

Ars Medica

A Journal of Medicine,
The Arts, and Humanities

Vol.
18
No.
1





Volume 18
Issue 1

Julia Yuan is an Internal Medicine resident at UC San Diego. Her work is often influenced by the patients she cares for and the art of medicine. This piece, titled “Bargaining”, was inspired by a terminally ill cancer patient who profoundly struggled with his prognosis and grief at the end of his life. To learn more about her artwork, please visit juliaportfolia.wordpress.com or [@juliaportfolia](https://www.instagram.com/juliaportfolia) on Instagram.



Bargaining



We are grateful for the generous financial assistance of the Departments of Psychiatry at the University of Toronto, Mount Sinai Hospital, and Centre of Addiction and Mental Health, and to support from the Canadian Association for Health Humanities / L'Association Canadienne des Sciences Humaines en Santé and Associated Medical Services (AMS). Published in partnership with CISP Journal Services, Simon Fraser University.

For subscription information or to submit a manuscript, contact arsmedica@gmail.com or visit: <http://ars-medica.ca>

ISSN 1910-2070



Ars Medica
Volume 18, Number 1

Founders

Allison Crawford, Rex Kay, Allan Peterkin,
Robin Roger, Ronald Ruskin

Editorial Board

Allison Crawford	Editor-in-chief
Suze Berkhout	Editor
Pier Bryden	Editor
Candace Couse	Editor
Kelly Fritsch	Editor
Maryam Golafshani	Editor
Robert William Hough	Editor
Emilie Kadhim	Editor
Rex Kay	Senior editor
Rachel Lallouz	Editor
Margaret Nowaczyk	Editor
Sarah Roger	Editor
Ronald Ruskin	Senior editor
Chloe Wong-Mersereau	Editor

Advisory Board

J.T.H. Conner, Paul Crawford, Jacalyn Duffin, Rebecca Garden,
Jock Murray, Thomas Ogden, Adam Phillips, Robert Pinsky,
Mary V. Seeman

Legal Advisors

Stanley Kugelmass, Adrian Zahl

Publishing

Marilyn Bittman	Managing editor
Anna McDonnell Dowling	Graphic designer



Contents

Volume 18, Number 1

EDITORIAL

On Standing at Keats' Grave, Rome, Italy,
August 29, 2024 by **Allison Crawford** 1 – 10

FEATURE PIECE

weak rn by **Rageen Rajendram aka RageMD** 11 – 13

PROSE

Cured by **Dustin Grinnell** 14 – 34

Escape From the Cancer Ward by **Thomas Belton** 35 – 45

Plain English by **Kain Kim** 46 – 50

My Injured Brain by **Beth Castrodale** 51 – 63

Conversations with Dr. Rowena Spencer (1922–2014):
The First American Woman Pediatric Surgeon
by **Charles A. Fishkin** 64 – 73

The Secret of Flourishing by **Mary Lane Potter** 74 – 85

The Witness by **Clare Mulcahy** 86 – 97

Wound Care: A Primer by **Denise Napoli Long** 98 – 107

PHOTO ESSAYS

Bargaining by **Julia Yuan** 108

Translation of Memory by **Isabella Cuan** 109 – 115



Volume 18
Issue 1

POETRY

Short Position / DNR by R.A. Pavoldi	116 – 120
Rivulets of Rain by Shawna L. Swetech	121 – 122
Prognosis— <i>for Danny Wallace</i> by Woods Nash	123 – 124
I Am a Customer Service Representative by Beth Goldner	125 – 126
Operating Room Rhythm by Jan Alexeis Lacuata	127 – 128
Hospital Fugue by Jenny Li	129
Liberation / Summit by Nidhi Agrawal	130 – 131
Inflammation by Marda Messick	132
Across the Sea by Aviva Goldberg	133 – 134
Aggressive Breast Cancer Treatment and Recovery by Elisa A. Garza	135 – 137

Editorial

On Standing at Keats' Grave, Rome, Italy, August 29, 2024

Walking along the Via Raffaele Persichetti in Rome on a hot, late-summer day, I find myself on an accidental pilgrimage, on the outskirts of the city, close to the Cimitero Acattolico, the Protestant cemetery where the poet John Keats is buried. Off the parched streets, I enter lush gardens of pomegranate and cypress, and find Keats' grave tucked in a far corner, presided over by the imposing eighteenth-century B.C.E pyramid of Cestius, visible high above the cemetery wall.

The Pyramid of Cestius



(Source: Crawford, 2024)

The graves of John Keats (1795-1821) and Percy Bysshe Shelley (1792-1822), another Romantic poet

also buried here, were an important stop on the nineteenth-century grand tours of young, upper-class men. Many, like Thomas Hardy, composed their own verses inspired by their reflections here. Hardy's 1887 poem, "Rome at the Pyramid of Cestius Near the Graves of Shelley and Keats," celebrates "those matchless singers" while pondering the forgotten history of Cestius.

Who, then, was Cestius,
And what is he to me? -
Amid thick thoughts and memories multitudinous
One thought alone brings he.

I can recall no word
Of anything he did;
For me he is a man who died and was interred
To leave a pyramid (p.144-145)

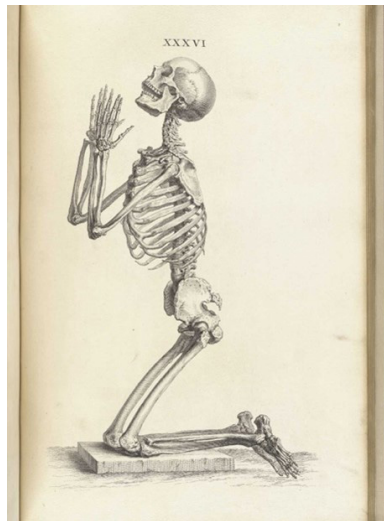
While Hardy dismisses Cestius' transient and forgotten fame, he overwrites a modern role for Cestius whose "ample fame" is to mark the spot where Keats and Shelley lie.

The anguish of transience is marked in Keats' own poem, "Ode on Melancholy," (1819) which mourns "Beauty that must die;/ And Joy, whose hand is ever at his lips/ Bidding adieu" (lines 21-23). John Keats' life was punctuated by loss, with the early loss of both parents—his father to an accident and his mother to tuberculosis. He nursed his own brother through tuberculosis, only to himself die at the age of 25 in Rome from the same disease. I think of these themes of transience, commemoration, and forgetting—a cycle of memo-

ry—as I am reading this issue of *Ars Medica*. This will to remember, to make transient lives matter, reverberates throughout these pieces.

Julia Yuan’s “Bargaining,” on the cover of this issue, is a *memento mori*, literally a reminder that we will die. This ancient practice of reflection on mortality, a reminder of the inevitability of death that goes back to Socrates, is given a modern rendition with beseeching hands bargaining in futility against the inescapable (has already happened!). It is also an echo of William Cheselden’s early eighteenth century surgical text, *Osteographia*, illustrated with praying skeletons. As Mary Winkler (1989) notes, *memento mori* gained prominence in the Renaissance, not only as a reminder of death, but also an affirmation of life and memory through the regenerative power of art.

Cheselden’s *Osteographia*. Plate 36



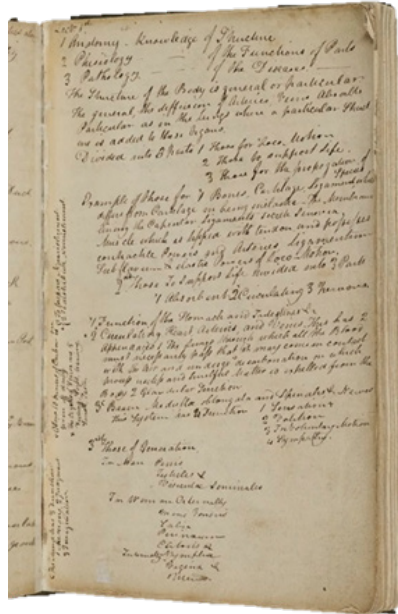
(Source: Cheselden, 1833)

This encounter with loss, while also gaining strength through art, is experienced in a featured piece in this issue. Rageen Rajendram—a.k.a. RageMD—uses rap to respond to loss. “Healing verses: ‘weak rn’” is a journey that is “Kubler-Ross, shattering/ Stages of grief life damaging.” Grief is encountered, but a connection is also made, and a vow to “Never let you suffer in silence.” Similarly, in the form of a photo essay, Isabella Cuan also uses the process of engaging with a patient to navigate her own grief and loss following the death of her grandmother.

Other pieces in this issue not only grieve mortality, but use their artistic force to resist it. In “Escape from the Cancer Ward,” Thomas Belton documents the caper of two young brothers who say “Fuck You! Time...” and spend the day “drunk on freedom, ready for anything that would get him away from the daily death knell on the Juvey Ward where today’s best friends became tomorrow’s empty beds.”

Many with interests in the health humanities will know that Keats trained in medicine. He was apprenticed to the apothecary Thomas Hammond in 1810 when he was only 14 years old, and qualified at the age of 20, though he left without pursuing membership with the Royal College of Surgeons. Hrileena Ghosh (2022) has written a book on Keats’ medical notebook, including an exploration of how his poetic sensibility seeped onto its pages. Keats left medicine to dedicate himself to his writing. Biographer Nicholas Roe traces the impact that his knowledge of anatomy and physiology, along with images of sickness, had on his poetic imagination.

A page from Keats' notebook, Keats House,
Hampstead



(Source: Royal College of Surgeons, England. n.d.)

Many of the pieces in this issue of *Ars Medica* explicitly call our attention to language and to the act of representing experiences of the body. In “Wound Care: A Primer,” Denise Napoli Long returns again and again—“Wait a minute. There’s more. I need to tell a little more, first. Let me start again.”—to ensure that the experience of taking care “of M.’s stage 4 sacral bed-sore” is brought vividly to the reader’s senses: “I can smell it, still. I can smell the sticky, sweet scent of the wound when I first open the dressing.”

Charles A. Fishkin shares the career and life of Dr. Rowena Spencer (1922–2014), the first American

female pediatric surgeon, through conversation and through capturing her words:

Here are her words.

About Herself

On her enthusiasm for babies:

I love babies more than a mule can kick.

On persistence:

*I happen to be hardheaded and stubborn,
and I don't let anything stand in my way if
it's humanly possible.*

On aging:

*I don't fret about it. I just let it do what
it's going to do.*

Through preserving Spencer's words, Fishkin conveys not only the highlights of her career, her dedication to treating young patients, her rejection of segregation and racism, but also traces of her:

... she was also self-deprecatory and spontaneous, evoking images of her childhood in rural Central Louisiana. She sometimes whistled.

Coda

Her usual way of concluding conversations:

Love to all.

Kain Kim, in "Plain English," in contrast, thrashes against the constriction of medical language, describing medical school as "not so much about storytelling as it was about recitation." A deluge of jargon creates distance from meaning and human relatedness: "words wallpapered every-

thing. Under fat bricks of acronyms, patient stories disintegrated into incoherent, fragmentary rubble, word salad.” This professional language is also disembodied, and the writer reminds us that these patients, “still lived in their bodies.” Read the poetry of Woods Nash, R.A. Pavoldi, Shawna Swetech, Beth Goldner, Nidhi Agrawal, Jenny Li, Marda Messick, and Elisa Garza in this issue, to experience the power of words to evoke the embodied, the sensual, the emotional, and even the stock market.

These and other writers in this issue recall Keats’ concept of negative capability. Writing in a letter to his brothers, Keats first articulated this idea in 1817:

At once it struck me what quality went to form a Man of Achievement, especially in Literature, and which Shakespeare possessed so enormously—I mean Negative Capability, that is, when a man is capable of being in uncertainties, mysteries, doubts, without any irritable searching after fact and reason. (p. 277)

This ability to suspend the ego/self, experience the unknown, and tolerate uncertainty, has been suggested by Jack Coulehan (2017) as a foundational skill for reflexive practice in healthcare. Certainly, many of the writers in *Ars Medica* inhabit their writing to explore ambivalent states, states of uncertainty, and even to tolerate new ways of relating to their ‘self’ after brain injury. Beth Castrodale, in “My Injured Brain” describes “a certain separation from my physical self, as if I were floating along in a sort of twilight state.” And

in “The Secret of Flourishing,” Mary Jane Potter contemplates the aspects of the self that are hidden from the critical gaze of the clinical assessment.

Clare Mulcahy in “The Witness” shares her encounter with Emily Dickinson’s “Because I Could Not Stop for Death”: “When I read it aloud, muttering to myself, I discovered a sing-songy rhythm and rhyme scheme that juxtaposed with the unsettling subject. I didn’t know words could work like this.” She uses poetry to navigate her own complex role as her “parents’ witness.” Through the “brutality of [her] father’s illness” she sees poetry itself as a powerful but ambivalent tool, “as a whip and as a ward.”

The main character Peter, in Dustin Grinnell’s story “Cured,” confronts uncertainty and also mystery, in his encounter with a young child with malaria. Towards the end of the story, Peter sits as these worlds of medicine and mystery, science and faith, come together: “Peter smiled in contentment as he watched them dance. As the roaring blaze crackled, he stared into its hypnotic center, watching tiny bits of ash ignite, fly off, and dissolve in the star-filled sky.”

Similarly, Aviva Goldberg’s poem “Across the Sea” explores the experience of hope in medicine through the apparent divide between science and faith: “We agree that you will continue to pray and I will page the surgeons and the nurses and the ICU,” finding instead “angels wherever we seek them,” to “make sense of the senseless.”

I am grateful to spend the time I do with Keats in the graveyard, and with these writers and artists who contribute to *Ars Medica*. They are *memento vivere*. Although Keats wrote in

“Ode on Melancholy” that the poet’s capacity to appreciate beauty has a counterweight in their proximity to melancholy—they “whose strenuous tongue/ Can burst Joy’s grape against his palate fine”—these writers can also bring us back to life, accompany us on life’s mysteries, and medicine’s uncertainties. Keats asked that instead of his name, his gravestone be inscribed with, “*Here lies One Whose Name was writ in Water.*” He brought great humility to the end of his life and to his final resting place, believing that he had failed to achieve immortal stature through his poetry. All of those who struggle to make meaning contribute to this great rippling pool of human experience.

Keat’s grave



This grave contains all that was mortal of a young English poet.
Here lies One Whose Name was writ in Water.

(Source: Crawford, 2024)

Allison Crawford
Editor-in-Chief, *Ars Medica*

References

- Cheselden, W. (1733). *Osteographia, or The Anatomy of the Bones*. (G. Van der Gucht & Mr. Shinevoet, Illus.). London, UK: [W. Bowyer for the author?].
- Coulehan, J. (2017). Negative capability and the art of medicine. *JAMA Network*. 318(24), 2429-2430. doi: 10.1001/jama.2017.19333.
- Ghosh, H. (2022) *John Keats' medical notebook: Text, context and poem*. Liverpool, UK: Liverpool University Press.
- Hardy, T. (1898). *Wessex poems and other verses: Poems of the past and present*. New York, NY: Harper & Brothers. p. 144-5.
- Keats, J. (1899). *The complete poetical works and letters of John Keats*. Cambridge Edition. Boston, MA: Houghton Mifflin and Company, p. 277.
- Roe, N. (Ed.). (2017). *John Keats and the medical imagination*. London, UK: Palgrave Macmillan
- Winkler, M.G. (1989). Tragic figures: Thoughts on the visual arts and anatomy. *Journal of Medical Humanities*, 10, 5–12. doi: 10.1007/BF01136376



Volume 18
Issue 1
2024

weak rn

Rageen Rajendram aka RageMD

Lyrics written and performed by Rageen Rajendram
aka RageMD
Produced by FinniX!Beats

You gonna, You gonna, You gonna,
Break me down
I'm usually strong but
I'm gonna im gonna im gonna
Just be weak right now
You kissing other people just to

I just can't be weak, can't be weak, can't be weak, yea
I just can't be weak, can't be weak, can't be weak, yea
Talk to me, private
Never let you suffer in silence
Be free don't you hold it inside
Tell me what you need no guidance
Talk to me, private
Never let you suffer in silence
Be free don't you hold it inside
Tell me what you need no guidance

Tears that were shed not far from the lens
News delivered weighin heavy on the head
I say this to you as you hold your kid tight
not knowin if you ever gonna hear it again
Looked the other way so you couldn't see it, perceive it
In denial you had to read it to believe it
100 miles an hour into a bend a dead end
thinkin you could runaway to flee the grievance

Talk to me, private
Never let you suffer in silence
Be free don't you hold it inside
Tell me what you need no guidance
Talk to me, private
Never let you suffer in silence
Be free don't you hold it inside
Tell me what you need no guidance

Playin games, Activision
Fake news, Fabrication
Wash my hands, sanitation
My blood pressure about to match inflation, like
Thrift shop, bartering
Paid dues, harbouring
Kubler-Ross, shattering
Stages of grief life damaging

I just can't be weak, can't be weak, can't be weak, yea
I just can't be weak, can't be weak, can't be weak, yea
Talk to me, private
Never let you suffer in silence
Be free don't you hold it inside
Tell me what you need no guidance
Talk to me, private
Never let you suffer in silence
Be free don't you hold it inside
Tell me what you need no guidance

Tore your world down, so we could build it up again
Peelin back pieces off the shell on your skin
An egg crackin all the groundwork that we built
The pain boiling hard, the words scrambling
Came to terms with it, let it percolate
Fermentation was the name of the game
And as I lay awake in this state, accepted my fate
it became a part of my make

I just can't be weak, can't be weak, can't be weak, yea
I just can't be weak, can't be weak, can't be weak, yea

About the Author

Rageen Rajendram is a doctor, researcher, and song writer. Email: rageen@gmail.com. His music may be heard on:

Spotify: <https://open.spotify.com/track/5QKnDd1ajAyo0WJyF9b4I7?si=687125296611498c>

Apple Music: <https://music.apple.com/us/album/weak-rn-feat-finnix-beats-single/1666176714>

YouTube Music: <https://www.youtube.com/watch?v=bfUf-5aXzMU>



Volume 18
Issue 1
2024

Cured

Dustin Grinnell

Peter Spaulding removed his sunglasses and squinted through the sunlight as he hesitated outside the hospital—a massive, dark green tent covering a patch of Kenyan earth. His stomach rumbled. Hungry, he glanced at his watch. Five o'clock.

He was thirsty, too, but he'd run out of bottled water. Everyone told him not to drink well water unless he wanted to spend the next two days in the bathroom, a putrid hole in the ground at the edge of camp.

Back at Harvard, Peter probably would have had a salad, but the lettuce would have to be rinsed with water, so that was a no-go. Who knew how much longer he'd have to survive on protein bars as he played what his doctoral advisor described as an "advocate for the malarial initiative" and flexed his "adventure muscles"?

Adventure muscles? I don't have a single adventure muscle in my body.

