

KALEIDOSCOPE

EXPLORING THE EXPERIENCE OF DISABILITY THROUGH LITERATURE AND THE FINE ARTS

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EBBS AND FLOWS

"Portrait with a Seagull" by Natalie Haney Tilghman

"Neverlander" by Deb DeBates

"No One's Looking" by Karen McKenzie



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Diana de Avila, *Serenity on Sanibel*, 2024, digital art

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This award-winning publication expresses the experience of disability from a variety of perspectives including: individuals, families, friends, caregivers, healthcare professionals, and educators, among others. The material chosen for Kaleidoscope challenges stereotypical, patronizing, and sentimental attitudes about disabilities.



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PORTRAIT WITH A SEAGULL

NATALIE HANEY TILGHMAN

Two summers ago, my five-year-old decided that he wanted a seagull as a pet when we were visiting the Jersey Shore. I could relate to his interest, which wasn't all that dissimilar from my own childhood fascination with catching minnows at the beach. It was harder to understand the particular appeal of the gull when the Atlantic is home to so many sea creatures that don't habitually steal boardwalk fries or poop on towels. But, that week, my son endured their screeching without covering his ears and even seemed to prefer their chatter to mine. He collected their dirty feathers without cringing as he often did at my kisses. I'd always disliked gulls, but as vacation continued and his interest grew, I came to resent them even more for their easy and immediate connection with my son.

After a few days, my son eventually found a lone bird to befriend. By the time I registered that he might actually pursue his new companion with the same passion he'd previously reserved for LEGO Minifigures, he was already running down the crowded shoreline chasing the gull at a full sprint. I attempted to follow, but quickly fell behind due to the crush of people, umbrellas, and chairs.

In the ensuing panic, a thousand awful scenarios, mostly involving accidents and water and loss, flooded my mind. But worrying about my boy was nothing new. It was set into motion the day he was born with the umbilical cord wrapped

twice around his neck and only gained momentum over the years with doctors' visits, assessments, early interventions, therapeutic services, and diagnoses. During his toddler years, when my son's struggles were at their height, he'd cry himself to sleep. Nothing I did comforted him, and usually, a soothing word or touch only frustrated him more. I'd sometimes stay by his side in bed after he was asleep, kept awake by my own tears and fears. What if he continued to feel misunderstood, even by those who loved him most? What if he blamed me someday the way I blamed myself for potential mistakes during my pregnancy and delivery? For my parenting style? For my DNA?

No one seemed to register my alarm that day on the beach, even as I paced the same stretch of sand, yelling my son's name. When I eventually found him some distance away, he was blissfully unaware of the grief his absence had caused. And no less enchanted with gulls.

Already, I could see how this might be a problem when it came time for family pictures on the beach later. It was hard enough to get my boys to put on matching shorts and smile at the same time as their little sister. The last thing I needed was a colony of sea birds. But that was exactly what I got—an entire flock, populating the sand dunes like little totems, right where we were supposed to pose.

The moment he saw them, my son's eyes flashed electric and a similar energy fired in his lanky limbs. This time, though, he didn't take off. I quickly praised him for using his words and promised he could play as much as he wanted with the gulls after our photography session. Waiting was no consolation—my son argued with me for several expensive minutes, then sulked. His lack of cooperation was contagious, and soon, none of my other kids wanted to pose or smile either.

Perhaps hoping to salvage the shoot, the photographer suggested trying some candid pictures. By then, my own mood was souring. Spontaneity had been a big part of my life before kids, but to better support my son, we tried to

bring structure to our household chaos with visual schedules. The session seemed destined to devolve into disaster without a plan. But then, salvation came in the form of the most unlikely hero.

A laughing gull hovered just above our heads, caught in a strong head wind. My son immediately jumped up and reached both hands toward the sky, his face brightening. His sister and brother followed, rising up to see our visitor better, while my husband watched and smiled. In the candid picture that captured that moment, the horizon seems no more than a seam in the sky, and my only focus is our bird, delighting in flight. ♦



No ONE'S LOOKING

KAREN MCKENZIE

Checking for dust, I brush my fingers over the living room's wooden blinds and feel gaps, and a realization slams through me. The gaps mean the blinds are *open*. I must have opened them this morning, knowing Vasilka, my support worker, is coming. Someone could be on the other side of the window, looking in. Maybe they were walking by on the footpath minutes ago, and decided to stickybeak. But who would want to watch a muttering blind woman shuffle around her house, anyway?

Negative thoughts have to be pushed away—that's what Renald always said. How a person thinks creates their reality. I am safe. No one knows what I did, and I'll never tell. Never.

Still, I have to check the house.

The blinds in the kitchen and dining room, and the curtains in the bedroom are open, too. Now I can remember opening them, yesterday morning. God, they've been like that overnight. People could have seen me through the windows without me knowing.

Heart racing, I check the light switches. All are off.

Get a grip Annie, the lights were off. I force a deep breath.

The talking clock beeps then the female electronic voice says "Nine AM."

Vasilka is due now. I flick on the lights, not wanting my place to be dark, appearing weirder to her than it already does. Last week she brought up the lack of doors three times, unsatisfied, it seemed, when I pointed out that the two bathrooms have doors, or that a handyman the real estate agent hired will be taking the doors from the shed and putting them back on.

If she knew the real reason for the doors being off, what would she say?

The doorbell sounds and I jump. When I open the door, Vasilka's loud, overly cheerful voice breezes in, her perfume of lavender and sandalwood filling the front room. I imagine she's wearing a flowy cheesecloth top over a full bosom, and chunky sandals, given

her steps are quiet. She's a big woman. I could tell the first time she took me grocery shopping, two months back, by the way she shifts the air around her, and of course when she guides me, I can feel her large, spongy upper arm and her small-stepped gait.

"This is different, I usually just help you in with the shopping," Vasilka says in her light Bulgarian accent that reminds me again of my third-grade teacher, Mrs. Milisheva. She'd been the only one to notice, or at least care enough to say to my mother, "Annie doesn't quite look at objects, or into your eyes. Perhaps her sight needs checking."

My mother, not understanding, said, "she just trips a lot." Her usual response about me.

"Do we work first in the lounge room?" Vasilka asks.

I nod, but a low rustle—maybe her handbag shifting on her jacket—makes me guess she's stepping into the lounge room, so she might not be looking

at me. So I say, “Yes.” I should say something more, but I was never good at small talk, even before Renald.

“What a lot of boxes to fill. But then, you do have five huge bookshelves to empty, just in this room,” she says.

She often says the obvious. Talks too much. Maybe it’s nerves. I’m her first blind client. She could think I won’t know where she is if she stops talking. And she has a point there, if that’s what she thinks.

“Would you like a drink?” I ask. “Tea, or coffee?”

“Let me make it.”

I hear a light thump. Probably, her huge, squashy handbag hitting the rug. I say, “It’s okay, I—”

Her fast breathing as she moves tells me she’s already barreling into the kitchen.

I hear her filling the jug, and in my mind, I work out where she is and how to explain which cupboard holds the cups, which drawer the spoons. Yet she doesn’t ask. Just opens and closes doors and drawers.

Does she think I don’t know where everything is? Who does she think packed the stuff away, the tooth fairy? And I make tea all the time.

“I know you only have tea,” she says, with a little laugh. “Given I’ve helped you buy it for months now.”

I nod, not caring if she’s looking at me or not.

The fridge door is opened and closed. I do have coffee in Renald’s sealed tin, and I’ve sometimes smelled that she drinks coffee, but I’m busy trying to not be angry. Vasilka’s probably just doing what she thinks is a good support worker, making the cuppas. She hasn’t meant to offend. Like so many sighted people, not meaning to offend, and not wanting to think about the practicalities of being me.

As she makes the drinks and brings them into the lounge room, I give myself a good talking to. I should be grateful for Vasilka. I *am* grateful. Besides, next time she comes, I can have the drinks ready, with the little milk jug shaped like a cow, and a sugar bowl, in the lounge room, and biscuits. Yes, that’s what I’ll do.

We sort out the seating. Last week I explained I want her help to fill the boxes before the real estate agent carts off most of the furniture so I can rent some and pretty up the house to sell it. Now I add: “A secondhand bookshop’s picking up the books next week. Today we pack up books and I want to go through the drawers and cabinets and work out what papers to throw away or keep.”

As she packs the books, she reads out the titles. I don’t want her to do that, but I can’t bring myself to say so. I could do the packing, too—you don’t need sight to pack a box, but I just let her do it. Being the boss of a support worker is beyond peculiar. I’ve never been the boss of anyone.

She reads, “*Fishing through the Ages . . . Secrets of World War II . . . The Best Catch of the Day.*”

Renald’s seriously boring books.

“This is a shoebox of photos,” she says.

“You can put that in the chuck-it-out box.”

“Oh wow, this one’s of you, so young and pretty, maybe twenty, in a purple dress, sitting with a hunk of a guy, both of you smiling like you’ve won Tattsлото. Your husband?”

“Yes, a third date with Renald. His birthday, at a posh restaurant. Nearly twenty years ago.”

My mind flashes back. My retinas had detached by then. No vision at all. Renald had been a volunteer at the blindness agency where we met. That night at the restaurant, he had guided me to the seat the proper way—with me taking his arm—and put his hand on the back of the seat so I could slide my hand down his arm to it and seat myself. Then he read aloud the menu with no fuss.

The waitress arrived and asked Renald what he wanted and after he’d answered she’d asked, “And what does *she* want?”

I was used to that kind of ignorance. I should have rushed in, said sorry, and given my order. It was easier to say sorry for sighted people’s mistakes. But the heat of a flush crept up my face. Renald and I had been talking so easily. He didn’t seem to mind my disability. But the waitress had pointed out that I was a blind “she.”

“Her name is Annie.” Renald said, his voice kind, the sound coming straight toward me, and I understood he was

gazing at me as he spoke, continuing the tenderness and thoughtfulness he'd always shown. He added, "Annie, what would you like?"

That night had begun a wave of gratitude in me that lasted many years.

Vasilka's voice brings me back. "Sure you don't want to keep any of these photos? I mean, someone could describe them to you."

She sounds sad, as if she thinks it tragic that I can't see old photos. Shit, really? That's the least of my worries.

"I don't care. It's like people saying how sad, you can't see that sunset, or see the pretty flowers. I don't give a stuff. That kind of thinking is sighted thinking. I don't even dream pictures anymore. It's irrelevant."

In the following silence, I wonder what she's thinking. I'm sorry. Yet I'm sick of saying sorry. If I could see, I might get a clue from her facial expression. Of course, wanting to see her face proves what I just said is rubbish. But not completely. It's complicated.

When Renald was alive, I didn't have to communicate with other people half as much. He made the decisions. Lost. I feel lost. I miss him so much. Suddenly I want to cry. I suck it back. People's pity can be worse than their indifference.

I hear the lid of the shoebox snick on and the faint sound of the box being placed in the much larger, chuck-it-out box.

Then: "This one's a Jack Reacher novel. And there's Post-it notes in it."

God, the Post-its. He was so proud of them. They helped show what a great husband he was. What everyone thought he was. I clench my hands into fists.

"The first Post-it, at the start of chapter one, says, 'Townsville ferry terminal.'"

Silence again. She must be looking at me for an explanation. I shift in my seat, "When Renald and I went on holidays, he would read a book aloud and sometimes he'd put in a Post-it note of where we were when he read."

"Oh, how lovely."

**Honestly, I wasn't
trying to remind him
of the night before,
when he'd dragged me
from the bathroom by
my hair . . .**

"Mm." I uncurl my fists. It's important to keep up the pretense, even now, if only out of habit. Of course that's not the only reason I keep quiet. Though I don't need to worry: the police believed everything I said.

"The second Post-it is near the end of chapter one. Says, 'Nellie Bay beach.' Is that also in Townsville?"

"Magnetic Island," I touch the top of my head involuntarily, and feel how short the hair still is.

We had been sitting on a beach towel side by side as he read, his deep voice clear and strong, the sound of the waves and drone of the ferry in the background.

He'd abruptly stopped reading and said, "Stop touching your head. That passive-aggressive bullshit's not going to work."

He liked to speak like that—"passive-aggressive"—when he was feeling guilty and I reminded him of what he'd done. Honestly, I wasn't trying to remind him of the night before, when he'd dragged me from the bathroom by my hair because I'd closed the door, blocking him out.

"Waiting for dinner at Stuffed on Seafood," Vasilka reads. "That Magnetic Island, too? Was it a nice holiday?"

"Yes, terrific. Warm." My fists are back. She isn't to know that the island is where he died.

"Stupid girlie café, Horseshoe Bay," Vasilka reads. "Sounds like he didn't like girlie cafés."

"Mm." My throat's too tight to talk. *When will she stop?*

My mind drags me back again, this time to the feeling of dusty sand sticking to my sweaty fingers as, sobbing, I crawled along the track, the sounds of crashing waves behind me, and my ears straining to hear cars on the road, hopefully somewhere ahead. Each time my fingers touched scrub and not track, I corrected back to the gravel and crawled forward again, desperate, knowing if I veered off the track, I might never find the road. Might never be found.

"'Arcadia Beach' is at chapter four. The last one," Vasilka says.

The last one, yes. After that we'd driven to a quiet spot and walked for several dangerous minutes, me oblivious to what was about to happen.

Renald described the great views of the rocks and ocean that he said I was missing out on. I could hear the sound of waves crashing on rocks far below, so far that I felt no salt spray on my skin, although there was a waft of rotting seaweed. My scalp felt raw—earlier that day, Renald had shaved my head as punishment, and he hadn't let me wear a hat or sunblock.

On the track beside the steep drop-off to the ocean, his next words came out of the blue. That's a strange expression, *out of the blue*. The sky and ocean are often blue. Nice things. But for me out of the blue rarely means nice.

"No one's around for miles and miles. I could push you off this cliff right now," he sneered, grabbing my arm, shoving me toward the edge, where the breeze was coming from.

I clung to him, wanting to scream "No!" But that's one of the banned words, so instead I pleaded, "Stop, please, *please*."

He pushed me in the back and suddenly my right foot felt empty air, my left still on solid ground. I screamed, twisting back toward him, and gripped his arm with both hands.

"She just walked off and fell over the cliff before I could stop her," he said. "I could do it. I could really do it. No one's looking."

No one. No one ever seemed to be looking. I was on my own.

Letting him go, I leapt to his right, away from him—and from the cliff, too, I hoped. My sandaled foot hit rock and I stumbled and fell, my shoulder banging into solid earth. I pushed up to hands and knees and grabbed for the smoothness of the track, at the same time alert for the ground dropping away on the right, where the edge might be close.

A blow to my back sprawled me flat, the sudden pain hazing my brain. He'd stomped on me. He'd done it before. As adrenaline kicked in, the pain receded and I clambered to my feet and listened for the sound of the waves as I shuffled away from the edge—*please God let it be away*.

A hand closed around my arm. His hand again. Then another shove to my back. He laughed so hard he was having trouble taking a breath.

I slid down and, vice-like, hugged his legs. He push-stepped me toward the growing sounds of the waves. As my knees scraped on the gritty sand, I had a terrible glimpse of what would happen. My lower body would fall off the edge of the cliff, and he would knee me in the head until my arms loosened and I fell to my death.

Unless I moved, now.

In a flash, I let go of his legs and scrambled behind him on my hands and knees, then sprang to my feet, holding up my hands in a stop gesture. But the truth was, he wouldn't stop: he was having too much fun.

"No one's looking," he'd said.

No one looking. My body acted before the thought finished, my hands shoving him hard in the upper arm and back—he must have been turning to look at me. He gave a surprised shriek as he fell, and fell, the sound cut off by a thump. Then another thump. Then just waves hitting rocks, far below.

I listened for his call. Strained to hear, "help," or "bitch." Anything. What had I done?

In the distance, a seagull cried.

My knees gave out and I sat, panting, a gust of wind cooling my face and sunburned scalp. No long hair to get out of my eyes and mouth. Renald had cut it off.

It would grow back, eventually.

His shriek had sounded so surprised.

But tears welled. Renald was gone. How could I live? How could I get back to the road and flag down a car?

"So, what do you want to do?" Vasilka asks.

"Sorry?"

"About the novel with the Post-its? Keep it?"

"No!" I press a hand over my mouth. I said a banned word.

"Okay," she says. Her voice doesn't sound angry, or calmly flat, like she's going to punish me later.

A thrill of relief courses from my head down to my toes, I'd told her no and it's okay.

A moment of courage surges. "You don't need to read out the book titles. I don't want any. I can pack them. Let's just focus on the boxes and drawers of papers."

"Right," she says. I hear the creak of the armchair she's sitting in as she leans forward with the Post-it note book and throws it out. ♦

GRACE KULLY

D/DISABILITY

I am disabled, but I don't know if I am
Disabled with a capital D.

apparently, Disabled means that we are proud
but disabled is just a part of who I am.

sometimes I am more proud
to be disabled for myself
than Disabled for people who I have to

explain my identity to
over and
over and
over again.

I am disabled because I cannot turn my neck,
because I am in chronic pain,
because my joints are weak.

I am disabled because I park in an accessible spot
and I have accommodations for a world that
is not set up for a student like me.

but I was Disabled when I wore my neck brace
and strangers could view my disability on their terms.

like unwanted attention from men
bred by a patriarchal society,
I lusted for this validation from the nondisabled.

for the first time
my pain was visible and real and communal.

but the patriarchy always crumbles
under the weight of its own promises

and I felt that validation vanish
as the Velcro of my neck brace came undone.

to remain Disabled, I had to explain my identity
over and
over and
over again.

you can no longer see my pain,
but it is there.

you no longer believe me,
but I am still Disabled.

but wait –
they also no longer stare
in the streets,

pray for my healing
in the produce aisle,

ask what happened
in the hallway.

I had the luxury to be
just disabled again,

on my own terms,
no longer for the nondisabled gaze.

holding on to that other part of me,
that Disabled with a capital D,
was active work

proving the validity of my identity
over and
over and
over again.

I have been both disabled and Disabled simultaneously.
but the nondisabled community
gets to decide

if disability and Disability and disabled and Disabled
and differently-abled and non-disabled and able-bodied
and handicapped and handicapable are okay for us to
call ourselves.

COLLATERAL DAMAGE

CYNTHIA STOCK

Today if I parked in an accessible spot without an appropriate plate or sign on my rearview mirror, you might see me and utter “Tsk, tsk, what a loser.”

My skin sizzled one minute; the next it felt like a feather or gnat teased my skin in the exact same spot. Later, I thought I’d been stung by a bee and expected to see a raised red bump when my skin protested enough for me to pause and take a look. The skin felt like it had been shocked. As a kid Dad had warned me not to touch one of the cathode ray tubes in the old TV set. Of course, I disobeyed. A hot vibration surged up my arm. That’s how this felt. I twisted to look where I’d scratched and saw only smooth, tanned skin.

On my days off from the hospital, I was doing what I loved, yard work. I wore my favorite bikini, the fabric covered with avocados. Each pass over the thick St. Augustine grass reminded me that few women bought, much less maintained, houses at the age of twenty-seven in the late ’70s. The repetition of the mowing provided comfort, the well-manicured yard a testament to my hard work. Divots in places where I’d dug up weeds and superficial tree roots jostled the mower. Otherwise, I pushed it with ease. *Dad, I wish you could see me now.*

Dad had died two years earlier on my birthday. I convinced myself it was his last special message to me. It secured our connection. For years Mom stopped acknowledging my birthday. We never shared our grief. Dad’s death was a lesson in burying emotions. Dad donated his body to a medical

school. He would have wanted a celebration of life. Mom never had a funeral service. Every birthday, I mourned alone.

As a child, I followed Dad back and forth when he mowed. Snippets of grass flew up at me from the blades of the old motorless push mower. Bits of green peppered his sweaty chest and fell like snow into my baby fine, light blond hair. *I love yard work as much as you. You taught me a body in motion stays in motion.*

My mom’s voice popped into my head. Mom had married when she was seventeen.

“Cindi that’s the dumbest thing you’ve ever done. How can you manage a house by yourself?” she commented when I told her I bought a house.

Quite well, thank you very much.

After finishing the yard work, I showered and slathered my skin with lotion. The tingling didn’t bother me if I kept busy which, being compulsive by nature, was easy to do. When I tried to go to sleep, however; it was utter torture.

A seasoned nurse, I administered myself a dose of denial and ignored the sensations for as long as I could. My mind, a relentless trickster, kept me awake and slipped into “what if” mode. The ever-changing, yet unrelenting, symptoms gave birth to mental chaos. Horror stories played out in my head. A spinal tumor. A brain tumor like the one that killed Dad. A virus.

The tingling became a constant. It wrapped around my lower chest. Naked in front of the full-length mirror in my closet, I hoped to find a rash from herpes. I had danced, body pressed against body, with a stranger. I searched for the rough patchy redness of eczema common in my family. I could always blame allergies. Mom almost hibernated in ragweed season. These choices were simple. Each could be treated. I sighed a sigh grand enough to subdue the sob fighting to explode from my body. *Think, woman. Be proactive.* I switched detergents and applied lotion every day, hoping a cure resided in these simple things.

My body is betraying me. I should have been warned that somewhere within me, the enemy remained, and that I needed to remain as vigilant as I did with my patients at work.

“Damn this tingling.” When the burn pushed past my tolerance level, I scratched until red lines streaked my torso.

Frustration and anxiety forced me to brave a neurologist’s office.

The doctor was a handsome, compact man with blue eyes as intense as the sensation that brought me to him. Isolated strands of gray streaked his dark hair. His lab coat needed a wash. He told silly jokes rife with adolescent humor, bathroom humor, inappropriate for a day on which he might tell me, a young woman who happened to be a critical care nurse, I had something terribly wrong with me.

The doctor seated me on a rolling stool.

“Take off your shirt,” he said. “Tell me when you feel this.” He poked me with a twenty-one-gauge needle. Needle size. Funny the things a nurse notices. The jabs didn’t hurt. What hurt was when I stopped feeling the needle touch my body. The doctor marked where my sensation changed with a black magic marker. He drew a map on my body. The black marks created a band around me the exact shape of a chart on the wall labeled The Dermatomes. The words stood out in thick, block letters, the kind used in preschool to teach the alphabet.

I left the doctor’s office and went home stuck in enemy territory, the unknown. I knew some of the latest monitoring technology and recovered patients after open heart surgery. But this ambiguous threat to my body and my role as a patient stranded me in emotional quicksand. I didn’t feel I had anyone to call for help, no one I could trust with the crumbling state of my self-perception as a woman of

independence and strength. I brooded and added miles to my daily jog. Instead of solace, the limited information the doctor provided multiplied my questions. I marked the days until the next diagnostic test on the calendar.

