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We Used To Be So Much Closer

by Laura Ajayi

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Editorial

Companions in "the kingdom of illness"

In her now classic text, *Illness as Metaphor*, Susan Sontag identifies the "kingdom of the sick," to which "sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens" (p. 3). When we do visit, the fortunate are accompanied by loved ones. This accompaniment, across generations and across all kinds of relationships, is an emergent theme in this issue of *Ars Medica*. Will we go when we are called on this journey, keep pace on roads that are often torturous, in lands where we can get lost in the fog of chronic illness, and to destinations that can be sites of departure and loss?

Mark Osteen writes, "we had returned to the kingdom of illness," as he charts this journey with his son Cam. Cam's lifelong engagement with the healthcare system has often been disempowering and disorienting to Cam, who lives with autism: "Being a patient means that you are not an agent, that others care for you and act on your behalf." The "we" Osteen becomes a constituent of protects that autonomy as much as possible, and when the reader realizes that Osteen has "started this essay," the very essay we are reading, while at Cam's bedside, we, too, become companions on their journey.

In "Translations," Raquel Gomes journeys as far as she can with her daughter Gabi, born with a rare genetic disorder. Gomes' writing "translates" between spheres of scientific writing, and the lived experience of seeing Gabi's life blossom despite her prognosis. When Gabi dies from complications of her degenerative condition, Gomes continues this soulful journey to reflect on Gabi through her writing.

Sometimes, in one of life's disorienting reversals, we accompany our parents in their own final and chronic illnesses. Alison Jones Webb is a sometimes-discomfited companion on her mother's decline due to older age and Parkinson's disease, in "Regeneration." When "we cannot bear to be ourselves," this journey can be lived through writing, "liv[ed] in the third person." This altered state of consciousness, as an outsider looking in, buffers against "contact with her scaly skin" and unwelcome physical intimacy. And yet, even as "the life that we have knit together" unravels, Jones Webb grasps at the regenerative intergenerational thread that weaves together her roles as child, parent, and grandparent, part of the "unfathomable arc of existence" found through the story's coherence of beginning–middle–end.

Andrea Charise also explores intergenerational connection in her poem "Bleach," (one of two of her works featured in this issue) "reaching around for lessons/ on how to grow old." Stories, with their "roots and vines," connect her to her grandmother, and she writes that interconnectivity through language—memories of her grandmother's affinity for bleach link with the act of pleaching, a gardener's trick of weaving together stalks of trees. Through the "tricks" of language and poetry, Charise "find[s] ways/ to keep grasping" and to weave intergenerational meaning.

In the health humanities, we often reflect on the existential impact of illness on identity and meaning. But, when the journey is over, the companion is often forever altered also. In Jenna Pastorini's "A Proliferation of Cells," the narrator also draws from her memories her father's death from cancer, as a counterpoint to her experience in the anatomy lab as a medical student. She refuses the clichés of her instructors, and she "chok[es] on formaldehyde and irony" to find a language equal to the reality of cancer and death, and to speak from "that place in my gut where I kept those memories rolled."

Pastorini is embarking on a lifelong professional journey that we take as health providers, as companion to many patients through illness and to death. Issam Koleilat, in "They Sent Me There to Die," and Mark David Zimmerman, in "Oxygen," both recount roads travelled in their medical careers as companions to patients, and of the ethics and limits of these relationships. Jen Jolin, in "The Shoes I Don't Wear Anymore," writes poignantly about the marks those relationships and losses leave, and how we witness and account for them.

All of the writers, poets and artists who contribute to *Ars Medica* bring new ways of figuring this journey, and ways to share in the journey through art. In addition to the pieces described above, you will also find the writing of James Nolan and N.R.M. Roshak; the poetry of Jordan Oakes, Erin McConnell, Grace Zhang, Grace Luo Xu, Dan Ray Campion, A. Rooney, Kenneth Mills, Sophia Wilson, and Andrew R. Orr. *Ars Medica* creates space for documenting these expeditions, for leaving traces of our voyages, and a place for our paths to cross.

The Covid-19 pandemic has also created unprecedented impediments to those of us wanting to accompany loved ones and patients on their journeys. How do you travel virtually? How can we digitize compassion? Our forthcoming special edition of *Ars Medica* will focus on responses to Covid-19. Until then, we wish you nourishment and joy on your journey.

Reference

Sontag, Susan. (1978). *Illness as Metaphor*. New York, NY: Farrar, Straus, & Giroux.

Allison Crawford
Editor-in-Chief, Ars Medica

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Convocation

Mark Osteen

On Tuesday, February 6, 2018, I sat beside the dirty window in room 435 at Good Shepherd Hospital, where my twenty-eight-year-old autistic son Cameron had been staying since Saturday. There was not much to see from my fourth-floor aerie: a parking lot, a few undistinguished trees, droning traffic passing in the distance. Wearing a yellow hospital gown, I typed on my laptop with surgical gloves over my fingers. Cam lay in bed, listening to one of his favorite CDs, *The Eagles' Greatest Hits*. While he took it easy, I recalled how we had returned to the kingdom of illness.

Lyin' Eyes

> *Eagles' eyes have a million light-sensitive cells per square millimeters of retina, five times more than humans. While humans see just three basic colors, eagles see five.* (H, 2017)

The previous Friday, Cam was scheduled to travel from Hagerstown, MD, where he lives with three other autistic guys, to Baltimore for an appointment with an otolaryngologist at a nationally known hospital. Ear infections had become a chronic problem for our son: this would be the third visit to this specialist alone. Cam would then spend the weekend with me and my wife Leslie. That morning we got a call from the lead staff person at Cam's residence, informing us that a large bump had grown on the right side of Cam's face, just below his mouth. Should they come to Baltimore or take him to a doctor in Hagerstown?

"Bring him here," I told her. He already had a doctor's appointment, so I figured we could get the bump and ears examined in a single visit.

We met Cam and his aide at the hospital and waited 45 minutes for the doctor, so I had plenty of time to look at my son's face. The lump resembled a boil, but lacked a clear white center. An infected bug bite, maybe? The spot didn't look terrible—a little red, with swelling extending about an inch around the center. Cam was subdued, smiling at me, but not launching into his typical hooting and clapping. There was no point in asking him how he felt: he barely speaks and answers questions only with "yes" or "no, okay," and only when he can muster the focus to pay close attention.

Our history of waiting room meltdowns prompted me to keep him busy, so we ran through our greatest hits. "If You're Happy and You Know It" and "This Old Man" gave way to the Famous Hands Game (straight handshake, soul shake, clasp, touch thumbs; repeat until bored). At length, we were ushered into the exam room, where a friendly nurse took Cam's temperature. He had no fever.

A few minutes later, the doctor strode in, shook my hand limply, and inspected Cam's ears. This was our third visit, but chilly Dr. Charles barely acknowledged that he'd seen us before. I told him that an ENT in Hagerstown had detected pseudomonas bacteria and prescribed Ciprodex ear drops. Dr. Charles noted that Cam's right ear showed infection. He wanted to add an oral antibiotic, but a suitable one was "contraindicated" because our son takes a low daily dose of Thorazine. The other option was penicillin, but Cam was allergic to that. There was nothing further to do pharmaceutically.

I asked him to look at the facial sore. He took a cursory glance. "It looks like a big pimple." Shrug. We were free to go.

Les met us at home. She was horrified by Cameron's facial swelling, but I reassured her that Dr. Charles hadn't seemed concerned. My thought: she's overreacting, as usual.

Les told Cam that she'd stay with him while I went to a meeting at work.

"By yourself?" he asked. Such utterances—appropriate to the situation and not a memorized script—are so rare that they always trigger questions. Did he mean, "Do you think you can handle me by yourself?" He often confuses pronouns, so more likely it was, "I'll be by myself?" These shards of spoken language emerge unexpectedly, like buried potsherds unearthed by a flood. The phrase—a lengthy one for him—meant he was worried.

As the day passed, the bump grew and Cam's energy dwindled. He refused lunch and an afternoon snack. The swelling increased. Les and I argued about whether he should go to the doctor—with me, as usual, downplaying the problem.

Nevertheless, I googled "facial swelling"; images appeared of something called cellulitis. They looked disturbingly like Cam's face: redness and swelling surrounding a central site of infection. The web sources said cellulitis, usually a streptococcus or staphylococcus infection, was potentially serious. These patients might even be infected with the dreaded MRSA, the methicillin-resistant *Staphylococcus aureas* bacterium that runs rampant in hospitals and institutions. This "superbug" can kill you.

As I scanned the photos, my gut swirled. We needed to get him to a doctor right now! But it was 8:00 p.m. on a Friday evening. I quailed at the thought of the ER. Then Leslie remembered that a new Express Care facility had just opened right down the street.

After forty-five minutes of waiting—during which Cam barely moved and never vocalized, which meant he felt lousy—a chunky, fiftyish doctor with a slight Caribbean accent briefly examined him. He diagnosed a boil which, although not centralized enough to lance, still needed to be treated. He scribbled a prescription for oral Bactrim and sent us on our way. Les and I heaved sighs of relief.

Prescription filled; problem pre-empted. We could relax.

If only.

Heartache Tonight

> *Many eagle species lay just two eggs and the older, larger chick sometimes kills its younger sibling once it has hatched. The parents take no action to stop the killing.* (H, 2017)

The next morning, the sore was worse. Cam's lips had swelled up, the whole right side of his face was puffy, and the central portion of the wound appeared painful and angry. All morning we hoped the antibiotics would take effect, but by noon he hadn't improved. Les's mother called, and when my wife described the sore, she advised us to get to the hospital right away, stressing that we should err on the side of caution. She had managed a physician's office for a decade, so Les trusted her expertise. I scoffed.

"Your mom doesn't know anything about medicine! You two are getting hysterical. Let's give it a few more hours and see if the antibiotics start to work," I said, hiding my own mounting dread.

"That swelling scares me. It looks like MRSA."

"Oh, I doubt it. Do you even know what MRSA looks like? I mean, the ENT didn't think it was anything to worry about."

"If this is MRSA and we let it go, we'll never forgive ourselves."

I rolled my eyes again, but I didn't really feel scornful. I wanted desperately to deny the seriousness of this infection. We'd been through similar predicaments so many times that I knew what would be in store: throbbing anxiety while we waited for a diagnosis, then a hum of mortal fear providing the backing track for hours and hours of boredom spent in a chilly, uncomfortable hospital room—endless days and sleepless nights. I couldn't face the prospect.

Then I thought of those photos, especially the captions warning that MRSA infections could lead to sepsis and death.

My face flushed. Les was right: Cam had to go to the ER. She called Good Shepherd, located ten minutes away, told the attendant that our son might have contracted a MRSA infection, that he was autistic and had a hard time waiting. Could they accommodate us?

"Bring him in immediately," she said.

Cam didn't want to leave.

"Hey, bud. You're sick. Your face is all puffy and you're hot, so we need to go to the hospital and see what's wrong," I said, trying my best to sound unconcerned.

Nope. He wasn't budging. Despite Cam's intellectual impairment, we try to respect his choices; he is an adult, after all. But this was different: his choice to stay in bed was dangerous. Ten minutes of coaxing and cajoling ensued, but our wan, lethargic son still refused to move. Finally, Les and I each grabbed an arm and started to pull him up. Maybe our desperation convinced him; he rose and walked to the door.

A half-hour later, we were ushered to a cubicle in the emergency room.

As we bided time, a female patient complained about her legs. "I don't have my meds," she wailed, "and the pain is so bad." She whimpered loudly. For the next couple of hours, she moaned and berated her toddler daughter, until she was discharged—without pills.

The resident, a youthful man named J. Gupta, confirmed that Cam had cellulitis, "a potentially serious, even lethal infection," and started him on intravenous antibiotics.

That's when I got really scared.

I remembered when twelve-year-old Cam had jammed rice and paper up his nose and had to be sedated so the objects could be removed (the surgeon also found sundry items in his ears). I recalled the numerous visits to emergency rooms after Cam's seizures, beginning when he was sixteen. These incidents seemed to blend together, but they never became routine: each episode introduced a new reason for dread.

After several hours, I left to get us dinner. When I returned, Cam was resting in room 435.

New Kid in Town

> *Eagles have a specialized mechanism in their feet that allows them to lock in position so they can sleep while sitting on a branch.* (CCB, 2020)

For the next day and a half, tedium alternated with terror. How serious was this illness? Was it MRSA? Our son looked terrible, his slim, handsome face ashen and bloated. The nurses took a culture and changed his IVs (loaded with the antibiotics clindamycin and vancomycin) as we sat with him. He was too sick to do anything but lie there—in some ways a blessing, because otherwise he'd clap, howl "hoo," try to rise, and noisily masturbate. Several hours passed, and the time began to weigh heavily—until I considered where we were and what this meant. Fear elbowed out the ennui. It wasn't only the sore and swelling that frightened me; I was also wary of the antibiotics.

In 2011, a round of clindamycin Cam took for strep throat wiped out his gut flora and brought on a *Clostridium difficile* infection, which caused a high fever and horrendous diarrhea, and led to three days in the hospital. Cam expressed his opinion about the experience early in day three after he'd leapt from his bed, only to be forced to lie back down.

"It's a bullshit!" he'd yelled.

This time he didn't even have the energy to shout.

Saturday night, Les dozed in a recliner in the room; at 10:30 I went home to sleep and returned early the next morning. Cam's face, though still grossly swollen, looked a little less grotesque. Oddly, his left side looked completely normal, but on the right side his lips had lifted from his teeth and his cheeks were inflated; the swelling had even reached his neck. The sight brought to mind a classic *Star Trek* episode featuring an alien race whose faces are black on one side and white on the other. Did Cam feel like an alien? Probably. But he'd had far more experience with hospitals than most people his age, so he knew what to expect. We explained why he had tubes running into his arms and why his face was swollen. He seemed to understand, then turned over in bed and tried to sleep.

The next morning, the resident, a tall South Asian man, told us that Cam was in sepsis, which meant that the infection had entered his bloodstream and become systemic. It's what we used to call "blood poisoning." Hearing this, my face flushed. My heart felt like it was going to pound through my chest. I looked at Les; she'd gone white.

The resident must have noticed our panic. He reassured us, "But the antibiotics are already working, which means that he's very likely to come out of this okay."

For several hours we anxiously monitored our son's breathing.

Later that day, Linda, who called herself the "nurse refresher," gave Cam a sponge bath and chatted with me about music. It was Super Bowl Sunday, so the conversation drifted to football. She didn't know much about the sport, but was excited that the Eagles were playing. For some reason, I thought she was referring to the halftime show.

"Oh, I didn't know they were performing. People think they're cheesy, but they're one of Cam's favorite bands." I recalled the first rock concert I ever attended. After driving 160 miles to see Jethro Tull, my friends and I impatiently sat through the opening act, an unknown band with a drummer who sang their first number, "Witchy Woman." "These guys aren't bad," I'd thought, "but they're too countrified. They should play more hard rock."

She gave me a blank look.

"I should have recognized the musicians," I explained. "Because The Eagles were a supergroup. The members had played in top bands like Poco and the Flying Burrito Bros." Her face told me I was lapsing into lecture mode, so I switched to Cam's love for music. He had carried his adoration of Raffi into his teens before switching to classic rock. The Beach Boys, Mellencamp, The Beatles, and Foreigner were favorites. And, of course, The Eagles.

Only later did I realize she'd been talking about the football team. No wonder she seemed puzzled.

