A Season of Hope

"Between Rooms" by N. T. McQueen

"Nacre Upon Nacre" by Jenna Pashley Smith

"Mother Bear" by Melissa Murakami
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**POETRY**

**BIOGRAPHICAL NOTES** 67

Kimberly Gerry Tucker, *Hope*, 2018, Paper (mixed media collage), 16" x 20"
Kaleidoscope, beginning in 1979, pioneered the exploration of the experience of disability through the lens of literature and fine arts. Fiction, personal essays, poetry, articles, book reviews, and various artistic media including two-dimensional art, three-dimensional art, drama, theater, and dance are featured in the pages of various issues.

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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Dinner is over but I know I still smell like my meal. When Junebug shovels spoonful after spoonful of puree into my mouth, cheeks smeared with her own leftovers, the majority ends up on my pants. Based on the searing pain of my tongue, I know it was warm but whether or not I have burns on my thighs, I can’t say.

She wears a purple skirt with a red striped shirt a size too big and spins across the hardwood while Del does the dishes. She always drops the pans on the counter as if she doesn’t care it startles me. But I can’t blame her. Between rooms, I can see Delilah’s back at the sink. My eyes strain as far left as they can. Just enough to see Junebug stumble and pirouette with her unsteady eyes checking to see if I am watching.

She’s just old enough to remember the year before. Kids experience trauma in ways adults can’t seem to grasp. She doesn’t notice I don’t hug her anymore or hear me tell her I love her when she’s under her blankets. Maybe she simply doesn’t mention it. She only knows one moment: I am there. A lamp or a vase or a fixture with eyes, a mouth, a heartbeat. She often will run and jump on my lap and I can see her tangled in my legs. When people come over, they are appalled at how rough she is with me. But to her, I am like jumping on the sofa.

Between the rooms, Delilah dries her hands on a hand towel and smiles at me. Or perhaps at a joke she heard earlier. She talks more now than after Easter last year. More than she did in the hospital or the countless appointments. I’m not sure she truly talks to me or herself, even with her eyes fixed on mine. Sometimes I imagine she is looking into a mirror and sees herself reflected somehow from my presence. As if her true desires or identity has been wrapped up in what I am and not who I am. And I can see that despondent, lost look in the way her shoulders sag and force her shirt strap to fall around her bicep.

“Did you like the trout?” she asks me.

She knows I haven’t eaten solid food since and I sure as hell don’t want her to puree fish into a smoothie for me. Then the words come. Well inside my throat and I can taste them, feel the warmth and the apologies they desperately want to say but they cannot blast through my teeth. No not the teeth. The words fail to reach my limp tongue and settle back into my soul.

“It was farmed but it was on sale at least. I’m thinking of trying scallops but the house will stink for days afterward. Remember when we . . .”

She stops. The beauty I adored twenty-two years ago still fills her face. But the joy gets lost in the corners of her mouth and all the weight gets carried underneath her eyes.

Yes, Del. I remember. I remember everything.
She squeezes my hand then walks past me. Out of sight and into the bedroom I guess. Junebug twirls with her arms lifted high above her head before me and my feet nearly trip her. I watch her dance to rhythms she can still hear, still move to, and wish I could smile.

*     *     *

Memories come at night. After hours staring into darkness or at the back of my eyelids, they creep from places I never desire to tread. I often reenact Easter. How the family gathered around the pastel-draped tables in the backyard as my nieces and nephews splashed in the pool. How it was cloudy but pleasant and Del wore the white dress she bought at Nordstrom’s with the open back which made me want her. A fragrant ham and nasty potato salads spread out and on paper plates. How Uncle Pete laughed when I told him the story of peeing next to Jerry Seinfeld in a Boston airport bathroom, on my way to some conference. London, San Francisco, Beijing, Miami. Even Boise. Always somewhere.

I often remember the depth of the pool. My pool. How I knew how deep it was since I bought it. How the words of Mom echoed through the waves of never diving into shallow water. How, after the impact, I could only think of my Bvlgari watch, not my wrist or my skull. How floating really felt. How sinking truly felt. Turns out I never knew the depth of my own pool.

Del breathes in sleep with her back to me and I lie in the same position I started in. The days of options have left now. I’m sure my muscles ache but they’ve lost their voice. They cry out to be moved. Even when the sores form behind my thighs or upper back, their voice sinks into the mattress, never to be heard. I stare into the darkness and shadows around me except for a vertical line of streetlamps cast between the curtains. The sliver slices across my dead legs.

The sound of the sirens came from far off. The notion of laying, wet and still, on the concrete surrounding my pool. As a boy, the sensation of warm water pooled on the concrete against my bare skin made me love summer. And I realized I couldn’t feel the warmth or the cold as I faced a clear blue sky and faces both terrified and judgmental. Someone held my head steady but I couldn’t see who. A droplet slid off my eyelashes and splashed around my open eye. And that is where it stayed. The same lingering itches or tickles fester on my skin.

Del mumbles in her sleep. Did she say my name? The simple act of turning my head toward sound resides only in my memory now. Sounds come and go faster than I can decipher. The other day, I sat by the open window and the sound of breaking, of wood and glass, filled my ears. But I couldn’t flinch. Or turn to see what had fallen or who had dropped it. The only solace I could hold to was the sound.

The beep of my heart monitor creeps into my dreams sometimes. Faint but close like the actual beat of my heart. The brightness of the fluorescent lights made me squint but I couldn’t speak. My jaw moved but the words became imprisoned in this body. The balding doctor with dry, cracked hands stood with his hands in his coat pockets and told me I would not have the same life I once had.

Mom and Dad and Delilah gathered around my bed, snaked with tubing and wires. The bags beneath their eyes carrying all the weight. Their eyes showed pity for me and, for the briefest of moments, I wished I had gone blind instead.

Then he told me that, due to the nerve damage in my spine, there was a high probability I would never have children. The ideal image of the big house and picket fence just lost the other kid.

Delilah broke down. All I did was stare at this stranger who told me what my life would be with a sobbing soundtrack. The beep, beep, beep a constant for the next several months as I gathered bed sores. While nurses cleaned my ass or changed my catheter. The endless banality of daytime television and the absence of choice in the matter. The visits with the physical therapist who really had nothing to contribute. How can you make the lame walk? Did Jesus Christ work at St. Mark’s?

Junebug said nothing when she first saw me. When she came in, I smiled at her, trying to give her a glimpse of something she knew, something familiar. She smiled back, but not a smile you savor. Del ushered her close, her stuffed pony tucked under her chin. Del lifted my limp hand and placed it in Junebug’s tiny palm and I stared into her green eyes.
She looked at my hand then turned to her mother and asked, “Why won’t Daddy hold my hand?”

Each night, in the glow of the sterile lights, I wondered if the disability checks were in the mailbox already. Did it work that way? Was it in my file and, somehow, it connected to a government office and they sent me money? If I could, I would have told Delilah, as she cuddled close on my hospital bed at night, only the weight of her legs on mine and the residue of tears on my gown, that we can now get some great parking spots. Did we need one of those massive vans with the mini-elevator now? How much do ramps cost to install? Will I need those stair elevators old people use? The thoughts continued, and still do, on my back in the night. My dad used to have a saying that a man who doesn’t work isn’t a man. I hear those words every time I see the postal worker open my mailbox. The thoughts of a thirty-eight-year-old ex-millionaire.

*     *     *

The bed creaks and Del curls next to me and, God, I wish I could lift my hand and hold her shoulder. Pull her close to me. The smell of Pantene floods my nostrils and the gentle caress of her hairs rub on my cheek, my chin. Even into my nose. I’m unsure if she knows she has rolled into me but I don’t care. In these dream moments, for a second, lost in shadows and memory, I can walk again. I can whisper sweet nothings. The feeling of sheets against my bare skin. I can brush my own teeth and lift my own glass of water. No straws or catheters or miscommunications. In the dark, we are ordinary again.

*     *     *

I watch the morning sun filter through the beige curtains. In fact, I forgot the feeling of being awoken by sunlight. Del’s back is turned to me and she stirs. Her joints click and crack as her body awakens. She sits up and faces the window. Her hair, a mess and back, bathed in shadow. The light simmers around her edges, catching the fringes of her hair like fire. Yet my hands lay dead in the sheets.

She turns to me and says, “Morning.”

I smile the only way my muscles will let me.

“I’m gonna make some coffee. You want any?” she asks, stretching her arms upward, revealing the small of her back.

I blink twice.

She smiles. Perhaps out of pity but I can’t decipher if it is for me or herself.

Rising, the sheets fall off the side of the bed and she walks to the bathroom. With a swipe of her hand, she opens the curtains before starting her routine. She closes the door and my eyes draw to the window at the brightness and the green tops of magnolias against a new blue sky. But the sharp blue feels more like a sea and I look back to the closed bathroom door.

The bedroom door creaks and I look toward the sound to see Junebug’s sleep-encrusted eyes watching me from the crack in the doorway. She cradles Lucy in her arms with a crumpled white sheet of paper crushed in her fingers. Seams exposing white stuffing and the dog missing an eye.

No straws or catheters or miscommunications. In the dark, we are ordinary again.

She sees me looking at her and she shuffles her slippered feet across the carpet toward me and stops next to the bed. Strands of hair dangle across her face.

“Can I go in your bed?”

I blink once.

In awkward and clumsy moves, she clamors onto the bed and lays under the sheets next to me. I feel the pressure, the weight, but not the softness of her youthfulness. The boniness of her elbows and knees. The still rounded cheeks and bubbled stomach remnants of years passed. Her frizzy hair tickles my nose and cheek.

“Papa, I had a dream that you and I were dancing.”

That sounds like a nice dream. At least, I would like to tell her it sounded like a nice dream. The memory of rubbing my hand across her arm as she cuddles in bed seems dim and distant now. I try to move my hand but it rests atop the mattress, smothered by her weight.

“You picked me up and spun me in the air. Like I was flying.”

She arches her back to face me and I strain my eyes down to my chest to see her upside-down face. Through the mess
of hair, those bright blue eyes fire back with a hopeful skeptic-icism as if she is afraid that what she is about to ask will never come true.

“See, I drew a picture of us. That’s you and that’s me.”

Her little fingers smooth the creased page and she points out a stick figure version of me. We stand on our skinny legs and hold hands, two dimensional and on the dance floor of her imagination.

“Are you going to dance again?”

Her intent but forlorn eyes won’t leave mine as she awaits my answer. In a way, I’m as afraid to answer as she is to hear mine. The running water from the faucet sounds behind the closed bathroom door.

I sigh, then blink twice.

The answer she feared spreads on her face and her once vibrant eyes soften, staring past me, searching for other options. I should cry at what I see but I can’t. We lay silent for a moment and I watch her tug at the ear of Lucy in absent gestures. Perhaps I should have lied. Told her I would one day dance again and make her feel like she could fly. But reality is no lie.

She squirms and then sits up, looking at me and smiles. Hope restored somehow in those wiggly teeth. She drops Lucy at her side and grabs my cheeks with both hands just like she has seen my mother do all her life. Leaning forward, our noses touch.

“Don’t worry, Papa. One day we will dance.”

The bathroom door opens and Junebug releases my face. Strapped in the back with Junebug in her booster seat behind me, Del drives toward Henderson Park. She pulls into a handicapped space just like I promised. Close to ramps and other accommodations I never wanted. Now the entire process begins again. When she opens the sliding door, I hear the screams and clamor of children. Junebug shimmies in her seat, eyes fixed out the window until her mother can get her father out of the van. Ten minutes later, I’m on the ground and Junebug runs toward the kaleidoscope of colors and shapes swarming the play structure like ants attacking some metal creature.

Del sets me in the shade of an oak, facing the playground and the faces of moms seated at metal picnic tables on the patio. Behind their sunglasses, I know they watch me with a fascination and pity reserved for children who have disa-bilities. I know they think they are above such blatant gawking and pride themselves on their inclusion. But here I sit, my head barely able to support itself on my shoulders. Placed in the shadows to not be a distraction or a sideshow.

Sometimes I still sense the need to rush but immobility stalls everything. On average, it takes ten minutes to get me in the car. The lift descends then Del sets my chair in place. It’s a pathetic elevator to get my hardware a foot off the ground. Once lifted, Del ducks into the open space and maneuvers the handle bars until the wheels lock into the floor. Then she fastens the buckles and I am ready to go down with the ship. And, in this pseudo-life I’ve been resigned to, going down with the ship is a viable option. Besides, I’ve almost drowned once already.
In the shade is a picnic bench, etched and scored with active hands and decorated with wads of chewed gum. Del slides onto the bench and scrolls through her phone. The weight on her shoulders roughly the weight of my chair. I watch the playground and the young legs and arms swinging, jumping, climbing, running, falling. I search for Junebug and find her walking the wavy plank, steadying herself on the railing. The waves of the bridge swell and as she laughs, I am terrified she might fall through the bars and end up like her old man. My eyes show me my fear over and over again and my heart beats. The one thing I can feel in my chest.

But Del sits and stares deep into her phone.

I blink twice still feeling the chuckles locked inside me.

* * *

We don’t eat out anymore. At best, Del orders take out for her and Junebug and we sit at the table after Del spoons pureed meals into my mouth. Sometimes Junebug likes to wipe my chin with a napkin and giggle when a large dollop splats on my lap. Hearing her laugh makes me smile. Sometimes it can make Del smile. Then she wheels me between rooms so I can watch Junebug.

She wears a pink dress with a purple Frozen shirt over it and spins across the hardwood while my wife does the dishes. I watch how she jumps but doesn’t jump. How she dances and shakes across the hardwood floors in her bare feet. My eyes strain as far left as they can. Just enough to see Junebug stumble and pirouette with her unsteady eyes checking to see if I am watching.

* * *

On Friday nights, Del liked to rent movies she felt I may like or might inspire me in some profound way. I had nothing else to do. Her first choice was My Left Foot. The following week, she rented The Sea Inside and admitted she only read the first few lines of the summary otherwise she wouldn’t have chosen that one. The following week, we watched The Diving Bell and the Butterfly and realized we were both too impatient to communicate that way. She tried to make amends by renting Million Dollar Baby because she thought I used to like boxing once upon a time. That night, I listened to her cry herself to sleep.

We don’t rent movies on Fridays anymore.

* * *

I lay immobile in my bed, eyes staring at the slow flashing light from Del’s laptop as it fills the room then disappears and obsess over Javier Bardem wanting to die in a noble way. What is nobility? Ethical or righteous? How can anything noble come from a man who can’t move or speak? Or was it dignity?

The world resembles a strobe light as I blink, blink, blink, blink.
The blue light prevents me from shutting the only muscle I have control over. On. Off. On. Off. Such a simple thought. Would it be noble to ask Del to place her pillow over my face and press the life out of my lungs?

On. Off.

Del sighs in her sleep. I’ve wanted to ask her to let me die. To free her from the prison I’ve put her in. But I can’t ask her. And she will never ask me.


Then there’s Junebug. I imagine tears down her soft cheeks and her eyes swollen. How in heaven or hell will there be no one who dances her way?

On. Off.

Perhaps Ramon Sampedro and I could dive and swim again in a bottomless ocean, where arms and legs slice the water and bed sores fade and no one has to wipe your ass. Where we live within rooms instead of between them. Where our wives don’t sigh in their sleep or wear your weight in the bags beneath their eyes. Where the memory of sinking and the burn of chlorine in your eyes doesn’t reside within your skull and only the good memories remain.

On. Off.

I decide I do want to die and that makes living my life even harder. If only Del would ask me. On the nightstand, between blue flashes, the faint outline of me and Junebug living in her imagination props against the lamp. The two of us look small as if miles away from where I am now out the corner of my eye.

The blue light stops flashing and the shadows return. Del sighs again.

* * *

My body yearns for her to ask me. I try to convey, to imply with the most pathetic, despondent look I can muster but Del, head adorned with a messy bun and crow’s feet in her eyes, places loving hands on my cheeks and kisses my lips so gently I want to weep.

Attempts increase. In the living room. The kitchen. The bathroom. Sitting on the patio watching Junebug bounce effortlessly on the trampoline with the empty pool in the background. Del brushes my teeth and I try to lock our eyes and push my words through them but her mind belongs elsewhere. I watch her slice the chicken with a knife for Junebug and morbid thoughts fill my mind. It wouldn’t take much.

Between the living room and kitchen again, I watch *Finding Nemo* with Junebug and wish I had drowned a year ago. Simply let the water fill my lungs and sink me to the bottom where I could slip into another realm and swim with Ramon Sampedro and ride in convertibles with Jean-Dominique Bauby. Tears slip from my eyes without a sound at the reality that I cannot live.

I cannot die.

All I can do is watch *Finding Nemo.*

* * *

The days crawl now, dragging routine behind them like a great chain that can’t be shaken loose. A weight on my lap, fixing me to this chair. In my station between rooms, I continue my role as spectator and wish Del would just let me sit here and wither away. No obligatory phone calls from Mom and Dad. No awkward Skype conversations with Neal and my nieces and nephews who don’t really know me anymore. Seeing my own numb face in the small window on that screen is a reminder that I am a shell. A mannequin. A figure along the Embarcadero in Madame Tussaud’s, minus the celebrity.

---

**The days crawl now, dragging routine behind them like a great chain that can’t be shaken loose.**

---

Yesterday, Gary and Jessica came by and tried to talk to me. Or rather, tried to foster a relationship with a vegetable. I could see in Gary’s round face and Jessica’s falling brow how they knew, and I knew, the man a year ago is not the man they see. Inside, I wanted to tell them to hell with the man they knew. What you see is what you get. No matter how pathetic. All I could think about is if Gary might do me the favor of rolling me to the backyard, re-filling the pool and letting the water finish what it started.

Junebug brings me back and I look at her, inches from my face, and regret floods me as if she had read my morbid thoughts. She takes my rough cheeks in her hands and looks deep into my eyes, deeper than the depths of me, and says:

“Don’t worry, Daddy. You will dance with me.”
With a kiss, she slides off my lap and plays in her own world where mannequins come to life.

*     *     *

She brings me drawings on a variety of canvases. Napkins, toilet paper, copy paper, even walls, which Del hates. Adorned with many colors, she draws us dancing. My stick legs and stick arms held tight to her sticks as we move on the canvas. No chair. No rooms. Only an open space for me and her to dance an imaginary father-daughter dance. The first few drawings welled pity for her but, by the tenth drawing, the same images made my teeth clench. Del asked me if I wanted Junebug to stop drawing pictures but I blinked twice and she left it at that. Did she smile?

As can be expected, Del gave Junebug a roll of tape. Soon, the pictures and their myriad of canvases pasted the walls of our home. Each room morphed to a gallery of Junebug and me in an eternal dance that shifted from room to room. With Del’s help, she even pasted one on the ceiling above my side of the bed.

I hate the pictures and, if she weren’t a five year old, I would hate her as well. But, she still climbs on my lap, grabs my cheeks, and kisses me, telling me not to worry. Why I can’t tell Del to stop it, tell her it hurts too much, is beyond understanding. I imagine Junebug standing in my depths up to her knees, splashing water on her Elsa bathing suit and laughing as the parts of me I never want to see rain down on her. I hate every second I’m around her but I can’t tell her to stop.

*     *     *

I’m forced to stare at drawing number fourteen above my bed. I try to close my eyes but the sense I am being watched overwhelms me, haunts me actually, and I open my eyes to stare straight into a version of myself I will never be.

Del sleeps and the street lights sneak, conveniently, across the ceiling, across the picture. Now, I feel like Job. God’s little toy to test its limits to see when it will break. But I have no desire for God or for life or for anything the world now has to offer. I only want to be like Ramon Sampedro again and to die with dignity. For Del and Junebug and everyone who ever thinks of me and shakes their head and says, “Poor Oliver.”

I stare at stick Oliver and stick Junebug again.

But then I see something on drawing number fourteen. I blink to wash the image from my mind but it doesn’t stop what I see. Junebug’s stick legs begin to move. Jittery at first but then she moves as I’ve watched her move a thousand times. Twirls and spins around the motionless stick figure of myself. Spinning and twirling a tornado around my immobile body. Then, in the shadows and in the pressure of the spotlight, I see my stick-figure self lift his arm and twirl Junebug before swooping her into his arms as the two dance across the white page for only them. Back and forth and around, lost in the movement and moment underneath the spotlight. The white background takes shape and breathes color and our hand-drawn selves dance among a forest lush and green. A ballroom with a glass chandelier. Dancing from scene to scene.