The myelogram took place in the guts of an urban behemoth, a hospital with innumerable beds divided among three different buildings. It involved an injection of dye into the spine and X-ray imaging. The radiology room was a dark cave illuminated by flashing lights, attended by anonymous beings in scrubs, masks, and sterile gowns. Strapped on a tilt table, I wasn’t sure I had the strength to survive such complete surrender. The table moved like a seesaw. I shut my eyes and prayed I wouldn’t fall off the table. I was the star of some macabre sci-fi movie. Passive. Tied down. No way out. Out of control.

The doctor blathered about protein in the spinal fluid. I shut out his droning prattle. He still couldn’t tell me what was wrong.

I never knew if the chemicals injected into my spine, or time, or prayer, or running further and harder than my usual seven miles caused the tingling to disappear. One morning I awakened to its absence. Normal sensation had returned; the band of numbness was gone.

I rejoiced. At work I easily fulfilled the physical demands of twelve-hour shifts. I kept allergy pills in my purse in case the tingling, which I convinced myself was from allergies, came back. I stowed the worst memories of the past months in the panic room of my brain. Dread lingered about disability and what form it could take. Functioning poorly at work. Not being able to dance until the bar closed down. Not being able to be the person I loved being. I packed it all away.

I remembered the last turkey trot I ran. I stopped at an intersection in downtown Dallas and marveled at the geometric design created by the tips of skyscrapers outlined by a pristine blue sky. That was the Cindi I had to be. “Isn’t this an amazing day?” I asked runners who swerved to allow me time to appreciate the moment.

A year passed before the symptoms came back, subtle, yet as aggravating as the first time. *My body is betraying me.* I should have been warned that somewhere within me, the enemy remained, and that I needed to remain as vigilant as I did with my patients at work. *I should have known. The doctor should have prepared me.*

This time I went to a doctor I knew, a doctor I didn’t particularly like, but one I trusted. I had stood beside him when he delivered hard truths to families.

“Don’t bullshit me, Dr. Lunsford,” I said as I turned on my side and twisted into a fetal curl on the examination table.

Bright lights and drab décor of the doctor's office created the ambiance for a critical moment of truth. A local anesthetic preceded the spinal tap. I felt Dr. Lunsford's hand tremble with the effort it took to penetrate my spine with the extra-long needle. I hated being unable to see his face. When I realized he couldn't see mine, the sense of anonymity hurt more than the procedure.

Forty-eight hours later, Dr. Lunsford called. No bullshit as requested. "I think we have to accept you have MS."

We? What an idiot. He didn't have to accept anything but reimbursement for a billing code. I had to live with this diagnosis. I worked a physically demanding job. I had a house payment to make. My biological clock was ticking. I ran every day to stay in shape and keep my demon depression at bay.

I shared none of those thoughts. My gut churned. Every drop of moisture in my mouth disappeared. All that existed for me at that moment was my body and the space it occupied.

At least now I had a name, something against which I could defend myself. Where would the next symptom pop up on a continuum that ranged from weird sensations to profound immobility? Could I risk getting pregnant? Who could I tell?

"You didn't do anything to cause this," he said. "It's not your fault."

Of course, I didn't do anything to cause this. Who would?

"I wouldn't tell anyone at work," the doctor said.

Oh, my God. That's something Mom would say. Why not? I wanted to scream. I didn't ask for this. I just try to live my best life. Relishing the evolution of science and drugs and technology in my work. Running races. Taking classes that tap into my creativity. Living with abandon. One day at a time. I do not want to be defined by a disease. I couldn't share this with anyone.

"Thank you," I said, too numb to ask any of the questions I thought of after I hung up the phone.

I needed to talk to someone. An ardent internal debate ensued. Mom was the logical choice. Mom, who thought discussing the natural physical changes of female adolescence meant providing a box of tampons, printed instructions included. All my friends were colleagues from work. I called Mom. I heard the frosty sound in her voice, a tone suspicious, a bit accusatory, and establishing distance. She sounded the same way when I shared the details of a first kiss from a boy I wasn't even dating, who'd driven me home from a party.

"I need to tell you something."

"Your stepdad and I are leaving for the Tetons with your aunt and uncle tomorrow. We're so excited. What's up?"

I knew how Mom's mind worked, how she would check off a voluminous "to-do" list to prepare for any trip, how with Mom, no time was a good time for anything but herself.

***I do not want to be defined by
a disease. I couldn't share this
with anyone.***

"I had this test done. The doctor says I have MS. But don't worry. I'm doing fine. Let me know how the trip goes."

Mom didn't pursue the subject. She didn't ask how I felt. She didn't ask what might happen to me. She shared her trip itinerary and timeline.

The conversation dwindled. The emptiness crushed me.

"I'll let you go, Mom. Have a good trip."

* * *

The MS Society provided a plethora of resources. It urged those newly diagnosed with the disease to try a support group. I had been a Brownie, a Girl Scout, but never a cheerleader or a sorority girl. The closest thing to a social tribe had been people on my swim team or fellow nursing students. Unearthing fragile emotions and runaway fears before a group of strangers went against my nature. I tried it anyway.

The group met in an oversized room in a rec center. A dozen folding chairs formed a circle. Every person triggered a noise that echoed and called attention to the culprit making the sound. I looked toward a tap-tapping and saw a girl walking with a cane. Huff. Puff. Creak. A boy maneuvered his wheelchair between two chairs into the circle. The scene looked like an AA meeting. If only MS were something I could give up. I walked slowly, one foot in front of the other, giving myself time to cut and run, before I took a seat. I dared to look at the other people.

They approached the circle with the same reticence.

One girl wore a patch over one eye. I wondered if I had the wrong room. I had nothing to show for my disease. What

insight could I offer to someone who lost the ability to walk or someone plagued by double vision? *What was I thinking? Why did I come here?*

After introductions, the facilitator said, “I want each of you to tell what brought you here.”

I now called it “my MS” because I felt empowered by taking ownership of it.

One by one, each attendee shared the MS experience.

Whether spoken or implied, I heard two recurring themes: I need to know I’m not alone. I’m afraid of the future.

I was next. All eyes focused on me, filled with genuine concern and empathy. One woman twirled her hair. Another bit a fingernail. A young man rubbed a spot on his thigh. I recognized that “tell.”

“My body feels like it’s on fire at times. It tingles. Sometimes it’s numb. Somehow it still tells me what to do with my hands and feet so I can still work and do the things I need to do.” I paused. “But I don’t know what to do, because I don’t know what I might not be able to do in a week or a month. Should I read in case I lose my sight? Should I finish my needlepoint in case my hands stop working? Should I sign up for a 10K race just in case?” I looked around and felt the courage and energy of the people in the room. “I know I’m lucky that these are the things I have to worry about.” My complaints seemed trivial when I saw how the bodies of the others had been violated by illness.

The reality of those in the group unnerved me. Their courage shamed and humbled me. I never attended another meeting.

* * *

The numbness became a familiar. I accepted it as an amiable companion unless the sensation ramped up and made me feel like I was walking on hot coals. Ironically, my feet burned when I walked barefoot on cool tile. I understood the concept of paresthesias. I jogged regularly. *Just like brushing my teeth.* I challenged myself by running in the heat of the day. Contrary to articles I read, the heat never bothered me.

When no amount of alcohol or music or dancing or sex could shift my focus from the pain, when I thought I couldn’t bear one more minute on Earth, I thought about suicide. I made an exit strategy. Joni Mitchell in the CD player, a full-bodied

cabernet, and my beat-up old car in the garage. Having a plan gave me control. I needed one thing I could control.

I swore my disease was sentient, because just when I thought I couldn’t bear another day, the burning and tingling faded again. My gait steadied. I stopped attributing every little bodily change to MS. Relapsing-remitting. I read about it. *Now I understand.*

“See, girl, just allergies,” I told myself, “Always worse in the spring.” Denial reemerged as trusted therapy. Suicide lost its attraction.

* * *

“Dammit, you won’t own me. I will own you.” I tried to live by that mantra. Occasionally raging angst triumphed over common sense and transported me to a dark place packed with worst-case scenarios.

I checked my visual clarity several times a day. Idling at an intersection, I read street signs one eye at a time. First the names of the streets, which were usually no challenge, then the block numbers. My right eye had always been far-sighted. My left eye saw the numbers, but with less focus. Nothing new. Incontinence. I never went anywhere without knowing where the toilets were. At the theater, I went to the bathroom before the show, during the intermission, and before leaving. In my car, I carried what I thought of as a mini bed pan, in case I ever got caught in traffic. It made me feel like a child struggling to gain control of its body. Once stuck in a line of cars stopped by road construction, I tucked a towel in the driver’s side window for privacy and actually used the plastic receptacle. It never dawned on me that loss of function was beyond my control. Immobility. I never could sit still. Immobility would kill me. Exit strategy. There was always my exit strategy.

My MS hibernated. I now called it “my MS” because I felt empowered by taking ownership of it. I ran compulsively, countless miles in the scalding Texas heat. No visor. No water bottle. No sunscreen. Just prayers and meditation. I saw beauty in thin, cirrus clouds and envisioned them in my body, linked like nerves, like axons and dendrites that had yet to demyelinate. I swore a good run burned my MS out of existence.

I thrived and lived an ordinary life marked by the usual rites of passage, navigating day-to-day survival. Work. Paying bills. Connecting. Staying upright.

* * *

Years of working, logging hours of overtime, continuing education, and eating on the run, took its toll on my body,

but not from my MS. My body blossomed. It was neither healthy, nor attractive. I couldn't control MS. I could control my weight.

I reduced my fat intake to almost nothing. I ran my usual seven miles, but added thirty minutes of tai chi to my bedtime regimen. The fluid movements of the man on the video relaxed me and diffused the stress of the day. The extra weight disappeared too rapidly for me to mentally keep up with the drastic change. I finally mounted the mirror on my chest of drawers, but still saw the hefty woman I had been. Losing seventy pounds in six months triggered an MS relapse.

Days before a planned visit to see Mom, my feet felt like they were packed with rice. Numbness simulated a pudendal block, something I'd learned about in nursing school. I felt nothing along the inside of my thighs or perineum. Losing feeling in intimate places turned my thoughts toward the unpredictable phenomenon of disability. Then, my MS disrupted sensation in body parts I couldn't ignore.

While I charted on the computer at work, two fingers on my dominant hand felt numb. The fingers found the right keys, even typed the correct letters, but hardly felt the letters etched in the plastic keyboard. *Please God. Don't take my hands away from me.* It was hard to pray to a higher power that was allowing my body to self-destruct.

"Mom, my MS is flaring up a bit. I can't make the trip down to the beach." I rehearsed the speech to deliver over the phone, rubbing the numb patch on my thigh. I pinched myself until my fingertips blanched but never felt a thing. I repeated the process numerous times. The next day purple blotches, like miniature flowers, covered my leg. In bed alone, I masturbated. I explored my body, noting the places I felt nothing. When my fingers explored my most private parts, the resulting arousal proved my nerves weren't completely destroyed. *I'm not dead yet.*

I went to see Mom after all. I needed to talk about what was happening to my body.

When I stepped off the plane, Mom, a woman who obsessed about weight, let her eyes roam up and down my body. "Oh honey, you're too thin."

I should have known no weight would ever satisfy my hypercritical Mom. *Weight is the fucking least of my worries.* Although my reality merited profanity, I would never talk to Mom that way.

On the ride from the airport, an awkward silence prevailed.

"Let's take a dip before we take you out to eat," Mom said.

I hurried to the edge of the pool and slid into the coolness. Every step hurt as if I were stepping on dull pins or my feet were so swollen the skin was ready to pop.

"So how are you feeling?"

Mom's comment about my weight undermined any willingness to share details about my MS. Mom would never understand living beneath an invisible threat, my MS, my personal sword of Damocles. What Mom couldn't see qualified as minutia.

"One day at a time, Mom."

During the drive to the restaurant, my stepdad updated me on my stepsiblings and his volunteer tax service. Mom glanced at me from time to time. I wore a top and skirt soon destined to be too big and my favorite open backed Aigner sandals. We entered the foyer of the restaurant. The sandals slapped the linoleum. Mom rated the house specialties. Halfway across, I watched one of my sandals fly across the floor. I never felt it leave my foot. A part of me laughed at the sight of the brown woven projectile. The other part, the sensible, vulnerable, troubled part, gaped, taken aback by the stealth with which my disease demonstrated its presence to the world.

Please God. Don't take my hands away from me. It was hard to pray to a higher power that was allowing my body to self destruct.

Mom's face expressed more than words could. *Is this a joke?* it asked with a grim, downturned press of her mouth. Her eyes surveyed the restaurant to see who witnessed this debacle. Only she saw a crisis.

"My feet are a bit numb," I said as I retrieved my sandal.

"Do you need a wheelchair?" Mom asked.

Mom's response, spontaneous and unfiltered, delivered a verbal slap. *A wheelchair? My sandal just slipped off. I'm still upright.* "I'm okay. I can walk."

* * *

Months of high dose steroids stifled the MS. The drug made me feel so good, I lost more weight and burst with energy. I pulled twelve-hour shifts, sometimes walking up to six miles. I moved patients twice my size from bed to chair and

back and lifted heavy equipment. *I will not be defined by my disease. I am not the nurse, the runner, the woman with MS. I am Cindi.*

MS altered how I treated patients. Cardiac patients became more than a cardiac output or a mean arterial pressure or a measure of hourly urine. Trauma victims were more than broken bones, compartment syndrome, or sepsis. There was the correctional officer with a big family to support, an orthopedic surgeon, a biathlete who flipped over her handlebars after hitting an unseen rock and desperately wanted to get back on her bike. All were people of depth, dimension, and dreams, just like me.

* * *

I developed a peaceful coexistence with my disease; I struggled to do the same with Mom, especially when it came to discussing our health. A priority with a woman approaching her century mark, our phone calls usually began with a tirade about Mom's current state of being and the health care system.

"My PCP sees me, charges me, and doesn't do a damned thing." With the phone on speaker, words seemed to emanate from a grand, universal authority. "And I'm still nauseated in the morning."

"Do you take what she prescribed?" I asked, already knowing the answer. Mom prided herself on taking just a few prescription meds, choosing the martyrdom of suffering over recommended intervention.

"I don't like to take pills. You know that."

Much easier to suffer and complain.

Mom's obstinance triggered a response that steered the conversation into one I usually avoided, MS.

"I wish I could still afford my meds." The biggest shock of retirement was my inability to afford the newer, most effective drugs. The doctor reassured me an aging immune system rarely caused flare-ups and discontinued the medication I could no longer buy.

"Well, I have a friend here at Jasmine Court who has MS and she is doing so well. It's amazing."

"Stop, Mom, I don't want to hear it."

"She's . . ."

"I don't want to talk about it. She isn't me," I said. *Does she work out six days a week? Does she write to publish? Does she live fearing the same things I do?*

Mom continued her monologue of accolades.

"Stop. Stop. I can't listen to this." *You will never understand what it's been like for ME.* The conversation ended with the promise of a Mother's Day call. I sat so still for several minutes. Surrounded by the comfort of my cats, my books, the creaks and sighs of an old house, I allowed myself several minutes of mourning.

* * *

A bug biting my left posterior thorax awakened me in the middle of the night. *A spider.* I patted my body and shook out my night gown and found nothing. Back in bed, I felt another bite. This time it sent a chill down my left leg that should have roused goosebumps. It did not. I scratched and scratched, before remembering the steroid cream my dermatologist had prescribed for dry skin. Minutes after applying it, the biting sensation stopped.

My leg still tingled. I blamed the ancient sofa in the living room and its deflated padding for putting pressure on my sciatic nerve. I blamed too much wine, although I never drank more than one glass. I blamed osteoporotic vertebrae putting pressure on my nerves. I blamed a bout of COVID-19 that put me in the hospital with a closed head injury from fainting.

I inventoried the things I'd not faced over the past months. When I thought I picked up a pill to take, I'd look and find it sitting on the countertop. My fork slipped from my grip on more than one occasion. My fingers never managed to get my earbuds securely in place the first time. I no longer took out my stud earrings for fear of being unable to get them back in place. I practiced finger opposition, touching each finger to the thumb as rapidly as I could. How many times had the doctor asked me to do this simple task at the MS clinic? Numbness failed to completely deaden my lower legs, but they felt different, as if gauze wrapped around then like a loose knee sock. They felt heavy. No. No. Not now. It can't be.

I ventured toward the abyss of depression, but backed away. My body had wrestled this foe for over forty years. It wouldn't defeat me now. The next morning, I finished my standard two cups of Jamaica Me Crazy flavored coffee and took a deep breath as if preparing for a deep dive with no oxygen tank.

"Siri, call the UT Southwestern MS Clinic."

For now, I am still upright. ♦

PMF

WHAT DID I DO TODAY?

I asked myself this question
 but I didn't care for the answer
-not much of anything-
 After getting dressed this morning
 in the same clothes that I've had on
 for the past three days
-oh, I smell them first
to see if I should wear them again
but who the hell cares
certainly not me-
 I dropped the kids off at school
 and went home
 the post office opened at 9 o'clock
 and I was there when it did
 I dropped off a package
 and went back home
 the house was cold
 I wrapped myself in a blanket
 and lay on the bed
 for a few minutes
 contemplating
 going back to sleep
 No! can't do that
 must do something, anything
 I went into the kitchen
 and got a cup of coffee
 still wrapped in the blanket

sitting on the couch
 in the living room sipping my coffee
 I stared at the clock—9:40 a.m.
 I should be doing something
 but what???
 finishing my coffee, I sat there
 just doing nothing
 staring at nothing
 thinking absolutely nothing
 when I focused on the clock
 it was already 10:30 a.m.
-that was productive-
 I thought to myself sarcastically
 get up, get up, GET UP!
 I have no motivation
 there's nothing I want
 and nothing I want to do
 except sleep
 But I know that sleeping
 during the day is a sign
 that my depression is taking over
 so, I avoid going back to bed
 but it's difficult to avoid
not caring
 about anything
 especially
 myself

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NESTING

SHELLY JONES

The bees were in her hand again, vibrating against her skin, prickling her palm. Their wings bumbled against her muscles, which spasmed with each lurch, each failed attempt at flight. Honeycomb stiffened her fingers, her hands unable to grip. She flexed her fingers and waited for the bees to settle once more.

“Patient complains of paresthesia in the upper extremities. Physical therapy recommended.”

* * *

In the winter, a spider crawled into her eye socket and wrapped its gauzy web across her sclera. When its babies hatched, spilling hungrily over her iris, they searched for their mother and devoured her, spindle legs crunching. Sated, they slipped down her sinuses, their many legs tingling her cheeks. They wrapped their many lines around her tongue, stiffening it silent, camped below her gums, and waited to sting any who invaded their motherland.

“Patient complains of blurred vision, occasional trigeminal nerve pain in

cheek and jaw. Ocular reflexes normal. No evident injury to the cornea. Recommended action: follow up with an ophthalmologist.”

* * *

Her feet sank into the mud in the spring, as though the earth was swallowing her, opening its many mouths with each squelching step she took. At night, her legs turned to clay. Bits of muscle sloughed off in bed, staining her sheets a coppery red. As summer days stretched long, she sowed seeds in her thighs and belly, cosmos and calendula, and sunned herself in the yard to watch them sprout, her legs unable to move. She picked at the stringy roots that latticed her flesh, keeping her body together, and could not feel when her legs crumbled into the earth.

“Patient exhibiting asthenia and ataxia. MRI ordered.”

* * *

A swallow built a nest in the back of her skull. “A cup nest,” she had

explained to the others sitting in the doctor’s waiting room, who nodded and turned back to their magazines. She had looked up the term online, watched videos of swallows flitting across rivers or nesting in barns, heads cocked inquisitively. The thatched hammock swung low down her neck and she tried to imagine the little bird zipping in and out, its jeweled feathers refracting the harsh fluorescent light of the office. As she waited for the doctor, the swallow skimmed her vertebrae, feeding on her desiccated discs. She shivered and pulled her hoodie up over her head.

“MRI results indicate a 4 cm mass in the occipital lobe. Additional lesions are seen at C1 and C2. Advanced stenosis and myelopathy present. Biopsy of mass is recommended.”

* * *

She read that when storms thundered, swallows were unable to find enough food, leaving their babies famished in their nests. She wanted to starve the swallow growing in her skull and spent hours in the local pool, swimming the backstroke, her head submerged

in the chlorinated water. The sparrow flitted up and down her spine, perching on each vertebrae, searching for protection. After swimming, she'd fester in the sauna, hoping the little bird would fly free to escape the heat or shrivel like an overripe grape on the vine. But the swallow settled in its cup at the base of her skull and seemed to bask in the thick air of the sauna. She'd trudge home from the community pool through drifts of snow, her screams drowned by snowplows scraping the roads, salt crunching in her boot treads. The bird ruffled its downy plumage and preened happily, unfazed by the harsh conditions.

"Patient is maintaining regular exercise. Recommend seeking additional therapies as needed."

* * *

In the new year, she strung a series of feeders and birdhouses in her yard, hoping to coax the swallow out. Wandering by the river's edge and along the old canal trail, she tried luring the swallow to dive into the rushing water, to arch and sway, to lunge for the insects skimming the surface. But the swallow would not leave its nest, and spat more mud into her skull, pecking at bits of gray matter to fill in the gaps, preparing for spring.

"Tumor is benign, holding size, and minimally symptomatic. Recommended course of action: watchful waiting. Repeat MRI in a year."

* * *

The swallow sang to her at night. Its chittering reverberated in her skull as she lay in bed, watching the stars wax and wane in the early morning light. Feathers rustled and molted, clogging her sinuses and ears, and she coughed bitterly, plumes lining the back of her throat. The walls plunged and careened upon her as birdsong wound around her head. The swallow flittered within its skull cage, battering her brain with its feeble wings. She pinched her eyes shut and sank further into the covers as the little bird whined its morning alarm.

"Patient experiences headaches, vertigo, and dysphagia. Is unable to take medicine orally. Start IV interferon."

* * *

When gray clouds peeled away to reveal a hazy blue sky, she laced her sneakers and walked to the park, her cane testing the path in front of her. The sun warmed her face and the swallow basked in its nest. Snowmelt had given way to greening grass and clots of mud.

Folks dotted the lawn with blankets, jackets shed. Then suddenly she could hear it, beyond the chatter and squeals of children on the playground. She could hear the other birds singing, living in those around her: wings fanning blood through their veins, beaks pecking holes in their muscles, organs. Their bodies were lived in like a favorite flannel or hoodie, comfortably frayed. Or, she thought, like a bird's nest, sinews sticking out like straw, a discarded ribbon threaded through. She walked and listened to the melodies spilling from a couple playing pickleball, a different tune from a woman walking her dog, another from a girl giggling on a swing. The birds crescendoed in her ears until she had to stop and catch her breath at a bench beneath the pines.

