

Number 86 Winter/Spring Online 2023



**DISCOVERING UNEXPECTED TRUTHS** 

"Awakening" by Jane Gabriel

"Dating My Doctors" by Stephanie Harper

"Li-Bear-lan" by Judy Lunsford



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



IN REMEMBRANCE...

Marian L. Kindel, past publicity and circulation manager for *Kaleidoscope*, passed away August 16, 2022. During her time on the staff, in the early years, she was an active and encouraging participant in the development of the magazine, and she is missed.



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### AWAKENING

#### JANE GABRIEL

watched dust swirl in the sunlight shining through the sliding glass door; a beautiful Texas day. Wispy white clouds floated across a perfect blue sky. Spring and summer were my favorite seasons, and we had just moved from one to the other. My son was in his room and my daughter, Libby, lay on the couch, headphones on, playing with her phone. I was curious about what she was doing, and because of a parental control program I'd installed that gave me insights into her phone, I knew I could check later.

My own phone rang, loud and echoing through the open family room. It was Libby's therapist calling in for her weekly session. I spoke to her for a few minutes, about the beautiful day, about Libby—the polite chitchat of two utter strangers with nothing in common but our one mutual concern: the mental health of my child. I was grateful for her call. It had been a tough week.

Libby's behavior was spinning out again in a now-typical pattern: increased outbursts and back talk; refusals to participate in the household; deteriorating personal hygiene. Without knowing Libby's medical history, most would see these as typical, hormone-driven behaviors of a thirteen-year-old racing toward adulthood. However, Libby's past three years had included almost two dozen mental health hospitalizations for schizoaffective and bipolar affective disorders, as well as five cases with Child Protective Services to ensure proper treatment. We recognized her current behaviors as

signs of an approaching storm. I shared the latest with the therapist: the fight over chores and bathing a few days earlier, the tension since, and Libby's steady withdrawal from the family since returning home in March from a year and a half in an institution and a foster home.

I walked over and handed my phone to my daughter for her therapy session. We effectively swapped places and devices. Libby left the couch with my phone, running upstairs to my bedroom for some privacy, and without thinking, I took her place on the couch and picked up her phone, which had gone dark.

It was a quiet moment.

Until a chime broke through and I woke from my daze. Libby's screen lit up with a message on an app I'd never heard of or seen before. The message came from someone called Slenderman and read: I can help you.

Curious, I opened it to find out what Libby had asked for help with.

Libby: I want to kill my mom. I think I'll do it in her sleep.

I don't know how long I sat there trying to comprehend the words. I knew them all individually but could make no sense of them when arranged in this order. *Kill? My mom? In her sleep? Help you?* 

My heart pounded in my chest and my ears. My breath whooshed back into my lungs as I scrolled down and found similar messages going back three months, almost to the moment she returned home from her last discharge.

How did Slenderman intend to assist my daughter in killing me? Why did he want to? And, oh yeah, who the *fuck* is Slenderman?

I found exchanges from others as well, faceless strangers encouraging Libby to murder me.

The weight of the betrayal sank into my stomach like a lead ball. Child Protective Services had said she was fine, she was stable. She had fooled us all. The child I'd loved and nurtured and guided and protected and fought for with all my strength wanted to end my life. In my sleep. My mind filled with visions of Libby lying in bed beside me. The countless nights I'd let her sleep next to me, to help her not be afraid at night. To help her feel less alone. And the whole time, she was plotting my murder. Using that subterfuge to get close to me at my most vulnerable moment.

She could have killed me any one of those nights. Why hadn't she? Maybe she chickened out, wielding a knife inches above my throat but unable to slam it down or slide it across. More likely it was her nightly medications that forced her into deep sleep.

I became aware of my son's voice. "Mom, are you okay? Mom, what's wrong?"

I couldn't move. I couldn't speak, my tongue seemed swallowed whole, my words lost in the utter annihilation of what I thought my life to be and who I believed my daughter to be. I wondered if I was asleep now. This horrendous nightmare couldn't be my life, couldn't be real life. The juxtaposition between past and present created a dissonance that kept my breath hitching in and out of my chest.

Then the present rushed forward to fill every space around me. My mind raced, considering options of what to do next. I called my husband from my daughter's phone. We spoke in urgent whispers, seeking each other's guidance through the terror and panic. His voice, warm and calm and soothing, pushed a small amount of the fear aside allowing me to think more clearly. We came up with a plan.

"There's no question. You must admit her," he said. "Take her back to the facility. She is a threat to your safety, to our son's safety."

His words hurt my heart, but they were true—Libby had become dangerous. We'd always known this was a possibility, but I had fooled myself into thinking I was the one person she would never harm because of how much love I showered on her.

I closed my eyes. Ever so slowly, the fear of what this all meant was pushed aside and replaced with all the things that needed to be done. "I'll need to get her to pack a bag. Should I bring our son? He doesn't need to go through this yet again, does he?"

"No, he's old enough to stay alone for a few hours."

"What do I tell him?"

"The truth. Or at least part of it, for now. Otherwise, he'll just be afraid and anxious. I'll talk to him," my husband said, and we hung up.

A feeling of determined control filled me, and I focused on the business at hand, a skill I had learned over years of dealing with Libby's mental health crises. Pack a bag, assemble her meds, bring the phone as evidence for the facility. Food and drink for the trip. My heart still raced but I no longer felt pressed by chaos. Our son's phone rang and he moved away, talking in quiet whispers to his father.

Upstairs, I demanded my phone from Libby, then explained to the counselor I would be admitting Libby again. I hung up the phone and faced my daughter, who looked shocked and confused atop the bed on which she intended to murder me.

"What's going on?" she asked.

"You need to pack a bag. I've seen your phone."

Her face fell and twisted with familiar rage. But there was something new, a hatred I'd never seen before. Her eyes hardened; her face became rigid. Darkness took over her features, twisting them. She couldn't keep quiet, the words tumbling out like some sick waterfall.

"I want to watch you bleed," she said. "I want to slit your face open."

I ignored the horror, the imagined ripping open of my body, the too-real ripping open of my soul.

I listened to Libby describe her desire to cut me, slash my throat, stab me in the heart, mutilate my corpse. Her wish to do the same to my son and her father. How she fantasized about it and planned it out every day, all day.

I focused on packing a bag and then rushed her to the car, keeping my face and reactions neutral, trying to give away none of my terror and overwhelming sorrow. But I couldn't stop myself. I had to know. I heard myself ask the questions, my voice sounding hollow and distant to my ears. Her hatred seemed to fill the car, suffocating me.

"Why?" I asked.

"Because I hate you," said my daughter, my sweet baby.

"Who is Slenderman?"

"He's my friend. He's going to help me."

"When?"

She looked at me. "Soon," she said.

I fought to push down the scream rising in my throat.

At the facility we'd been to so many times before, we went through the screening process, then sat in the waiting room, surrounded by strangers. Libby flitted from one person to the next like a cheery butterfly, engaging in breezy conversations. She watched cartoons and laughed. She looked like any normal, happy teenager. She didn't belong here.

But beneath that happy exterior, in the deep interior of her mind, heart, and soul, was something I had never seen before. Was it evil? Or the deepest and darkest recesses of her mental illnesses? How could anyone tell the difference? How had we lost her?

Had I created a monster? But this was my child! How could I ever think of her in those terms? A million questions with no easy answers. There was no solace in this cold place filled with strangers.

Libby came over to hug me, as if nothing had ever happened. I shied away. Guilt swept in. This was my child, who I was supposed to love unconditionally. Could I love a would-be murderer? Was she capable of the things she talked about? Uncertain of the answers, I knew I couldn't let her hurt our family.

## I fought to push down the scream rising in my throat.

I was frozen in a sterile realm, waiting for someone to beckon us to the world beyond the double doors, where I hoped my daughter would find herself again. Find sanity and reason. Healing. A world I had turned to countless times before to help me navigate Libby's rage and delusions and paranoia and hallucinations.