Beauty overwhelms me. Not a new beauty but a beauty that was always there. The tears fall down their dried tracks and onto my pillow and I watch the beauty of life before me once again. A beauty from my depths held captive in my body, perhaps lost in the waters a year ago. The two continue their dance, the warmth of Del beside me, and I bathe in the tears until I drift to sleep.

*     *     *

She wears a blue dress with a striped tank top over it and spins across the hardwood while Del does the dishes. I watch how she jumps but doesn’t jump. How she dances and shakes across the hardwood floors in her bare feet. Between rooms, I watch the beauty of life around me and the flow of dish water and the soft steps of Junebug on the hardwood floor. I watch the specks of dust falling in the sunlight. The smudge of handprints on the living room window. The scent of brewing coffee and the vibrancy of the colors. Surrounded by drawings, I find love in the warmth of tears on my cheeks. Junebug stumbles and pirouettes with her unsteady eyes checking to see if I am watching.

Now she knows I always am.
DORITT CARROLL

WHEELCHAIR POEM #2

i called it steerage
the neurology department at GW
always filled with more patients than seats
contortionists of necessity we learned to push our backs
against the slippery corridor walls and lower ourselves
to the floor with each braced or casted leg extended in an L
the sheer mass and drape of us in the packed space
like the tangle of misery found in the hull of a ship

i was lucky i came with my own chair
wheeled in by my husband whose 7 ft. enormousness
caused even the recalcitrant to make grudging room
then he spent the next two hours standing on one foot
then the other with pressed lips and bulging eyes
as if an emu had been penned in
with this crammed unwilling cargo

when some lucky patient’s name was called
the entire deck of us wriggled with efforts to clear a path
while the nurse, accustomed to long days
of foot-dragging leg-swinging locomotion
stared into the middle distance of her clipboard

i’ll leave out the part about pins
stuck into nerves and mildly electrified
and bring you straight to the reception desk
an octagon set in the center of the open lobby

the appointment-making nurse lifted her lids
heavy with false lashes and rolled her eyes
up to see my husband so that her sclera smiled
blankly at me sitting below her
an Orphan Annie touch

“when can she come back?” she asked him
i had my mini-calendar in my hands
“Wednesday afternoons are good” i said
“excuse me sir i asked when you could bring her back”
the nurse repeated
“do you have any appointments on the 26th?”
i volunteered, a little louder
“if you do not respond to my questions,”
the nurse said implacably to Butch
“i’ll move on to the next patient
and you can use our telephone reservation system but”
and here she began to take a flashing call off hold
“i should warn you there may be a long wait”
1950 – Dancing to Tchaikovsky

Suzanne Yuskiw

"Believe me, the reward is not so great without the struggle."
~ Wilma Rudolph

"I have a house," I said, spreading five cards across the table. “A full house,” my Aunt Ruth murmured between her teeth, squinting at the three queens, and two eights in front of me. Of all the cards in the poker deck, I liked the pretty queens best. “Well, Sharon Theresa,” my aunt said, “you are quite a card shark.”

We sat in the blue-draped parlor of our house on Pearl Street in Newton, Massachusetts, Ruthie and I. The Victrola played Vaughn Monroe, a song called “Racing with the Moon.” Ruthie sang a few phrases in her quiet alto. I stared at my five cards and waited for further instruction. I’m sure she cheated for me upon occasion, but on this particular evening, she had left me to my own counsel, and I triumphed. She pushed the pennies in my direction.

It was an early winter evening in 1950. I was trying to grasp the fine points of poker under the tutelage of Ruthie, my maiden aunt. Gram and Mom clattered the dishes in the kitchen; Uncle Dan, thin and athletic, bent over the Boston Globe at the dining room table; Grandpa drifted through the house, humming shreds of a drinking song—"I had a hat when I came in and I’ll have a hat when I go out"—before settling into his chair by the kitchen stove. In the parlor, Ruthie and I had dismissed the easy games of Old Maid and War as old hat, and opted for poker. I was now five and a half, stuck in the house more often than not, despite the unusually warm January weather. Missing kindergarten that year, I learned numbers and letters at home, read the funny papers with Gram, nearly memorized The Little Engine That Could with Mom, graduated from Old Maid to War and then to poker with Ruthie. After dinner, she’d smoke a Lucky Strike, haul out a little box full of pennies, and on most nights we would go at it in the parlor.

*     *     *

My earliest memories fall gently over our front parlor on Pearl Street. I remember as a four-year-old making a tent behind the red brocade couch, tinkling on the brown upright piano, kneeling to recite an occasional rosary with the family on the threadbare oriental; and of course, as soon as I could lift the lid, playing the Victrola. This was not the old-fashioned kind of record player with a crank and giant horn—ours plugged in—but it was big and antique-looking, and everyone in the house called it a Victrola anyway. Ruthie and Mom preferred the songs of the late ’40s, Bing Crosby and Doris Day. These songs ran in the background of my early life. But I recall especially three large albums, bound like books, their giant pages filled with heavy records. “These were your father’s,” my mother said. “He loved classical music.” My favorite one had a little soldier on the cover, a nutcracker as it turned out, and contained six records, six nuggets of magic.

From the time I was big enough to open the album which Mom called The Nutcracker Suite, probably around the age of four and a half, I would escape to the parlor, lift one of its heavy graphite records out of its envelope, and put...
it on the Victrola. Hidden from view of my grandmother in the kitchen, I would swathe myself in my mother’s silk kerchiefs and dance around the room to the “Dance of the Sugar Plum Fairy.” Its delicate melody lifted me onto my toes, and I danced here and there around the tier table and behind the brocade sofa.

I never met my father, a second lieutenant in the United States Army, who died in Normandy a few days before I was born. Mom showed me the Purple Heart she kept in a buffet drawer beside the good silver. I rummaged through his footlocker when I got a bit older, hungry to know him. I found a musty green uniform, a silk parachute, and a packet of letters I was too young to understand. Perhaps I was also too young to realize that his spirit was in the recordings and the leather-bound books that witnessed my growing up. Even as a four-year-old, I liked the look of those books with the gold lettering and the nameplate inside the cover, inscribed in a feathery calligraphy: Lieutenant Robert E. McCormick.

*     *     *

Those sweet, early memories of the parlor, the dancing, and the books turned with a sharp clarity at the end of the “polio summer” of 1949. Epidemics had rampaged through the country during most of the mid-twentieth century. Perhaps my family felt their strong Catholic faith protected them. Perhaps they simply didn’t know that summers were especially vulnerable, as the water-borne virus moved viper-like through wading pools, thick with kids. Did anyone, medical experts or otherwise, suspect that our Cape Cod beaches were also vulnerable?

For as long as I can remember, our family spent a few weeks “down the beach.” Sometimes this meant a little cottage in Falmouth, or Hyannis. This year they chose Swift’s Beach in Wareham. During the first week of our vacation, my mother stayed back in Newton where she worked at the telephone company. She would join us later. So Gram and Uncle Dan entertained me with beach afternoons, and some memorable outings into town. On one evening, we went to a local talent show where kids performed songs and dances. When I saw those kids singing behind a big round microphone, I knew I wanted to do that, too. I wanted to sing something. “Next year,” Gram said. That night I practiced dance moves in the cottage, and Gram said I could start ballet lessons in the fall. Another night, we saw *The Wizard of Oz*, at the local movie theater. I was so excited. It may have been my first trip to a movie theater; certainly the most memorable. I was fine when the screen turned from black-and-white to color, and the angelic Glenda floated into view. I was a little wary of the army of Munchkins and their galloping hyperactivity. Everything was fine until the wicked witch flew into view. Her furiously green face, angular and angry, that sharp, hideous nose, it was all too much for me. I pulled on Gram’s arm, furiously. “I want to go home,” I said, crying and covering my eyes. “Ah, well,” she said. And that was the end of our movie excursions for that particular vacation.

On Friday night, my mother drove in from Newton to begin her week-long vacation, and took me down to the beach. It was sunny and hot with the clear breeze that Cape Cod is known for. My beautiful Mom. I was so happy to be with her, to have her all to myself, just the two of us stepping into the low waves. I hadn’t learned to swim yet, so we paddled around in the shallow water. She pulled me along by my arms, telling me to kick a little, telling me to float. We held hands and jumped the waves. I remember it with the clarity of unclouded joy. I also remember quite clearly being bitten on the baby toe by something sharp. I suppose I was mollified with ice cream and a warm towel and my mother’s comforting arms.

The next day I got very sick. For a day and a night, I slept. Intermittently, I’d wake to waves of nausea as my body—my cells, I suppose—succumbed to some foul yellow intruder. There was pain in every muscle, every limb, and there was whatever sort of delirium my five-year-old self experienced. Sometime in those days a doctor came—doctors still made house calls in the late nineteen-forties. I remember his kindly face and a black bag. My mother sat me in a chair opposite him. He asked me to walk toward him, but my legs wouldn’t work. I tried, but with the first step, my legs turned to jelly. He held my arms as I collapsed. That afternoon while I slept in the back seat, my uncle and
mother drove me to a hospital in Boston where I spent the next three months.

Three months feel like centuries when you are five. I’ve forgotten most of those days, but there are nuggets of memory, long suppressed, that this exercise in remembrance has called up. I recall lying on a brown leather pallet in the hospital when I was first examined. I remember being alone in that sterile room. I recall no doctors or nurses, no faces, either friendly or unfriendly when I was admitted to the hospital, though I’m sure a doctor was there, testing my muscles. Sometime in the first weeks of quarantine, I remember scratching furiously at my head under the blond hair, and being taken to a white sink where I was washed with strong shampoo. As the acute sickness of the virus faded, I remember feeling better, and interacting with the four or five other little girls in the ward. One lively girl across the way encouraged me to a contest. Both of us grabbed the exercise bar above our beds and pulled ourselves up by our arms in a kind of chinning motion. When we let go, and the way encouraged me to a contest. Both of us grabbed the exercise bar above our beds and pulled ourselves up by our arms in a kind of chinning motion. When we let go, and fell backward on the bed, our backs too weak to sit up, we

But on this day, the blankets had become loose and I was busy setting up my dozen or so get-well cards across the top sheet. I lost track of myself and all of a sudden I was sliding down the side of the bed, and landing on the cold floor in a small lump. By some miracle, I hadn’t hurt myself, but within an hour, I was strapped into a small harness attached to the sides of the bed. It didn’t work well. In a few days, I had slipped over the side again, dangling like a parachute caught in a tree. The thing was, I was five years old and I had never, up to that time, slept in an adult single bed. I had slept in a crib at home in my mother’s room. I can’t imagine why. I suppose my mother and Gram thought it was the most convenient and practical way of protecting me. Maybe my mother didn’t want to spend money on a new bedroom set for the two of us. Whatever the reason, the hospital bed was my first test in a big girl bed, and I flunked it. After

Only once did I allow myself to feel sad. It must have been during a Sunday afternoon visiting period. My mother, and Aunt Ruthie, who visited after the quarantine lifted, held me up to look out of the tall hospital window beside my bed. It seemed a long way down, maybe four stories. Below, clear enough to see their faces, I saw Uncle Dan, and his younger brother Buddy and Buddy’s girlfriend, Mae. She was always nice to me, sweet and funny. I saw her bright smile and circle of dark curly hair, and felt sad. They were so far away. I remember turning my face from the window, the distance between us made clear.

This was the only time during those long, unnatural months, that I remember crying, and that for only a minute or two. Even when the dreaded blood cart came by a few times a week, and a gentle nurse pricked my finger tip with a tiny razor; even when a stern nurse mocked my shy self, or chastised me for drawing with crayons on the clean, white foot rest. In those months, I remember few tears. Maybe I choked them back, learning at an early age the value of showing a façade of strength. I would cry a little in that hospital window in the comfort of my mother and Ruthie, but I would be a strong soldier in front of strangers.

One day I fell out of the bed. It was a high, metal framed hospital bed. I seemed to be ten feet off the ground, an easy height for nurses to deal with. I usually kept well in the middle of the mattress, penned in by sheets and blankets. But on this day, the blankets had become loose and I was busy setting up my dozen or so get-well cards across the top sheet. I lost track of myself and all of a sudden I was sliding down the side of the bed, and landing on the cold floor in a small lump. By some miracle, I hadn’t hurt myself, but within an hour, I was strapped into a small harness attached to the sides of the bed. It didn’t work well. In a few days, I had slipped over the side again, dangling like a parachute caught in a tree. The thing was, I was five years old and I had never, up to that time, slept in an adult single bed. I had slept in a crib at home in my mother’s room. I can’t imagine why. I suppose my mother and Gram thought it was the most convenient and practical way of protecting me. Maybe my mother didn’t want to spend money on a new bedroom set for the two of us. Whatever the reason, the hospital bed was my first test in a big girl bed, and I flunked it. After

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the episode in the harness failed, I was back in a crib, and stayed in it until I left the hospital.

After some weeks of healing and growing stronger, my crib and I were moved to another ward, filled with older girls and a few grown-up women. There was a wonderful doll’s house, and a radio played the tunes of the day. I must have known all the words to “I’ve Got A Lovely Bunch of Coconuts,” which played constantly on the radio. I would never hear it again in my life without being propelled back to that time at Haines Memorial Hospital. Most days I sat in a very large, wooden-backed wheelchair, often situated out on the sunporch. I had some tentative physical therapy, and played countless games of checkers. Summer gave way to fall, and my hair, growing longer and darker and increasingly out of control, splashed awkwardly across my forehead. I peered through it like curtains. One of my therapists decided to address the issue. She may or may not have asked Mom’s permission, but one day she took a sharp pair of scissors, told me to hold still, and then cut a new set of bangs across my forehead. She held up a mirror for me to see. I liked the look. My wan little face, sprinkled lightly with freckles, seemed fuller, prettier. I smiled at myself. When my mother saw me, she was shocked, but she soon warmed up to the
new look, and by the next week, she, too, came in with a new hairstyle, complete with Jane Wyman bangs.

When I returned home just before Thanksgiving, I still could not walk. But I could crawl. Traversing the distance from parlor to dining room to kitchen, and back again on my knees, I began to feel more strength in my weak left leg. I didn’t care that I was crawling instead of walking; didn’t care a whit. I was moving under my own steam, that was the important thing. After the initial illness, the strength in my back and right leg had returned. Mom did physical therapy every afternoon during her midday break from the telephone company. I began using crutches around the house, and gradually just needed one. By January, I could walk carefully through the house, holding on to furniture for balance.

The Victrola, that squat playmate, waited for me in the parlor. The Nutcracker sat in its album. I wondered if its magic would still work. At first, I tried a tentative swishing movement to the music. “The Russian Troika” was too fast for me—I knew that—but “Arabian Dance” was slow and easy. My upper body swayed with the woodwinds, their eerie and sinuous melodies. Occasionally, I would think about what I had lost and grow sad. I even wondered about my own death as I sat in the parlor one winter afternoon. I don’t know if most five-year-olds entertain thoughts of death, but I did, having already brushed up against my own mortality. I recall comforting myself that old age, being sixty or seventy, was a long way off. Anyway, I prayed, Jesus will take care of me. I shook off all morbid thoughts, walked to the Victrola without holding on to anything and played “Waltz of the Flowers.”

Evenings, Ruthie would continue her guidance in card-playing surrounded by the pop music of the time. That was the winter I learned how to play poker, how to crawl, and how to walk again. I never imagined as we sat at the little table in the parlor that life would stretch out in ways both ordinary and extraordinary; would be full of adventure, of music, theater, books, songs, stories, poetry, travel, love, and loss. And, dance. In my own way, though I would never study ballet, I would, somehow, dance.

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**THOMAS SHEA**

**ON THE ANNIVERSARY OF YOUR DIAGNOSIS**

No one sends sweet, store-bought cards wishing you recovery smooth and swift.
No one praises you as a survivor, nor grants any triumphal gift.
Your story is not one people share to a child’s spirits lift.

Because no victory is decisive, no “all clear” is ever cried.
Any promise of cure or ending is a dream that since has died.
The enemy persists, insurgent, invisible, intractable, inside.

I witness you waging this war I have no part in;
bearing a burden I can’t shoulder.
Watching you fight inside your skin limits set by no one, for no reason, that you must live with, and within.

I won’t tell you to get better;
That prayer has been denied.
There are a thousand useless things We’ve said, and done, and tried.
But know this much, my love: I watch your fight with pride.

Every day is a chance to quit, to lose, or fade. To die.
Each time, you choose the other way, stare demons screaming in the eye.
I can’t know how much it costs you, to give each day a valiant try.
But know I’m filled with wonder, as you let your battle-banner fly.
Cami was exhausted. This was the third time this week that Henri decided he did not want to go to school.

“No.”

Bears don’t go to school,” he said as he climbed to the top of his bunk bed, “I don’t go to school.”

Michael had just left for work, leaving Cami alone with the task of getting Henri out of the top bunk and to school. At this point Cami knew she would be late for work.

Henri wore the same hoodie as always. It was the brown fuzzy one with two little round ears on the hood, allowing Henri to not only play the part, but look the part as well. Cami’s mother-in-law had gotten it for him on his seventh birthday and through the next year and a half it was all Henri would wear. He wore it to bed every night, he wore it while playing outside in the seventy-degree summer sun, he even tried to wear it into the shower—which Cami quickly vetoed. It wasn’t until her brother’s wedding a few months later that she’d finally convinced Henri to leave the hoodie at home and wear his tux jacket instead. He hadn’t given it up without a fight, but eventually, he agreed when Cami convinced her brother to let Henri’s official title in the wedding to be “The Ring Bear.”

Preparing for that wedding was the first major event after Henri was diagnosed. Cami took him to the church a few days before the rehearsal, so that he could be familiar with the building before being involved in such an occasion. She had learned from experience what happened when they didn’t prepare ahead of time. She let Henri roam the sanctuary, bear-crawling down the aisles. His fluffy brown hoodie was the only thing Cami saw, the little round ears flopping as he crawled among the pews. Cami let him feel the shimmering keys of the grand piano in the front and listened as he plunked on the keys, making music just as cringeworthy as what an actual bear might sound like playing the piano. She let him familiarize himself with every inch of the sanctuary, so that they could avoid any possible outburst or catastrophe like in the stories that she had heard from other mothers. Besides getting Henri to leave his hoodie at home, they avoided any trouble on the day of the wedding.

Henri’s hoodie was slightly too big for him. The shadow of the oversized hood combined with the enclosed space of the top bunk made it hard for Cami to see her son’s face. She hated that. Nevertheless, she knew what he was up to. He only climbed up to the top bunk when he was in trouble, or if he was trying to prove that he was a bear.

The puffed brown fur of the hoodie brought her back to the teddy bear that sat on the dresser in the room when Henri was still a baby. He was only slightly bigger than the bear, and his tiny hands could barely grasp its plush arms. Cami and Michael would talk to Henri in typical baby-talk fashion, complete with silly faces and gibber-
ish noises. Even then, Henri never made eye contact. He would never look directly in the eyes of his mother and father, nor anyone else. The most fixated Cami had ever seen Henri was the evening she caught him staring through the bars of his crib directly at the teddy bear that lived on the dresser. That was the only thing he seemed to keep a social connection with.

Henri was late on every other developmental milestone: rolling over, crawling, walking, speaking. But he eventually got there. It was just in his timing. He was always the kind of kid who was on his own timeline.

That teddy bear sat on his dresser still, looking directly past Cami, the way that Henri did now from the top bunk. Henri avoided eye contact, but still waited for her response. Cami studied him, trying to understand, the same way she did every time this happened.

“Oh, well buddy, Mom’s got to go to work, and you can’t just stay here alone,” Cami said.

Henri looked down, playing with the sleeve of his hoodie. “Yes I can. Bears can take care of themselves. They don’t need anybody else.”

“But bear cubs do.”

Cami looked at his rough hands as they draped over the guard rails of the bunk. His knuckles were covered in benign scrapes and small cuts from running around outside, climbing trees, and bear-crawling. Every time she watched him play outside, Cami couldn’t help but think that he for sure could make the school football team when he got to high school with all the strength he was gaining. But Henri’s bear crawls were not warm ups to him; they were part of a lifestyle that Cami desperately tried to understand.

Henri’s fingernails were shorter than the average kid’s. This was a product from the nasty habit of biting his nails.

“Bears with short claws climb fastest,” Henri would say.