The swallow chattered excitedly, flitting up and down her spine, and finally, she opened her mouth wide so it could sing. ♦

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ESCAPE CHOICE

EMMA BURNETT

*D*ear Dr. Baek,

We regret to inform you that there has been an incident with Max at school today during our mandatory evacuation drill.

Max will be required to stay after school tomorrow to repeat the drill, and we feel we need to meet with you to ensure this behavior is taken seriously for everyone's safety.

*Yours in voyage,
Maresa Lehrer*

* * *

Max glanced at his mother's face. She had that line between her eyebrows, which sometimes meant that she was thinking, and sometimes meant she was annoyed. He looked briefly at his teacher, sitting across from them. Her face was too blank for him to interpret.

He looked out the window and started counting stars that looked blue.

"Max, it would help if you engaged in the conversation." His teacher had asked something, and wanted an answer.

He muttered, "I hate the escape pods."

"Yes, you've said that," his teacher said.

"I don't like getting into them. They have no alone space and they're too noisy. People touch me." He glanced at his mother. She nodded with what he thought might be encouragement. "They have no bathrooms."

"There's a flip-out toilet in each one."

"It's not private." He looked back out the window. "I don't like them, is all."

"But . . . that doesn't matter. You're not supposed to like them. If there's an emergency, no one's particularly going to like them, are they?"

"All the other kids like the drills, though. I don't."

His teacher took a breath to reply, but his mother cut across her. "I really don't think this is helping," she said. "We've been trying to work through this for years. He's always had a problem with chaotic spaces."

Max hated when people talked about him while he was in the room, but they did it a lot. He crossed his legs on the chair and fidgeted with his fingernails, picking harder when their voices started to rise.

"I'm sorry, but I don't think you're dealing with this the right way," his mother snapped.

Maresa's face wasn't blank anymore, and her voice was edging toward the volume she used in a busy class. "Yeah, well, maybe I'm not cut out for this!"

"Maresa, you signed up for the job."

"I signed up to help teach half a dozen kids, ten years ago. No one predicted this bumper crop of kids." She looked down at her desk for a moment. "I didn't realize what I was signing on to."

"There's another option."

"Oh, come on. You know I'm a bad candidate for cryosleep. We both are. All those complications with people under thirty, and now," she gestured at Max. "It's not like we can go to sleep and leave them. I get that I'm not the ship's best teacher. I'm a road planner. I'll be properly useful when we arrive. But I'm trying, here."

Max was getting restless. The office was too bright, the chair's fabric too creaky. The adults were too loud, and anyway, he didn't like listening to them argue. He wanted to be in his quiet, tidy room.

Something moved across the window, blocking his view of the stars. He stared for a moment, then uncrossed his legs and walked to the window. He suddenly wished he could be the person blocking his view, and he touched his forehead to the glass.

"I want to do that," he said loudly. He pointed at the window, at the person doing a hull inspection. His mother and teacher looked at him, confused. "I want to be out there, where it's quiet. If I take care of our home, I'll never have to get in an emergency escape pod."

"But," his mother said, "but, Max, I'm a scientist."

"So?" His forehead scrunched.

"So, I . . . I just assumed you'd, you know, work with plants. Like me."

Max felt his stomach tighten. His mother worked in a busy laboratory. There were sharp smells and bright lights in there,

and lots of people with elbows that bumped you. "Do I have to do what you do?"

"I never thought about it. I guess, maybe not?"

Maresa stared at Max for a moment, face unreadable again. Then she nodded. "Hmm. That's an idea, Max. I will talk to maintenance, find out what training you need to do in order to work with them." She smiled. "We need ship caretakers. It's a long journey."

* * *

Dear Max and Dr. Baek,

Keeping you both in the loop. As you know, Max's training finished last week, but we can't offer him a position until he's prepared to do regular space walks. We'd like him to join the team, but he'll have to suit up and go out.

Max, we'd be excited to have you on the team. Please let me know your decision.

*Best,
Wayan*

* * *

Max was relieved to be done with a busy day and away from the crowded cargo hold. The day had been full of people talking and bustling around him. It had been draining.

He leaned a hip against the countertop in their little kitchen, stirring the gently simmering sauce. He wished his mother would let him concentrate.

"This is what you wanted, Max. You trained for it." He thought she sounded frustrated.

The timer rang, and he turned off the cooker. He poured the noodles and vegetables, picked fresh from the ship's gardens, into the sauce. Then he mixed everything gently together.

"Dinner will be ready in two minutes." He glanced at his mother's hands. There was vermiculite under her fingernails.

“Wash.” He pointed toward the bathroom. She tutted, but went.

He took a deep breath in the suddenly quiet room, and stared at the countertop. He counted flecks of red in the molded plastic. Once he’d reached twenty, he started to pull out plates and cutlery, two glasses and a bottle of cold water.

He could feel the safety cord anchoring him, but otherwise he drifted in the nothingness.

“You love being out there,” his mother said, coming back into the kitchen, wiping her hands on her trousers. He was tempted to tell her to wash them again, but tried to pretend he hadn’t noticed. “You’ve wanted to work with the exterior maintenance team since you were little.”

The folds around her mouth meant uncertainty, that she didn’t understand.

He put on his thinking face and tried to order his thoughts. She didn’t rush him. They set the table and sat down.

He stared into his plate for a moment, then said, “I *do* want to be out there. It’s beautiful. And so quiet. It’s easy to focus.”

“So, what’s the problem, then?”

He wished she didn’t sound so aggressive. It made it hard to find the words to explain.

“There’s no shitguard.”

“I . . . what?” she asked, around a mouthful of noodles.

“The EVA suits don’t have shitguards to absorb cosmic radiation. The ship does. The emergency shuttles do. Even the cryosleepers have shitguards, in case of emergency evac. It’s part of the waste system, but it also protects us. It’s not right that the maintenance crew don’t have protection.” The noodles were soft and flavorful, the vegetables just slightly crunchy. He chewed, satisfied. “I don’t think it’s fair. I don’t want to walk out into space and immediately get irradiated.”

She frowned. “Have you raised it with your boss?”

“I did, yeah. He said a shitguard would make the suits too bulky.” Max took another bite. It had taken a long time to get used to combined textures, but now he loved it. “I think he was blowing me off.”

“Right,” she said. Max waited for her annoyance to bubble over. Although she tried to stay calm, his mother often told him to stop whatabouting and just get on with things. He’d mostly stopped trying to explain that his whatabouts were important to him. “So, what are you going to do?”

He looked at her in surprise, and nearly burst into tears as a rush of gratitude welled up.

“I guess, maybe I could talk to Wayan about doing more training inside the ship. There are all sorts of internal maintenance things I don’t know. Maybe I could learn more about navigation, too. I was talking to one of the trainees, Kaley, about it.”

“Oh, yes?” His mother smiled.

He looked back down. “We talked. She was nice. Also, I was wondering if maybe you could show me around your lab?”

“You know I’d love to. But why?”

“Well, I have some thoughts about the EVA suits, how to develop an algae shield, maybe? Thicker cell walls or something? I thought, maybe you could help me.”

His mother smiled, and reached across the table to touch his hand briefly, before he could pull away. “I’d be delighted. You know I’ve always wanted to get you involved in my plants.”

* * *

FFS, Max, you can’t be serious about staying. The ship will be fine by itself. It doesn’t need a crew, it’ll be in geosynchronous orbit. Besides, you’d be alone up here, for, like, ever.

*Don’t be an idiot.
Kaley*

* * *

Max hung from the ship. He could feel the safety cord anchoring him, but otherwise he drifted in the nothingness. His comms were turned off, so he couldn’t hear any chatter on the line. No one would ping him unless it was an emergency.

He stared at the planet below.

They had arrived over a month ago, spent weeks scanning, sending scouting missions, making sure the calculations from decades before were correct. His mother had gone down with one of the early groups, to start off the farms they’d need in

order to support the ship's residents. Her messages sounded excited. Max missed her, but had absolutely no interest in joining. The planet looked foreign to him, and he wasn't into it. He'd been born on this ship. It was his home, and he wasn't planning to go anywhere.

He looked back at the booster he was fixing. The weld looked solid, and the readouts were good. He moved back toward the airlock.

Once inside, he drained the algae from the suit. It sloshed back into the vat, lit by grow lights. He liked to think it was happy to be home after the excitement of going out.

Then he put on his headphones. The ship was busy, full of bustling people packing up their lives, getting ready to start a new one. It was noisy, chaotic. He'd taken to wearing the headphones whenever he was in the corridors, dulling the echoing noises. People assumed he was listening to something, and left him alone.

He checked his to-do list. Broken food court dispenser. Unlikely to be quiet there. Leaky sink. That'd be easy and he could lock the bathroom door. Perfect. Max turned a corner, and nearly ran into Kaley. She gestured for him to remove his headphones.

"Hey," he said.

"Jackass." It was a response, though not the one he'd hoped for. She leaned in and kissed him briefly. "You know, you wouldn't need those headphones if you just did your EVAs and then came back to my quarters."

He shrugged. "There are things to do. Plus, I won't need them when the ship is empty. When everyone else is planetside, it'll be calm. Quiet."

Kaley's face was hard to read, but he thought he detected anger. She was good at hiding her emotions, though, and he sometimes struggled to guess. He'd asked her before to tell him outright, but he wasn't sure this was the right moment to remind her.

She turned and started walking. Max decided he was supposed to follow her, so he tucked his pad into a pocket and fell into step next to her.

"You're not actually serious, right? Like, for real?" she asked.

"I mean. Yeah, I am. We've talked about this before. It's what I want to do."

"I don't get why you get to make this decision, though." She was storming down the corridor. She pushed past people, and

a few of them stared after her. Max tried to look apologetic. "You're choosing for both of us. We are supposed to be partners."

Max hurried after her. "I'm sorry."

"You're sorry I'm your partner?" She took a left and opened the door to her rooms. He followed her in.

"I . . . no?" He paused to think, stared at a spot on the wall. "I'm sorry we want different things."

"You don't seem to care what I want. This is all about you."

Max felt this was unfair. Her perspective was all about her, after all. He had suggested that Kaley stay up here, at least for a while. She could manage the satellite launches that would support the new planet's comms system, work with the ground crew on continuing to unload the huge amounts of supplies still in storage on board. Kaley wasn't interested.

**He'd been born on this ship.
It was his home, and he wasn't
planning to go anywhere.**

Max didn't want to have this argument again, so he shrugged.

"No one else thinks you should stay here, either. Not your mother—"

"Actually, I think she's OK with it, now she knows we can talk on messages," he said. "I got a message from her—"

"Don't interrupt me. Maybe she says it's fine, but I doubt it. And the rest of the crew think it's crazy. You're separating yourself from everyone. It's not normal." She prodded him with a finger. "Hey! Look at me when I'm talking to you."

He made eye contact for a moment, then looked away again. It was too much, trying to think and look at her.

Max wished he had the words to convince her, to convince everyone, that he was making the right decision for himself, but in the end, he didn't have to. This was what he wanted to do. It felt right to him, and they didn't have to agree.

"Look, the ship is going to be parked, but it needs someone to make sure things are OK. Like, today, I was outside, did a fix on one of the boosters, which could have died and the whole ship might have careened down to the planet. Or last week, I mended the water link to the biodome. Without it we'd have no seedbank. Or—"

"Yeah, fine, whatever." She kicked the wall, and Max briefly felt annoyed. He'd just been talking about mending the ship. He guessed that's why she'd done it.

"You could stay?" Max tried again.

"No, I couldn't." Kaley's face had gone unreadable. "And I don't want to. Everyone is going down. We're waking the last of the cryos today. It's all kicking off."

Max tried not to make a face. He wasn't looking forward to even more people bustling round the ship. At least it would be temporary.

"This is what our parents set out to do, it's what we've been raised to expect. Brave new worlds and everything. I want to be part of that." She stared at him for a moment. "You just don't get it, do you?"

Max shook his head. "No. But I don't think you get where I'm coming from, either. This is my home, it's where I belong. You know I used to get upset when they'd make us pretend to emergency evac? It's gonna be chaos down there. You say that's what you want, to be part of all that. But I don't. I want to be somewhere calm. Somewhere I feel safe. I'd like that to be with you, but if it's not . . ."

"Fine."

It sounded like a very final response.

"Maybe we can keep talking, though? You could tell me how it's all going down there?"

She shrugged and turned away. Max thought this was fury, though it might be sadness.

He felt sad, too. He knew it would be a lot of change for both of them. They'd been together since she'd taught him

about the ship's navigation. But he hoped that she'd find new, satisfying work down on the planet, find the kind of relationship that worked for her. Because he felt good about his choice to stay and maintain the ship, and keep doing research on things that mattered to him.

His pad pinged from his pocket. He pulled it out and looked down. Drama in the cryoroom. He looked up at Kaley, but she still had her back to him. It was a clear signal.

Max put his headphones back on, and left the room.

He would miss her. And his mother. And so many others. But, really, he was looking forward to just being here, being himself, in the deep quiet.

* * *

Heya mum,

Yep, I got the data you sent—your adapted plants are looking amazing! I've got a new strain of algae going, working on one that's transparent when it's not photosynthesizing. I'll send more info soon.

Also, I've been watching the roads getting laid out from up here. NGL they don't make sense to me, but I'm sure Maresa knows what she's doing.

Had another satellite launcher failure, but it's under control now. Good times.

Love to everyone (esp. Kaley. I don't think she's ready to talk, but maybe pass it along?).

M♦

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JANET ENGLE FRASE

PROMISES MADE

I reach for his hand,
which is cold and stiff,
though his fingers curl
in the warmth of mine.
Love is in our clasp.

Looking into his blue eyes,
dull with brain's erasures,
he whispers, I'm anxious.

On the far side now
of promises made, never
to let the fingers of fear
prickle at his neck, I run
my fingers over his head
and down his neck, a warm
caress to ease the sting.

Today's reality . . .
there is a tremor
in our together hands.

TRYSTAN POPISH

BIOLUMINESCENCE

Another winter in Seattle,
and the Emerald City has slipped
beneath the Sound, settling
like a shipwreck
to the bottom
of an ocean of gray.

Each day I drift
down watery streets
with other sinking shells,
my skin
forgetting the feel
of sunlight's fingertips.

I wish that I could leap
above the waves, jump
with the joyous rebellion
of an orca breaching,
breaking her bonds if only
for one sunlit moment.

Instead, I dive deeper,
sink so far there is
only the dark.
Where life, to survive,
has learned to burn
with its own light.

I begin wearing neon pink
tennis shoes with glowing
green laces, a reminder that other hues
exist outside this monochrome,
fluorescent feet my best attempt
at bioluminescence.

THE UNWELCOME GUEST

LORI HAHNEL

Freshly-harvested fields roll out in gentle gold and green waves in the distance ahead as I drive from Calgary to Medicine Hat on a warm September morning in 2015. That afternoon, I lead a writing workshop at Medicine Hat Public Library as part of Alberta Culture Days. As a participant shares a freefall piece she has just written, I feel a sudden rush of severe dizziness and have to hold on to the table beside me to keep my balance. The floor feels like it's rushing up to my face, and I close my eyes for a few seconds. I'm pretty sure it will pass because this has happened a couple of times before when I've been teaching over the past year, although this dizzy spell is the worst one yet. Soon it fades, and I make it through the rest of the afternoon without a problem. The previous dizzy spells I'd written off to low blood sugar or fatigue, but this one was a little disturbing. I will mention it to my doctor.

* * *

A month earlier, I'd noticed my left ear felt plugged. I tried an over-

the-counter cold remedy, which did nothing. My doctor tried a couple of different antihistamines and a steroid spray, which also did nothing, and then referred me to a specialist who I saw two months later. The ENT prescribed yet another antihistamine, and gave me a requisition for a screening MRI.

Maybe this was something serious. "An old friend of mine had an acoustic neuroma," I murmured, staring at the form.

"This is just to rule anything like that out. They're extremely rare."

Nine months later, in August 2016, I got in for my non-urgent MRI. Two days after that I got a callback and returned for an MRI with contrast. Now I was panicked, and waited for a call from the ENT. She was on vacation, I was told when I called her office two weeks later, and apparently had no colleague to handle test results. So I reviewed the results at my doctor's the next day: I had a small (1.3 cm) vestibular schwannoma, also known as an acoustic neuroma (AN), a benign,

typically slow-growing tumor of the Schwann cells of the myelin sheathing covering of the acoustic nerve. They are classified as brain tumors, my doctor said, and the occurrence is rare—three in 100,000 (lucky me). Except that an old friend and my husband's coworker's spouse had both had one. And now I had one.

The diagnosis was terrifying initially, although my doctor also said that if you have to have a brain tumor, this is the one to have. My first reaction was that I didn't want to have a brain tumor at all. I knew something of what they were like: my husband had a meningioma—a benign tumor of the meninges, the lining of the brain. He was diagnosed and had surgery in 2004, and had a course of radiation two years later for some regrowth. A few years later, a family friend was stricken with an aggressive astrocytoma. In three weeks, she went from diagnosis to death, devastating her husband, twelve-year-old daughter and ten-year-old twin sons.

The first acoustic neuroma was discovered during the autopsy of a

deaf man in 1777. Depending on the tumor's size and location on the nerve, it presents with different symptoms for different patients: dizziness, tinnitus, loss of hearing, facial paralysis, vision problems, loss of taste or smell. Worldwide, for as long as they've known about acoustic neuromas, only a handful have been malignant. For an unlucky few whose tumors are located near the brain stem, the first symptom may be death. Once diagnosed, I had the explanation not only for my hearing loss, but also for the fatigue and intermittent dizzy spells that had been dogging me for years. I had given up on getting any help for those symptoms. When I was forty-eight, one doctor told me that at my age I should just expect to be tired all the time. Many blamed my mostly vegetarian diet, and several suggested I take an antidepressant, probably out of sheer exasperation.

* * *

The first night in our new house in September 2008, my husband and sons are out at a Scout camp, and I am alone with our pets. I decide to watch a movie on DVD, since our cable isn't yet hooked up. While setting up the DVD player, and after *The Adventures of Robin Hood* is over, I notice a humming sound that I eventually decide is coming from the clock on the original, decrepit 1963 built-in oven.

"The clock on that oven is making a really annoying sound," I tell my husband when he returns.

"I don't hear anything."

"You can't hear that humming?"

"No."

That guy needs to have his hearing tested, I thought.

* * *

With diagnosis, I also understood for the first time that I had tinnitus. People with tinnitus hear constant ringing, humming, whistling, buzzing, or chirping sounds. ANs cause tinnitus by damaging the acoustic nerve, as my new ENT explained. I had become accustomed to it by this time and didn't really notice it until I was asked about it.

Referral to an ENT who handled ANs—there are two in Calgary—took six months, which seemed like forever. Acoustic neuromas are *not* brain tumors, he said emphatically when I finally saw him in March 2017, but are often classified as such. He also said I had probably had it for at least fifteen years, since they are slow-growing. I could easily have another ten years on watch and wait before I would need to treat it. Watching and waiting would allow him to determine the rate of tumor growth, and my symptoms, he explained, were likely not as bad as the aftereffects of either surgery or radiation. And best-case scenario, since the rates of growth of ANs are unpredictable, I might not ever have to do anything to it.

That turned out not to be the case. Over the next year the tumor grew from 1.3 cm to 1.7 cm in length. That doesn't sound like much growth, but as well as causing more dizziness, it had a devastating effect on my hearing. When I was first diagnosed, I still had 70% hearing in my left ear, and a year later, I had 23% left (luckily, I have 95% in my good ear). While it's not uncommon

for AN patients to lose all hearing in the affected ear, I wanted to do something about it before that happened, even though there was a chance that radiation might cause me to lose what I had left. I chose to have radiosurgery, also known as gamma knife radiation, at the Tom Baker Cancer Centre on Sept. 12, 2018.

* * *

A block into a morning dog walk a few weeks before radiation is scheduled, I realize I have forgotten to wear my hearing aid, and instead of going back, decide to carry on without it. Soon I notice that although my dog is walking on my left side, the AN side, I hear his claws click on the pavement on the right side. It's disorienting and a little disturbing to realize I have so little hearing on that side, and to realize there is a good chance that my perception of where a sound is coming from is faulty.

Not only that, I worried I might lose my hearing to the point where I couldn't enjoy music again. Music had always been an important part of my life—was I about to lose my enjoyment of it?

* * *

When I arrived at the hospital at 7:00 a.m. that day, a six-pound metal frame known as a halo was screwed into my skull. The halo would guide the beams to the exact spot in my head where the tumor was located. Most of the rest of the day was spent waiting for the surgeon and his team to work out a plan for the treatment, involving computer modeling of a minutely precise nature to direct the radiation to exactly where it would blast the tumor. At close to six that evening, the treatment started. They asked me what music I'd like to

hear during the procedure and I asked for Bach. I heard ten minutes of the *Brandenburg Concertos* after they bolted my halo onto the operating table and began the radiation, which I did not feel at all. Then at last the surgeon took the halo off. And my husband, who had sat with me all through that long day, drove me home and helped me apply antibiotic ointment to the four holes in my head.

I had a hell of a headache for a couple of days after that. It took a couple of months for my energy to return, but it gradually did, and I got back to doing most of the things I usually do.

* * *

My Facebook AN support group has been a great help to me, with members from all walks of life, at all ages, from all over the world, many of whom have also been told to just take an antidepressant before being diagnosed. Many members name their tumors—mine is called “The Unwelcome Guest” after the Woody Guthrie/Billy Bragg song. It isn’t known what causes ANs; possibly a genetic abnormality. They are not caused by cell phone use (recall that they’ve been found in autopsies since the 1700s). For what it’s worth, though, I spent hours on my parents’ landline with the childhood friend I mentioned who also had one.

Many in the group have had their symptoms brushed aside or minimized when seeking medical attention. A 2016 report by the UK-based Brain Tumour Charity on the treatment of brain tumor patients found that almost a third had visited a doctor more than five times before being diagnosed, with nearly a quarter not diagnosed for more than a year. Often, AN patients wait much longer than that to be diagnosed because of the slow-growing nature of our tumors. The study also found that women and low-income patients experienced longer delays, were more likely than men to wait longer for a

diagnosis, and usually made more than five visits to a doctor before diagnosis.

I continue to be surprised at how thoughtless some people are when they encounter hearing loss.