Peter inhaled deeply, dipped his head as he entered the tent, and gazed up. Two gigantic trees, covered in chop marks from the handmade axes that had cut them, pierced the thick canvas, stretching the material high into the air. Kenyan men and women talked among themselves and exchanged words with the nurses, doctors, and

scientists who tended to patients. The tent smelled of disinfectants and sanitizing solutions. Second-hand hospital equipment hummed and displayed vital signs. Patients hooked to beeping machines suffered in their cots, soaking their beds with sweat and other bodily fluids.

One brightly dressed Kenyan woman caught Peter's attention. She was speaking with a tall, dark-haired German doctor he'd come to know in the past couple of months—Dr. Leon Becker. The woman was cuddling a squirming infant and pointing to a tiny red mark on the child's arm.

Peter watched Dr. Becker's angular face as the doctor nodded and pressed the soft skin around the inflamed bump. As a scientist, Peter could only watch and let the doctors do their work, but he approached the bed, curious.

"My daughter was bitten by a mosquito." She rubbed the child's head, which was covered in a thin layer of black hair. As the woman explained her child's worsening condition since being bitten a week before, Dr. Becker examined the infant. He stared at the ground absently as he gently pressed the baby's belly, checking her spleen.

"You can help her?" the woman asked, finishing her explanation.

"Yes," Dr. Becker began, avoiding the mother's eyes, "we can help your daughter." The mother showed no signs of noticing Dr. Becker's detachment. Her expression told a story of absolute faith in the West's seemingly infinite knowledge and magical technology.

Dr. Becker noticed Peter and waved him closer. "This is Peter Spaulding," he told the mother.

“He’s from the Harvard Department of Immunology and Infectious Diseases.”

“*Jambo*,” Peter said, immediately regretting using the Swahili greeting.

His presence felt foolish. He wasn’t a doctor here to treat patients, and it would be three years before he obtained his PhD, assuming he made some inroads with his research on antimalarial drugs.

“Your daughter has malaria, ma’am,” Dr. Becker explained as he fiddled with a bag of intravenous solution. “This bag of fluid contains medication that’ll make her feel better.”

Once he’d finished hooking up the IV, Dr. Becker stripped off his latex gloves and threw them in the trash. He turned to Peter and whispered, “It’s *Plasmodium falciparum*.”

Of the five species of malaria, *P. falciparum* was the most lethal. Peter had swirled colonies of the parasites around in a beaker hundreds of times, trying to find a way to beat them, but he’d never been able to. It had always been an abstract problem for Peter. He’d never seen the parasite’s effects up close, so tragically effective in the human body. The child couldn’t have been more than a year old.

As Dr. Becker discussed the child’s condition with her mother, speaking of her enlarged liver and inevitable demise, Peter studied the mother’s face. He expected her to cry or maybe get angry and shout like other parents had, like the ones who now clutched at their children, understanding they had only hours to live.

But she didn't get mad. Nor did she cry. Something did change, though. Hope drained from her face, and her faith in the doctor crumbled.

She glanced at Peter, and their eyes locked.

What can I do for her? Nothing.

Peter wanted to leave. He wanted to go back to where things made sense, a life of quiet experiments, exams, presentations, and beers with friends after the lab.

"Well, I'm going to check on the others," Dr. Becker announced, scribbling notes on a chart.

"We will do everything in our power to help your daughter, ma'am." He then walked to the far corner of the tent, leaving Peter with the mother and patient.

"My name is Amara," the mother said.

Peter introduced himself. "What's her name?" he asked, glancing at the infant.

Amara was still caressing the child's head.

"Her name is Malia."

"The doctors will do everything they can," Peter echoed.

Even as he spoke, Peter knew the medication flowing into Malia's arm probably wouldn't stop the infection; the parasite had likely developed a resistance. The doctors were smart, but for as long as Peter had studied the disease, malaria had proven itself smarter.

"The doctor does not believe anymore," Amara said, looking down at Malia.

"Believe?"

"He does not believe he can help us. I can see it." Peter carefully searched for words. "Malaria is a challenging disease."

Amara tilted her head. "Do you believe?"

If she had seen through Dr. Becker, she would see through Peter. She likely knew this tent, this conversation, was agonizing for him, and that Peter had wanted to leave ever since he'd arrived.

"I'm not really a doctor," Peter muttered, feeling uncomfortable.

Malia coughed and scrunched up her face. The soft pout turned into a breathless cry. As the mother began to rock Malia, her eyes filled with tears. "Please help!"

"U-um," Peter stuttered. "I-I-I will try."

Malia started wailing, provoking other children to cry as well. Voices lifted all through the tent, trying to calm the sobbing children. Tears streamed down Malia's face.

Peter ran through the tent, hurrying past distressed families consoling the unwell. He burst through the exit and into the hot African air. Gazing up at the sky, he inhaled deeply.

The aroma of meat roasting over a nearby fire filled his nose, but the odor of a cigarette tainted the fragrance. Peter turned his head to see Dr. Becker staring idly into the village and smoking. The doctor inhaled and blew out several smoke rings.

"So, do you believe?" he asked without turning his gaze from the sunbaked huts. Blowing out more smoke rings, he chuckled. "She asked you that, didn't she?"

"Yes," Peter replied.

"Of course she did. They all do. And you know what? When I got here three years ago, I believed. I thought we could stop this thing. But

people like you have been working on the malaria riddle for decades. And what have you got to show for it? A few drugs, many of which the parasites evade.”

Dr. Becker shrugged. “Let them have their faith, I say. It’s all they’ve got. Now, if someone asks if I believe, I say yes and move on.”

“Will Malia die?” Peter asked.

The doctor nodded. “I doubt she’ll make it a week. Two, if she’s lucky.” He threw his cigarette on the ground and crushed it underfoot. “But you don’t have to worry about that anymore.”

“What do you mean?”

Dr. Becker reached into his coat pocket and handed Peter an envelope. “Your advisor sent this letter. You’re going home early.”

Peter opened the envelope and pulled out a plane ticket to Boston.

It had been a few days since Peter returned from Kenya, and he hadn’t yet recovered from the seventeen-hour journey. If the brown coffee stain on his lab coat hadn’t expressed his fatigue, his messy hair, the bags under his eyes, and his general dim-wittedness certainly would have. While he often reveled in the emptiness of the lab—in particular, his isolated section of bench space—it had been difficult to focus lately. The soft ticking of the machines, usually relaxing, only added to his malaise.

The spreadsheet on the monitor didn’t help lift his spirits either. It displayed the results of an experiment he had run the day before, showing

quantities of *P. falciparum* cultured in Petri dishes. In addition to the standard cocktail of nutrients the parasites needed to thrive, experimental populations were subjected to a drug formulation he'd developed from medical literature. Nonetheless, the data presented high rates of growth in all populations, including those subjected to Peter's compound.

Another failure. What's new?

Since he had begun as a doctoral student in Harvard's Department of Immunology and Infectious Diseases two years before, every one of his antimalarial formulations had failed. A few dozen unsuccessful experiments were considered normal, but two years of disappointment had put him at his wit's end.

Frustrated, he closed his notebook and shoved it across the granite-topped lab bench. It bumped an opened cylindrical bottle and tipped over a large tray of pipette tips, spilling them across the bench and onto the floor.

"Someone's a little hungover from their African adventure."

Andrea Malloy and Chris Livengood, two of Peter's lab mates, strolled into the lab. Andrea walked by a mosquito-crossing sign and pulled a flyswatter off the wall. She stepped over the pipette tips on the floor and smacked the swatter on the bench just to annoy Peter. He rolled his eyes.

Andrea was a fifth-year grad student and a hippie intellectual: big brain and superior attitude cloaked in a deceptively laid-back disposition. She wore a flannel shirt and baggy jean shorts, with socks pulled up to her calves. As she leaned over to squint at the numbers on Peter's computer

screen, the scent of body odor and sweat assaulted his nose. He knew she must have come from the insectary, where she bred mosquitoes.

“You know, you’re right,” she stated, inspecting the spreadsheet. “You should have been a doctor.” She smirked. “Looks like another letdown.”

Andrea studied the genetics of the malaria parasite. Her work generated mini successes every day, discoveries like new genes and molecular mechanisms—publication-worthy stuff. She seemed to delight in reminding Peter of his fruitless doctoral concentration—career path, even—and that medicine would have been easier. She loved to recap how impossible basic research was, as well as how much soul-crushing disappointment was involved. The work was dismally funded, and they were always battling for hard-to-win grants to back experiments that, in all probability, would fail and, if successful, would have only a slight impact on the scientific community. Meanwhile, a friend had graduated from medical school and just finished his residency; in two years, he’d be making six figures. With two post-docs ahead of him, Peter would be lucky if he earned that in ten years.

Nonetheless, every time Andrea had Peter thinking about the challenges of their chosen professions, he reminded himself of his passion for the puzzles science offered. While he liked to complain about the futility, he knew he had made the right choice. And while Andrea thought she was so cool with her “mosquito lab,” who the hell wanted to cut up spit glands all day?

Chris, a second-year grad student studying the transmission of malaria from mosquitoes to hu-

mans, dropped to his knees to help with the mess. “How was your adventure?”

Why does everyone insist on calling my trip to a disease-infested camp in the middle of the African wilds an adventure?

“Yeah, it was quite the learning experience.” Peter didn’t want Andrea to know that he hadn’t enjoyed himself. No doubt, she’d tell their advisor who had dispatched Peter to see the “true” effects of malaria because he had believed Peter was far too removed from the disease, too theoretical.

Peter thought back to the Kenyan hospital, to Malia, and to her mother, inquiring whether he believed. It didn’t take much introspection to see he did not.

“Trivia night at Shay’s,” Chris said. “You coming?”

Typically, Peter was first in line for trivia night at the bar, but he was too tired. And he couldn’t shake Malia’s face from his mind.

One thing was now true: The illness wasn’t just a puzzle anymore.

“I want to try a couple more formulations.” He distractedly clicked open a file on the computer.

“Suit yourself,” Andrea said as she and Chris headed for the exit. She hung the flyswatter back on the wall.

Peter frowned. Had the trip made that big an impression on him? Who *actually* changed in two months? Would one more late night in the lab cure malaria?

The African trip had been intense. *But I could use a little fun.*

“You know what?” He shut down the computer. “Wait up! I’m coming.” As he grabbed his coat

and shut off the lab's lights, he remembered the plea from Malia's mother, asking for his help, and the empty promise he'd made to try.

Amara set her daughter down in a small crib. Malia's fever had worsened since Spaulding left several days before. Whenever the fever did break, chills took its place, causing her to shiver despite a cocoon of blankets. When the fever returned, Malia's skin turned crimson as her body heated like a small fire in Amara's arms.

Amara dipped her nose into a colorful bouquet of flowers her brother had delivered. The arrangement's sweet aroma wafted hopefully, providing a temporary relief from the hospital's constant despair. Her brother was just exiting the tent, followed by the tribe's shaman, who had spent the night with Malia and the family. Amara considered herself wise for seeking counsel not just in the West's magic, but also in the ancient intelligence of the tribe's spiritual healer.

Throughout the night, the shaman had rocked the sick baby in his arms, blessing her while in a trance, humming prayers and chanting as he tried to draw the bad spirits from her body. Just before the sun rose, he had received a vision from the spirit world: an image of a young man carrying a gift for Malia and a boon for the hospital.

Amara knew it had to have been a vision of Peter, the young scientist who had left without a goodbye. The shaman was predicting his return.

Late for his rounds, Dr. Leon Becker approached the hospital with the heavy taste of liquor still on his tongue. Coffee in hand, he skimmed the daily report. Apparently, they'd lost a child in the night.

As he stepped into the tent, he passed the exiting shaman. Leon pitied the hopeful Kenyans who followed him, believing that a few waves of the witch doctor's hands would magically enable their loved ones' immune systems to outmaneuver malaria.

In many ways, though, he also envied the families of the sick and their unwavering faith. He'd yet to see hope change the course of the disease, but perhaps the delusion helped suspend rationality, providing its own kind of solace.

More than the families and their faith, Leon envied Peter Spaulding and his quick visit, his psychological distance from the sick and, most of all, his escape from Africa and the madness that had transformed Leon from idealistic hero to determined cynic these last three years, causing him to detach from the ones he'd once hoped to cure. Every day, he thought about going home, but who would do this important work if he left?

Shaking himself from his thoughts, Leon surveyed the tent, and his gaze landed on Amara. He walked over, said hello, and looked the child over. He tugged on her IV and squeezed the clear bag of antimalarial medication, which had no doubt lost ground to the parasitic infection. He made a few notes on Malia's chart, remarking that the disease had progressed classically. He suspected Malia's kidneys would fail soon, followed by anemia and possibly respiratory distress. Using his penlight, he inspected Malia's retinas for whiteness, which

would indicate that cerebral malaria had set in. He made a note when he found them normal.

“Do you think the scientist who left will come back and help Malia?” Amara asked as he wrote.

Leon understood the reference to Peter, and the answer was no. The “advocates for the malaria initiative” never returned. Certainly not any from Harvard, who couldn’t wait to leave the moment they’d arrived.

“Yes,” he lied, faking a smile. “We spoke before he left. You and Malia made quite an impression on him.”

“What is ‘made an impression’?” Amara asked, looking confused.

“It means he thought highly of you and Malia.”

A strong wave of self-hatred washed over Leon then. He hated the doctor he’d let this place turn him into. He hated his disillusionment, his excessive drinking, and the man he’d watched himself become. But he hated Peter more: his dispassion for humans and his ruthless pursuit of grades, degrees, and titles.

No, he wasn’t going to lie for Peter Spaulding anymore.

Leon tore off his gloves. “You should know something. Do not put your faith in that man. He hated this place from the moment he arrived. And he is *not* coming back.”

Flustered, Amara put a hand over her mouth. When Malia started to cry, she picked her up and turned to Leon in desperation. “B-but the vision...”

Leon snorted. “That man you call a shaman, who whispers chants over your sons and daugh-

ters . . .” Leon jabbed his finger at the tent’s exit. “He won’t cure anyone. And he *certainly* won’t help your daughter!”

Lost in rage, he didn’t try to temper his volume, which rose as he pointed at Amara. “To you, and all the others with misplaced hope, let me share *my* vision. Most of these children will die, including yours, and mark my words, you will never ever see Peter Spaulding again.”

Amara’s eyes filled with tears. The hope instilled in her by the tribe’s shaman, her faith in Western medicine, and the motherly strength she’d nurtured throughout Malia’s sickness all disintegrated, replaced by a profound sadness for her dying child and a hopelessness from which she’d never recover.

With a commanding lead in trivia night, Peter’s team of Harvard doctoral students, affectionately known as the Mosquito Crew, was in good spirits at their favorite bar, Shay’s Pub, as they relished the momentary respite from lab work.

“13.8 billion years,” Peter whispered to Chris in answer to the trivia question the heavysset man on the stage by the bar had just read. Peter took a sip of his beer and sat back while Chris wrote the answer on an index card before handing the card to a waitress. The young woman delivered every table’s card to the stage.

Still holding the microphone, the host straightened the cards and repeated the question: “Okay, the Big Bang took place how many years ago? Let’s see what you all came up with.”

He lifted the first card. "10 billion years ago." He slid the card to the back. "13.8 billion years ago." He read the next card and chuckled. "Okay . . . 25 years ago?" He shot a sarcastic look at the bartender. "Hey, Joe, no more drinks for the table that thinks the universe began in 1997."

The bar erupted in laughter.

The trivia host read cards from four more tables, including the Mosquito Crew's, then paused dramatically.

"The correct answer is . . . 13.8 billion years ago."

Everyone at Peter's table began clapping and laughing, excited over their fifth consecutive win. Chris offered Peter a high five.

"Are you getting a degree in physics too?"

Andrea asked arrogantly, frustrated that most of the night's answers had come from Peter. He ignored her and took another sip of beer while the host prepared the next question.

Chris leaned toward Peter. "Ah, she's just pissed she has to clean up mosquito crap all day." Peter chuckled. "Wouldn't theoretical physics be nice? All they need is a pad of paper and a sharp pencil. It takes me five hours just to prepare a single experiment."

"And ten seconds to watch it fail." Chris laughed.

"Funny."

"Ah, but they're theorists," Chris mused.

"We're experimentalists. It's where the glory is."

"I don't know, man. I'm beginning to wonder if all this failure fulfills some dark psychological need." Peter sat up. "You know what I've been thinking a lot? Whether we've been mistaken in how we approach the fight against malaria."

“What do you mean?”

“The parasite is just too clever. Perhaps we can’t really attack it head-on.”

“You think too much, Pete.” Chris slapped him on the back, then took a sip of his beer. “Tonight, just have a good time.”

He was right; Peter always had a tough time shutting off his brain. It’d been even more difficult since returning from Africa. The puzzle had become an obsession. Malia had made everything so tangible, which made Peter’s efforts that much more urgent.

The host began again. “Okay, ready for the next question, everyone? Here we go. In Ancient Greece, the storyteller Aesop wrote this popular fable to illustrate the moral ‘slow and steady wins the race.’”

Andrea bounced in her seat and leaned across the table. “The Tortoise and the Hare,” she stated with enthusiasm. “The Tortoise and the Hare!”

Chris turned to Peter, looking for approval. Peter nodded. The same answer had popped into his head, but stirred by the question, he’d remained silent. As he watched the woman collect their card, a jolt of energy hit him.

He spun in his seat. “What if we ignored infection cycles?”

“But that’s the traditional approach,” Chris answered, obviously disappointed the malaria talk was continuing.

“And after all these years of trying it that way, we *still* don’t have a cure. What if we concentrated on the body’s natural defenses?”

“But the parasite changes too fast for the immune system,” Andrea chimed in.

“Indeed,” Peter said. “It’s just like the story of The Tortoise and the Hare. The parasite runs circles around the immune system.”

“Strengthen the immune system?” Chris asked, his curiosity piqued.

“And make the tortoise as fast as the hare!” Peter catapulted from his seat. Euphoric, he ran for the door, weaving through tables. As he pushed open the bar’s front door, the host announced, “And the answer is The Tortoise and the Hare.”

Sitting in the driver’s seat of a rental truck, Peter grabbed the foam box containing his prototype drug and pushed open the door. Stepping out onto the harsh Kenyan landscape, he marched toward the medical tent he had thought he’d never see again. Only a week before, just the thought of joining rounds in the hospital would have made him nauseous.

Now, as he walked toward the entrance with the foam box tucked under one arm, he felt useful for once. He’d spent eighteen-hour days in the lab after sprinting out of Shay’s, testing a variety of formulations to boost the immune system’s production of antibodies.

He ducked through the entrance and made his way toward Amara, relieved she was still there. She rocked in a wooden chair, gripping her unconscious child in her arms.

“You came back!” Her eyes held a mixture of joy and disbelief. She looked down at Malia. “You can help us now?”