But the conversation inspired me to find out more about eagles—the birds, not the band—so I did a Google search. Did you know that a gathering of eagles is called a convocation? ("Your Dictionary, n.d."). That the golden eagle can fly at a speed of up to 200 mph, which makes it the second fastest bird in the world (after the peregrine falcon)? (H., 2017) I didn't. For some reason I found these factoids comforting.

After dinner, we watched the big game on the tiny TV wedged onto a shelf near the ceiling in a corner of the room. Or rather, Les and I watched the game while Cam alternately dozed and reviewed Imagine Dragons' *Smoke and Mirrors* video on his mini DVD player. I shouted with glee when the Philadelphia Eagles dispatched the New England Patriots in the final minute. Unfortunately, the (other) Eagles did not perform at halftime (it was only Justin Timberlake). Cam took it all in stoically, though he clapped with us as we celebrated.

That day I read most of Rachel Hadas's *Strange Relation* (2011), a memoir about her husband's dementia, finding it therapeutic as well as wise. I ummed in agreement at this passage: "The kingdom of illness gives some gifts; it bestows an alarming clarity on the way those inside it view those outside" (p. 33). Of course, autism is not an illness, but a lifelong condition. Nevertheless, her words reminded me that we'd been living in this kingdom for twenty-seven years. At certain moments, such as the present one, everything beyond its borders, even the Super Bowl, feels trivial.

Even so, the weekend's confluence of events seemed meaningful. Hadas recognizes this too, quoting a line from Wallace Stevens's *Notes Toward a Supreme Fiction*, which reads, "Life's nonsense pierces us with strange relation" (as cited in Hadas, 2011, p. 46): A relation between a rock group and a football team, between a dangerous infection and a hype-laden sporting event, or between awe-inspiring avian raptors and an autistic man and his parents. Strange, but somehow fitting.

Best of My Love

> *In most eagle species, females are larger and stronger than males.* (H, 2017)

That night snow and ice fell, so the next morning I couldn't get back to the hospital until 10:30. I hustled through the corridors, frantic about Cam, worried about Les's fatigue, only to find room 435 empty. My mouth flew open and my gut churned.

Oh my God! Did something terrible happen? Calm down, I told myself; Les would have called.

Moments later my wife and son returned from the immunology department with good news: Cam was no longer allergic to penicillin. These were welcome tidings, because they brought back into play a whole class of less risky antibiotics. Even better news: the swelling had gone down and Cam's color and mood had improved. By noon, he even felt well enough to play the "ha ha" game with me.

> Cam: Hahahahaha!
>
> Dad: Haha haha haha!
>
> Cam: Ha ha ha!
>
> Dad: Hoo hoo hooo hoo!
>
> Cam: (Bemused look.)

On Sunday and Monday, a stream of medics passed through the room. We met Dr. Prentice, an African American infectious-disease resident who looked like a college student; we were introduced to the affable, brisk Dr. DeLand, a white woman in her late forties; we shook hands with Dr. Margolin, a chubby surgeon with reddish blond hair and a confident, congenial manner. He announced that he would lance the abscess on Cam's face. He added, to our dismay, that MRSA "presents like this."

Cam had been as brave as an infantry soldier and my wife had been sleeping (badly) in the chair and tending to his every need. I spelled her each day for a few hours at a time, feeling helpless and inadequate. But as Cam's well-being improved, the stay grew more fraught, because he now had to be entertained. Several times he tried to get out of bed (hollering "potty") without noticing the IV lines attached to his arm. Each time we had to stop him and make our careful way to the toilet, taking tiny steps as we rolled the IV cart beside our son.

On Monday, he rewatched (for the thousandth time) his collection of kids' videos and his Train and Imagine Dragons concert videos. This time, I listened to Imagine Dragons' lyrics. These lines from "Shots" resonated: "Am I out of luck? / Am I waiting to break, / When I keep saying that I'm looking for a way to escape?" Cam couldn't escape yet, so he reviewed his video of the gray, pudgy Eagles performing live. Then he let *Aladdin* play from beginning to end. If only we had that magic lamp.

It struck me then that Cam had spent a good portion of his life as a patient. Glancing at him calmly watching his video, I grasped the word's meaning anew: being a patient means that you are not an agent, that others care for you and act on your behalf. My son, who seemed so helpless and needed so much support, was exercising his agency by remaining patient. He was demonstrating how to handle boredom, pain, and fear.

On Monday, I began reading a biography of the eighteenth-century literary forger and prodigy Thomas Chatterton, a fatherless boy who died at seventeen. Despite its many fascinations, this book troubled me. Cam was older than Chatterton was when he died. Youth offers no protection against mortality. This book and Hadas's will be forever linked in my mind with this Super Bowl weekend. Strange relations.

As Cam got into the chair that would wheel him to the OR and get the abscess lanced, I started to tear up. It did little good to tell myself that there was no reason to get weepy, that this was a minor operation, that the worst had already passed: I knew that my son couldn't speak or care for himself and that, despite his strong heart and spirit, he was extremely vulnerable. As he sat there gazing up at me, I read his eyes: Mom and Dad are here. I'm safe.

I wished I had his faith.

Already Gone

> *The Navajos believe that eagles are charged with carrying prayers from this world to the heavens.* (Morales, 2015)

Dr. Margolin lanced the spot expertly. As usual, it took Cam a long time to wake up from the anesthetic. The anesthesiologist checked on him several times and a nurse named Beverly tried to rouse him. Finally, after almost three hours of twilight sleep, he opened one eye and announced, "Potty!" He had to get up NOW. My son is around my size, so I struggled to hold him down as he writhed and yelled and Beverly tried to remove the IVs.

She shouted, "Could we get some help here?!" Within seconds we were surrounded by nurses and doctors. It was a convocation of medics, a huddle of scrubs! Breathing hard, I helped them calm

Cam and unplug him from the machines, then held his arm as he woozily walked to the bathroom.

Now the most vexing problem was keeping the dressing on the wound. Cam has always hated having anything on his skin. For years he wouldn't wear clothes at home. In 2009 he accidentally put his arm through our picture window and had to get stitches. After an entire morning in the ER, we went home; within five minutes he removed the stitches, forcing us to return to the hospital, where the doctor reluctantly discharged him without stitches. The gash eventually healed on its own. As expected, moments after returning to room 435, Cam yanked off the bandage and packing on his face. The nurse applied a new one; he pulled it off. And again. When I started this essay, Cam was wearing hospital mittens to prevent him from scratching the wound. He couldn't eat or drink while wearing them, so he ripped them off several times to grab a cookie and spoon up some apple sauce.

He was picking at the wound as I typed the first draft of this essay.

Two pieces of news highlighted our day. First, Cam did not have C. *diff*: vancomycin is a preferred treatment for it, and he had been taking that since we arrived. Second, his facial infection was MRSA. Our son contracted a superbug just in time for Super Bowl Sunday. Hence the mask and surgical gowns, which we were told to wear every minute we were in his room. The garb made me feel like some weird blend of baseball catcher and bio-weapons soldier. Strange relations again.

The news about MRSA terrified us, but we took comfort in knowing that the antibiotics were working. Cam's face looked more normal again, aside from the bandages (and the four-day whiskers). Even better, Dr. Gupta dropped by to tell us that our son would likely be discharged the next day.

Tequila Sunrise

> *Eagles are smart birds. For example, in Greece, golden eagles eat turtles, dropping them from great heights onto rocks to break open their armored carapaces.* (H, 2017)

Cam was released from the hospital on Wednesday afternoon. At 1:30 p.m. he'd fallen asleep, so we had to work hard to get him into the wheelchair and out the door. He was still sleeping at 5 p.m.—not surprising, since he'd spent much of the previous night pulling at the dressing. The nurse had insisted on replacing it each time he removed it; two minutes later, he would tear it off again. This went on, Les told me, for several hours. Nobody got much sleep. When I arrived that morning, he had no bandage on his face.

I gritted my teeth when I considered that picking at a sore was probably how Cam got the staph infection in the first place. How do you keep a grown man from hurting himself? A wave of anger washed over me—not at him but at the aides who had neglected his hygiene. We were told to apply warm compresses four times per day so it didn't heal too rapidly and fail to "allow drainage." But the absence of a bandage exposed the sore in its true hideousness. My son had a hole in his face! How could I not worry?

Another splinter of pain poked through the relief: Cam had had a runny bowel movement that morning. Was it *C. diff?* Dr. Gupta explained that all antibiotics can cause diarrhea. Unless Cam defecated four or five times and spiked a fever, we needed only to watch him closely. Believe me, we did.

Despite our fears and our son's suffering, this was one of the most positive experiences we'd had in two decades of dealing with Cam's medical professionals. They'd cured his illness, quelled our fears, and cared for him respectfully. But something had to go wrong. Fortunately, it was minor this time: he was in the hospital records as "Carmeron." Les corrected it at the allergy test, but his discharge papers retained the misspelling.

"Discharge": the word conjured up images of yucky bodily fluids prepared to contaminate any careless handlers of those trash cans with the frightening yellow labels. It was as if the hospital ingested patients and spit them out, or as if Cam had been in the army and was now returning to civilian life. His discharge was honorable; in fact, he deserved a Purple Heart. Perhaps, then, his new name was appropriate, for this experience had changed us all.

Make no mistake: hospital care is institutional care. Patients get meals (most of which Cam wouldn't eat) at set times, and good luck trying to get a Coke (one of Cam's cravings) on a short-stay floor. There was never more than a single good chair in the room, which is why I had to drive home to sleep. More important, we'd been shown again (as if we needed more proof) that the neurotypical realm—even the domain of healthcare, which is designed to be humane—struggles to accommodate the Camerons of the world.

And yet his presence created ripples; because he needed care, he invoked compassion. He had called forth a convocation of professionals and had enabled them to be heroes. He had brought us all together.

The Long Run

> *Bald eagles tend to pair up for life and*
> *share parental duties. The male and the*
> *female take turns incubating the eggs,*
> *and they both feed their young.*
> (CCB, 2020)

On Friday, Cam returned to Hagerstown. His primary care physician assured us that the sore was healing well and that the "vanc" would prevent *C. diff* from taking hold. Not only was she pleasant and competent, but unlike Dr. Charles, she took time to chat with us about Cam's health, personality, needs—his life. She treated him like a human being.

We returned to the quotidian crawl with renewed admiration for our son, who had coped with this terrifying experience without complaining or causing trouble. Yet a sense of unease lingered. The MRSA could have killed him. What if he hadn't been home with us? Would his aides have acted quickly enough? He has no way to say what hurts and how much. I couldn't bear to think of what might have happened then.

In fact, all of Cam's recent medical problems—the *C. diff* of 2011, an eating disorder in 2014, his chronic ear infections and the MRSA attack—are indirect consequences of his autism and intellectual disability. Neurodiversity advocates argue that autism is merely a different way of being human, no better or worse than the neurotypical way. In many respects I agree with this stance, and I applaud how it helps to preempt prejudice. I also know that Cam's autism is more than a difference. Even if you grant, as I do, that a disability always involves a relationship between a person and the environment, this experience reminded us that no environment, not even a hospital, can fully accommodate Cameron. Our world is not set up for people like him and never will be.

And we only seemed to have dodged a bullet, for the slug damaged Cam's face (which would bear a noticeable scar) and overall health. It also hammered a big dent in our sense of security. His well-being, we learned once again, depends on the alertness and diligence of people who don't know him, as well as the love and devotion of those who do. Hadas (2011) puts it beautifully in her poem "Bath":

> Now that I am far away I see
> clearly that your illness is a bath
> in which you soak, then presently climb
>   out.

> In vain: this bath goes everywhere with
> you … (p. 81)

Cam carries a hospital wherever he goes: he takes a packet of pills daily to dispel his anxiety and aggression, prevent seizures, dampen his acid reflux, heighten his mood and boost his appetite. He requires someone to help him bathe and brush his teeth, fix his meals, give him his medications, drive him where he needs to go. In other words, Cam is in some sense always a patient, and the hospital was, for him, merely an extension of his daily life. Like a guest at the Hotel California, he can check out, but he can never really leave.

The books I read during his stay were valuable, but the most significant reading I did was in the Book of Cam. That text provided helpful instructions about how to handle discomfort and dread and revealed again that music gives solace for the soul. I realized once more that although our son depends upon us, we also look to him for a different kind of strength and for alternative types of knowledge. We are interdependent. Before long, I knew, we would re-enter the kingdom of illness, counting on love to sustain us. That love would have to be a strong one; it would need to be as super as he is.

> *Some eagles use columns of hot rising*
> *air to enable them to soar for long*
> *hours without a single wing beat.*
> (H, 2017)

References

Center for Conservation Biology, The [CCB]. (2020). *Facts about eagles.* College of William & Mary. https://ccbbirds.org/what-we-do/research/species-of-concern/virginia-eagles/facts-about-eagles/.

H, Petr. (2017). *25 interesting facts about eagles that might change the way you see them.*

List25.com. URL: https://list25.com/25-interesting-facts-about-eagles-that-might-change-the-way-you-see-them/.

Hadas, R. (2011). *Strange relation: A memoir of marriage, dementia, and poetry*. Philadelphia, PA: Paul Dray Books, Inc.

McKee, B.A., Reynolds, D.C., Platzman, D.J., & Sermon, D.W. [Song writers]. (2015). "Shots" [Song]. *Smoke + Mirrors* [Album]. Interscope Records.

Morales, Laurel. (2015). *Eagle feathers: Sacred to Navajos, protected by U.S.* Arizona Public Media. URL: https://news.azpm.org/s/31531-eagle-feathers-sacred-to-navajos-protected-by-government/.

Your Dictionary. (n.d.). *List of names for groups of animals*. (n.d.). URL: https://grammar.yourdictionary.com/word-lists/list-of-names-for-groups-of-animals.html.

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Translations

Raquel Gomes

When Gabi was born, the hospital kept her in the NICU for three weeks because they couldn’t quite figure out what she had. She looked a little different from your average infant, her eyes were spread further apart than usual and slanted slightly downwards. She had long fingers, and low muscle tone kept her hands slightly open instead of the familiar clenched fists of newborns. She had a dislocated hip and left leg, for which she got a minute cast at just three days of life. They did echocardiograms, X-rays, CT scans, and an MRI. Doctors agreed she had a syndrome, but they couldn’t agree on which one. Something called Shprintzen-Goldberg syndrome was their best guess.

A week after coming home from the hospital, we had our first appointment with Dr. Rosenbaum, a geneticist at Children’s National Hospital in Washington, D.C. Dr. Rosenbaum personally opened the door for us at the Children’s outpatient center in Rockville where he was in clinic that morning, seeing us for an early appointment before the building even opened. I pushed Gabi, tucked in her stroller, alongside my then-husband, Carlos, and my Mom, the four of us following Dr. Rosenbaum through the quiet hallways to an exam room.

Dr. Rosenbaum was serious, articulate, and soft-spoken as he examined Gabi. Thankfully, he was just as thoughtful in helping me chart a course of action with what became a growing list of subspecialists—cardiology, neurology, neurosurgery, ophthalmology, gastroenterology, orthopedic surgery, and ENT. He even helped me get organized, suggesting I start one of those thick three-ring binders with dividers for each specialist.

Other advice I cherished from Dr. Rosenbaum came during one of our early consults. “It’s frustrating that we know so little about Shprintzen-Goldberg,” I vented. His response: “You know, there are some syndromes we understand very well, but about which we can do very little. In Gabi’s case, we may not have all the answers, but everything she has is manageable.”

