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WHOLE PERSON CARE

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AN ANNEALING

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where the state is hospital association to deliver a talk on the lessons of her second double lung transplant, as a patient advocate. I was presenting on my own critical illness and recovery, as a critical care physician. My invitation was based on an essay I had recently published in the New England Journal of Medicine, and public speaking was new to me.

She recounted having spent her childhood in a body ravaged by cystic fibrosis, tethered to breathing treatments, hospital beds and complicated antibiotic regimens. The first pair of donor lungs she had received offered a tentative way forward. When her body quickly and violently rejected the new organs, she believed she would die. She somehow found a way to settle into the cataclysm of her body, without resentment or regret, and said her goodbyes, only to be unexpectedly granted a second pair of donor lungs. It was disruptive, she said, finding herself alive again, having prepared herself to die. She may have even used the word annoyed. The audience loved her.

Hers was a visceral, bodily kind of knowing. She was so attuned to her internal landscape, she could tell if her immunosuppression levels were off by how irritable she was when she was hungry, or how poorly she slept. In this way, she embodied the kind of intangible knowing I'd been trained to devalue. She was practical and oriented almost exclusively to the present. She demanded only a utilitarian competence from her medical team and was intolerant of errors. She lobbied for authentic integration of the patient voice,

© 2023 Rana Lee Adawi Awdish. This article is distributed under the terms of the Creative Commons License <u>CC BY</u>. International Journal of Whole Person Care Vol 10, No 2 (2023) believing doing so would prevent medical errors. She genuinely and sincerely viewed compassion as added fluff. While it may be nice to have, she'd explain, it was not necessary for her survival. Her opposition to empathy baffled me.

I had come through the entirety of my illness believing that competency was not at all sufficient. I maintained that medicine could not heal in a vacuum, that it required empathy, and connection. I fervently wanted more humility in my profession. In contrast to her laser focus on the present, my focus was generally either the past or the future. I had entered a kind of covenant with redemption narratives. I believed that by pressing on painful memories, I would access some essential truth that years of training had obscured. I thought I could transfigure the suffering, sublimate it into coherence that would both right the balance of what I'd lost during my critical illness and advance my vision of an aspirational future state. She needed and wanted the change to happen now, where I was content to cast a kite off into some future sky.

Despite beliefs and timelines that were often in opposition, we shared a common purpose in wanting to improve healthcare by fundamentally redistributing power. Like convergent plates of earth that are compelled to move closer, we held each other in place long enough to ask the hard questions. Solid in our respective beliefs, neither of us sunk under the weight of the other. Instead, through friction, some new range of possibility was forced up between us.

She was fashionable with a side of playfulness, where I tended to be plainer and more austere. She loved swing dancing and buying new clothes and would shop for weeks to find the perfect blazer for a presentation, whereas I would pack an entire suitcase of tonal clothing for simplicity. When I arrived to give a joint keynote in all black, she marched me to the hotel gift shop to buy a colorful floral scarf and excitedly showed me eight different ways of tying it.

Though I had experienced more illness and debility than most of my peers, in her eyes I was a novice. The inversion was oddly liberating. It meant that on dark days I could send her a text to that said, "I feel like pulp. There's just nothing holding me up anymore," and know that she would understand. Know that she had probably felt like pulp herself and had long ago accepted it as the consequence of inhabiting a body. There wasn't a thing I could tell her between living and dying that would have fazed her.

"Ok, so now tell me, what's this pulp thing about?" she'd ask, smiling through the phone. And all the thoughts I didn't know I was holding in some kind of cognitive suspension would come pouring out, filling the space between us.

"I don't know," I said, "Maybe I did the math wrong. When I found out about the cancer, I just gave them whatever pieces of me they needed to take. You know, I just like laid it all out at some operating room Alter, like a sacrifice I was trading for more time. And I don't know, maybe there wasn't enough support left behind to hold me up. Maybe the ledger of losses and gains isn't balanced anymore. So, now I'm just pulp."