Peter placed the foam box on the bed, lifted off the lid, and began unpacking its contents. He pulled out a syringe filled with a cloudy solution, cautious of the inch-long needle at the end. “Inside this syringe...”

“What do we have here?” Dr. Becker interrupted, sauntering toward them. “Jonas Salk?” His voice rang with as much surprise as the woman’s had, though his words were laden with sarcasm.

He knocked on the foam cooler as if it were a door. It was clear he wasn’t happy to see Peter. In fact, he seemed downright hostile. In the two months Peter had spent in Kenya, Dr. Becker and he had gotten along well, but it was scorn that had bound them. They’d shared many meals criticizing the hospital and those within it, complaining about Kenya and sharing their contempt for the entire system. Misery loved company.

Now, Peter just pitied the tortured, beaten-down cynic before him.

“I’ve created a drug that I believe...”

“You’ve created nothing,” Dr. Becker broke in. “You tinkered in the lab for a few days and came up with a potion that, in all likelihood, is ineffective and causes a host of side effects.” He pointed at Malia. “This child is in a coma. She has cerebral malaria. Do you understand? It means she’s going to die.”

“I believe I can save her,” Peter maintained calmly, trying to avoid a confrontation. He set the syringe on the bed. “This treatment doesn’t directly attack the blood stage of the parasite’s life cycle. Instead, it stimulates the immune system to manufacture more antibodies.”

“So now you want to start injecting people with it, is that it?” Dr. Becker snickered. “I can only imagine what kinds of immunological reactions that stuff will cause. Did they even teach you about anaphylactic shock at Harvard?”

Peter’s heart pumped faster. “Leon, please.”

“You’re all the same, you American students! You come down here, so idealistic, believing you’ll change the world, hoping you’ll cure malaria, of all diseases! I thought you were different. That you were a realist. But look at you! All pumped up with pride, thinking you’ve got the cure. And when it doesn’t work, when it fails like the others have, what will you do? That false zeal you’re feeling right now will vanish. You’ll go back to your easy life, sipping beers and snacking on peanuts in Harvard Square, talking about how you took your shot once. And I’ll be here, tending to the sick, watching this wicked disease evolve.”

Normally, Peter would have engaged the doctor, but quarreling seemed trivial when so many around them needed aid. Dr. Becker shouted more accusations, his face enflamed, spit spraying from his mouth.

Suddenly, Peter pictured a reflection of himself. A self he might have become had he never returned to Kenya. Dr. Becker was right, the Peter Spaulding who’d gotten on that plane a week ago had hated this place, and he *had* wanted to escape. But he’d returned. And that life of chasing grades, fretting over getting published, and laughing away time at bars was over. Finally, he cared about the people his research might cure.

Furious, Dr. Becker motioned to a guard, a large African man with crossed arms. “If you think

I'll just let you waltz in here and treat my patients with some cockamamie remedy, you've got..."

The doctor abruptly fell silent, his gaze glued to Amara, who held the syringe Peter had left on the bed. The inch-long needle was buried in Malia's arm, the plunger fully depressed.

Dr. Becker pushed Peter out of the way and ripped the empty syringe from Malia's arm. "Why did you do that?" he demanded, dumbfounded.

Amara stared at Peter. "Because I believe."

Peter watched Amara's face glow in the moonlight. She grinned at him and then nodded in the direction of the tribe's shaman, who led vibrantly dressed men and women around a blazing fire, twirling and singing in celebration of Malia's recovery.

"You saved my daughter," Amara said. "Just like our shaman said you would."

Peter smiled in contentment as he watched them dance. As the roaring blaze crackled, he stared into its hypnotic center, watching tiny bits of ash ignite, fly off, and dissolve in the star-filled sky.

Malia let out a healthy cry as she shifted in her mother's arms. It had been a week since her mother had given her Peter's drug. She had come out of the coma the day after it was administered and had improved every day since. Peter smiled as she whimpered, still awed by her recovery, which seemed like a miracle. In science, the path from theory to bedside was an arduous, unpredictable journey, yet in Peter's case, it had happened with

blistering, unprecedented speed. He'd finally gotten that win he was looking for.

"Well, she'll live," Dr. Becker declared. He wore jeans and a blue T-shirt rather than his usual button-down shirt and white coat. "There's nothing I can do about that cry, though."

He grinned at his quip, and Amara and Peter chuckled cautiously. The doctor seemed sheepish, but they were still guarded since he had yet to apologize for his behavior.

"She experienced a few more fevers after she came out of the coma, but all in all, the drug worked." Dr. Becker shook his head and scratched his jaw. "I still can't believe it actually worked."

He interlocked his fingers and exhaled as if to say something, then paused.

"You know, Peter . . . I just want to say . . ."

"I know," Peter assured when Dr. Becker couldn't seem to find the words. "And I'm sorry, too." He took a deep breath. "The infected aren't the only ones who suffer."

Dr. Becker nodded. "Your medicine might just put an end to that." He smiled. "What will you do now? Head back to Harvard? Accept praise for having created the drug of the century, the cure for malaria?"

"Malia's just one child," Peter protested. "We'll need more testing."

"That means years of planning, millions of dollars for research, large-scale manufacturing, and clinical trials."

"It won't be easy." Peter paused. "But I . . . have faith."

Dr. Becker nodded, looking impressed. “So, I got a call from your advisor yesterday. He wondered where you were. What should I tell him?”

Peter looked at Amara, the baby in her arms now sleeping. “Tell him thank you for sending me here. Tell him I’ve found all the humanity I need right here.”

“You’re staying?”

Peter looked into the bonfire and nodded.

“You’ll need a good doctor to deliver all those shots.”

Smiling, Peter stood up. “Let’s talk about it over dinner.”

“Just like old times.” Dr. Becker grinned, but the expression soon softened. “One thing’s for certain, Pete.”

“What’s that?”

“You made me a believer.”

About the Author

Dustin Grinnell is the author of *The Genius Dilemma*, *The Empathy Academy*, and *The Healing Book*. He holds an MFA in fiction from the Solstice MFA Program at Lasell University and an MS in physiology from Penn State. Email: dustin.grinnell@gmail.com



Volume 18
Issue 1
2024

Escape from the Cancer Ward

Thomas Belton

I slipped out of the stairwell, crept across the corridor, and past the abandoned nurses' station and the broken elevator door that opened and closed like a mechanical mouth, mutely chewing the iodine-soaked air. I ran across the hall and into my brother's hospital room. Joe looked up wearily from his bed, probably thinking it was another intrusion from the technicians who constantly took samples of his blood.

He saw my face and grinned. "What the hell are you doing here?" he asked, slipping to the edge of the bed and planting his feet on the safety bar like a diver ready to launch.

"Let's go!" I said and gave him that creepy old look from one of our more infantile brotherly games as I peeled off dad's huge plaid raincoat and threw it on the bed. Not a word from him as he threw on the raincoat and pushed his pale white feet into the carpet slippers that mom made him wear for his chemotherapy treatments. *What a stupid, poisonous term for a medicine to kill the leukemia by slowly dripping poison into his veins like murderous dwarves looking for an ogre to kill, I thought.*

He giggled like an imbecile as I shushed him. We tripped the exit door alarm momentarily before entering the stairwell and running down

twenty flights of stairs to the lobby of the hospital. Out we went, scurrying through the crowded lobby, with Joe's pajama bottoms peeking beneath dad's raincoat, spinning through the revolving door and into the blistering heat of a New York City summer's day.

In dad's oversized raincoat, Joe looked just like Mr. Toad of Toad Hall in the *Wind in the Willows* the first time he saw a motor car; the smog black fumes of First Avenue offered a heady wine to Joe's fevered soul. He was drunk on freedom, ready for anything that would get him away from the daily death knell on the Juvey Ward where today's best friends became tomorrow's empty beds.

He's grown up too fast, I thought, as we ran across the street, dodging Yellow Cabs and itinerant mopeds. After the first round of chemo a few weeks ago, he'd become a veteran of the great war on cancer and, with that thousand-yard stare, a stranger in my 17-year-old brother's flesh. For now, though, we were out and free on the streets! Just like old times when we'd sit all night yakking under the huge samovar at Café Wha? down in Greenwich Village, sipping espresso until our tongues got fat and swollen with the caffeine shakes, our brains roiling with too much thinking about existential philosophy overlaid with the morbid fatalism of Irish Catholicism. Or the time we cut down to the dive bar, Sammy's Bowery Follies, and swilled pitchers of beer at the long tables filled with college girls, ridiculously pretending to be hip while singing ragtime ditties to the accompaniment of a Roaring Nineties banjo band.

We were just like all the other nerds out for a cheap drunk.

That was last year, before he got the verdict from the docs. Joe found out the hard way that you all you can do when fate throws you an upper-cut is to bob-and-weave and punch back, take what's dished out, and hope that you'd do it with dignity and not look stupid. That was a lot to learn for a teenager. Joe was a tough little bugger, so when he got sick, he chomped down on the bit that God harnessed him to and pulled hard against the sweat-slathered warhorse of mutagens racing through his bloodstream.

But today! Man, today he was free!

I'd sprung him and we were out on the town. No one to tell him to take his meds, sleep out his fever, or talk to some social worker who only saw him as a case file. It was *Fuck You!* time and we were out.

We headed across the street and went into a school playground where I pulled a joint from my pocket and lit it, flamboyantly, with a flick of a steel-jacketed Zippo. Joe pulled it greedily from my hand as he sat down on a playground hobby horse and the two of us sucked the bone down to our bare, singed fingertips. Joe's eyes got bigger as he stared up at a big and blue mural that loomed over the park, a depiction of the man in the moon painted on the side of a brick apartment building.

"You know, this is the first time I really can use this stuff," he said.

"What do you mean?"

“You take that chemo crap; it tears your guts up! The marijuana helps you put the sickness down. But go figure, they won’t let me have any inside. This is the best my stomach has felt in days.

“With my compliments,” I said as I bowed. “What now?” he asked, looking greedily at all the people rushing by on the street. They walked the way only New Yorkers can move, zigging up the sidewalk, zagging across the middle of the street. They looked like crazed ants, on a speedway to get nowhere fast, probably thinking something amazing was about to happen and they didn’t want to miss it.

On seeing a lighted marquee projecting over a sidewalk right up the street, I said, “Let’s go!” We headed out of the playground and up Lexington Avenue to Bloomingdale’s department store. Due to our marijuana induced state of mind, its revolving doors and flowing crowd of shoppers beckoned us like a Ferris wheel and the chance to ride the escalators.

Bloomies! We were in every housewife’s *Fantasy Island*. First floor: select lingerie to delight hubby when he gets home. Second floor: a place to register the flatware and silverware for the daughter’s wedding. Third floor: pick up a riding toy for the baby. Then up the escalator to the fourth floor, where Godiva chocolates and sweet-scented coffees await, that Olympian nectar, which we assumed suburban housewives crave on their shopping sprees. Alternatively, you could take the escalator to the bargain basement, where bright multi-colored scarves and cheap handbags awaited in bin

for the city-born working girls, native New Yorkers and recent immigrants who spoke Spanish, Turkish, or English with a Caribbean lilt.

Joe and I felt like strangers in a strange land with the buzz of the reefer on us as we goofed around the women, moving from escalator to escalator. We wore the moonshine madness of our escape like a crown of smoke, reveling in the wonderful anonymity of a New York City department store. We gaped and we gawked, giggled like children at the most improbable parade of shoppers that cruised the aisles in all their seriousness. We went up to the perfume and cologne counter where Joe took the raincoat off and draped it across his arm like a Matador, standing there in his pink striped pajamas and carpet slippers. He asked a saleswoman if the store carried the men's aftershave, Brute.

The diminutive blue-haired saleswoman dragged her eyes up and down both of us, then tilted her head to one side as if it was too heavy to deal with yet another day of foolishness on this earth. She said, "What! They lose track of you two at Bellevue Hospital? I'll have the booby squad in here in a minute, chase you both back uptown," which sent the two of us into paroxysms of laughter.

"Lady!" Joe said, "No truer words were ever spoken."

"Yeah," I added, "we escaped the nuthouse and thought we'd come down here and spray ourselves with Brute."

"Can you spare us some Brute, ma'am, for my last rites?" Joe said. "I'll gladly pay you on the flip side of the pearly gates."

“Boys, security is coming,” she said kindly and nodded past our shoulders.

Looking back, we saw two security guards making their way through the midday crowd, so we hit it!

“Joe zipped and dodged past a couple of young pretties with teased hair a mile high above their penciled eyebrows. Broken field running was never my forte, so I plowed into the shoppers, knocking them and their packages into the stratosphere as I trailed the fading pinstripes of my brother’s PJs. At the exit, we jumped down the stairs two at a time and hustled out onto Lexington Avenue before the company cops had a chance to nab us.

“What now?” Joe asked breathlessly.

Looking up and into the distance, I noticed a theatre marquee on 59th Street with the word Woodstock flashing in the early evening twilight.

“How about a movie?” I asked.

In 1969, my brother had been too young to go to the Woodstock Music Festival when the counter-culture youth rumbled upstate on the New York Thruway to mingle, copulate, and writhe to the devil rhythms of Rock and Roll in the muddy pastures of Max Yasgur’s dairy farm. I had missed that seminal event, too, as I’d heard a huge ship had run aground down the Jersey shore and had broken in two. I headed south to Spring Lake that weekend rather than grooving with the hippies in Bethel. I hitch-hiked to the Jersey shore where I climbed into a busted freighter and spent the night blissfully contemplating the destructive power of the sea from deep within the broken

bowels of a bouncing ship as it sloshed about in the surf.

We were equally clueless as to what had gone on at Woodstock, so we went into the theatre to see what we'd missed. After climbing up the stairs to the balcony, we discovered that the sight of Joe in his PJs was no more unusual than the other denizens of Woodstock Nation. Next to us sat a man wearing a brightly-colored, floor-length Kenyan dashiki. A girl beside him wore an indigenous headdress with feathers running down her back. Beside her sat a young woman wearing a metallic blue halter top and red satin hot pants, her entire body painted gold. Joe sat down next to her as she bounced up and down in her seat, her long, raven-black hair flying to some unknown rhythm in her head.

Finally, the lights went down and the flickering rays of the projector came on. The dulcet voice of Joni Mitchell rose up into what was then an unknown song about a celebration we had missed; one that, in a way, was about to change the way the world saw itself. Joe and I melted into our chairs in the darkness and slowly watched the myth that would soon define a generation unfold. Woodstock Nation, a belief that good music and good vibes, with true Panglossian idealism, could make the world stop being bad.

We really began to see the thing materialize as we watched The Who sing "Pin Ball Wizard," a song about a disaffected youth struck deaf, dumb, and blind by his own will, simply to ignore the world and its misery and the war machine that raged around him in Vietnam.

We watched as Carlos Santana stepped up and played “Soul Sacrifice,” fresh and as new as the first day of creation. A lit hash pipe was passed down the aisle and I took a toke, suddenly believing I could understand Carlos speaking directly to me through his guitar, sensing that all the Latinos uptown in Harlem were with us, too, in that east side movie palace.

Then Jefferson Airplane came on and played “Volunteers.” The whole theater audience jumped to its feet, climbed onto the seats, and sang along at the top of their lungs, believing we could make the moment last forever, if only we could hold that final chord.

Incredibly, my brother Joe grabbed the golden, painted princess beside him and kissed her as deeply and as hungrily as if they were two long-lost lovers, his hand groping beneath her halter. All emotions were on display now; some of us were weeping. That’s when Jimi Hendrix came on and played the “Star-Spangled Banner” with such ferocious guitar feedback that we thought bombs were bursting around us, the horror of the Vietnam war being exorcised as we cringed with the ferocity of his guitar attack, seeing and believing that the power of music could make the world change.

Finally, the lights came on and we all shuffled sideways towards the exit, eyes meeting other eyes with familiar knowing looks in the too bright lights, hands reaching out and touching others as if we didn’t want to lose the moment before we got outside. But too soon, there we were back on the street again.

Joe looked at me and said, “What now?”

I could see he was tired. His body, sustained by the adrenaline rush, had simply run out of steam. We walked back to the hospital and went through the revolving door. The lobby was empty that late at night and the receptionist was busy with a security guard, so we merely strolled to the elevators, got out on the children’s floor, and crept across the hall and into his room.

Entering the darkness, we were surprised by a voice that said, “Well, where you boys been? You had me scared a bit!” Flipping on the lights we saw a duty nurse named Junie who had been taking a nap in the corner chair.

Joe broke out into a grin and said, “Oh, Junie, we went to the Woodstock Music Festival. It was amazing!”

“I’m proud of you, darling,” she said in an Irish brogue that made me feel all warm and fuzzy inside. “I’m so proud that you and your felonious brother here escaped this dragon pit for a day. But now it’s time for your meds and for you to get into bed and get some rest.”

Joe went into remission after that and was released from hospital. Like most leukemia patients back then, he had his ups and downs, some normalcy at home for a few months after chemo and then a relapse as his blood cells reverted to their malignancy. He spent five years fighting the cancer, living his life unencumbered for a while, healthy enough to go to college, drive cross-country with

some friends to LA, or sleep out all night in the Appalachian Mountains, watching the stars glowing overhead and wondering what role he had to play in their flickering.

Eventually the cancer and the side effects of the anti-tumor drugs wore him down. I didn't know it then, but his generation of cancer patients were guinea pigs in the early days of the war on cancer as doctors tried to figure out the right dosage and combination of drugs to keep the disease at bay.

Of course, today's leukemia patients live a lot longer as a result of Joe's suffering, as new treatments like immunotherapy arrived to encourage the body's own immune system to fight the cancer instead of poisoning it to death.

That's fate and it's worthless to speculate on what was possible then versus now. The night we escaped from the cancer ward is what I like to think about. When Joe was alive and not sick.

Taking a chance at escape into the unknown streets for a laugh, a kiss with a beautiful stranger, dancing in the aisles to a movie soundtrack, believing for a few moments that we were on a field in upstate New York with half a million other kids partying like there was no tomorrow. I remember the passionate, dreamy expression on his face when he looked up from kissing that gilded girl in the balcony of the movie theatre. That's the image I held against the back of my eyes when I walked up to his coffin as it sat suspended above that dark hole in the ground a few years later.

I imagined him standing in a crowded farmer's field upstate, with my dad's raincoat draped across

his arm like a matador's cape, laughing his ass off while Jimi Hendrix played the national anthem on an electric guitar that sounded like some antediluvian monster screaming from the La Brea Tar Pits, and Jimi saying, "Don't mind us man, we're just jamming!"

About the Author

Thomas Belton is an environmental scientist and public health official for the State of New Jersey. He is also an author with extensive publications in fiction, poetry, non-fiction, magazine feature writing, science writing, and journalism. He can be reached at tombelton@aol.com



Volume 18
Issue 1
2024

Plain English

Kain Kim

The night before my first rotation, my best friend toasted my ascent through a Zoom screen: “Here’s to you. Tomorrow, you stop speaking like a normal human being.” We had met studying abroad in Florence, two English majors charmed by the twisty *largo* and *allegretto* of Italian poetry.