Everything is manageable. That’s what I kept repeating to myself. It’s what I told friends who asked.

Thus, Carlos and I embarked on parenthood. As most other first-time parents, we lived with that sense of elated exhaustion, awed by the miracle of having Gabi in our lives while also adjusting to sleeplessness and what seemed like the endless cycle of feeding-burping-changing. We also managed mounting appointments and tried weaving insights across subspecialists; this in an era before electronic medical records.

Having only a tentative underlying diagnosis for Gabi, we consulted other geneticists, making our rounds through Johns Hopkins Hospital in Baltimore, Children's Hospital of Philadelphia, and Boston Children's Hospital. At Hopkins, we met Dr. Hal Dietz who, like the others, methodically analyzed our medical records and examined Gabi. This was 2004, when Gabi was two.

A year later, Dr. Dietz called me. "I have some news for you," he said. "I don't think your daughter has Shprintzen-Goldberg. I think she has this new syndrome called Loeys-Dietz."

A week later, Carlos, Gabi, and I were back in his clinic. Dr. Dietz and Dr. Loeys were there, both of them personally drawing blood samples from the three of us to look for the mutation associated with Loeys-Dietz. The results for Carlos and me came back negative. They were positive for Gabi, a one in a million "spontaneous mutation."

That same month, Dr. Dietz, Dr. Loeys, and their team published their first article on Loeys-Dietz in *Nature Genetics* (2005):

> We report heterozygous mutations in the genes encoding either type I or type II transforming growth factor b receptor in ten families with a newly described human phenotype … (p. 275)

Translation: Researchers identified ten families with similar physical traits (phenotypes) that didn't fit under previously existing diagnoses. In trying to figure out the genetic mutations associated with these traits, they found something odd about the genes affecting the behavior of the substance that shapes how cells grow, differentiate, and develop (transforming growth factor b receptor).

> We describe ten families with a new aortic aneurysm syndrome characterized by widely spaced eyes (hypertelorism), bifid uvula and/or cleft palate, and generalized arterial tortuosity with ascending aortic aneurysm and dissection. (p. 275)

Translation: In common, these families exhibited aortic aneurysms. That's when the large blood vessel (aorta) that distributes blood from the heart to the rest of the body weakens and stretches for some reason, creating a balloon-like bulge (aneurysm). This stretching can lead to a sudden tearing of the layers of the aorta (dissection). In addition to this frail structure, images of arteries in these families showed jumbled twists and turns instead of flowing vessels (arterial tortuosity). These families also looked a little different. They tended to have widely spaced eyes and, if they opened their mouths, you'd see a split in the soft flap of tissue that hangs from the back of the mouth (bifid uvula) and a slight opening in the roof of the mouth (cleft palate).

> This syndrome shows autosomal dominant inheritance and variable clinical expression. (p. 275)

Translation: If one parent is affected by the genetic mutation associated with Loeys-Dietz, their children have a fifty percent chance of also being affected. And like other syndromes, Loeys-Dietz has a spectrum of implications for patients.

Okay. We weren't the only ones. There were at least ten other families out there with this syndrome and here was an article explaining what no other geneticist had managed to figure out. Though the genetics of Loeys-Dietz read like a foreign language, the different physical features associated with the syndrome were by now familiar.

Loeys-Dietz affected Gabi from head to toe. She had an aneurysm at her aortic root, right where the aorta joins the heart. That's why we had been seeing a cardiologist every six months for imaging and had started Gabi on propranolol, believed to slow the growth of the aneurysm. Gabi's beautiful brown eyes were also widely spaced and she had a bifid uvula. She didn't have a cleft palate, but rather a submucus cleft, which always seemed inconsequential.

"Variable clinical expression" meant a lot more for Gabi. In addition to the standard features, Gabi also had a premature fusion of the skull bones (craniosynostosis), abnormal accumulation of cerebral-spinal fluid in her brain (hydrocephalus), a lazy eye (strasbismus), chronic inflammation of the lining of her large intestine (indeterminate colitis that morphed into ulcerative colitis), and low muscle tone.

Despite the countless appointments, stressful surgeries and procedures, and a growing medicine cabinet, Gabi was this joyful and engaging toddler. One of my favorite pictures from this period is one that Carlos took of the two of us in front of our home on a crisp fall afternoon, laughing as we ran to grab the leaves dancing on their way to the ground. Gabi's wearing her matching red hoodie and pants, her hair is flowing with the wind, her arms reaching to grab a leaf. I can still hear her laughter. Another picture is of the two of us sitting on a pier near Chincoteague Island, where we went for a long weekend. We're sitting right next to each other, our legs swinging off the pier, both of us barefoot. We're both looking down to something in the water, I think some tiny fish.

Gabi thrived and we took comfort in knowing we were in the best possible hands. With Dr. Dietz at Johns Hopkins, it soon became the world's premier center for patients with Loeys-Dietz, with an expanding cadre of doctors advancing our understanding of the syndrome in the lab and in the clinic.

* * *

A year after that seminal article, Gabi now four, Dr. Dietz and his team published their findings in *The New England Journal of Medicine* (2006). Now they drew from a cohort of 40 affected families.

> We found a mutation in TGFBR1 or TGFBR2 in all probands with typical Loeys–Dietz syndrome (type I) and in 12 probands presenting with vascular Ehlers–Danlos syndrome (Loeys–Dietz syndrome type II). The natural history of both types was characterized by aggressive arterial aneurysms (mean age at death, 26.0 years) … . (p. 788)

Translation: There's more than one type of Loeys-Dietz syndrome, but they're both as deadly, with patients dying on average as young adults. They continued,

> There were 59 vascular surgeries in the cohort, with one death during the procedure. This low rate of intraoperative mortality distinguishes the Loeys–Dietz syndrome from vascular Ehlers–Danlos syndrome. (p. 788)

Translation: Most patients with Loeys-Dietz have vascular surgery, but they rarely die from surgery itself.

> The craniofacial severity index was used to determine the severity of symptoms of the Loeys–Dietz syndrome. … The scores can range from 0 to 11, with higher scores indicating more severe abnormalities. Patients were given a score of 2 for marked hypertelorism … a score of 6 if both [cleft palate and craniosynostosis] were present. For malformations of the uvula, a bifid uvula was given a score of 3 … . (p. 789)

Translation: Though all patients with Loeys-Dietz live with the risk of having aneurysms and dissections, those risks are higher for patients who have more of its outward features.

* * *

Twenty-six years. That's what stayed with me from this article. That and the fact that Gabi had the highest possible score on the craniofacial severity index.

No, that can't be right, I told myself as I sat at my desk, pencil in hand, studying each line of the article. Even though researchers now had a larger sample size, these patients probably represented extreme manifestations of Loeys-Dietz since it's the most severe cases that make it to hospitals like Hopkins. Moreover, these young adults dying from Loeys-Dietz had been misdiagnosed all their lives. Outcomes would surely be different for newer generations of patients being effectively managed from a younger age. Gabi would live much, much longer.

Carlos didn't understand why I read these articles. "They just make you worry about stuff that may never happen," he'd say. "These articles don't tell us anything about how to care for Gabi. That I'd understand."

He was right. I stopped reading these articles. We now counted on the expert guidance of Dr. Dietz and other leading doctors at Hopkins. Towards the end of our follow-ups, after discussing their latest assessment of Gabi and suggestions on management and meds, we asked about their latest research on Loeys-Dietz. We often couldn't follow the medical jargon, but we got the gist. More importantly, bright minds were hard at work searching for ways of improving the lives of people with Loeys-Dietz.

And Gabi's symptoms were all manageable. A simple eye muscle surgery when she was an infant corrected her strabismus. Cranial reconstruction when she was a toddler addressed her craniosynostosis. Open heart surgery when she was four fixed her aortic aneurysm. She was on the indicated combination of meds that would helpfully keep other aneurysms from developing.

Gabi somehow just skipped through it all. I remember this day at Hopkins, Gabi five or six, the two of us walking hand in hand along the corridor by the cafeteria, the one with the nice internal garden where they house the turtles every year for the Turtle Derby. We must've been there for an MRI since we were walking from the Meyer building back to the outpatient center. We were chatting when she turned to me and asked, "When will I be a guest here again?"

Not anytime soon, I thought to myself.

She wasn't thinking about the post-operative recovery, the discomfort of removing the breathing tube, the hourly bright light shone in her eyes. What came to mind as she asked me that innocent question were the silly clowns that visited her room and made her laugh hysterically as they bumped into the doors, the nurses who painted her nails, the child life specialists who came by with crafts and toys, the countless movies we watched, the ride on the red wagon to the play room as she was recovering.

I also stopped reading those articles because, most importantly, Gabi was thriving. Yes, we had the morning and evening meds, the follow-up consults, the yearly MRIs, but those became mundane parts of our lives.

From kindergarten through elementary school, most days were so normal that we'd sometimes even forget about Loeys-Dietz. Every year, she'd be nervous about the first day of school, only to come home excited about her new teacher, her classmates, the possibility of singing in the choir, running for student government, or auditioning for the musical. She had her school friends, with the usual giddiness and drama that I learned started much earlier than in my day. She embraced each and every holiday, our home somehow decorated continuously from Halloween through Epiphany, then again for Easter. Summers she'd explore arts, dance, and drama at her favorite camp at Norwood in Potomac. We traveled to visit family in Hawaii and Brazil, we traveled to explore Boston, New York City, Philadelphia, the Disney parks in Orlando, Historic Williamsburg, and the Von Trapp Family Lodge in Vermont.

Life was easy, precious.

* * *

The winds changed about the time Gabi entered middle school. During our annual cardiology appointment in early 2014, Gabi now almost 12, doctors realized that the synthetic graft they had placed over her aortic aneurysm when she was four had somehow "migrated"; the aneurysm, more aggressive than they had imagined, was bulging beneath the graft. Gabi had another open-heart surgery two months later.

During a routine checkup a year later, they found something called a pseudo-aneurysm at the site of one of her earlier sutures. Imagine a garden hose with a pinpoint hole where, instead of the water squirting out, the outer layer of the hose expands out at that orifice like a tiny balloon. Left unchecked, the wall of that balloon eventually bursts. This time, we went from the cardiology clinic, Gabi still in her school uniform, directly to the ICU where days later she had her third open heart surgery.

Gabi never fully recovered from those back-to-back heart surgeries.

"I've never been able to run again like I used to, you know, even just at recess, like running out to hang out by the jungle gym," she shared one day as we were having our usual chat before bedtime, me sitting at the edge of her bed caressing her hair.

In early April of 2016, Gabi developed a terrible backache that took us back to Hopkins (just to be sure). She had the beginnings of what turned out be a descending dissection. She survived surgery, but not the subsequent hemorrhage, the cascading organ failure, and sepsis. Gabi was 13. She had just been accepted with merit scholarships to her two top high schools and was excited about her upcoming eighth grade graduation, fourteenth birthday sleepover party, and plans for the summer.

Yes, Loeys-Dietz was very manageable.

Until it wasn't.

***

I recently decided to do a quick search on Loeys-Dietz just to see what came up. Four hundred and eighty articles. I picked one published in 2017 in *The Journal of Thoracic and Cardiovascular Surgery* (2017) on intermediate outcomes of cardiovascular surgery authored by a team from Hopkins, including the four surgeons who had operated on Gabi over the years.

> Growing experience with Loeys-Dietz syndrome has confirmed the early impressions of its aggressive nature and proclivity toward aortic catastrophe. Surgical outcomes are favorable, but reintervention rates are high. (p. 406)

* * *

Aortic catastrophe. No translation needed.

References

Loeys BL, Chen J, Neptune ER, et al. A syndrome of altered cardiovascular, craniofacial, neurocognitive and skeletal development caused by mutations in TGFBR1 or TGFBR2. *Nature Genetics 2005*(37), 275–281.

Loeys BL, Schwarze U, Holm T, et al. Aneurysm Syndromes Caused by Mutations in the TGF-β Receptor. The *New England Journal of Medicine 2006*(355), 788–798.

Patel ND, Crawford T, Magrduer JT, et al. Cardiovascular operations for Loeys-Dietz syndrome: Intermediate-term results. *Journal of Thoracic and Cardiovascular Surgery 2017*(153), 406–412.

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Regeneration: A Modern Song Cycle

Alison Jones Webb

1
Third Person

My mother is 85, and I am 60. Recently, we have been living in the third person, apart but together. She subsists, barely, with my father in a small apartment in a complex for senior citizens in a coastal town in Maine, where she has lived nearly all of her adult life. She has been bedridden for almost a year and is dying. I live in an affluent suburb nearby and take care of her on some days, and when that happens, we cannot bear to be ourselves. Awkwardly shaped bedpans and tepid water sponge baths force an unwelcome physical intimacy that unravels the life that we have knit together for sixty years. Her hard work and good deeds as a devoted mother recede from my memory, and contact with her scaly skin repels me. My mother says she pretends to be someone else in these moments. I pretend I am somewhere else, where everyone is young and healthy. I wonder, *are we imposters, this mother and daughter*? How long have we been pretending?

2

Fellow Travelers I

Together we travel to new places. In the early stages of my mother's Parkinson's disease, we talk about options, go to neurologist's appointments together, and share research articles about experimental treatments. I help her follow the countless suggestions the physical therapists and occupational therapists propose to help her maintain her physical strength and coordination. We make garter stitch squares with large knitting needles and a leftover ball of purple yarn from a project completed years ago. We ignore the dropped stitches and uneven edges that signal her diminishing dexterity. We giggle as we march in place in the living room, pretend we are majorettes with fancy batons, make sweeping circles with our arms, and sashay sideways along the kitchen table. As her disease progresses, when these movements are no longer possible and we are learning how to transfer safely from the wheelchair to the hospital bed, we wear forced grins at this new role reversal. Now the daughter helps the mother to stand and take small steps, offers encouraging words when the mother's old body freezes in place and her conscious efforts cannot force her feet to move, dishes out false praise when she is safely in bed. We no longer talk about future options, but ponder instead quality of life with the hospice nurse.

3

Time Without Mind

Separately, we travel to murky destinations. There was a time when my mother's life was a smooth straight line, reflecting cause and effect and linear time, from childhood to adulthood, and from old age to an afterlife. Now, her brain makes peculiar connections, creates new neural circuitry, and the straight line is knotted and tangled. In her confusion, she sees furniture from her childhood bedroom in Ohio, her mother sitting in her room here in Maine, and small children she doesn't recognize, in church basements from the past. She knows she is hallucinating, and initially she is distressed, but later on, she doesn't care. I think, perhaps cruelly and perhaps not, that dementia is a godsend when the body deteriorates at a glacial pace.

4

Time Travel

I travel back in time and explore my childhood. For months, I look for times when my mother and I were happy together, but I can't retrieve them. I need a bright spot in this grim reality, but I find only angry wishes for a different upbringing. I wish I'd had a guide to steer me out of the bizarre bubble of our religious household, where the afterlife was more important than the here and now. I desperately wanted to live in the normal world of the teachers and students in the nine schools I attended in twelve years. Instead, I stumbled between the sacred and the secular on my own. I knew the ins and outs of church sanctuaries and vestibules, naves and narthexes, and the cupboards that stored the stainless steel communion trays—the outer ring reserved for tiny glass cups of Welch's grape juice for alcoholics and the inner rings for cups of cheap wine for everyone else—but I didn't understand how to shop for brand name clothes at the mall or order appetizers from a restaurant menu. I had to learn on my own how to navigate where I actually lived, in the present tense. Now, when I take care of my mother's body, I am well served by that scrappy transition to adulthood and my stubborn insistence on figuring out how to live in the world of the flesh.