She knew it was a habit that should be broken, but Cami couldn’t help but feel a spark of joy whenever Henri’s nail biting came to her attention. It wasn’t until college that Cami was able to force herself to quit that same habit out of an unreasonable fear of it preventing her from ever being successful. Unlike her, Henri’s nail biting wasn’t a habit; it was a conscious, intentional act. Regardless of the reason, it was a connection between them, a simple trait that reminded Cami that Henri was indeed her son, no matter how distant she felt.

Her eyes wandered up to Henri’s face, still shaded from his oversized hood. He avoided eye contact, the way he always had. Cami breathed out. Three times this week.

Three times this happened, each time the same fight, and each time more exhausting than the last. She couldn’t fight this time.

Back when his refusals to go to school began, Cami would ask about bear trivia. Henri would be so busy reciting facts about the Sun Bear that Cami could nudge him along from chore to chore and into the car for school without any fuss. When that stopped working, Cami would bribe Henri with a rewards chart, promising trips to the zoo, Brother Bear movie nights, and his favorite snacks. But even that didn’t work anymore.

Perhaps it was time to consider homeschooling. She would have to quit her job. But was she really doing her job now, anyway? At one point, everything she had, she put toward her job. Now, everything she had, she put toward Henri. What she had once loved, she no longer burned for in the same way. Henri was her passion now. But that didn’t stop it from being hard.

Maybe tomorrow would be better. Maybe tomorrow Henri would come to breakfast wearing his yellow rain jacket instead of his hoodie. Maybe tomorrow he would get into the car for school without a single word of rebellion. Maybe tomorrow he would tell her a funny story that happened at school instead of a new fact about the North American Black Bear. But today, like all the other days, Henri was on his own timeline.

But even when she felt as distant and exhausted as she did today, she had to keep going. No matter how late Henri was in development, no matter how many bear facts he knew, and no matter how many times Henri refused to go to school, there was one thing that Cami was sure of—a mother bear never stops loving her cub.
THE SYMPHONY OF SUMMER

Summer has a song for those who listen.
It begins with the soft chirping of the crickets,
And then the deep baritone voice of the toad joins in.
The hooting of the owl is added.
The humming of the cicadas can be heard from miles around.
A steady sound of a babbling brook is also heard,
It’s soft music adding to the symphony.
The howl of the lone wolf is the crescendo.
The symphony softens with the soft rustle of the leaves,
The wind its conductor.
While the music is playing
Fireflies dance -
Their light glows…
Not adding noise, but the magic of their illumination instead.
Summer has a song for those who listen.

LIFE

Life is a journey
Everyone has taken…
Like riding a bike for the first time.
Training wheels were put on
As you mentor through it all.

When you get older
They’re taken off.
You wobble and shake at first,
Falling into bushes now and then,
But with each day you progress,
And the next thing you know
You’re off around the block
With your friends,
Doing ‘pop-a-wheelies.’

Once in a while,
You come across
A hill that’s very steep.
It’s challenging your skills.
With each breath and each pedal,
you get closer and closer,
And with that,
You succeed.
“Where am I?”

“In limbo.”

“Where is limbo?”

“Here, where we are.”

The woman, in a crisp white suit and white high heels, checked her clipboard. “Right on schedule, ma’am. You’ll find it very comfortable here. Much more comfortable than down there.”

I’d been confused for quite awhile, and now this. How do I even know what’s real?

She added, “Don’t worry dear, you’ll get used to it quickly. They all do.”

“Are there other people here?”

“The floor is just shiny, it’s not wet or slick, but I’ll stay right with you the whole way.” Her manner was easy and gentle.

As we approached the blue door, it opened slowly and we entered a large room. The furniture was arranged in seating groups of four, comfortable chairs with tables nearby. It smelled like lavender and clean sheets. There were people there. Some were playing bridge, others reading, others painting, and still others in deep conversation. All were in regular clothes, not hospital gowns like I was wearing. I looked down, and was surprised to see I was no longer in my hospital gown, but my favorite purple dress and sandals. I touched the fabric, “How did you know?”

The woman stopped walking, “Oh my dear, we always know. We want you to be comfortable and happy while you are here.” She looked around the room, “Ah yes, I think you will like Agnes and Dorothy.” She took my hand and we walked over to an area that looked like a garden. Two women were planting flowers in a tabletop flowerbed. “Agnes, Dorothy, I’d like you to meet Maggie. Maggie, meet Agnes and Dorothy.”

The ladies smiled at us. “I’m Agnes, pleased to meet you, Maggie.”

“Pleased to meet you both.”

“Now, I’m off to meet another arrival. Y’all have a good afternoon.” The woman headed back toward the blue door.

“So, Agnes, Dorothy, where are we?”

“Not sure where we are, but limbo is for those of us who are in the last stages of dementia.” Agnes said. She picked up the trowel and dug another hole. Dorothy pulled an orange Gerbera daisy from its pot and placed it in the hole. Agnes poured soil around the root ball and tamped it down.

“So, are we dead?”

“No, our bodies still function but our
brains can’t hold our souls anymore, so we come here.” Dorothy picked up a pink Gerbera daisy. “It is hard for our families, but I like it better than the nursing home.”

Peace replaced my confusion and anxiety as I watched Agnes and Dorothy plant more flowers. “So, how long do we stay here?”

Agnes paused, her trowel in the air, “It depends, I guess you could say we are here till our body wears out, down there.”

“Can we go back? There were times I came out of the fog and could talk.”

Dorothy said, “Sometimes after I first got here, I would pop back and forth, but that hasn’t happened in a while. I guess that means I’m getting close to going home.”

“Look on the bright side, Maggie,” Agnes said, “we get to be our old selves rather than just stuck in our old body that won’t quit.”

Evening falls quickly
A sad soul strives to stay home
The brain can’t hold it

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**POETRY**

**LUIGI COPPOLA**

**LOST KEYS**

They were in my coat pocket but I won’t know this for another hour and a half, just enough time to check under the heavy couch, every drawer in the house and of course the coat pockets of every coat in the house including, I thought, my own, where the keys actually are.

Five minutes before finding them, I slump on that heavy couch, slightly off angle now, and consider the day wasted: the train I have now missed, the rush hour I’ll hit for missing that earlier one and the emptiness of a life lived alone and how if you only have one set of keys (the need for more non-existent), once lost, you have no recourse, no back up, no support structure.

Five minutes later, keys found, I’ve changed my mind. Who needs to go out anyway? How much more safer can you be knowing you can lock your door and no one else has a key?
FADING

I surround myself with things:
a guitar I don’t play, books I don’t read
vegetables that I leave in plastic
to suffocate away. My clothes
live more than I do
twisting around the room
showing off their parkour skills
skipping the light elastic.
How did I get here?
What went wrong?
Why do I lean toward the door
but never make it through?
Why is it that the beer can lies empty
but the half glass of water mosses over?
Why is the ashtray full and hot
but the exercise bike that I bought
in the January sale still in its box?
I am lost. I step on toenail clippings
and imagine them sharp rocks on a cliff.
I finger the curry stains on the coffee table
and imagine them wet leaves in a rainforest.
I sit on a worn and wheezing couch
and imagine it the seat of a Ferrari
as I drive off the cliff and crash
into the forest below
bursting into a fireball
instead of fading away.

ECHOPHENOMENA

On the train someone yawned:
I wasn’t tired, but I also yawned.

On the bus someone smiled:
I wasn’t happy, but I also smiled.

On the boat someone screamed:
I wasn’t scared, but I also screamed.

On the underground someone shouted:
I wasn’t angry, but I also shouted.

On the road someone cursed:
I wasn’t hurt, but I also cursed.

On the plane someone prayed:
I wasn’t a believer, but I also prayed.

On the funeral march, someone cried:
I wasn’t dying, but I also cried.

In the crowd, I saw the
tired, unhappy, scared, angry, hurt, lost and dying
run for their lives: and I was also
tired, unhappy, scared, angry, hurt, lost and dying
and so, I also ran.
“The secret of seeing is, then, the pearl of great price.”
“Live water heals memories.”
–Annie Dillard, Pilgrim at Tinker Creek

The pearl-bearing mussel is a creature intimately acquainted with the wounds of tenderness. Disguising pain, it lodges the memory of hurts within its body. We have this in common, the bivalve and I. Faced with a parasite or foreign object, a freshwater mussel can isolate the irritant in layers of nacre. Nacre is strong and resilient, transforming what pierces into something that shines. I have no such defense mechanism; no nacre exists to shield me from myself.

I am not strong. Crack open my knees, peer into the linings of my phalangeal joints, and see a body seeded with irritation. I am flooded with the corroding effects of rheumatoid arthritis, my polluted immune system responding to the wrong set of instructions. Yet these knuckles contain no pearls.

When the disease first attacked, I moved slowly along the edges of my life, bathed in pain. Muscles withered and energy washed away. I fantasized about amputation to end the agony. My hands were useless. I couldn’t hold on to anything.

I don’t mean that in the Biblical sense, like men in parables who sell their worldly possessions for buried treasure or a single pearl. I keep things for bad days: a walker, special braces, piles of medications. Back then, I literally couldn’t hold on. Glass jars slipped through my fingers, crashing into shards littering the floor. When I became a mother, I strapped my babies to my body, wrapping them tightly to the parts of me that would not give out. I carried them in my arms with fear and wondered: What will they learn from me? What have they inherited, embedded in their cells?

They carry themselves now. I breathe easier, although I cannot shield my children from suffering. Not even my own. When they are hurt, we breathe through the stings together: scratched knees, swollen elbows, swallowed tears.

Breathe in. Breathe out.

Perhaps this is my pearl of wisdom, an inheritance to leave behind.

Admitting my limitations is still new. For the longest time, I hid in a shell of denial, tucking my hands into pockets, softening the limp, masking the disease, a litany of “I’m fine” slipping from my lips. Anything to keep out prying eyes, or worse, praying lips.

Prayers weren’t the problem. Pray-ers were, those well-intentioned people bringing sacred words, miracle cures, blessed oils. All comforts for the giver, not me. I’ve been doused in holy water, sipped óleo de capivara, worn magnetic socks, and injected therapies derived from the genes of Chinese hamsters. Each time, I held my breath and hoped.
Even the best of these offered only partial relief. When they didn’t work, whose fault was it, whose prayers too weak? Mine. Disguising the struggle protected me from the pearl farmers who would rub extra sand in my wounds and tell me to look for gems in the morning.

Regardless of our pain, the mussel and I will wake and carry on with our business. We must. No rest for the weary. It’s a biological imperative hardwired into our brains: predators single out those too slow or injured to offer up a fair fight. So we chin up, hide the signs, fool the hovering vultures. We bury our pain deep, throw it into flowing water, douse any flicker of weakness.

Douse (or dowse) is a resilient word, both its meaning and spelling changing with context: submerge, put out, or find. For example: I was baptized by dousing at a church in Indiana, a place that also encouraged dousing the temptation to self-pity. As an adolescent, a neighbor taught me how to dowse for water. This practice is viewed with suspicion in the Bible Belt, much like yoga, lying somewhere between unscientific superstition and perilous witchcraft. I bent metal clothes hangers into L-shaped rods, which twirled loosely in my hands. Defying logic, the rods crossed for me over a patch of brambles.

Where we dug, living water bubbled up from the ground. The trick is not to hold on too tightly. Like many things in life, you find what you’re looking for only when you let go.

*     *     *

Next to the Bible on my childhood shelf stood a glass bottle of breathtaking treasures: a polished hunk of amethyst, foreign coins in states of tarnish, two strands of yellowed mother-of-pearl beads. There were feathers and fossils but no pearls.

One day, my mother let me try on her satiny, hand-knotted strand.

“How do you know they’re real?” I asked.

“Rub one against your tooth,” she said. “A real pearl scratches.”

That shimmering surface hides exceptional grit. False ones slip along our enamel, smooth and illusory.

And so began my hunt for a pearl. Who wouldn’t want a pebble of such strength and beauty for their own? That thing we call beautiful is the visible manifestation of a lifetime of discomfort. I never questioned if the pearl was worth it to the mussel.

Finding pearls in Indiana wasn’t a farfetched dream. The White River has been home to many different species of freshwater mussel over the years. Ancient peoples dumped their molluscular refuse in giant heaps, shell middens, along its banks. And during the heyday of pearl hunting and button farming in the early nineteen hundreds, one source mentioned that patients at a mental hospital spent a summer hunting pearls there:

“One old man has been lucky, finding several pearls... [he] hoards them like a miser does his gold. He keeps them in a bottle, and his chief delight is to hold the bottle so that he can see his prizes as the sun strikes the gems.”

Imagine that man, wading up to his neck in the water, pulling up pearls with his toes. That man knew the secret of seeing, really seeing, whether it was with his heart or feet or pure Midwestern persistence, for he got not one, but many pearls.

He’s so different from the merchant in the Biblical parable I learned as a child:

“. . .The kingdom of heaven is like a merchant seeking fine pearls... upon finding one pearl of great value, he went and sold all that he had and bought it.”

I have never understood this parable. The merchant didn’t douse himself in search of a pearl. There was no hunt, no risk. He saw something pretty, sold everything he had to purchase it, a man in possession of a single pearl and nothing else. How is that a good investment? Surely the one

1https://newspapers.library.in.gov/cgi-bin/indiana?a=d&d=PT19080820.1.8&srpos=11&e=-------en-20-PT-1--txt-txIN-pearls-----#

2https://www.biblegateway.com/passage/?search=Matthew+13%3A45-46&version=NASB
who discovered it knew the pearl’s value and applied a reasonable profit margin to the sale price. What does this teach me about where I should lodge my future hopes? Am I to be merely a consumer? Or the person barefoot in a river, fumbling around in the muddy dark, holding my breath against its current with no certainty of success?

To find pearls, not merely buy them, experience is the only guarantee. You might come home empty-handed, dripping mud. You might find nothing, or everything. But one thing is for sure: you will have held your breath, reached down to peer within the shell, grasped possibility and doused yourself in hope.

Tell me that’s not a treasure worth having.

Unlike the merchant, you can come to the water again and again, even if your wallet is empty, your heart or body broken. All that’s required is a willingness to look.

To find my buried treasure, the shadow within the shell, I had to dive into the water and look for the suffering creature in the darkness where beauty forms.

* * *

Officially, bivalves don’t breathe air. They are filter feeders, accepting the water as it comes in, trading oxygen for carbon dioxide as it leaves.

* Filter in, filter out.

Inhale, exhale.

So much of our health is tied up with theirs. The archaic word “hale” means “healthy.” I am ex-hale, unhealthy, beyond healthy, past whole. I need to be filtered, cleansed.

Mussels refine the water’s memories, trading pollutants for purity with each “breath.” What was diseased becomes hale again. Mussels can cope with toxins, currents, battering rocks, and the curiosity of children. Without memories, they filter and feed, iridescent shells sparkling for themselves alone. They excel at being.

My own muscles get jittery, ill at ease, dis-eased as I am. I find it hard to just be. The English language lacks a distinction for the verb “to be.” In Portuguese, my adopted tongue, you can choose between ser and estar. The latter is a temporary state: I am in the water. At some point I will get out. I am sick today, but tomorrow I will feel better. The former is immutable, or nearly: I am water. Water is me. I am chronically ill; it’s not a situation likely to change. Humans are living water, about sixty percent. If it’s true that water is constantly recycled and returned, what percentage of me has been purified by the mussel?

What have they saved me from?

What will I become?

* * *

On my parents’ farm was a spring-fed cow pond where my siblings and I swam every summer like a pod of muddy dolphins. The glossy black mud of its banks housed a bed of freshwater mussels whose thin, flaky shells lacked the uneven texture of their riverbed cousins. A paucity of environmental stress had kept their shells pristinely smooth, although this habitat was not without its dangers.

Freshwater mussels aren’t generally found in landlocked bodies of water. They have a curious life cycle, spending part of their life as parasites. The microscopic larvae, called glochidia, are blown into the water by their mother. Filtered into the gills of a particular species of fish as it respires, they embed themselves into its flesh until adolescence. The host fish gains nothing from this arrangement but weariness and pinched gills. For the parasite, it’s an uncertain adventure.

The juvenile mussels have no idea what’s in store when they emancipate themselves. If their host fish is removed from the stream and dropped off in an unsuitable place, like our pond, that’s it for their gene pool. But like all adolescents, I suppose, the glochidia feel invincible. I know I did. With curiosity and childish cruelty, I used to pry open living mussels and peer inside, looking for pearls or seeding them with infinitesimal grains of sand. I still remember the way the shells struggled against my rough hands and pocketknife.

Once, I thought a mussel fought back. Barefoot, up to my waist in the water, I felt something slice my heel. Instead of a jagged shell, we extracted a disintegrating metal barrel, its skull and crossbones still visible on the rotting label. Our pond was no living water, but another generation’s midden, a dump leaching its poison into the water, the mussels, me.

I never found any pearls.

You can’t check for pearls in the White River any more. Even if the practice were legal today, no one recommends standing ankle deep in that water, much less up to your earlobes. For years, my hometown falsified reports and sent untreated sewage flowing unchecked into the river, the bowels of a whole community swept downstream. Between the human feces and the pesticides, it’s amazing the mussels are still hanging in there. Really, that any of us are. Perhaps the pond mussels lucked out after all.
But the great hope of nature is that in spite of our vulnerabilities, we can adapt. Nothing is invincible, but if something as small as a mussel can create life for itself in sub-optimal conditions, why can’t I? Trapped, like the mussel, in these polluted waters, I am unable to choose what enters, only how I will respond. Will I breathe in and become one with the pain’s sharpness? Or will I continue to struggle?

Some say the true name of God is the sound of breath moving through our lungs. If true, every inhale is a prayer, every exhale a plea. Holding tight to the truth of myself in a current of swirling tides, I pray for strength.

Respire, inspire.

Breathe in, breathe out.

During a period of unexpected energy, I try yoga, that practice I feared as a child. In the mirrorless dark of the studio, I learn to accept that some poses will be forever out of reach. This body needs many modifications. Every movement requires some slight variation for unbending wrists, crooked arms. My downward dogs become dolphins.

Accept yourself where you are, the instructor says. Inhale, exhale. Just be.

In the wobbling stillness, I see.

I am not doing it wrong. Not yoga, not life, not illness.

I just need to breathe.

* * *

For the past year, I have enjoyed relative remission. Pain merely whispers at the edges of my days, a ripple barely breaking the surface, although the rare waterspout can still flare up and suck the wind from my lungs. Thankfully, like other acts of God, these are short-lived.

I hope I won’t be. But there are no guarantees.

From childhood on, it is human nature to deny mortality, the entropy of the body. We believe we’re invincible in spite of ample evidence to the contrary. It takes a shock, some unexpected realization for us to acknowledge reality. My epiphany arrived earlier than most; I’ve had decades to live with my grain of sand. I’ve finally accepted its existence. Hiding disease is futile. Some battles we are born to lose. Sometimes, surrender is the best course of action.

Beginning swimmers learn a paradoxical truth: giving up means floating, not drowning. With this in mind, I go back to the water, my chlorinated gym pool so unlike the algae-brown pond of my childhood. In the water, I am exposed, all flesh and breath and trust. I breathe in, I breathe out. The water holds me even as it slips through my fingers.

Nothing breaks.

My body doesn’t betray me.

When I swim, baptized in the present moment, there is only me and my breath. I come face to face with myself, every worry and fear magnified in the water. And I let them go. With each stroke, I grow stronger. The lead weight of forced hope slips away, releasing me to simply be. I am living in the serenity, set free. Droplets fall from my arms, circles expanding, growing, swallowing me up in a great, glittering now. Held up to the light, bathed in waves, I’ve never felt more present, more at peace, more me.

Inhale, exhale.

Like a mussel in an inhospitable environment, I have filtered the good from the bad and made a new life for myself. What once pierced in the darkness has been transformed, nacre upon nacre, breath by breath. Out of the water emerges a shimmering thing of strength and beauty, worth every moment of struggle. Peer within my mussel shell and see what those years of irritation have wrought:

I have become my own pearl.
Reminders of John’s illness and death continue to haunt me. In our paranoid twenty-first century, the cable company won’t take my word that John is dead. They require written proof. And a photocopy is not acceptable; it must be an original certified death certificate. Once I supply this, they will add my name to the cable account, and I will be able to change service details. It’s almost two years now since my husband died, and this makes a total of fourteen death certificates I’ve needed.

John suffered from Alzheimer’s disease for more than seven years before he died at the age of eighty-two. Difficult, depressing, and dehumanizing are the best words to describe the last years of his life. Much of that also applied to my life during that time. Alzheimer’s is a disease of gradual but inexorable disability—a loss of health and self, as well as a loss of others, as it continues for so long.