I loved writing because it demanded I risk my own skin: writing was sieved through subjectivity, steeped in the personal. I could not remove self from the equation the way that a calculator or formula delivers the same result, every time. But medical school wasn’t so much about storytelling as it was about recitation. There was no artifact of self to be found in our multiple-choice answers on exams; even simulated patient encounters began to sound scripted, shared. “*I’m sorry to hear that.*” “*That must be hard for you.*”

The language of the classroom insulates you from medicine’s tangible reality: the rash becomes a needle, becomes a tube, becomes a barcode, becomes digitized numbers on a screen with a down-trending arrow. I entered clerkships ready to be bewildered by the body, to feel words in the flesh. Yet even here, words wallpapered everything. Under fat bricks of acronyms, patient stories disintegrated into incoherent, fragmentary rubble, word salad.

This ultimately prepared me not for the patient, but for the performance—the dreaded patient presentation: standing before a team of jaded professionals expecting me to speak eloquently, sell a story, defend a thesis, and predict the future. All while maintaining eye contact. Not in all my time in the humanities had I struggled so much to make myself intelligible.

The ideal clinical note, I was finding, narrowed the gap between what was seen and what was known, the subjective detail and the objective finding, the case and the category. Smoothing out these idiosyncratic wrinkles gave you something easier to work with, a narrative that might more easily mold to a template found in a textbook or article. Such a template would give you direction to treat and manage, give you guidance.

And yet, to me, personhood and language remained inextricable. Feeling excluded from a lexicon was, in some ways, akin to feeling your sense of belonging threatened. In the inner circle there persisted even deeper pockets of language. “Received a tracheostomy” became “trached”; “non-contrast CT” became “non-con,” delightfully lazy on the jaw. “Crumping” (somehow) meant that the patient was rapidly declining. We erected a palace of jargon to pedestal our understanding, then rejoiced in razing it all down.

Sometimes, I heard my residents referring to their patients as “unreliable narrators,” or “poor historians.” *But they still lived in their bodies*, I thought. They inhabited their words, as confused or digressive as they may be. How could I expect patients to shelve the self, while I existed in all my

clumsy articulation and disjointed knowledge? If the patient was an unreliable narrator, what exactly did that make me?

From day one, Helen* refused to be read. She'd been admitted to the hospital for no less than three major intracerebral hemorrhages in the last month. No one could explain their etiology. Now they were suspecting vasculitis. She rarely acknowledged me, answering my absurd mental status checks in a clipped, deadpan tone that suggested *I* was unwell. A row of staples stood stiff as a mohawk on her head, shaved freshly bald for the cranioplasty, and had the odd effect of making her seem rough yet childlike, almost juvenile. She burrowed deeper into the blanket when I entered the room, eyes glaring balefully, screwing shut when I parted the curtains.

“Close those.”

Helen had a history of hospital-induced delirium. “It’s important for patients with delirium,” I explained, “to let in as much sunlight as possible, to help regulate sleep-wake cycles!” I tried to inject pep into my tone to mask how I really sounded: like someone reading from a textbook.

“Well, I also get migraines, and sunlight doesn’t help that.”

I lingered there, fabric still clutched in my fingers, weighing the risk. What was more dangerous: migraines or delirium? I realized how ridiculous it looked to keep the curtains open despite knowing about her pain, and whisked them shut.

“We’ve come to do a lumbar puncture. Are you familiar with the procedure?”

She twisted in bed so her back was to me. “Don’t want to know the details. Just do what you gotta do.”

As far as routine procedures go, lumbar punctures are unnerving. Seeing Helen’s face drawn tight, forcibly wiped of all emotion as she curled up into “the tiniest ball possible” (our instructions), made me cringe from how vulnerable I knew she must feel, how visibly she strived to keep it hidden.

I had spent that first week trying to embody the language I spoke, resisting my classroom instinct, constantly reminding myself: *feel this*. But right then, I held the needle and willed my mind to disaggregate from the pure horror of what my hands could do: stick a needle between the knobs of someone’s spine and drag out the fluid that cushioned their brain. The world narrowed to just that moment: the puncture of skin, the drag of dura on needle, the hiss of *ow*, the *click* of bone, my reflexive wince.

When it was done, she turned to look at me. “Want to hear something stupid?” I nodded.

“That was scarier than the brain surgery.”

In the following days, I returned to Helen’s room with renewed resolve: if I couldn’t yet move among patients with the internal confidence of a real doctor, I could at least bend my body to its mannerisms. I painstakingly asked every question, tested every reflex, tried to anticipate her needs before she voiced them.

One day, watching me do these things—picking up the socks strewn on the floor, double-checking her medication, gently sponging the

dark glaze of iodine from her sutures—she said, “You really *are* a student, aren’t you.” Her voice was not unkind.

I will likely always feel like a learner, but this doesn’t have to be alienating. I try to inhabit the moment, to dwell inside of an individual encounter instead of standing back at a distance. Often, this means approaching patients as myself and granting them, in turn, the grace of being messy, deconstructed, humans.

It took me days after discharging Helen to realize while chart reviewing that she had been a nurse: a fellow healthcare worker. It’s the details, the ones that defy diagnosis and classification, that deserve attention—not to reveal similarity to ourselves, but because in spite of it, difference persists. Unknowability persists, which is why we care.

The words in the medical chart have everything and nothing to do with what I see. It’s the disconnect that wakes me up. I want to protect that distance—to leave room for the spark to catch.

*All patient names and identifying information have been changed to uphold privacy.

About the Author

Kain Kim is a third-year medical student at the Emory University School of Medicine. Email: kain.kim@emory.edu



Volume 18
Issue 1
2024

My Injured Brain

Beth Castrodale

For years, it's been common for me to run errands, quite literally. Almost weekly, I tuck cash or a credit card into a sock top, lace up my running shoes, and jog to a coffee shop or store. Once there, I pick up nothing more than I can consume on site or carry home on my own two feet.

This was my plan on October 22, 2009, during a visit to my elderly parents in my former hometown, a suburb of Columbus, Ohio. Not long before my visit, a high school friend's mother was laid to rest in a local cemetery, and because my friend now lived more than 500 miles away from this cemetery, I wanted to leave some flowers on the grave in her stead. On the morning of the 22nd, I ran 2.1 miles to a local supermarket. The plan was to buy some flowers and walk them to the cemetery, just under two miles from the store.

I remember reaching for a pot of mums. They might have been yellow, or they might have been orange. Then the flowers, the store, and any sense of myself ceased to exist. I can't say these things vanished, because that would suggest that I understood something had happened or changed. The next thing I saw was my brothers, smiling at me from either side of the hospital bed I'd been laid out on. Behind them, an Ohio State football game played on the wall-mounted TV.

What are they doing here? was my first thought, as happy as I was to see my brothers. Grant lives in North Carolina and Neil in Virginia, and with their busy lives, they couldn't have just swung up to Ohio in a flash. Soon after, my beloved husband entered the room, after having traveled 700-plus miles from our home in Boston. A dear cousin also appeared, having made her way to the hospital from West Virginia, where she held a more than full-time job. Seeing her brought me to (good) tears.

As it turned out, my brothers, husband, and cousin had had plenty of time to travel to Ohio. Not long after emerging into this new reality, I learned that I'd reached for those mums two days earlier. Sometime before or after getting them into my hands, I'd fainted for the first time in my life, fracturing my skull on the floor of that supermarket. At some point between my fall and my arrival at a local hospital's trauma unit, a kind soul fished my cell phone out of the backpack I'd been carrying, found a number in my contacts labeled *Mom and Dad*, and started the chain of calls that would bring many loved ones to my bedside.

A central concern: my cognitive functioning. My brain.

I remember my mother sitting in a corner of my hospital room, smiling when I caught her eye. Only in retrospect did I see that we'd become connected in a new way, a way that neither of us would have wanted. Though I didn't know it at the time, her brain was in trouble too.

I'd traveled to Ohio to drive my parents to a family gathering in Pennsylvania. My father's vision was declining, making him more and more wary of getting behind the wheel, and my mother had always avoided highway driving.

But Dad didn't want her driving at all. A year or so before, he took me aside and told me he'd started insisting on driving Mom to her regular destinations, mainly the local library. Her judgment wasn't what it used to be, he said, and he feared she'd get in an accident. Though this concern came from a self-described "professional worrier," I respected his decision.

What he said next was far more difficult to hear: "I feel like I'm living with a stranger." The woman he'd fallen in love with seemed to be vanishing, he said, becoming more and more detached, mentally and emotionally. Sometimes, he said, he'd find her just sitting on the couch or at the kitchen table, staring blankly ahead.

I don't remember what I said in response, but I'm sure it wasn't helpful. How could it have been?

What I didn't say: *I don't see what you're seeing, Dad.*

Though my mother had slowed down physically, she seemed as socially active as ever, keeping in touch with her many friends and staying on top of multiple pursuits: art class, family-history research, and book group, to name just a few activities. Also, I didn't sense that our relationship had changed in any way, nor had I noticed any changes in her behavior.

Looking back, I think, *Maybe I only saw what I wanted to see.*

Those first two days in the hospital—before I woke to the sight of my brothers—were a blank for me, and my husband tells me that I seemed to be in a deep sleep. When I came to, I felt no pain, an absence that was to continue, even though the back of my skull had been split open and then fastened closed with staples. No doubt strong painkillers were a factor, but, especially in those early days, I also sensed a certain separation from my physical self, as if I were floating along in a sort of twilight state. During those rare times I wasn't sleeping, I was somewhat aware of my weight on the bed—and of the comings and goings of hospital staff—yet never fully present in the living world.

After my transfer to a rehab facility, I began to gain a clearer understanding of my diagnosis—traumatic brain injury (TBI)—and of what it might mean for me, not only as a wife, a daughter, a sister, and a friend, but also as a writer. Not quite a year before, I'd left a publishing job to devote more time to writing fiction, allowing me to finish one novel and make good progress on a second. Now, I couldn't even read—at least not the way I used to. I remember picking up a *New Yorker* someone had left at my bedside and trying to take in the opening lines of an article.

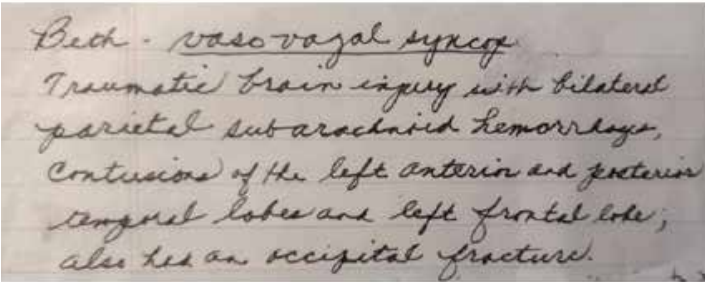
There's a word, and there's a word, and there's a word...

If someone had asked me to define one or more of them, I probably wouldn't have been at a complete loss. Still, I could only take the words in separately, as if stringing beads, and I was unable

to make sense of whole sentences, much less connect them to understand the writer's larger point.

If I couldn't make meaning from someone else's words, how could I possibly assemble my own, not only logically but also in a way that might interest me, or anyone else? As for making any further progress on that half-finished novel, I tried to push that notion out of my mind, never fully succeeding.

My TBI followed vasovagal syncope (VVS), a sudden drop in heart rate and blood pressure that, in my case, led to fainting. Although my doctors presented various theories about why I'd experienced VVS for the first time in my life, nothing was certain, and no explanation ever felt satisfactory. One theory was dehydration, but as a nearly lifelong runner, I'd always been careful to drink enough water, especially before long runs and during road races. What was clear were the details of my TBI, which my mother—long the family documentarian—recorded in her elegant cursive on a sheet of notepaper, which I discovered tucked into her address book after she died.



Beck - vasovagal syncope
Traumatic brain injury with bilateral
parietal sub-arachnoid hemorrhages,
Contusions of the left anterior and posterior
temporal lobes and left frontal lobe;
also has an occipital fracture.

Note: My mother's notes about my brain injury, indicating hemorrhages, contusions of the left anterior and posterior temporal lobes and left frontal lobe, and an occipital fracture.

Even before my accident, I understood that injuries to the left side of the brain might be especially bad news for someone like me. Specifically, they can make it difficult to express oneself in spoken or written language, and to understand language of both kinds. My experience with *The New Yorker* suggested that my future as a reader wasn't promising. As for my future as a writer, that wasn't put to the test during my days in inpatient rehab, and I dreaded when it would be. The only cognitive tests I recall were being asked to repeat brief series of words forward and backward, and to draw a clock face with hands pointing to a particular time. I don't remember how I did on these tests, but if my performance was lacking, no one let on.

A few years after my TBI, my mother underwent the same types of tests from her GP. She'd done so at my father's urging, and she seemed untroubled that he'd found such tests necessary, as if she was only humoring him.

She appeared to accept the result—a diagnosis of mild cognitive impairment—with the same equanimity, and she continued with life as she'd known it.

For my part, I tried to square this diagnosis with my latest impressions of my mother, who seemed as active and socially engaged as ever. But perhaps her afternoon naps, an old habit of hers, were longer than I remembered? And maybe she was having a bit more trouble following the plots of the movies we watched together?

I wanted to face facts and not deny any clear signs of decline. Still, I thought, *at 83, she's still going strong. She might go on strong for years.*

Perhaps I wanted to believe this for my sake as much as hers. Maybe I, too, could live to be a bright and active eighty-something, if only out of sheer force of will. As if I'd never injured my brain.

Within a few weeks of my TBI, two old, interrelated drives resurfaced in me and helped keep me going, both in the rehab facility and beyond it: the desire to run, something I've done almost every day as an adult, and pure stubbornness. I wanted to get back on my feet and get moving, and the turtle's-pace stride on a treadmill that was part of my physical therapy just wasn't cutting it. Feeling especially emboldened one afternoon, I snuck out to the parking lot of the rehab facility and jogged around it a couple of times, worried I'd be found out and hauled back into the building and also elated to be breaking a sweat on a crisp fall day.

After I returned to Boston, my desire to run stayed with me. Although, paradoxically, I spent most of those early months sleeping, I was eager to go out for short runs every day. What I couldn't do was read anything lengthy or complex. I also couldn't write.

However, within hours of returning home, I did read the opening lines of a pamphlet that my husband had been given at the hospital or rehab facility, a pamphlet that, in retrospect, I think of as a coiled snake. I don't remember how I came across it, but I'll never forget its effect on me.

Accept that your loved one will never be the same, that they will be diminished ...

I'm sure these aren't the exact words, but they're the gist of what I read. I remember the jolt they delivered. And I remember looking between them and the nearest window, three stories above the ground, and sensing an invitation: *Jump*. Although I knew I'd never accept that invitation, the pamphlet's message lent a cool logic to the notion of doing so.

Then my stubbornness kicked in, and my anger. I marched the pamphlet to the trash bin and tossed it, and I remember thinking this: *If enough of my old brain power remained for such doom-saying to equally horrify me and piss me off, not all could be lost.*

And it wasn't. In the weeks and months that followed, I took a measure of relief from each small success I logged during outpatient rehab in Boston, whether that was making blueberry muffins from a boxed mix in occupational therapy, or finding my way to a list of destinations at a local train station. All along, the running (and stubbornness) felt inseparable from the healing of my brain and body, and from my return to reading and writing. At a distance of more than ten years, I can't recall the experience of reading a book for the first time in months. Nor can I remember what it was like to reopen the computer file of my novel-in-progress and, eventually, find my way back into a story that I thought I might have been locked out of, for good. All I can say is that somehow, I did, and eventually, it became my first published novel.

I can also say that there was nothing magical or especially remarkable about my return to that novel. Looking back, it seems that at some point I just reacquainted myself with that close cousin of stubbornness: routine—in particular, my old routine of sitting myself down in front of my computer and trying to put down words, a habit enforced by my inner taskmaster, and by the certainty that, for me, there’s no such thing as creative inspiration. The only way I can start, and hopefully finish, a piece of writing is to put in plenty of time trying—often, unproductively. But every now and then, time itself seems to vanish as I immerse myself in the world of a novel or story. Sometime in 2010, I was able to achieve that state once again.

In describing my return to writing, I’m not aiming to tell a tale of redemption or of persistence paying off. And the notion of trying to extract, and share, any lessons from my experience feels both simplistic and irresponsible—an attempt to impose order and meaning on something (the state of my post-TBI brain and my powers of cognition) that presents an ongoing and evolving mystery. Yes, I keep writing. Yes, I have hope for my future as a writer, and as a person with a purpose and interests and many beloved people in my life. At the same time, I realize that hope is a fragile and perishable thing, and for me, for now, its major opponent is fear. Fear of my mother’s fate becoming my own.

A couple of years after her diagnosis of mild cognitive impairment, my mother underwent surgery

to clear a mostly blocked carotid artery. The procedure failed and had to be repeated, and she developed serious post-surgical infections. Far worse, in my view, was the toll that the surgery had taken on her mind. When she wasn't sleeping, which was most of each day, she kept to herself, not wanting to see friends or extended family or even take their calls. And she repeated questions, something she'd never done before. In short, she'd descended into full-blown dementia, which was eventually diagnosed as vascular in nature.

I believed that I'd failed my father in not seeing—or refusing to see—what might very well have been the earliest signs of this descent, something that had been so clear to him. And I understood that when he first told me he was losing her, he was already deep into a grieving process that, for me, was only beginning.

Although my mother's surgical infections eventually healed, her decline continued, and she died 16 months later, four months after my father, whose mind was sharp until the end. Is it selfish that I've found relief in that sharpness—a hope that I might have inherited its lastingness—even though it became a curse to my father, as he witnessed my mother's descent?

Even before my TBI, even before the loss of my mother to dementia, I feared the failure of my brain more than anything else that might befall me. Since I've become aware of the association between a major TBI and dementia, that fear has intensified and grown more present—though physical activ-

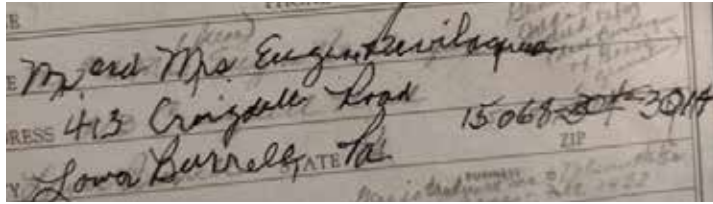
ity seems to be a mitigating factor, according to a recently published study (Raj, Kaprio, Jousilahti, Korja & Siironen, 2022). When I enter what seems like a longer-than-usual blank state while writing or struggle more than I remember to enter the world of a story, I often wonder whether my cognitive abilities have begun a new, more lasting descent and, if so, how far and how fast they might fall.