Memories filled my mind. Looking into my baby girl's eyes for the first time. Watching her play with our puppies. Seeing her run and laugh through bluebonnets in spring. Cuddling in bed together, watching cartoons and movies. Skipping with her at the park and laughing as she came down the slide. A million hugs and kisses before bed. A million I love yous.

I sat in that waiting room, surrounded by people but feeling more alone and lost than ever before. I longed for the reassuring arms of my husband, the warmth of his touch, the security of his love. I needed an anchor, something to ground me amidst the swirling emotions, unanswerable questions, and terrible pain. After three hours of waiting, I went numb and sat staring at the bright white wall ahead of me.

I focused on every blink, and then I began counting them. When I reached one thousand, I started over. Over and over again, visualizing the numbers on the wall. I didn't speak or look at anyone. I barely breathed, trying to find respite from the chaos inside.

When they called Libby's name, instantly I knew I would not pass through those double doors with her. Not this time.

In that moment, I knew our life paths had split forever. I wanted to hesitate but couldn't. Somehow, in those three hours of sitting, I'd made a decision I didn't even realize I was debating.

Libby ran up to me, smiling. I told the nurse it would just be her. Libby's face dropped, confusion written across it. But

she didn't argue or question. Instead, she hugged me and said, "I love you, Mommy."

I wondered if it was true, then hated myself for thinking it.

"I love you, Libby." I meant it. I loved her despite the pain and the terror and the swirling emotions. But I also knew it would be the last time she would hear the words. We were broken beyond repair. I hugged her and made myself let go. I watched her skip into the secure waiting area beyond, oblivious to what the future held. It felt so final.

I sat in my car in the bright sunlight and let the tears fall, my sobs filling the car. I screamed and pounded the steering wheel, raging against it all, not caring who saw me. I closed my eyes and let it all come out, an agony so deep I thought I might rip apart.

After fourteen years of loving Libby and ten years of fighting for her sanity, I knew, with every ounce of my being, I'd lost her to mental illness. When the tears dried and my breath calmed, I put the car in drive and went home. I sat in the driveway, raw and exposed, and watched the sunset.

The apartment door opened, and our son stepped out. I took a deep breath, then another, and watched him walk toward me. He looked so small, as if hunched over, the streetlights turning his red hair a yellow gold. I wondered how I would protect him from a world that had helped twist his sister into his would-be murderer.

He, too, was a victim of her mental illness, second always to a crisis. All family members are, especially children who are forced to experience the constant threat or manifestation of trauma. I rolled the window down. "Hey, sweetie. You okay?"

"I'm okay. Are you?" The worry in his voice pricked my heart. Tears welled but I swallowed them back, trying to be the strong mother he needed.

"I'm not okay, but I will be." I said, as we walked inside.

I learned that would be true. A week after admitting her, we found a seven-inch butcher knife hidden under my bed. Family therapy sessions—the few she would allow—revealed that Libby was determined not to talk about the circumstances that led to her admission. Instead, she used the sessions and phone calls to torture me. She used school computers to cyberbully me on social media through fake accounts, telling me to kill myself and that she hated me. After fifteen months, CPS determined Libby needed permanent care for ongoing psychosis and the state took custody of her until age eighteen. She hates me for reasons I cannot begin to understand but have had to learn to accept.

Some days I wake up and lie in bed, blinking in the early rays of the day, warm and content. Everything is right with the world. My son and husband are in their beds. Libby is in hers, down the hall. Then it all rushes in. The pain and loss. Libby. The reality she's no longer with us. And a new day begins. It turns out, some wounds last forever. But I've grown stronger. I've learned to accept the grief now part of me. •

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JUDITH KRUM

#### On the TIP of My Tongue

Sometimes it is right there, on the tip of my tongue,

And I just can't shove it off the edge.

It hangs there with both hands

Squeezing my taste buds so hard they pop.

But the word won't come out.

All I can say is "You know, that thing that cuts the grass"

Or "that jar with the white spread for sandwiches."

I have come up with some doozies of definitions.

I have my own dictionary,

And it keeps getting bigger and bigger.

Those recalcitrant words can be so noncompliant

That sometimes I have to send them to a time-out.

Like that word for the pain in your side

when you run too hard.

Or the word for the feeling of having been tickled too much.

And the word for the itch in the middle of your back

that you just can't reach.

That word for the word that you cannot dislodge

From the electric misfiring of synapses and sounds.

I often think that somewhere on my tongue

There is a conference of stubborn words talking to each other,

And the lexicon that's used to enhance their deliberations

Would, as they say, make a sailor blush.

Smiling, I continue to search for the word

That says what I mean; you know,

That thing on the end of the hose

where the water comes out

And the place on the cell phone that lists the people you call

And the way that the dog hops around on two legs.

And then, again, maybe there just isn't a word for that.

Maybe sometimes you just have to describe something

The way you see it. Or you just have to make up words

Like Lewis Carroll did in "Jabberwocky."

I think I'd like to gyre in this brillig day

And have a picnic of liverwurst sandwiches

And, you know, those small crispy sour things.

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### REHABBING

#### SHARON HART ADDY

he old farmhouse sat in a neighborhood of more modern homes. It needed siding, windows, and a new roof. Inside, the faded wallpaper had to go, the wood floors need refinishing, everything painted needed sanding and repainting, and the kitchen and the bathroom were from another century. The house was in bad shape, but it appealed to us.

Well, it appealed to me. It reminded me of the house I grew up in, so I saw it as a home. Mike saw it as a challenge, and he needed one. His time in the service left him uncertain and restless, uneasy with sudden noise, unable to sleep all night, and his injuries, though healed, had him questioning his physical ability. Rehabbing the house, doing the physical labor and seeing the results, might be just the thing to soothe him, to help him settle, to bring him back to who he had once been.

We bought the house in January, at the end of first semester, and moved in over a weekend. Everything we had in the apartment fit into the living room, and that's where we left it. Our plan was to live there and spread out as we redid rooms.

On Monday, I left for my new job. Mike waved from the front window as I passed our oversized, metal mailbox. Below it, the green plastic box for the local paper hung, lopsided, on the side of the post. When I returned that afternoon, our names were on the mailbox. Black letters proclaimed: Mike and Lisa Stanford. Mike's handiwork, I was sure of that. My smile grew when I noticed that he'd straightened the green plastic paper box, too. The mailbox was empty, but a square, white envelope sat in the paper box.

Opening the envelope, I expected to see a note card welcoming us to the neighborhood. Instead, I found an unsigned sympathy card. For the longest while, I simply stared at it. Did someone know about Mike's PTSD? Were they sending sympathy because they knew how much work the house needed? Or, was there something the realtor hadn't told us—snakes in the walls, or druggies

using the shed out back as a drop off point? I shuddered and hid the card in my purse so Mike wouldn't see it and get upset.

I found Mike on the back porch. Settled next to him on a lawn chair, we compared days. I described the office and told him about my coworkers. He told me he'd met the mailman, Jeff, and that they'd had a nice long talk.

Remembering the unsigned card, I asked, "What did you talk about?"

Mike got the funny frown he gets when he's being evasive. "Not much."

My stomach churned as I waited for him to say more. Instead, he stood up. "Crock-Pot supper. Hungry?"

He slept rather well that night, but I stayed awake listening for rustling in the walls, or voices out back. In the morning, he woke eager to get busy. I gulped coffee and still felt limp as I left for work. By the end of the week, I'd given up my snake vigil and was pretty

sure the drug runners found another transfer point. Every day, I checked the paper box, but there were no more strange cards.