Good friends slowly retreat when what I call “tragedy fatigue” sets in. Even though you try to be upbeat, as years go by, people get tired of listening to your problems and witnessing his distress. There’s also a secret primal fear that they might fall victim to this disease. Science says that’s not possible, that Alzheimer’s is not communicable, but since no one really knows what causes this disease, who can say for sure? I was in a restroom stall when I heard someone from church tell another member that it wasn’t worth taking that risk. And mere acquaintances avoid you completely; they want to avoid even thinking about Alzheimer’s. You say nothing, but there’s no way to avoid your resentment and anger. You store your silent fury.

Early on in his disease, my husband complained to me that he was slowly turning into the Invisible Man. He had become slower to answer questions, so doctors, nurses, and many others had started talking to me instead, asking me the questions they used to ask him. Did they think he wouldn’t notice this? Did they even care? I tried at first to relay those questions back to him, but it didn’t work. I’ve recently learned that people in wheelchairs and scooters also experience this indignity. My bad back now forces me to use a scooter to get around. I’m often ignored. Remarks concerning me are offered to my companions as if I’m not there. And I sometimes wait for several minutes for people to move out of my way. Many will push right ahead of me in line.

We all know people say incredibly stupid things. Several added to my silent fury by commenting that Alzheimer’s was so much easier on the patient than on the caregiver. It’s not easier, just different. He hated it when he couldn’t recall the answers to simple questions. He’d get incredibly upset. He might forget my name, but he always remembered my birthday and actually cried when he could no longer go to the store and get me a card. Later, when he had forgotten how to use a knife to cut his food, it made him red-faced in anger.
Even watching television became a problem for him. He’d get the remote mixed up with the telephone, and when the channel didn’t change, he’d throw the phone across the room in frustration. And those midnight meanderings most Alzheimer patients do! He’d forgotten his way around the house and would get lost, stumble, curse, knock things over, and cry out for help. You never get a full night’s sleep when caring for someone with this disability. Incontinence was another problem. It was far from easy for him to start wearing an adult diaper. It took weeks to gently talk him into that.

How terribly sad to see all this happening to a highly-educated man, an engineer, later a manufacturing manager and the vice-president of a company—a man who was now unable to remember the names of his grandchildren.

Each week seemed to bring a new loss. Happily, there were occasional small time-outs. Once in a while, he’d have several minutes of clarity and would act like the John of better days. At first, I’d wonder if he were actually improving. This would happen most often when we had company. It was as if he were making a heroic effort to be more himself again. Of course, it didn’t last. And that last year, it didn’t happen at all. Many nights I would dream of his becoming well and happy only to awake to the terrible reality of Alzheimer’s.

Money became a problem. I tried hard not to become quietly furious when those huge bills arrived. Few people understand that Medicare won’t pay for rehab or nursing-home care unless you’ve been admitted to a hospital beforehand and then spent three nights there. Rehab-center care, after a fall or illness, costs $400+ a day in our rural area, with everything extra, and everything adds up quickly. I shudder to think what it costs in a large city. My husband was in rehab once for more than two months. We received no government assistance and were responsible for every bill. You’d be furious, too, when having to write out a check for $40,000. Remember, your household expenses continue at the same time. And don’t forget the cost of medicine. We used to reach the “donut hole” in April or May. By this time, I had to have part-time help. Don’t forget, not everyone is willing to work with someone who has Alzheimer’s. With all this going on, you run through money at lightning speed. John died before we had to put him in the memory unit of a nursing-home facility. Those costs are unbelievable. And it takes months to apply for and get Medicaid. By the way, keep your checking and savings account records for five years; you’ll have to account for every single dollar spent when you apply. The government wants to make sure you aren’t hiding or giving away money.

As you live through these situations, you realize how wonderful some people are and also how terrible a few can be. I’ll never forget that idiot woman who made me instantly furious. She actually questioned why I had decided to put him under hospice care “because they would let him die.” And she was indignant when I didn’t have a feeding tube inserted at the point he could no longer swallow without choking. I can still remember her saying, and with a loud voice and great passion, “You could have kept him alive for two or three more months!” Alive? Why? For what? His body would be alive, but his mind, his spirit, and his personality were long gone. It was supremely difficult to remain calm hearing all this, and I came very close to smacking her.

Thinking back, I’ve realized so many different things contributed to my silent fury. I’m not a saint. Sometimes, I just needed to scream. I learned to go into my bedroom and hit the pillow a few times when my fury or frustration became too much. This, unfortunately, did not always work. But I always tried to remember that it was the disease that caused my frustration and rage—the disease and a few insensitive people—never my beloved husband.

NOTE: In this country, people regularly live into their nineties. If you’re still married into old age, your future includes the strong possibility one of you will have this disease. One in nine people aged sixty-five years and older already has Alzheimer’s—about 11% of the population. It’s estimated that soon there will be almost one million new cases diagnosed annually. With no cure on the horizon, this is another very troubling reason to be furious.
Days Before:
She looks good. By “she” I mean the fake arm on the
table across the doctor’s office, and by “good” I mean,
well, how you would expect a fake arm to look. I was wor-
ried I would end up looking like a mannequin, but no—she
is sufficiently sleek and metallic.

My gaze shifts from the arm to the various posters around
Dr. Hart’s office, outlining what constitutes a full serving of
vegetables and the dangers of secondhand smoke. Riveting
material, but my eyes keep landing on the twisted piece of
metal across the room. The space between us feels weird. I
feel like I’m about to go on a blind date, except we are go-
ing to be forced to enter a very codependent arranged mar-
riage.

I kick my legs against the exam table beneath me, but then
immediately stop because the sound is too loud for the
small room. My mom looks up at the noise, but then returns
to checking her email on her phone. I think she’s avoiding
looking at the arm. I shift my weight, and the paper crinkles
beneath me.

We’re here to learn the functions of the arm and have one
final checkup with Dr. Hart before I surrender my body to
him, trusting that he’ll return five-sixths of it fully intact.
I’m not really sure what’s gonna happen to the arm that
they’re cutting off. It’s not an organ—I wouldn’t make
very much money selling it on the black market. I suppose
they’ll take it to the lab and run tests on it, so that the next
person who shows up with a rare disease might not be so
unlucky.

There’s a knock on the door, and then it opens.

“Big day! How are we feeling?”

I like Dr. Hart. He’s young and funny and attractive, which
makes more of a difference than it should in terms of how
much I trust him. He washes his hands while exchanging
pleasantries with my mom, and then picks up the arm and
holds it out for me to take. I grab the hand and shake it.

“Pleased to meet you.”

Dr. Hart laughs. My mom doesn’t. He then places the arm
in my hands and starts walking me through the differ-
ent parts. I tune him out, giving the occasional “yeah” or
“okay” when it seems appropriate.

My arm feels foreign in my hands. I would compare it to
a baby, with how carefully I am holding it, except it feels
like the antithesis of lifelike. I think it’s sturdier than I’m
giving it credit for. Or at least I certainly hope so. I wonder
how much my net power as a human being will increase by,
considering there will now be this indestructible aspect of
myself. An entire super-limb. I could really do some dam-
age if I hit someone with it.

I’ve missed the how-to, but if I can’t figure out how to use
my own arm then we have bigger problems to worry about.
Dr. Hart ends his spiel with some words of encouragement and then takes the arm and leaves the room, on to the next. We stop at the bathroom on the way out. I wash my hands thoroughly.

My mom and I don’t talk for the entire walk back to the car, but as she pulls out of the parking lot, she takes a deep breath and looks at me.

“So. One more week.”

“Yes.”

“How are you . . . how are you feeling?”

I look out the window.

“I mean, I’m nervous, of course, but it’s kinda nice that I just have to lie there. Like I won’t have to actually do anything, just let things be done to me.”

“Well, yeah, but then after . . .”

“Yeah. After will be hard.”

There’s a prolonged silence before she speaks again.

“Look, I know we’ve been over this, but I just need to make sure—”

“Mom.”

“I mean really make sure that you’re set on this. I mean the doctors said that—”

“Mom, I know what the doctors said.”

We’ve stopped at a red light, and she looks over at me. I study the signs of the restaurants and coffee shops that line the street.

“It’s just, there are so many unknowns and—”

“Mom. I know that there are unknowns. I really do. And no, I’d really rather not chop my fucking arm off. But I have to. Because one of the biggest unknowns is if I would die once this—this whatever—spreads to the rest of my body. And that is not something I am willing to risk, okay? I’m sorry. But I’m just not. So please, please just let me live my own fucking life.”

I’ve gone too far and I know it. She cares about me and is having a hard time dealing with the fact that she can’t fix this hardship. Neither of us really knows what to do.

When I was younger my sister would give me advice on how to deal with our parents. She had two more years of experience and would use the added wisdom to tell me which strategies generated the best results. No matter how carefully I followed her steps, she would always pull them off better. I often let my stubbornness get the best of me.

We drove the rest of the way home in silence.

3 Days Before:
The CVS parking lot is hard to maneuver with one arm. I have to slow down a lot before the curves to account for my limited steering abilities and end up reparking twice before I finally get it right. But I am here, and my car is between the white lines, and the front doors will open automatically, so I feel unstoppable.

I told myself that I would only use my left arm today to practice while I still have my training wheels on. So far it has been difficult but manageable. I made a mess of the bathroom counter when I tried to wash my face because it’s practically impossible to both cup and splash enough water with just one hand. Luckily, toweling is a one-armed job.

I head inside and make my way to the shampoo aisle. Okay. Here we go. I grab a bottle of shampoo, but when I try to grab a bottle of conditioner with the same hand, I realize my mistake. For a second I consider cheating and using both hands to carry my things, but no. I have to hold myself accountable.

I make my way to the front of the store, grab a basket, and return to my bottles. By the time I make it to the register I’ve traced the same path through the store four times and feel sufficiently idiotic. The cashier watches me as I carefully set my basket down and load the bottles onto the conveyor belt one at a time.

“Do you have a CVS card?”
“Yeah, just a sec.”

I grab my wallet and pin it in between my stomach and the counter while struggling to undo the snap. By the time I make it to the section of my wallet that holds the cards, a line has formed.

“A phone number works, too.”

My cheeks are burning as I give him the number, and when he tells me the total, I give him the biggest bill I have so I don’t have to dig for change.

“Oh, and could I get a bag for those?”

He looks at my two items.

“Yeah. Something happen to your arm?”

When he finally gives me my change and receipt, I stuff them in my pocket and speed walk out of the store, a streamer of coupons trailing behind me.

I get to my car and sit down. It’s only 10:43 a.m. Fuck.

I watch TV for the rest of the afternoon.

When my parents bring home chopsticks to eat our takeout Thai food with, I get up and silently grab a fork.

I Day Before:

I don’t want to die. I really, really don’t want to die. Maybe I’m an idiot for going on a run in the rain, and maybe I’m a bigger idiot for then climbing to the top of a water tower, but please God, don’t let me slip. Only a loser would die from falling off a water tower.

I wonder if I could get in trouble for trespassing if I were dead. I hope they wouldn’t transfer the consequence to my parents—they have enough to deal with.

I stand up and walk to the edge to look over the surrounding land. My legs are tired from the run, and my heart is pounding, and I am slightly out of breath, but I am alive. And my legs will continue to carry my weight, and my organs will keep on pumping, and I will be able to counteract the force of gravity because I am alive. I laugh out loud at my aliveness.

My sister and I used to always fight over who got to sit in the passenger seat of the car. One day, when I was twelve and she was fourteen, our mom gave us a coin to flip to see who got to sit up front. It was supposed to be the start of a new era, one where the world was fair and sisters didn’t fight. She won, but I was okay with it because I knew that it was the nature of probability to work out in the long run.

I cursed that coin when a driver drove through a red light and directly into the passenger side of our car. I cursed that coin as I lay in the backseat and heard the sirens grow louder and louder and knew that I was okay, and she was probably not. I cursed that coin when they rushed us to the hospital only to announce that she had died on impact and probably hadn’t felt a thing.

I wanted to burn it, throw it away, drown it in the ocean. I wanted the coin to suffer for what it had done. The thing is, coins are stupidly indestructible. I settled for putting it back in my wallet so that at some point I would spend it without realizing it. I let the coin continue its cycle.

Matter is neither created nor destroyed. Momentum is conserved unless there’s an external force. Energy is conserved unless work is done. If the universe is a closed system, everything should be perfectly engineered to balance out.

I used to hate the universe, yell at it, ask it why. I figured I had good things coming for me because I had experienced so much bad. Having to amputate my arm is not what I had in mind. If anything, it’ll make me even more unbalanced. I am not ready to have to learn how to live without another piece of myself. I envy starfish and their regenerative properties. I want to know what it feels like to not live in fear.

Starfish don’t have a centralized brain. They can’t marvel at the world, plan their actions, question their existence. They live through a series of reactions to external forces, which isn’t really a life at all.

I don’t envy starfish. There are currently billions of billions of billions of atoms that make up my body whose sole purpose is to give me life. And they are reacting, and they are sharing and stealing electrons and forming new bonds and breaking old ones and taking up space—all so I can be alive. So that I can be aware of that aliveness and the beating of my heart and feel and grow and move on from pain.

So yeah. Tomorrow morning I am going to chop off one-sixth of my body, and it’s gonna suck. I will probably cry, become angry at my newly-limited capabilities, curse existence. But I will handle it, if only because I don’t have another choice. And soon my new reality will become a habit, and anything is manageable when it’s a habit.

And it’s okay that I am lost. Because you can’t determine both a particle’s position and velocity, and you can’t measure a phenomenon without invariably affecting it, and there is no unified quantum theory, but I am moving.
JUSTINE JOHNSTON HEMMESTAD

TIME FLIES

For the one in search of more –
Something in the mist calls.
Her hands are dampened,
Her lips are moist;
Her fingertips yearn to touch
What she feels but cannot see –
She’s aware and yet dreamy,
of seemingly real but fleeting.
Her time comes to seek the myth in a story,
Her legend haunts the truth –
she questions its validity.
She calms her mind,
Releases her fears –
Receiving joy left behind;
A blessing of creation
Streams through each breath –
Until the void casts a brilliant light.
Within the rays,
Between the flickers –
Lies the reality of melted love –
Its truth she cannot bear.
The gaze of loved ones
liberates her soul –
As they come to her in her realm,
Of congruent worlds and crossed swords –
An invitation to march forth,
Into a world untouched by time.
A gift to the ages,
With purity of heart to see –
White petals of eternal life,
Floating between the tides in endless sea.
Worlds on the tip of her tongue,
Streaming through air, cascading over time –
Heavenly being,
Swept up in mystery.
“Being different and being quiet does not mean we are broken.”

~Kimberly Gerry Tucker

Finding Her Voice

Sandy Palmer

From the outside, the home of Carol and Joe Gerry may have looked no different than any other, but if you saw the inside, your jaw might drop to the floor. Behind closed doors and curtains, unseen by the outside world, were stacks upon stacks of paraphernalia. Crammed. Piled from floor to ceiling—everywhere. As a young girl, Kimberly Gerry carefully navigated her way through the narrow walkways within the home and says, “There was a path to my bed, stacked to the ceiling with interesting objects—bicycle parts, eggbeaters, clothing, you name it. The shadows cast by the piles scared me and I couldn’t see the walls. More often than not, I slept with my parents. They had a path and piles too, but at least I felt safer with them and it was easier to block out the shadows and mountains of stuff.” During the day, Tucker took solace in nature under a spectacular canopy of trees. The woods were a magical place where she felt a kinship with the majestic structures that reached toward the sky with arms intertwined. Nature provided a safe haven she could nestle into, whenever she needed it.

Life hasn’t been easy for the artist. She was the seventh baby born to a woman who decided to give the tiny infant to a childless couple in a private

Kimberly Gerry Tucker, Hugging Trees (first in a series), 2010, Acrylics, 8” x 12”
adoption. The Gerry’s lived in Connecticut and described their young daughter as “shy.” Perhaps shyness was the simplest way to explain why she didn’t talk to people. They were loving parents but when they said she was shy, it aggravated her. She knew what she was experiencing was more than mere shyness. It felt like her vocal chords were paralyzed. It wasn’t that she wouldn’t talk—she couldn’t talk. “I can’t say my mother understood me, but she instinctively knew how to handle my confused, hyperventilating, crying meltdowns.” In a dark room her mother would rock her back and forth, soothing her by “raking her long nails” through her hair and along her scalp. Unable to verbalize her thoughts, she would write notes, clip them to clothespins, and throw them in the room where her parents were. They would tell her to stop throwing things and never realized she was trying to communicate with them the only way she knew how.

Unable to speak to peers or teachers at school, she reflects on those years and says, “I was not seen. Not by classmates or teachers.” Without a diagnosis, no accommodations were made in the classroom. She felt “less than” and chastised herself for not being able to do the things that seemed so effortless for everyone else. Sadly, kids can be cruel and she was often on the receiving end of their harsh words and relentless teasing. Looking back she says, “It never occurred to me that school was a place to make friends. I didn’t bond with anyone.” She found refuge in the library and in solitary activities like reading, writing reports, and tumbling. She loved learning and earned good grades. Eventually she found her voice in the art room, where she flourished. After seeing a picture of a mosaic, she wanted to create one but didn’t know how to communicate that to her father. She didn’t know the word for “tile”
and couldn’t find any in stores that she could show him. Defeated, she resorted to tearing colored paper into pseudo-bits of tile and glued them together to make paper-mosaic pictures.

While discovering art as an outlet, she also began writing, and kept notebooks filled with her words “in sacred boxes.” When they moved from one house to another she made sure the boxes moved along with them.

She ate the same lunch every day because “it was dependable and necessary.” Much like the soft sweater she refused to take off because it was comfortable, and comforting. When it no longer fit, letting it go was devastating. She clung to the familiar because it provided security but she didn’t know why.

When she was fourteen, she met the young man who would become her husband. In the beginning, Howie Tucker would ask her questions and she would write her answers on paper. He visited her at home and was shocked by the hoarding but never disparaged her about the living conditions. They were married ten years later. Eleven years after that he was diagnosed with amyotrophic lateral sclerosis (better known as Lou Gehrig’s disease). She cared for him at home, along with their three children, and he passed away five years later.

When her oldest son, Jeff, was in high school he was assessed for autism. During a home visit, the evaluator noticed some of her behaviors and suggested she receive an evaluation as well. Tucker was thirty-five years old with three children of her own when she finally received the diagnoses of Asperger syndrome and selective mutism. Jeff was also diagnosed with autism. Since that time, she has learned she has dysthymia (a mood disorder/flat affect), alexithymia (inability to identify and express one’s feelings), and social anxiety as well. “I am communication impaired and contrary to some beliefs about people with autism, very empathic. And empathetic. I become overwhelmed easily, absorb other people’s energies (good or bad), and I like to be in self-
made, comfy, homey sanctuaries where my senses are not bombarded.” In order to achieve that, she works from home, hired primarily to find bugs in software and says, “I’ve created a life that works for me and I strive for balance. But, the challenge of communication takes its toll.”

Her story is included in the book Selective Mutism In Our Own Words and an image of herself as a child appears on the cover. As with most people who have selective mutism, hers is situational. She can speak fluently with “select, safe people” but simply cannot utter a sound around others or in certain situations. Since so much of what she feels and thinks goes unexpressed verbally she says, “Writing is an expression I absolutely must do.” She has written a memoir titled Under The Banana Moon: Living, Loving, Loss and Aspergers, that shares some of the struggles she has faced as well as the laughter and love she has experienced on her journey.

Sometimes her unexpressed feelings can result in vivid, heart-pounding night terrors that cause her to wake up screaming. Last year she created a series of nightmare collages that brought the darkness into the light, helping her process the frightening images that plague her when she closes her eyes at night. While caring for her husband during the last years of his life, she was responsible for all of his needs along with the care of her children. She lost eighty-six pounds during his decline and experienced “a terrifying recurring dream that my body was a limp rag doll that was being thrown from wall to wall, and even to the ceiling, by some unseen force. It was one of the nightmares I depicted in the series.”

She has a tendency to work on a string of images until she has exhausted all need to continue and then she focuses on something else. Trees and protecting the environment are two subjects that continually resurface in her work because she feels a strong, personal connection to them.