The change in my hearing has been the hardest part of all this for me. For years, I noticed hearing loss in my left ear, and chalked it up to my youth spent in a rock band, and going to one too many loud shows, particularly Teenage Head’s historically loud show at the Stampeder Inn in the early ’80s. Puzzlingly, I was told my hearing was perfect when I’d had a hearing test in the early 2000s. When I asked why I felt like my hearing was off, I got a shrug in response. At the time I didn’t know that I’d had a tympanometry test, which measures the function and movement of the eardrum and middle ear. An audiometry test, which measures the softest sound a person can hear, would have shown something different—the hearing loss caused by damage to the acoustic nerve by the AN. I have a hearing aid, which helps, but in no way restores what I have lost. Rather it maximizes what I have left.

I continue to be surprised at how thoughtless some people are when they encounter hearing loss. In a conversation at a conference once, I asked someone to repeat what she’d said, and she responded, “Are you deaf, girl?” I chose to ignore this thoughtless remark (being deaf, after all). In another similar crowd situation, I told the man talking to me that I couldn’t hear him. He nodded sympathetically and said, “Ah, yes. The things that happen as we get older.” Again, I chose

to use his remark as a lesson about not making assumptions about people.

Some seem to take it as a personal affront when you say you can’t hear them, as though you are not hearing them on purpose. I have encountered waitstaff in restaurants who roll their eyes if you ask them to repeat something. I don’t leave tips or return to businesses that employ staff with this kind of attitude. I also avoid restaurants with excessively loud music, as I have no hope of hearing conversation in them.

* * *

The first concert I attend after radiation is a performance by the Tetzlaff-Tetzlaff-Vogt Trio at Mount Royal University’s Bella Concert Hall in April 2019. As much as I have been anxious to hear live music again, I’ve also been avoiding it. A lifelong music lover and sometime musician, this aspect of hearing loss has been difficult for me. I’m afraid I won’t be able to hear the music properly, afraid that this important part of my life is changed forever. Maybe enjoying live music is now a thing of the past for me.

Perhaps thanks to the Bella’s amazing acoustics, I enjoy the concert; I forget about my hearing, immersed in the music of Robert Schumann. Instead of mourning my loss of hearing, I enjoy the evening immensely, grateful for the hearing I have left.

The Facebook AN group has some 68,000 members at present. Among this number are many professional musicians—instrumentalists and singers of every kind, whose livelihood is linked intimately with their ability to hear. Like everyone in the group, musicians and music lovers are devastated by the loss of hearing at first. But we adapt as we are able to, and gradually accept as we must. It’s true, going to concerts is not the same now. But it’s also true that I can still

hear, and I still enjoy music as much as I ever did.

* * *

In the five years since radiation treatment, which has stopped The Unwelcome Guest from growing, my symptoms have stabilized. The standard for follow-up after Gamma Knife is one MRI every six months for two years, and then if all looks good, once per year. My first MRI after the procedure showed tumor shrinkage, which is good—often there is swelling for a year or so before shrinkage begins. And subsequent MRIs have showed no change, which means the tumor is dead. Most days now, I don't think about the AN much.

The dizzy spells are much less severe and frequent now. I do exercises to help my balance. I cope with fatigue by napping or at least resting in the afternoons. I play my electric piano with headphones now, an arrangement which suits everyone in the house. And for the last two years, I've been learning to play mandolin. Why not, after all? Maybe I can't hear as well as I used to, but music has always been an important part of my life. I'm relieved that it will continue to be.

This year was my sixtieth birthday, and I decided to get the tattoo that some of the Facebook group members have: a "speaker off" icon (a picture of a speaker with an "x" beside it). I've been thinking about it for a long time, but hesitated, thinking that a tattoo is permanent. Then again, so is my hearing loss. The tattoo symbolizes my acceptance of that—and reminds people to talk on the other side. ♦

MARJORIE E. BRODY

I'M IN HERE

I'm in here.
I know you see me.
The body of me:
 my useless legs and weak arms,
 my bobbing head and shaking hands,
 the spine that leans to the left.
I know you see *that* me.

I'm in there.

I can see you.
 The confused expression
 on your face
 when I attempt to speak
 Cursing the effort it takes to form
 my lips, to place my tongue,
 to get my damned
 larynx to utter sounds.

You want to understand me, you say,
 taking my hand, searching my eyes,
 seeing only your opaque reflection.
Your lips move easily,
 your tongue swirls like a gymnast,
 your voice modulates with ease.
Are you trying to tell me something? you say.
Try harder. But you release my hand. Move back.
I try harder.

He's babbling again, you tell the nurse
 and prepare to leave.

But I'm not.
 I'm telling you I'm scared.
 I'm telling you I hurt.
 I'm telling you I love you.

I wish you could see me.
That me.

I'm still in here.

THE BODY HAS ITS DAY

ANGELA TOWNSEND

I wanted to go to the book fair today. I wanted to write excellent essays.

But days do backroom deals with bodies, and the morning showed signs of scheming. As my cat unfurled on my chest, snorting hairy sonnets on my cheek, I felt a familiar weight. It was not twelve pounds of cat. It was three hundred points of blood glucose.

I would sleepily discover that my insulin pump had backed up, lively river turned to bratty bayou. My continuous glucose monitor had discontinued its services, wandering off to buy itself a beignet.

I was nauseated and wobbly and seeing pink.

It always struck me as ironic that ketone strips are a palette of pinks. My favorite color has no business being the one to tell me that I'm in danger. But there it is.

Cool cotton candy whispers, *Excuse me, you may want to deal with this.* Cherry blossom is concerned: *We have a bit of a situation.* Darkening mauves mean deeper peril. And they all leave it to luxe purple, regal velvet, to break the news: *Probably time for the hospital, kid.*

I have been ketotic many times in thirty-two diabetic years, rubbing the rim of ketoacidosis like a genie. My only wish is

not to vomit. I have, by God's mercy, never entered full-on diabetic ketoacidosis (DKA). But the longer I'm granted this queasy prayer, the larger it looms.

I blame and thank Dr. Pipo, the terrier-sized pediatric endocrinologist who trained me. In the brittle early years, he enlisted my parents and me in a boot camp that saved my life and made me strange.

We had the numbers for his bedroom and his boat, plus his blessing to call at all hours. When the hours were wee and the ketones enormous, Pipo's powers flared.

"OK," he yawned. "We'll keep her out of the hospital. Things are under control. Have her drink a gallon of fluid an hour. More if you can. Call me at 4:00. Sooner if you need me."

Thus began the military hydration that left my little-girl belly a basketball, but flushed the purple monsters into oblivion.

My mom distracted me with coffee table books about gnomes and France. My dad put on terrible country music about achy breaky hearts. My parents picked up my pieces. I picked up another glass of water.

Dr. Pipo picked up the phone. "Good! We're making progress. Keep her drinking." My mom heard him urinating. "If she needs to sleep, set an alarm for a half hour."

The hours passed. The ketones surrendered. We rose to greet the day as though the night had been kind.

That's what you do when you're born on this bayou, called into a body that drops acid and drop-kicks you for its own amusement. You tune the radio. You look for gnomes among the weeds. You cling to your parents.

You unearth humor in hard ground. A specially-purposed hoodie can become your mantle of lilac power. You can drink the ocean in an hour.

But you can't control the craps table where your body and your brain are calling each other's bluff.

I have knuckled my way through ketotic work days, giving grand tours while peeing purple. I have downed Cherry Zeroes in the bathroom between donor visits, reassuring them my screaming insulin pump is "just being goofy."

I gritted my teeth through my high school graduation, stumbling to the ground in a glucose haze, only to raise my arms in a sunny salutation, *Everything's under control!*

But I cannot command creativity.

I cannot compel the words to hopscotch with me when I can barely walk.

And I cannot go to the book fair if I'm a ketone machine.

So the days come when I must barter with my body.

OK, Mr. Day. I will stay in my den and hydrate heroically. But I will roar at the screen even if all must be edited.

OK, Mr. Day. I will skip the book fair in favor of survival. But I will read joy into these hours, and I will put on my makeup, and I will put you in your pale pink place.

OK, Mr. Day. I will acknowledge that I have a body, and I will grant its rights. But you will slink into dusk remembering that I shine at night. That's my smile reflected in the bayou, you bastard.

OK, Mr. Day? Let's try again tomorrow. ♦

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Diana de Avila, *Tides of the Imagination*, 2023, digital art

RESILIENCE!

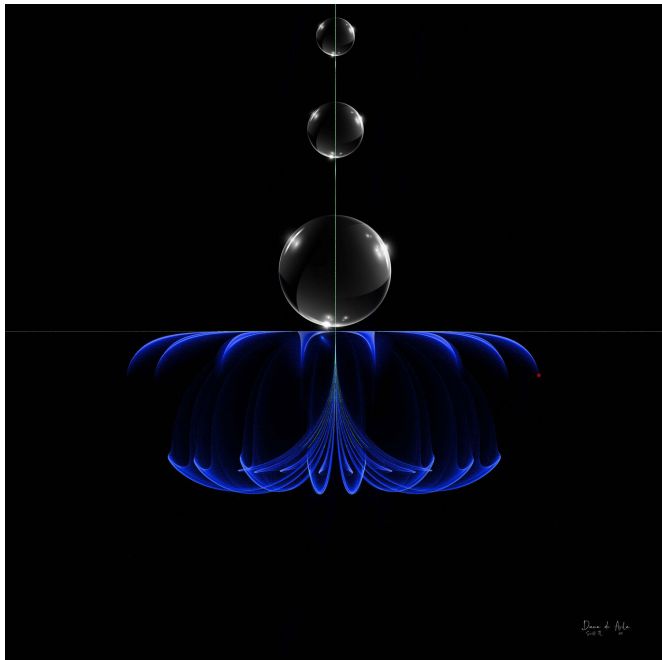
SANDY PALMER

“People tell me, without me revealing it, there’s a spiritual aspect they sense in my work.”
- Diana de Avila

Imagine suddenly seeing vivid colors and shapes floating in front of your face. Startled, you reach out to touch the swirling array, but your fingertips find nothing. You know the shapes aren’t really there, yet, they *are*. That’s exactly what happened to Diana de Avila several years ago. She was not an artist, but the moment those shapes and colors appeared in front of her, she was. The visual aura arrived in a split second. “I was hearing sounds, music, and seeing visions of colors and shapes. I also felt a compulsion to create. It happened in the blink of an eye—like lightning struck me—and it’s never stopped.” With a background in computer technology, writing code, and web applications, she picked up an iPad, and began to depict what she was experiencing. And so began a quest to harness what she was “seeing” and produce it.

De Avila grew up in Rockville, Maryland, one of six children, a twin. She entered the US Army after high school,

but her career as a military police officer ended abruptly when a motorcycle accident split her helmet in half and landed her in the hospital for nine months. With a traumatic brain injury, blood clots, and the threat of having her right leg amputated, she says, “I remember making a bargain with God, ‘If you let me keep my leg, I’ll find a way to serve you.’” That led to entering the convent three years later.” Joining the Daughters of St. Paul in Boston, she worked in the book bindery but after a few years, in 1990, experienced health issues and lost vision in her right eye—likely one of the first symptoms of multiple sclerosis, although she wasn’t diagnosed until 2001. She joined another order in 1993 and after serving for seven years as a nun, left the convent and earned a degree in sociology and a graduate degree in education. Working as a school psychologist for a short time, she became interested in computers and coding, which led to a career as a web architect for General Electric Global Research. While the vision in her right eye improved as the

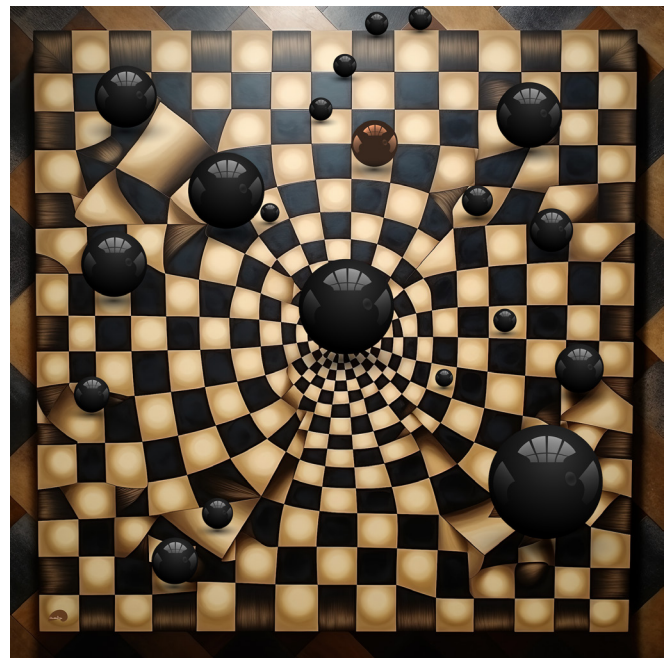


Diana de Avila, *Hanging by a Thread*, 2019, digital art

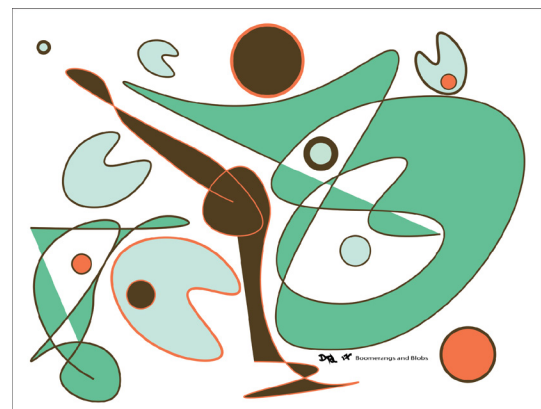
MS exacerbation abated, new symptoms, thyroid issues, and other chronic medical conditions made working difficult, leading to her retirement in 2005.

In 2017, she was experiencing a severe bout of vertigo and ended up in the ER. Doctors checked for a stroke, among other things, but determined it was an MS relapse and optic neuritis in her left eye. She received high dose steroids, which calmed the vertigo, but made her feel manic. Released from the hospital on a warm, sunny evening she decided a swim might help her relax. In the pool, she was suddenly overwhelmed with *synesthesia*. When one sense is activated, this neurological condition triggers the perception of another, unrelated sense—certain sounds might involuntarily create perceived colors, the sight of words or letters might evoke the sensation of taste. “It can be very anxiety-provoking, and in the beginning it was like, ‘What is happening to me?’ It felt like a constant intrusion—these floating pieces were about a foot away from my nose. It was craziness.”

What de Avila learned later was that she was experiencing a rare phenomenon known as *acquired savant syndrome*—the sudden emergence of an extraordinary skill, perhaps in art, music, or math, often the result of a traumatic brain injury or illness. Without any prior interest or formal training in art, she compulsively began to create artwork and intuitively knew color theory, balance, perspective, and so much more. “I never learned any of it. It’s just there. I worked with Jeremy Chapman who is part of the Treffert Center which works with savants, whether acquired or autistic, and it was Dr. Treffert who really gave me solace and told me, ‘You



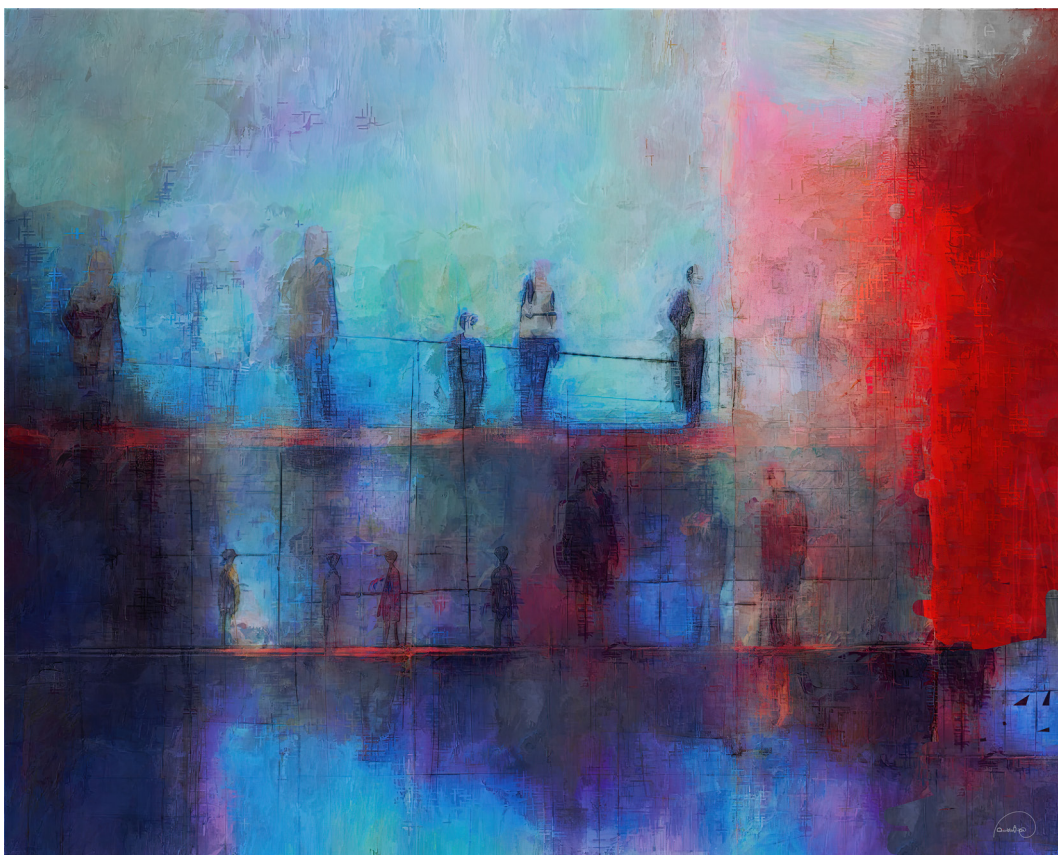
Diana de Avila, *Gambit Quest*, 2023, digital art



Diana de Avila, *Boomerangs and Blobs*, 2017, digital art

are not crazy. This is a gift.’ Jeremy would put a program in front of me and wanted to see what I’d do with it, and I just intuitively knew how to do things. I can’t explain it.” Through the Treffert Center she learned she is one of an elite group of people with the syndrome. The mystery of it and the way it has impacted de Avila are explored in *Psychology Today*, where she is one of three individuals whose unexpected mastery is revealed in the article, “The Mystery of Sudden Genius,” published in April of this year.

Once she completed the first drawing, *Blobs and Boomerangs*, on her iPad, she felt driven to create but thought she needed to do so in the traditional sense with paint and canvas so she loaded up on art supplies while simultaneously playing with vector images in Adobe Illustrator and other programs. She discovered within



Diana de Avila, *Orwellian Overture*, 2023, digital art

three weeks it was quicker to create images digitally due to a tremor that impeded her ability to control her hand movements. She abandoned traditional mediums and has created digitally ever since.

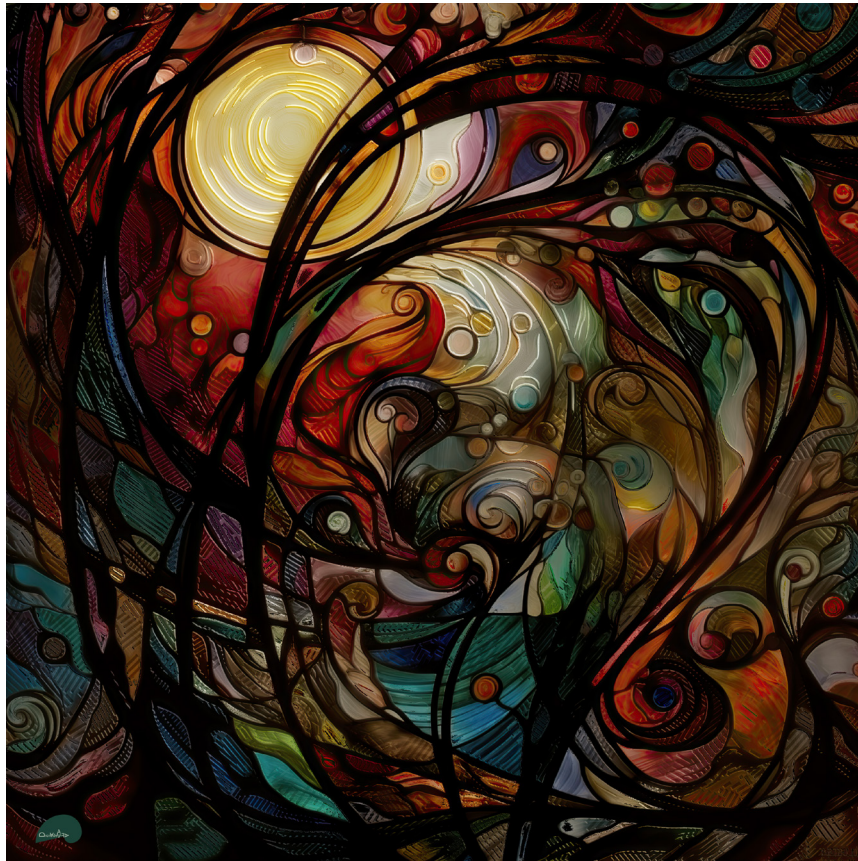
“My roots are in fractal geometry.” Fractals are the basic framework to most of the work she has created to date. Instead of paint, her art supplies are code and algorithms, inspired by quantum physics, chaos theory, and divine order, all of which produce fascinating images bursting with color, texture, depth, and movement. Coding is the process of entering information (alphabetic or numeric) that tells the computer what to do and how to do it. In her case, she begins by entering a fractal geometric algorithm which produces an image containing “self-similarity and infinitely repeating patterns.” A simple equation that repeats endlessly.

After the framework of an image is generated, she manipulates each one using a select combination from more than one hundred different software applications. Each one is akin to a spice one might use when cooking. “I use one spice for this and another for that. I’m just reaching in the cabinet knowing I’m working and using apps in ways I’m sure they weren’t totally meant to be used, but I love experimenting.” JWildfire is a fractal software app she uses often. She loves to bend the rules and use technology in novel ways. This led her to a group of artists who use technology in their work,

just as she does. They are members of the Techspressionism movement, a term coined by Colin Goldberg in 2011, where technology and self-expression merge.

In recent years she has incorporated augmented reality (AR), blending reality with technology. Expanded versions of her static, two-dimensional pieces can be viewed using a device, like a smart phone or tablet, with a special application loaded onto it. The viewer opens the app, points the device at the artwork and then the AR layer can be seen on the device. With AR she brings the image to life, incorporating movements like billowing smoke, flowing water, fluttering birds, or swirling colors. This augmented version is a piece of art in itself and some examples can be seen on her website.