5

Surviving the Patriarch

My father is in charge now, like he always has been. As a pastor, he was called to interpret life and death for his flock, and he created his identity as the pundit with the answers to life's mysteries. He has softened in recent years, and no longer insists he has a monopoly on the solutions—the keys to the kingdom—at least not all the time. My mother sees herself in the biblical story of Ruth and, like Ruth says to her mother-in-law, my mother says to her husband, "For where you go, I will go, and where you lodge, I will lodge. Your people shall be my people, and your God my God. Where you die, I will die, and there will I be buried.” I finally understand this path she has chosen, to follow a way forward that was only dimly in focus, and lit by her husband’s light. She has made few decisions of consequence in their life together, and now she makes none, but she will have the last word. “I made that,” she said one afternoon, looking at a color photo of her three children and seven grandchildren at her granddaughter’s wedding on an alpine meadow. While he was working days, nights, and weekends ministering to his congregation, she was at home making her own mark on the world.

6

Eat the Rich

My father came from a poor family, and sometimes his impoverished past seeps into the apartment and fills the rooms like a noxious gas. It suffocates conversations I have with my mother, who remains silent when he is in the room. He watches cable news and he mutters hostile epithets at slick politicians who only help rich people get richer, while poor people get poorer. In the elevator, he chats with the Puerto Rican building janitor and imagines a humble, kind man being taken advantage of by rich people who pay low wages. He talks to his neighbor down the hall, a widower who is stooped and walks with a cane, and somehow he knows this is a rich man who hoards his wealth instead of sharing it with people who need it. He pays the rent for the apartment and insists that the building owners are ripping him off.

Everywhere he sees the same thing. The rich exploit the poor. The rich get richer, and the poor get poorer. He keeps a tight rein on this narrative. This scaffolding he has erected to contain his experiences remains intact. He cannot escape his past.

7

Retrospective

For Mother's Day this year, I put together a small album of old photos. I dig through cardboard boxes in my cluttered basement and find photos of my parents' first few years of married life. They were a fertile couple and had four pregnancies and three children in the four years after their church wedding in 1956. My mother took most of the square black and white snapshots with her Brownie camera—a few of my father holding his infant children, a few documenting the construction of their first house, and several of toddlers splashing in a blow-up backyard pool and eating popsicles. Yellow Scotch tape marks stain the corners of the photos. My mother is in just two of the faded prints from those early years. In one, she is holding my younger brother on her slender hip. He is about eighteen months old, and he is looking up at her, showing her a dandelion in his hands. She is looking back at him, smiling. There must have been a soft breeze, because her hair is wafting just slightly away from her face. I see a tender moment of motherhood. I imagine myself as the mother holding the child, and I smile, too. In the other picture, I am four years old, and she is sitting next to me on a split-rail fence, a grassy pasture in the background. Her right hand is behind my back, and her left hand is on the fence, steadying us both. We are grinning at each other, squinting in the sun. I don't remember this mother-and-daughter moment, but I imagine being that child and loving this afternoon in the country with my mother. As I put the photos in the new photo album, I realize this will probably be her last Mother's Day and I find this unbearable. I cannot manage life without a mother, my mother, and I cannot bear the thought of losing this connection to my past and myself, and finally, I weep.

8

Fellow Travelers II

My mother's life is fading, and another is coming into view. She counts the days to the end of life, while my thirty-year-old daughter, who will soon have a child, is counting the days to the beginning. The promise of new life inspires my mother to live, just a little longer, to meet her great-grandchild. My daughter, busy with work and planning for the baby's arrival, focuses on her swollen belly and barely notices her grandmother's demise. I will soon be a grandmother, and this reassures me. My transition from daughter to mother to grandmother is the past in the present in the future, and I feel connected to the unfathomable arc of existence. My mother made this transition, and perhaps my daughter will too one day. Our lives are forever entwined, at times like neatly crocheted chain stitches and at other times like a jumble of different pieces of yarn, impossible to untangle. My daughter will soon learn what daughters learn when they become mothers. She will learn that a mother is a fellow traveler who knows you like no one else. She was with you from the very beginning, even before the beginning, but not always to the end.

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Bleach / Fire Fallow

Andrea Charise

Bleach

I've been reaching around for lessons
on how to grow old. For stories that guide me
toward roots and vines, lines and lives here
and here no longer. My grandmother
always reaches back from places

where I'm surprised to find her.
She caught in her hand ninety-three
years. Wash your dishes with bleach,
no vegetables, drink scotch, eat oatmeal—
this is how you hold onto ninety-three
years begun on a dairy farm where
the buckets were cleaned by little
girls. Children who, in a moment of boredom
or exhaustion, left proof on the pails
of milk's lacy traces. Those stains
were deadly. Discovered by a surprise
visit from the health inspector, the farm
was punished with closure. It was

the Depression. Everyone was reaching.
I think a lot about bleach. A little does

the trick. Dishes, clothes: just a splash stains
things clean. As I nurse my own hair’s
whitening, I coax age through
and out of me—my body, in time, entangling

these hard traces of the past. Missing you
has let me find you in new places. Did you know
that the stalks of young trees, growing close
enough together, can be braided? There
they live, separate but entwined, aging
into the future. I laughed when I learned
this gardener’s trick is called
pleaching. In words, their letters turned,
our lives interweave. We find ways
to keep grasping.

Fire Fallow

When I was seventeen, I visited the ancient city of Pompeii. Two thousand years ago this abundant place was suddenly buried under ash when a nearby volcano erupted. Those who couldn't escape were trapped in the blistering dust: running, crawling, curling into the final poses the cinders both destroyed and preserved.

Centuries later, that land bore an alien yield. The Garden of the Fugitives unburied the enduring dead, as poured plaster casts engorged each body's earthy void. Walking around the ruins, it seemed so reckless to build a city at the foot of an active volcano. How abundant could this land really be to risk living here? Years later, I understand that what enables survival—what nourishes and protects—is cut through with danger. What lights our way will burn our skin and scorch the earth.

If you're used to the ground shifting beneath your feet, why would one day's quaking be any different?

Burnout is a word that means something to me now. The World Health Organization calls it a "life management difficulty" and they're not wrong, I guess. Exhaustion, memory loss, cynicism, hopelessness: burnout is the signal of a self scorched. It develops slowly, in minor quakes and accumulations, until air transforms into ash. When I finally realized what had happened, I wished I could say I felt like a sparking socket, a blazing failure. All I sensed was the hollow outline of a plaster mould out in the elements: cold, damp, degrading.

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Pompeii's erasure had sheltered life's traces: frescoes, artifacts, vital signs all brought back to light, pristine. But one day, a few years ago, the House of the Gladiators simply collapsed. No one knows why, exactly. Perhaps a little water, or decades of visiting hordes, eroded those sturdy foundations. The official charge is prolonged neglect.

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A Proliferation of Cells

Jenna Pastorini

> *"You might hold the tumor that killed someone."*

We, the first-year medical students, fidgeted nervously in the room full of dead bodies. Perhaps because we felt that we ourselves were the anatomy lab scalpels; all sharp edges and corners, arms folded across our chests to keep from touching anything we weren't meant to, including each other. We were still basically strangers, after all. We filled the room with assumptions: that you were the only one who thought of *Silence of the Lambs* every time someone seriously used the word "skin" as a verb. Are you the only one who thinks it's a little hot in here? Was it just you or is the sex of the body actually not all that evident when they're laying supine? But the most pervasive assumption was the one Sidney Kimmel Medical College presented us with: that we were all eager to slice into skin, pull apart muscle, go elbows deep into cavities, absorb all of the knowledge from these decaying bones as if their lives were merely vessels to our success. Or worse, perhaps they thought we assumed these bodies had the best and worst days of their lives, had a favorite ice cream and a pet peeve, laughed, cried, danced, ran and died purely so we could pass a few anatomy practical exams?

Although the more senior instructors put visible effort into referring to the bodies as our "human gifts," the beginnings of the word "cadaver" would always slip out before they could stop themselves. I thought the phrase was nice the first time I heard it. I was returning to Jefferson's medical school after being accepted for Second Look Day and upon hearing them tell us about our "human gifts," I was impressed. But as I watched one professor after another catch himself, tilt his head, and painfully push the phrase out, I wanted to roll my eyes. To be fair, it was obvious that for some of them it was more than just semantics: "You might hold the tumor that killed someone." The man at the front of the room said this with great emphasis, as if expecting a gasp to follow or perhaps somewhere a rabbit to be pulled out of a hat. And so, as they went on trying to force feed humanity to a room of overzealous graduate students, I stood choking on formaldehyde and irony, and thought about how they were getting it all wrong:

> *"You might hold the tumor that killed someone."*

Tangible; my anatomy lab was providing me with yet another lens to try and see my father's cancer more clearly through. But no matter how many times I learn p53 and TGF-alpha, I cannot see my father's death as an abnormal proliferation of cells. I wonder if I will ever see cancer as a purely medical phenomenon.

> *"You might hold the tumor that killed someone."*

Would it feel like jade, professor? The way it jaded my 14-year-old self as I watched cancer steal my father from me? Would it show me that cancer is not simply colorful ribbons and promises that "we'll get through this!" and a Nicholas Sparks film starring Miley Cyrus running down a hospital hallway in a ballgown?

No, it's only an aggregation of tissue. Maybe a sprinkle of calcification.

It felt like the professor was mocking me. Logically, I knew he was just trying to make a point, but that place in my gut where I kept those memories rolled over as his comment struck like a slur to my experience. As a young teen, blind-sided by my father's mortality, cancer was many things. Cancer was a pamphlet on the kitchen table, a bag of urine peeking out from under his shirt, my father on the sidewalk in the rain with an oxygen staff, a "nothing left for us to do," and Christmas morning planning a funeral. Cancer was life in fragments.

No matter how many times I learn it, I do not see my father's cancer as an abnormal proliferation of cells, metastasizing from bladder to colon to bone. I do not see white spots on X-rays and carcinogens infiltrating cells. Cancer feels 15. Cancer feels like it has no explanation. Cancer is trips to the hospital, pushing food around a plate, a new tremor, eyes always looking at me from sympathetically cocked heads; it's the ice machine where my mom told me on Christmas Eve, "No, this is it." It's mourning an alive man in a hospital bed on a ventilator and wondering if I should worry about jinxing his survival; does cancer jinx? Cancer turned me superstitious. Even now, as I barrel towards seven figures worth of education, I think of his cancer less like a carcinoma and more like an idiopathic karma.

No matter how many times I learn it, microbiology, pathology, histology—cancer is not an aggregation of cells. Cancer feels more like praying to a God I no longer believed in.

If I could touch the tumors that killed my father, I do not think I would feel sentimental. In too many ways, the tumors were the least painful part of the experience. They came in and out of my life at 14 and 15 and I never thought about them. It never felt like they were to blame, because my father's cancer was never some medical phenomenon. At 15 it was a lot of things: it was a secret blog where I could be honest, it was mandatory attendance to church, so I could get the sacrament of confirmation even though I was certain there was nothing for me above that altar. It was him. Like a hyphen, it just tacked onto him and he affected it as much as it affected him. Maybe, cancer is more like bacteria—symbiotic. But that's too romantic. There was no benefit in this relationship; they ruined each other.

Cancer was a season. My father's was nice and round; November 2009 to December 2010. Cancer is notorious, like a person who knows all of your secrets. Cancer acts like you owe it something. Cancer has this dark sense of humor; I could swear I heard it laughing at me on Christmas morning 2010, when the phone rang at 4:00 a.m. I heard the laughter following my mom down the driveway as she raced to the hospital. It echoed in the house alone with me after my sister rushed to follow my mother to his bedside, refusing to be left behind. The laughter came out of my own mouth for the next nine years as my own humor darkened to cancer's morose hue.

* * *

On Christmas Eve of 2010, I went to Hackensack University Medical Center in northern New Jersey to visit my father. If my memory serves, two days earlier we had decided he should go in to get more treatment so he could be home for Christmas. Understanding the course of cancer, the way I do now, I see that what I believed would happen then was probably never the case.

His oncologist wore a baseball hat. He wore a baseball hat because he was bald. He was bald because he was going through chemotherapy. My dying father's oncologist was going through chemotherapy because he had cancer. I don't quite remember the words the doctor said, but I remember thinking this must be so hard for him. He stood a few feet from the foot of my father's bed and had to look at my father while he told my family there was nothing left to do. I wondered if he felt like he was looking at his own future.

Apparently, my fixation on the doctor's state of mind—as opposed to the news he delivered—wasn't the expected response, so I ended up in the hallway behind the ice machine with my mother (Did she leave and I followed her? Was I summoned outside with her? Does it matter?). This was my first time at the Losing-a-Parent-Rodeo, so I was unsure of the etiquette. I felt like I was doing something wrong, like I was supposed to know something I didn't. I felt like I had a starring role in one of those old black-and-white films and was watching as the words coming out of my mother's mouth weren't synchronized with the movement of her lips. My mom was telling me we would wait until after the holidays to do it, there was no rush. By "it," of course, she meant "pulling the plug." By "pulling the plug," she meant taking my father off the ventilation machine that was allowing him to breathe. By "taking him off the ventilation machine" we meant letting him die. I wondered how this was any different than putting down an animal. I wondered, is it just semantics? And yet wouldn't my grandparents just hate it if I told them we needed to put down their son-in-law? Because that would be inappropriate.

My mom stared at me while my older sister and her ex-boyfriend of eight years were still in the room with the body that was technically alive but nearly empty. What stage of grief was this? Is it uncouth to mourn your father when he is still breathing not 100 feet away? I decided I needed to take a walk. The problem with cancer is there are not enough chairs. I did not want to sit in a waiting room. I was no longer waiting. "It" was here. I did not want any more glassy eyes looking at me, or silent hands on my shoulder, on my arm, on the back of my neck. I needed to think. I needed to catch up, but there was nowhere to sit.

I think perhaps they shape hospitals like mazes, so you can walk in a haze for 20 minutes away from your father's death bed, sink down against any wall to cry, and know you won't be found.

"It's called a button hole."

One of my professors stuck his finger through an extra incision he had made in the skin of my human gift's back. This allowed him better leverage as he cut away at the fat of her scapula to reveal muscle. *Fantastic*. I realized I wasn't nauseated or faint. I found myself in a mindless, peaceful state as I traveled through the monotony of cutting away this old woman's skin. Perhaps they tried so hard to shove humanity down our throats that first day because ultimately, they knew we'd have to swallow ours in order to do this? The word disgusting hung in my mind. Not her, not the tissue and fat and fascia and bone—me. It is not that I was necessarily opposed to the ethics of what we were doing; these bodies were, after all, "donated" to science. But perhaps it was that for some odd reason, I preferred people whole. That maybe I did not go into this profession to see ventricles and valves, but to be the strong, unshaking hands people can trust with their broken parts.

* * *

I requested to speak to my father alone. This seemed to surprise my mother, maybe because prior to that moment I had refused to visit him. They gently respected my choice because I was a child. I imagine they thought it would ruin my idea of my father, seeing him in that state. I think I just didn't see the point. I did not know he was dying, as obvious as it may seem now. I thought we were just in this perpetual state of suffering we had been living for a little over a year, that "heaven forbid" old people drop out of their mouths at the end of gossipy sentences. We were heaven forbid.