“I have to be doing some type of art expression. It’s ingrained in me to do so. I can create for hours and hours, forgetting to go to the bathroom or

Kimberly Gerry Tucker, Lady Tree Book, 2018, Acrylics, 18” x 24”
eat.” Although she enjoys working with acrylics her focus has been on collaging in recent years and she says, “I find that the repetition of cutting paper and tearing it into desired shapes is very satisfying.” She calls it “painting with paper.” Loving the tacky sensation of glue on her hands, using her fingers she smears it all over the various elements she’s incorporating. “When I begin a piece, it’s not so much inspired by something as it is a physical manifestation of subconscious chatter or feelings being identified. For example, I haven’t had as many night terrors since I did the nightmare series, although that could be a coincidence.” Without really being aware of it, any unresolved issues and pent up anxiety are released through the creative process. Slowly, piece by piece, repressed feelings bubble to the surface and are emptied into the image developing in front of her. As a result she says, “Art is a therapeutic necessity.”

She works on multiple images at the same time. Easily spending eight hours on an image, she’ll put it away for a few weeks and return to it later, often able to see what else it needs. However, she rarely feels that a piece is ever truly completed.

Tucker met Keri Bowers, founder of Normal Films, when Bowers interviewed her in 2006 for her documentary ARTS. Bowers is also the co-founder of The Art of Autism (AoA) and Tucker now serves on the board. “I love being behind the scenes helping judge contests, reviewing books for publishing companies, promoting contests, representing AoA at events, and sometimes interviewing people or helping them shape their blogs.”

The artist has three adult children who have acquired talents similar to her own. Jeff is great with technology and rebuilds computers. He is also a great storyteller and has two children. Jeremy is a gifted artist whose work has been on display in a museum in Rhode Island. He also has two children. Her youngest, Silas, is a talented writer and artist who was born female but is now
her son. He participated in Keri Bowers’ upcoming film, Desire, which explores sexuality and disability and will be out within the next year. “My children are very nice adults, I am proud of them, and my grandchildren are the lights of my life. Thankfully, I can be ‘me’ around them all, and around Al, my partner of ten years. We fill each other in.”

In a blog that originally appeared online in 2015 she wrote a note to herself as a child, providing some sage advice to the younger version of herself. Here is an excerpt:

Dear Child Self,
Your childhood truly is magical. There are so many wonders, so much laughter, so many animal friends to love. But some emotions seem as big as the universe. You will experience fear, tragic loss, indignities and confusion, and all of that seems so overwhelming. But guess what? Huge uncomfortable feelings are survivable . . . . Keep journaling! One day people will read what you have to say. Your words will become the biggest clothespins ever thrown into the world—and people will unclip the words and hear what you have to say! Keep creating! You have the ability to lose yourself for hours “just” drawing. You can’t begin to realize how therapeutic art truly is. One day you will even show your paintings in galleries and you will sell them! Your art will be on the covers of books, too! All human beings have ways to de-stress and for you that is art, and always will be, even when you are grown. Write what you cannot say aloud and save those journals. Draw what goes unexpressed. And be easy on your young self when you are overwhelmed and lose control. So much of what happens is a learning experience even though it is often painful. Above all, trust me, Your Future Self, when I say: Your art and writing will sustain you. It will always be your safe footbridge over turbulence.
When her cat of nineteen years was nearing the end of his life, she created a collage of herself with Mister Po nuzzling her neck. It is a depiction of the devotion felt between the two. The image stands out among others and is one she will never sell.

Her work has been exhibited in several New England galleries. In addition to the publication of her memoir, she’s had several stories published by various anthologies, has a personal blog (www.ravenambition.wordpress.com), has created videos, and her artwork has been featured in magazines, books, calendars, and book covers. Often unable to speak, she expresses herself best through art and writing.

“Being diagnosed later in life is like rearranging the remnants of what everyone else seemed to perceive as a ‘broken’ person . . . suddenly you are valid, and more whole in this new picture of yourself.” The painting Shattered Image reflects that perception of brokenness. Her affinity for mosaics is a way for her to take bits and pieces and assemble them into one complete image. Maybe that’s why she rarely feels like a piece is ever really complete, because just like those mosaic images, we are comprised of bits of time that makes up our lives and we are ever-evolving, growing, changing.
talking blocks

piano was the word you couldn’t get me to understand
you dumped out the bucket of legos and built one
holding it up to me, see?

I hate the detours in our communication
the developmental glitch that takes your clear thought
launches it through static, rolling the picture like an old
antennae’d tv
until it emerges broken, garbled

as your teacher
what hurts most
is that I can’t find the buttons
to adjust it
to break the code
to enable you to deliver the inputted message with the clarity
of your initial shining thought

as you labored to communicate
jamming one block onto another with intricacy and exasperation
a thought wedged unsettled

society declares me typical
you are zoned as special

if I had to build my thoughts
using my own limp fumbling spatial talents
i could not

i would hold up my piano and others would guess
box? table? doghouse?

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A Painful Reminder

Wendy Kennar

I had spent close to two hours, sitting outside at my favorite coffee shop, writing. It was my idea of a perfect morning. As I walked the block-and-a-half to my car, I had a nagging feeling I had forgotten something. I paused on the sidewalk and checked my bag. Keys, glasses, wallet, laptop, file of papers. Everything was there, but still I felt something was missing. I took a few more steps, and abruptly stopped on the sidewalk.

I knew what it was.

Pain was missing.

It was a jarring feeling. The absence of pain. But instead of feeling euphoric, I felt intensely sad.

I walked to the car in shock.

This is what it feels like not to be in pain. This is how other people usually feel. This is how I used to feel.

I had forgotten what it felt like not to be in pain.

I made it to the car in time to wipe the tears from my eyes.

I don’t like the pain scale with the illustration of ten faces, each with varying levels of smiles and grimaces. I don’t like when an intake nurse asks me to rate my pain on a scale of one to ten. I can’t. The way I feel right now may not be how I feel in thirty minutes. And after living in pain for nine years, my scale is warped, distorted, a fun-house-mirror version of what it used to be. Pain is just a part of my everyday existence, so I’m guessing that my tolerance for pain is higher than it used to be. By now, my seven is most likely someone else’s fourteen.

Before my son was born, I knew I wanted to attempt a drug-free, natural childbirth. I wanted to feel the contractions, because I knew that each contraction of my body was really a physical sign that my son was closer to entering this world. I writhed, I cried out, “This hurts,” but that was the extent of my complaining. No curse words, no blaming my husband, no demands to “get this thing out of me.”

My younger sister, on the other hand, wanted every drug she could have when her first son was born. I remember sitting in the delivery room, watching her, seemingly detached from the miracle of her body, hearing a nurse tell her, “You’re having a contraction. Push now.” I didn’t want to be that disconnected from my body.

I never used my pregnancy and my expanding waistline as excuses not to do things. I went out on maternity leave two days before my son was born. (He did choose to enter the world about a week earlier than expected.) And the Sunday he was born, I had planned to go grocery shopping.

When our son was born, my husband and I had been married for nine years. He knew me. He knew if I said something hurt, it was an understatement.

Before my diagnosis, when I was still traveling from one specialist to another (vascular surgeon, geneticist, neurologist, rheumatologist), it was difficult to describe the pain I felt in my legs, primarily my left leg. I told doctors it felt...
like a hammer was continuously hitting my leg. I told doctors that my calf felt tight, like a giant set of pliers was squeezing it. I told doctors my legs felt heavy like an elephant had sat down on my lap.

Now, the pain feels different. Sometimes it feels like my leg is being twisted, the way you wring out a washcloth. Sometimes it feels like I have shackles strapped on, pulling me back, dragging me down, slowing me down. Sometimes I feel like I need to hoist my leg in and out of the car, because it has suddenly become heavy as if my eleven-year-old son is resting his entire weight on my left leg.

I wonder what so many years of pain have done, are doing, to my body, my mind, my spirit. I don’t always know what to do—struggle through the pain and hope it naturally eases up, or take a pain pill and wait a couple of hours for some relief. And there is also the other unknown—what are the pain pills doing to my body long term?

I don’t often cry. But sometimes I do. And when I do, I’m not always sure if I’m crying because of the physical discomfort, or the mental beating I’m feeling. Do I cry because it was difficult to push the shopping cart at the market, because I was too fatigued to carry my groceries into the house, and I feel exhausted and now I still have to put everything away? Or am I crying because my legs feel so worn out from grocery shopping?

My son doesn’t remember me before, the way I used to be. He doesn’t remember the walks we used to take to the museum in the neighborhood. Now we drive. He doesn’t remember our regular walks to the local bookstore. Now we drive. He doesn’t remember our hour-long neighborhood walks, me pushing him in his stroller as I pointed out butterflies, squirrels, hummingbirds, star-shaped leaves. Now our walks max out at twenty minutes.

But as my eleven-year-old son continues to grow, he is becoming more attuned to my pain. He notices the way I curl my lip. The way I grimace. The way I hobble a bit. And he knows. He asks if I’m okay. And he doesn’t accept a flippant, “yes.” “No, are you really okay?”

I’m never quite sure what to do, what to tell him. We teach our son that honesty is the most important element in a relationship. At the same time, I don’t want to worry or scare my son. I want him to feel secure in the knowledge that regardless of the pain in my leg, he is safe, and I am capable of taking care of him.

Each day, my husband of twenty years calls me on his hour-long lunch break. We catch up on our days. He asks how I’m feeling. And I don’t always know how to answer.

If I’m honest and tell him my leg has been twitching on and off for an hour, he’ll worry while he’s at work. Worry more than he usually does. If I tell him that I had a hard time standing up from the couch, that in fact I plopped back down because my knee couldn’t support my first attempt, he’ll worry. If I tell him that it’s only three o’clock in the afternoon, but since I have picked up our son from school and I’m not driving any more today, I already popped a pain pill, he’ll worry.

Before my diagnosis, my life as a patient began with an inexplicable swollen left calf. Excessively swollen, like an overfilled water balloon about to burst. So tender that when a doctor placed his hand on my calf, I cried out in pain. While waiting in the emergency room, my calf grew and reddened, looking like a grotesque, over-ripe tomato. (A food I have never liked.)

During the doctors-can’t-figure-me-out stage (which feels like it’s never really ended), I remember sitting with my sister, her sons, and my son on the floor in her home. We were playing a board game, and I couldn’t find a comfortable way to sit. I tried stretching my legs straight out ahead of me. I tried sitting cross-legged. I tried tucking them to the side. Nothing seemed to work. Except me. I was still teaching fourth grade in a public elementary school, still trying to keep my life going as it always had. With the addition of daily pain and the fear that came with doctors’ confusion about my mystery illness, it was often a struggle to keep going.

I don’t remember what I had said, or what I had done that prompted my sister to say, “You’re not the only one whose leg hurts, you know.”

It was dismissive. It stung. A suggestion that maybe I was overreacting. That I should suck it up and just handle it all better.

It brought tears to my eyes, because she didn’t get it. No one got it. How could they? When you look the same on the outside, when doctors can’t easily diagnose you, how much of it was my fault, in my imagination?
It took almost a year and a half and a multitude of doctors’ visits, lab tests, scans, exams, and a muscle biopsy to get a diagnosis. Finally, my pain had a name—an autoimmune disease called undifferentiated connective tissue disease. My rheumatologist described my illness as having overlapping symptoms of rheumatoid arthritis, lupus, and myositis yet it wasn’t conclusively any of those. He said it wasn’t fatal, it was something I would learn to live with.

There’s almost a sense of validation when lab tests reveal increased inflammation. I feel strangely triumphant. “You see. There. That’s what I’ve been saying. That’s what I’ve been trying to tell you. That’s why I hurt.” I have objective proof that my pain is real.

They say what doesn’t kill you makes you stronger. But sometimes, I feel like what doesn’t kill me is slowly wearing me down—mind, body, and spirit. Chronic illness coupled with chronic pain that never completely goes away.

But then there are those rare pain-free moments. Glimpses and reminders of my past. And I don’t know what’s worse. Feeling my usual pain or being gifted these rare, unicorn-like pain-free instances. Because all it does is remind me of who I used to be. And who I will never be again.

**Ode to My Muscles**

The words for you were hidden in your fibers, buried in your tissue, emblazoned instructions on every cell membrane to jerk, shake, whirl, and beat to a rhythm of your own making, as if I were meant to dance while still. You who are taut when the brain says to bend, you live in a world of infinite impulse; you weaken my grip and pull me back into the body I yearn to escape from each sleepless night. I do not blame you, my incessant muscles, though I ache to unstring you like bows and lay you to rest by the riverside. For I have wept at the thought that you were never there, And as I walk through this chasm between cerebrum and palsy, I find that I have fallen a little too much in love to call you, the indomitable, my enemy.
This sound, my steady breathing a muffled loudness in my ears, reminds me why I run. My vision blurs for a moment when I glance down at my black lace-up trainers, at feet made special, feet I wasn’t born with, feet landing as thunder onto hard-packed dirt. I know . . . I know . . . so I run.

I cross lawns without sidewalks, skirt parked cars, garbage bags, cardboard boxes overflowing with bottles.

A few birds flitter and follow me toward the park, on their way to oaks and maples to nest warm for the night. Evening’s coming fast to shade the world. I feel the heaviness of the gray clouds that always linger near . . . they’d found a confidante, a tortured soul to fill with sadness. If I were tough enough, I might cry, but instead, I run.

The edge of the neighborhood is quiet now, other than the occasional light squeaks coming from my socket joints needing lubricant. Every step of my Triton prosthetic legs and feet is smooth, working in perfect harmony—mechanical perfection.

Feeling almost cold now from the dampness of the wooded lot, but I suffer no real pain; although, I wish to feel it—want to remember . . . to embrace the phantom aching in my joints, But everything’s just fucking perfect, so I run.

“You carry flesh memories,” says Doc Huntington. “That’s why you fall out of bed. You forget your legs are gone.”

Remembering, I stare at the ceiling, my thoughts on Yemen . . . I can still hear the screams. I see his face . . . Rashad . . . and so I run. Run until I’m breathless. Run until the earth ends. Run until . . . I forget.

* * *

Kami comes on Wednesdays. Her petite features . . . those blunt-cut bangs bring a warmth to my soul. Her eyes sparkle with an indescribable blue light.

“Why don’t you use the track, Daniel?” she asks. “Running through this neighborhood can be dangerous . . . so many obstacles.”

I smile. I try not to look at her tight stretchy top hugging her perfect breasts. The bitterness inside buries that desire down deep, because I must focus, so I run.

“Did you mail your letter to the Embassy?” I ask, knowing already she’s sick of hearing this question.

She closes her eyes for a moment. “The village is gone. Al-Qaeda-linked activist’s bombs leveled his village . . . survivors fled for their lives.”

“I’m telling you!” I scream, pounding my hand on the kitchen table top. “I would know if he’s dead. I’d feel it.”

“It’s been ten or eleven years,” she says. “You have a son now. You’ve got to find a way to put this behind you, so he can come live with you.”

My boy, my little one, Simon. The doctors held me hostage from my own child, citing PTSD as a problem. Like I said, if only I were tough enough, I’d cry . . . so I run.
I’m hard on Kami; saying the wrong thing. I think she really cares about me.

“I’m just going to go,” I tell her. “I’ve already called the airlines. I can get a flight out in three days.”

“Did you give the airlines your name?” I don’t answer.

She stares at me. “Your doctors will not allow you to go alone.”

“Then come,” I say. “You can make sure I take my meds and I don’t fall down. Come on, Kami, I’ve waited so long to be able to go. I need to find him.”

“Is it really necessary to find the man who saved your life?”

“Yes,” I say. “He changed everything.”

“I’ll talk to your doctor. I’ll see what I can do.”

I wonder, where does wisdom get its legs? At what point is wisdom able to walk, to run, to fly? At what point do we embrace the sagacity of life without fear? So, I run.

I approach the clearing, where the grass is mowed to exactly one-and-a-half inches in height. No grand memorial in our town for my fallen brothers, not yet.

The bronze casings of an angel, arms outstretched holding a sword, like the one in Volgograd, Russia, stands atop a granite stone. A metal bench in front . . . a dedication to the fallen from many wars, a small, almost forgotten, thank you.

The cool air rushes against my skin as I slow and circle her, feeling bitterness rising as bile in my throat. Where’s this avenging angel when we need her? Disgusted, I turn from her false saving grace and so I run.

My cell phone rings. It’s Kami.

“Good news, Daniel, we can go. We can find your friend.”

I sit in my chair with my hands covering my face. And I wait while they search records. I wish for my legs. Inside my thoughts, I run.

Kami is saying my name. “Daniel. We found him. But, it is too dangerous to travel at night. We will go in daylight.”

It’s $24 a night for the hostel next door. I cannot read the words on the bullet-holed wall, perhaps I don’t want to.

Clean sheets, clean bed . . . restless nights. Waking to someone screaming . . . I realized it was me. Now, I am desperate to run.

In the morning, we drive out to the dust bowl of western Asia, dangerous borders. The world suddenly feels like a more dangerous place.

Our driver does not speak English, but it doesn’t stop him from talking. The translator, Lieutenant Shawn Mac Murphy sits quietly listening, and frowning.

A rolling pain in my stomach replaces the nervous flutter. Fear. I don’t know why. My hope of joy holds apprehension. After all these years, am I finally going to connect with Rashad so I can properly thank him?

After a long ride, our Jeep quietly comes to a stop in front of a building with dusty cloth flaps covering the windows, they move with a slight breeze as if someone is looking out, perhaps they are.

Kami rushes to set up my chair.

The other men knock on the door.

After what seems like an eternity, the door finally opens. A child about eight years old shuffles out onto the porch.
I wheel around the side of the Jeep and stop near my translator, Shawn.

The child says in English, “American . . . soldier, Daniel?”

Now someone else is coming from the building . . . coming slowly, eyes locked onto mine. My breath leaves my voice as I call his name barely above a whisper. “Rashad!”

“Daniel Alon,” he says my full name and repeats it.

He rushes toward me and stops when he sees my legs are gone. He falls to his knees and weeps.

I unstrap myself and slip down onto the dirt in front of him. Lord if only I was tough enough . . .

He reaches for me not speaking English. I don’t know what he is saying. Tears fill up his brown eyes. He weeps and cries my name as if my name alone might cure his torture.

His face, that wonderful face that worries my dreams, and makes me smile. I cannot stop the words, and so I keep saying them, “thank you.”

Kami drags Shawn down into the dirt with us. “What is he saying?” she tugs at his uniform. “Tell us!”

He looks at Kami, “Rashad thinks Daniel’s injuries are all his fault.”

“But, Rashad saved Daniel’s life. He would be dead if it wasn’t for him.”

“No, you are wrong,” says Shawn. “Daniel saved Rashad and his pregnant wife. He gave up his seat on the transport, so they could escape. He stayed behind and killed every one of the rebel insurgents. He was left alone to die, but survived many days, before they came back for him.”

* * *

The rain falls fast, the wind howls and still I run.

Kami’s Honda’s in my driveway. She follows me inside, and puts on the kettle to make tea.

“Are you ready to talk?” she asks.

“I guess,” I say reluctantly.

“Daniel, why didn’t you tell me the truth?”

“You know the movie, Dances with Wolves?” I ask. “Costner’s character . . . well, that was me. I wanted to die. I did everything short of painting a bull’s-eye on my uniform. Dumb luck kept me alive. But, when I was alone out there with all the dead, crouching in a small hole with only the sound of my frantic breathing, waiting for more rebels to come to kill me, something happened inside my numb head. I wanted to live. I needed to live.”

Saving those two lives gave my own life purpose. After a while, there was only one thing I wished I had—legs . . . my legs. If I had them, I would have run, and kept running until I made it home.”

Kami smiles, reaches across the table to take my hand.

“You see, Kami, wisdom got me home, and wisdom gave me legs so that’s why I run.”
The Hotel Reading

No!, this can’t be it! I think
as I look at the white wheelchair logo
spray-painted on the hotel’s black brick wall
in the back by the loading dock
just below a camera and a speaker.
But then I remember I live in a land
where lifts and ramps are optional
at historic, public front entrances,
where wheelchairs are still loaded like freight
onto trains never level with platforms,
pushed up or down metal ramps by porters,
who must be requested hours in advance.

I push the button and a man asks
who I am and what my business is.
I tell him I’ve come to read
for a group on the fourth floor.
I give him their name, which he’s never heard,
but he still sends someone to let me in.

A minute later a cook in a white apron
appears on the loading dock
holding a silver remote control.
He lowers the metal lift to street height
so I can roll in. As I reach out
to push the UP button he says,
“No. Don’t touch. I control everything
with this,” waving the remote.