With each day that passed Mike seemed so much better. By the time tulips popped up along the front porch, he was sleeping through most nights, and his injured arm didn't seem to bother him as much. His voice even had that familiar lilt that told me he was happy with his world. And, it was good to come home from work and find Jeff there, with Mike. The two had become good buddies, swapping stories of their time in the service, doing things together. I met his wife, Judy, and we got along fine, too. Jeff and Judy's kids were grown, so they were free to go out for dinner now and then, or to a show in the city. Through them, and my job, we met others and a quiet social life developed. Life couldn't be better.

Gradually, Mike's hard work made the house habitable. Our living room became a living room and we slept in an actual bedroom on the second floor. We decided the next project should be the antiquated downstairs bathroom. Jeff recommended a plumber who turned out to be an amiable fellow. He was pleased to have Mike lend a hand. As the downstairs fixtures were replaced and a small bedroom upstairs became the bathroom for our master suite, Mike joked about being the plumber's apprentice. I rejoiced that his sense of humor had returned.

Late summer came bringing long, warm days. We bought a grill and picked up fresh corn at a roadside stand, soaked it in salt water, then roasted it in its husks. We loved driv-

ing out to the produce barn on the highway and bringing home vegetables fresh from the fields. When bushels of apples and bunkers of squash appeared, we knew we were running out of good weather. We needed to take on the kitchen if we were going to have it finished before snow flew. On the Saturday that Mike planned to gut it, Jeff showed up to help. I stayed in the living room, out of the way, until sounds of lumber cracking, swearing, dragging noises, and the creak and slam of the kitchen's screen door ceased, telling me the appliances and cabinets were out of the house and on Jeff's truck. Curiosity led me to the kitchen.

The empty room looked strangely forlorn, almost abandoned, with layers of paint outlining the cabinets and appliances, showing the room's color history. For a moment, I leaned against the door jamb and thought about the people who'd lived in the house, the ones who picked the colors—cheery yellow, grass green, royal blue, cherry red, white, then back to yellow, a pale hue this time. I wondered about the women who cooked the meals and washed the dishes at the sink under the window. The thought brought an image from a picture book: an aproned mom with her hands in soapy bubbles with a dark-haired girl about half her size standing on a box drying a plate with a huge cloth towel. The two were smiling at each other.

I blinked to banish the vision and looked for something practical to focus on. The floor needed sweeping. I could do that.

Splintered wood and years of dust littered the bare boards that had been

under the cabinets. Broom in hand, I started at one end of the kitchen and worked toward the back door. Halfway there, where there had been enough cabinet surface to form a work area, a yellowed, curling slip of paper caught my attention. I picked it up by a corner, shook it to remove some of the fine dust, and carried it to the window so I could see what it was. The writing was faint and hard to decipher, but the format suggested it was a recipe, written in a language I didn't know. I imagined how the recipe had been wedged in a crack where the cabinet met the wall so the cook could see it, and at some point slipped down behind the cabinet. Or maybe the paper fell off the counter and was accidently bumped under the cabinet by someone shuffling their feet as they worked there. No matter how the paper got under the cabinet, I had it now. I stared at the faded blue ink and the strange words, once again caught in my vision of the past. This time the little dark-haired girl dropped flour into a bowl while the mom stirred whatever they were making with a wooden

The guys trooped in then, dispelling my imaginings. I held the paper up for them to see. "Look what I found. It must have been caught behind a cabinet." I held it out. "It's not in English."

Mike took the paper, looked it over and passed it to Jeff. Jeff studied it, then said, "It might be German. There's a woman on my route, a few blocks from here who speaks German. She might be able to translate it. Do you mind if I take it to her?"

Of course I said yes. I was curious.

Jeff took the paper with him when he and Mike left on their trip to the dump. That evening, Jeff called to say Greta would like to meet us.

The next afternoon, when Jeff's truck rolled up the drive, we were on the back porch with four glasses and a pitcher of lemonade. He parked his truck, got out and walked up to the house. I waved to the woman in the truck, wondering why she wasn't getting out.

Jeff stopped short of the porch and sent a questioning look at Mike. "Greta's daughter came, too."

Minutes passed. The silent exchange between Jeff and Mike contained a world of conversation. Finally, Jeff told Mike, "She's really excited." He sounded like he was pleading.

Mike glanced at the sky as if he'd find a message there. Finally, he shrugged and nodded, yes.

Jeff turned to me. "Greta and Meemoo are anxious to meet you."

"Meemoo?" I asked.

Jeff grinned. "A nickname from the first time she met a cow. I'll go get them."

I went inside for another glass. When I walked out again, a woman about my age stood next to Jeff. He said, "This is Greta and the silly goose behind me is Diane."

"No!" a giggly voice shouted. "Meemoo!"

Jeff stepped aside. The round face and distinctive eyes of a child with Down syndrome took my breath away. My mind slid back in time, to Janie. When I saw the girl's hair was blond not brown and she was taller than Janie ever grew to be, I could breathe again. As a teacher, I was used to having my kids move on, but not to having them die. She'd been one of "my kids," part of my daily routine for years as she

moved through grade school, and then she was gone. Out of my life forever, injured in a playground accident, falling backwards off a swing, and having everything go wrong even though the ambulance was there in record time and the emergency room personnel rushed to help her. Losing Janie shattered me. I wasn't able to teach, or even go near the school. I mailed in my resignation and Mike went to the school to gather my things from the desk and closet. I couldn't even do that—or spend any time around children.

Mike put his arm around me. I blinked my way back to the present and the blond girl standing in front of me, smiling.

# The round face and distinctive eyes of a child with Down syndrome took my breath away.

Meemoo's smile stretched as she held out an envelope. "Here," she said, "I brought you roses."

I took the card and thanked her. As I opened the envelope, Greta leaned close and whispered, "She doesn't care about the words, just the flowers. When she was little she had trouble saying the letter F, so she started calling all flowers 'roses.' We should have corrected her. but—."

I glanced at Meemoo. I wouldn't have corrected her either. Only a monster would willingly destroy Meemoo's brilliant smile. I couldn't help smiling

Greta continued her whisper, "Thank you for returning the cards she's left in your paper box. She enjoys playing mailman when we ride our bikes." For a few seconds I was puzzled, then remembered the card I found when we first moved in. The sympathy card I hid so Mike wouldn't see it. The only card I had found. I glanced at Mike. He'd been playing along with Meemoo all this time, ever since we moved in, picking up the cards before I got home and hiding them so I wouldn't see them. I nodded at Greta, too overcome with love for Mike to tell her I understood that Meemoo was just playing when she left the cards.

"Oh!" Greta turned to Meemoo. "We left the pie in the truck." To me she said, "The paper you found was a recipe for brown sugar apple pie. We made one for you."

I watched Meemoo run to the car, marveling at her energy and zest, delighting in her exuberance, aware of the happiness spreading through me.

Mike stepped close and put his arm around me. "You okay?"

"Oh, yes. Definitely okay. You?"

"As right as rain on a dry field." He touched my temple with a gentle kiss. "Welcome back, Lisa. I haven't seen you smile like that in a long, long time."

I snuggled against him and let the last of my sorrow drain away. Janie was gone—but there were other children to know and love. As I watched Meemoo march toward us carrying the pie like a crown on a pillow, my heart opened wider. Someday soon, I would think about going back to teaching.

Mike's lips brushed my ear as he whispered, "I knew moving here would be good for you."

Laughter danced inside me. I thought we moved for him. ♦

# How to Load a Wheelchair into a Car

#### MATT FLICK

ou have issues with your legs due to spina bifida.

As you get older, walking has become more difficult and now you use a wheelchair to get around.

Most able-bodied people will consider this terrible news, but not you! You understand all the so-called advantages—better parking, no waiting in lines, people are constantly offering to help you. One factor you didn't consider is that you drive and will have to transport the chair. Dammit!