Still, I've tried not to dwell on the details of my TBI, though I sometimes revisit the address book where my mother recorded them. Among all the possessions of hers that I've held on to, it may be the one that I value most, because it served as an impromptu journal for her, a record of her ongoing interest in the lives of friends and family, which she maintained until she couldn't.

Throughout its worn pages, she recorded—mostly on sticky notes—various updates and also quotidian information preserved (presumably) for future reference:

*Charles ____ had a stroke last August.
2006: Kelly is back in Syracuse. Has job as PR
manager...
Steeler and OSU scarf lady, _____. Cost
per scarf \$20.00*

The address book also holds evidence of her decline. Paging through it after her death, I discovered what must have been some of the final jottings of a woman who for years had taken so much care with the form and substance of her writing. In them, I saw the new unsteadiness of her hand, and mind, as she struggled to maintain her cursive's elegance.



Note: An update to an old address in my mother's address book, made after she developed dementia.

I'm haunted more, though, by how my mother's love of books outlasted her ability to read. My most abiding memory of her, from better times, is of her stretched out on the side of the couch lit by the reading lamp, engrossed in one of the thousands of books she'd read over her lifetime. If ever I had cause to interrupt her, she'd look up over the rims of her reading glasses, not unhappy to see me, but clearly ready to return to her book as soon as she could.

Sometime before her failed carotid-artery surgery, she borrowed *The Warmth of Other Suns* (2021) from the library that was a second home to her. During one of my phone calls to her—early in her first postoperative hospitalization—she asked me to bring her this book and her reading glasses. After I delivered them, they were to travel with her to a rehab facility and then back home and then back to the hospital and then back to rehab. As I recall, the book and her glasses remained mostly at her bedside, ignored. But every now and then I'd find her with the book, always open to the middle, on her lap. Although it appeared that she'd made no progress through it over the course of my visits, she seemed to have found comfort from the physical memory of her old routine, from the weight

and feel of a book. At one point, I was surprised to hear her say how much she loved *The Warmth of Other Suns*. Even if she never read a single word of it, I believe she was completely sincere. In that praise, I heard and felt her love for all the books she'd ever enjoyed, and for reading itself.

These memories of my mother's decline haunt me because they remind me of everything she was in her best days, and of everything she lost. I can't deny that the memories also intensify my fear about the fate of my own brain and cognitive abilities. A family history of dementia, coupled with the TBI, almost certainly puts me at a heightened risk of experiencing the sort of decline that my mother did. So every day, I try as best I can to train my thoughts toward the here and now, telling myself that for as long as I can, I'll continue to run and read and write. And without basis or reason, I sense that my stubbornness will outlast all of these drives and abilities, and that I'll continue to feel—or remember—myself striving and striving and striving for something even if, eventually, I no longer know what that something is.

Reference

- Raj, R., Kaprio, J., Jousilahti, P., Korja, M., & Siironen, J. (2022). Risk of dementia after hospitalization due to traumatic brain injury: A longitudinal population-based study. *Neurology*, 98(23), doi:10.1212/WNL.0000000000200290
- Wilkerson, I. (2010). *The warmth of other suns: The epic story of America's great migration*. New York, NY: Random House.

About the Author

Beth Castrodale is a novelist and book reviewer. Email: bcastrodale@gmail.com



Volume 18
Issue 1
2024

Conversations with Dr. Rowena Spencer (1922–2014): The First American Woman Pediatric Surgeon

Charles A. Fishkin

Part I: The Education of a Pediatric Surgeon

It was the Fall of 1958.

Rowena Spencer was establishing a reputation as a talented and dedicated pediatric surgeon. In her thirties, she was an Assistant Professor at Louisiana State University (LSU) in New Orleans. She had already separated her first pair of conjoined twins, an area of specialization within pediatric surgery that would interest her throughout her career and in her retirement.

My father, a New Yorker, was beginning his academic career. At twenty-eight, and with a PhD from the University of Iowa, he was the first biochemist to join the research group of Gerald Berenson, the LSU cardiologist who was just beginning his six decades of research into the factors that contribute to cardiovascular disease.

Rowena and my father often ate lunch together in LSU's common faculty dining room. Rowena usually joined the biomedical scientists at their table—that is how she and my father first met.

My mother, twenty-two, was pregnant with her first child, expecting to give birth in early November.

My parents, who had recently moved to New Orleans, needed a pediatrician for their expected baby. They consulted Rowena for a recommendation.

Wanting the baby to have the best possible medical care, Rowena referred them to her colleague Sue Schaefer, the head of pediatrics at Touro Infirmary. During our family's six years in New Orleans, Dr. Schaefer would become an important source of guidance and encouragement to my parents, who had no other family members nearby yet were raising four young boys, eighteen months apart.

Figure 1: Rowena Spencer as an assistant professor of surgery at LSU School of Medicine during the early 1960s



Photo credit: Miscenich, 1960.

On a Sunday afternoon in mid-November—shortly after the first baby was born—Rowena visited my parent's walk-up apartment on Plum Street in the Garden District. She brought the baby a gift, held him, and sang to him.

Approximately eighteen months later, I was born. Both my older sibling and I later became Rowena's surgical patients, further strengthening our family's friendship with her.

Our family did not realize it then, but many years later we learned that Rowena was one of the first women in the country—if not the first—to specialize in pediatric surgery.

Rowena was born in 1922 in Shreveport, Louisiana. She was the third of four daughters in a family that encouraged her academic success. Her interest in medicine was inspired by her father—an orthopedic surgeon—and nine other doctors in her extended family.

In 1943, Rowena graduated from LSU in Baton Rouge. Then, like her father, she entered medical school at Johns Hopkins University. She was one of four women in her class, receiving her medical degree in 1947.

From 1947 to 1948, Rowena continued at Hopkins, becoming the institution's first woman to hold an internship in surgery, working with Alfred Blaylock and surgical technician Vivien Thomas. The following year, she began her training in pediatric surgery at Children's Hospital of Philadelphia with C. Everett Koop. From 1949 to 1950, she held the role of "assistant in surgery" with Alton Ochsner at Tulane University. During 1950-1953, she held residencies in pediatrics and surgery at Charity Hospital in New Orleans. In the fall of 1952, while Rowena was still completing her surgical residency, she joined the surgery faculty at LSU, the first woman to be appointed to this role. In 1954, she received further

specialized training in pediatric surgery with Theodor Ehrenpreis at the Karolinska Institutet in Stockholm, Sweden.

Figure 2: Rowena Spencer in an undated photograph



Photo credit: The Historic New Orleans Collection, Gift of Rowena Spencer, 2003.0109.1

Rowena returned to New Orleans and began to build LSU's pediatric surgery program. Unlike many other doctors in the Deep South of the 1950s, she treated all her patients in one common ward, refusing to segregate them on the basis of race. Many years later, she shared with me a concise explanation for her decision, which she never doubted. "Green, blue, or purple—what difference does a baby's color make. A baby is a baby."

Rowena remained in New Orleans throughout her career. She retired from surgery in 1984 and began writing a comprehensive textbook on conjoined twins, titled *Conjoined Twins: Developmental Malformations and Clinical Implications*.

It was published in 2003 by Johns Hopkins University Press and is considered to be the definitive work in its field.

In 1964, our family moved to Las Cruces, New Mexico, where my father joined the faculty of New Mexico State University. Four years later, we moved to Omaha, Nebraska, where my father remained on the faculty of Creighton University for over four decades.

During our years in New Mexico and Nebraska, my parents apparently had minimal contact with Rowena, yet whenever they talked about our family's time in New Orleans, they often mentioned her. They were among the many parents who trusted her surgical judgement and valued her kindness, conviction, intelligence, and enthusiasm.

In 2010, when my father died at the age of eighty, my mother and I began to wonder about Rowena. We learned that she had moved to Alexandria, Virginia, to be near family. We subsequently arranged to meet her in her apartment, a visit that was particularly memorable for us given the passing of years since my mother last met Rowena. She died in 2014 at the age of ninety-one. She is buried in the Spencer Cemetery in Nebo, Louisiana. Her gravestone reads "Pioneering Surgeon Dedicated to Children."

She is remembered for her extraordinary commitment to her patients and their families—a bond she described early in her career as "the joy of saving a whole life, not just a few years of one."

Now, ten years after her death, we also view her life in a broader context and further recognize

her as an innovator and early leader in the field of pediatric surgery; an advocate for racial equality in medical care; and a source of inspiration to women who are pursuing careers in medicine.

Part II: Reflections on Life, Medicine, and Family

Rowena and I first spoke in February of 2011. That led to other conversations on diverse topics, both medical and non-medical. We continued to speak, by phone and in person, until several months before her death. During these conversations I took notes, and I was able to record her most memorable observations and aphorisms. Now, ten years later, her remarks seem even more relevant.

She described herself as a “baby doctor with strong opinions.” She spoke quickly, with a discernible Louisiana accent. She was formal and precise when needed, as might be expected of a surgeon, yet she was also self-deprecatory and spontaneous, evoking images of her childhood in rural Central Louisiana. She sometimes whistled.

Here are her words.

About Herself

On her enthusiasm for babies:

I love babies more than a mule can kick.

On persistence:

I happen to be hardheaded and stubborn, and I don't let anything stand in my way if it's humanly possible.

On aging:

I don't fret about it. I just let it do what it's going to do.

On her life:

It has been interesting, without question. It's been a pretty good handful.

Pediatric Surgery

On her passion for the field:

I enjoyed every minute of surgery. I love the field. I loved taking care of babies.

On the most enjoyable part of her work:

Holding the babies. It was a gift to handle little babies. There is no feeling in this world that matches wrapping up that baby in your arms.

On her approach to pediatric surgery:

Plan the procedure. Do what you plan, and get it done promptly.

On the commitment needed to be a pediatric surgeon:

If it's my baby and I am responsible for it, I'm going to be there. You just can't turn around and walk off. You can't just go fishing.

Patients

On babies:

They make life worth living.

On her relationship with her patients:

I felt that my patients were my babies. I felt mentally and physically attached to them.

Medical Training

Of the demands of the field:

It was worth it.

On her experience as a medical student at Johns Hopkins:

It was built for me. The minute I laid eyes on it, I knew it was my place. I loved every minute of it. It was an honor and a privilege.

Advice

For surgical residents and pediatric surgery fellows:

You have to have compassion. You have to have strong sympathy for the children you are working on. You have to make the experience positive for the child.

For medical students and residents:

You can't just dump a baby on the exam table.

For young people:

Don't be discouraged. Don't quit. Keep going.

Family, Friends, and Colleagues

On her father, Lewis Cass Spencer, in whose memory she established an endowed chair at Johns Hopkins:

We both loved the country. We both ended up loving surgery. We had a great deal in common. We both loved each other very dearly.

On Vivien Thomas, a mentor in surgical techniques at Johns Hopkins:

He and I were like a kitten and a warm brick. We got along very well together. He was a gentleman and wonderful to work with.

On Suzanne Schaefer, the head of pediatrics at Touro Infirmary:

She was a remarkable woman. We treated many a baby. She knew her babies and she loved her babies.

Interests

On writing:

I have always liked to write. I am obsessive about writing. It has to be easy to read and easy to understand.

On whistling:

You might say I'm a congenital whistler. It would be out of character for me not to whistle.

Her favorite tune to whistle:

"Rock-A-Bye, Baby"

Coda

Her usual way of concluding conversations:

Love to all.

Acknowledgements

I would like to thank Rowena Spencer, Lewis Spencer Roach, and Rowena Worley.

I would also like to thank Megan Vu and Mary Brandt for sharing their historical research relating to Rowena Spencer's designation as the country's first woman pediatric surgeon, as well as the following individuals who shared with me their memories of Rowena Spencer or provided other historical background: Gerald Berenson, Ann Case, Alvin Cotlar, Susan Dorsey, Jane Paul Fishkin, Raymond Gasser, Jay Grosfeld, Andrea Herrington, Charles Hill, Jennifer Lloyd, Spencer Marks, Colin McMahon, Stephen Marshall, Catherine Musemeche, James O'Neill, Willie Primeaux, Hans Rasmussen, William Robichaux, Nancy Ross-Ascutto, and Emma Roach.

The professional staff at the following libraries and collections were invaluable for their assistance: the Chappaqua Library; The William and Anita Newman Library at Bernard M. Baruch College of The City University of New York; Howard-Tilton Memorial Library-Tulane University Special Collections; Hill Memorial Library at Louisiana State University; The John P. Isché Library at Louisiana State University Health Science Center in New Orleans; The Historic New Orleans Collection; and the Alan Mason Chesney Medical Archives of The Johns Hopkins Medical Institutions.

Reference

Miscenish, E.R. (1960). *Rowena Spencer with baby*. [Photograph]. Kappa, Kappa, Gamma Archives.

About the Author

Charles A. Fishkin lives in the New York City area, where he works in the financial services industry.



Volume 18
Issue 1
2024

The Secret of Flourishing

Mary Lane Potter

Train

“I’m going to give you five words to remember,” the nurse said. “You can remember them any way you want, like *train*, Choo! Choo! or *baby*, Wah! Wah! I’ll ask you to repeat them after you finish your paperwork and we do some other tests. Ready?”

She said five words. Four nouns, one adjective. No context, no connection, no story. Just a set of random objects and the name of a color, all floating in a sea of unreality. I didn’t want to drown, so I hung on to those words while I completed the questionnaire printed in letters so small they looked like squashed gnats. Do you smoke? No—well...a few Kools, the occasional joint—fifty years ago. How often do you drink alcohol? *One to two times a week*—more when I feel like jumping out of my skin, like now. Do you need help with everyday activities? *No*—and I don’t need anyone’s help to remember *train* or *baby*. Please don’t infantilize me. Have you fallen recently? *No*—Wait! Just now, walking along, minding my own business, I fell into your camouflaged trap and now I’m at the bottom of a pit, pacing, building up enough power to leap at the walls and keep jumping until I can claw my way out. How do I get out of here? How often are you anxious?

Depressed? *Never*—unless feeling as desperate as I do right now counts, now that I’m hyperalert to your game: you the hunter, stalking me, watching for signs of weakness, waiting to catch me in a vulnerable position; me the prey. I am at your mercy. Why spring this on people? Like a mugger jumping out at you from a darkened doorway, jamming a gun in your ribs, and yelling “Give me your wallet!”

Blood pressure rises in a doctor’s office. Nerves. So does scattered thinking. Nerves again. Is that why I’m losing my train of thought? On my way to panicking? What if I don’t pass?

Train-chair-hat-blue-egg.

Egg

“Draw a clock face with the time forty minutes to eleven,” she instructed, handing me a blank sheet of paper.

“A.m. or p.m.?”

Wariness flickered across The Hunter’s face. I could see her calculating: Just how diseased is this woman’s mind? Already sundowning?

“Kidding!” I said, smiling. Humor’s a sign of intelligence, isn’t it? I read somewhere that people who appreciate humor about distressing topics like death and disease may have higher IQs, be less aggressive, and are better able to resist negative feelings, like anger or fear.

She didn’t smile back.

“Finished!” I said, handing over my clock. “That’ll be a lost art soon. How many digi-drunk millennials can draw an analog clock?”

“I’m not a millennial,” she said, adding my drawing to her pile of notes.

I decided I’d better walk on eggshells with her.

Train-blue-hat-egg-chair? What mnemonic to use? I’m hopeless at visualizing. Acronyms? Boring. Rhymes? I’m no poet. Chunking? The word itself is ugly. Where would I place these five things in my refrigerator? Absurd. A riff on my favorite Sesame Street song? “Four of these things belong together/One of these things just isn’t the same”?

Blue-hat-train-egg-chair.

Chair

“Name as many animals as you can before the timer runs out.”

“Mammals? Fish? Birds? Reptiles? Insects?”

“Doesn’t matter.”

“Do *we* count?” I wanted to ask. *We’re* animals. The philosopher Mary Midgley argued that point decades ago in *Beast and Man* (1980). “Human beings and other animals” (p. xiii), she writes, to remind us we’re not the qualitatively distinct creatures the Western tradition has claimed we are for millennia. No one trait or ability sets us apart, not reason or will, memory or cooperation, use of symbols or tools, feelings of empathy or grief. We’re just a more complex organization of the capabilities we share with all living organisms, from bacteria on up.

The latest science backs Midgley up. What distinguishes us from other animals is our morphology, our upright posture and our hand—specifically our hand’s emptiness and its long opposable

thumb, ready to grasp, manipulate, make. That unique combination expands the possibilities for interacting with our environment, hence increasing our ability to make conscious, intentional, intelligent choices. *We know, we think* with our distinctive *human* body. That's why we're *homo sapiens*, which doesn't mean rational or intelligent, but *wise*. Like other animals, we're intelligent, always selecting what to attend to in our world and how to respond so life flourishes. We're named "wise" because our marvel of a body opens up seemingly infinite possibilities for responding to our environment—laughter among them.

Given my current environment, I decided it was wise to keep my mouth shut about what it means to be a human animal, lest The Hunter decide I was "confused" or unable to sort things into their "proper" categories. I had an almost uncontrollable urge to say to her, *Yes, I'm old, diminishing daily, and you are young, fully empowered. That doesn't mean you can assess and dispatch me as if I'm a specimen. I'm a human being, like you. Look at me! Laugh with me! Being human is so precious and so fleeting.*

"Ready? Go!"

"Wolves, coyotes, bobcats, wolverines, alligators, crocodiles, rattlers, cottonmouths, copperheads, cobras, orcas, sharks, barracudas, hawks, vultures, falcons, hornets, yellowjackets, fire ants, tarantulas, Tasmanian devils, warthogs, wildebeests, cheetahs, jackals, hyenas—"

Ding! The Hunter leaned forward in her chair. "Okay, what are the five words?"

My stomach soured, my hands trembled. Fever flooded my face, neck, chest. “Train, chair, blue, hat ... *what?* ... egg.” Relief washed over me, the trap evaded. “Wait! Do you need them in the original order?”

Shaking her head and scooping up her notes, she said, “Back in a few minutes.”

EGG! Egg-train-hat-chair-blue.

Blue

Alone, I paced, from wall to door and back. Terror wouldn't release me from its grip. Why hadn't she said anything? I had passed, hadn't I? I wasn't expecting a blue ribbon, but not a word? Nothing? To calm myself, I arranged and rearranged the words. When I hit *train-egg-chair-blue-hat*, I saw the letters t, e, c, and a blue hat, and my body smiled. A toe-tapping techie sporting a blue hat! Who could forget such an amusing scene? Unless... I didn't need Antonio Damasio (2018) or any neuroscientist to tell me Alzheimer's disease disrupts the formation and access to long-term memory of integrated scenes. I'd seen the evidence close to home. My dad's mom, my dad. “If I ever show signs of Alzheimer's,” my sister used to joke, “plunk me on an ice floe in Antarctica and let me drift away to die.”

