers his anxiety prior to this procedure. She

remembers the way he walked slowly around the house, his delicate hands as he held his favorite rocks and a family picture. It was like he knew he was never coming home. The tracheostomy was successful, but he had to be placed on a ventilator for subsequent pneumonia, on which he would live thereafter.

A few weeks into his daughter’s second year of school, the patient transferred from a hospital in his hometown to a care facility where his daughter resided. They both knew he was dying, and he willingly left his home, so he could live out his last few weeks by her side. She vowed to hold his hand on the good days and bad days. She vowed to wear her yellow raincoat on the rainy days to remind him of March flowers and the sunshine. She knew these would be the last four walls he would ever see, and she vowed to make it feel like home. With the help of her dad’s speech therapist, she decorated the room with old pictures, mementos, and some of his favorite rocks from his collection.

When he woke up from a nap and saw his favorite memories surrounding him, he burst into tears and wrote out a simple “Thank you.”

I know this patient’s story well because he was my dad. I had the unique parallel of learning the workings of a healthy body in medical school and watching as his body failed him. I memorized every muscle in the body, every innervation, every blood supply. At home I watched as those carefully studied muscles atrophied in my father, how the complex array of muscles and innervations degenerated. The week I learned lung physiology in medical school, I watched as his lungs failed. My experience with my dad helped me learn that medicine is not solely about medicine. I have the utmost respect for the surgeons, physicians, nurses, and speech and physical therapists involved in his care. Their sole goal was to make my dad comfortable, from organizing transport to a distant city, to helping me decorate his room so it felt more like home, to respecting his

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The Arnold P. Gold Foundation holds an annual essay contest to encourage medical and nursing students to reflect on their experiences and engage in narrative writing. The contest began in 1999 focused on medical students and expanded to include nursing students in 2018. Students are asked to respond to a specific prompt in a 1,000-word essay.

For the 2019 contest, students were asked to reflect on the following quote and share an experience in which they or their health care team engaged compassionately and respectfully with a patient to help them feel accepted and seen.

I long, as does every human being, to be at home wherever I find myself. —Maya Angelou

More than 300 essays were submitted. A distinguished panel of judges, ranging from esteemed medical professionals to notable authors, reviewed the submissions. Three winning essays from medical students and three winning essays from nursing students were selected, along with 10 honorable mentions. The winning essays will be published in consecutive issues of *Academic Medicine* and the *Journal of Professional Nursing* in the fall/winter of 2019.

The contest is named for Hope Babette Tang-Goodwin, MD, who was an assistant professor of pediatrics. Her approach to medicine combined a boundless enthusiasm for her work, intellectual rigor, and deep compassion for her patients. She was an exemplar of humanism in medicine.

The Arnold P. Gold Foundation infuses the human connection into health care. The nonprofit organization engages schools, health systems, companies, and individual clinicians in the joy and meaning of humanistic health care, so that they have the strength and knowledge to ensure that patients and families are partners in collaborative, compassionate, and scientifically excellent care.

Please see the end of this article for information about the author.

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wishes when he asked to be taken off his ventilator and die on his own terms.

A physician once told me, “You will not be able to cure or save every patient in your career. However, you do have the opportunity to heal every patient.” I did not truly understand what this meant until my experience with my dad. He suffered from an incurable and progressive disease. There was no ability to save him. He found healing in being around the people he loved as he was dying. He found healing in still being able to squeeze my hand three times to tell me he loved me. He found healing

in my yellow raincoat, and how seeing it reminded him of the sun and his favorite flowers. He found healing in knowing the fullness of relationships he had on this earth and knowing I would be there for his final breath.

My dad was able to find home in a person and not a place. He carried his home with him, within himself. I am thankful for the opportunity to be with him in his final moments. I am thankful for some of his final “words” that I will carry with me throughout my medical career and life: “Because of the challenges I face, I am less than half the man I used to be

on the outside, but more than twice the man on the inside.” He taught me the lessons of compassion, vulnerability, and dignity firsthand. His unbelievable selflessness and fortitude to allow me to continue to pursue my dreams despite his suffering will be my motivation on days when it is wearing thin. It is an honor to have the opportunity to be a physician and offer the same level of care, respect, and healing my dad received, and I am thankful for the chance I have every day to be a little more like him.

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