Here's how the process works. You roll yourself toward your 2008 Subaru parked on a busy street in Midtown Manhattan. Once at your vehicle's passenger side door, you realize you need to be on the driver's side. The *unlock* button on your key fob doesn't function and you have to unlock the doors manually. You glance around to find that you've parked in the middle of a long city block and the accessible curb cut is about four miles away, at the end of the block (it could merely be about fifty feet but you're terrible at estimating distance). So, you roll back to the corner, dodging New Yorkers who are not paying attention because they're too busy avoiding eye contact and tourists who are too busy looking up at the tall buildings. You then propel yourself to the intersection, roll down the cut and push yourself back down the street to the car, hoping to evade being run over by the New York City rush hour traffic, dodging bike messengers and that one skateboarder.

You arrive at your car and unlock the driver's side door. As you open it, the driver of a bright yellow taxi cab leans on his horn to make sure you are fully aware he is about to hit you. He swerves at the last minute narrowly missing your door. You punch the button to open the trunk and slam the door closed.

You must reach the trunk so now you have a decision to make. You can either make a U-turn in your chair, inching a little further into the hectic street, or you can just roll yourself backwards down the street to your rear bumper. With the second option, you won't have to travel farther into the street—you'll just have to blindly roll down 23rd Street for about twenty feet or so, hoping the entire time you don't get hit. You resolve that if you're going to die, you'd rather not see it coming, so you choose the second option.

With your eyes clenched, you push like hell and in a moment you make it to your trunk. Of course, this is New York and space is at a premium. The late model BMW parked behind you is mere inches from your rear bumper, so you wedge yourself and your chair between the two vehicles. You stand up and brace yourself against your car as you disassemble the wheelchair. First, the \$500 gel-filled cushion—which feels no better on your ass than the \$30 Amazon cushion—goes into the trunk. Then the back of the chair

folds down to rest on the vinyl sling seat. Finally, the wheels come off and you arrange them in the car next to the cushion.

Now comes the fun part. The last part to go into the trunk is the biggest, most awkward piece to handle—the aluminum frame. Including the chair and the two cars, you are squeezed between roughly \$100,000 worth of finely-engineered machinery and you don't want to scratch any of it so you ever so carefully pick up the chair frame with one hand while bracing yourself with the other. You feel your legs buckle and your grip loosen. With one brisk motion, you get the slightest corner of the frame onto the lip of the trunk. With the frame's weight supported by the car, you delicately shove the frame the rest of the way into the trunk, being sure to rub the grease-laden axles across your ridiculously expensive cushion, while simultaneously putting the two hundredth scratch into your bumper. You waddle back to the driver's side door. Gripping onto the car like a free-soloing rock climber, digging fingers into any available handhold, your fingertips either numb from the cold or burned off from the heat, depending on the season. The whole time you mentally beat yourself up for buying an all black car. You also reflect about how you will have to repeat the entire process once you get home. Finally, you grip the door handle, only to realize you locked the door with the keys resting on the driver's seat, silently mocking you. ♦

Previously published on Medium.com. Reprinted with permission of the author.

#### DAYLYN CARRIGAN

#### COCHLEA

The seashell inside my ear is balding. The bristles fall out in waves, polluting the fluid of the canal.

But the shell is not broken, it came this way, being flushed out day to day with sound until I wake to find none left.

I do not always mind the thought of this. I have heard more than I should. But I know that I will miss his groggy *Good morning*,

when his voice is deeper, too deep to find its way through the canal and into the last thinning hairs of my tiny seashell.

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# Quicksand

#### **EVELYN ARVEY**

Teattle—Few things are worse than telling your seventeen-year-old daughter and fourteenyear-old son that their father is in the clutches of a disease. I prepared as best I could for the Big Reveal: the Tuesday after William's diagnosis, trying not to notice my shaking hands, I made spaghetti and French bread, everyone's favorite dinner. I served pasta on my wooden platter, a souvenir from last year's trip to the Peruvian jungle, a hand-carved, fanciful thing with toucans and monkeys on the rim. I was finishing my special meatballs with fresh herbs when a mud-slung Nick burst into the kitchen after soccer practice, lifted the lid from the frying pan, snatched the smallest meatball, popped it into his mouth, then turned his grinning face to me, still chewing. "What's the big occasion, Ma?"

Blinking, I turned away to drain the spaghetti noodles.

At the table, William placed a manila envelope beside his plate. I knew its contents all too well: a printed MRI showing lesions on his neck and spine, four cloudy blobs that looked, to me, like miniature time bombs. The kids would have questions, so three days ago William and I had gone to the bookstore, where he chose two books about multiple sclerosis and I tried not to look at a young woman making her painful way down the aisle while clinging white-knuckled to her walker. It was red, a red walker with sparkles embedded in the glossy enamel.

William read the books the next day, filling a page with notes. Getting ready.

"Damn, Emily," he said. His eyes said: *This isn't me*.

"Oh, honey," I said, putting my hand over his. I was in the middle of the second book. "I'm so sorry." My eyes, also, held a message: *I am with you*.

And now, here we were. Tuesday. Dinner. Time for the Big Reveal. Laura slid into the seat next to her father, then reached for a piece of French bread and the butter dish. William didn't tease her about having a little bread with her butter, and Laura didn't come right back

with a zinger about his habit of having a little steak with his salt.

No. He just watched her.

Laura didn't notice her father's quiet new fragility, but I sure did. After only one week I was developing a new sense of William, a new gathering of threads that went from him to me, pulling me toward him, keeping me aware of his every movement and facial expression and inflection of voice. Was this normal, this exquisite tuning-in to an ill spouse?

"Kids. We need to talk," William said. He cleared his throat. "Ever heard of MS?"

"Multiple sclerosis," I added.

"Naw, I don't know anything about it," said Nick after a moment.

"That's, like, what Jane's mother has, I think." Laura set down her bread, then picked it up again. "Yeah. I'm pretty sure that's what she has. Why?"

"Well, I have it," William said.

The kids stared at him.

"MS?" said Laura, her voice thin. "You have MS?"

William nodded. "I was just diagnosed last week." He picked up the MRI file. "You guys are the first to know, other than Mom and me."

Nick glanced sideways at his father. "Dad. That totally sucks."

"Yeah," said Laura. "Really sucks."

The three of them bent over the MRI images. William explained that the myelin lining of his spinal cord was eroding in several spots, which would eventually—*might* eventually, I silently added—lead to damage of the nerves within the cord, which in turn *might* lead to an unknown level of impairment.

"I've been diagnosed with primary progressive MS," he told them. "It's the most aggressive kind. There's no cure. The only treatments are for the other kind of MS." He took a deep breath. "I won the lottery, guys. Men like me in their late fifties aren't supposed to get MS. It's usually a young woman's disease."

Right, I thought, but it happened anyway.

I pushed my plate away. How was it the kids seemed so calm? I leaned back in my chair, picking at a tomato sauce spot on my jeans as William explained how balance was one of the first things to be compromised, told the kids there was a slightly higher chance they might develop MS because they had a parent with it. I held my breath, looking from William to Laura, to Nick, then back again. The kids had to have known something. You couldn't live in the same house with him and not notice things: the strange hitch in his gait; how he tired too quickly during outdoor activities; how he fell apart in higher temperatures; the way he gripped the back of a chair when standing up. All symptoms of MS, although we hadn't known. Had the kids thought their father was accident-prone all this time?

And there was Peru. We'd all known something was going on in Peru.

Four days later, I heard low voices wafting from our bedroom. I peeked in to find Laura sprawled long-legged on the day chair. She'd dragged it across the room to where William still lay in bed. Their heads were close, their voices solemn. "Daddy, does it hurt?" I heard her ask as I crept downstairs to the kitchen, leaving them be.

After Nick's soccer practice, I heard William's car drive up and park in front of our house. When they didn't come in, I pulled aside the front curtain: there they were, still sitting in the fogged-up car. All I could see of them were the dark blobs of their heads and occasional flashes of Nick's blue jersey. They stayed there, in a cocoon of their own making, for over an hour.