I redoubled my efforts, calling up the techie-in-a-blue-hat scene each time I listed the words. I repeated it so often I feared I'd lose the individual words in the flow of the rhythm.

The Hunter was gone 19 minutes. I timed her with my phone's stopwatch. When she reappeared,

I blurted, “Train-egg-chair-blue-hat! Those words are seared into my brain forever.”

She grabbed something off her desk and left.

The doctor entered, checked my heart, lungs, ears, reflexes, skin. Pronounced me healthy and fit. We chatted briefly, about Persian food, women’s ways of body-knowing that doctors often dismiss, mores and modesty, here and in Iran. Before the exam, we’d shared a laugh. When she asked me to undress and I peeled off my shirt, she stood facing me, instead of leaving the room to protect my dignity, the way American doctors are taught to do. “Oh,” she said, covering an embarrassed giggle with her hand and turning her back to me for impromptu privacy. I laughed with her. “I’m not modest,” I reassured her, hastening to add, “I mean I’m modest, but not ashamed of my body. And you’re a *doctor*. What’s to be afraid of?” When she turned to face me, she was still smiling. I liked her. She was fun. Her braces twinkled in the fluorescent lights.

“See you next year!” she said on her way out.

Train-egg-chair-blue-hat all the way home. Heart pounding, stomach knotting, mind racing. *Train-egg-chair-blue-hat* every night before bed, every morning waking up, cooking dinner, showering, planking, walking to the store. *Train-egg-chair-blue-hat*. Like a mantra to calm the monkey-mind or a spell to ward off evil. Like a singsong chant a woman repeats to herself when scenes flash across her brain: her grandmother smiling vacantly as she unravels her knitting, cooing to a plastic baby doll; her dad, lost in his own house, walking naked down the street, speaking

in numbers because he's lost all words but *Our Father, help me, I want to die.*

Train-egg-chair-blue-hat. I am not at their mercy. Train-egg-chair-blue-hat. I am not in danger. Train-egg-chair-blue-hat. I am safe. I am safe. I am safe.

Hat

I delayed my next annual visit by months, too scared to face the tests. "Study," an older friend suggested. "Everybody I know practices before they go in. Drawing clock faces, listing animals, trying out memory tricks." I wanted to be sanguine, like them, to treat it as old hat, a silly game. But I was too spooked. My amygdalae were screaming, "Run!"

When another friend, a nurse, suggested I didn't have to take the test, I made an appointment. I counted the days until I had to go, crippled by dread. What if they didn't accept my refusal? What if I didn't pass?

Train-egg-chair-blue-hat all the way to the doctor's office.

As the nurse weighed me, she asked, "Do you want me to convert the kilos to pounds?"

"It's 130 pounds and a couple of ounces."

"Exactly!"

After the blood pressure and general intake questions, she reached for a file stashed on the wall. "Just the cognitive test left."

Nausea. I pressed the reflexology spot between my left thumb and index finger for relief. "I want to skip that. I'm still traumatized from last year's

test.” I laughed to show her I was not a “difficult patient” but a “nice person,” a person she wouldn’t mind doing a favor for, like overlooking an item on her mandatory checklist. This is what aging had come to: bowing and scraping, the way the powerless do, to signal, *I’ll behave, please don’t hurt me.*

She shrugged. “I’ll note *patient declined.*”

When she left, I had a new worry. Would my name go on some government list marked as “noncompliant?” Would they take away my Medicare? If I didn’t take the test this year, would I fail it the next? Chronic stress leads to memory loss. Was I already declining? In denial?

After the doctor completed the physical exam and we talked about women here and in Iran, the classes I was teaching, and the book I was writing, I told her about my year of torment since the last visit—the constant search for holes in my mind. “Now I’ve got an anxiety disorder,” I joked. “I’m turning into an obsessive compulsive, choking on a chain of words.”

She looked concerned. “You always have a choice,” she said. “I’m sorry we gave you the impression you didn’t.”

You always have a choice. *That’s* what I’d forgotten.

Cells hold the secret

You always have a choice. Hearing those words from my internist set me free from terror. Paralyzed by fear, I had been acting as if I were a strict or “hard” determinist like B.F. Skinner, believing I

was absolutely dependent on systems and circumstances beyond my control, both biological and social; that intention, purpose, genuine choice did not exist, for our existence was beyond freedom and dignity. I had forgotten I was *also* free. The philosophy and science I'd been reading confirmed that freedom, although until my doctor's frank words, I hadn't taken that research to heart. Antonio Damasio's *The Strange Order of Things*, for example, and George Lakoff and Mark Johnson's *Philosophy in the Flesh* explain that even individual cells are not absolutely determined: they have a kind of freedom, an agency that enables them to thrive. They select, then accept or refuse elements in their environment—without intention, without consciousness, but with *intelligence*, from the Latin *legere*, to read, to pick out, to choose. Amoebas, for example, sort food from nonfood, decide what to move toward and away from.

Now I understood what I had to do. My *cells* knew the secret of flourishing: *they* never forgot to select and respond. I needed to remember I, too, was free. I had to fully inhabit being *sapiens*, to relish the power of my embodied mind to navigate freedom within limits, to sort what's life-giving from what's life-denying—consciously as well as unconsciously. I needed to choose how to respond to the possibility of my body-mind developing the same disease my grandmother and father had suffered from.

Though freedom is a given for all living beings, it is never absolute. “The mind is inherently embodied,” as Lakoff and Johnson (1999) argue, and “[t]hought is mostly unconscious,” which means

“[s]ince reason is shaped by our body, it’s not radically free.” (p. 3) All living beings are free-yet-*determined*. “For example, every living being categorizes ... The amoeba cannot choose whether to categorize: it just does. The same is true at every level of the animal world” (p. 17). We humans are always sorting, whether we realize it or not. Food, not food. Pleasure, disgust. Friend, enemy. Run, resist. Terror, laughter.

We also cannot choose not to be dependent on our environment, our circumstances, or other beings. All beings are “being-with, a being-in-relation,” argues the philosopher Albert Memmi in *Dependence* (1984), which means “[n]o thing or person is ever completely or permanently safe” (p. 47). What makes old age tragic is that the elderly “suffer most of all from the progressive loss of their ties to other people ... What is a personality, a human character, but those complex webs that individuals weave around themselves and that bring meaning, joys, and sorrows into their lives? Without them, life is all silence, immobility, and neglect, and before long individuals start to fall apart, like abandoned factories, and resign themselves to death” (Memmi, 1984, pp. 152–153).

Here’s another choice no living creature has—from prokaryotes like bacteria cells to eukaryote cells to the multicellular organisms called *metazoans* to creatures with complex nervous systems to beings with mental experiences of feeling and consciousness, beings like us, with minds made up of images, minds with “their secret for narrative or storytelling” (Damasio, 2018, p. 92): we cannot choose not to die.

We are determined, yes. And we are free. Free to respond in life-giving ways to our biology, our circumstances, other people, our social and political systems. I can't choose whether I carry any of the genes linked to the risk of Alzheimer's. I can't choose whether they will activate in my body-mind and isolate me from those I love, turn me, despite all my efforts, into an abandoned factory—or not. I can't determine whether I'll live long enough for scientists to find a way to prevent, slow, or reverse the disease. I can choose how to respond to that possibility, now and every moment. I can choose not to run away in terror, but to turn to face it. I can choose to exercise my body and mind, and to follow the MIND Diet and other scientific recommendations, in the hope they may lessen my chances of developing the disease.

I can choose to live, every day, every moment, not in fear but in love—nurturing relationships, deepening love, giving thanks for life, sharing laughter as well as sorrows. I can choose to be amused by the world, its inevitabilities and accidents, mishaps and absurdities; laugh in playfulness; laugh lovingly at the foibles we share, the choices we make, the illusions we comfort ourselves with, and the ways we unnecessarily limit our lives. Laughter may not be unique to human beings—at least 65 different animal species laugh—but being able to respond with laughter, even in the face of disease and death, is one of the gifts of our existence. We are free to laugh. Rumi reminds us of this oft-forgotten freedom when he writes, “What is hidden in our chests? Laughter” (Barks, 1997, p. 92).

Here are the questions I now ask myself every day and that I would be happy to answer on the medical intake form at my next annual wellness visit. What life-affirming choices have you made lately? How often do you laugh? Because when my doctor asks, “How have you been?” I plan to respond, “I’m flourishing.”

References

- Barks, Coleman. (1997). *The essential Rumi*. Translated by Coleman Barks with John Moyne. Edison, NJ: Castle Books.
- Damasio, Antonio. (2018). *The strange order of things: Life, feeling, and the making of cultures*. New York, NY: Pantheon Books.
- Lakoff, George & Johnson, Mark. (1999). *Philosophy in the flesh: The embodied mind and its challenge to western thought*. New York, NY: Basic Books.
- Midgley, Mary. (1980). *Beast and man: The roots of human nature*. New York, NY: New American Library, 1980.
- Memmi, Albert. (1984). *Dependence: A sketch for a portrait of the dependent*. Translated by Philip A. Facey. Boston: Beacon Press, 1984.

About The Author

Mary Lane Potter is a writer of books and essays. Email: potter.lane.m@gmail.com



Volume 18
Issue 1
2024

The Witness

Clare Mulcahy

My sister and I had a recurring joke that our father loved our mother the most, then us, while our mother loved us the most, then him. Our mother was the sun and he was a sunflower, always turning his head to find her, and our mother shone her warm loving gaze upon us all.

In the casual cruelty that's typical of children, I sometimes found my mother *too* accessible. She was a lab technician who dedicated much of her life to raising her four children. I have beautiful memories from my childhood, but I can remember feeling sometimes suffocated by her consistent presence and that my father was by comparison more mysterious and exciting.

My father was an extremely dedicated English and drama teacher who often spent evenings and weekends working. He would sit in on the fancy new couch in the living room with his family but was not fully present. With my father grading in the background, I would play Scrabble on the living room floor with my brother and our mother (who would suggest words for me, my brother groaning in protest against her helping).

When my father did bring his undivided attention to me, I felt the full force of his love. I would sit with him on the big, white bed in my parents' room, looking at an illustrated copy of Tolkein's

The Hobbit (1937), the classic fantasy novel. Curled up under his arm, trusting the warmth of his torso to hold me up, I'd stare, mesmerized, at our favourite full-page images, like the one of the dragon Smaug, its scaly belly resting on a golden horde of treasure.

Other times, we'd sit at the scarred, wooden kitchen table, and my father and I would take turns drawing a scene on scrap paper. He'd often sneak in a woman who I came to recognize as my mother, his artistic choice indicating his devotion.

These moments instilled in me my father's passion for literature and creativity, and many of my earliest memories are of disappearing into books. I would read until dinner, when my mother would warn me to put away the garlic salt (apparently not every meal needs garlic salt), and to put down my novel. As a teenager, I fell into the heady world of poetry, enraptured by each poet's ability to create something so much greater than the sum of its parts.

I was stunned by Emily Dickinson's "Because I Could Not Stop for Death" (1890) when I first encountered it in eighth grade, sitting in a cramped desk. The formal opening was initially intimidating: "Because I could not stop for Death – / He kindly stopped for me – The Carriage held but just Ourselves – / And Immortality" (par. 1). But the more I dug into the poem, the more it revealed itself to me. When I read it aloud, muttering to myself, I discovered a sing-songy rhythm and rhyme scheme that juxtaposed with the unsettling subject. I didn't know words could work like this.

Though I came by my love of poetry honestly, it also served as a bond between me and my father during a complicated period. As I experienced the teenage desire for more *and* less intimacy with my parents, my father was also changing. He was “thin, sort of stretched, like butter scraped over too much bread,” to quote Tolkein (2012), but he remained a celebrated educator. When I attended the highschool he taught at, I could see why people worshipped him. He was attentive, kind, and spontaneous, but I sometimes felt that his delight in his students didn’t extend to me. One day in the auditorium, we negotiated my use of the family car and that local celebrity persona faded, replaced by my tired father, wanting to be done with the exchange. I felt like a household chore he needed to check off his list.

What I didn’t know at the time was that the problems were much deeper than daily stresses. When I was 16, my father and mother called me and my sister into their bedroom. They were on their big white bed, the one I’d spent so many hours in as a child. My sister sat next to me, her expression a mirror of what mine must have been—face red with crying, a look of frozen disbelief at what we were hearing. My father had cancer, had what I would eventually come to understand as non-Hodgkin’s lymphoma.

When I later spoke of my father’s cancer, I became almost smug in my use of the term “non-Hodgkin’s lymphoma.” I pronounced it meticulously, showing off my newly grown-up vocabulary to my friends. I was distraught at the way cancer was breaking my father, but I also felt

a sliver of specialness from going through such a difficult time that, from my perspective, far outweighed my friends' worries.

My father had taken a leave of absence from teaching, beaten down by cancer and the treatments. I'd go to school and be inundated by people asking after him. Their expectations of my father—to be in good spirits, to be fighting—would come crashing against the reality I'd discover waiting for me at home. At times he would be shakily crying, lying on the couch that he used to work on. I might find him huddled under the blankets of his bed, and I would come into the dark room, uncertain how to help. I'd rub his feet through the blanket, hoping that I was doing enough to comfort him, not sure if I could handle it if he asked for more from me. Other times, the house would be filled with visitors, and a flash of my father's humour and energy would return.

I leaned heavily on literature as a coping mechanism, which proved an inconsistent support. In the same class in which I'd encountered Dickinson, I was assigned Karl Shapiro's (2021) poem "Auto Wreck," which focuses on a car crash and death in general. In his closing stanza, Shapiro emphasizes the horrific randomness of car accidents with a comparison that troubled me: "death in war is done by hands; / Suicide has cause and stillbirth, logic; / And cancer, simple as a flower, blooms" (par. 5).

When I read these lines, they felt somehow like a betrayal. I was already feeling alienated, from the fan club who didn't seem to grasp just how devastated my father was, from my friends

who had the luxury of making teenage mistakes, and even from my father, experiencing something I couldn't comprehend. Now I felt that Shapiro had misrepresented what my father and my family were going through.

Joining the class discussion, I responded with a shaking voice that cancer was *not* simple as a flower, but that didn't convey my churning emotions. I hated the poem for using my father's disease as a metaphor. I'd recently started writing poetry and I dedicated a new one to the ugliness of cancer; I felt my father deserved better than a single line.

My father was finding more comfort in poetry, but he clung to a poem that spoke to a similar anger in him as in me: W.H. Auden's "Musée des Beaux Arts" (1938). Auden's poem uses Pieter Breughel's *Landscape with the Fall of Icarus* for a discussion of pain. In the myth, Icarus escapes a labyrinth with the help of his father, who constructs wings for him. Icarus defies his father's warnings by flying too close to the sun, falls into the sea and drowns. Breughel's painting focuses on the coastline, ships, and labourers, and in the corner of the painting Icarus's legs are barely visible, his head already under water. No one seems to notice the Greek tragedy in the background; as Auden notes in his poem: "everything turns away / Quite leisurely from the disaster" (par. 2).

Auden used this startling painting as a metaphor: "About suffering they were never wrong, / The old Masters: how well they understood / Its human position: how it takes place / While someone else is eating or opening a window / or just walking dully along" (par. 1).

For my father, this poem expressed something essential about humankind. He received excellent treatment from his healthcare providers, but he also sometimes felt like a background character in someone else's story. While he was undergoing chemotherapy, the nurses would be chatting about weekend plans and, though he understood that this was normal behaviour, he also wanted compassion and attention. He didn't want his suffering to be taking place while "someone else is eating or opening a window or just walking dully along."

Though my father and I were on different paths, we were often united in our hurt and even resentment toward people who we perceived as minimizing his cancer and the way it impacted our family. Our shared resistance to the world "turn[ing] away quite leisurely" from our family's disaster only grew more complex in the years to come. After months of brutal treatments, my father's cancer went into remission. For years, reminders of his cancer lingered in things like his strange toenails, warped from chemo. In my early twenties, we heard the news that we were dreading: my father's cancer had returned. With it, returned the sense that our family was living through a tragedy akin to Icarus's, especially after my mother's diagnosis.

My mother had buoyed our family during my father's first cancer, but she began developing her own mysterious symptoms, losing words, twitching involuntarily. In between the cancer years, she was finally diagnosed with Huntington's disease, a degenerative illness that impacts motor and cognitive abilities. As her Huntington's worsened, my

father began caring for her, the sun to his sunflower. As a caregiver who was also a cancer patient, my father's identification with Auden's poem only compounded.

He didn't want his or his wife's suffering to be shuttered to the corner of a painting as Breughel does with Icarus. He wanted to be known, to be seen. My siblings had left home, and I was an obvious choice to be my parents' witness, a complicated role. There was an intense intimacy to staggering through trauma with my parents. My father once said to me, "We've really been through the trenches together," and I felt special and strong.

That closeness could turn to claustrophobia, though. Our house had thin walls, which was convenient when someone called your sister, and you could yell "PICK UP THE PHONE!" from your bedroom to hers. Later, it also meant that there was nowhere far enough away from my parents' sick bodies. I woke up at night to the noises of my father throwing up, and I celebrated my birthday with my mother bruised from a fall caused by Huntington's, trying not to betray how much she was hurting. There was still a deep sense of love, but I increasingly felt that I had to either witness my parents' suffering or run.

As I grew into adulthood, I moved across the country for graduate school, but there remained within me a belief that truly loving someone meant walking with them through their pain. It makes sense, then, that when I began teaching undergraduate English while writing my PhD thesis I assigned the play *Wit* (1999) by Margaret Edson. *Wit*, which was adapted into a movie, focuses on Vivian, a pro-

fessor of literature. She is diagnosed with cancer and *Wit* tracks her illness, treatments, and interactions with insensitive doctors. Vivian frequently delivers her lines directly to the audience, and we are forced to watch as she declines and dies.

When I watched the movie adaptation, it was devastating, especially with the similarities between Vivian and my father: their love of literature, their frustration with healthcare workers they felt lacked empathy, even Vivian's changing body. When I visited my father in hospital, he tried to smile reassuringly, but he'd had to take out his false teeth, a party trick that he would do when I was a child, my cousins shrieking in delight and horror. Now, it made his newly skinny face look even more like a stranger's.

Yet I found *Wit* validating in its ugly realism, especially in comparison to other movies that addressed cancer. *Wit* (Nichols, 2001) was released amidst a swath of romantic cancer stories, like *A Walk to Remember* (2002) and *Sweet November* (2001). My mother loved romance in pop culture, a trait I'd inherited, and I watched these movies despite my resentment toward their depictions of cancer. In them, the heroines are rosy-cheeked in their illnesses, and the healthy male love interests are forever changed by the cancer patients' lives and eventual deaths, which often occur with them still looking gorgeous.