I didn't think he'd notice if I visited or not. When he was home, he didn't see me in rooms. I would speak four times before he'd look in my direction and say, "Jenna, good morning!" as if I'd just arrived.

To be fair, it was also around this point that he started eating dimes. We laughed about this, because you have to laugh. You laugh or you cry, so we laughed. My mom came home from hour fourteen at the hospital, while also somehow maintaining a full-time job, a feat I will never understand, and told us how he kept asking her for change. So, she would give it to him, because you don't say no to husbands with cancer who are mentally reduced to children. And as time passed, she would notice the change had disappeared. She would ask where it went, and he would say he didn't know or perhaps not address it at all. It was funny. We told ourselves it was funny. He would've thought it was funny.

> *"Make sure you leave a wet rag in the cavity."*

A professor floats by as one of my anatomy partners across the table squirts water onto the cloth lying on our human gift's open back. He patiently squeezes the bottle as forcefully as he can, but this has no effect on the small tepid stream coming out. I hold the skin flaps of her shoulder and down by her waist, where I imagine someone once held her for a slow dance. It is not that it seems undignified, but rather painfully intimate; she is mine now. Her life was given to science and science has given her to me. I, and ultimately the other 270 or so of us in my medical school cohort, are to benefit from her sacrifice. At times, the weight of this responsibility feels unbearable. I believe it causes us to take the little tasks we can do for her too seriously. I spend extra time making sure she is appropriately moist and covered in towels before being bundled back up into the plastic she arrived to us in. I cringe noticing scalpel cuts too deep and excisions that didn't need to be made, feeling as though I have let her down.

The gloves make a snapping noise as they come off, and I relish the minutes I am expected to spend washing my hands. I wish to think of nothing. Instead, I realize how inadequately I am prepared to honor her. I ruminate on the fact that dead people may be the hardest to care for. Not because of her unbeating heart, her bloodless veins, and empty lungs, but because the only skill I feel confident in is my ability to connect and to comfort. Four weeks into medical school, I am as useless at medicine as I was nine years ago. But in those nine years I learned the power of having eyes that listen, a mouth that can hold the emotion someone might not be ready to share, hands that can quiet loneliness, and a breath that can find yours wherever you may have lost it. I found skills in years of feeling helpless. Even still, I smile as my lab partner graciously hands me a paper towel to maintain my sterility, ignoring how much of this experience cannot be washed off with soap and water. I look back at the flesh that is barely visible through the dense plastic containing her and I feel bitter at death for taking those skills away for me. I curse death for once again rendering me helpless, and I resent medical school for reminding me of it.

The big moment. The "last words," the tearful *I-love-you, I'll-always-be-your-little-girl* moment. I tried to place myself in the role. I'd seen it before: tragically in movies, season finales of medical dramas, exceptionally melodramatic young adult fiction novels. But I couldn't quite figure out how this one goes.

The sound of the ventilator was deafening, or was it the silence? Was it the anticipation that whatever "big moment" words I let out into the world would just float there, flat, uncaught, unrequited? My words would be alone. I was alone.

Except I wasn't. The ventilator reminded me of that. I hadn't really looked at him yet. I stationed myself to the right of his bed, gripping his open hand, pretending he was reaching out for me. I stared out the window across the room. It was *so* blue out; we must've been on one of the top floors of the hospital because all I could see was sky. Out there, no one was on their death bed. Out there, no one was listening to the mechanical sounds of incompetent lungs. Out there, it was Christmas Eve. The thought of a fat man in a red suit and parents griping to each other about unwrapped toys and unprepared roasts seemed wildly absurd. I laughed out loud.

It was the "big moment" and I *laughed*. My head snapped to the left to look at him, expecting him to react, expecting him to be offended. In my private forever goodbye moment with my father, I laughed.

But there was a tube and there were wires. His head lobbed to the side, begging to be let off of his body. His eyes were shut, undisturbed. He clearly wasn't as nervous about the "big moment" as I was.

I cleared my throat and stared firmly at my hand holding his. In stories, in the "big moment" details like this are noticed, these “strong fatherly hands.” It would describe the horror of how paternal heroes turn human in hospital beds. But the hands were just my father’s hands. The bed did not swallow him whole. The wires and the screens and beeping did not confuse me. And as I gripped at his open palm, I realized he had already let me go. I realized the “big moment” was only mine, and I had no idea how I wanted to spend it.

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They Sent Me There to Die

Issam Koleilat

"They sent me there to die."

He looked up at me, a man of no more than, maybe, 52. He, like many, had been tricked and conned and likely socially pressured into a tobacco addiction before the medical outcry once the long-term effects of nicotine became known and widely publicized. Like so many before him, he had developed complications related to his smoking.

I happened to be on call when he came in. A relatively young man, emaciated from chronic disease, he had a history of prior aortobifemoral bypass by another surgeon. The left bypass limb had become occluded and he was experiencing symptoms of claudication again. His right bypass limb was patent and the leg asymptomatic. For unspecified reasons, he was lost to follow-up, but now, several years later, he had been admitted to an outside hospital for acute right bypass limb occlusion resulting in ischemia.

Unfortunately, attempts to revascularize were unsuccessful at this other facility and ultimately he underwent "an amputation." He was discharged to inpatient palliative care for reasons unclear to me at the time. I guessed it was because of the chronic wounds, or maybe because his condition at that hospital was so severe. He had been transferred to our hospital because of an elevated white count. But when I saw him, he looked like any other vascular patient except he looked young for this degree of disease burden.

Something about him looked familiar. Maybe his very Arabic name tipped me off. I watched him as he struggled to export his thoughts into a clearly alien formulation, and in Arabic I said, "Assalamu alaikum."

His eyes lit up, as so often happens when I surprise patients with fluent Arabic, especially in a hospital where they least expect it. From here on out, we only ever spoke Arabic to each other.

"Where are you from?" he asked me.

"My parents are Lebanese. How about you, where are you from?"

I had never heard such sadness over one's motherland mixed with a happiness at seemingly finding a blood-brother: "I'm from Yemen."

"God help you and your people." I shared his sadness.

It was the summer of 2018, and the war in Yemen had just made national news. We chatted for a few minutes about how governments wage war, but it's the people who suffer. Then things became serious.

As I began taking a history, I lifted the sheet over his legs. I couldn't tell which side was worse. On the right, he'd had an above-knee amputation

(AKA) that was not healing well, clearly the product of revisions given its proximity to the hip. An associated groin wound was healing poorly, also. On the left, his mid-lower leg and foot were black and desiccated—dry gangrene, with a clear demarcation against his naturally tan skin. I had seen toes like this, but never a whole foot, mummified.

We formulated a plan together. He didn't have many viable options, but we would try an axillary-femoral bypass (profunda femoral through a lateral approach, for the surgeons who are wondering) to maybe salvage a below-knee amputation. This might allow him more mobility compared to a second AKA. He became excited.

"They sent me there to die," he reminded me.

Over the next few months, we became as close as the physician-patient relationship could allow. I debrided his AKA wounds, grafting them with biologic grafts (very expensive—I received several notifications from administration about the expense). I bypassed him as discussed, but unfortunately his disease was too advanced and the vessels too small. His bypass occluded, and we performed an AKA on the left.

He spent the next year in rehab. Once his stumps had healed, I cleared him for prosthetic fitting and gait training. I encouraged him, telling him that it's the young people who walk again. His confidence was inspiring—"I'm going to walk, you'll see."

But this is not a story about ambulation.

He'd come in, mostly I think to chat in Arabic. His family was largely back in Yemen. I'd always give him a follow-up "as needed," but I'd tell him to come in and show off the day he was able to walk again. I had skeptically signed the orders for specialized prosthetics, and I wasn't sure I'd ever see the day.

He graduated to discharge from rehab but needed a disposition. He was so motivated to find a place to live and move on with life. He kept telling me that I "saved his life." I wasn't buying it, but it made him happy to say it and me to hear it. Clinic visits were always punctuated with hugs and even those kisses on the cheek pervasive in Arab culture. Even his family was grateful—he'd conference them in by phone.

A few weeks ago, my staff told me he was coming back. He was bringing in a video of him walking, and I was excited.

But this is not a story about ambulation.

He showed me a video on his phone. Walking! With bilateral prosthetics and a walker, but independent of any human assistance. He wasn't winning any races, but by God he was walking! Unbelievable.

But then he told me something I truly couldn't believe.

"I'm moving back to Yemen and I had to say goodbye. I wanted to do it in person."

I took a few seconds to process.

"Isn't it still a war in Yemen?" I politely probed.

"Yes."

"But then how are you going back? Why are you going back?"

"My family is all there." He had spent the last four to six months trying to find a place to live, but he was unable. He was still in the rehabilitation facility. His flight back to Yemen was three days away. He already had a ticket.

"You know you saved my life. They sent me there to die. I just wanted to thank you again."

He was actually happy with all of this. No legs, barely able to walk, and now *choosing* to go live in a war zone. Maybe he had just already come to terms with it all, maybe he was hiding it.

I teared up. "Well, you're always welcome back in my clinic, open invitation, come any time."

"I know," he said, looking up at me from his wheelchair as I stood up. His anabolism now evident in his protuberant abdomen since he wasn't consuming all of his caloric intake in trying to heal.

"And if I'm ever in Yemen, I'm going to come look for you." We both came to that conclusion simultaneously.

Hugs again, and the next thing I knew, I was looking at the back of his wheel chair rolling through the hallway door back to the checkout area, as though the secretary there was the greeter for the next stage of his life. At least he's tobacco free, for the time being.

I couldn't fathom it: after everything he had been through, he was moving back to Yemen? And then it hit me: Despite all of our resources, medical knowledge, technology, social workers, multidisciplinary everything—wound care, inpatient, outpatient, providers and practitioners, and everything in between— this man felt his only solution was to move to a war zone.

We had no way to help him further. His status did not afford him the social benefits that he needed. He was in a class that aspired to be forgotten, for to be forgotten you must have been known once, and in this country, he had never been known. At least in Yemen he might find a home in being known.

Like I said, this isn't a story about ambulation.

And as he left, a thought crossed my mind.

"Are we sending him there to die?"

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Oxygen

Mark David Zimmerman

I'd come to Nepal after my internal medicine residency for what I thought would be a four-month stint and wound up staying two years. Though I'd originally gone there on a whim, medicine in Nepal looked like the real thing, a place where patients travelled long distances just to see a doctor, often with serious but curable illnesses, and where a lot could be accomplished with limited resources. It gave me a perspective on the excesses of medicine in America.

After my first two years in Nepal, I went back to Syracuse, New York, and worked for a year in an emergency room to pay off my medical school debt. During that period, I grew tired of the bureaucracy and paperwork and, pining for the simple effectiveness of practice in the developing world, I eventually committed to a longer term of overseas service with a mission organization, which sent me back to Nepal.

Two months after my return to Kathmandu, Shanti came into Patan Hospital. We admitted her because her pneumonia had not improved on oral antibiotics and her breathing was becoming difficult. She was a slender 16-year-old girl, who pinned her long black hair in a bun atop her head and wore western-style clothes. She attended a private boarding school in Kathmandu and when I spoke with her on the ward she insisted on using English, hers being better than my Nepali.

"How's Shanti today?"

"Fine, doctor. Except for this cough ... and the fever ... which is also … hanging around. When does it ... get better? I've been on your medicines ... three days already."

"Are you able to eat any food?"

"I'm trying ... Doctor. I don't have much ... of an appetite." She had an IV in one arm and oxygen coursed through a nasal cannula.

"Sometimes pneumonia is slow to improve, Shanti. We've put you on strong antibiotics. Don't worry."

"I'm not worried, doctor." Her smile showed perfect teeth.

Her mother sat at the bedside and seemed content to let her daughter speak with the foreign doctor. I turned towards her and repeated my report in Nepali, imploring her to feed Shanti more.

Later that day we repeated her x-ray and found the pneumonia had spread to the other lung. By evening, the group of relatives at her bedside had increased and included a man in his fifties, who had a fleshy face and wore a checkered sports coat and tie. After I examined Shanti, he motioned silently with a hand for me to come out into the hallway with him.

"Namaste, Doctor. As far as I can tell, my niece Shanti is not doing well. Would you be so kind as to give a report of her condition?" He also preferred English and spoke with his chin pushed forward and a grin fixed on his face. His stylish shoes gleamed.

"Shanti has pneumonia, sir. It's been slow to respond, so today we've added other antibiotics."

"She'll get better, then, right?"

"Yes, I think so."

"Okay. Then that's all we need to hear."

He handed me a greeting card indicating he was principal of a large boarding school in Kathmandu. "Please call me if anything comes up."

"Sure, sir. We will."

Her chart showed a temperature of 104°F from earlier in the day. I went back inside her room and rotated the knob on the oxygen concentrator until its small red indicator ball bobbed half-way up the clear plastic cylinder.

I'd seen my share of patients with pneumonia in New York and sometimes they'd gone bad there, too, but in the U.S. there was usually a strong microbiology lab and we had a broader range of antibiotics. Of course, in almost any American hospital there was also an ICU with ventilators. In Kathmandu, there were only two hospitals with ICUs— Patan wasn't one—and those beds were almost always full.

The next day, more family members arrived from their ancestral home in eastern Nepal and Shanti's room became crowded. Her condition remained critical. I added another antibiotic, the last type we had in our pharmacy.

That night, I left the hospital around seven and went to eat dinner at a local restaurant. Just after I arrived home, the resident, Dr. Amar, phoned me.

"Sir, we have an emergency in here. It's Shanti. Come quickly, please, sir."

I cycled in on a back lane, took the hospital stairs three at a time and turned into the medical ward hallway, which was abuzz with people. A nurse beckoned me to the nurses' station and I edged through the crowd and entered to find Dr. Amar, who looked relieved to see me.

"Sir, there's been a major disturbance here and I'm not sure I did the right thing. The patient in bed 154, that old man with the chronic renal failure? He collapsed, so while I was trying to resuscitate him, I told the nurse to bring an oxygen concentrator. Two are broken, so the only one we had on the ward was with the girl Shanti. When the nurses took it away, her relatives went crazy."

"What's the man's condition now?"

"We worked on him for a while, sir, but he died."

"How's Shanti?"

"No better, but she's got the oxygen back on. The family says they're guarding it now."

Oxygen concentrators, ICU beds, and kidney dialysis all were in short supply in Nepal. There were no plants to "bottle" oxygen cylinders and the concentrators—squat boxes on wheels which plugged into wall sockets—frequently broke down.

The man in bed 154 was Keshab, a farmer from a rural village, who'd been brought in two days before because of body swelling. He was soft-spoken, wore tattered clothes, and the soles of his feet were darkly lined and calloused. When we came to see him on rounds, he somehow managed a smile despite having almost no remaining kidney function. He had no immediate family and it had taken weeks for his neighbors to convince him to come to the hospital. We were trying to revive his kidneys by intravenous infusions and, because they were of normal size on ultrasound, we'd hoped his problem was reversible.

Events proved us wrong. On this particular evening, as Shanti's family passed the time in her room two doors down, Keshab suddenly went into cardiac arrest. With only one oxygen concentrator on the medical ward, Dr. Amar had to prioritize and was correct in assuming no one could be sicker at that moment than Keshab. What he'd not anticipated was the reaction as the oxygen was removed from Shanti.