That evening, William set aside in the corner of our bedroom his prized possession from our trip to the Amazon jungle—a walking stick with an anaconda head carved on the handle. Sighing, William went on the other Amazon

and ordered his first official mobility device: a folding walking cane with a specialized hand grip.

\* \* \*

Amazon Jungle, Peru—William was tired and out of sorts, which was a shame because this was the last day of our Amazon jungle adventure. He was exhausted. We'd been in this no-electricity, no-running-water research lodge on a tributary of the Amazon River for almost a week and we'd barely had a chance to rest.

Everyone agreed it had been stunning. We'd gone on crack-of-dawn trips in wooden canoes to look for birds with our guide, Ruben, a charming young man with a gap between his front teeth. He'd taken us through the jungle in search of monkeys, poison dart frogs and medicinal plants. Nick and Laura had even played *futbol* with young men from a local village. *Local*, meaning half an hour down the river in a canoe; *village*, meaning ten palm-thatched stilted huts loosely arranged around a grassy field.

William managed to pull himself together for one last excursion.

"This walk, it is not difficult," Ruben insisted as we gathered on the split-plank deck. "We will visit a beautiful, how do you say? Cascada? Fall of water? You will like it very much, I promise you."

"Waterfall, dude," said Nick.

"I want to see a waterfall," said Laura.

I swatted a mosquito. Already it was make-me-into-a-dripping-mess hot out, and we'd only just finished breakfast. "How far, Ruben?"

"Not far, Mrs. Emily." Ruben held up his hand, showed me his thumb and finger an inch apart. He thrust a pair of rubber jungle boots at me after tipping them upside down to dislodge creepy-crawlies. "We will swim, and there maybe will be river dolphins." Ruben grinned, handing Laura another pair of mud-flecked boots. "You have swim clothes on?"

She nodded. We all wore our swimsuits under our clothes, adding an additional layer of sweaty itchiness to our heat-and-mosquito-tender skin.

"My boots are too loose," said William, stomping on the deck, making sloppy *clump-clump* sounds. "These are way too big for me, Ruben. Can you find the ones I wore yesterday?"

"I'm sorry, no." Ruben explained that another guest had taken them. "Don't worry. These will be okay. See? My boots, they are big also." He grinned. "Okay? We will leave now?"

"They're too big," William muttered.

I wiggled my toes in my own generously-sized boots, my eyes following flickers of brilliant yellow in the trees: was it a parakeet that darted, flitted, and chattered just out of sight? Or was it a golden-tailed, black-bodied oropendola? Birds were my favorite part of the jungle.

Ruben led us to a waiting boat, a metal one this time, shining and sun-hot. The four of us were uncharacteristically quiet as Ruben steered the boat into ever-shallower tributaries with a small outboard motor. I gazed at a dazzling land, violently green: layers of viridian and teal, lime, emerald, and chartreuse, hues I hadn't known existed. Ruben killed the motor every ten minutes and we held our collective breath, waiting as jungle sounds rose around us—whis-

tles, rustles, and mysterious splashes. An hour up the river, Ruben tied the boat to a low branch. He jumped out and hacked at vines with his machete. "Here it is! The trail to the *cascada*."

Some nights I cried myself to sleep, lying next to him in rigid self-imposed silence so as not to disturb him, wishing I could vanquish this thing!

"I'm not sure I can make it up there in these boots." William frowned at the steep, if not very high, slope.

Ruben helped him up the muddy bank. There was an overgrown path leading into the jungle. Ruben slashed invading greenery with his machete, and we followed behind, single file. William walked at the end, picking his way carefully through slippery, muddy ground, over roots and fallen vines. He looked like he wanted to grab the occasional branch as we passed, but he didn't. William grabbed onto me instead.

"I can't keep my balance," he said. "How far is it, Ruben?"

"Not far. First we will cross a little river."

"Cool," said Nick. "We're going to ford a river!"

"A river?" I gasped. "On foot? In flood season?"

"A small river," Ruben insisted. "It is so little it has no name. No problem. You will see."

\* \* \*

Seattle—William's one cane became two canes. His daily naps became fatigue-driven slumbers lasting an hour and a half. He found it harder to dress himself, to bathe, to read the thousand-page biographies he adored, to keep more than two things in his head at once. He no longer coached Nick's soccer team; instead, he and I took walks around the block. He'd loved going to University of Washington football games; now he watched his Huskies on TV.

"What *else*?" he said to me, after a particularly sluggish walk. "What else can I do, Emily?"

I didn't know, I just didn't know.

William was on a mission to do everything and anything that might help: he met regularly with his neurologist and went to physical therapy once a week. He injected himself daily with a drug meant for the other kind of MS. He tried a cleansing diet prescribed by a naturopath. Nothing helped. William was getting worse.

Some nights I cried myself to sleep, lying next to him in rigid self-imposed silence so as not to disturb him, wishing I could *vanquish* this thing!

I was still in denial. Or perhaps I'd moved on to anger. This wasn't supposed to happen to *my husband*! William was twelve years older than me, and retired—but he was still young. We had plans. We were going to see the world, and Peru was supposed to have been only the beginning. We were going to take dance classes. We were going to hike the mountain trails that surrounded Seattle. We were going to take extension classes at the University of Washington. We were going to *enjoy* ourselves.

After our walk, we settled into our recliners. On the far wall was a framed print of the four of us, mugging for the camera, crossing a no-name river in matching teal-colored jungle hats.

For the first time, I thought he looked old. We both did. My life was slowly slipping into his because someone had to be with him, fragile now, all the time. What did the future look like for us? Was I going to be his caregiver one day? I didn't want to be a caregiver. I wanted to be a *wife*.

Beside me, William muted the TV. He turned to me, his timing impeccable. "Emily."

I raised my eyebrows.

"Thank you," he said softly.

When the box from Amazon arrived he opened it, lifted out the plastic-wrapped parts, then threw them back in. "Idiots! They sent the wrong one! Who would want a red walker with *sparkles*?"

\* \* \*

Amazon Jungle, Peru—Ruben and the kids were waiting for us at the river, wide but slow-moving, dark with forest tannins, and swampy. I imagined it harbored piranhas, electric eels, and anacondas, or at the very least, leeches, but Ruben assured us, "It is shallow in this place. In and out. We never lost a guest yet."

Someone had fixed a synthetic green rope from a tree to a jutting stone on the other side. The cord dipped in the center, falling below the water line.

Nick and Laura were already ankledeep in the water.

"Hold the rope and follow me," Ruben said, "Mr. William? Do you wish to rest?"

"Now is fine," said William, watching the kids, frowning slightly. "I guess."

I waded in after Nick, clutching the rope. The water was refreshingly cool, the silty river bed firm and easy to

walk on. Water rose past my calves, my knees, up to mid-thigh, stopping at my waist.

The waterfall leapt over a craggy stone cliff and splashed into a pool, sending spray all the way to where we stood at the end of the trail.

"Take our picture, William," I said over my shoulder. "Can you do that?"

"Already did," he said. "I'll pass the camera forward and ask Ruben to take one of all of us. Here it comes!"
William sounded better.

The best was yet to come. Ruben's waterfall was at the center of a sundappled clearing rimmed with jungle. The waterfall leapt over a craggy stone cliff and splashed into a pool, sending spray all the way to where we stood at the end of the trail.

"What did I tell you?" said Ruben, grinning. "It is worth it, no?"

Nick had already shed his clothes down to his swimming trunks and had his toes in the water. "Can we go in, Ruben? Can we?"

"Only if you wish to have fun!" Ruben shrugged off his T-shirt, tore off his boots, and took three bounding steps into the pool.

"Dude!" said Nick, following him.

"I'm going to sit down," sighed William. "Go ahead and swim with the kids if you want, Emily. I'll take pictures. I'm . . . so . . . hot." Rivulets of sweat carved trails down his temples.