I didn't watch these movies with my mother, but she would have been a sucker for them. She didn't share my outrage over misrepresentations of cancer. I can imagine her wiping her eyes at the end of one of them, chuckling at how much the

tearjerker had worked on her, before getting up to get dinner ready. By contrast, the first time I finished *Wit* I was left weeping and exhausted.

Years later, I forced my students through a similarly emotionally intense experience by assigning *Wit*, believing it would increase their empathy. As I once again put the movie on in a dark classroom, I wondered if my motivations were more personal than pedagogical. I had mentally accused people of avoiding my parents' illnesses, but I felt I'd been guilty of the same thing, turning away from them through escapism, through physical or emotional absence. *Wit* felt like a punishment and an opportunity to try again. If I hadn't been there enough for them, then I would be with Vivian. I wouldn't look away.

This sense that I should remain a witness from afar was hard to shake. There's something comforting in long-standing family dynamics, even when they've become tight and suffocating. In a movie my father would have appreciated, I found a poem that helped me transition toward a life that did not centre my family's diseases.

I first encountered the opening lines of Mary Oliver's (2017) "Wild Geese" as a magnet on my sister's fridge: "You do not have to be good. / You do not have to walk on your knees / for a hundred miles through the desert repenting. / You only have to let the soft animal of your body / love what it loves" (par. 1). When I eventually read the whole poem, it was a revelation, a religious experience for an atheist.

Oliver's poem balanced Auden's, which criticizes a society in which suffering takes place in

the corner of a painting. She continues, “Tell me about despair, yours, and I will tell you mine. / Meanwhile the world goes on. / Meanwhile the sun and the clear pebbles of the rain / are moving across the landscapes.” (par. 1). The poem showed me that, as individuals endure trauma, everyone and everything carries on, and there’s beauty in that. Oliver acknowledges pain but positions it in a world that “... offers itself to your imagination, / calls to you like the wild geese, harsh and exciting,” meaning that there’s still opportunity for wonder, for joy, for communion (par. 1).

In my youth, I’d resented the fact that the world didn’t break from my parents’ illnesses, but in my adulthood I found Oliver’s vision comforting. On days when it felt too easy to equate being a good person with guilt and sorrow, I repeated the poem like a protective ward. It helped me understand that, as much as I saw bearing witness as a form of love and compassion, I had to extend that same empathy to people “eating or opening a window or just walking dully along” while others suffered. If I could do that for other people, I had to do that for myself, too.

As I internalized Oliver’s lessons, my father found ways to recommit to witnessing. He wrote and directed a play for a community troupe that explored mental illness. He became a respected thinker and speaker on the importance of empathy in health care. Recalling his latest conference, he recently joked to me that he’d been appalled when the preceding speaker referenced poetry—and Auden’s poetry at that!

Today, my father has cancer for the third time, a new medical term for me to memorize: multiple myeloma. He's undergoing treatments with only the hope of prolonging his life, but he remains as interested as ever in words. I sit down in my living room with a warm cup of tea in my hands and FaceTime with him to discuss our latest read for our book club. "Hi dear," he says. "What's going on with this video? Oh, for goodness sake." "Press the camera button, Dad!" I shout, because he's forgotten his hearing aids again. His elfin face, older now, pops up on my phone, and we talk about Oliver's "Wild Geese," which I've sent him as an offer of hope. Time has passed, but for us literature is still a joy to analyze, a way to better understand each other and everything else. From the other side of the country, he says, "I love talking to you, dear. Keep sending me this stuff." "Love you, Dad."

After years of teaching *Wit* (Edson, 1999) to my undergrad students, I stopped assigning it in class. There came a point when I didn't feel the need to push my face or my students' against the brutality of my father's illness. When it felt more important to think of my father not just as a cancer patient, but also as the person who taught me to love reading and delight in silliness. As my father's daughter, I will never stop being in awe of literature's power, and that includes *Wit*. I am also my mother's daughter, and I have come to see that there is no moral failing in only encountering depictions of cancer in the romantic tearjerkers that my mother would have loved. That I can put the movie on, have a quick cry, and, when it ends, get up and walk away.

References

- Auden, Wystan Hugh. (1938, December). *Musée des beaux arts*. *Emory University*. <https://english.emory.edu/classes/paintings&poems/auden.html> [June 11 2024].
- Dickinson, Emily. (1890). Because I could not stop for death. *Poetry Foundation*. www.poetryfoundation.org/poems/47652/because-i-could-not-stop-for-death-479 [June 11 2024].
- Edson, Margaret. (1999). *Wit*. New York, Faber and Faber, Inc.
- Nichols, Mike (Director). (2001). *Wit*. HBO Films, Inc.
- O'Connor, Pat (Director). (2001). *Sweet November*. Warner Bros.
- Oliver, Mary. (2017). *Wild geese*. *Watershed Ecotherapy*. www.watershedecotherapy.com/articles/for-everyone/eco-poetry-mary-olivers-wild-geese/ [June 11 2024].
- Shankman, Adam (Director) & Janszen, Janszen (Screen Writer). (2002). *A Walk to Remember*. Warner Bros.
- Shapiro, Karl. (2020). *Auto wreck*. *Poems that move*. www.poemsthatmove.com/post/poem-4-karl-shapiro-s-auto-wreck [June 11 2024].
- Tolkein, J.R.R. (1937). *The hobbit, or there and back again*. London, UK: George Allen & Unwin.
- Tolkein, J.R.R. (2012). *The fellowship of the ring*. London, UK: Houghton Mifflin Harcourt. (Original 1954)

About The Author

Clare Mulcahy is a professor living in Edmonton with her beloved partner and cats. Email: clarem@nait.ca



Volume 18
Issue 1
2024

Wound Care: A Primer

Denise Napoli Long

This is how to take care of M.'s stage 4 sacral bed-sore.

No, no, let me start again.

M. was an accountant. He was in his late eighties when he was admitted to home hospice. The first time I met him, he was still working, still doing his daughter's taxes, sitting up in his hospital bed in what used to be a formal living room in the front of the house. *The Price is Right* was on TV, loud. What do you want, the guy was eighty.

M.'s wife was on a futon on the other side of the room, asleep, with two small dogs in the bed with her. Bichons, something like that. The ones where the mouths get all brown around the edges. They growled at me as I stepped over their wee-wee pads to M. The wife didn't stir.

"She has her own health issues," said M.'s daughter, referring to the wife. I don't remember the daughter's name, now. I can see her so clearly, her hands over her mouth, and I can feel her, the smallness of her when she let me hug her, at the end. But I can't for the life of me remember her name.

M. was gruff. "Who are you?" he said.

"I'm your new best friend!" I said, and his daughter laughed, and he groaned. "I'm here to do your wound care for Kathy today. She's out sick."

"Lucky me," he said. He rolled his eyes.

Kathy was his regular nurse. Kathy had told me he was a pain in the ass. She said this over text earlier that day. *He's a pain in the ass. Sorry!!* Then the emoji with the mouth in a rectangle and all the teeth showing.

“So,” I said to his daughter, “do you usually pre-medicate, or ... ?”

I meant, do you usually give morphine before you change the wound? Sometimes we do. It's painful, or it can be.

“Hell, no!” said M. “That stuff makes me sleepy. Just get it over with.” Then he turned his head toward the entrance to the room and hollered: “Julianna!”

A tall, strong, beautiful Jamaican woman came into the room. Her skin was the smoothest, deepest brown and her teeth were blindingly white. She smiled, first at me, and then M.'s daughter, and then, with a special softness, at M.

“This is Julianna,” said M.'s daughter. “She's his aide.”

“Help me, damnit!” M. said.

“Dad!” cried his daughter. “Don't be so rude!”

“For the love of Christ,” he muttered, and turned his face to the wall, so that I could get to his backside.

Julianna smiled again and moved to stand against the wall and with two huge, capable hands she pulled him over, so that he was balancing on his left hip and I could get a clear view of his ass and his wound. He weighed nothing, 85 or 90 pounds at most. She held him there, leaned down, and whispered into his ear, “It's okay, handsome. It's okay.”

I began the wound care. Stage 4 means the wound, the bedsore, went through his skin, and then through the fat under his skin, and then through the muscle. At the base of the wound was white bone. The wound was maybe ten inches wide and seven inches long, all around his sacrum. Just above his ass. Just there.

Wait a minute. There's more. I need to tell a little more, first.

* * *

Let me start again.

Before I was a hospice nurse, I was an ICU nurse. One night, I took care of an old man whose daughters loved him very much. They loved him so much that they wouldn't let him die. They wouldn't sign the papers that would let us nurses and doctors stop banging on his chest every time his heart stopped. They wouldn't let us disconnect the tubes from his groin that filtered his blood through a dialysis machine every time his kidneys stopped. They wouldn't let us take out the tube into his trachea that was hooked up to a ventilator that made him breathe every time his lungs stopped. Their love for him was torturous.

It was Easter, and Jesus was rising, and he (the patient, not Jesus) mouthed to me, soundlessly, because the tube in his trachea didn't let him speak, *Let me die. Let me die.* Then he went into v-tach, which is a fancy way of saying that his heart went apeshit.

I didn't let him die, dear reader. Don't worry. I saved his life. I'm a hero.

What I did do, after that, was become a hospice nurse, because although I am a hero, I am not a sadist. There are no emergencies in hospice care. No one is on dialysis. No one needs CPR. No one is on a vent. People still beg you to let them die, sure, but at least you're not actively withholding it. On hospice care, when patients say, "Let me die," we nurses say, "Go right ahead!"

Thing is, just because someone is ready to die, and their body is trying to die, it doesn't mean they're going to die. Some people decide to stop going to the hospital, stop going to doctors and being treated for things, and then they get better. Sometimes there's nothing to be done, and the patient seems to have days or weeks to live, and six months later they are still lying in a hospital bed in their living room, eating farina and watching *The Price Is Right* with a Jamaican lady named Julianna while they do their daughter's taxes. In those cases, lots of times, patients get bedsores.

Which brings us back to M. and his ass wound. I was going to tell you how to take care of it. I was going to write an essay about what you have to do to take care of a wound like that.

Ah, not yet. Let's wait a little longer. I'll tell you about the wound in a minute. Just, here, let this sink in for a minute: In order to keep M.'s wound from festering, it needed to be packed with gauze that was soaked in bleach. Bleach, in his wound.

Just remember that for a minute, will you?

* * *

Let me start again.

I mentioned M.'s wife, earlier. How she was on a futon, asleep, with two small dogs bouncing all over her, and the TV blaring, and a nurse walking through the room making obnoxious wisecracks, and the daughter saying that her mother had her own health issues.

M.'s wife was a mess. Remember that movie *Death Becomes Her*? Goldie Hawn and Meryl Streep unlock the secret to eternal life, or something, but their bodies keep decaying and have to be glued back together. At the end, Goldie Hawn's face is all runny and patchy, and Meryl Streep says she needs some more glue, and Goldie says, "I need to get to the hardware store!"

That's kind of how M.'s wife looked, in the face.

Because the thing about hospice is that it's never only one person that is dying. Everyone is dying, all the time, all of us. I am dying as I write this. I am one moment closer to my own demise, right now. And now. And now. We are all in varying states of decay. M. was decaying quite literally from the inside out, while he still breathed, but M.'s wife was dying, too. Her heart was giving out, little by little by little, her heart and her brain, at the same time. She slept most of the time and when she was awake, she seemed not to understand that her husband was dying—we nurses weren't to say the H word in front of her. Hospice, I mean. Not Hawn, as in Goldie.

There was also M.'s daughter, whose name I can't remember. She loved her father very much, and loved her mother, too, and she had grown up in this house. She drove over every day from where she lived with her husband and her chil-

dren, a few miles away, to check on her father. She had a sister, too, who was in Florida, or Virginia, or somewhere. M.'s daughter would ask Kathy, the regular nurse, whenever Kathy visited, "Is it happening? Is it now? Should I call my sister? Should I tell her to come?"

"Yes," said Kathy, every time. "It's happening. It's still happening."

When we take care of hospice patients, and their ass wounds, and the ten million other things that are the matter with them, or when we take care of patients like my kamikaze ICU man, we aren't just taking care of the patient. We are taking care of his wife, and his daughter, and his aide, too, and the dogs with the brown around their mouths, and all the people who have a stake in his suffering, which is everyone he knows and has met and could have met and could have known. They are all crowded around there, watching us, in M.'s smelly, dark, cramped living room, hundreds of eyes, thousands, watching. They all see that it will be their turn, too, despite their currently intact asses, and they all want to know: how does one do it? How does one die? And how does one care for someone who is dying?

Back to M's wife and daughter.

They didn't want to see the wound. I can't blame them. Not only was it stage 4, but it was also unstageable in parts, because it was black, and there was no way of telling what was going on under the blackness. Some areas of M.'s wound were holes, deep tunnels into his flesh, and a person could stick an eight-inch cotton swab in. I mean all the way.

I can smell it, still. I can smell the sticky, sweet scent of the wound when I first open the dressing, and the rest of the skin around the wound, which hasn't been showered or properly washed outside of the confines of a hospital bed for months and months. I can smell the bleach, the bleach plus the dogs, the dogs with the brown mouths, and the wife with her mouth a little open as she sleeps, and the aide Julianna whispering in M.'s ear and stroking his back ever so gently, *It's okay, handsome, it's okay. Almost done, handsome, almost done.* Even though, you know, we had just begun.

* * *

Let me start again.

Today I went to see a woman, 91 years old. When I walked into the living room, she was sitting up in what I thought was a chair, with her aide nearby, and her husband, Carl, sitting on a couch on the other side of the room, his eyes red from crying. "Good morning!" I said cheerfully, which is just like how I was with M., and as I try to be with everyone. She had just returned home from the hospital, this woman, after being there a week. It was my job to explain hospice to her so that the next time she tried to die she could do it at home with some morphine, like she wanted.

I chatted with her and her husband and her aide for about ten minutes before she said, "Excuse me, it won't come out."

"What won't come out?" I said.

"The shit," she said. "It's stuck."

That's when I realized that she wasn't sitting on a chair but on a commode, right there in the living

room, four feet from the front door. She was actively trying to take a poop while I was discussing the philosophy of hospice, and our roles, in this life, as caregivers, and the fact that Medicare was not likely to pay for both hospice and her aide, and wondering if I correctly understood that she had a DNR order, and did she have a copy in the house?

I took a look. Sure enough, she had a baseball-sized poop stuck in her butt, and she weighed 95 pounds, and she was covered in bruises and sores and cuts, and there was no way she was going to be able to push that poop out on her own, and there's no way I was going to be able to leave that house until she was done shitting.

“Do you have any Vaseline?” I asked.

That woman's name was—goddamn it, I was just there today and I can't even remember her name. You disimpact one half-dead old lady, you disimpact them all.

Gloria? Gwendolyn? Gabriella? Something like that.

Anyway, this woman I saw today doesn't have anything to do with M., who has been dead for months now. I only mention it because I have been thinking about M., obviously, and today, when I was confronted with this woman's ass, bony like M.'s, and packed so full of shit that it probably reached up to her esophagus, I thought: I also want to make sure I mention, in that essay about how to clean M.'s stage 4 bedsore, that it was good when he was constipated. He would be constipated for three weeks at a time. Farina in, nothing out. Farina in, nothing out. Over and over and over. And then, every three weeks, for about four days, there

would be a flood. A nonstop, completely liquid, absolutely rancid flood of shit. His anus was involved in the wound by then. The dressing was basically a bag for the shit, so that when you pulled away the tape, as his wife dozed and the dogs barked and Julianna whispered in his ear and his daughter pretended to take a call in the next room, it would pour out like a watering can.

To recap: stage 4 bedsore. Bones and blackness and tunnels through the flesh so deep they could hide a pencil. Shit, spilling out, once a month or so, for days at a time. Bleach. Pack it with bleach, to kill the germs from the shit. Got it?

Good. Almost done. Stay with me.

* * *

Let me start again. At the end, this time.

In the end, over the course of the time I knew him, I would visit M. and clean his wound a dozen or more times. I would get to know his daughter, and she would let me hug her one day in the hall as her mother puttered around the kitchen looking for dog treats and her father slept in the living room and the aide, who was not Julianna anymore but some other aide that the agency sent, watched soccer in a room off the hall. One of the dogs died, the day she let me hug her. The daughter found it in the hall when she came over to check on her father. It seemed to be the last straw, the thing that put her over the edge at last.

In the end, I would tell M. that we didn't have to do the wound care if he didn't want to. It was his ass and he could do with it what he pleased, because it hurt him to turn to the side, and it hurt

him to know that the thing I was doing back there was taking care of a dead body, more or less—cleaning it and tending to it and pouring chemicals on it so that the body’s mind, which was basically fine, could go on watching Drew Carey give away dinette sets on TV.

In the end, he let me do it. The wound care.

This is how you do it:

Julianna turns him to his side. She whispers in his ear, and strokes his back, and you watch her hands, and you feel that what she does for him is something that, for all you are about to do for him, you could never do. You could do it for your children, maybe, and for no one else. You wonder why she can, what she has that you don’t have, what she knows that you don’t know, won’t ever know, no matter how long you do this.

You gather up the materials: Washcloths. Wound cleanser spray. A basin of warm water. Non-sterile gauze. Sterile gauze. Bleach solution, a special concentration ordered from the pharmacy. Cotton swabs, the extra-long ones. A paper tape measure. Two big pink bandages, the color of rosy cheeks. Tape, at least a full roll of tape, to keep it all in place. Gloves, an entire box, so that you can change them after each step. A garbage pail. Extra pads for under him, and diapers, and hand sanitizer.

Then you say, “OK, handsome, it’s showtime!” And you take a deep breath. And you start again.

About The Author

Denise Napoli Long is a hospice nurse with the Visiting Nurse Service and Hospice of Suffolk, New York. Email: denise.napoli@gmail.com



Volume 18
Issue 1
2024

Bargaining

Julia Yuan



About the Artist

Julia Yuan is an Internal Medicine resident at the University of California, San Diego. Email: jyuan@health.ucsd.edu



Volume 18
Issue 1
2024

The Translation of Memory

Isabella Cuan

I am writing this on the one-year anniversary of my grandmother's passing.

When I began my clinical rotations as a medical student six months ago, I saw her everywhere. I saw her in the faces of women who looked nothing like her, but spoke Spanish with a familiar vivacity and conviction. I saw her in patients, young or old, diagnosed with the same cancer that selfishly consumed her. I saw her in every grandmother accompanying her grandchild to the pediatrician.

When will this stop? How do I prevent this raw, unhealing wound, a wound I have spent months so clumsily suturing, from re-opening time and time again? Just when I would begin to sense solid ground forming beneath me, my stomach would twist on itself, the acuity of remembrance flooding my system faster than a shot of epinephrine, depriving me of oxygen and leaving me gasping for air; my flimsy, now damp surgical mask the only visible marker of pain; so silent, so shamed.