Once up on the loading dock
he rolls me through a supply room
stacked with brown cardboard boxes
and white china bowls, plates and cups
then past the kitchen’s steel pots and pans
and rising steam, blue gas jets at eye level,
as I think, just for a moment,
of Billie Holiday in the ’50s,
until my front wheels suddenly stop
dead against a raised doorway lintel
catapulting my bag out of my lap,
(with a thud onto a hard tile floor),
and me up and out of my chair
where I stand momentarily weightless
on the footrests in midair
just before the point of no return
until I grab the armrests and pull myself
back down and into my seat again.

Finally inside the hotel lobby
there’s no one in reception to greet me
or to direct me upstairs to the room
where I am to read. I ring the number
on my mobile from the email invitation.
A woman comes down and leads me
to the lift and then to a hot room
on the top floor, a balcony bar,
where I unpack at the front table
and discover two dented spines
in the ten books I’ve brought to sign
Better these than mine, I think,
too shaken and warm to be bothered
about what or how I will read.
THE BRACES

They stand in my shoes
at the end of the bed
the legs I now use
when I travel out of town
on holiday or to the city;
black plastic knee pads
held up by steel rods
fused to metal soles
perfectly balanced
inside a pair of my shoes
standing up on their own.

I’ve worn them ever since
that afternoon I lost my legs
on Amsterdam’s Leidseplein
stranded for half an hour
amidst the jugglers, their
crowds and the pickpockets
sitting on my rollator
before I thought to crawl
sideways the last meters
into a Central Station bound tram.

Hidden braces that protect me
from train passengers who
push and crash to the toilet
or rush to the disabled seats
their luggage smacking
against the plastic pads
instead of my kneecaps
as they hurry past
too busy to stop and say:
“Sorry” which in Dutch
can mean: I’m sorry,
May I get by? or
GET OUT OF THE WAY!

Braces that hold me up
in return for a little pain
from Velcro bindings
that pinch and red-band legs,
the blood trapped underneath,
but which also decrease swelling
so after a long flight I can still
find my ankles when I finally
undress in my hotel room
and lay down exhausted
from a day of travel
my legs still standing,
waiting at the end of my bed
BRYAN R. MONTE

HERE’S SOMETHING FOR THE PAIN

Once again I am forced to listen
to the big magnets’ machine gun mating
locked inside the hot, tight
white tunnel as the MRI
scans, slices and maps my head,
so accustomed to the hard cushion
of noise and heat, I start to fall asleep
until the control room technician shouts:
“Wake up! You’re ruining the results!”
Unlike the first hospital where the kindly orderly
told my nervous partner it would be 20 minutes
and apologized an hour later when I was still
stuck inside the noisy, narrow, plastic tube
a third contrast IV in my arm.

The next day at the university hospital
I asked for calm, classical music to drown out
the scanner’s metallic, arrhythmic, robotic orgy
but instead Mozart’s Requiem
jeered through headphones
I couldn’t switch off or remove
the technician suddenly gone
to prepare another patient.

Sometime later I looked up in the mirror
and saw the tech and a white-coated doctor
pull up chairs and point at a monitor
then wave in students from the hall,
who took pictures with their cell phones
and in those flashes I saw myself
rolling with wheels in five years
before the doctors even told me
about the scars in my brain,
then tossed me out of the hospital
that very evening saying:
“There’s nothing we can do.
Here’s something for the pain.”
You’re Never Too Anything to Travel!

Michael Timko

The title is not simply a conundrum. I happen to live in an assisted living facility (ALF) and I have heard that sentence over and over. There’s only one problem: most of the residents don’t believe it; instead, they think and often say they are simply too old or sick or tired or disabled to travel. I was one of them until I decided it was time to hit the road again. My wife and I have celebrated our eighty-ninth birthdays and are looking forward to our ninetieth. Before retiring, we both pursued active careers and, indeed, traveled a great deal. She had been to Japan twice, and I once. We had taken many tours to many places: China, Russia, South Korea, Central Europe, and northern Spain to name a few. I was a scholar and did much research on nineteenth-century British literature, research that involved much reading in the British Library, and research that brought us to London many times. Domestically we had traveled to see our daughter in northern California and my wife’s brother in Arizona. Needless to say, we enjoyed every minute of it.

Flash forward to my eureka moment: What had stopped us? Why hadn’t we traveled since we had moved to our ALF some five years ago? Were we going to give in to the old folks’ syndrome and really believe that we were too old to travel? No way! It’s true that I now use a cane and my wife uses a walker, but that did not seem to be a real deterrent. We got busy and began to travel again, the first trip being to northern California to see our daughter and our now adult grandchildren.

How did we do it? We Googled a great deal and hired a travel companion. It was both a revelation and a delight. The key word is “companion” or “chaperone.” That’s how we were able to see more of the world again. The word companion covers a lot of ground; there are child travel companions, disabled travel companions, elderly travel companions, medical travel companions, and personal assistant companions. I’m pretty sure you can find others.

What does a companion or chaperone do? Well, just about everything you might think of to make your journey easier. First of all, you, the traveler, need to give them some information: how many traveling, exact needs, day and time of travel, destination, class of service on flight (economy, business, or first-class), and any other specific needs. The companion takes care of all the arrangements: all tickets, cabs, limos, airport needs, meals, rental cars, cruise arrangements, and any other special requests. What you need to cover are all the expenses of the companion plus the fee for the service.

Our companion on our cross-country flight was terrific. She arranged our pickup to the airport. She made sure that my wife had the wheelchair handy when we arrived to take her through the airport rigormarole and get her safely aboard. She sat next to my wife and made sure she was comfortable, had a good meal, and enjoyed all the amenities of flying. When we arrived at our destination, everything was all set to get off the plane, get our baggage, and the transportation to get us to our daughter’s house. The process was repeated on the way back. I had been responsible for all this in my earlier life, but now all I had to do was sit back and marvel at our companion’s skill and travel expertise.

Still skeptical? If you aren’t persuaded by what I have written so far, go to Google, or get your grandchild to do so, and glean all the information you need. I guarantee you will be gratified by the results. I was, and for our sixty-seventh anniversary my wife and I are going to travel to Australia, something we missed doing during our earlier years. As the saying goes: Sayonara!♦
The walls were pale green; two twin beds separated by a small table holding Styrofoam cups with straws, half-filled with liquids. No photos, no pictures, no flowers. I stepped into the room, a small woman lying sideways on her bed, hair uncombed, motioned to me, with the forefinger of right hand to come near. A bit nervous, I came in and stood next to her; she reached out with her hand exposing her arm, lean, white, but what caught my attention were the numbers scrolled into her arm.

This is the summer of 1969. I am on the third floor of the University of Colorado Medical Center in Denver. I have been assigned to the tuberculosis ward as a summer intern chaplain. The tuberculosis ward was a catchall for patients who were poor, with no hope for recovery. Persons on this ward were often homeless, alcoholic, or long term TB patients and many of these were migrant workers from the fields east of Denver, who physically could no longer do the work.

There were numbers on her arms. In that moment, I did not know what I was witnessing. She pointed to a man in the other bed, and as she did so, she patted her heart, lightly, tenderly with a shy smile dawning. This man had dark hair, sunken eyes, and he surprised me for he, too, raised his arm, shirking off the bed sheet for me to see numbers indented into his skin. So far there have been no words, no prayers, gestures, or rituals: the tools of my trade. I remained silent in the stillness of this room. My theological training had no weight here. I felt I had been beckoned into a sphere of a new world that was both confounding and oddly attracting.

Slowly these engraved numbers made sense. Nazi Germany. Jews in concentration camps. Now hospitalized as their bodies were giving out, and yet I was invited into their private space. The man closed his eyes. Was he sleeping? Possibly remembering another time as a child with a mother and a father and maybe siblings? I do not know. He never again turned toward me with his eyes open, ready to meet me, the chaplain with a blue shirt and yellow tie and a white medical jacket. In his world I was neither visitor nor a guest. He had already begun his leave taking.

I do not know sign language, but whenever I entered the room, she smiled and pointed to a chair in the corner for me to bring over. I will name her Sarah. Sarah would often reach out and hold my hand, I felt a warm, pulsing current shoot up my arm, across my chest, then my neck, and filling up my cheeks. This experience was unsettling. Not just the pulsing but the sense I had of being attracted to her. And me a chaplain. And married. And she older than me, hospitalized. My vulnerability scared me.

Each Monday morning, the group of us intern chaplains had individual reflective sessions with Claude, our chaplain...
supervisor. So as I started telling Claude about Sarah, tears burst from my eyes. I choked up and stopped talking, trying to get control of myself. Claude sat there, a warm smile radiating out from his eyes. No furrows on his brow, just a simple inviting clarity on his face. After a long pause, Claude asked some simple questions: “What did you do? Yank your hand away? Did you feel called on to pray?” As I answered these questions in the negative: I felt a surge of relief embracing my heart. These sessions were called “verbatims.” The intern had written down the dialogue with a patient that she or he felt uncomfortable with. This was to be a time of learning, yet I was sharing with Claude a dialogue of silence, some gestures, smiles or frowns on faces but few words. I wanted to impress Claude. Yet my verbatims seemed inadequate. I felt pulled to write down what I could, notating how much was communicated through touch, gesture, and eye contact. I needed Claude to provide a safe space for me to be honest.

The nurses thought that Sarah was from Eastern Europe. They knew little else about her or her husband. When the doctors, residents, and interns made their rounds, the teaching resident would raise his hand and speak with authority, “How are we doing today?” Sarah usually nodded in the affirmative, and the group would move on to the next room. With me, Sarah would awkwardly speak a few words in English but also resorted to the use of her hand and eyes. I remember a few stories about her favorite doll, a sister, and her mother. No stories about Hitler. No stories about trains. No stories about concentration camps. Just some short stories about her childhood. After some silence she would point at me, your turn. Her stories begot my stories of joy and sorrow. Of growing up without a mother. A father commuting to Washington, D.C. during and after World War II, leaving me alone with “Mother Winsor,” an elderly woman in the neighborhood who would stay with me while my father was out of town. Mother Winsor suddenly disappeared when my father brought another woman home and told me she was my “new mother.” I was six. Sarah nodded. We both chuckled.

The summer of 1969 was disruptive, not just the fires and violence in the cities or the photos of the innocents suffering in the Vietnam War. But disruptive for me as a theological student confronted by my feelings for a woman I was visiting in a green-walled hospital room. This woman was slowly dying, without friends or family, next to a husband who would probably precede her in death. I wanted some rules, some dos and don’ts. Claude offered me a comforting smile, sometimes the nod of a head, most often a gentle hug at the end of our session, meaning it was time for me to return to the tuberculosis ward. In a way, I thought of him as teammate as I made my way into unfamiliar ground.

Seldom did I notice any nurse or doctor come into this room. I went to the weekly staff meetings about concerns and progress of the patients on my ward. These lasted fifteen to twenty minutes. No drama, no hope for recovery, no cure. They bundled their clipboards, holding them to their chest, and off they went to see other patients, who actually needed their ministrations. So I walked the halls pretty much alone. Newly departed from Peace Corps in Bolivia, I could speak Spanish with the migrants and their families but it was a long distance to Denver and visitations were infrequent. The other patients had no visitors. Most often I was the only “visitor.” Some were angry and turned their backs on me. Others were fearful and asked for prayers. Some exhibited such a deep resignation that I just stood next to them or brought a chair and sat beside them. I don’t know when I ever have felt so helpless. Slowly I learned what I could give, could no longer be measured in words, fine phrases, or a misbegotten faith that God would bring them healing.

When Sarah tired out from gesturing, speaking hesitantly a few words in English as well as trying to understand me, she would reach out with that hand, with that arm with the numbers engraved on it. And that is how we ended our visit, quiet and still, holding hands.

Sarah weakened considerably by the end of the summer. Her husband had a feeding tube attached, and I noticed that the verve in Sarah’s eyes had diminished. Nurses came to the door occasionally, smiling and asking how she was doing. Did she need anything? No doctors, no residents, no interns ventured in. When we met in the conference room, I noticed that seldom was Sarah’s name mentioned. I be-
gan to feel isolated on the ward. Most of my patients had become more and more invisible. Just bodies taking up bed space. Not humans with stories or feelings, hopes or fears. Occasionally I would hear a doctor raise his voice in irritation at a meeting, “goddamnit, he is just a drunk!” He yelled this out, usually after a nurse had reported some hope for recovery.

Claude and I drew closer as we moved toward Labor Day and the end of my internship . . . From him I was learning how to trust myself. I was also learning how to be more comfortable with silence, both as a safe refuge but also a recognition that I, the intern, may have little to say and a lot more to learn.

On my last day I stood on the threshold of Sarah’s room. She seemed to be so much smaller, taking up so little space on the bed, almost like a child now. I walked over to her. We both knew this was my last visit. I had a little speech memorized about my gratitude, but before I began speaking she reached out to hold both of my hands. Tears flowed down my cheeks, washing away any words. Her eyes glistened, and she offered me her soft smile. Then she released my hands and turned away from me.

And this is the image that I carry with me today. The two of us, me next to Sarah’s bed, me holding her hand or Sarah holding mine. Me, mysteriously trusting that beauty has emerged out of this utterly broken world.

MAJA HAAVISTO

AWARDS SEASON

glossy magazines tout
hottest pajama looks
palest facial tones
untouched by the savage sun
sexiest sunglasses
to match your pillowcase
most stunning impressions
left on the mattress

fancy ceremonies honor
toes touching the floor
heroic ventures to the bathroom
the superhuman strength
needed to chew food
best attempts to leave the house
words laboriously uttered:
one, two, three
no, that’s enough, please stop
don’t wear yourself out

empty chairs at gala dinners
hosting only we’re-there-in-spirits
my cheek caressing the red carpet
of the so-called living room

would you spoon
more smoothie in my mouth,
my darling
I swear the bits of kale
taste like finest chocolates in my dreams
next year, every year, in my dreams
I will win the trophy
for finest daydreams
moved to tears
in my whispered speech
I picture you
gently picking kale bits
stuck between my teeth
LIZA MARSALA

NIGHT TERRORS

Have you ever wondered whether those were your own hands in front of your face, shaking? Your own head that’s pounding, aching? A cat or an intruder in the garden, the two are near the same to a lying brain that processes thoughts too quickly.

Do I hear a monster’s footfalls or my own heartbeat, I know that ears can be mistaken, but louder! Louder! Louder! It pounds. Louder grows the beat of a heart under floorboards where no body’s lying. Though it’s I grown mad under the watch of the evil eye, tonight it is I who’s dying.

Here I lie at the end of my wits, the end of my wick. Candle, don’t burn out and leave me here in shadows.

Everyone has a few skeletons in the back of their closet, but mine have late night meetings in the hallway just beyond the door or around my bed. The barely there light highlights barely there figures. Barely there whispers of secrets barely remembered.

A sound wakened me from the terrors that distracted, a groan, it could’ve been the sound of a million things but that sound I knew it was the groan of mortal terror, a sound too familiar from my throat, still I over-reacted. Terror from my own chest or a ghost, the two are near the same to a lying brain that cannot process thoughts any longer.

Not quite awake but aware, my jaw hurts from gritting my teeth. I didn’t open my eyes because I didn’t want to see. Louder, louder! It’s only a bird pounding against my window, it cannot see what’s killing it, neither can we. I fall slowly back to nightmares disguised as sleep.

Surely, the morning will find me, wide eyed, sweating and paralyzed, deafened by fear but still alive, left without sleep. Until then this is my own nightly fight against the ghost of an overactive mind. I lay me down to sleep knowing that the sun will eventually rise.
I wasn’t sure what they were hunting when I started watching Charlie. No one bothered to tell me, and I didn’t care enough to ask. Hearing the maids whisper about him for a week, though, finally sparked my curiosity. When I was alone, I recited three words and concentrated and a picture of the countess’s nephew formed on the water in my clay mug.

Charlie was tall and walked easily, never tripping or missing his footing. I squinted into the mug, being careful not to shake it and disturb the image. I couldn’t tell whether he was going east or west from the castle, only that he was walking alongside his well-groomed horse instead of riding. The sunlight gleamed on the horse’s tack, which was so polished I could have used it to scry.

His brown hair flopped over his face until he brushed it absentmindedly away. A touch of magic—or even a strip of leather—would have kept his dark curls out of his eyes for good, but it never seemed to occur to such an exalted boy as Charlie. My lip curled. He had plenty of time to waste fussing over his appearance, so down his hair stayed.

The door to my room opened and I hastily put a hand over my mug. When I lifted my pale fingers, the water was only water. Scrying wasn’t an unusual skill for those who cared to learn magic and had the talent to do so, but it never seemed to occur to such an exalted boy as Charlie. My lip curled. He had plenty of time to waste fussing over his appearance, so down his hair stayed.

The door to my room opened and I hastily put a hand over my mug. When I lifted my pale fingers, the water was only water. Scrying wasn’t an unusual skill for those who cared to learn magic and had the talent to do so, but I squirmed inside at the idea that someone would catch a glimpse of Charlie and know that I had taken the time to look at him.

I eyed the maid who crept over the stone floors with quick, quiet steps, hauling a basket in front of her that was piled so high that it hid her face. It was full of linen napkins. My mother insisted that even the thick homespun cloths the servants used to clean their faces and the floors alike be folded just as carefully as the delicately embroidered squares of soft fabric the nobles used to dab at their lips. I tried to keep my own face serene, but if it was Dianne, I knew I could only stay patient for so long.

The basket landed on the table next to my bed with a thump, and Joanne smiled at me. I nodded to her. She and her younger sister were both pretty in a farm-girl way, with moon-round faces and red-gold hair and the same pert nose on each. They walked alike and sounded alike, but Joanne was a lot more restful on my nerves.

“Your Ma says you can fold these napkins as well as any of us,” she said. “There are a few more baskets to go, but I thought I’d carry them myself and make a few trips of it.”

“Thank you,” I said. My voice sounded harsh even to my own ears and I tried to smile at the other girl.

She smiled at me again and her blue eyes crinkled over her upturned nose. It made the freckles dance on her face, and when she turned back to the door, her two thick braids swung out behind her.

When she returned, I was almost halfway done with the first basket. I had only to touch a napkin for it to obligingly smooth itself out and flip over and over until it was a tidy
rectangle. I had offered to teach the maids with magic the spell, but they claimed that I was the only one with a knack for it. I suspected strongly that they simply didn’t wish to learn.

Joanne didn’t speak to me, but she poured more water into my mug and twitched the blankets around my feet, mothering me. I didn’t need it, and I didn’t want it. I scowled at her back. She looked twice her age when she fussed over me, and I thought she’d be a round and fat matron any day now if she kept it up. I pictured her, heavy and ugly, warts replacing her freckles, and had a brief moment of shame.

I finished all the napkins I could, but she left the second basket more than a foot further away than I could reach.

When she returned, I gestured at it with a sharp movement of one wrist, trying to keep the irritation from my voice. "Leave it where I can reach it, or I can’t fold a thing," I said. "Shove it over here, will you? And leave the next basket on the bed with me. I’m almost done anyways."

"As you say," the girl said. I heard the familiar catch of Dianne’s voice and sighed. Fear sounded strange on her, she was so used to giggling. Her pert red mouth was set in a scowl as she leaned over to drop the basket on the end of my bed, pushing it closer and closer to my hand with one finger until I could grab it and yank it closer to me.

She would have looked ridiculous if she weren’t so irritating.

Dianne pushed the other basket a few inches closer to me and then fled, with one hand around the rough-carved wooden sheaf of grain that she wore on a faded ribbon around her neck to honor Lia the Earth Mother.

She didn’t even bother to shut the door of my room. The heavy oak creaked most of the way closed on its own, but stayed open enough to let in too much light and noise from the kitchen down the hallway. I twitched my long, pale fingers angrily and it closed the rest of the way with a snap.

I took a few deep breaths, fighting the nausea that always hit me when I used my magic on something too far away. Anything I could touch I was safe to work my will upon as I chose, but trying to affect something on the other side of the room was hard enough work that it gave me the sweats.

At least the silly twit had moved the baskets close enough for me to reach them. I continued the chore, letting the monotony of the task take all my attention.

Too soon, and it was done. I pushed the baskets of neatly folded and stacked linen napkins off the bed so that whichever maid fetched them back to the laundress wouldn’t have to come too close to me. The first hit the floor with a satisfying thump, but the second wobbled and tipped as it fell, spreading its contents all over the whitewashed stone floor.