"Dad!" called Laura, "C'mon!"

I didn't like the exhausted grayness of William's face. I lowered my voice, put my hand lightly on his shoulder. "You'll feel better if you go swimming. Just hang out and enjoy the cool water with me. Please?"

A slow smile lit up his face. "Ever kissed under a waterfall?"

\* \* \*

Seattle—My fun-loving husband made a brief appearance for the Great Wheelchair Race. William challenged Jessica, a fellow MS patient with a sporty yellow wheelchair, to a competition in a rarely-used hallway in the physical therapy clinic, but I only found out about it after the fact when I picked him up from his appointment.

"I blew her *away*." William's face showed more color than it had in weeks as he executed a slick transfer from his wheelchair to the driver's seat. He still drove our car using the hand controls we had installed. "You would have loved seeing us fly down that hallway, Emily. We started out even . . . then Jennifer pulled ahead."

"Oh, no."

"But she started laughing so hard she lost momentum and I sprinted past her. She didn't stand a chance."

"You won?"

"I won."

"I wish I'd been there," I said, laughing. "You always pull through at the last moment. Remember Peru?"

He lifted his legs into the car, using his hands. He didn't answer.

\* \* \*

Amazon Jungle, Peru—Too soon it was time to leave our private paradise. The five of us dried off, tugged clothes onto our still-slightly-damp bodies, then left forever that lovely clearing

with the waterfall and its sweet memories of spray-blasted kisses.

William picked his way along the trail, heavy step after heavy step, me lending a shoulder or an arm. After a while, the kids asked if they might go on ahead with Ruben.

"Fine," sighed William. "Go ahead. I'm slowing everyone down."

After they disappeared from view, I wished we'd asked them to wait. Instead, William and I picked our way alone along the trail.

William's legs weren't in sync with the rest of his body as he lurched and wavered his way, complaining about his feet sloshing and sliding in those wretched boots—but I thought it must be, it *had* to be—something more.

Malaria? Surely not. We were taking pills for that.

Yellow fever? No way. We'd been vaccinated.

"We should have asked Ruben to cut you a walking stick," I said, peering up the trail, but there was no sign of Ruben or the kids.

And then it got worse. When we finally made it to the river crossing, the rope was gone.

\* \* \*

Seattle—William fell in the night: his legs gave out on his way back from visiting the portable commode we'd set up in our bedroom. We'd thought he only needed his wheelchair for longer distances. We'd been sure he could manage inside the house with his walker.

Keeping up with William's disease was a moving target: once we got used to a level of disability, William would get worse and we'd be forced to readjust everything we'd been doing. Those time bombs on William's spinal cord had come of age—he'd recently had

another MRI—and they were now detonating. Damaged myelin and frayed nerve axons were disrupting signals from his brain to his limbs. William was sinking into his illness, sometimes quickly, sometimes slowly.

The crash in the night—and his shriek—woke me. "William? William?"

Nick called from the other room. "Dad?"

"Help!" William gasped from somewhere he shouldn't have been. "Help!"

"Are you okay?" I jumped out of bed, flicked on the light, and knelt by him on the floor. He lay sprawled and twisted, one leg under our bed, his head inches from the corner of the dresser. "Did you hit your head? Honey? How's your neck? Did you break anything?"

"No. Help me up." His voice sounded frail.

I sensed Nick hovering in the doorway. "Can you pick up the walker?" I asked. "Straighten Dad's legs too. Gently, now." I turned to William. "I need to know if you hit your head."

"No! I didn't!" William struggled to sit up, then he leaned against the bed. "Damn it, Emily, I can't even take a piss on my own."

He wasn't injured, except for a tennisball sized bruise on his hip and an aching shoulder, but getting William back in bed wasn't easy. We did it in stages: I buckled the gait belt around William's middle. Nick and I hauled on it as William heaved himself to his knees, flopped onto the bed on his stomach and lay panting as we swung his legs up and around.

There has to be a better way to do this, I thought, but what it is, I have no idea.

This was the future we were so frightened of, only two years since his diagnosis. What would the next two years look like? The next five?

\* \* \*

*Amazon Jungle, Peru*—We stood by the river, staring in disbelief, wondering where the rope had gone.

"What the hell?" breathed William.

"We're at the right place. See?" I gestured at the oddly-shaped stone to which the rope had been tied. A green frayed remnant dangled from it. Where were the kids?

"The rope must have worked loose after they crossed. Ruben!" William put his hands around his mouth. "Ru-ben!"

We held our breath, but all we heard was the call of an oropendola.

"Laura! Nicky!" I yelled. And then, I saw something. "The rope!" It was about five yards downriver, snaking in the slow current just below the surface of the water, and entirely within reach. "It must still be tied to the tree on the other side. I'll go get it."

# William was sinking into his illness, sometimes quickly, sometimes slowly.

"No, let me," said William.

I stared at the rope, then at him. "But, honey, that doesn't make sense." I flinched as something shrieked in the not-far distance. It would be dusk in a few hours. Hadn't Ruben seen jaguar tracks a few weeks ago? "You're not feeling well. I can do it."

Something jumped in the river. A fish. Nothing but a fish.

But William was on a mission. He handed me his day pack, then picked his way along the bank, barely slipping, to where the rope fluttered a few feet from shore. He peered into the water. "It looks okay. A little siltier here than where we crossed. Muddy." He leaned over. "I think there's a layer of dead leaves on the bottom. The water's dark. It's hard to see."

"Be careful. You don't know what's hiding in that mess."

He took a step so squishy I could hear it from where I stood. He paused. "Wow. The mud is kind of deep here. It's . . . um . . . sucking at my boots." Holding his arms out, with a grunt, he lifted his foot—his boot muddy past the ankle—and took another step, this time into the water. "See? I can almost reach the rope." He took another step, then reached into the water. "Not yet. It's moving away." Calf-deep in water, he freed his boot from the mud and took another step.

Where did he get the energy for this? Five minutes ago, he'd barely been able to walk. "William! Come back. Ruben said there were bad areas here. We'll cross without the rope."

"Ugh. This mud, it stinks. In a second, honey. I've almost got it now." He pulled at his right leg with his hands. William's boot tops were out of sight now. He strained mightily and moved his right foot about six inches, but in the meantime his left leg sunk way too far into the mud. It made him lopsided; at any moment he would fall. He wind-milled his arms and looked wild-eyed at me over his shoulder. "Emily? Emily? I think I'm stuck."

"I'm coming! I'll help you."

"No!"

I stopped short at the panic in his voice.

"If you come over here, you'll get stuck too." He stopped thrashing, wet up to his waist. He was right, but how could I stand there and watch him sink into an Amazonian river?

"I'm coming." I looked wildly around. "I'll—I'll snap off a tree limb! I'll get you something to grab onto!"

"Wait," he said, catching his breath. "Not yet. I have an idea. Just watch."

# He windmilled his arms and looked wild-eyed at me over his shoulder. "Emily? Emily? I think I'm stuck."

William seemed to relax. As soon as the silt and mud settled, he allowed himself to slump into the water, sitting down on the muddy surface, treading water gently with his arms. In a single long graceful move, he extended his upper body and lay down on his stomach, pike position, his legs still buried in the grasping mud.

"William! What are you doing?"

"Wait," he said calmly, his face tight with concentration. "Watch."

I clutched a nearby tree as he lay on the water. And then I noticed something: he was wriggling and pulling his legs and body and, little by little, he was freeing himself. First one boot broke the surface of the water, and then the other. He squirmed on his belly toward me, half swimming, half mud-skating. I leaned over. He took my hand, rising to his knees, then his feet. Dripping globs of foul-smelling mud, he staggered into my arms.

"William! How did you know?"

He grinned. "I saw it on a survival show about quicksand. The trick was to go from vertical to horizontal. It actually worked." "You were amazing." I smoothed his hair and rubbed mud from his cheek. "But that wasn't quicksand. That was quick-mud. You almost drowned in quick-mud."