One summer day, when I was rotating through a healthcare clinic in the Lower East Side of New York, I met Evelyn¹. At a remarkable 94 years old, Evelyn was outrageously alive, and is to this day. Born to an immigrant mother from Austria

and a U.S.-born father, she has called New York City home since the day she developed a mind audacious enough to get her into mischief. Nearly a century later, the Lower East Side remains her beloved home, even now, in the temporary residence of a skilled nursing facility. Due to a host of unwieldy medical conditions, Evelyn finds herself with an increasingly undependable body despite the stubborn objections of her exceedingly independent mind.



From the minute we first met, Evelyn indulged me with adventurous and provocative stories, from her tales as a rebellious young child window shopping in Chinatown, to her stint working for the 1950 Census, to her proudest moments conducting research in the lab run by George Papanicolaou, the physician-scientist who invented the Pap smear. Besides a few bed-bound friends, Evelyn is on her own. She never had children and her partner and siblings passed decades ago. Her contagious optimism and witty humor are rivaled only by a growing loneliness and anxious despair about the state of the world.

Not long after our first meeting, Evelyn was hospitalized. Though she survived a risky surgery, I was struck with a harrowing realization. Had she passed, I might have been one of the only human beings she shared her life stories with at the end. I began carrying the weight of this realization around with me in the hospital and with every sick and dying patient I cared for.



How is memory preserved when there is seemingly no one left to preserve it for us? We might have photographs and mementos, no doubt powerful physical objects that aid in remembering, but is memory something to be confined to a book we dust off from time to time? Or is it a living and breathing entity within us?

I am reminded of the words of Oliver Sacks, the late neurologist whose philosophical meditations in “The Man Who Mistook His Wife for a Hat” I recently re-visited in light of my experiences in the hospital:

Each of us is a singular narrative, which is constructed, continually, unconsciously, by, through, and in us — through our perceptions, our feelings, our thoughts, our actions; and, not least, our discourse, our spoken narrations. Biologically, physiologically, we are not so different from each other; historically, as narratives — we are each of us unique. (Sacks, 1998, p. 105)



Much in parallel with Dr. Sacks' worldview, the only way I could seem to make sense of memory—of how we remember our loved ones and the strangers we hardly knew—was by understanding memory as something that is translated through and in others. With multiple generations between us and many stories later, I came to appreciate the psychological and emotional depth of this in my relationship with Evelyn.



Evelyn had the ability to bring to life the spirit of my grandmother, evoking memories I previously thought too painful to share. In turn, I was the vessel through which Evelyn revisited the nostalgia of her youth, honoring a life she thought she

had parted ways with amidst the threatening tides of her illness. In seeing my grandmother in the faces of so many of my patients, I came to understand this was not the theft of grief, but the poignant presentation of shared humanity.

Experiencing memory through others is fundamentally possible because of our connectedness. Doctor-patient relationships are no different. It is because of, rather than in spite of, the gravity of my grandmother's presence that I am unequivocally a more patient-centric listener and empathic caretaker.

Historically, western medical culture has argued for the segregation of the personal and the professional, so much so that the essence of our beings—our emotions, language, dress—are subject to regulation to ensure the preservation of this distinction. But how can we expect our patients to venture into deeper and darker waters for us if we are unable to do so ourselves? Boundaries are essential, but vulnerability is not in and of itself about what we share or how much we share; it is about how we move through the world and occupy space in it. It is about how we confront our own mortality in order to be present in our patient's mortality. It is about how we say "I don't know" because that is the truth.

My grief is still there, just as much as it was at the start of this year. I don't expect it to go anywhere anytime soon, nor do I want it to. This past week, my team empowered me to lead my first goals of care conversation with a patient suffering deeply from terminal cancer. I cried with the family, as the flood of memory—of my grandmother,

of my patient, of Evelyn, of so many human lives long-lived and not yet lived—submerged me.

For once, I let it, realizing it was possible to breathe underwater.

Note

1. The subject's name has been changed for privacy. All photographs were lovingly captured with the consent of the subject.

Reference

Sacks, O. (1998). *The man who mistook his wife for a hat*. Suffolk, UK: Richard Clay Ltd.

About The Author

Isabella Cuan is a photographer, writer, and psychiatry resident at Mount Sinai. Email: isabellacuan224@gmail.com



Volume 18
Issue 1
2024

Short Position / DNR

R.A. Pavoldi

Short Position

the dot-com bubble, 1999

Vertical is splitting twenty to one
Monday and mother is dying,

metastatic renal cell carcinoma
multiplying like a penny stock

in a perfectly manipulated
pump and dump campaign,

a new Harley for me, a hearse for her,
Vertical is splitting twenty to one

Monday and mother is dying, now
I have a deadline, get back

to the book of poems about her family
she knows I've been working on

between bread winning, day-trading,
baseball, swimming, and soccer,

build in six months, a year maybe
to read, show to friends,

Vertical is splitting twenty to one
Monday and mother is dying

though no one knows, she does not
want to be treated differently she tells us

makes us promise to keep it to ourselves,
she does not look like she is dying

going about her business with a smile,
dignified, driving herself to the oncologist

each day for another shot of poison,
kidding with the young nurses,

Vertical is splitting twenty to one
Monday and mother is dying

she asks me to help organize
the cupboards, empty the closets,

I am taking short and long positions,
recoup my initial investment

then hold the rest for the next Microsoft,
there will be 50 to 100 million

new internet users in China by 2002...
content seeping through portals,

spreading to the Pacific rim,
hers through lymph, from *the right*

retroperitoneum popping out
lateral to the inner vena cava

measuring 2 centimeters, the last
pages of the book await revisions,

she said she waited seventy-two years
to live, because some things just take time,

Vertical is splitting twenty to one
Monday and mother is dying,

and there is plenty of time to suffer,
Interleukin, 5-FU, Alpha-Interferon,

speculation. Are the kids old enough
they won't forget her? I know Marina is,

but what about Dominic and Leonardo?
How do I build their wealth of memory?

What dividends and interest
will she yield?

Compounding and steady growth,
higher than expected returns,

a cup running over, those shares
in their eyes a hedge for my broken heart,

Vertical is splitting twenty to one
Monday and mother is dying.

DNR

He dreams of a thrush on a sill,
the detail of its feathers his insulated sleep

layered between quick small heart
and shimmering sun,

tapping at its reflection
a dull staccato on the surface of sleep.

Up through the ripples
he sees the high hazy sun,

swims toward the light
to find himself young, his tie loosened

his coat in his arms
having overstayed his time at a party

dozing in an easy chair
with an unfinished drink, dreaming

of the evening's twisting conversation
no one agreeing on anything except,

we cannot remember our birth,
or the moment we fall asleep,

how it must be the same when —

You'll be late for school!
His mother's liquid voice under water,

the thrush flies from the sill,
his first wife shaking him gently

taking his arm to help him
up from the chair, whispers,

come on honey, it's time to go.

About the Poet

R.A. Pavoldi is a self-trained writer, crediting the Napolitano-American dialect and the school of hard knocks for his voice. He's published in *The Hudson Review*, *North American Review*, *Italian Americana*, *FIELD*, *The American Journal of Poetry*, *Crab Orchard Review*, *Tar River Poetry*, *Atlanta Review*, and others. Email: rapavoldi@yahoo.com



Volume 18
Issue 1
2024

Rivulets of Rain

Shawna L. Swetech

Cochlear shells break
saline rises in my eyes
too much too much
I fall blue
into blue
into blue
on the shoreline
relentless waves
hospice-colored clouds
shadows cast
transparent
now I see
into you
your skin, your loss
the uncountable years
of pain
so that I too turn
translucent, bare
-ly visible
oh god, oh
god
I can't.
this break
-ing this sorrow
its full-stone weight
crushing
the perimeter

of my heart
now—I must
quickly quickly
to slim window
steady my gaze
on ray of winter-
solstice light
trace rivulets
of rain weeping
weep
-ing
down
the
pane

About the Poet

Shawna L. Swetech, a retired hospital medical/surgical nurse, is a poet, visual artist, and integrative wellness coach. Shawna believes poetry and art are important healing medicines for the ills of our modern world. Email: shawnaleah@mac.com



Volume 18
Issue 1
2024

Prognosis
—for Danny Wallace

Woods Nash

It's a regular checkup—
a wellness visit, the clinic calls it—
but I ask the doctor to tell me
I'm dying. *Say it plainly,*
like Samuel Beckett, I suggest
helpfully. *Or like a sunset figure*
from Cormac McCarthy.
Only then might the curtain rise
and let me see what the play
has been: maybe just a man
standing in rain, alone outside
the diner's glow. He placed an order
long ago, but still he's waiting
for to-go. *Please, I say, grant me*
the relief of a final verdict. The faith
of a finished script. My hands hang
limply. *I don't even have lines to forget.*
The doctor opens her long white coat,
plants both fists on her hips. No,
she says gravely, *you've been served*
enough. If it's clarity you want, start
with the woman who scrubs your tub.
Ask about her arthritis, her plastic crucifix,
her three teenage kids. Offer her
a glass of water. You'll find death
and life in covalent bonds. I begin
to object that I can't speak Spanish,

flunked basic chemistry, but the doc
interrupts. *You must stop outsourcing
everything—especially the turbulence
of concern.* Now I try to flee
the exam room, but the doctor side-steps
to block the door. *Your prognosis is worse
than terminal,* she says. *If you don't learn
to ignore yourself,
you'll be condemned to live
apart. And like a shuttered theater's
darkened seats—red, plush,
abandoned—you'll go on expecting
to be spared destruction.*

About the Poet

Woods Nash is Assistant Professor of Bioethics and Medical Humanities at the University of Houston Fertitta Family College of Medicine. His scholarship and creative work are at the intersections of narrative medicine, literary studies, and ethics. Email: mwnash@central.uh.edu



Volume 18
Issue 1
2024

I Am a Customer Service Representative

Beth Goldner

I work at a hospice,
fielding calls from oncologists, neurologists,
caseworkers, and clergy,
referring their patients and parishioners, knowing it is time.
Sometimes the families call, weeping or angry,
giving me too much information, or not enough,
needed to get their loved one on service.

Nurses used to do my job.
They called it Intake.
Now they hire English majors and call us Customer Service
Representatives.
They give us business cards.
They equip us with headsets and a checklist of questions.

Occasionally, the person who is dying calls, for a chat, a
look-see.
Like M—, who called every Tuesday.
She was a former Avon lady, had once lived in Prague, mar-
ried four times.
She'd ask the same questions about hospice services on
every call,
but would never consent to care.
My boss, a middle-aged woman with bitten fingernails, told
me to push M—.
She's getting there, but isn't quite ready, I said. She says she's
not in pain.

My boss' brow, a knot of annoyance: It's your job not to let her get to that point.

When I am dying,
if I'm not lucky enough to have a widowmaker heart attack
or a ruptured brain aneurysm,
I want my sister,
(who will be the one to call hospice)
to reach an LPN or RN or BSN,
who will take charge. Delicately, but confidently,
ask my sister my diagnosis, my physician's name, what medications I take
—if I am in pain—

I do not want the person who answers her call
to be a customer service representative,
some person who knows nothing about my pain:
the causes and nuances,
the trajectory and uncertainty,
a person who has never studied the human body,
or smelled the smells of medicine,
or heard the sounds of decay.
I do not want the customer service representative to tell my sister
at the end of that first call,
that if she should have any questions later, to please—
just please—call them in the Customer Service Center.

About the Poet

Beth Goldner is a fiction writer and poet. She is the author of a story collection, *Wake*, and a novel, *The Number We End Up With*. She lives in Philadelphia. Email: bethellengoldner@gmail.com



Volume 18
Issue 1
2024

Operating Room Rhythm

Jan Alexeis Lacuata

Purple ink
Curving across her neck
A surgeon's guide,
A future scar.

“Cutting!”
The blade touches the tissues
And they part
Seamlessly

An orchestrated dance
Of scalpels and scissors
Of ties and clamps
Of hands moving back and forth
Crossing over
Under
Next to
Each other.

A torrent of blood!
We halt and search
For the culprit vessel
Suction this, grasp that
Tie this, cut that

The outpouring of red has abated
Let us resume.

Pangs of hunger go away
All urges disappear
Standing for hours on end, effortlessly
Our minds engrossed
Suction this, ligate that
Tie this, cut that
Identify this, preserve that
Cauterize this, coagulate that.

The floor is littered with
Gauze and gowns and gloves
24 hours have gone by
In a second

The surgeon's mind returns
to the present
to sleep
to study
to rest.

Tomorrow is another day
To cut

About the Poet

Jan Alexeis Lacuata, MD, is based in Manila, Philippines. He completed his residency training at the Department of ORL - HNS, UP - PGH. Email: alexlacuatamd@gmail.com



Volume 18
Issue 1
2024

Hospital Fugue

Jenny Li

This cacophonous polyphony of machines
with no rest between phrases, spirals
into chaotic counterpoint, echoing
in the wards of the hospital
in the chambers of my mind.

Like a lifeless concerto of soloists
vying for the attention of exhausted ears,
robotic dissonance saturates
each note with the subtle flavor
of an anxious, never-ending *stretto*.

The vital essence of lives, reduced
to a minimalistic fugue of discordant beeps
in a distortion of harmony by this uninspired
monotony of clashing polychords, brews
a messy accompaniment to stories of illness.

On this *ostinato* of digital beats
float the voices of the white coats,
dictating in a monotonous *presto*
like rappers who lost their cadence.
Period. New line.

About the Author

Jenny Li is an internal medicine resident in Vancouver, Canada.
Email: li.jenny.xy@gmail.com



Volume 18
Issue 1
2024

Liberation / Summit

Nidhi Agrawal

Liberation

If separating the devotee from her lord
Is sin, Shiva! Why don't you
Dart the sinner with the poison?
They obliterated your lingam
From my courtyard,
Blamed me for desecrating you.
How can I invite your wrath through
Desecration when my body is
Your hearthstone?

The joy of finding love in separation is
Super sensible, ethereal and ecstatic.
You perform *Ananda Tandav* (The Dance of Bliss)
In my dreams;
I manifest the cosmos
You dissolve the same.
Together, we attain liberation (*moksha*).

Summit

Enough of preying on my flesh.
Sucking my blood
Won't take you to heaven.
When your fervent devouring is done,
Kali will consume you.

About the Poet

Nidhi Agrawal, who grew up in India, focuses on issues of emotional and physical trauma in her poetry. She strongly believes that poetry is a source of joy, pain, and wonder—a tool that keeps her going in life. She is driven by the intense physical and emotional trauma she encountered through her medical condition. Email: Anidhi201@gmail.com



Volume 18
Issue 1
2024

Inflammation

Marda Messick

Inflammation shows
in cardinal signs—
heat, loss of function,
swelling pain

a hammered finger,
attacking heart,
slice of knife—
any *-itis* of many

warrior cells wield
a metabolic sword—
forged in furnaces
stoked by air

this body battles
the pyre of age—
my singed shoulders,
my welded knees

this mind blazes—
old smoldering rage,
desire's wildfire,
new creation's solar flare

my fierce burning bird
rising live, unharmed,
reborn from ash—
sings of the torch

About the Poet

Marda Messick is a former nurse and caregiver living in Tallahassee, Florida. Email: mmessick@embarqmail.com



Volume 18
Issue 1
2024

Across the Sea

Aviva Goldberg

We sit at the side of this tiny crib
as we have for many days now.
I tell you things aren't getting better.

You say you understand,
but tell me that you have faith
that you believe in miracles
and that there are people praying,
across the sea.

I say I understand,
but I have faith in science, and creatinine
and in the miracle that is dialysis
because the numbers are not falling, only rising.

I too believe, in a way,
but have sat at the bedside of other parents whose prayers were not answered
in time.

I know that there is still room for faith, even at the bedside of the suffering,
but God can be hard to see in the corners of a children's ward.

We agree that you will continue to pray
and I will page the surgeons and the nurses and the ICU,

that we will call on our angels wherever we seek them,
that we will retreat to the corners where we make sense of the senseless,
and that we will meet somewhere in the middle.

And then ...
and then ...
and then ...

There is hope in loud pagers and quiet devotions.
There are numbers that are better.
Just a little for now but the promise of more.
There is a light.

I thank medicine and you thank God,
but I whisper “hallelujah” and you want to know the potassium.
I don’t know whose angels answered, whose certainty won out,
But it is of no matter, for now, as somehow,
at the side of this tiny crib,
we have, together,
made room for both.

About the Author

Aviva Goldberg is a pediatric nephrologist, ethicist and medical educator at the University of Manitoba. Email: agoldberg@hsc.mb.ca



Volume 18
Issue 1
2024

Aggressive Breast Cancer Treatment and Recovery

Elisa A. Garza

Abecedary of Chemotherapy

after Laura Kolbe

Anticoagulants flow first, clearing the way.
Blood return lets them know veins are ready.
Chemotherapy hopefully kills the cancer.
Digestive cells die, and
epidermal layers, also hair
follicles, although that is later.
Gas builds and you burp,
heartburn flares, worse than the worst
indigestion, like something
jamming your chest,
knocking against the heart,
lungs heavy and tight.
Memory is lost, the mind
numbed by endless nausea.
Oral hygiene might prevent
painful pustules in the mouth that make you
question your food choices.
Remember your last full meal?
Stay home during your nadir, safe from germs,
tiny terrorists of your now fragile,
unreactive immune system.
Victim of increasing fatigue, you
watch the world move on, enduring each infusion,
x-ing events out of your calendar, each day
yearning for certainty, for confirmation of shrinkage,
zero-sum game odds, for the win.

To My Chest Muscles, for Defending Against an Implantable Port, One Year Later

I can feel the armor you have built,
or maybe it's a weapon, a stout club
to beat the surgeon's knife,
to resist and smash the next port
instead of bleeding into the hole,
filling the cavity until the box
floats, my chest ballooning into pain.
You lost that battle, blood drained,
artery sewn closed,
port secured and ready
to connect needles with veins.

Still rebelling, you allowed
healing fibers to grow and block
access, you shifted the box,
lower, to the right,
let the flexible base bunch up
at the edge, anything to save me
from chemotherapy,
immunotherapy,
steroids, anti-nausea meds,
from anticoagulants,
antihistamines,
and electrolytes,
especially magnesium,
because who wants
all that dripping slowly
into the heart,
destroying blood and guts,
forcing kidneys into overdrive,
inflaming liver,
for a chance?

Because one year later,
port six months removed,
I find your knot under skin
and wonder: is this a new tumor,
or simply another scar?

Found: Patient Reminder

Thank for screening.	you choosing	At age forty, discuss
Records mammogram.	risk, indicate routine	breast health.
Breast easier	cancer	If you already, disregard.

About the Poet

Elisa A. Garza is a poet and editor. *Regalos* will be published by Lamar University Literary Press in Fall 2024. Email: poems99@yahoo.com