Amar continued to recount the story as the nurses chimed in. When they realized what was happening, the ten or so family members around Shanti's bed rose, shouting. At first, they tried to prevent the nurses from taking the concentrator away and when the nurses insisted, the family members accused them of taking bribes from Keshab's visitors. They roared insults at the nurses, threatened to beat them, and one man finally declared, should Shanti not survive the night, they'd burn Patan Hospital down.

After hearing the whole story from Dr. Amar and the nurses, I walked down the hallway. The uncle saw me and strode out from his crowd to meet me. I was probably not the right person to pacify this dispute, for upon hearing the story and seeing our cowering nurses, I'd also grown angry. Limitations were a reality of which everyone in Nepal was aware; individuals, whether rich or powerful, couldn't put themselves above the healthcare system.

"Doctor Sahib, you have to do something about this hospital of yours. Imagine nurses trying to take away a dying girl's oxygen!"

"Resources are limited, sir. This is a district hospital. You should know that. It's not up to your family to decide who gets oxygen. Our doctors and nurses make that decision."

"Are you trying to insult me, doctor?"

"This hospital is for the care of many, not just one. If your family can't behave, you'll have to take your niece to another hospital."

On hearing this, he spun down the hallway to join his smoldering clan. A doctor, he declared, a supposed humanitarian, had just ordered a serious patient out of this hospital. More shouting ensued. I caught up with him and addressed the mob. I emphasized that we wanted to care for their relative, but their disruption of hospital work could not be tolerated. Several of the young fellows became more agitated, raising their fists in the air and shouting slogans in unison, as if at a political rally. I walked back and told the senior nurse to call the police.

At that point two things happened to diffuse the situation. One was the news of police possibly arriving. More immediately, Shanti's uncle, the school principal, began to have an attack of angina. A young man sheepishly poked his head into the nurse's station and asked me to come see his uncle right away, saying he'd had a previous heart attack. The young man thought things might be headed that way again. When I went down the hallway to the uncle, he was sitting slouched against the wall. We hoisted him onto a stretcher and wheeled him to the ER.

He was a rotund man lying still with sweat beading his amber brow. His shirt was open at the chest and he looked scared. We placed him on oxygen from the only concentrator in the emergency room.

"How's the pain, sir?"

"Moderate. Not as bad as my heart attack. Thank you for seeing me quickly, doctor. I really appreciate this."

I asked the nurse to bring some nitroglycerine and placed a tablet under his tongue. His color improved and I gave him another nitro. His cardiogram showed no new changes; he appeared not to be having a heart attack. Fifteen minutes later, when his pain had subsided, I walked back upstairs to check on Shanti. In her room, only two elderly ladies remained, keeping watch over her. She still looked ill.

"How are you, little sister?"

With some effort, she focused on my face, but couldn't manage any expression.

"Going on, Doctor. Going on."

"You'll get better. Don't worry, Shanti."

She closed her eyes. I waited to see if she was crying, but she wasn't.

The nurse said the police had come and gone without incident. The place had cleared out before they arrived.

A little after ten, I walked from the hospital gate and headed towards my apartment. A street lamp lit the dusty patch of ground outside the morgue. There lay Keshab's body, wrapped in white cloth and tied like a long, thin parcel. Over it stood four young men talking quietly and they opened their circle as I approached.

"Namaste, Doctor Sahib."

"Namaste."

I looked around at them, all village youths, none more than twenty-five years old. "I'm sorry about your friend Keshab."

"Thank you for your treatment. This is a good hospital and people took good care of the old man. We were satisfied." The others murmured in assent.

"Well, he only lasted two days here."

"No, no. It's a good hospital."

It was cold that night and our clouds of breath mingled in the air over the man's body. We talked for a few minutes more about their journey and then I left them there, waiting for a vehicle to take him across town to the Bagmati River to be cremated. As I walked home, I considered how far I'd travelled from a medical world where oxygen is assumed, and I wondered when next we'd have to face another crisis like this one.

From that night onwards, Shanti's condition improved and six days later she walked out of the hospital on her own. The day of her discharge was the first time I'd seen her uncle since the night of the disturbance. After that, he'd stopped his daily visits and now he stood with his back to me, chatting with several of his relatives. I came around to his side of the bed, caught his eye and smiled. He stepped towards me and shook my hand.

"Namaste, sir. How are you?"

"Namaste. Fine, thank you. And thank you for your care of our dear Shanti, Doctor."

"Sure. I realize it was a hard time. Really hard for all of you."

"Yes. Well. Thank you again, Doctor. As they say, all's well that ends well."

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The Shoes I Don't Wear Anymore

Jen Jolin

"URRRPPP!" came a wet-sounding burp behind me, signalling that vomiting was likely to follow.

Alarmed, I whipped my head around and asked, "Are you ok? Are you feeling sick? Do you need to vomit?" Before I could ask anymore redundant and rhetorical nurse questions, a cascade of bright red vomit showered over the railing of the stretcher and hit the treatment room floor … and then another wave … and another.

I stood at the sink with medicines in my hand, paralyzed and dumbfounded. My brain was indignantly thinking that STABLE patients are NOT supposed to vomit blood across an ENTIRE room. I looked at the bloody floor, then up at him, and back at the floor, trying to process the change in scenery. Another gasp and cough from him snapped me out of my stupor and I awkwardly tiptoed back to the bedside, trying to avoid the puddles of blood—like a child playing "The Floor is Lava," only with a gross twist.

As I reached the stretcher, he started vomiting again and I managed to dodge the splash. I can see this is too much blood—way too much, too bright, and too fresh. I call for help, throw towels over the blood on the floor, and watch my patient turn from pink to pale to ashen gray with beads of sweat on his forehead. He makes a feeble joke that I only half-hear—but I laugh anyway because I need him to think he's being heard. I'm juggling medicines and vomit bags and losing my footing in the mess on the floor, but I am still confident that my years of experience are going to pull us out of the fire again.

A doctor flies into the room with a medical student hot on his heels. They're mumbling and muttering between themselves about putting a tube in the patient's throat to help stabilize his condition and get him to the operating room for repair of whatever is leaking. They plug in equipment and talk through the steps together. Across the bed from me, an ER tech is trying to get another IV. Another tech arrives with two units of blood for me to give the patient. The housekeeper is throwing down sheets and blankets for us to walk on until he can mop the room. In other words, the whole room is charged with chaos and buzzing and noisy.

In this cacophony, I realize that no one is actually talking to the patient. He looks terrified. And gray. The "gray" I can blame on the blood loss. The "terrified" I blame on the people loss. He'd become so unstable so quickly that he caught us all with our pants down, and we were now scrambling to regain control of a situation that had been boringly normal just ten minutes ago. After all, emergency staff love playing with fire, but we hate when the curtains catch. In our frantic reaction, we forgot the guy who started it all.

I stopped what I was doing, leaned down just inches from his face, looked him in the eye, and we did the traditional Sick Patient Dance—the one where I explain what is about to happen and why, and he nods and "uh-huhs" in all the right places. And then I say,

"You're gonna be okay."

Because that's what we say. That's the confidence-inspiring, trust-soliciting, reassuring thing we say when the patient is scared and we're trying to show them we aren't.

He sized me up, smiled a thin smile, looked down at my feet standing in a pool of his blood and said, "You're a shitty liar … but please tell my wife I'm going to be okay."

Those were his last words. He went to the OR, had a complicated surgery, flirted with death in the Intensive Care Unit for a couple hours (I was there for that, too), and was helicoptered to another facility for more complex care. All told, I spent six hours of my day (including two hours past my shift) scrambling to prove to him that I wasn't a liar—that he *wa*s going to be okay. At 6:00 a.m. the next day, the family finally arrived at the other facility, talked to the doctors, and decided to withdraw care. He was dead before noon. Less than twenty-four hours after that wet-sounding "UR-RRPPP," he was dead.

Most people assume death happens frequently in the ER, but it really doesn't. We either receive already deceased patients that we can't do anything about, or we receive patients who are old, frail, and chronically ill, who are expected to die and our job is just to make it easier for them. Rarely do we have alive and (normally well) patients come in who then have poor outcomes. Those stick in our teeth. I remember most of my unexpected patient deaths, but this one is always on top.

I know I was the last person who saw him. Not in a visual sense, but a person-to-person sense. I know I was the last person who talked to him. I know I heard the last words he said. They say energy doesn't ever die; it only transfers to another object. Call me Isaac Newton, but I think I picked up some of his energy that day.

That energy is still with me. I still tell the story to new nurses. I teach classes on the equipment that we used to try to save him. If I close my eyes for a second, that same treatment room is carpeted in bloody linen again. Anybody who comes in with the same medical condition makes sweat break out on the back of my neck, and I wait anxiously for the wet sound that might summon Death and his scythe into the room.

They say Post-Traumatic Stress Disorder is a real thing for people in high stress jobs like mine. Frankly, I don't like to steal the thunder of people who have had bad things happen to them—people like soldiers, firefighters, or crime victims. So the PTSD label has never fit me very well. It just doesn't seem "traumatic" to do such a (mostly) satisfying and fulfilling job, even at its worst moments. Maybe I don't like admitting I even need a label because I inherently have a problem admitting weakness or acknowledging emotion—something that makes me a cool, calm, hardworking ER nurse. But I do know that when I took off the shoes I wore that day—the black Nikes with neon stripes and new maroon stains in the creases of the sole, I put them away. I never wore them again. Each time I purge my closet for Goodwill or look for an old pair of shoes to cut grass in, they stay. I'm not even sure I can tell you why. I don't know if they're still there as a reminder? An homage? Feelings I didn't deal with? And I don't know when I'll be ready to get rid of them.

All I know is that a dying man called me a shitty liar five years ago, and I don't wear those shoes anymore.

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Hell Dog

James Nolan

When I come to, I'm relieved not to find a breathing tube jammed down my throat, although the surgeon warned there might be one. Through a morphine fog, I glance around at the peeling pea-green paint of my room in the Intensive Care Unit, a fluorescent light wincing overhead. My body has turned into a giant squid, its myriad tentacles connected to a bank of beeping machines with flickering red lights. Every few seconds a woman's high-pitched voice chirps a staccato word from one of the computer screens.

Gloom. Doom. Boom.

Are these messages from hell about my condition?

I close my eyes and whoosh through Moorish archways painted in geometric arabesques of brilliant color, as if flying through the vaulted dome of the Mezquita in Córdoba, Spain. Sunlight streams through peaked windows, illuminating the mauves and forest greens of intricate patterns etched Escher-like on the endless ceilings and pillars, narrowing into the far distance and resonating like a Bach organ fugue. I'm in heaven and want to stay here forever.

When I open my eyes, what I see are dilapidated walls, a mute TV suspended above the bed, and the gray chute of an airshaft outside the window. My hand clutches a remote control with a single button and when I press it, the TV doesn't pop on but instead, eyes closed, I'm elevated back to the vaulted dome of the Mezquita.

"How you doing, honey?" The pudgy face of a caramel-colored woman in uniform is hovering over me, bringing me back from my throne on high. "Any pain in your chest? Now don't forget how I told you that morphine-drip works. You just press this here button to up the dose." Her face dimples into a kindly smile. "Know where you at?"

"Hôtel Dieu?"

"That what it used to be called. You in the ICU of University Hospital on Perdido Street after heart surgery."

"This is where I was born. Hôtel Dieu."

"See, you come home."

"To die?" On Perdido Street? Lost on lost street. I wish she'd go away so I could get back to the arched tile arabesques, but they've disappeared behind opened eyelids. The beeping machines take over.

"Did they cut a zipper in my chest?" I feel along my sternum. No bandages, and it doesn't hurt.

"No, just a teeny-weenie incision under your left nipple. Called a mid-cab open heart."

I'd flunked my recent stress test. I thought I'd ace it, since all it entailed was walking. A lifelong nondriver, I walk everywhere in my pedestrian-friendly French Quarter neighborhood, usually at a brisk New York pace. But the stress-test treadmill scrolled backward not forward, and I wasn't used to scurrying along a rubber sidewalk racing faster and faster in reverse under my feet. Winded, I couldn't keep up.

That was the second bad sign. The first had been a mild heart attack. When I saw my cardiologist, he told me I had a blockage at the intersection of two arteries in my heart, for which he gave me the clinical names. With his fingernail, he made a menacing slice down the front of his chest.

"That's the only way to fix it. Otherwise," he said, "you could have a fatal heart attack any moment."

"I won't be doing open-heart surgery." I'd heard horror stories: a surgeon cracks open your rib cage, lifts out your still-beating heart connected to a heart pump, and while a respirator breathes for you, repairs the damage. Some patients never recover cognitively or physically from the trauma.

"No thanks," I said. "I'd rather take my chances with a heart attack, and just drop dead one day, rather than wheeze and muddle through the rest of my life. Open-heart surgery sounds too much like Aztec ritual sacrifice. Besides, with me you wouldn't get any blessings from the gods. I'm not a virgin."

The cardiologist didn't seem to get my joke. "It's the optimal procedure—"

"Look, I'm in charge of my own health," I said. "Doctors are just my technical consultants."

"Then you should know that the artery with the blockage," he continued, "often called 'the widow maker'… ."

Even though I'm not married, that term got my full attention. If anyone ever doubts the power of poetic description to deliver a memorable impact, consider the metaphor "widow maker." The scientific term had sailed right past me.

I did some research, and discovered that a new procedure called a "mid-cab" could accomplish the same results. It involved a three-inch incision that allowed the surgeon to insert a robot to repair the artery. "Zipper" was used to describe the scar on the sternum that regular open-heart surgery left, of the Aztec ritual sacrifice variety. "Mid-cab" sounded as easy as catching a cab at midnight in midtown Manhattan. This is the associative way we poets think.

Now my heart has been invaded by a robot, and I'm tracing the oozing bandage under my left nipple. "You mean here?" I ask the nurse. Not to alarm them, I'd told some friends I was going into the hospital for a nipple tuck. A couple of days, at most. I didn't even bring my cell phone charger, my fatal flaw.

"That's it. Your pulse is okay," the nurse says, checking one of the machines.

"What's that machine saying?"

She shoots me a quizzical look. "What you mean what it say?"

"Sometimes it says 'gloom,' other times 'doom,' or then again 'boom.'"

She shakes her head. Then she takes my hand, speaking in a soft fairy-tale voice, as if telling a bedtime story to a child. "'Gloom' mean your oxygen levels ain't so high. 'Doom' mean they way down low. 'Boom' mean you doing just fine. What it saying now?"

I listened. "Boom."

"See? So your blood just a-booming away." She gives me an indulgent smile.

When she leaves the room, the machine distinctly chirps *doom*.

I close my eyes and go back to the arabesque arches of the Mezquita.

Back again, she shakes my arm. "Mr. Nolan, doctor says we got a new drug for you. Make you feel like a million bucks. It called Hell Dawg," she drawls.

"Hell Dog?" I try to picture Cerberus, the triple-headed dog that guards the gates of hell, but can only conjure the label of a bottle of rotgut you'd chugalug behind a 7-Eleven. "That sounds like fun."

***

I always swore I'd never end up like my mother, popping pills and hanging on to every word of the many doctors she visited. Or like my father, sneaking after-dinner cigarettes behind the garage. That they both had heart conditions was a memo I received, but didn't pay much attention to. I swam three times a week, walked everywhere, cooked only fresh, natural food, and postponed doctors' visits, intending to remain strong and healthy. I was determined to avoid the complex medical procedures that plagued my parents' old age. But genetics has taken the place of Greek fate in our lives. Oedipus vows he'll never kill his father and marry his mother, as the blind soothsayer Tiresias prophesizes the child will do when he grows older.