And then the two of us were laughing. Holding on to each other, without the rope, we slipped and slid and squished our way back to the river crossing. We were debating whether to cross on our own when Nick, Ruben, and Laura appeared, waving and hollering. A moment later Ruben was splashing his way across the river toward us, pulling the green rope through his hands. He secured it to the rock so Nick and Laura could cross, too.

William sat on the stone for a well-deserved rest, telling his story to an enthralled audience. Ruben listened, his face abashed, horrified, admiring in turn. "Wait one moment, please," he said shyly when William finished, "I wish to make something for you."

Ruben walked back to where William had been mired in the mud, where the river bed still churned angrily. With three mighty whacks of his machete, he cut down the sapling I'd clung to. He trimmed its branches, smoothed the pole with a straight-edged stone, and, with quick flicks of his pocket knife, whittled an anaconda head on its top.

With a formal bow, he presented it to William. "A walking stick, with my apologies, sir." He took a breath. "I should not have left you. It was a terrible decision, but Laura was stung many times by fire ants, and she had pain. I went to my boat for medicine for her." Ruben was contrite. "I did not know the rope was broken. I thought we would make it back in time."

"It's okay, don't worry about it." William took the walking stick, hefted it, balanced it on his palm. "It's beautiful," he said, looking up at the young Peruvian who'd spent the past week with our family, helping us, showing us his world. "Thank you, Ruben." William's eyes were wet. "This will

help me on the way back. I'll treasure it always."

\* \* \*

**Seattle**—William depended on that walking stick more and more during the year to come, as he began his slide into the disease men William's age weren't supposed to get. Three and a half years later, he could barely stand, much less walk. I would lie awake in bed for hours after William fell asleep, tormenting myself with what-if scenarios from our as yet unknowable future: he was pretty disabled now-how bad would it get? Would he need a power wheelchair? What if he became so disabled I couldn't take care of him by myself? How would we afford it all? How would I deal with everything all by myself?

One morning, as the room filled with dim gray light, William stirred. He rolled over onto his back. He stared at the ceiling for a long while, then turned to me. "I've been thinking," he said, his voice low, serious, fragile-sounding.

"Yeah? Me too. What about, honey?"

"That walking stick."

"Oh?" I glanced to where it was propped, gathering dust in the corner. "What about it?"

"I'm glad we went there. I'm glad we met Ruben." He paused. "And I'm glad we have all those memories. Good memories."

"Yeah," I said. I took his hand. It got lighter in the room, and the details on the anaconda head came into view, the blunt nose, the depressed eyes, the sinuous neck.

"It's more than just good memories, though," William said ten minutes later. "The stick could be a symbol of struggle, of overcoming shit that life throws at us. Overcoming some of it, anyway. We ought to display it somewhere downstairs, as a reminder."

Something relaxed inside me. I nod-ded, squeezed his hand, thought about how nice the stick would look if we hung it horizontally on hooks under the framed picture between our easy chairs in the family room. William was right: we needed to be reminded that he—and I—were stronger than we gave ourselves credit for. He'd gotten mired in quick-mud and then freed himself. He'd trekked through that sweltering jungle on slippery trails with compromised balance, and made it back safely.

Like that journey through the Amazon, the future wouldn't be easy. He would falter; I would give him a shoulder to lean on. He would stumble; I would help him up. He would grow ever more disabled; I would be unable to do a damn thing about it. We would, both of us, be stung by fire ants, get stuck with too-big boots, and be forced to navigate unfamiliar territory.

William would sink into stinking mud. He would struggle to pull himself out, again and again.

It might not be pretty. But if we looked for them, there might be waterfalls along the way. ◆

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### AT SEA

#### FAY L. LOOMIS

tsunami of images and information began to saturate my brain last winter. Scary protective gear, intubated elders in over-crowded hospitals, and spiking statistics of the infected and the dead pounded my senses. Mixed messages on how to cope added to my anxiety and feelings of helplessness. I learned that at age eighty-three, with a history of a heart attack and stroke, I was at high risk for a visit from the Grim Reaper. I began to drown in waves of fear.

The virus stormed on, and I had to sort out what was within my control. I shifted my source of information from TV to online where I could limit news and images. My nerves began to settle down.

When Jeremy came to plow my driveway and shovel my back walk, I asked him to hollow out a space from the two-foot swell of snow on the deck to hold a chair. No longer able to take walks after a stroke three years ago, I needed to break through my confines, be embraced by nature. The brisk air, sun, and snowy quiet had a calming and nurturing effect; the deck felt like a solid port in a sea of chaos.

I was disappointed that my longtime writers' group was on hiatus, took the plunge, and accepted an invitation to join an online workshop. The friendly poets spurred me on and helped fill the loneliness gap. I hunkered down and wrote like I never have before. Wave after wave of acceptances flowed in. I felt anchored, my mind less adrift. I started to believe I was going to make it safely to shore.

## FIGHTING THE PANIC

#### DAWN RACHEL CARRINGTON

hen the world closes in around me and darkness wraps me in its inky fingers, I don't want to be the center of attention. I need space. Time. To breathe. To focus. To remember that this is momentary panic. It will pass.

Unfortunately, panic attacks don't arrive at times that are convenient. They sneak up on me like a bill I don't expect, demanding something I don't have to give. In my car, at work, in a doctor's office, or out to dinner with friends, I can feel the tension start in the back of my neck. My heart starts to race, and then I'm outside my body, watching the world unfold around me. I'm on the outside looking in. A kid standing outside the candy store watching the neighborhood kids buying chocolate I can't have.

During normal conversation, when I'm laughing, or reading a good book, my hands will start to tingle. And I know another one has arrived. Fighting it serves no purpose because it always wins. For a few seconds or even minutes, the panic will overtake me, and I can't move. So I sit, waiting for the familiar tightness to wane, and then I cry because I don't know when the next one will come.

"Just get over it."

"Don't think about it."

"What do you have to panic about?"

Friends offer solutions or ask questions I can't answer because I don't know why I panic. How can I walk down the street with the wind in my hair and a smile on my face one moment and be besieged by a crippling, unknown demon the next? So I nod and tell them I'm trying to get over it, I try not to think about it, and I don't know what I have to panic about. It's simpler than trying to explain this beast that resides within me.

Alone at night, I force myself to stay busy, hoping I can keep the panic at bay. The darkness is the hardest, so I stay awake long into the night until I'm sure other people are getting up to start their day. Maybe it's knowing lives are being lived outside my door that offers a level of comfort. There's someone awake to call.

Anxiety is my constant companion, a disorder that brings these attacks at random periods throughout my life, debilitating, and disabling. I can't set a timer or prepare myself for the onslaught because there is no warning or schedule.

Days can go by where this insidious monster doesn't rear its ugly head, and I'm lulled into a sense of complacency. Maybe, just maybe, I've endured my last one. It's possible. I have talked to people who no longer suffer from panic attacks, and I can't help thinking that one day, that will be me. But as soon as comfort sets in, the right hook hits me. Once again, I'm felled by the intense chest pain and clammy hands.

In the grip of panic, I'm helpless, completely at the mercy of my body's overreaction to absolutely nothing. There's no stranger approaching me with a knife in his hand, no tornado looming on the horizon. My fight or flight response shouldn't be activated. Yet, my mind tells me otherwise.

I've often wondered if I panic because my body knows something I don't, like maybe there is a reason to be scared. Is there something or someone around the corner just waiting for me to relax my guard? Is the knot in my stomach necessary? I've even tried to make something good out of the misery, like perhaps these attacks will one day save my life. But then, knowing how incapacitated I am in the midst of the storm. I realize how ludicrous that is.