Her work is largely driven by the compulsion to create coupled with the synesthesia she experiences. Over the years she has learned how to identify and turn the volume down on the sensations and compulsions so they aren’t as intrusive or overwhelming as they were in the beginning. One unusual form of synesthesia she experiences involves the sense of touch. If she looks at something with texture, whether it be gritty, grooved or fuzzy, she can feel the sensation on her fingertips without touching it. “If I have a lot of synesthetic noise, I have to sit down with one of the pieces I’m working on and get it out. That’s the therapeutic part of art. It impacts me personally.” Conversely, there are



Diana de Avila, *When the Forest Danced*, 2023, digital art

times when she experiences insomnia or migraines, and some pieces have been driven by those factors. *When the Forest Danced* was created during a bout of insomnia “but it was costly and I paid a personal price for that one with a big migraine that lasted for days.” In this alluring piece, a source of radiant light illuminates a dark yet whimsical landscape, beckoning it to come alive with graceful arcs and swirling motion—interconnected, yet flowing freely. A captivating performance.

De Avila is now represented by The McKernon Gallery in New York, where patrons can enjoy her printed originals and AR works within the gallery. Physically maintaining work in a brick and mortar location can be a challenge. MS flare ups, vertigo, migraines, nausea, multiple comorbidities, and recent issues related to toxic exposure while in the military have taken a toll, and she relies on a wheelchair when in public. “All of this has added to the burden of why being out in the world has become so difficult.” At home she uses a walker when needed. As a result, she was very excited when she was contacted about a new venture and national representation with ArtLifting, an online platform that promotes and sells the work of artists who have disabilities and other challenges. She looks forward to collaborating with them and the prospect of reaching a wider audience.

The partnership with ArtLifting prompted “a foray into a more minimalistic vector art series.” Having an interest in this style for a while, something recently clicked regarding vectorizing artwork. “With a new migraine medication, the creative channels expanded, and I’ve had the capacity to learn and assimilate just like I first did in 2017.” There are no fractals in these lighthearted works that includes beach scenes, sea animals, and sunsets. Mainly working in Adobe Illustrator and Photoshop, she has been creating them at lightning speed, especially when insomnia and a multitude of bright, beautiful colors keep her awake and creating.

The artist’s work has been included in numerous juried exhibitions and won several awards. Her mysterious evolution as an artist has been detailed in the award-winning memoir/art book *Soldier, Sister, Savant*, and in a short documentary titled *The Color of Genius*. The book was written in collaboration with good friend and author, Wilma Davidson, who felt strongly de Avila’s story needed to be told. Subsequently, they worked on *Super Cat! Splat! Splat!* together, a children’s book drawn from the artist’s life. Toddlers are invited to share their thoughts as events unfold in the story conveying the importance of kindness, compassion, and acceptance. The duo has a second children’s book in the works.

Resilience best describes the message de Avila wants to communicate through her art. “Find your therapeutic outlet, whatever it is—cooking, art, music, whatever. Don’t focus on your past and don’t get too far ahead in the future. Enjoy the present. Make an impact. Don’t give up.”

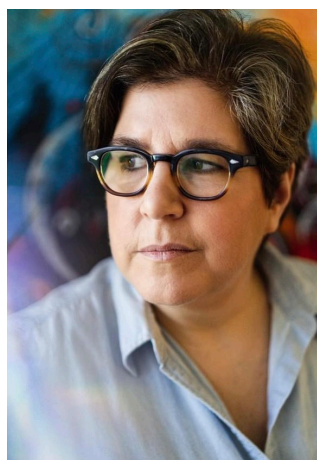
Brilliant seems like a fitting descriptor for her work. There’s also something spiritual about the ability she has been blessed with and the mystery that surrounds the art she creates. A damaged frontal lobe and medical maladies suddenly collide and unleash astounding artistry and aptitude for aesthetics. There’s something supernatural about that. While no longer living in a convent, she continues to live a life of faith, prayer, and worship. “One Thing Remains,” is her fight song. Written by Brian Johnson, Jeremy Riddle and Christa Black Gifford, it is often played on repeat in her house in Florida. During her prayer time each morning, as she gets set for the day, she sings the lyrics:

Higher than the mountains that I face
Stronger than the power of the grave
Constant through the trial and the change
One thing remains, yes, one thing remains

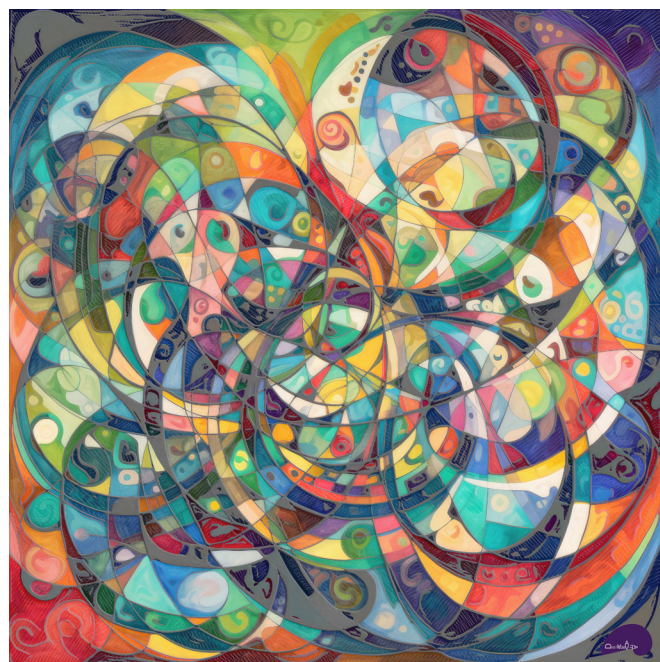
Your love never fails
it never gives up
it never runs out on me

The empowering words bolster her spirit.

You can see more of her work at dianadeavila.com where you can enter the Swirly Whirly Virtual Exhibit that allows you to move around within the virtual gallery space to see some of her artwork on display. Links to the books mentioned, as well as the documentary, can also be found by visiting her site. ♦



Artist Diana de Avila



Diana de Avila, *Joyful Chaos*, 2023, digital art



Diana de Avila, *Withered Whispers*, 2023, digital art

THE PRESSER OF BUTTONS

TARA K. ROSS

Today will be different. Whimsical clouds guide us through skyscrapers, traffic flows like a melting Popsicle, and Lucy actually napped. Even Benny's Roblox shirt miraculously dried after the bubble fiasco on the highway. The ducks are in a row, and my pulse is normal. For once.

"Look Benny-Boo," I say through the rearview mirror. "We made it with ten minutes to spare."

"Ten minutes to spare," he repeats with mirrored intonation, then yanks on the door handle.

"Just one sec. Yikes! These spots aren't meant for minivans." I crank the wheel, gaining an extra half millimeter between my bumper and the pillar invading the only empty spot near the elevators.

"Just one sec. For the minivan," he echoes for Lucy, his slight hand clasping her slighter one.

"You got it. The minivan needs our patience." *As does Mommy.* I reverse, inch forward. Repeat. I loathe Toronto parking garages, but this therapist is worth the near scrapes. Even with another reverse and repeat.

After shifting into park, I cut the engine, but keep the doors locked. "Remember, stay close to our car or Mommy, OK?"

He nods, pumping the handle.

"One, two, three, and . . ." I pause as Ms. Valerie suggested, then unlock the door.

"Go!" The door catapults open, his body following, until the seatbelt wrenches him back. "Ow! That was a big one."

"Yeah, buddy. That was a big yank. But you're OK." I arrive at his side and unlock the three point harness. "First, we get Lucy out. Then we go see Ms. Valerie, OK?"

"Elevator 3." He twists his hands together, spins around, then looks back to the elevator entrance, repeating, "Elevator 3."

"Good reading! We'll go down Elevator 3 as soon as I latch Lucy's lunar vessel onto her space wheels." I throw open the trunk and Lucy babbles when I appear. "Hello, sweet girl. We'll have you out of there quick as a whip."

"Quick as a whip." Benny slaps at his thighs. "Elevator 3."

"Quick as a bee, to Elevator 3," I rhyme off as I heave open Lucy's stroller, then pop in her baby bucket. She squeals in delight as I plant a loud raspberry on her cheek.

"Stay clear of the doors. The doors are now closing," Benny says, with the robotic quality of a subway announcement.

I play along and arch Lucy's stroller far from the car door. Benny's face scrunches as though he were sucking on a bag of Sour Patch Kids. He echoes his subway phrase, but with rising urgency.

The aroma of expensive cologne draws my attention. A suit-clad man pauses at the bumper of my car. “Everything OK?”

I give a double thumbs up. “We’re good.” Which is far from true, but what would he know? “He just doesn’t like the subway,” I say before crouching down to conjure up my mellow-mom voice. “Sweets, no subway today. I promise.”

“Quick as a bee?” He looks at me for a fleeting moment.

“We’ll be quick as a bee. Talk time with Ms. Valerie. Then we can stop by Pet Poochtique. See Mr. Sniffles?” I hold out my hand, and while I’m checking that The Suit has left, he latches on.

I exhale, then ask, “Do you want to push Lucy with me? We can be the pushers of Lucy.” I tickle my other hand down his back, the way he loves, but with our first step, he drops.

The subway announcer returns with swelling fixation. Lucy’s face twists. She adds her own wails of support. Or maybe frustration? I should know which, but the rebounding voices are overwhelming. A familiar tightness binds my chest. I squeeze my eyes shut, two fingers over each ear.

We were so close.

That ten minutes has come and gone. Valerie is gracious, but she’s going to charge us whether or not we show up.

“Benny, you need to get up,” I say, firm and direct. “Ms. Valerie is waiting.”

He swings his head from side to side, his words dissolving into a mumble.

“Benjamin, not today. Get up.” My tone is now cold. Frightening. But I need him to move.

He tucks himself in like a potato bug, rocking back and forth. I could pick him up, toss him into the car and be done with this. I pace in a six-step circuit around Lucy. But I won’t get my money back. We’ll be losing out on groceries for nothing.

We need more words. If only we had more words . . .

With authority, I thrust Lucy’s stroller toward the elevator entrance. “Fine. You freak out, but I’m taking your sister to your overpriced speech session!”

He races behind me. “Ben pusher of Lucy! Stay clear of the doors!” He’s next to me, clawing for my hands to release the stroller.

But I’m stronger. I refuse to lose this forward momentum. At the elevator, I slam the down button. He lunges in front of me, eyes locked on mine—wide, wild. “Stay clear of the doors.”

“I get it. God! How I get it! I’ll stay clear of your *precious* doors.”

Arms wide, hands splayed, he spins, then stops, eyes so very desperate.

Then I remember.

We’ve been here before. Elevator 3. Not for months, because we’re usually higher—Elevator 5, 6—never a space on floor three. But three was where the doors slammed shut on Lucy’s stroller and Ben splayed his hands, ready to save her. We never made it to our session that day.

“You remember the doors. And Lucy getting scared? Benny, I’m so sorry.” I squat and place both my hands on his shoulders. “Benny pusher of Lucy? Mommy presser of buttons?”

He wipes at his eyes, nods small, shoves me away from Lucy’s stroller.

“Open door button pressed the whole time,” I say.

He reaches on tiptoes to the top of the stroller handle.

When the elevator arrives, I enter first and press that button hard. And we all stay clear of the doors. ♦

DOUGLAS G. CAMPBELL

MOURNING MYSELF

words and
 sentences
 don't work
 right arm
 right leg
 don't work
 walk funny
 use a cane
 need a brace
 walk slowly
 on the same paths
 not too difficult
 not too rocky
 not too steep
 not too far
 it's boring
 can't choose my own path
 it's been chosen for me
 therapy
 therapy
 therapy
 I want to
 climb a mountain
 paddle a kayak
 ski a slope
 swim in a lake

I want to
 write poems
 on my own
 no help
 it's not the same anymore
 as thinking of words
 that come from
 my soul
 my experiences
 my former self
 no writing letters
 to friends
 and family
 one-handed tasks
 are difficult
 no driving a car
 I am a passenger
 in my own life now
 not in control
 of me
 myself
 or I
 independence diminished
 sitting in a chair for hours
 wishing to go
 somewhere
 anywhere

ALEXANDER ETHERIDGE

BLAST FURNACE HEART

Ungainly and ugly,
 white-hot on the inside.
 Over time it
 destroys itself with love

and incinerates
 what it touches.

It melts the decades
 into lava and pours it
 into huge crucibles.
 Its memory is long,

but it sees only
 fire, only smoke.

At last its structure
 implodes, clanging heavily
 into dark. But a red coal
 lives on, recalling

all the burning,
 and everyone that

cindered while near it.
 What's left of the heat
 mourns, what's left of the
 heart passes into cold.

DOG BISCUITS AND OTHER TREATS

SUZANNE KAMATA

Back in Japan, up until the start of the pandemic, Sophie had been living in a dormitory at the School for the Deaf. She was supposed to be developing independence, but there were a lot of rules, and a lot of things she wasn't allowed to do by herself, like use the dorm kitchen. This summer, which she and her brother and mom were spending at Aunt Parisa's beach house, she was allowed to cook or bake whenever she wanted, so she'd been experimenting with recipes. The day before, she'd made dog biscuits out of peanut butter, eggs, flour, and honey. She had used a heart-shaped cookie cutter to cut them out. Now they were in a plastic container in the refrigerator. She would give her aunt's Labrador, Chester, one after their walk.

This morning, when she went out onto the deck with leash in hand, and Chester surging ahead, her brother Yuto and her cousin Dahlia, who now wanted to be called D, were sitting in canvas chairs with girls sprawled on their laps. The one on Yuto's lap was tall and thin with bobbed pink hair. She wore a tie-dyed bikini, and the ring

piercing her belly button glittered in the sunlight. The girl on D's lap had spiky black hair and a dragon tattoo on her shoulder. She looked Hispanic, but Sophie couldn't really tell. They were all eating Popsicles. Sugary pink water was running down Yuto's arm.

Sophie threw up her hand in a casual wave. She was embarrassed by their intimacy—all those entwined legs and arms. Public displays of affection were exceedingly rare in Japan. She had hardly ever seen her own parents hold hands or kiss even when they were in the house. She hurried to the beach, leaving them behind.

A couple of weeks before, she had met a guy named Dante on the beach. They'd bodysurfed together a couple of times and started texting each other. She looked forward to seeing him again. She didn't see Dante on her walk, but when she got back to the house, Yuto, D, and the girls were gone, and there was a text from him on her phone.

"Do you want to go to the aquarium today?"

Her stomach fluttered. This was a bit more formal than running into each other on a stretch of sand. Was he asking her out on a date? Like, would he come and pick her up in a car? And would she have to tell her mom? Sophie cringed, thinking about how overprotective she might be. She'd want to meet Dante and ask him a million questions. She might even ask Yuto to go along with them as a chaperone—or worse, volunteer to accompany them herself. Then again, her mom wouldn't be home for another few hours. Aunt Parisa had already left the house. She would leave a note. She might even be able to make it to the aquarium and back without anyone noticing she was gone.

Sophie replied with an emoji of a bear making the "okay" sign.

Dante sent back a thumbs-up emoji. "I'll pick you up in an hour. Is that okay?"

Yes. Yes, it was.

After coming into the house, Chester had gone straight to his water bowl and

gulped up half its contents. Sophie added more water and took the container of dog biscuits out of the refrigerator. She held one up in front of Chester.

He woofed.

Sophie patted his head and let him take the cookie from her fingers. He gobbled it up without hesitation, licked his chops, and looked up at her eagerly, ready for more.

Sophie laughed. “Later,” she signed. “Be a good boy while I’m away.”

She quickly changed from her shorts and tank top into a cute, flirty dress with a dinosaur print that swished around her knees. She tore a piece of paper from her notebook and carefully wrote out the words in English: “I went to the aquarium with Dante. I will be back at about 3:00 p.m. Love, Sophie.” If someone really wanted to check up on her, they could send her a text.

A little while later, Dante pulled up in the driveway in a Jeep. He hopped out in a polo shirt and blue jeans. She couldn’t see his eyes at first because they were hidden by Ray-Bans, but then he lifted them onto his forehead and raised his eyebrows.

“You look cute,” he signed.

“Thank you.”

He ushered her to the passenger side of the Jeep, opened the door, and helped her climb in. Once she was buckled up, he closed the door and got in beside her. And then they were off.

The air was somehow hotter and stickier away from the beach. Maybe it was the asphalt of the city streets, or the extra heat of bodies. Tourists had begun to swarm again, after seasons of staying away. Even so, Dante easily found a parking space near the aquarium. He inserted a few coins into the parking meter, and they walked toward the building.

The staff members at the aquarium wore masks, but most of the visitors were bare-faced. Sophie didn’t mind wearing a mask. It was pretty normal in Japan during flu season and when pollen was heavy in the air, but she had already gotten vaccinated at a clinic in Japan. She figured Dante had been as well. Neither one of them covered their faces.

She reached for her wallet, but Dante was already laying crisp green bills on the counter. After exchanging a few words with the clerk, he turned to her and moved his arms in a flapping, floating way, mimed eating, and raised his eyebrows.

Sophie laughed. She had no idea what he was trying to say. Was he asking if she wanted to eat something? Asking if she wanted to eat a bird, like chicken? She shrugged.

He held up one finger and pulled out his phone. He quickly tapped out a few words and showed the screen to Sophie. “Do you want to feed the stingrays?”

Sophie nodded. “Okay.”

Dante finished the transaction and handed her a ticket and a voucher.

Inside the building, the air was refreshingly cool. The blue water and the dim lights soothed. They approached a tank and gazed at small colorful fish darting around a reef. Dante made the sign for “fish.”

As they walked toward the next exhibit, his knuckles brushed against hers and he reached for her hand. She let him lace his fingers through hers. If they were holding hands, she wouldn’t be able to sign or spell out texts on her phone, but that was okay. It was nice to touch him like this. They could communicate with their eyes, their smiles.

They walked slowly through the exhibits, lingering especially long in front of the jellyfish tank. Sophie had seen jellyfish before, of course. Once, back in Japan, she and her family had taken a glass-bottomed boat out into Naruto Strait to see the enormous naturally occurring whirlpools. From up on deck, they could see how the water churned, like the inside of a washing machine, but underneath was another world, a more peaceful one of gelatinous creatures with wavy tendrils. They were beautiful, but Sophie knew that they were poisonous and not to be touched.

Dante let go of her hand to ask Sophie, “What is it in Japanese?”

She took his hand and wrote with her finger on his palm: くらげ.

“*Kurage*,” he said.

She nodded, warmth flowing through her veins and blooming in her chest. He

was trying to learn her languages, just as she was trying to learn his. Hardly anyone had ever made such an effort before. She wondered if it had been like this for her parents in the beginning, when her mother had first arrived in Japan. She didn't know all that much Japanese when she had first met Sophie's father, and although Masahiro, her father, had studied English in junior and senior high school, he had been by no means fluent. Olivia, her mom, had once told Sophie that they had carried dictionaries with them on their early dates—actual books made of paper. Sophie imagined them leafing through the pages to find just the right words.

Dante threaded his fingers through hers again and they moved on. The largest exhibit at the aquarium was the Great Ocean Tank, in which sharks and many kinds of fish swam past, some circling in schools.

"Look!" Dante pointed to the enormous loggerhead turtle which seemed to be flying through the water. It probably weighed over two hundred pounds. On the beach, they looked somewhat ungainly, but in water, this one was full of grace and dignity.

Sophie noticed that there was a human diver in scuba gear in the tank as well. He seemed to be feeding the sharks, presumably so they wouldn't try to eat the other fish. She wondered what it would be like to work here. If she learned to dive, she could go into the tank and feed the sharks, too. Or she could put on one of those blue T-shirts and the khaki pants that seemed to be the staff uniform and hand out brochures. Maybe she could help clean the glass smudged by faces and fingers that had pressed up against it. Even that would be more interesting than the jobs that her teacher at the School for the Deaf had suggested she might think of in the future, after graduation next spring.

A boy who had graduated a year ahead of Sophie now worked in an office,

entering data in a computer. The school also had a program training deaf students to cut hair, but Sophie wasn't really interested in that, though she didn't think she would mind grooming pets. One of her older friends worked in a factory, sewing pieces of fabric together all day. Another worked on a farm picking fruit. But Sophie was thinking more and more that she wanted to spend some time in America. She had an American passport, after all. Wasn't it her right to get to know that side of her heritage? And wouldn't working at this aquarium be more exciting than working in some stuffy office or factory?

"I would like to work here," Sophie signed. Her mom always told her that if she wanted something to happen, it was good to put your wish out into the universe, on record. You never knew. You might just happen to express your dream to the one person who could make it happen.

She wondered if it had been like this for her parents in the beginning, when her mother had first arrived in Japan.

They wandered slowly through the rest of the exhibits, studying each one closely, and stopping at times to look up words. Sophie had brought her notebook along. She wrote down new vocabulary: bald eagle, salt marsh, lionfish, pelican, conservation, debilitated turtle syndrome, horseshoe crab. Later, she would try to look up the signs.

She and Dante found the shallow pool where the cownose stingrays were kept. The brown creatures looked like kites waving through the water. Sophie

watched and imitated as a young woman in a blue T-shirt and khaki shorts demonstrated how to feed them. She took a small fish from a plastic container, and held it in her fist, with half sticking up, then lowered her hand into the water. Almost immediately a ray swooped by and sucked up the fish. Dante did the same, but he jumped back in surprise when a ray bumped against him. Sophie laughed. "They don't have teeth," she signed. "They won't bite you."

The stingray she'd fed came back around and stuck its face up toward Sophie. She reached in the water and stroked its back. The skin was smooth one way, and rough, like sandpaper, the other. The creature seemed to enjoy being petted. After a few strokes, it set off with a big flap, splashing both Dante and Sophie.

The front of Dante's polo shirt was soaked. He laughed as he wiped the salty water from his face. "Wanna go get some ice cream?"

Sophie nodded.

They went outside onto the wharf, where a vendor was selling cones from a cart. They sat at a picnic table overlooking the water. It had been a perfect outing, and Sophie wanted it never to end, but she had written on the note that she would be home by three.

Back at the house, Dante pulled up in the driveway and turned off the engine.

"Want to go inside?" Sophie asked. She would have to introduce him to whoever was there, and maybe endure her brother's teasing and her mother's concern, but it would be rude not to invite Dante to stay for a few minutes.

Dante jumped out of the Jeep, and hurried around to open the passenger side door for her. He followed her up the wooden steps and into the house, where Chester was the first to greet them.

Her note was still on the table. Her mom and Aunt Parisa didn't seem to be around. Yuto, D, and those two girls from earlier were in the living room area, sprawled over the sofas. They were laughing about something. When Yuto noticed Sophie and Dante, he waved them over.

"Hey. I'm Yuto." He held out his hand. Dante went over to shake it.

Sophie took note of the crumpled chip bags, glasses with melting ice, and the almost empty plastic container. There was one heart-shaped dog biscuit left. She picked up the container and rattled it.