But then he does.

So at sixty-four I had a mild heart attack, or at least the doctors told me I did, although I didn't feel much. No, I didn't drop to the floor clutching my chest, and I learned only later that mine was called a "silent heart attack." My father had his first heart attack at the exact same age, cutting the grass one June in the unforgiving New Orleans heat, and his father had died of a fatal one at age sixty-five, pulling vines from a live oak in July. My father's maternal grandfather, an Irish immigrant, died in midsummer of a heart attack at fifty while driving the mules of a drayage wagon heaped with cotton bales along the Mississippi levee.

So I decided to pay attention to my genetic fate.

I'd been experiencing some symptoms of angina, not like an elephant sitting on your chest but rather like recurring heartburn. Maybe, I decided, it was something I ate. But the doctor that I finally visited at the Musicians' Clinic that Wednesday afternoon in November reported that my heart was beating irregularly, in a state called atrial fibrillation, and the EKG indicated I could be suffering a heart attack at that very moment.

"If you were my father, I'd tell you to go straight to the emergency room," she said. That I was old enough to be some jowly doctor's father woke me up, like a bucket of ice water to the face. And then I thought of my own father. And his father. And his grandfather.

"But I don't have time to have a heart attack," I protested. "I have eight guests coming tomorrow for Thanksgiving. Besides I don't have insurance and can't afford to go to a hospital."

"Guess what, James?" The nurse at the Musicians' Clinic was checking my file in her computer. "Three days ago you qualified for Medicaid. And we'll pay for your cab to the University Hospital ER. I'll give the taxi company our credit card number."

At the time, I was a poet occasionally performing in several New Orleans clubs, collaborating with jazz and flamenco musicians, so was having free yearly checkups at the Musicians' Clinic and suddenly—how did the social worker wrangle it?—that very week I'd gotten on Medicaid.

"Just remember," the nurse told me, "when you walk into the ER, say 'chest pains,' and they're required to treat you immediately." Lesson learned: "chest pains" is the open sesame to any ER, even if you have a broken foot.

The decrepit taxi driver waiting for me downstairs was about ninety years old, couldn't figure out how his dispatch radio worked, and no, hadn't gotten the credit card number.

He shook his skeletal grey head. "Ain't gonna live to see the next Carnival."

"Then we'll have to get the number from the nurse again. Follow me."

He shuffled behind me to the elevator, in which he faced me to say, "Shouldn't be working at my age. Ain't gonna live to see the next Carnival."

When we entered the Musicians' Clinic, the receptionist took one look at my stumbling cabdriver. "We're not seeing any new patients."

"He's not a patient," I explained. "He's the taxi driver taking me to my heart attack."

At that moment the social worker waltzed into the waiting room, narrowed her eyes to take a closer look at my cabdriver, and volunteered to drive me herself to University Hospital.

Down in the lobby, the cabdriver tried to exit by walking straight into a plate glass wall. We helped him back into his cab, still muttering "Ain't gonna live to see the next Carnival."

Once at University Hospital ER, I was escorted directly into the ward from the chaos of the jam-packed waiting room after I patted my heart and said "chest pains." The blood work indicated that I was indeed having a heart attack, and I was told I'd be sedated to undergo an angiogram. If any large blockages in my arteries were discovered, I'd be given an angioplasty: a stent would be inserted to reopen the blood flow. I was put in a hospital Johnny and lay on a gurney, cancelling the Thanksgiving dinner on my cell while being wheeled through the noisy corridors into the operating room. "Sorry to cancel at the last minute," I shouted into the phone, "but I'm having a bit of a heart attack. Can we reschedule for Friday?"

Then a wall of blue scrubs surrounded me. The eager young faces of the residents who staffed this public teaching hospital were staring down at me under the blazing lights, as if I were a splayed Thanksgiving turkey ready to be stuffed and trussed. Waiting for the cardiologist to arrive, I realized I needed to take a leak before the ordeal began.

“Excuse me,” I said, sitting up on the gurney, “but where’s the rest room? I just need to step inside to urinate before—”

“Oh no,” said one of the female residents. “We’ll attach a catheter.”

While the smirking Greek chorus of residents observed, the woman flipped up my hospital Johnny and unrolled a condom attached to a tube onto my shrinking penis. I’d never been less excited in my life during this routine intimacy, normally restricted to bedrooms.

“Are you ready?” she asked.

I looked down at my flaccid member and laughed. “Never been less so, baby.”

“I mean for the anesthetic?”

When I regained consciousness in the post-op ward, a resident with a three-day stubble told me that I’d have to remain motionless, spread-eagled for twenty-four hours, until the angioplasty tube could be removed. Two stents had been placed inside my heart, and I’d need to take cardiovascular medication for the rest of my life.

“Doing a lot of cocaine lately?” he asked, eyebrow cocked.

I wasn’t sure if this was a resident’s sophomoric attempt at gallows humor, or if he was trying to establish his street cred with a patient from the hip Musicians’ Clinic. “Why, you got some?” I asked, nostrils flaring.

Maybe it was the anesthetic wearing off, but I was feeling a rush of hilarity. I’d have done a standup comedy monologue, if I could have stood up.

"I haven't snorted a line in twenty years, but have been doing a hectic book promotion, living on Cuba Libres and cheese omelets." That got a knee-slapping cackle out of a red-headed nurse. I later told her that this antsy patient had never remained stock-still for twenty-four hours in his whole peripatetic life.

"I need Valium for that. Blue. Ten milligrams. Every six hours. " Years ago, I'd learned about downers on the streets of San Francisco.

She nodded, as if she knew I meant business.

When I checked out a day later AMA, or Against Medical Advice, I gave the red-headed nurse who brought me the Valiums a bear hug and told her I was in love with her. Would she marry me? After all, at one point I would have shacked up with any chick who gave me four blue Valiums on the streets of San Francisco.

And so instead of Thursday, I had the Thanksgiving dinner at my house on Friday, with two stents in my broken heart. The nurse had said she was already hitched.

***

Gloom, chirps the machine.

As soon as I regain consciousness in the ICU, I tell a nurse to take out the catheter. It's excruciating. This plastic tube isn't connected by a sexy Trojan but rammed into the opening of the most sensitive part of my anatomy. I insist on a bucket so I can stand up to pee.

“But that way we can’t measure the urine quantity in these collection bags,” she protests, holding up a plastic udder striped with red lines.

“Then stick a damn ruler in the bucket,” I thunder.

I’m not about to suffer ongoing agony to make someone’s paperwork easier. Now, whenever I stand up to piss in the bucket, the wires attached to my body send the monitors into a cacophony of beeps and alarms, and nurses come rushing into the room. “Mr. Nolan,” they cluck, steering me back into the bed.

This must be why they’ve taken away my morphine and put me on Hell Dog. But I’d stopped punching up the morphine even before the remote disappeared. The ascents into arabesque heaven followed by the descents into ICU hell were too jarring. Eyes closed: *heaven*. Eyes open: *hell*. Closed tight: *heaven*. Wide open: *hell*. So like most people, I settled for the permanence of hell on earth because my glimpses of heaven were far too fleeting.

There’s something about Hell Dog that keeps me from being able to read, concentrate, or think straight. Nor am I sleeping or eating. The microwaved slop arrives in a flat brown plastic container with a swirled top that resembles a cow pie. I gag every time I see it.

A young male nurse talks with this troubled patient as if he actually sees me as a person. I tell him I’m a writer who lives in the French Quarter, and he jots down the titles of two books of my fiction. My cell phone has lost its charge, since I didn’t think I’d be here long enough to recharge it, so I can't talk with friends. I treasure his conversation. I'm surrounded by bossy middle-aged women, who make me feel like either a rambunctious juvenile delinquent or a crotchety old man.

It's three in the morning and I'm fully awake, bursting with vitality. The young man asks me if I need anything.

"Yes. I need to get out of this bed, put on a robe, and sit in that chair to read the *New York Times*."

He looks skeptical, but helps me out of bed and into my cotton kimono, the only robe I have. Then rearranging the wires so that the machines don't beep, he seats me in the chair. I feel normal for the first time in days, that is, until bloody water starts gushing out of my incision. It soaks my hospital gown, the robe, and the chair, pooling around me on the floor.

The young nurse is beside himself. He pushes an alarm button. A siren wails. A swarm of orderlies takes over the room with X-ray machines, hypodermic needles, and bright lights. My sopping self is dumped back in bed.

"Looks like my water just broke," I say. "What should I name the baby?" Something about hospitals brings out the comic in me. Could humor be the front man for panic?

It turns out that my chart clearly indicates the surgeon's instructions: that I should sit up three hours a day so the chest wound can drain. None of the nurses noticed this, or probably didn't want the fuss of rearranging the wires and helping me into a chair.

How much easier to give me a Hell Dog.

I overhear the nurses at their station talking about moving me onto the cardiology ward, "whenever there's a bed free on the clean side." It's not reassuring to learn there's a clean and a dirty side to cardiology. The first time I visited the surgeon on the hospital cardiology unit, I rode the elevator alone with a shackled prisoner in an orange jumpsuit being led on a chain by his guard. This place is one step up from Parish Prison.

I punch the keys of my dead cell. I've got to get out of here.

"Time for your little ole' Hell Dawg," one of the nurses singsongs.

I purse my lips and shake my head in a defiant *no.*

Doom, squawks the machine.

* * *

Day four on the ICU: I overhear the head nurse talking on the phone at her station and make out the words "Palo Alto," "your cousin James," and "heart surgery." I jump out of bed, sending the monitor alarms into a strident burst of beeps, and bang on the window separating us.

"Is that my cousin Melinda calling from Stanford University?" I shout. "I need to talk with her."

"This is the unit's landline," the nurse tells me, "with a short cord."

"Please tell her to call you back on your cell phone and bring it to me."

Two minutes later I'm speaking with Melinda. "Look, Mixie, this filthy place is going to kill me, and my cell is dead. Call our cousin Jim and ask him to come pick me up at three tomorrow afternoon in his truck. I'm signing out AMA, and I know they'll give me a hard time, so ask Jim to bring along my social worker friend, Kichea Burt." Melinda sounds doubtful, so I pour out my whole story. "Not sleeping or eating for four days isn't the right formula for healing. By the way, have you ever heard of a med called Hell Dog?"

"Hell Dog?"

"Well, I've stopped taking it, and suddenly what I have to do is crystal clear."

* * *

The next afternoon I shave, unfasten the wires attached to me, dress, and sit in the chair to wait. Up and about in the room for the first time, I stare out of the grimy window into the airshaft, notice that the TV remote lacks a battery—no wonder it never worked—and glance into a dank closet that contains a stopped-up toilet that probably hasn't been cleaned since the day I was born in this hospital. Then I read the *New York Times*.

"We're here to see your favorite patient." Like me, Kichea Burt grew up in New Orleans, but lived for a long time in California, and I'd recognize her clear, crisp accent anywhere. Her gray dreadlocks swing around the door frame. "You're looking good," she tells me.

"Time to blow this joint," I say, jumping into her arms.

My cousin Jim Flynn, a riverboat pilot, saunters into the room and glances around. "Jeez, this looks like the hold of a Libyan freighter."

"Not so fast," Kichea says. "Signing out Against Medical Advice is a serious move, especially if you're not cognizant enough to take responsibility for yourself. Who's the President of the United States?"

"Oh, come on." For once in my life, I cooperate. "Barack Obama."

"What year is this?"

"2012."

"Where are you?

"University Hospital in New Orleans, Louisiana. Kichea, have you ever heard of a drug called Hell Dog?"

"Hell Dog?" She squints and repeats the name in the local drawl. "You mean Haldol?"

"That's what they're giving me here."

"You mean they're dosing you with the heavy-duty antipsychotic Haldol? That's a drug for managing violent schizophrenics. How many times a day?"

"Four or five."

"Is your bag packed? We're going."

Without reading the document, I once again scrawl my name on the AMA form presented to me on a clipboard along with a disapproving look. "A bed just opened up on cardiology," the head nurse tells me. "There can be fatal consequences if you leave now."

"Even if it's on the clean side," I say, edging toward the swinging ward doors, "I'm not interested."

"Wow, look at Canal Street," I murmur five minutes later, staring out of Kichea's windshield. "It's so beautiful." Actually, it's seedy, but such is my first impression on being back out in the world.

Hands propped on my shoulders, my cousin Jim walks behind me on the majestic curved staircase that leads up to my second-story French Quarter apartment. I bolt ahead, taking the steps two at a time.

For the next two days, I live on mint chocolate-chip ice cream in front of the TV, napping and talking on the phone. I pull the bandage off the wound under my left nipple and soothe it with the gooey juice squeezed from spikes of my aloe vera plant. I scrub off the patches of adhesive stuck to my skin where the monitor wires were connected. I hose the ferns hanging on my balcony, drink lots of water, and stand up to take gloriously unfettered leaks. My heart, invaded by robots and all the widow-making dogs of hell, feels on the mend.

On the third day, I walk the eight blocks from my apartment on Dumaine Street to Canal Street, which still looks beautiful. Then I amble home, stopping at a grocery along the way. This isn't a stress test, but life. The only kind of stress test I can't pass is being incarcerated in a hospital. Just think, I could still be languishing on the dirty side of the cardiology ward popping Haldols.

"Boom," I say to myself strolling down Royal Street. "Boom."

In memory of Kichea Burt,
who died of a heart attack
June 24, 2019

James Nolan has published twelve books of fiction, poetry, essays, and translations. His *Flight Risk* won the 2018 Next-Generation Indie Book Award for Best Memoir. Email: jnolan77@bellsouth.net

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Invasion

N.R.M. Roshak

I found out about you the day before the invasion.

I knew I was pregnant, of course. But I'd pictured you as a fetus, slowly taking shape inside me.

Instead, what I saw on the ultrasound monitor was you: a lacework of dark spots, stretched across my uterus.

"I don't see a heartbeat," said the technician quietly. She left the room to get the doctor, while I stared at her last picture of you, frozen on the screen.

* * *

I call it "the invasion," but I'm not sure that's the right word. "Invasion" is troops fighting their way into an alien land. This was much quieter. One day you were the only thing on my mind. The next, the invaders were everywhere.

At the coffee shop, an invader glowered at me from the barista's shoulder, its tiny fist clenched on her collar. It was 5:15 in the morning, because you'd woken me up early to vomit, and I wondered if I was seeing things.

The invader was the size of two clenched fists, and the awful purplish color of a stillbirth. Its little chest heaved. Its dark eyes glittered with malice. A pulsing umbilical cord led from its belly to the nape of the barista's neck.

I told the barista she had something on her shoulder. Her head started to turn … and then the thing on her shoulder *growled*, and she looked at me like I was crazy. I took my coffee and left.

***

The doctor had explained: I was, technically, pregnant. But not with a baby.

The doctor had called you a "mole," as though you were something awkward on the sole of my foot. Not a regular mole, though, a "hydatidiform" mole. "Hydatid-i-form," she explained: shaped like a *hydatid*, a tapeworm's larval cyst.

My hydatidiform mole, you are no more tapeworm than baby. You're a placenta gone wrong.

***

The city had started stirring when I left the coffee shop. I passed early-morning joggers, polo-shirted store openers, dog walkers. An invader crouched on every shoulder but my own, squatting toad-like on their hosts. Each one turned to glare at me.

I stopped to give a homeless man a dollar.

