



## What they teach us

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When my mother died, it was December 1997. I was 12. Her black hair was spread out over the hospital pillow. Her face was swollen and she was engulfed by what seemed like an infinite number of life-sustaining apparatus including a tracheostomy and NG tube.

The week before she died, a resident on her ICU rotation came and sat beside me and my younger brothers. I was suddenly self-conscious of my outdated scrunchy, pink sweatshirt, and pyjama bottoms. The latter had bagel crumbs all over them.

She said to us, "Meeting you and your family has taught me so much. I can't imagine how difficult this is for you. I will be thinking of you and the lessons I've learned for years to come."

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When you first came to our complex care ward, you were in and out of consciousness. You breathed through one tube and were fed through another. When your eyes did open, they were wild and darted from side to side, trying to comprehend your surroundings. When they closed, you sighed in relief as you returned to comforting darkness. It was spring then and the sun streaming in from the window beside you was bright, but cool. Your side of the room was bare, but your roommate's blue lilacs and yellow tulips turned toward the sun, and thus toward you.

You hovered somewhere between life and death—closer to death, if death was defined philosophically as the cessation of meaningful life. However, as much as your existence did not seem meaningful for you, it remained all-consuming for your mother. I guessed who she was when I first saw her. She stood outside your room, hunched over, clutching a rolled-up public transit newspaper in one hand. She had sunken cheeks and wore a threadbare shirt and sandals. Her eyes were similar to yours: round, dark, full of both fear and defeat. When a nurse came into the room to suction you and you grimaced, she held your hand, kissed your forehead and murmured, "It'll be out soon. You'll be up, walking and talking."

Through your mother, I came to learn that you liked hikes, waterfalls, math, oranges, and *ogbono* soup that

your aunt made for you. I learned you had 2 younger sisters who were struggling in school. You used to teach them. You took all of what you had learned in your short 2 decades and sat with them for hours, imparting the knowledge of everything from fractions and cell membranes to how to change a flat tire. You drove them to school in the mornings, then went to your college classes and then to your shift as a parking lot attendant.

A year and a half passes. You have good days and bad ones. When winter comes around and snow beats at your window, you have gone through more infections than what some elderly patients go through, including 3 pneumonias and urosepsis. You nearly arrested once. Since you came here, your mother has understandably wanted your advanced directives to include full resuscitation. As time has gone on and you remain unchanged, I dread needing to run that code. Each time you suffer through an illness, you decline. You have lost weight and have some skin breakdown. When your eyes open, they no longer dart. They stare at the window. Or your feet. They still do not follow me when I say hi and bye or leave the room.

One July day, it is so hot outside that the sky is melting and shrubs lining the hospital entrance appear charred. I am arriving late after a mess ensued with a hand sanitizer explosion at my daughter's day care.

I have a clerk with me today. He is sharp and pensive, but lacks conviction as most clerks do. We review the topic he read about yesterday. I feel a pang of anxiety as he asks me a question to which I do not know the answer. I reassure him I will look it up. He looks embarrassed for asking the question and switches the topic. To you.

He has been following you, invested in your story and disheartened by the cruel unfolding of events. We talk about how your mother is coming in today for a family meeting. She wants to know how you are doing. Though, she is more aware of how you are doing than any of us. She is not coming to us for knowledge or statistics, but for hope. I haven't seen her since the winter, when she asked me to fill out disability forms for you. She left a gift for you then, on your birthday—an exam paper with a red "94%" scribbled over it. It was your youngest sister's science exam. They imagined you beaming with pride.

"Would you be comfortable talking about goals of care in the meeting?" I ask the clerk.

He looks surprised and then slightly anxious. "Sure."

"Only if you're comfortable—no pressure. We can talk about it beforehand."

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Dr Bhayana's story is the winning story of the 2019 Mimi Divinsky Award for History and Narrative in Family Medicine sponsored by the Foundation for Advancing Family Medicine of the College of Family Physicians of Canada. This award is named in memory of the late Dr Mimi Divinsky for her role as a pioneer in narrative medicine in Canada. It recognizes the best submitted narrative account of experiences in family medicine.