"Delicious," Yuto said, making the Japanese sign which was like wiping drool from his chin with the back of his hand.

Sophie put her hands on her hips in a gesture of anger. She pointed to the last biscuit, to her mouth, and then to Chester. She could see understanding dawn on their faces.

Yuto and D, whose eyes were strangely red, looked at one another with horror. One of the girls suddenly gagged.

Sophie would just let them believe that they were made with some non-human-friendly ingredient. It would serve them right to have eaten crushed crickets or raw horsemeat or something. She hoped that, at least, they had given Chester his share. ♦

Excerpted and adapted from the author's novel Cinnamon Beach (Wyatt-Mackenzie Publishing, 2024).

IVY RAFF

WHAT REMAINS

His mind's great hall empties of words
like *constellation* and *triangle*.
Pegs ripped from walls, paintings taken down,
the spatial knowledge that placed them erased.

There's nothing but breeze inside. Closing
the dishwasher door begs planning.
Straightforward logic mushrooms into mad,
unsolvable puzzles, frames drained of filling
and it's confusing, in the way a death always surprises
no matter how long it smoldered.

The hand tremors, the neck spasms, twin his bearing
to a mortally injured bird of prey.
He shakes on the inside. Stomach painted
with muscle. Pancreas, liver swaddled
in sheets of muscle we control until
they begin to quake and never cease.

His brain no longer permits sleep
Instead, forty-minute lapses
into fitful unconsciousness take him like thieves.
I turn around and he's curled on himself
in his chair, tendons tightened over
bones like rubber bands on slingshots,
and I leave him so. Unconscious discomfort
his respite.

Every day is the worst he's lived
and the best he'll live again.

GIFT OF THE MOONLIT SEA

BEN GOOLEY

The wind stank of seal and fox as Urai sat on the ice and watched the water. Mother Moon was lying full and low in the gloaming sky and cast a faint red sheen across the whiteness.

Urai muttered quiet curses to herself, remembering the morning's Thingstead meet. She flushed with equal parts shame and anger as she recalled the way she'd filled the hall with her yells. Urai knew she would be a useful part of the annual spring expedition going south, but her voice was a sighing into the wind, unheard. Her opinions were of no interest to the Thing. Why should they listen to a woman who was neither wife nor mother? And who would have her, with her withered left hand, twisted and curled like an eel salted and dried by Father Sun?

Urai watched the dark water closely for any movement, spear held at the ready, net by her side on the loose snow. If they wouldn't hear her voice, perhaps they would listen to the satisfying thud of a seal carcass. A silent witness to her talent.

A dark movement on the waves beside an outcropping of rock caught her eye and she tensed, subtly shifting the angle of her spear in readiness to strike.


Something moved on the surface of the water, but it wasn't a seal. As it drifted closer, she saw what seemed to be a box or casket that bobbed low in the water's swirling currents.

Urai scurried across the ice toward the outcrop and waited in the keening wind as the object drifted closer. She could see clearly now the simple woven basket floating on the water, just out of reach of her spear. Straining forward, she felt her feet slip on the slick ice at the water's edge, and for a moment she teetered, arms flailing, then fell backward with a soft thud onto the slippery ice. The basket had drifted past her, already out of reach of the spear. Should she risk jumping in? Dangerous at night and this far from home. Curiosity overwhelmed her and she began fumbling with her jacket buttons, before she remembered the net lying at her feet. Swapping spear for net, Urai set her jaw and prepared to throw. She'd only get one chance before the basket was completely out of reach. Standing firmly on one end of the net, she cast it across the water. A perfect shot.

Grunting from the weight, Urai hauled her catch onto the ice and peered inside the lidless basket. A cry caught in her throat.

The basket was lined with oiled seal skin to keep out the freezing waters, and inside was a bed of white bear fur, on which rested a tightly swaddled infant, nose and mouth poking through a gap in the cloths.

Was it alive? Her pulse racing, Urai leaned close and was relieved to see the swaddling move with the baby's tiny breaths, little puffs of steam rising into the freezing night air.



Gently pulling the cloths to the side, Urai saw the baby boy's sleeping face. At first she thought he bore a wound, but it wasn't that. One of his eyes was missing, replaced by smooth flesh where the eye should have been. That, at least, went some way to explaining the driftling. She had heard rumor that among the Turik villages to the north they did this sort of thing. Urai shuddered to think what might have been if Mother Moon had chosen to form her in a womb in that place.

Carefully lifting the child from his place, she held him close, withered hand supporting his head. He smelled of bear and smoke and seaweed.

"What's your name, little one?" she asked. "Are you cold? You're going to need someone to keep you warm."

She may never be a wife, but perhaps she could yet be a mother. Perhaps, as a mother, the Thing-meet would hear her voice.

Urai's shoulders tensed. If she took this child, how then could she join the party on their voyage? Could she take him with her? Hardly. He would need a wet nurse and constant care. As Urai watched the boy, he stirred, opened his eye and looked at her, face calm. He wasn't handsome, but he *was* alone—clearly and absolutely alone. Looking at him now, Urai knew with fierce clarity that Mother Moon had chosen her for this task. Who else would take him? Who better to save him?

Sometimes courage involves putting down the spear for a time to face greater quests.

Urai laid the boy back among the furs, collected her things and hefted the basket. Already she could begin to see an outline of the path ahead. Larai would consent to suckle him, she was sure, until he could be weaned. It would be difficult, but Urai would pay whatever price was asked of her to keep him safe—he had not come to her by chance and Mother Moon would not be mocked. Then next year, or perhaps the year after, Urai *would* head south. The boy would join her, and together they would see the high forests, the colorful markets, the walled cities. Perhaps the Thing-meet would see reason and let her join the spring journey when that year came. Perhaps they would not, and so the two would head off alone.

"Kun-Larak," Urai said as she turned and began the walk back toward the village. *Moon gift*. "That will be your name my son. I am going to show you the world." Gently, she bent and kissed his forehead. "My one good hand does more than twice what others can with their two. Your eye will drink in more than twice what most others ever get to see."

Behind her, the wind sighed its song, and the murmuring waters seemed to wink as they reflected the light of Moon's bright orb. ♦

EMMA BAKER

CARBONARIA

I'm welded to an email chain
 with the Office of Student Services.
 They would like me to prove, as I have countless times with countless people,
 that I legally deserve license for my unevenness,
 my sensitivity, my single-mindedness.
 I show how I have been marked
 to the nurse at the ER
 and to the overzealous TSA agent
 and to the employer at the job I always wanted
 and to the professor I hope to never see again.
 I give them the proof of my difference cordially, of course,
 because making an exception is tricky,
 and there are studies that show
 that people like me come across as less likable
 when we don't do as the Romans do.

Those letters cost me half my life,
 my teenage sanity.
 They stick between my fingers when I type them,
 as I once signed copies of papers
 calling me oppositionally defiant
 and certifying I would finish sophomore Biology.
 Now that I carry them,
 the same people talk to me about spectrums, infinity signs, superpowers,
 a flourishing diversity of color
 to legitimize the days
 where I sit stinking,
 chewing on my hair,
 reading about nothing for hours.

I got into a hot tub once with a woman
 who introduced herself
 and asked me, not five full minutes later,
 if I had been diagnosed.
 With what, I asked, and I knew what she would say,
 and she said it.

Nothing to feel but sad? proud? resigned?
 Nothing to note but the angry scars
 carved into her thighs
 where her bikini bared them,
 almost unthinkably brave.
 I wonder if other people averted their eyes when they looked at her,
 or if it was just me and people like me.

Sometimes it's that obvious, I guess.
 In sophomore Biology, which I almost failed,
 we learned about moths
 with genes out of time.
 Before the soot of the factories blackened the tree trunks,
 their coloring matched their home,
 kept them safe from hawks
 and let them live peacefully,
 long enough to copy themselves.
 Now, their grime-colored siblings reign.

Justice! I wanted to scream,
justice for the peppered moths.
 Give them back their peppered homes.
 Let them live in a world
 where they take themselves for granted
 and would never even think about painting their wings.

THE LIGHT

I'm thorns and broken glass. I'm burning fire visions. I'm sandpaper skin. I'm barbed wire wrapped around a barking throat. I'm the thrum of agony. I'm barnacles on sunken anchors. I'm void. I'm radio static. I'm pathological. I'm a symphony of grief transcending up my spine. I'm detached. Depersonalized, but I'm alive. I'm broken bones. I'm cracks in the foundation. I'm gold. I'm slivers of sun. I'm light rays. I'm killing the pain. I'm shining. I'm beams of life burning bright. I'm forever, the light.

*Previously published in Do Not Tap On The Glass anthology (2023).
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JAX BIDMEAD

MY SKIN IS A COSTUME

Cheap, rough and itchy,
Often red and raw from
Scratching uncontrollably, and
Tight, too tight, I wish I could
Unzip, even rip off the fabric of
My flesh, and maybe then
Escape its tortured touch

JAX BIDMEAD

HUM

when the dull buzz of
electricity screeches,
when whispers and giggles morph
into scrutinizing insecurity,
and waves of dread pulse
through my veins,
when my nerves flinch at the sharp
burst of jubilant laughter,
and the painful ringing lingers,
fueling the faint throb radiating
through my skull

I hum softly

a low, monotonous sound
vibrating
in my chest
soothes pins and needles
crawling
up my spine

rocking slowly, back
and forth waiting desperately,
for the ringing to fade,
leaving only a hum

NEVERLANDER

DEB DeBATES

In the darkness backstage, Micah sits at the end of a long table. Its black surface is partitioned off with neon pink and orange masking tape into squares and rectangles of varying sizes. Each space is labeled and holds an individual item: a gold pocket watch, a plate of fake fruit and cheese, a stack of boarding passes, a wad of dollar bills, a cup and saucer, a black velvet ring case. These are props for his high school's spring theatrical production, *Murder on the Orient Express*.

I enter through the performing arts classroom door, walk through a dimly lit space that takes me backstage. Slowly, because my eyes are adjusting to the darkness, I make my way past several costumed actors and tech students dressed in black pants and T-shirts. I see Micah and his para who stands away from the table. I thank him for staying with Micah the first hour of rehearsal. After he leaves, I see a chair at the opposite end of the table and sit down.

Micah's job as props manager is not complicated: fill a couple decanters with juice (cranberry to look like red wine, apple to resemble whiskey), help the actors locate their props, and make sure the items are returned to the right squares.

For the next hour, actors approach the table in their 1920s costumes: bobbed wigs, drop-waist dresses, fur coats, and roomy pin-striped dark suits. Hastily, they grab their props, then return after their scene, replacing them in the correct

masking-taped space. They don't seem to need any help and are always accurate in returning them to the right spot.

It is all hush-hush behind the stage. No talking. Micah and I look at our phones to pass the time.

I can't help feeling a little down sitting back here, although Micah seems content and happy as usual. But I long for the days when Micah was on stage rather than behind the scenes in this lonely darkness.

It seems like yesterday when Micah was in fourth grade and the Missoula Children's Theater came to his elementary school to stage the play, *Peter and Wendy* (a version of *Peter Pan*). He'd been excited to audition and got the part of a "Neverlander." During this week-long practice, I watched as the kids, Micah included, learned their songs, lines, and where they needed to be on stage.

On a Saturday morning in February, the day of the performance, I helped him get into his costume at home before driving to the school. He wore baggy brown pants, a white blousy shirt, evergreen vest, and a flouncy orange cap that kept slipping over his wire-rimmed glasses. In the band room we found a spot in the large floor circle with his peers.

"Break a leg, buddy. Do you know what that means?" I smiled.

"No, Mom."

“It means, good luck out there.” I winked and gave his shoulder a little squeeze.

Micah continued to be in plays throughout the next few years. In fifth grade, he performed in another Missoula Children’s Theater production, *Treasure Island*. In sixth grade he was a king in *A Trio of Fairy Tales*. It was *Elf, The Musical, Jr.* in seventh grade and, during his last year of middle school, when the pandemic was still raging, there was an abbreviated song and dance show (a medley of rock and roll songs from the ’50s and ’60s). Micah was still involved—he was at every practice, mask on like everyone else—happy to be there, eager, willing.

Not once, during all these years, did anyone imply that Micah might be a distraction or unable to perform well enough with his castmates.

If I could have stopped time—if I could have lingered in that middle school era a bit longer, I might have prevented the next transition. But that is not how life works. It’s not an option for any of us.

High school descended on my son. I had no choice but to escort him into the fray and do my best to help him through it.

On a late August day in 2021, Micah’s first day as a freshman, I walked into the school around three-thirty and met Micah inside the special education classroom. He wanted to sign up to audition for the fall musical, *Guys and Dolls*. Together we walked down the long hallway to the theater wing. I spotted a tall, middle-aged man with mussed brown hair I took to be the director.

“Hi. I just wanted to introduce myself. I’m Deb, and this is my son Micah,” I smiled. “He’s very interested in theater, and I just wanted to tell you a little about him,” I continued. I told him about all the plays he’d been in, especially his experience in *Elf, The Musical, Jr.* It was Micah’s favorite play, the pinnacle of his seventh-grade school year. Seven lines, three costume changes, and learning the choreography was more opportunity than I’d thought he’d be given. For four months he rehearsed with his middle school castmates, memorizing lines, learning the music, the dances. During the last few days of a brutally cold January, we attended all five performances. Not once did he miss a cue, and the hours we

spent practicing the choreography in our living room helped him blend in well with the others. Todd and I were so proud of him.

As I was telling the director my story, I hadn’t noticed Micah walked away and was now at the end of the corridor. He was standing next to a window by himself—talking and gesticulating.

“Is he going to behave like that on stage?” The director asked with a chuckle, but in a way that insinuated he wouldn’t want that kind of behavior in his play. Although he probably didn’t mean to be rude, his comment felt like a little stab in my heart. *You would say this about my child?*

“Oh no, he wouldn’t do that. He just likes to sometimes pretend he’s a Disney character or superhero to pass the time.”

Could it be that Micah was on the chopping block, even before auditioning? The director’s comment made me hesitate, but I walked Micah to the board and helped him sign up anyway.

He didn’t get cast. Big surprise.

The next year there was a new director. I was thankful and thrilled that he cast Micah as a villager in *Beauty and the Beast*. But then I learned he’d only be in the first scene (one song) as part of a large ensemble. I was confused. There were multiple scenes for the twenty-some villagers. Why was Micah only allowed to be in one when the others were in all of them? Granted it probably took him longer to learn the choreography, but I’d make sure he’d get the help to learn it. I’d teach him myself if necessary. I felt bad he had to remain behind the stage for most of the show, uninvolved.

I was angry at this lack of inclusion, and sad that his opportunities seemed to be diminishing. Was this a foreshadowing of what we could expect for him during his adult life?

After many years of being welcomed wholeheartedly into his elementary and middle school theater experiences, high school was proving much different. Students had become more developed in their skills, singing and dancing with more precision and expertise. I understood not everyone who

auditions gets a role, especially in high school. But it was also apparent that kids who might have quirks and stims stick out—and that is not what a director wants to see.

Oh, but there are so many other ways he can participate, they told me. There are the student one-act plays, there's improv, and there's always the tech crew. Is sitting at a table with nothing to do being involved? Is being in a much shorter play and given a one-word line to say while sitting on stage being involved?

Perhaps I was being too sensitive. Maybe I was expecting too much for Micah.

I tried to put myself in the directors' shoes. Wouldn't I want the best show possible? Wouldn't it be more difficult to incorporate a student with special needs into the production? What would it be like to be responsible for fifty or sixty teenagers, to get a play performance-ready? Would they have time to devote to a student who needed extra help?

I wrestled with these questions.

Toward the end of the school year, I came to a conclusion on how to move forward and make the most of Micah's involvement in performing arts, not to mention any activity he was involved in.

I would cherish the memories of Micah on stage, of how he was accepted as is—the way he moved (a little slower, yes, with his head swaying at times, yes), the way he sang (maybe not getting all the words), and, of course, the amazing, expressive way he said his lines.

But now, I need to look to his future. There are things I can control and others I can't. It isn't useful to Micah (or anyone else) for me to harbor bitterness toward those who refuse to give him stage time or meaningful involvement in thespian activities. I can't make anyone do anything.

What I can control is how I respond, how I deal with some of these hard emotions like sadness, frustration, and fear as Micah journeys through these last years of high school. I must keep putting one foot in front of the other for his sake, making use of everything that can enhance his life. And yes . . . keep telling him to try, keep him involved, keep communicating, keep advocating.

Together, we will make the most of what he's been given. If his job is to manage props, then I will show him how to be kind and friendly to his fellow thespians, show him how to keep a neat table, show him how to model quietness backstage, show him how to ask if someone needs help finding what they need. If his job is pulling the curtain (as it was for his performing arts class night), I'll encourage him to do the best job possible. Treat it like a wonderful opportunity. These are the attributes that are going to make a difference in his adult life, the things that will transfer to work and volunteer responsibilities he will hopefully have someday.

Micah already has a love and appreciation for the performing arts. I will always be thankful for the early years when this interest was developed because that means a future of enjoying theater from the audience as well (or perhaps someday on stage once again). I have no doubt Micah and I will joyfully attend plays together for many years to come—and that is a priceless gift that will remain long after these challenging days have disappeared. ♦

CALL FOR SUBMISSIONS

Kaleidoscope magazine has a creative focus that examines the experience of disability through literature and the fine arts. A pioneer in the field of disability studies, this award-winning publication expresses the diversity of the disability experience from a variety of perspectives: individuals, families, friends, caregivers, educators and healthcare professionals, among others. The material chosen for *Kaleidoscope* challenges and overcomes stereotypical, patronizing, and sentimental attitudes about disability through nonfiction, fiction, poetry, and visual art.

Although the content focuses on aspects related to disability, writers with and without disabilities are welcome to submit their work.

• Double-spaced, typewritten • 5,000 word maximum • Electronic submissions preferred

Submit online at www.KaleidoscopeOnline.org or via email at kaleidoscope@udsakron.org



BEES

BETSY MILLER

My ninth grade lit teacher says we're going to have Writer's Workshop sometimes on Friday afternoons. This is the first time we're doing that. Since this is October, she says maybe we could write about something scary. We don't have to though. We can write whatever we want, and we don't have to turn it in.

I'm not sure if I want to write about something scary. Would writing about a scary thing make it even scarier? I don't know. I've never tried it before. I take out my green binder. I turn to the third sheet of clean binder paper because I like threes. Probably it would be best to invent a character so that if someone ever sees this they won't think it's about me or that I'm writing about someone in class. That would be creepy and stalkerish.

I need a name for my character. Jimbo. I saw that on TV once, but no one I know has that name. Plus I'll make him younger so he will be even more different. I click the lead in my mechanical pencil to the right length and carefully write on the paper.

Jimbo was seven years old. He was afraid of bees.

That's a good start. Bees don't bother me personally all that much, but I can imagine this little boy worrying about bees. So I continue the story.

He was not so afraid of bees that he couldn't leave the house. It was more like if he saw a bee he would avoid it, you know, walk the other way. He knew all the places where bees liked to go on the way to school—the bottlebrush plant, which he called the bee tree was worst of all. He always made sure to cross the street to the opposite side to avoid the bee tree.

I stop and look at the last sentence. The spacing between the words doesn't look right. I erase it and write it again. Still not right. The third time I decide it looks okay.

Jimbo looked a little funny walking to school sometimes, especially in spring when there were lots of flowers. While the other kids walked in pretty much a straight line down the sidewalk, he wove his way in a wandering path

moving from bee-free place to bee-free place, trying to stay out of the street because of cars. He probably ended up walking twice as far as anyone else.

Even though he isn't real, I feel bad for Jimbo—so scared of the bees, so afraid of the wispy touch of a wing, the feather-light feel of insect feet against his skin, the warning hum of approaching danger, the sharp, burning pain of a stinger.

I wonder how many rows are on this piece of binder paper? I have counted the rows on binder paper before. I think I remember, but I'm not sure. Plus, this piece of paper could be different. I count the rows going from top to bottom—thirty. I like that number because it has a three in it, plus it's also even, which makes it even better. I count twice more from top to bottom and three times going from the bottom to the top. That's two threes. If I count again that would be three threes, which is a nice idea, but it would also be uneven because I would have either more top-to-bottom counts or more bottom-to-top counts instead of the same number of each. I write "30"

very lightly in the margin while I try to figure out the best number of times to count.

The teacher says that Writer's Workshop is over. We can turn in our papers or take them home. I don't like to leave things unfinished, so I decide to take mine home.

After school, Mom reminds me that I have a doctor's appointment today. This is the doctor that has a lot of experience with teens and knows all about meds and exposure and response prevention. That's when they make you practice doing scary things and stopping yourself from doing everything that seems to calm you down.

I forgot about that. I don't want to go. I think about inventing a reason why I can't, like a stomachache, which isn't that far from the truth because my stomach is starting to hurt, but I don't think she'll let me skip. Or maybe she'll say that's even more of a reason to go to the doctor, duh! So I don't say anything.

Instead, I go to my room and get my roll of paper towels out from under my bed. I keep it inside a Ziploc bag so it stays clean. I go into the bathroom, and take the paper towels out of the bag. I wash my hands three times, and dry them with three paper towels, throwing them away as I work. It is such a relief. I try not to do that at school, but it's a long time to go without washing my hands. I put the roll of paper towels back into the bag and put it under my bed. I get out my green binder, click the lead in my mechanical pencil to the right length, then I work on my story some more.

One day the school called Jimbo's mom because he was always late. She wondered why because she sent him out the door in plenty of time. The next day she took time off work so she would be able to walk to school with him. At the

last minute she decided not to tell him. Instead she waited a couple of minutes after he left and she followed to see what happened.

She could see Jimbo weaving his way down the sidewalk. He didn't look up at the other kids who said hi to him. He didn't look up at all—only from side to side at the trees and bushes. When he got to the bee tree, she saw him dart across the street to get away from it. A car slammed on its brakes to keep from hitting him, but Jimbo didn't even notice. His mom ran to catch up with him and walked him the rest of the way to school.

Mom knocks on my door to ask if I want a snack. I say, "No thanks, my stomach is kind of bothering me right now."

Jimbo's mom walked to school with him. At first she walked on the side near the traffic because she didn't want him going into the street, but she could see that something really bothered him about the plants and flowers. She didn't know about the bees, but she said sure, if he held her hand and stayed out of the street they could trade sides. Jimbo relaxed until they got to the bee tree. The tree was alive with the angry hum of bees. They hovered. They darted from flower to flower. Every once in a while a bee would zoom away from the tree, adding an element of unpredictable danger. Jimbo could picture the bees coming at him, covering him with hot, sharp stings. Even with his mom between him and the tree he was too scared to walk past it.