"Did you wake up with that on your shoulder?" I asked him.

His invader made a foul face, as though I reeked.

"I don't know what you're talking about, lady," the man said.

* * *

My hydatidiform mole, the doctor said that you're one in a thousand. Every embryo should become two things: a placenta and a fetus. But one in a thousand never figures out the fetus part, becoming a scrambled, scattered placenta instead.

The lace veil on the ultrasound screen was your network of cysts. Black cysts, little bubbles of failed placenta, clustered in a white net of tissue. You are slowly filling my womb.

* * *

I put in a pad, because you bleed from inside me, and went to work. The bus driver had an invader, as did each passenger. Silently, without making eye contact, the other passengers shuffled away from me while their invaders glared and grimaced.

I studied the back of the bus driver's neck, where his invader's umbilical plunged into him. His nape was cankered with growths radiating outward from the cord.

His invader, invading him. An invasion not of troops, but of the flesh.

I was the only one on the bus without an invader growing into me. I couldn't make sense of it. Why they were here, why they were invading everyone's bodies but my own.

The driver's invader bared needle-sharp teeth at me as I left the bus, and the driver scowled.

* * *

My hydatidiform mole, the doctor said that you'll grow like a cancer. There's a one-in-ten chance that you won’t be contained by my uterus. That you will keep growing, into me and through me.

The doctor told me to schedule an abortion. But the next day, the invasion happened instead.

* * *

The clinic called me at work to arrange your removal. (“Curettage,” they said, not “abortion”. There’s no baby to abort, only you.)

I pictured the medical secretary at his desk: phone on one shoulder, invader on the other, both wincing at the sound of my voice.

I pictured the clinic’s kind-voiced doctor, curette in hand to scrape you out of me. I pictured the invader riding on her shoulder, invisible to everyone but me.

I pictured her invader, grimacing with hate for me as it guided her hand.

I put down the phone.

* * *

My cubicle-mate didn’t smile or greet me when I slid into my chair. Her invader screwed up its face and held its nose. My co-worker turned her back on me and spent the morning pretending I wasn’t there. I watched the back of her neck blister with purplish boils that grew and spread, over the hours, like water boiling in slow motion.

After ignoring me all morning, my cube-mate complained to our boss. I smelled wrong, she said. I smelled off.

My boss is usually very nice to me, but today he couldn’t stand the sight of me. The invader on his shoulder gagged and retched while my boss told me to go home.

***

I threw up twice on the walk home.

I imagined your cysts inside me, slipping the bounds of my womb. I imagined you, spreading through me like the angry growths radiating down my co-worker's neck.

You will grow like a cancer, as the doctor warned. But you aren't one.

A cancer would be made of me, my own cells gone wrong. But you, you are not-me, your genes only half mine.

You are *you*, you are other. Another life, inside of me, as familiar and foreign as my own child.

***

Did they invade us to control us, or to destroy us? Or simply to have a place to call home?

Their purpose is as obscure to me as yours is. I only know that they hate me.

My hydatidiform mole, you are why the invaders hate me. They smell you growing in me, and they know: there's no room for another, not with you spreading through me.

You: you are my invader.

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Surgery

Jordan Oakes

The skin is soft,
splits passively
at the red
line drawn
by the scalpel—
a precise violence,
a controlled battle
between scrubs
and bedgown.
I must have
a memory
of the knife,
the shiny scissors,
the laser eyes
burning me
with concentration.
But it’s off
the record
of consciousness,
a slice of life
between sleep
and death.
I wake up
with my chances

looking good,
sewn up
beneath
a mummy arm.
I'm on a rolling bed,
attached
to an external vein,
moving down
a corridor
that's thick
with the stench
of recovery,
awake
just enough
to be aware
of my own
mortality.
Soon I'll be easy
prey for pain,
my wounds
at the mercy
of time's
ability to heal,
the corrected body
unstitched,
ready to resume
the calculated risk
of being
human.

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Barren 2.0

Erin McConnell

In the hallowed hall
of maternal fetal medicine
expectant with the antenatal waiting
I anticipate a future here.
Molding my time, the frequent visits
I will make this work
already envisioning myself
timing my appointments
to accommodate my patient schedule
in pursuit of having the mythical all.

I know the import of the test results
before I endure them
and despite my doctor's reassurance.
How many ova left?
Any small follicles?
Six? Two? One?

And what a strange name
"Anti-Müllerian hormone"—
a Trumpian weapon
of endocrinologic terror

And I pity my blighted ovaries
and the empty womb
that would never be occupied,
could only be rented
and who would seek out
such cold soulless shelter?

Woman or androgynous anomaly?

At the pediatric well visits
as I delight in the milestones achieved
and the inches accrued,
the proud parents
make innocuous inquiries
that sting like venom:
"Do you have children?"

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S.O.A.P.

Grace Zhang

ID:
54-year-old male diabetic, admitted for pneumonia and acute kidney injury, new lung mass NYD
This
is how you are identified here.
In this short line
I will invalidate your accomplishments
reduce you to relevant organ systems;
so just forget about how it felt to be well.

S.O.A.P.
Into these four letters I will write your life.

S:
Breathing improved. Patient complaining of ongoing cough.
Denies fevers.
In the one section driven by you
I will stifle your contributions —
ask closed-ended questions
censor your concerns;
after all, I have been told
this is the least important part.

O:

Afebrile, vital signs stable. Normal heart sounds. Crackles
heard on auscultation of right lower lobe.
I will pit your claims
against my astute observations;
if you have told falsehoods
your body will now expose you.
I will open the door
to your most private places —
document them
for the world to see.

A/P:

54-year-old male with pneumonia improving on antibiotics,
now on room air. Continue antibiotics and IV fluids for
pre-renal AKI. Refer to lung diagnostic clinic as outpatient.
Now that I've met you
I will return to my computer
to treat your numbers and your pictures.
It is here, behind your back
that I decide your future.

S.O.A.P.

With these four letters I have washed away your story
and replaced it with mine.

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The Artist

Grace Luo Xu

You knock on the door gently, the whites of your knuckles
rapping against wood, and poke your head into the room.
This time, you are greeted by a room of silence,
dim voices of television characters flickering above you.
She sits up in the bed, her gown flattening
against the worn hospital linens.

Artwork is plastered across the walls, empty canvases
mottled by loose streaks of watercolor.
A blank sheet lies on the table, her fingers poised
to grip a brush in mid-air. She turns from you and
presses the bristles down into a palate. Her hand trembles
as she drags it across the surface of the paper,
fresh globules of paint seeping into one another.

The soft etchings of faces are strewn in the corner,
and you recognize yourself amongst them.
Her eyebrows furrow as she attempts to
parse through a set of sepia-tinted memories.
As you step into her view, her gaze remains devoid,
a tabula rasa unmarred by the past eighty years.

The shards of her life fall away from one another,
each edge blunted by the passage of time.

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Progression

Dan Campion

The indications are undoubtedly
the indications. The indications
are undoubtedly the indications.
The indications are undoubtedly.
Interpretations yield anomaly
upon anomaly. Interpretations
yield anomaly. Interpretations
yield anomaly upon anomaly.
The nodes are sentinels, the sentinels
are nodes. The nodes are sentinels. The nodes
are sentinels. The nodes are sentinels.
Say *journey*. *Daffodils*. We speak in codes.
We speak in codes. Say *journey*. *Daffodils*.
Say *journey*. *Daffodils*. We speak in codes.

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The Parkinsonian Poems

A. Rooney

Reflections on Parkinson’s

At first, before I knew much about the disease,
I thought of Colonel Parker,
Elvis’ longtime manager,
which then made me think
of Colonel Sanders,
the chicken magnate,
or, stretching a bit,
Colonel Tom Thumb,
Barnum’s diminutive character.
But wait, he was a general, yes?
These military men.
So, for clarity I googled it
only to find there was a real Parkinson.
A Brit, no Colonel,
who discovered the disease,
and though there’s no definitive blood test,
we can blame him for lumping the symptoms—
stooping, limping, shaking, dragging—
into one diagnosis that made him famous,
the Elvis-chicken-dwarf disease.

Demise in the Under-Ten-Items Line

Scratching my crusty lesions,
I wonder about the days to come
and my unattractive demise.
Will it include the shaking palsy,
a protruding tongue, and slurred speech,
tumbling down stairs and losing teeth,
or painful organs and a thundering heart?
How about something less dramatic,
like collapsing at Whole Foods
in the under-ten-items line
and being worked on
by store security
to no avail.

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Twenty Seconds

K. Alex Mills

Take as many moments as you can to
dip your hands in the faucet's flow and
gather up the suds, summon them.

Lather the spaces between your fingers,
the cracks across your palms,
the ridges of your finger tips,
the spaces between your nails.

Chant a dirge softly
to yourself
to make the rhythm,
to keep the time.

Rinse away your worries.
Wash away the waiting,
the knowing that the wind still blows.

Dry your hands.
Return to the world
clean for the present,
however long it may last.

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Word Flight

Sophia Wilson

I woke to hear the murmurings of a new language:
‘*brainstem compromise, cerebromedullary disconnection,*
de-efferented state…’
The soft, coiling marrow-substance of my pristine,
  tree-lined landscape
was inundated and turned to slosh, like plains after the
  flood’s passed through—

speech swept away by torrent, vocal cords divorced from
  breath,
expression marooned, and I am now a strange and silent
  island—
devoid, of movement and of gesture, no matter how I
  muster will
to lift a hand in acquiescence, signal ‘stop’, or raise a
  lip-corner of smile.

Monotony weighs in, a daily groan of repetitive successions:
Nurses flit. Fluids enter and exit via tubes. Medical students
  loom,
dangling stethoscopes like rattles. At night—lights out,
  lights on,
clang and roll, beep and blip, fractured sleep.

I'm locked in, looking out, tracking the movements of others
who are teaching me to employ eyelid-flutter as speech,
but I haven't achieved competence with the new Morse;
lid movements are effort-laden, unreliable, and my code,
    indecipherable, so

I can't tell them I'm leaving, that I'll employ the words
    crowding my head like gulls around a shoal of fish,
    aim their acuity at the slosh, dissect and redefine it—
I'll fly out through the key-hole if I have to.

They assume I'm wallowing in my own rubbish-tip,
but word by word, I'm gathering strength to soar.

Sophia Wilson is a poet whose work most recently appeared in *Not-Very-Quiet, Intima, Corpus,* and *Hektoen International.* She is based in Aotearoa, New Zealand. Email: gesarspeak@gmail.com

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Work Hours

Andrew R. Orr

In the waning hours of my last overnight call as a resident in the ICU, I watched one of my patients mount an improbable recovery. As dawn broke, he passed his spontaneous breathing trial, and my shift ended as the medical team prepared to extubate. Whether from a shared look with his wife, my surprise at arriving at that moment, or the emotional disinhibition that accompanies frank exhaustion, I found myself wiping away tears of joy while leaving the hospital. This had never happened before. Now, several years into independent practice, I can't say that it has happened again since—and not for lack of similarly impactful work experiences. Reflecting on the power of this particular moment, I started to wonder why others like it seemed to pass me by.

The ancient Greeks conceptualized time as two separate entities: *chronos,* time as a series of discrete moments and *kairos*, the transcendent quality of a single moment within the oceanic collective of deep time (Tippett, 2017). As healthcare providers, we accompany our patients through the *chronos*, mutually swept along by this sublime stream that silently propels generations (Tippett, 2017). Along the way, we contribute and bear witness to our patients' best (though inevitably unsuccessful) efforts to combat it. From this vantage, an initial encounter throws in relief the longstanding relationships and formative years of health, illness, joy, and tragedy that have shaped the life of the patient in our examination room. *Kairos* is recognizing the monumental in these moments, then acting accordingly.

Using this lens, we can detect the "little daily miracles" of everyday life and realize their potential in real-time (Woolf, 1981). A *kairos* lens restores gravity to that which has become routine. A *kairos* lens crystallizes individual moments, effecting permanence in what is otherwise fleeting. A *kairos* lens is what has been missing since I sensed its immediacy in the ICU early that morning years ago. Pressured by the flow of *chronos*, I've stopped generating the questions required to unearth the "*kairotic*" from the quotidian within clinical practice: How did this encounter come to pass? Why is this particular patient's path intersecting with my own? Why now?

Faced with an apparent abundance of moments ripe for *kairos* in healthcare, why have they been so difficult to find? The ironic answer is that, as a profession, we simply lack the time. Discovering beauty in the seemingly mundane requires energy, reflection, and a spaciousness that many healthcare providers, already squeezed for every minute of the day, do not possess. Instead of dedicating time to these high-stakes encounters, we spend it on hold with insurance companies, buried in electronic health records, or otherwise rushing to accommodate an ever-increasing volume of patients into our schedules. Creating the space for *kairos* requires reframing our current approach to medical practice on two fronts: the structural and the artistic.

Structurally, replenishing our capacity for *kairos* begins by establishing a healthier relationship with *chronos*. Engaging in a constant race against the clock to complete daily tasks limits our ability to bring full presence and attentiveness to a given encounter. Similarly, when clinical responsibilities overflow beyond the constraints of the traditional workday, fatigue may further dull our perceptiveness to the remarkable currents lying under the surface. If attempting to unleash the power of *kairos*, institutions can start by raising serious inquiries into optimizing provider workloads. What thoughtful measures will we take to leverage technological advances to reclaim lost time? How will we redesign modern medical practice so that practitioners identify *kairos* moments because of healthcare systems and not in spite of them? Bold answers to these questions will be needed to liberate us from *chronos* and allow for the curiosity and communion that often reveal *Kairos* (Block, 2018).

Shared exploration of the medical humanities, in simultaneous pursuit with structural change, serves as an additional avenue to rediscover *kairos* moments. Like works of art, these moments are expansive, preserved in time, and able to singularly color their audience's worldview. The gifts of reflection, deliberate attention, and community-building promoted by the humanities prepare the way for us to receive these moments when they strike. Study of literature, music, and visual art also offers the chance to travel across time and outside of ourselves. By broadening our focus, these works afford the opportunity to step back into the deep rhythm, the *kairos*, of our lives. They transform time into an ally, treasured for the relationships and experiences it carries, rather than an adversary. They reinfuse creativity and encourage solidarity for humanity's ongoing struggle to band together in the face of an indifferent universe. Embracing this theme, manifested on a daily basis in healthcare, generates greater appreciation for the daily stakes of the human condition and makes us more likely to respond gracefully when *kairos* takes us by surprise.

When I returned to the ICU the following day, I learned that my patient's respiratory status had worsened again shortly after the end of my previous shift. He was not extubated. In fact, time revealed that he would never leave the ICU. In that one *kairos* moment, however, everything was possible—and that is the feeling I remember. I remain hopeful for a time when health systems are designed so that we are better able to find the meaning in these moments. In the meantime, deliberate practice of compassion and social connection through the medical humanities can prime us for when that time comes. That single moment in the ICU imprinted in me a message of hope and surprise that I carry to this day. Reflecting on that experience instills confidence in me about our ability to create space for *kairos* through change and renews my sense of wonder about the good that will come once we do.

References

Block, P. (2018). *Community: The structure of belonging*. Berrett-Koehler Publishers.

Tippett, K. (2017, August 31). *The inner landscape of beauty*. [Radio broadcast]. NPR. https://onbeing.org/programs/john-odonohue-the-inner-landscape-of-beauty-aug2017/

Woolf, V. (1981). *To the lighthouse*. Harcourt Brace Jovanovich.

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