It took half the afternoon for me to shove each napkin back into the basket with magic and tip it back onto its reed bottom. It was just close enough that I could reach over the side of the bed and pull it up next to me, to re-fold every napkin that had gotten mussed, and smooth the ones that had kept their shape.

A spot of wine on one of the bleached napkins for the nobility caught my eye. I gathered my magic and summoned a few drops of warm water, rubbing them into the fabric and whispering the words of a charm against stains.

There was still too much time before someone would bring a tray of supper for me. I shut my eyes, but I could still have recited every inch of the room around me. Low ceiling, stone walls, small window with thick shutter. The ceiling hadn’t been whitewashed in two or three years and it looked dingy and sad. Cracks were showing in the faded paint around the edges of the room, and one dark spreading stain covered the corner over my bed for several feet. The dark stone and sickly white paint made me feel as though I were in a cave. What sunlight drifted through the window was weak and pale even in the height of summer.

My bed was narrow for two but ample for one, with undyed linen sheets and a pile of patchwork quilts at the foot. It was barely fall, so I hardly needed the warmth of the blanket,
but I spread one over myself every morning with an ir-
ritated twitch of my arms. Anything to disguise the useless
lumps of my feet at the end of my wasted legs.

*     *     *

It took another two weeks before I looked at Charlie again.
A great physician visited the Countess and Mother kept
me busy. I folded napkins, carded wool for the spinners,
hemmed sheets, and polished silver. Anything that could be
done with two hands and no feet, I worked on, whether or
not I had a spell to make it easier.

The work ran out suddenly after the doctor left and I was
alone in my room, staring at the blank walls and the closed
door. A small stack of books on magic waited by my elbow,
but I’d already read each of them at least twice. If I could
have walked, I could have crept into the library, but no low-
class servant was allowed to linger there. They chose maids
who couldn’t read to dust the shelves.

Without really thinking about it, I picked up my mug of
stale well water and frowned at the surface, whispering the
spell to spy on others.

Charlie was striding through a forest as though he owned it.
I didn’t see his horse or his companions, but I figured they
would be right behind him. With a little focus, I shifted the
view in the mug to look down the path in one direction and
then the other. The woods were bright and sunny and the
boy walking through them looked warm and comfortable in
his sleeveless tunic. A small smile stretched his wide mouth,
as it usually did. I wondered if he was simple. Perhaps his
mouth was too long to do anything but smile. It almost
made him look foolish and vacant, but his eyes saved him
from appearing to be an imbecile. They were clear and
bright and as green and brown as the forest he walked
through.

I’d seen those eyes close-up a few times, when he’d stopped
by my room to speak to me or give me a new book. My
mother said he was being kind, but I saw the guilt twisting
his mouth when he didn’t think I was looking at him.

*     *     *

The year dragged on. I continued to do the busywork of the
castle. I continued to watch Charlie.

Sometimes he was alone, his long legs moving him inexo-
rably through quiet valleys or patches of sandy desert. I
never saw him with the company he’d set out with, but he
was rarely alone. I watched him walk for miles with his arm
thrown over another lad’s shoulder, both of them laughing
or weeping.

I was carried to the privy another two hundred times.

By the third month of his trip, winter set in and he got a
heavy jacket of leather and wool out of the saddlebags his
patient horse still hauled for him.

I abandoned all pretense even with myself and placed the
mug where I could see it even as my hands stayed busy
with mending or cleaning. Casting the spy-spell was the
first thing on my mind when I woke up. I didn’t always
remember to banish it before I slept, and sometimes upon
waking I tried to drink from a mug that still held faint,
twitching images of a boy or a mountain or a pony.

Without really thinking about it, I picked up my mug of stale well water and frowned at the surface, whispering the spell to spy on others.

As I watched him walk on, I began to wish that one day,
he’d trip and fall flat on his face. I’d seen him scorched
by the fire of a tiny dragon. I’d watched him bandage the
bleeding wound a manticore left. He’d favored that side
for weeks, wincing and holding a hand against his belly as
though he was afraid his guts would fall out. I’d even seen
him puking his guts up on the side of the road.

I’d even watched him sell his horse, sliding the coins into
the leather purse on his belt and wiping at his eyes angrily
as a farmer led his fine horse off towards the dark entrance
of a wooden stable that looked like it would fall apart if
someone blew on it.

All of his adventures, though, and I’d never seen his legs
fail him.

The priests or priestesses who stopped by my room every
year or so usually mumbled sermons about accepting my
fate and wishing others well, but I couldn’t bear to do that.
On cold winter days when I had gone weeks without seeing
true sunlight, the rage turned my thoughts twisted and red
and I wished I could hurt anyone who came into my path.
I didn’t. I kept my face as serene as I could make it. I took calming breaths, practiced my magic lessons, and folded dozens, hundreds, thousands of napkins. When I felt I could stand it no longer, I would twitch my blankets aside and dig my fingernails into my useless legs as hard as I could. They could still feel pain.

None of it helped. I would wipe off the blood and magic away the scrapes and lie awake into the night, staring at the dark ceiling and wishing for death.

That winter, I begged my mother for a small hand mirror. Charming the frost away from my mug of water was annoying, but with the scrap of mirror she gave me I could watch Charlie easily.

It was the pebble in his path that made me realize how far my magic could reach.

As my fingers mindlessly knitted on the shawl I’d been set to make for one of the old women who tended the herb gardens, Charlie paced along a path through a strange forest. He evaded every root with ease, and once again, I cursed him for how he never set a foot wrong.

I frowned at the small stone in his path through the mirror, and it moved.

Oh, not much. It mostly twitched, but it was enough to knock a few other pebbles and start a small cascade.

The toe of Charlie’s boot caught the shifting stones and he pitched forward. Before I had realized what I’d done, he was sprawled in the dirt, unmoving.

A cold feeling closed my throat. Had I killed him? I hated him, I was bitterly jealous of him, but even in my darkest hours I had never wanted him to die like that.

When he pulled himself to his feet and walked on, a little more slowly than before, I let out a sigh of relief.

* * *

After that, if possible, I watched him even more than before.

I couldn’t do a lot. Nothing large at all, I couldn’t shove him over sideways out of the blue.

Most of the first spells I tried didn’t work from a distance. After I tried to tear a large rent in the back of his tunic, I was so weak and shaky that I couldn’t even knit for two days. My mother sent for a cheap healer, who gave me herbal tea and told her to let me rest up. That earned me long boring stretches without any tasks to do while my stores of magic replenished. I almost screamed with frustration.

Once I recovered, I found enough spells that did work that I could entertain myself, though. I wondered if he thought he’d angered a trickster god. He was traveling alone at that point. I wasn’t sure why he’d left his companions behind, but he was as alone in his wilderness as I was in my bedroom.

My world had narrowed from one small room to a shard of mirror, but at least this time it was my choice.

Twice as much salt as he poured out would wind up in his food, and I smiled as I saw him grimace at the taste. I took to scouting the path ahead of him, to drop winter flowers and berries to the ground, so that he walked through a desolate landscape of brown and gray.

Whenever he came close to killing a fat winter rabbit or squirrel with his bow, I startled it just before he fired his arrow, so that he had to eat gruel and never taste fresh meat.

I was careful never to hurt him, but I tormented him for weeks. He tripped and fell, he ate bad food, he was never as warm or as comfortable as he could have been. His clothing ripped and it took him twelve or fourteen tries to thread a needle when he sat to mend it in the evenings.

His mouth took on the same pinched lines that I saw on my own face, and I felt a quiet gladness.

I was happier than I had been in years. I didn’t even mind when Dianne was the one to drop off work for me to do and she refused to so much as look right at me. It had been so long since I was anything but a pair of hands, but now I had a purpose.

Joanne tried to ask me about helping her make presents for the solstice, but I brushed her aside. My world had narrowed from one small room to a shard of mirror, but at least this time it was my choice.
After almost a full month without seeing anyone in my mirror but him and me, Charlie ran into strangers. His back was tense as he spoke to them, and I wished I could work the spell well enough to hear what was said, and not just see what was done. Their faces were set in cruel lines, but Charlie’s bow was stronger than their crude daggers and he stood with confidence.

They parted without coming to violence, but the strangers—bandits?—watched him go. Just before he got out of their sight, he sagged and stumbled, the false confidence evaporating from him, and the men traded knife-blade smiles.

They followed him for days like a wolf pack tracks an elk, and I started tripping them as often as I did Charlie. I didn’t like the looks of them, with their hollow eyes and their sharp blades.

They caught squirrels and rabbits in traps and roasted them every night, sucking the bones and licking the glistening fat off their fingers. I wondered if Charlie could smell the meat, if thoughts of dripping roasts and a full belly haunted his dreams.

I found that if I summoned just a trickle of warm water, like I used when cleaning small stains or refilling my own cup, over one of their gloved hands, they would wet their own breeches in the night. After that, there was never a morning when they all woke with dry breeches and I saw their noses crinkle at the smell of each other. Two of them—there were five, or so, but they were rarely all together in the same place—came to blows over it one morning.

It should have shamed me, I knew that, but instead I felt giddy and alive for the first time in years. Those men would never know I existed, never see the small room where I lived, yet I had power over them. I raised my hand and conjured little sparks of purple and green, watching them dance over my skin, and I smiled.

* * *

My legs worked fine when I was born. I learned to crawl like other children, I walked, I ran, I climbed.

It wasn’t until I was seven years old that I got sick.

The wasting disease went through the land, but Charlie and I were two of the sickest who didn’t die. We came close, both of us, over and over. They put us in the same room and nursed us carefully, even though my mother was a servant and his was a noble.

I was feverish and drugged, but I heard the healers talking to each other. They were running out of medicine. There was only, truly, enough for one child left.

Charlie got the herbs. I got tea and cold water. We both lived, but he walked out of the sickroom and I never stood up again.

That’s why I hated him.

That’s why the strongest footmen in the castle carried me to the privy that had been specially built in the little storeroom every morning and every night. That’s why I was allowed to live in the castle, even though I was a mostly-useless slip of a girl. By all rights, even though I was the daughter of the housekeeper, I should have been cared for by my own family or abandoned at a temple.

Those men would never know I existed, never see the small room where I lived, yet I had power over them.

His aunt’s guilt carried through making me a bedroom, setting orders for me to be taken care of, and then forgetting me.

That’s what I thought about when the bandits set a trap for Charlie.

To everyone, even healers who had taken vows to Lia to care for all, his life had always been worth more than mine.

I watched as two of the bandits slipped ahead of Charlie, winding their way through trees heavy with rain. Charlie was so worn out that he was barely putting one foot in front of the other, turning to look over his shoulder every few minutes.

I watched as the bandits tied a thin rope across the path. It was such a stupid way to try to catch a person that it almost made me laugh, but I had a nagging fear that it would work. Charlie was so tired—because I had kept him from rest—and sore all over, based on how he winced and frowned and stretched like an old woman.

If it worked, it would be my fault, I realized.
I wouldn’t have just teased a boy who owed me, I would have set him up to die. That would be as bad as sliding the knife across his throat myself.

The bandits were too lazy to go far ahead of him. Charlie was making his way inexorably toward the trap. The bandits were waiting on either side of the trail, weapons clutched loosely in their hands. Every time a squirrel ran past, they’d raise their knives and look wild, and then slowly relax.

When Charlie drew into sight and the men tensed like hounds before the hunter’s cry, I magically grabbed one of the men by the earlobe and yanked. He appeared to howl like a dog and he grabbed his head, dropping his weapon and continuing to mouth words that I suspected were foul curses.

The other man drew his sword, abandoning all pretense at an ambush and running at Charlie with his blade drawn, but the warning had worked. Charlie had pulled his own weapon and, tired and stiff and defeated though he was, he was more than a match for the bandit. A few strokes, a lunge, and the bandit lay on the path, bloodstain growing on his tattered tunic.

I watched the rest of the fight although it turned my stomach. Four men attacked him, but with their plan ruined, they lost their heads and ran at him one at a time. Some of them scored slashes on his arms and one pierced his shoulder with a throwing knife, but less than ten minutes after I’d spooked the scout, all of the bandits were dead or had faded back into the trees and ran, and Charlie was upright. He went to his knees and vomited in the dust of the road. He knelt there so long that I wondered if he’d ever get up again.

Finally, I reached out with my magic and slowly, hesitantly, patted his shoulder.

Charlie was almost close enough to see them when I realized that this was wrong.

No matter what his aunt had done, I couldn’t allow him to be attacked by bandits. Not when I was the one who had brought him so low. I would have as good as killed him myself.

I had never been able to talk or hear through my little spyglass, but I had to get his attention. I pulled his clothing and shoved him a little, hoping to make him more alert to his surroundings. He just shook his head and winced. The guilt, the first thing I had felt other than anger and shame in years, stabbed me, feeling raw and new.

I tried again and again, growing so frantic that tears fell down my face, and all I got Charlie to do was bat at his clothing and look hunted. I’d tormented him too much to get his attention this way.

Desperate, I cast my mind around for anything else to do.

A squirrel ran across Charlie’s path, and I realized that if I couldn’t get him to react, I might get one of the bandits to show themselves.

The path was dim, but I cast my mind along it until I saw a glimmer of light on the rough rope and searched the bushes on either side of the path for the bandits waiting in ambush. They were easy to see from above.

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The young man flinched, but when nothing else happened, he slowly relaxed. It worked. He stood up and walked to the nearest body, patting it down methodically and taking what little food and coin the man had had, stowing it carefully in his own pack.

I didn’t stop watching Charlie.

Instead of pinching him, I patted him on the shoulder. Instead of hiding berries from him, I shook them invitingly. After a few days, his color came back and he walked as he used to, like he had never doubted his own feet. When my mouth twisted at the sight, I smoothed my hand over it and bit my lip instead.

My door opened slowly, almost bashfully, and I tapped the mug with a finger, banishing the image. The footman sticking his head around the door seemed less real to me than Charlie and the bandits, but I made myself smile at him.

“Dianne brought your supper by, but you didn’t answer the knock so she reckoned you were sleeping and took the tray back,” he said. “You awake now?”

“Yes,” I said. “Thank you.”
“Would you like to use the privy?” he asked.

I nodded, not sure what to say. I wanted to be friendly, but the words stuck in my dry throat and the smile felt pasted to my face.

After he and his friend had helped me to the privy had carried me back to bed, I reached out and asked them to stay a moment.

They looked surprised and exchanged looks. When I thanked them for helping me, stiffly, they ducked their heads and looked surprisingly young.

“We all know it’s not fair you got so sick,” the one who had opened the door said. His name was Elrik, I thought. It had been a long time since I’d really looked at one of the ones who carried me across the room every evening. Elrik was lean and fair-haired. He had a kind smile, but his face was too round and his eyes were too big. “It’s no problem, and besides, when I’m sent to you, I don’t have to serve Lord Jared at table. He’s rude and he drinks too much wine.”

The younger one, dark-haired and sturdy, elbowed him, but his eyes crinkled and I saw he was trying not to laugh.

I found myself smiling, truly. It felt creaky, even strange, but it felt good.

My mother came to my room only a few minutes after Elrik and Joseph left. She looked wary, and the guilt stabbed harder.

“I have been thinking.” My good intentions didn’t stop me from sounding terse and formal.

“Are you well?” she asked. I saw the worry on her face.

“I’m fine,” I said. I was surprised at how concerned she felt. “I just . . . I don’t think that being in this room all the time is any good for me. I know it’s more work to move me, but the maids waste a lot of time running things they need magicked to me. Perhaps some days, Elrik and Jos could help me to a chair in the kitchen or the laundry.”

“Yes,” she said slowly, “I don’t think that that would be a problem. What about your studies, though?”

I looked at the bowl of water on my lap, and the stack of books I had hardly opened since Charlie had left on his trip.

“Oh,” I said, “I think I’ve learned all I can teach myself for now. If I get stronger, I can ask the librarian for permission to read some of the less precious tomes. Do you think that would be all right?”

“Yes,” she said, slowly. “I should have thought of it years ago. When you first took sick, you were too young for that sort of thing.” Her voice trailed off.

“I’m older now,” I said. “Charlie and I both are.”
"I just don’t think it’s a good idea, Lily," Mom said. A breeze blew through the backyard and I watched the brown grass sway back and forth. Although unhealthy, it looked free in a way that I would never be.

The Labor Day barbeque came with bad news. While our neighbors milled about the dead lawn and traded plastic chairs for visits to the drink table, I huddled in the corner, cold even in the summer evening. When I coughed, it caught in the wind and blew in my mother’s direction. Her mouth turned down either in pity or frustration, I couldn’t tell.

"But you said I could make my own decision this year," I argued. "True, you are twelve." Mom rubbed her chin while staring at a group eating hot dogs and exchanging small talk. “I’ll tell you what.” She sat up in the lounge chair and pulled down sunglasses. “If the doctor clears you to take that IV out before school starts, then you can go.”

"The first day is Wednesday!” I jumped from the comfort of the corner porch swing and walked over to the pool. The tape covering the IV tube in my arm pulled against my skin as I walked. How many times had I had to explain that an IV was like a needle? I told confused onlookers that it stayed in my body for weeks at a time to send medicine right into my veins. Normal people just took pills to get better. Since I had allergic reactions, I needed medicine through the tube every time I got sick. It usually brought strange looks from other kids.

"You might not even like public school, Lil’.” Mom shrugged.

"But I know I hate homeschooling,” I said. Jen, our next-door neighbor walked over to me and put a light hand on my shoulder.

"How’re you doing, Lily?” She asked. Jen glanced at the IV then gave my shoulder a slight squeeze before patting my back.

“‘I’m fine,” I said. I could feel Mom’s eyes burning into the side of my skull. I resisted shaking my head and added, “Thanks for asking.”

Jen gave me an apologetic nod. Then she turned to Mom and started a conversation about what type of pool cleaner we use. I hated the pity, the sad looks, the polite but intrusive questions about the tube in my arm. With school only two days away, I dreaded tomorrow’s doctor visit. If he said it was time to pull the IV, I could go, if not, I’d be stuck another year at home. At least the loneliness of homeschooling helped me avoid more pity from inquiring mothers, teachers, and faculty.

I noticed Mom and Jen glance at me. Mom didn’t look away fast enough. Jen’s gaze lingered and her voice carried on the breeze.

"I wouldn’t be comfortable sending my child to school with those allergies either. I just feel so bad for you two. Must be tough being isolated in this house all the time.”

My mouth twitched. I shut my eyes as if that would block hearing more from the conversation.
“I don’t think she’ll be going to school this year.” Mom’s voice this time. My eyes shot open and I ran for the open gate in our wooden fence. As I tore through the backyard bits of grass flung up and tickled the backs of my ankles. My bare feet warmed against the concrete sidewalk that took me all the way to Atlantic Middle School.

I stood outside the fence wiping tears with the palm of my hand. Though deserted in the late summer evening, the school looked as bright and lively as ever. Even the chipped paint gave a beautiful worn and well-loved look about the place. I could almost hear the shouts and laughter as people played capture the flag on the green field or talked in circled groups about what they did over the weekend. It was perfect.

The tape on the stupid IV tugged at my arm as I reached to wipe my nose. My ticket into that red brick building, the blacktop court, the green field, was the absence of the IV. I looked down at the tube.

Butterflies fluttered in my stomach. I pulled at the edge of the tape holding the tube in place. The butterflies seemed to panic and rush to my heart as it pounded and leaped around inside me. In one smooth move I ripped the tape from my skin and clutched the tube. The thumping in my chest tried to warn me but I didn’t listen. I dragged the tube from the hole in my arm until it popped all the way out. Blood oozed gently from the opening. I placed my palm over the hole and walked home.

Before rounding the corner into my neighborhood, I glanced over my shoulder at Atlantic Middle School one more time.

I pushed through the gate on our wooden fence and trudged back into the yard. Everyone had left. Mom shoved plastic utensils and used napkins in a trash bag. She looked up as I stepped close. Her eyes widened and nearly popped out of her head before she gasped. I hung my head. Mom said nothing. There was no need. Instead, she placed an arm around my shoulders and led me inside the sliding glass door. Dad stopped wiping down the counters under Mom’s instructions. He fetched alcohol swabs and a Band-Aid.

“I’m sorry,” I finally spoke.

“You only had one more dose of the antibiotics. This isn’t good, Lily. But we’ll make it work. I’m glad we have an appointment tomorrow.” Mom swiped the sterilized swab across my wound. She gently pressed the sticky parts of the Band-Aid down on either side of the hole then patted my wrist.