Some of my handwriting looks crooked. I erase the last paragraph and write it over. Mom knocks on my door and says it's time to go. I ask if I can bring my binder and keep writing in the car. She says, "Sure, no problem."

Buckled into the passenger seat, I click the lead in my pencil and start

to write, but my handwriting is too messy because I'm in a moving car. I erase what I've written. I watch the odometer click through the miles like bees alighting one by one on Jimbo. In the waiting room at the doctor's office I click the lead in my pencil and continue.

Finally, Jimbo told his mom about the bees.

"Oh," she said. "Lots of people are afraid of bees, but you don't have to worry because bees are really not that interested in you. They just want flowers. I'll tell you what, we'll practice going near bees a little at a time until you get used to it."

She stood right next to the bee tree looking totally at ease. Jimbo was amazed and horrified at the same time. A bee flew onto his mom's arm and she didn't seem to mind. A moment later it flew back onto the bee tree.

The receptionist calls my name and Mom and I go in to meet the doctor. The doctor wears normal clothes, not a white lab coat. She's very friendly. Mom tells her about my roll of paper towels and how I write and erase and rewrite, and the time I pushed a kid into the parking lot when he tried to take my mechanical pencil. She doesn't know about the counting. Mom leaves the room because I'm over twelve and that's the privacy rule.

The doctor says, "So, James, can you tell me a little about yourself?"

"Can we just talk about bees?" I ask. ♦

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LISTEN WORLD. MY MOSTLY NONVERBAL CHILD SPEAKS.

SHEERSTY STANTON, M.S.

Six weeks after we painted the nursery pastel green with life, disability was born through my body. Two days beyond the end of the contractions, our daughter remained in the NICU swaddled in wires and tubes, suffering from a hit of colostrum to the lungs and an imbalanced ratio of carbon to oxygen. I was, regretfully, released “home” to midnight-rock my hollowed-out self in the muted eeriness of that re-purposed room. In a pocket of the soft green rocker where I was to hold my firstborn, my fingers traced, instead, the pages of a tiny lullaby book and a tube of nipple cream waiting to be needed. My body swayed forward and back subtly as I wept from both my eyes and my breasts, knowing nothing.

For the more than eight years since, I have been reckoning with this epistemic severance, sifting through the beautiful wreckage of this fierce-loving-thing called motherhood. Resembling an infant always needing to eat, I have rooted ravenously for an understanding of how—or who, if we could emphatically point a finger—was behind this painful divergence, this banishment, from normalcy and health. Inherent within my directionless asking has been that ubiquitous question with the power to unravel everything. “Why?”

Sometimes, on woodland walks for reprieve, ushered by the something deep inside me that trusts life, I have inquired with open curiosity and been met with interpretations soft as a bed of pine needles calling to me from damp ground. In one such karmic musing, nature giving a generous allowance, I

imagined my beloved child and I once ceremoniously chose each other for this valiant undertaking, like proud but gullible tributes drawn to represent the best districts in *The Hunger Games*. In our fleshly arrangement as mother-daughter now, we strike deals all the time—bathroom trips for French fries, clean ups and calm downs for tablet time—characteristically shaking Cheetos-powdered hands with excessive vigor and goofiness.

More often, however, this covenant of joyous acceptance has dusted my pant legs and fallen to the floor, feeling wrong. Trust in life, and enduring self-love, could be entertained as possibilities but not yet steadfast realities. The same woodlands echoing kindness also echoed harshness, as I dragged myself along the prickly ends of the molted pines and felt deserving of them, restless in my wishing for the stabbing finality of a reason our path must be so ruggedly different. Maybe, early on, I unconsciously decided I was the easiest target for blame, especially when God felt unreachable. I determined my internal violence the lesser of many evils and well warranted. I mean, *what kind of mother was I to indulge in even tiny morsels for myself when I should be vigilantly adding images to communication apps, picking wax out of hearing aid molds, and filling my bathtub with a sensory feast of noodles?*

Over time, I began to see myself reflected in the mirror of my beautiful child striking herself with balled fists whenever she felt too much and not enough. As I moved to intervene, encouraging softness while assuming fault, I realized my

own self-talk could have been allegorically portrayed by a mind and heart absorbing knuckled blows. With this new sight came the sobering acknowledgement that most of us, principally mothers (of both the able and disabled), are hustling with Pinterest-inspired Halloween costumes and homemade baby food to compensate for feelings of inadequacy. We, in a thousand ways, punish and forget ourselves, attempting to keep at bay the shame-inducing doctorly assessment that we came out “wrong.” That we surreptitiously are—as a well-meaning friend once called my daughter when I accidentally let myself vent of abiding struggle—“an effing problem.”

* * *

From my twenty-seven-year-old body, our little miracle emerged screaming red with all but one faultless pair of twisted chromosomes—the last, a slight mismatch above the corkscrew. Although her father and I’d received lab-drawn clues of potential errancy in the first trimester, our fears were assuaged by her stubby appendages waving over sonogram. We opted out of invasive procedures that might risk dampening our excitement as newly expectant parents. And, although I was pursuing a family therapy graduate degree at the time, I, unfortunately, hadn’t enrolled in Genetics.

Our daughter arrived full-term, instinctively sheltering inside me as long as she could and making her debut only on the eve of my induction. Despite adequate bake time, she was a not-so-whopping five pounds, fifteen ounces. This fact—coupled with her slightly-tilted tiny ears and the “abnormal” placental ropes medical team members tugged from me with great interest—caused a flurry of day one visits from various examiners who mumbled to each other with wide eyes and anointed me with uneasy smiles.

My delight quickly turned to a fearful loss of control. By the time we’d definitively given her a name, our baby was choking on forced formula. Our baby was struggling to breathe. Our precious newborn was stripped away and carted through a tunnel under the road, through the hellish bowels of the hospital, past large, scuffed bins overflowing with soiled laundry.

Disability was born through me only hours earlier, and already my wheelchaired, unslept mother-body could not keep up, let alone keep her safe.

On day ten—two intubations, a surgery, many expert contradictions, and a chartered airplane flight to a level-IV children’s hospital later—we received her diagnosis.

I recall meeting with the geneticist in one of those stuffy rooms with the pods of chairs set facing each other. Lore has it that, within them, some people breathe expansive sighs of relief.

I am exhausted from days spent dozing in liminal space between alarm bells and meal call-ins, inheriting the circadian rhythm of shift changes, my arms tingly from the weight of cord-laden baby, waiting for “rounds” and for chicken strips, in a lounge that I dutifully roll out of the way for ladies wielding vacuums.

The doctor introduces herself, launching into focused medicease of which I pick up little but the words “interstitial deletion” and “wrong” (*wrong*, *Wrong*, *WRONG* . . . reverberating in my head). She provides a pamphlet outlining a handful of case studies from children globally with a variety of similar conditions. Prognosis ranges severely from never talked, never walked, never fed themselves, and died young to C-student, struggles in school.

**Disability was born through me
only hours earlier, and already my
wheelchaired, unslept mother-body
could not keep up, let alone
keep her safe.**

She describes the cause as *de novo*, basically a scientific term for “fluke.” It feels like colostrum in the lungs to hear this, and I want to yell. Instead, I sit numbly as she goes on, objectively peering over her thick-rimmed glasses, telling us our chromosomes are likely in order and intact.

But. By a lottery, something, somehow, went amiss between the egg and sperm in the flash of conception. A slice of information scurried off to an unretrievable place, letting its absence be known in every cell. In the wake, potential vulnerabilities and developmental delays ensuing like an unfurled scroll sentence one can’t even begin to conceive: She’s at higher risk of choking, of falling, of seizure, of hospitalization. Of self-harm behaviors. Of being stared at and bullied and abused.

We are told it’s probable that no one on the planet has the same diagnosis.

The educated woman finally leans forward with a crescendo into feeling, clearly wanting to impress us with her competence. She asks, “What questions do you have?”

What questions do we have?

My then-husband offers a few while I listen to the heater kick on (the *wrong*, *Wrong*, *WRONG* . . . incessant) and sense my

breasts ready to ooze again for my little one, or for all the plastic needed between us to convey nourishment.

Through brave authenticity, we are finding ways to belong.

I'm having my Tower of Babel moment, coherence diasporic, unknowingly enlisted to mother a child who would struggle to form words but speak volumes. Set on a spiritual pilgrimage to re-discover Love—the primordial, universal language.

* * *

When our daughter is almost three, I go away for the first time to a weekend journal-quilting retreat. I don't really know what I'm getting into, but I need-beyond-all-needs to ephemerally extricate myself from the realm of medical appointments, shape-sorting, and crushed Cheerios always underfoot.

"Begin with a question, and let it guide you," the facilitator says. She exudes a warm and spacious presence from being educated by her garden, her entrepreneurial ventures, and her share of life's hard knocks. Here, at last, unlike in the hospital, the questions I carry need not be utterable. They need not be caged, tamed creatures, but wild ones approached indirectly.

I'm given a fabric rectangular backdrop to collage upon from bountiful source materials housed in canvas bins. For almost two days, I sift through and scissor a mess of colorful tatters that cannot seem to agree with the frame. I iron some on, even though they don't feel "right"—because I still mistakenly believe one must always appear as if having it, or at least getting it, together. I take short wandering breaks onsite, at the jarring edge of prairie and woodland ecosystems, finding pockets of snow and feelings hiding under evergreens. Finally, nearing the retreat conclusion, I get exasperated with the impossible task of fitting my life into a box. I take a roller knife to the whole thing.

* * *

Isn't *wrong* just the broad stroke we give what we don't yet care to understand, or what touches some quivering vulnerability within ourselves we would rather let die than tend? Might it be that a revolutionary "rightness" waits exiled just 10% beyond our current worldview, or an untapped layer-too-deep within us, yearning to usher us into a more expansive reality?

* * *

From the pieces I fuse together, the structure I create works better. I finish the bold, oblong cloth masterpiece with glued-on traces of the eternal: broken old watch parts with gears spilling like guts, a timeworn key that would surely get me into *The Secret Garden*, suns and moons drifting, and beaded whimsy threads.

It's perfect.

* * *

Faith is subject to constant disentanglement. This essay is the truth, being continually rewritten, not needing reasons.

* * *

Because disability was born through my body, now, each day, it must atone as a shock absorber between my daughter's sweet, petite but gangly, puts-the-Energizer-Bunny-to-shame, magnetic, dancing, star-loving self, and the rest of the world. My unceasing choreography is that of an interpreter, a guide to the well-meaning and ignorantly blissful, an ally to the embodiment of imperfection, and cultural reconciler to what is "other."

Through brave authenticity, we are finding ways to belong.

* * *

Just last week, as we paged through her first-year baby book and revisited the pictures of her hospital stay, my daughter learned the word "different."

When she said it back to me, I sobbed.

* * *

My unwavering search for kinder meanings borrows slivers of cognizance between IEP meetings, navigating difficult transitions, and creatively having to coax the toothbrush, nail clippers, and hairbrush around sensory resistance.

I am divorced, so I must work. And I want to—I want so, so many things. Remember? There are no reasons and too many reasons. This is the truth I'm writing. It doesn't have to make sense.

* * *

I become master of Tetris to halfway inhabit my life like a type A professional worthy of common human experiences like friendship, dating, advancement, and hobbies. Although I feel averse to having another child, I bear dreams to nurture the world.

My energy and health have ebbed. Nowadays, it is a given that I must devote gobs of money and time to my own well-being. I understand my religious tithing to clinicians and bodyworkers is an unselfish act that keeps my nervous system tuned to handle overwhelm.

See, I cannot fully abandon the notion that “good mothers” do it all. Most supremely, we care deeply; and, in so doing, we are changed.

I’m more convinced than ever that my dear daughter, with her precious, awkwardly sprouting vocabulary, hearing aids, and communications device, has very important things to teach us.

Every day I am learning she gives voice to the story of nature’s ever-unfolding creation through her authentic presence, plucky personality, and through a steadfastness to survive and energetically connect. Along with an increasing number of atypical children, she represents a breakthrough—the adaptive emergence of a re-membering, an inconvenient invitation for our species to return to a more interdependent way of life.

This truth, amended, requires the expansion of “good mothership” to include seeking and receiving help so the “doing it all” somehow paradoxically yields a lesser load. It

requires writing over narratives of ostracization with ones of abundance and belonging *because* of difference.

Maybe that’s why I sobbed when she said it. *Because* the truth is re-writeable. And communal.

To wish for the eradication of disability is to support the erasure of our needs for one another, to serve as coconspirators in eroding our social fabric and diminishing our collective capacity for love. From our tattered places, strewn against an obsolescent box backdrop, we need compassionate severance from constricting ideologies. So then, by choice or by holy fluke, we might be arranged together into softer forms. Becoming more chimeric, mycelial—like the Pando forest organism, relating as parts of a vibrantly-greater, enduring whole.

* * *

Disability was born through my body—it’s true. Reasons or not, my body once carried something divine.

Among the various approximations of words she reaches for today, my darling finds the most magical to fixate upon and practice. Rain. Stars. Moon. Solstice. It’s as if, by some echolocation with the heavens, she knows we are all *rightfully* born to constellate with majesty.◆

GREEN BEANS AND ALIENS

JOANNE FEENSTRA

The challenge of the two-day writing intensive is to write about something small, or as a second choice, write about the butterfly effect. I want to do one of those, or both of them together, write something different from the usual, something explosive, burst out of my cocoon, explore the far reaches of outer space, some creative fiction bit. Or write a long poem, like *Beowulf*. Instead, I acquiesce to the Overlord of my brain, writing as always, about the Gordian knot that is my relationship with my mother.

Write about something small or the butterfly effect. While I want to write a space opera, my mind jumps to the same old, same old, but quite strangely, to a specific moment in time, a moment when my mother and I prepared a winter's worth of green beans for the freezer. Maybe that moment because I still have my own stash of dried beans that I hoarded three years ago, during the tensions of COVID-19, and this morning I pulled some out to make hummus. The rest of the beans, black, kidney, garbanzo, pinto, and the black and red lentils hunker down

in the bottom pull out drawer in the kitchen: I get rid of them a bit at a time in black bean burritos, chili, or bean soup. Maybe I think about that moment and the green beans because there are borlotti beans cropping up in my own yard. Maybe that moment about the beans came up because I will end up writing about my mother, regardless of what I want, and any moment I remember spending with her is a place to start.

In 1968, on a summer day, we dig into a pail of green beans she had harvested. I am twelve. It is hot on the back deck. My mother then was as old as my daughter is now, thirty-six. "It was Mary-Anne's parents' wedding anniversary last weekend," I say. "How come you never celebrate yours?"

Mom says nothing while she uses the kitchen paring knife to cut off the top of a long, fat green bean, a bean so large that nine giant pods were clearly visible beneath the green skin. *This will be a tough one*, I think, *she'll boil it for half an hour*. She cuts off the bit of stem that is still attached, the stem that nurtured this particular green bean for a

too-long time. Mom says nothing while she holds the knife and tears the string, as tough as sinew, off the bean's side. Her mouth tightens as she snaps the bean in half.

It is hot on the covered wooden deck of the three-story house. I think she doesn't need to grow green beans but she also doesn't look like she's enjoying herself. We are not a poor family but for her, a freezer full of large, chewy green beans must be more satisfying than fewer, softer, fresher ones, or even more satisfying than going to the store and buying green beans, the frozen ones, like the ones my friends have at their family dinners. She had a weekly menu and homegrown, frozen green beans are on it, on Tuesdays.

I've seen her wedding pictures, her and Dad, tucked away in photo albums under their bed. They looked happy. I persist. "When's your wedding anniversary anyways?" I ask. She looks up at me, her mouth pursing while she snaps another long green bean. "June," she says. "June 17."

With twelve-year-old panache, I still remember I did this on purpose to make my point obvious, I put down my handful of green beans and the paring knife so I can use my fingers to count. June, July, August, September, October, November. One, two, three, four, five, six. I'm the oldest. My birthday is early December. Seven. Now, I'm twelve. I know nothing for certain about how long it takes to make a baby but I have a suspicion that it is longer than six or seven months. I can not be direct with her so I ask a question. "Doesn't it take nine months to have a baby?"

There are many babies in our extended family. I am one of the oldest cousins. We live in Abbotsford where Dad and his two brothers and a brother-in-law own a tractor dealership. Every family except ours has three kids, even Dad's oldest sister whose husband is a dairy farmer. I'm the oldest of four siblings; there are sixteen grandchildren when my grandparents come to visit from Friesland, where the tallest, and blondest Dutch people live.

Mom is short, dark, and swarthy. She has a sheaf of black Mediterranean mustache growing on her upper lip. There are a lot of family parties and family gatherings at Christmas and New Year's and Thanksgiving and birthdays and anniversaries. These are all my dad's relatives. Dad's siblings and their spouses would have known about the quick marriage but it was never mentioned, even in jest, and my parents never celebrated their wedding anniversary for as long as they lived.

In 1968, there are wars going on. Martin Luther King and Robert Kennedy are assassinated, medal winners Tommie Smith and John Carlos lift black-gloved fists at the Summer Olympics, white Captain Kirk kisses black Lieutenant Uhura on screen, Apollo Eight makes it around the back side of the moon and hyperkinetic reaction of childhood is mentioned for the first time in the *Diagnostic and Statistical Manual of Mental Disorders*, a label for people displaying

an excessively short attention span, hyperactivity, and restlessness.

Two early springs ago, on a phone call, she says, "Mom, maybe this is what's wrong."

Maybe in 1968, Mom was hoarding in case of catastrophe reaching into the enclave, like I did during COVID-19. She could have had PTSD from her life in Holland, when the Second World War started. She would have been eight. My grandson was eight three years ago and I imagine him, living in the suburbs, on a small farm, in that war. The soldiers were down the road living in the school. "A bunch of nice guys," Mom told me once. They'd trade cigarettes for meat and fruit, and everyone smoked. "Even I did," she said, "when I was eight." She smirked. "Everyone smoked." It was kind of funny, imagining my uber straitlaced mom smoking. I imagine my grandson smoking at eight years old. Mom told me her friend, and her friend's family, were taken by the soldiers, and she never saw her friend again. "They were Jewish." Mom was eight. Imagine my eight-year-old grandson. Imagine myself.

While 1968 happened in the outside world, my siblings, my cousins, and I attend a private Christian school. We are all middle-class Dutch, each and every one of us. All my friends have Dutch last names. We attend church, twice on Sunday, Christmas Eve, Christmas Day, New Year's Eve, New Year's Day, Easter, Good Friday, and catechism class on Tuesday nights. If the regular minister is not available, we hear *prake lezen*, written sermons, read out loud in Dutch by a church elder.

We all fit together. Except we did not, our family does not. There are five of these Christian Dutch immigrant

churches in Abbotsford and my mom chose to attend the one the rest of Dad's family did not attend. Dad immigrated with his siblings. Mom immigrated alone. Mom calls the parents of my friends "stupid farmers" and won't let my friends over for sleepovers. There are more things that are weird, too many. Our branch of the extended family operates like Keill Randor in *Galactic Warlord*, piloting alone through the outer reaches of the Inhabited Galaxy. Our branch of the family is on some intergalactic journey.

"Yes." Yes, it takes nine months to make a baby. She picks a handful of green beans out of the bin. Snap, snap, snap. Off go their heads. "Yes." I watch her purse her mouth. "Well." I reach into the bucket, take out a small handful of green beans and snap off the stems. I am only half as fast as her. If these beans had been left to dry and placed in safe, quiet storage over the winter, they would be the embryos of the next generation but we destroy them now instead.

My thirty-six-year-old daughter, as old now as my mom was then, is a nurturer. She nurtures her child, her farm, chickens, dogs, her four stepsiblings and when she has time and energy, me. She's a farmer, with a vegetable farm with actual customers, she works so hard, and she makes money. She pickles, cans, and dehydrates food and saves seeds. Of course she grows beans, tender young beans that are delicious to eat, and saves the big seeds for the next spring planting. In the fall and winter and into early spring, she takes courses at the nearby college. We live close to each other so we see each other often. Two early springs ago, on a phone call, she says, "Mom, maybe this is what's wrong."

She was born in 1987. In 1987, I do not marry or even live with the father of my daughter, Margaret Thatcher is elected for the third time, Aretha Franklin is the first woman inducted into the Rock & Roll Hall of Fame, Liberace and Andy Warhol die, and the *Diagnostic and*

Statistical Manual of Mental Disorders changes the name of hyperkinetic disorder in children to attention deficit hyperactive disorder.

“What! What’s wrong?” My mind jumps around like fireworks, death, dying, someone is maimed. “What?”

“Maybe you have ADHD. It’s in my textbook. Listen.”

She reads me the symptoms and I spend the next week hyperfocusing on ADHD. I cry. I’m a sixty-five-year-old female with the textbook issues of a nine-year-old hyperactive boy. A jumping bean. These symptoms define me, they are me. I can’t sleep. From what I read, I’m not just maybe ADHD, marginal, or borderline, or halfway there; I am all the way in. For a week, I read everything there is on the computer and walk and eat too much. My entire working career, I worked with people with disorders and disabilities; now, I am them. I’m ashamed that this makes me devastated. I normalized them for themselves, but I never wanted to be them. It takes me some long days to let that sink in and a week or two later, I tell my daughter, I think she’s right. I’m a jumping bean.

A month after that, I agree with the doctor’s three-page form that I am neurologically hampered. The polite way to say it is atypical, I am neurologically atypical. There is an actual label to the reason I can’t focus on one thing for a long period of time unless it’s the thing my brain decides to focus on. There is ADD or ADHD. I’m ADHD, both distracted and hyperactive. ADHD is why I’m always marginally depressed or so thrilled or so worried or so anxious or so exuberant or so miserable or so loud or so quiet. I’m always so something. ADHD seems to be a matter of either exaggerating or minimizing, of operating at high speed or no speed, of hyperfocus or non-focus. In the two-day writing workshop, I sit in a room down the hallway so I can talk aloud to myself, get up and down, go

to the bathroom, or walk outside. I sit in a room down the hallway because it drives me crazy when other people talk aloud to themselves, move their chairs, or cough. Or breathe.

ADHD is not a matter of want, like telling a fellow with a broken leg to get up and walk; for God’s sake, I’m not Jesus. It’s a matter of *can’t*. I can’t. But there is no cast to remove. I won’t get *better*.

The polite way to say it is atypical, I am neurologically atypical.

But I do *want*. In April, after the medical doctor agrees with my self-diagnosis, I have a week’s worth of stimulant, a medication unchanged since 1955, a year before I was born, securely tucked in my purse. I am on my way to Vancouver with my friend Mary. A month before, she said, “Let’s go to the coast to see a Valerie June concert.” That’s a ten-hour drive from here, one way, but if you have ADHD, you say, “Great idea,” before you find out who the singer is or think about how you’re going to get there.