He nods, uncertainly at first then more briskly, as if he is convincing himself.

In the afternoon, we sit in a sweltering conference room. Your mother came early. She sits with her hands clasped around a coffee cup, knuckles white. The respiratory therapist gives a succinct report about how you will likely need your tracheostomy lifelong. The speech-language pathologist and dietitian talk about your feeds and how you will likely need your gastrostomy tube lifelong. The physiotherapist and occupational therapist say there is no role for therapy. With each report, your mother's face crumbles. When her eyes meet mine, I want nothing more, as a fellow mother, than to tell her you will once again be the son she knew. Instead, I tell her unfortunately that your eyes still do not track and your arms and legs are stiffening. I tell her your chance for recovery remains slim.

I glance at the clerk. He looks pale and faint. He stammers and his words come out garbled. I open my mouth ready to jump in. Your mother looks distraught at the term *cardiac arrest*. But then suddenly, the clerk catches himself. He apologizes and speaks earnestly, "I'm sorry. Could I please start again? I'm a learner and

this is the most difficult conversation I've ever had with anyone. Your son has taught me a lot since being here." He speaks with clarity now—about values, what you were like before your overdose, and about goals of care. He goes through all possibilities, from aggressive management to a more palliative care approach.

Your mother, recoiling earlier, listens to him and slumps back in her chair. She drinks his words, embracing them and enveloping herself with them. She nods her appreciation and, if you look closely, there is a flicker of acceptance.

Whether we are clerks, residents, or staff physicians, we all exist in a cycle of teaching and learning. While cliché, it is true that our patients are perhaps our most valuable teachers. They educate us about life, resilience, vulnerability, and gratitude. Many of them know their own conditions better than we do. Above all, they leave us with lessons for years to come.

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La traduction en français de cet article se trouve à [www.cfp.ca](http://www.cfp.ca) dans la table des matières du numéro de janvier 2020 à la page e39.

## What are the health humanities?

The health humanities field is expanding globally. This discipline links medicine with the humanities, the social sciences, and the arts. You might be connected to this field daily without knowing it or identifying it as such. When we take into consideration ethics, philosophy, or law in a medical context, that is the health humanities. Reflecting on your clinical experiences through writing is participating in the health humanities. Reading about the history of medicine in order to better understand how we practise today is an exercise in the health humanities. I am convinced that connecting medicine with the humanities makes us better doctors and communicators, helping to foster empathy for our patients and ourselves. It deepens our understanding of what we do. We would love for you to get involved.

### Upcoming opportunities in the health humanities

Mimi Divinsky Award for History and Narrative in Family Medicine

- Recognizes the best submitted written work about experiences in family medicine
- Open to CFPC members, family medicine residents, or medical students
- The piece must be 1200 words or less and can be submitted in English or French
- Submissions should reflect the annual theme, which this year is artificial intelligence in medicine. We are also open to important off-topic stories that do not strictly adhere to the theme but that need to be told
- The prize will be awarded at the Awards Gala during Family Medicine Forum 2020
- The piece will be published in *Canadian Family Physician* in January 2021
- Submission deadline: March 1, 2020

- To submit your piece, please visit [fafm.cfpc.ca/h-a/awards-of-recognition](http://fafm.cfpc.ca/h-a/awards-of-recognition)

Creating Space annual conference: Vancouver, BC, April 17-18, 2020 ([www.cahh.ca](http://www.cahh.ca))

- Abstract deadline: January 15, 2020

Family Medicine Forum humanities stream (<https://fmf.cfpc.ca>)

- Actively seeking presenters
- Select the humanities stream when submitting your abstract
- Session and workshop abstracts tentative deadline: February 2020
- Posters and papers tentative deadline: April 2020

—Dr Sarah Fraser, Section Editor, *Art of Family Medicine*