“I guess you’ll never let me go to school now, huh?” I couldn’t look her in the eye.

“Is that why you did this? But the nurse always removes them. You knew they’d likely take it out tomorrow. Why pull it out yourself?”

“Because I hate it!” My eyes stung again. Tears threatened to spill down my cheeks but I straightened my back and lifted my chin up refusing to give in.

“I know—”

“No. I’m not talking about the IV. I’m talking about being stuck home. I want to go to school. I want to hang out with my friends and have homework and recess and drama.”

“Okay,” Mom stood from her crouched position. “You’ve been watching too much TV.”

“Mom . . .”

“I’m sorry, Lily.” she folded her arms. “I’m not holding you back. It’s your choice to go to school. I just want you to think about it very carefully. You seem to have this idea that it will be perfect.”

I stood up. If I stretched my feet I’d be as tall as her. Mom uncrossed her arms and pulled me into a hug. My arms dangling for a moment before I responded with a squeeze.

“I know it won’t be perfect. But I want to try it. I have to at least try.”

“Of course. Just remember—”

“I know, I know,” I said interrupting her before she said her favorite phrase. “The grass isn’t always greener on the other side.”

*     *     *

With my backpack hanging off one shoulder and a water bottle in one hand, I walked across the field. Following the blacktop would be a shorter route to the playground area but it seemed the popular thing to do to spread out on the field. The ground crunched with each step. I looked down to see the grass wilted and dry in most spots. Patches spread across the field with some areas greener and softer than others.

“Can I ask you a question?” A girl stepped up to me. She had a gang of friends surrounding her. They all stared at me. I expected nothing less, being the new girl and all.

“Sure.” I shrugged.

“Are you the sick girl?”

“Are you the sick girl?”

“What?”

“My mom wanted to bring treats for the class since it’s the first day of school. But our teacher said no because we have to be sensitive to your sickness, or something.”
“Oh.” My eyes dropped to the grass again.

“It’s cool,” she said. “It makes you all mysterious.”

“It’s not cool. And I don’t even have those types of allergies.” I shook my head then shrugged my shoulders again. “But thanks.”

“You should hang out with us. Want to play a prank on our teacher?”

“I don’t know.” I would have shrugged again if my backpack hadn’t slid off my shoulder. I grabbed the strap and yanked it back up.

“Oh come on,” she whipped rosy hair away from her face. “Let’s trick her into thinking that you’re sick from something you ate during break.”

“That sounds kind of mean,” I muttered. I wanted to say it louder but couldn’t bring myself to defy this girl. She brought too many new options for new friends to turn away. They smiled and seemed nice enough.

I rolled my eyes to one side as though I were thinking about their proposition. Instead, I stared at the grass. The dry blades bent over against the breeze. They stood tall again and stretched their golden tips out when the wind gave way. Even though they lost their brilliant green color, the blades looked lovely, like they captured the afternoon sun and held its golden warmth to brighten the world.

I knew I needed to decide now. School would be different. I had a lot to learn. A loud alarming horn sounded.

“So, prank?” She asked.

“I don’t think so,” I said. “I pulled an IV out of my own arm two days ago.” The girls gasped. “I’m all pranked out.”

“That’s crazy!”

“Is that like a needle?”

“You’re brave, I could never do that.”

They followed me with curious questions and laughter. Not one of them pitied me. I picked a blade of grass and twirled it in my finger. I decided to like it, golden brown and all.♦

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**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

Email submissions to kaleidoscope@udsakron.org or online at kaleidoscopeonline.org.
“On the day that you were born,” Mom said, “your dad nicknamed you Peacock. Your hair stood straight up. Because of your two cowlicks.” She swirled her fingers, pointing to the crown of my head.

With my hair, it’s always been feast or feathers.

“It’s shiny, at least,” a mom of my elementary-school friend said cheerily one morning when we were getting ready for church. “Even if you can’t smooth it down.”

I remember in small-kid years how I’d have to move it to the side when I wanted to sit, how much length there was to yank, how my hair would knock the teeth right out of wide-toothed combs silly enough to step to raggedy knots that huddled at the base of my head like villains. I remember the dreaded ends.

“So much nicer than my limp white-people stuff,” Mom said when she’d tease a ponytail for me before school, hair-spraying a helmet to wrangle my baby hairs down.

I cut it all off in the fourth grade. One thick braid forgotten in a Ziplock. I traded in hair the length of my back for a bob and an undercut. Things I wanted for my Southern California ’80s-baby flannels. Things that were unfortunate for my braces and the neck gear that was supposed to correct my overbite. I wore that neck gear all day to our primarily white grammar school, even though I was only required to wear it at night. I dared somebody to tease the neck-gear-rocking brown kid. I would stand in front of my sister’s full-length bedroom mirror with the rubber straps secured at the nape of my neck, cradling the stubble of my fresh undercut, and practice saying, “Whatever! Racists!” the S’s hung up on the wires sticking out of my mouth.

I remember the anticipation of going to school the next day, of wondering what Jordan or David or Kyle—my sometimes crushes—would say, if maybe I’d be seen in a new way. I was the Indian girl nobody ever had a crush on. It was an unspoken (racist + heteronormative) truth that brown girls went with brown boys, and for most of elementary, there was no brown boy in our class to heart me back. But maybe my new hair would change that?

I was climbing the last of our grammar-school stairs when Jordan exclaimed, “You cut off your hair!” My heart knocked in my throat with preteen anticipation. Of being seen, but in a good way this time, maybe. “I liked it better longer,” he said.

I found that braid so many years later, in the back drawer of one of grandpa’s captain’s beds. I reveled at the weight of that hair’s thick foot. Its optimism. Its dark brown girlishness. I was in my twenties and had swallowed my heart, deep down my throat. There was 1) a breakup after nearly a decade together, 2) our grandmother passing away after Alzheimer’s, 3) our stepdad passing too, the moment of encircling him for his last labored breaths: Mom’s, Dad’s, our middle sister Maya’s, and my hands held together in the hospital, burned into memory like a picture nobody wanted. It was then that my hair had started falling out in gleaming white patches, the result of what I
would learn was an autoimmune disorder likely triggered by stress and for which there is no cure. Hair that fell with surprising frequency, new, eerily smooth patches arriving and widening like a rip in a stocking all throughout a hot and increasingly sore scalp. Acid drops on silk. And then: the panic to cover up those spots with remaining hairs. Poor inspiration for awkwardly pinned-down bangs that looked stapled to my forehead when I paddled out into the Pacific to surf (despite the fear of wet hair betraying white skin), the reassurance of dry fluffy bobs, low braids I wouldn’t let part, wouldn’t let betray an embarrassingly vacant stage. I worried that I would be bald. That I would have nothing to hide behind. That perhaps like the brownness of my skin, alopecia would be something I’d have to make peace with, try to find pride in, too.

But the little saplings, with their wired, reaching hands, sometimes white, sometimes gray, sometimes black, came back, went, and debuted again. The returning hairs not unlike the shaft of a feather stripped of barbs. Something to smooth down and down.

“Come any color you want,” I told them at night. “Any texture you want. However you want.”

The nest on my head wilded.

In the single years of my early thirties, I learned to enter the water after a quick prayer to the ocean and let my hair get wet and heavy. I worked not to let my fingers drift up like a tick to check spots, to distribute hair.

Once, a young one paddled over to flirt even though the breeze was kissing my scalp. Couldn’t he see? Shouldn’t he have fled? I laughed and laughed.

“The ones who matter won’t care,” my friend Aiko had said.

I heard this but, in the midst of the madness of dating, I was more likely to get completely naked than let a foreign hand loose in my hair, in the dangers where spots lurked. The thought of being with someone who wouldn’t care about my body’s pathologies was too much to imagine.

But then I did fall again, and my love disappeared into a bathroom and emerged with his own head shaved, a surprise reminder of what a myth this hair is.

Now thirty-five, almost thirty-six, I have accepted, finally, that my hair comes and goes like tides. A sudden rush of foamy white on salted scalp. The return of black roots to pray over and promise. The reassuring thickness of filling in that I know, nevertheless, I cannot trust. There will always be bathroom vigils, of parting hair and counting lost strands against dull shower floors. Because the white patches always come back. (Moons dawn and dawn.) But the hair comes back too, wild and nested and full. This feast or feathers. This ravenous scalp. These lessons always in swelling and shedding, of thickening fans, reteaching me who I am along with the hard lesson in the grace of letting go.

The Perfect Grandchild

Nancy Julien Kopp

Dad couldn’t deal with individuals with disabilities. He changed the subject when a child with special needs became the topic of conversation. If you don’t talk about it, you don’t need to recognize children born less than perfect. He never voiced it, but his actions and attitude spoke volumes.

Ironically, I taught a class that included several children with disabilities. Maybe his attitude is what made me so bent on helping these children. My dad didn’t want to hear about them when I came home to visit. He abruptly changed the subject whenever I tried to tell a story about one of them. I hoped he’d see they were no different than any other child. They laughed, they cried, they wished for special things, and they had likes and dislikes.

When our first baby arrived shortly before Thanksgiving of 1966, our anticipation and joy turned to shock, for Julie was born with spina bifida. Along with silver-blond hair, big blue eyes, and skin that shone like satin, she had an open spine and paralysis of her legs, bowel, and bladder. My husband relayed the sad news to both sets of grandparents. The message we received from three of them showed nothing less than hope and acceptance. My dad had nothing to say about his first granddaughter. He visited me in the hospital and pledged his support and love to me for rough times ahead. Sadly, his visit didn’t include a peek into the nursery.

Within days, Julie became a patient of a well-known neurosurgeon at a children’s hospital in Chicago. He closed the opening in her spine and inserted a shunt to drain fluid from her brain. It was so much to endure for one tiny soul. I wasn’t able to stay with Julie, as a difficult delivery, a slow recuperation, and distance kept me at home where I agonized over our separation and spent a great deal of time in prayer.

My mother and I spent our phone calls talking about Julie. I tried to live with hope, but sometimes hope is a fragile entity. Mom’s positive words buoyed me up when I occasionally fell into despair. I spoke to the nurses daily, and we went to visit our little girl every weekend. To us she was perfection.

One night during the second week, my dad called. “I went to see Julie today,” he blurted out before even saying hello. My heart skipped a beat, and I clenched the phone. Dad went on to describe all he’d seen at the hospital, how impressed he’d been, and how beautiful Julie looked. His voice quivered more than once as he talked to me. Tears flowed down my face at the knowledge that my dad was beginning to accept a grandchild with a disability. I knew how hard that visit had been for him.

It was the first of many such visits. Dad worked several blocks from the hospital, and he spent many of his lunch hours walking through the cold, rain, or snow to check on Julie’s progress. His reports to me were descriptive and filled with love for both his daughter and granddaughter. I could detect a little more acceptance on his part with each visit to see her. One evening he called, and I noted excitement and pleasure in his voice as he told in great detail of seeing Julie receive a Christmas doll from a hospital auxiliary volunteer. The woman tied the tiny doll to Julie’s isolette within her line of vision while Dad watched. He described the doll from head to toe as well as the red satin ribbon used to fasten it. They were words I needed to hear since I had not been present, words I came to treasure.

Dad’s visits came to an end in the middle of January when Julie died. Despite our grief, I gave thanks that my dad had come to accept, what to him, was a less than perfect child as part of our family. Her time here was limited, but she taught Dad a lasting lesson, and the bond between my dad and me grew stronger than it had ever been. A loving God worked yet another small miracle using a tiny soul who worked her way into her grandfather’s heart, one short visit at a time.
Judi Calhoun is an author and artist living in New Hampshire. Her work has appeared in Appalachian Journal (Winter/Spring 2019) and Blue Moon Literary & Art Review (May 2018), among others. As an artist, her watercolor and pencil sketches have won multiple awards. She sees herself as “a sparkly small star in an expanding universe finding fulfillment in common threads.”

Doritt Carroll is an attorney and the mother of two grown daughters. She has been nominated for a Pushcart Prize and Best of the Net. She is also the founder of Wicked Woman poetry prize. Her work has appeared in Main Street Rag, Coal City Review, and Poet Lore, among others. She has rheumatoid arthritis and says, “I think my writing focuses on vulnerability . . . . I’d like to think I’m someone who can use her unusual way of seeing the world to connect with others.”

Suzan Christensen is a native Alabamian who now lives in Alaska and says she writes “because the act of writing brings clarity to life.” Having also lived in Georgia and Tennessee, she tends to write about “the people and places in the south,” because it is what she knows best. Her biographical sketch of Eugenie Marx was published in the online database “Women and Social Movements in the United States, 1600-2000.”

McCabe Coolidge is a potter, writer, and a firm believer in paying it forward. He lives in North Carolina and sees writing and working with clay as important parts of his spiritual journey. Now in the last chapter of his life he spends time “giving myself to those nonprofits that are trying to shape our commonwealth toward justice and freedom.” Therefore, he gives his pots away to organizations such as Habitat for Humanity and Urban Farm. His work has appeared in The Sun Magazine and Rattle.

Luigi Coppola teaches and writes in London, England. He is a first-generation immigrant and avid drinker of rum and coke who has been shortlisted for Bridport Prizes, long-listed for Ledbury and National Poetry Competitions, and published in Worple Press’ anthology The Tree Line, Acumen, Iota, and Magma, among others.

Emily Fluke lives in California and is a survivor of congenital heart defects who discovered a love for writing when she was given a blank journal during her recovery from open heart surgery. Her stories have been published in Dragon Soul Press (February 2020), Youth Imagination Magazine (March 2019), and Clarendon House Publications (October 2018).

Maisja Haavisto is a journalist, author, medical writer, and patient activist who lives in The Netherlands. She has had eight novels, six nonfiction books, two poetry collections, and a children’s book published in Finnish. Characters with various disabilities are developed in her fictional stories and most of her writing deals with disability themes, especially chronic illness. Her debut full-length play Marian ilmestykset was produced in 2014.

Justine Johnston Hemmestad is a writer with a master’s degree in English literature. Her essay “Writing” appeared in Chicken Soup for the Soul: Recovering from Traumatic Brain Injuries (June 2014), and her novel Visions of a Dream was published by Turtle Shell Publishing in 2017. Hit by a car when she was nineteen, she says, “Recovering from my brain injury has guided me into a deeper sense of what it means to be human.” She credits writing with helping her brain heal, clarifying her thoughts, and moving her forward.

Wendy Kennar is a writer, proud wife and mother, and former elementary school teacher. Her work has appeared in Chicken Soup for the Soul: It’s Beginning to Look a Lot Like Christmas (October 2019) and Breath and Shadow, among others. She says, “I write for connection, to learn I’m not alone in navigating an unpredictable, chronic medical condition.”

Nancy Julien Kopp lives in the Flint Hills of Kansas and began writing late in life, fulfilling a longtime desire. She has a background in teaching and has a blog where she continues to teach writers. Her work has been published in twenty-three Chicken Soup for the Soul books, other anthologies, newspapers, e-zines and magazines.

Liza Marsala is passionate about poetry and art. She is currently studying English at Massachusetts College of Liberal Arts and says, “Writing is a very grounding activity for me . . . . I think about things just a little differently and poetry is one way I can show people my feelings and my anxiety-related struggles.”

N. T. McQueen is a writer, adjunct English professor, and father of three beautiful girls. He has received two Bzzanella Literary Awards (2011, 2012) and says he writes because, “I can express my heart and beliefs in the most effective way.” He has done humanitarian work in Haiti, Mexico, and Cambodia, with a desire to help others and “provide hope and resources to those who feel forgotten.”

Bryan R. Monte is an anthropologist, writer, and editor. His poetry has appeared in Bay Windows, Friends Journal, Poetry Pacific, South Florida Poetry Journal, and in the anthologies Gathered: Contemporary Quaker Poets, Immigration & Justice For Our Neighbors, and Voices from the Fierce Intangible World.
Melissa Murakami lives in Washington and has a degree in storytelling and visual design from Whitworth University. She is a creator and lifelong learner with a passion for visual storytelling—through words and art. “The power of a written story is the ability for the reader’s imagination to fill in the visual space.” When creating art she says, “I am expressing a piece of me that can’t be shown any other way.”

Sandy Palmer studied graphic design at The University of Akron and is a freelance artist who works with a variety of media. She contributes to Kaleidoscope as the writer of visual artist profiles, having joined the staff as art coordinator in 2002. Palmer is the full-time graphic design specialist at United Disability Services.

B. E. Pengelly is a retired artist, communications manager, forensic document specialist, and business owner who lives in Maryland. Her book of thirty-four fictional short stories, A Little Shiver, was published by Rusty Wheels Media (2018). She describes herself as “an eighty-three-year-old progressive thinker and a believer in the statement, ‘Well behaved women seldom make history,’ by Laurel T. Ulrich.”

C. L. Prater is an early childhood special education teacher and advocate for young children with disabilities. She grew up on the Rosebud Sioux Indian Reservation in South Dakota and says, “My writing often reflects the people, places, and spirituality of this rich cultural ecosystem.” Her work has been published in Mainfest West: Women of the West Literary Anthology (2017) and Voices for Diversity and Social Justice: A Literary Education Anthology (2015).

Amanda M. Robidoux is a student who has always been a creative writer but following a near-drowning accident, resulting in anoxic brain injury, she feels that poetry is the best way to tell her story. She is now blind and uses a wheelchair but loves to read, enjoy nature, and improve her community by collecting goods to donate to those who are less fortunate.

Anjoli Roy is a creative writer, high school English teacher, and cohost of the podcast, “It’s Lit.” She earned a Ph.D. in English from the University of Hawai'i at Manoa and currently lives in Honolulu, Hawai'i. Her essay, “Little Red BMW” published in StoryQuarterly (April 2019) and was the first runner up for their creative nonfiction award. “Tiger, Woman, Eels: A Family History” was published in Cog (2018) and was the winner of their Page-to-Screen Award.

Grace Rubardt is a student at Tufts University and believes that “putting words to thoughts and feelings and experiences can help us understand ourselves and the world a little better.” In her writing she has explored the relationship she has with her own arm, along with odd feelings, since she has a brachial plexus injury to her right shoulder from birth.

Thomas Shea is a technical writer living in San Antonio, Texas, with “a wife, two daughters, chickens, and a number of opinions.” His work has appeared in Cliterature (September 2019), On the Premises (October 2019), and The Poetry Marathon Anthology (August 2019). The poem included in this issue was inspired by a loved one who struggles with chronic, invisible illnesses.

Amanda Grace Shu is a poet, speculative fiction writer, and college student from Massachusetts. Her poetry has appeared in The American Journal of Poetry (January 2020) and Mass Poetry: The Hard Work of Hope (June 2020). She has mild cerebral palsy and chronic fatigue and says, “As a gay, biracial Asian woman, I stand in solidarity with all those protesting racially-motivated police brutality and affirm that Black Lives Matter.”

Jenna Pashley Smith is a writer and poet whose recent work has been featured in The Annals of Internal Medicine, The Texas Poetry Calendar, and others. Professionally curious, a dabbler in all things artistic, she enjoys raising children and chickens in the suburbs of Houston, Texas. Living with rheumatoid arthritis, disability is reflected in her work as “first-person accounts, personifications of pain, and imagined personas who feel misunderstood and misrepresented in the world.”

Michael Timko holds a Ph.D. from the University of Wisconsin and is a retired professor who says, “I write to teach as well as to keep learning.” Two of his published books are Carlyle and Tennyson, published by Palgrave Macmillan (1988) and Innocent Victorian: The Satiric Poetry Arthur Hugh Clough, published by Ohio State Press (1966). He and his wife live in California and he was inspired to write because of his wife’s struggle with her disability.

Britomarte Van Horn lives in North Carolina, is self-employed, and reads more than 250 books per year. She writes about characters with disabilities because, “I think it’s vital to include people beyond the white, straight, cisgender, able-bodied, neurotypical ‘ideal’ that has been featured for so long. Frankly, that ‘ideal’ person is boring. I’ve heard enough about them.”

Suzanne Yuskiw contracted polio when she was five years old, and has written a creative memoir, Becoming Sharon, which focuses on “living a full and productive life in the shadow of polio.” The story published in this issue is an excerpt from her memoir. Her work has appeared in Story Star (2016) and Goodwill Industries International Magazine (1984-1995), a series of articles on international activities.
Kimberly Gerry Tucker, Goddess of Change, 2020, Digital, 7" x 9"

Kimberly Gerry Tucker, Thinking, 2020, Digital, 7" x 9"