"You're feeling a little hollowed out right now, and that's a hard feeling. It will pass though, it usually does," she offered, leaving space for me to cry.

"The thing is, I don't want to find, I don't think I *can* find any lessons in this. Too much has happened, and I just don't sense a forward trajectory anymore. You can't make anything out of pulp," I said.

"I want you to hear me say this. You don't have to make anything out of this. Not for anyone," she paused. "But you might, because it's what you know how to do, it's who you've been. You make beauty and sense out of terrible, difficult things."

I reiterated that I was pulp now and that I planned to stay pulp forever. In fact, I now believed my job was not to transfigure the pulp, but to find a home there, in the sticky potage of what I had been.

"Oh sure, you can stay in that soup if you want to. Consider this permission to not be anything other than what you are. Hell honey, just surviving is enough. You are enough," she said.

I considered her suggestion that there was nothing more to find. That I could allow myself to return to and remain in a more essential and natural state. Half my heart believed her, the other half was wondering what form the pulp could take.

Quickly and without warning, she dissolved into a uremic underground world, where she believed she was part of a government conspiracy. I stood helpless, as the scaffolding of her sanity collapsed. She would tell me later, when she returned from the cavernous hollow of her delusion, that she had stayed focused on trying to crack the code, studying the movements and actions of each facsimile of family and friend who entered the room. She believed that was the only way out. It was a completely terrifying experience devoid of any reassurance from her team. It almost sounded as if she were arguing for more compassion in her care.

"What if I told you," I said, "that in the ICU, we tell families that uremia is a pleasant way to die? That they should feel at peace, deciding to stop dialysis on a beloved parent or spouse, because it is a good death." I cringed, waiting for her response.

"Well, isn't that interesting," she sighed, and in those words, I felt how fragile knowing could be when it's not built on a foundation of actual lived experience. How easily the sand of my words could be blown away by her sigh.

"Is it possible," she wondered aloud, "that you all might be describing the death from your own point of view? That a bloated, but quiet patient slowly dying of renal failure was not a burden to you emotionally. Easy for you should be easy for me."

That was her way, heating the handfuls of shapeless sand passed between us, melting it into absolute transparent clarity. And despite the window her words afforded me, I still felt as if I were entering a dark, unmappable woods, where none of what I'd been taught was of any value. I had a deep somatic sense that to survive in the new place, I'd have to rewild, relearn how to trust the physicality of an experience.

"Maybe the pulp is a good thing for you," she offered. "Maybe it will let you seep into spaces that weren't accessible before, like a mountain turning into mud."

The goal of our friendship was never agreement. Rather, it was one of allowing space for disagreement while still willingly entering the perspective of the other. The clearing that emerged in the space between us was the most authentically generative ground.

The day she died, a large cardboard box was delivered to my porch, with her name and return address. I set it on the kitchen counter and stared at it, as if encountering her in a new form. I was not at all ready to regard the contents, knowing it would bring our final conversation to an end.

When I unpacked the box, I found an ivory dress with a colorful banded waist, a delicate floral coat she had worn on a trip to the Netherlands, and a locket and a small note written in shaky, uremic handwriting, *I love you always*. Realizing I was wearing all black and she was still editing my wardrobe, I exhaled deeply, and an unexpected guttural sob emanated from my throat.

And then, like the sea under the pull of the tide, I felt her receding until she was gone. I felt the tear of pieces of me that went with her, and the swell of the pieces she'd left behind.

Biographical note

Dr. Rana Awdish is the author of *In Shock*, a critically acclaimed memoir based on her own critical illness.

A pulmonary and critical care physician, she serves as the current Director of the Pulmonary Hypertension Program at Henry Ford Hospital. She also serves as Medical Director of Care Experience for the System, where she has integrated compassionate communication strategies and Narrative Medicine practice into the curriculum. She is board-certified in Internal Medicine, Pulmonary and Critical Care Medicine.