I said, “Great idea.” Then I quickly add, “I’ll take my car.”

She looks at me with her honest and beautiful face and says, “John always drives when we go to Vancouver.”

“No problem,” I say. With one dose of the stimulant, at the level prescribed for my peers, nine-year-old hyperactive boys, I drive for five hours, clearheaded and alert. We pull into a fast-food restaurant in Princeton. We go to the bathroom, order some food, and sit outside. I eat my fries and take my coffee for a short walk where I also take one more pill. I sneak it in, it’s a secret, me and my ADHD. Five hours later, we arrive at my sister’s place in Vancouver

where I have a rational conversation, a glass of wine, dinner, and fall asleep.

I keep this up for the whole weekend. I never crash, I never get angry, the noise level is never too much. I am level, calm, and bright. I do not eat too much. I do feel like I am a bit too straightened out, too calm, too not-tired but I enjoy this break from my overly emotional life. I drive the ten hours home. When I look over at Mary, she is asleep. She wakes and tells me she is exhausted.

Over the next few days, I moderate my intake of medication. Now the housework is getting done and I’m not frustrated, angry, or impetuous. My doctor asks me if I am sleeping enough. “Yes,” I say. “The stimulant doesn’t seem to bother my sleeping.” This is how “normal” people feel, is it? I like this feeling. I’m so level.

I ask my doctor for another week’s prescription, then two more. We are both so happy this is working. The days pass into autumn and I do another MA level course. My husband notices the difference in me. I am not as easily flummoxed when the propane stove runs out of propane. I do not lose my keys as often. I am not mortally wounded when my daughter is too busy to talk to me.

I read words and understand them. An ADHD brain will start a paragraph and then jump to the end of it; in my previous life, I read the same words three or four times and used highlighters, arrows, and wrote in textbooks in order to stay on track. Now, I only read words once. There are a lot of seventeen-letter German words in this course. I get an “A” on my first papers and later an excellent mark for the whole course. I am smart. I never knew that. I never knew that before.

When I am not in school, I take the dogs and walk up the hill and sit on the rock I usually sit on, three-and-a-half-kilometers one way, easier on stimulants than slogging up the hill while my Overlord brain is consumed

with thinking about how difficult it is to walk up this hill. Winter comes and I still walk up the hill, even in the snow. I stick to a task. I take a plastic bag to sit on. I sit on that rock, look over the lake, and think about how I can kill myself. I realize I have been doing this for a week. Or more.

“This medication doesn’t work,” I tell my doctor.

We’re on Zoom and I watch her shake her head. “It works for most of my people,” she says.

But I know better, of course, because I’m ADHD and I have hyperfocused on ADHD medication. I know all the brands of medications available in BC. I think I know about the side effects. I tell her I’m feeling depressed for no reason that I know of, it must be the meds, but I do not tell her the part about killing myself because who knows what kind of intervention that would trigger. I don’t want to seem crazy.

“Can we try something else?” She gives me a prescription for a short-term stimulant medication. After a week, my mouth twitches. Not that you can see it but I start to purse my lips all the time. Parts of my personal anatomy where I’ve had external surgery become painful and itchy beyond belief. I use anti-itching cream and quit drinking coffee. The itching and twitching persist for a month. I quit those meds. A year later, my mouth still twitches and the doctor finds lesions where I had my surgery and now we have to watch for cancer.

The last medication we try is a non-stimulant. It helps me concentrate in a quasi-linear fashion, something I’m not used to in my non-drugged life, and I’m calm, maybe not able to drive the ten hours to Vancouver, but now I don’t care if it takes eight or fifteen hours to get there. At home, I paint a seascape and use only three colors, white, blue, and a bit of gray to highlight a few clouds. I don’t like this painting but

everyone else does. “It’s calm and peaceful,” they say. It’s boring beyond belief and I can’t believe I painted it. I sell it later in trade for lumber; it’s the first money I’ve made from art. It’s more socially acceptable than the multicolored abstracts I have stashed upstairs in my office. I don’t find this fun. But I don’t feel crazy. I am calm. So that’s the price I pay, I think.

I sit on that rock, look over the lake, and think about how I can kill myself.

In the local community band, I play bells, a xylophone made of metal. On the non-stimulant medications (we ADHDers call them non-stims: stims and non-stims, that’s the lingo), just as with the stims, my sight-reading has improved, I am not morose and frustrated if the conductor goes ten minutes past 8:30. I used to go home and say, “I hate band.” I never say that now. On non-stims, I say nothing.

One Thursday evening, at band practice, I find I do not have the energy to put my instrument up on the music stand. I take the chair in front of me, turn it around and put the bells on the chair instead. I do not stand up to play. I can not see the conductor and I do not care.

A week later, I easily put my fifty pound instrument on the stand. I quietly tell the forty-five-year-old male conductor I have ADHD but I’m not medicated and he nods. The next week, he tells the whole band he has ADHD and from the back row, I nod back at him. I’m a sixty-seven-year-old white female with a lot of curly gray hair who has played bells for three years. He’s a thin, brilliant forty-five-year-old male musician with a new crop of dreadlocks. He’s my bro.

In the spring, in the psychologist’s office where I am trying to get an official diagnosis from an official shrink, she says, “Did you ever have birth trauma?”

I say “No,” because I have said “No” to a lot of her previous questions that I suspect relate more to bipolar disorder and autism and I am looking out the window at the lake just beyond the front of the yard. Then I shout. “Yes, wait. I did.” She wants me to tell her about it. “Four days stuck in the birth canal,” I say. “The doctors told my parents I was dead and to prepare for the worst. They couldn’t find a pulse.” Their first child, the six-month baby, a stillbirth. The psychologist tells me that’s another marker for ADHD, not for the parent but for the child.

The psychologist wants to know about other trauma. I tell her. You can’t see these traumas, no black eyes or such. No one beat me. In this writing intensive, I do not want to write about this again. So, I imagine how I’d talk about this on a podium in front of educators who want to know about ADHD but who are not expecting to hear how a sixty-six-year-old still has not moved past their privileged white childhood. I would say something suave and unrevealing, something like well, ahem, I read that some adults, because of thwarted emotions, lack of social support and isolation, sometimes turn narcissistic and make the rest of their lives about how they look to others. They might use their children as fodder to give themselves social status and when their children fail, there is always a price to be paid. By the child. When I release myself from my own narcissistic fantasy of my own brilliant speech, I wonder how different are my mom and I? How different am I from my mom?

She blurted and yelled, as did I, at her husband and children. As I do. She was unable to process noise in the house, as am I. As I still can not. She never spent time in the kitchen with her children,

as I also did not. She had lots of rules in the house, as did I, as do I, because rules of operations are how ADHD people stay sane, how they don't fly out of control. She was so angry, as was I. As I am.

I remember the first time we had chili with ground beef on a Wednesday. Dad hated it and Mom cried. Maybe she wanted to be impetuous and creative, and Dad wanted potatoes. Maybe in 1968, in the church, in our family, she had to obey her husband in all things. Well, not maybe. She did. Those were the rules. She liked most rules, just not the ones others imposed. I remember Mom saying, after women were allowed to vote in the church, she had to vote the same way that Dad did or she would just wipe out his vote. Maybe she tried her best to believe all that junk. Maybe she had ADHD and thought she had to live in that world of Overseers, but always felt like an alien. That might have been what made her so angry.

During the Second World War, the Dutch schools were closed because the invading soldiers lived in them. When they reopened, Oma kept Mom home to do the housework while her younger sister and six brothers went back to school. "I hated my mom," Mom said. "She made me her slave." I shudder at how that sounds, how I have said the same thing. I'm sixty-seven now and she's long gone. I've said dreadful things about her, none of them untrue. I hope I raised my daughter, not well, but better than I was raised, and I think my daughter is raising her son, not perfectly, but I hope better than she was raised. If then, like a statistics formula, if then, maybe my mother raised me better than she was raised. If she had ADHD, with all its undiagnosed emotional dysfunction, undiagnosed learning disabilities and lack of impulse control, feelings of dejection and unmanageable energy levels, less ability to comprehend written language although we can read the words, an inability to process numbers even though we can see them clearly on

the page, unless we are also dyslexic, which I am, who was she really?

After she immigrated, not long after, only eighteen years later, she had it all, the big house, the financially successful husband who was loved by those outside his own house. In 1968, we looked like a family from *Good Housekeeping* magazine, but those inside our small world circle of 600 Dutch folk, they knew our family was a bit different. We lived with Kiell on the alien planet Moros. But they didn't know why we lived there. I suspect Mom did not know why either.

The same summer I am diagnosed with ADHD, a friend gives me about thirty borlotti beans, "Best thing since sliced bread," she says. I don't know what borlotti beans are; I only know green beans. My friend grows them on poles that she says her husband put up, twelve feet tall. "Easy," she says. "The pods turn bright red in the fall, when they're dry and ready for winter storage or you can eat them when they're green. Use them in bean soup."

Another friend says, "When they're young and tender you can just boil them or eat them in a stir fry."

Then they both say together, "And they're so delicious."

I don't know about borlotti beans but I have ADHD so I give them a try. Why not? I plant them and quickly the leggy vines grow up and over the six-foot poles I scrounge off the beach. Then, I don't water them or even watch them. Of course I don't. In the fall, the bright red pods catch my eye and I pick small, malnourished bean seeds and put them in two very small—because there were only a few that survived my malfeasance—glass jars.

I tell myself that next spring I will plant these beans again and water and fertilize them. I will plant them on taller poles and the vines will look amazing in the fall, bright red spots growing up tall poles along the side of the house. I

will have more beans, even enough to eat.

Maybe she had ADHD and thought she had to live in that world of Overseers, but always felt like an alien.

In the spring, I open one jar with thirty tiny beans and plant them around the yard, not on twelve-foot poles, because, well, really, seriously? I plant them against tall board fences and along the back of the wire fence. I remember then I am already mad at myself because I will not want to pull all those dead vines off the fences when winter comes.

I open the other jar, with its thirty tiny beans. And bugs. Right then, I do not know what kind of bugs they were but later I looked them up; they might have been ticks. If I had been calmer, I could have drowned them with rubbing alcohol or gin or in the toilet, but then I just scream and throw the bugs and the beans out into the side yard where I have a garden bed of dirt, compost, dead plant stems, roots that I don't know what to do with, and an old rhubarb plant that annoys me because I can't kill it and it won't die on its own.

The bug-infested borlotti beans grow there, even without nurture and care and water. Those borlotti beans do not have any poles but they support each other; they form a bushy, heaving membrane of green vines and leaves and many many bean pods. I watch as they wilt, as those infested borlotti beans die and dry in the hot summer sun. I never water them. In the past month, this autumn, with a bit of rain, new borlotti beans sprouts grow, already a foot high, already entangled with each other because there is still no support system. They survive, going and growing, nurtured, not nurtured, neglected, suffering from the

dysfunctional gardener's inattention. Winter is coming. I wonder how they will fare.

ADHD is the reason that one year I canned peaches, pickles, relish, plums, and jams and now I have dozens of empty canning jars with new lids in unopened boxes tucked into the eaves. It's the reason I yell at my husband so often. In 1968, I whipped poor old Jock, a horse we had, with a chain. I'm so, so sorry.

At the end of the first day of the two-day writing workshop, Anne, the facilitator, asks a skill testing question. If we answer it correctly, we win a book on writing. She says, "Who can name a novel that made you cry?" I know she's been fairly clear on the protocol of raising our hands to answer questions because it's confusing when we all talk at once.

Educated by Tara Westover made me cry. I shout out "*Educated*," as if I'm happy I can relate to this tale of paranoia and isolation. She hands me the book I've won. *The Emotional Craft of Fiction. How to Write the Story Beneath the Surface*, by Donald Maass. My heart plummets. I don't want this book. I don't want to write more about the story beneath the surface. I don't want to craft emotions. I want to write stories like Douglas Hill's, where, while Keill Randon is slowly dying of

radiation poisoning, he embarks on missions to avenge the destruction of his home, the planet Moros. I want to write *Galactic Warlord*.

Then, Anne hesitates. She turns to me from the front of the room. "But *Educated* isn't a novel," she says. "It's a memoir." In that moment, I'm grateful I was wrong. It's a good reason not to explore crafting emotions, it is not the right book for me, it's karma that I give it back, this book unfairly won by my shouting and even shouting the wrong answer. I thrust the book back at her. "You can have it back, if you want. Regift it." She shakes her head and moves on to the next one.

Driving home that evening, alone in the car for forty-five minutes, I turn on the radio. CBC is boring so I turn on commercial radio to keep my shame at bay. I feel the shame like a mosquito bite, not quite gone but not quite hurting. Why did I blurt out? Why can't I raise my hand? I'm a nine-year-old boy. For the rest of the night, I work on not beating myself up. It was the ADHD Overlord. I'm exhausted thinking about going back to the writing intensive the next day, to sleep without fretting, to not hang my head in shame at my blurting and then blurting out the wrong answer. But because I now know I am neuro-atypical, I can forgive myself. I am

the first one at the workshop the next morning. I tell her I'm sorry I blurted. "I have ADHD," I said, not because I'm comfortable with it, but just because it's true. I have ADHD.

And now, I sit and write in a room separate from the rest of the people attending the writing intensive. I write from the now dead planet in the outer galaxy, from the planet Moros. I tell myself I will accept evidence and assistance, as Keill said to the Overseers. If I ever write it, which now you must know, may or may not happen, I could write a story about meeting my mom in our alien world where she lived her whole life by herself. I would tell her about my daughter, how wise she is, how smart, how she nurtures me, even though that's backwards of how it's supposed to be.

Mom and I would fly a spaceship and take painting classes together. We would push a button and decide whether or not we wanted to eat beans. We would fight off the evil Overlord because I would tell her what I learned about us, I would tell her about me, her born too early daughter, who I really am, me and my ADHD. We'd grab onto a sword and slice through the Gordian knot, me and her, together, aliens sorting all the beans. ♦

Emma Baker is a dramaturg, writer, and student at Los Angeles City College, where she is expected to graduate in 2024. Appearing in publications such as *The Citadel* (April 2023), *JAKE* (February 2023), and the *Long-Winded* anthology (June 2024), Baker says, “I’m curious about the difference between a thing’s essential nature and the way people label it, and I often examine what words can and cannot do for people.”

Jax Bidmead is an illustration student at the Maryland Institute College of Art. A resident of Canton, Connecticut, he has always been an artist first, though recent years have ignited a passion for writing. Bidmead aims to one day write a graphic memoir covering his experiences growing up with undiagnosed disabilities.

Marjorie E. Brody of Schertz, Texas, is a retired psychotherapist, mother, poet, and author. Obtaining her Ed.D. in 1987 from Auburn University, Brody’s works have appeared in *Short Story America* (2011-2015), *Twin Bird Review* (Winter 2023), and *Black Fox Literary Magazine* (Summer 2013), among others. The poem in this issue, “I’m in Here,” was inspired by residents in nursing homes who are not able to communicate. Brody writes because she believes it is “an honor to touch the readers through my words.”

Emma Burnett is an author, recovering academic, and researcher living in Oxford, United Kingdom. She is currently working on her Ph.D. at Coventry University with plans to graduate in 2024. Her work can be found in *Elegant Literature* (2023), *The Hellebore* (2023), and *Android and Dragons* (2024), among others. Burnett doesn’t like to dwell in the dark, but says, “I know neurodivergence, and I know depression, and I think that comes through in many of my stories.” Interests include cats and sports.

Douglas G. Campbell of Portland, Oregon is a retired professor emeritus who obtained his M.F.A. from Praat Institute in 1973 and his Ph.D. from Ohio University in 1979. Campbell says that life has been a struggle since his stroke. Despite this, he uses poetry and art to stay positive. His works have appeared in *Quibble Lit* (2022), *The Path* (Winter 2022), and *Night of Aphasia Arts* (April 2024), among others.

Deb DeBates is a writer and voice-over artist residing in Oxbow, North Dakota. She has been published in *The Writing Disorder* (Fall 2023) and the *Publish Her* anthology (September 2023). DeBates enjoys writing about her journey alongside her son, who has autism and type 1 diabetes, and enjoys sharing her stories to “help others better understand the life of someone with these diagnoses.” Her interests include dogs, cooking, baking, and going to coffee shops for chats with friends.

Alexander Etheridge is an author living in Dallas, Texas. His works have appeared in *Susurrus* (2022) and *Abridged* (2022), among others. Etheridge’s awards include the Struck Match Poetry Prize in 1999. Attributing depression as an influence on his work, he states, “my poems about depression are written in periods of recovery, in looking back.”

Joanne Feenstra lives in British Columbia, Canada, and obtained her master’s in integrated studies from Athabasca University in 2018. She declares her life “has been a whirlwind on top of a roller coaster” and is proud to still have her motorcycle license. Feenstra enjoys her marriage, her wonderful daughter, and celebrating the good things about ADHD.

Janet Engle Frase is a retired nurse residing in Altoona, Wisconsin. Her works have appeared in *Portage* (2021) and *Red Cedar* (2022), among others. She started writing poetry after retirement to keep her mind active and says, “writing helps me relax and cope with life’s challenges.” Frase has traveled the world with her husband of sixty-one years and has eight great-grandchildren.

Ben Gooley is a manager of scholarly communications and lives in New South Wales, Australia. His works have appeared in *Intrepidus Ink* (May 2023) and *Etherea Magazine* (March 2022). Gooley states, “Disability can create additional societal hurdles, but these shouldn’t be allowed to hold anyone back.”

Lori Hahnel is a writer who lives in Alberta, Canada. Published works include the novels *Flicker* (2022) and *After You’ve Gone* (2014), among others. Hahnel writes because she’s compelled to, and her work *Vermin: Stories* was shortlisted for several awards and won an Alberta Literary Award in 2022.

Mattie-Bretton Hughes is a nonbinary-transmasc writer out of Detroit, Michigan. Hughes’s works have been published in *Snowflake Magazine* (August 2023), *Wishbone Words* (August 2023), and *Querencia Press* (March 2023), among others. He hopes his writing can be a beacon for others and enjoys reading books with a cup of tea alongside his blind cat, Mr. Ray Charles.

Shelly Jones is a professor and writer from Oneonta, New York. Their works have appeared in *If There’s Anyone Left* (January 2024) and *MASKS Literary Magazine* (Fall 2023), among others. A self-proclaimed introverted nerd, Jones loves nature, knitting, and cats. They state they’re “always tired, but always doing more.”

Suzanne Kamata is an associate professor who lives on the island of Shikoku, Japan. Kamata has published several books, including *Cinnamon Beach* (2024), *The Baseball Window* (2021), and *Indigo Girl* (2019). A mother of twins, Kamata writes to make sense of the world. She lives with her husband and two cats.

Grace Kully lives in Belfast, United Kingdom, and expects to obtain her M.A. in creative writing from Queen's University, Belfast in 2024. Kully's work focuses on the human experience, society, and connection, which she appreciates more after spending time within the disability community.

Karen McKenzie is a Braille teacher residing in Melbourne, Australia. Her works have appeared in *The Australian* (2001), *Australian Women's Forum* (2001), and *Verandah* (2001), among others. In 2011, McKenzie won the *Australian Literature Review* short story competition in the Young Adult category. Legally blind since her mid-teens, she is a passionate audio book listener.

Betsy Miller is an author, publisher, and retired technical writer living in Northern California. Published works include *The Parents' Guide to Hip Dysplasia* (2013), among other guides for parents, and the picture book *Hip, Hop, Hooray for Brooklyn* (2017). Miller plans to release a book for those who need a hip replacement while they are still young.

Sandy Palmer is a child of deaf adults (CODA) and a freelance artist who works with a variety of media. She contributes to *Kaleidoscope* as the writer of artist profiles, having joined the staff as art coordinator in 2002. Palmer is the full-time graphic design specialist at United Disability Services.

PMF is an applied behavioral analysis (ABA) therapist who was born in Heidelberg, Germany and now resides in New Jersey. She obtained her master's in ABA from Caldwell University in 2019. Working with children, she says she enjoys humor and making others laugh. PMF believes in peace, love, kindness, honesty, and fairness.

Trystan Popish is a volunteer coordinator residing in Denver, Colorado. Her works have appeared in *Ache: The Body's Experience of Religion* (March 2024), *Rogue Agent Journal* (February 2024), and *Sante Fe Writers Project Quarterly* (Summer 2021), among others. Popish lives with her husband, their baby, diabetes, depression, two dogs, and two hairless guinea pigs.

Ivy Raff is a freelance web designer, copywriter, grant writer, and translator who calls Queens, New York home. Raff shifted their focus to writing in 2021 after a twenty-year career in health technology/public policy and serves on the editorial teams at *Reckoning* and *Seventh Wave Magazine*. As a Jewish artist and human, she advocates for a free Palestine.

Tara K. Ross is a writer, podcaster, and audiobook narrator based in Southern Ontario, Canada. Her works have appeared in *Tamarind Literary Magazine* (Spring 2024), *Iron Stream Media* (May 2020), and *Wells Street Journal* (Spring 2019). Ross is also a speech-language pathologist who "advocates for every child's voice and believes stories can be read and written by anyone, despite our physical and cognitive differences."

Sheersty Stanton, M.S., is a leadership consultant and entrepreneur who lives in Wichita, Kansas. Her work appeared in *Kosmos Journal* (January 2022) along with a self-published poetry book in December 2021. Stanton is passionate about cultivating well-being. As the parent of a child with a rare genetic condition, she says, "it is as amazing as it is difficult, and I wish to share what I'm learning and experiencing with the world."

Cynthia Stock of Garland, Texas, is a retired critical care nurse currently in the process of reinvention. Her works have appeared in *Shark Reef* (Winter 2022), *BigCityLit* (February 2023), and *Intima* (November 2022), among others. Stock states that her life is enriched by her family, a partner, her son, a stepdaughter, and two cats.

Natalie Haney Tilghman is novelist, editor, and educator living in Glenview, Illinois. She is the coauthor of the young adult novel, *A 52-Hertz Whale* (2015), and her work has appeared in several publications including the *First Generation Sons and Daughters Anthology* (2017). A mother to three children, Tilghman's writing explores loss, loneliness, hardship, and "the unlikely remedies that help us to heal."

Angela Townsend of Langhorne, Pennsylvania, is a development director who earned a master of divinity from Princeton Theological Seminary in 2006. Her work has appeared in *America* magazine (March 2024), *The Penn Review* (January 2024), and *The Razor* (October 2023), among others. Writing because she feels "an overflow of love," Townsend states she is "incurably infatuated with people, animals, and the thousand glistening gifts of any ordinary day."



Diana de Avila, *A Symphony of Color*, 2023, digital art



Diana de Avila, *Psychedelic Rorschach*, 2024, digital art

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