What could I possibly do to save myself if the panic served a purpose? I'm frozen, encased in this veil of fear that robs me of voice, logic, and calm. Though my friends reach out to me, I feel nothing but the cold tendrils of fear invading my veins.

Two minutes. Five minutes. Seven minutes. I'm forced to watch the clock, counting the minutes until the pressure begins to ease, until the narrow vortex I'm trapped in opens. And I can catch a glimpse of sunlight again. At the ten minute mark, terror crashes the party.

What if this isn't panic? Could it really be a heart attack? Everyone's watching me now, but I have to get up, get outside. Breathe. Fifteen minutes in, my friends have called an ambulance. They don't know what else to do, and I can't tell them whether or not I'm dying.

The panic has crushed me. Once again, I find myself inside the emergency room, being reassured. My heart is fine. My blood pressure is normal. As I lie there on the gurney behind a striped curtain, I give in to the tears I've been holding at bay because, at that moment, I hate my life. I hate battling this invisible demon, and I'm not sure I can do it anymore.

I'm released from the hospital and told to follow up with my psychiatrist. And the merry-go-round starts all over. For a while, I can face the attacks because I know there's nothing wrong with me. It's just a dragon I cannot slay, but as time passes, and the panic grows stronger, more intense, I'm trapped in the darkness again, searching for light.

Breathe in. Breathe out. Focus on something other than my racing heart. Listen to music. Dance. Write. Draw. I've tried the suggestions, have even become hopeful when a week has gone by without a visit from this monster. But panic attacks aren't easy to tame. They tighten around me like a tourniquet, cutting off all logical thought, and no matter how much I fight, desperately claw for air, I'm at the mercy of the mind that's betraying me. And during the worst of the attack, it can still convince me I'm not going to survive.

# VELÁZQUEZ'S WORKSHOP

#### CAROL ZAPATA-WHELAN

Te moved through brick tunnels in the Alcázar with lighted torches that stretched our shadows. Tadeo's limp was worse. And his wild black hair had reached his shoulders since the accident. If a time ever came, I thought, when we must flee Spain, would my little brother keep up?

Since his mishap, which began as a prank, Tadeo moved stiffly, like an old man, not the fourteen-year-old he was. Tadeo and his friends, pages all, in gray doublets, had galloped into the Alcázar, past the gilded thrones, over Moorish rugs, their Majesties receiving the Duke, don Julio, back from Mexico's mines with silver trays and clay búcaros (jugs).

On the Liars' Walk the rumor was the King laughed at the galloping pages. He still loved pranks. But then Tadeo's horse, Excalibur, reared, throwing my brother to the flagstones, toppling silver trays. Phillip IV, wooden, dismissed my brother as palace page.

To make matters worse, our addled father continued to sink us, gambling away our mother's vineyards grape by grape since her disappearance years ago. Whenever I inquired of the future my father would quote: "Our lives are rivers, ending in the sea...."

Saving my family was up to me, Soledad de Zúñiga y Mendoza. I was eighteen and I would soon be too old to

be what I was, a maid of honor, a *menina*, to the Queen of Spain.

A plan was in order.

As we reached our tunnel exit, I smoothed my blue-green satin hoop skirts (matching my eyes) and tugged on my wig (a giant brown hair bowl with jewels). This day our court artist, Diego de Velázquez, was to paint the portrait of five-year-old Princess Margarita.

The Infanta's portrait had inspired my plan:

#1: I had asked Queen Mariana to grant me the honor of attending the Infanta's sitting. The little Princess had high spirits. And low portrait success. If I succeeded, my star would rise.

#2: I had asked Velázquez to discreetly enlist my brother as an assistant. Since his accident and difficulty moving, Tadeo had devoted his time to his art and advanced. If Tadeo helped me, a grateful Queen might convince the King to reinstate him as page. Until then, secret tunnels. #3: I would elicit a marriage proposal from a rich, powerful Spanish nobleman. My choice was dark handsome don Julio, the young Duke, home from running mines in Mexico. No matter if he sparked my breathing fits. No matter if my brother said, "Don Julio is the Devil!"

Since the accident curbed him, Tadeo, ever an artist, sketched on any free surface with a sliver of charcoal. His

handiwork the day of the portrait sitting surprised me at the studio's tunnel door—and made me jump. Tadeo's image of Velázquez on wood—long black locks, keen dark eyes—was so alive it might be a ghost in tunnel shadows.

As Tadeo and I entered the workshop, we found don Diego in our "Spanish black," skeleton key of an *aposentador mayor* on his belt, reading aloud from a folio to his son-in-law, don Bautista: "Our Lady should be painted in the flower of her youth, with fine, solemn eyes, with as much perfection as a human brush can muster." Velázquez removed his ivory-rimmed *quevedos* (glasses). "So writes my own dear teacher, don Francisco."

Bautista, like Velázquez in coloring and stature, began his apprentice work, dabbing greens on a canvas, foliage of el Retiro, Madrid's summer palace. Outdoors, don Diego would capture His Majesty on horseback. This work began in studio to spare fragile colors from the June sun. In his short time assisting, Tadeo had learned this trick among others, saying, "My body is slower, but my eyes are faster."

Deep in the Alcázar, the studio's vaulted ceilings and lofty windows allowed sunlight to stream into the heart of the room. Raphael, Rubens, Titian lined the terra-cotta walls' highest reaches. Under their framed copies was a door to stairs for the Queen's chamberlain. Next to this door hung a Moorish mirror in Peruvian silver.

Don Diego had brought in one of his old paintings, *Adoration of the Magi*: Our Lady, in rose tints, eyes downcast, white veil hiding deep gold hair as the artist's master described. In this Epiphany our Blessed Mother held the miracle of the Infant Jesus swaddled in white weave, protected by Saint Joseph. And before them, the Three Wise Men paid homage to our Savior on behalf of mankind: Baltasar, the African sage, kneeling in his vibrant red cape; Caspar, behind him, silver bearded—and Melchior, genuflecting in colors of the earth. I studied the statue-like profile of Melchior, his strong nose and thick black hair, dark eyes absorbing the Infant's peaceful gaze. My eyes were drawn to this third Wise Man.

"You are Melchior, don Diego!" I marveled. "Bearing the Christ Child a gift on behalf of the future!"

Don Diego smiled modestly—and he said something most unexpected: "If only in that future we were not persecuted on His behalf for distinguishing ourselves. Hebrew, Arabic, English, or Spanish: all tongues are primary colors in God's palette."

These seemed dangerous words when the Holy Office was still jailing converso Jews and Muslims for observing their holy days in secret and Spain was warring, openly or not, with Protestant nations.

I could make no reply. At that moment arrived the Princess, heralded by fellow meninas, Agustina, Isabel, and Maribárbola, in *guardainfantes* (hoop skirts) of jewel colors. They were ushered by our little Italian, Nicolás Pertusato, in his tidy red doublet.

The Infanta Margarita appeared like a small sun in the studio, bringing her own light. She was an exquisite little girl with golden hair, in her white guardainfantes, hands opening like flowers. She did not rush to embrace us, as any other well-loved child might. She knew, even at her young age, that only the select were allowed near her.

And instantly she had us racing the four winds after her silk slippered feet flying up and down the back stairs.

"You are most independent, Highness," said don Diego, mopping his brow, ready to end the session before it began.

"What does 'independent' mean?" The Infanta's eyes danced.

"That you can do many things all by yourself," I offered.

"I cannot juggle," objected the Princess. "Like Ánima." Ánima en Pena—Suffering Soul—was what the King's jester called himself. He was a son of the Earth, with no father to give him a name—and he had the understanding of a child. Along with dexterity, Ánima had the gift of recalling conversations by heart. (On the Liar's Walk they called him a spy.) Velázquez had painted the jester: regal, eyes shining with sadness. Just as our court artist had depicted courtiers such as el Primo, as distinguished for his books as for his small stature, and tiny Maribárbola, peer to the Princess.

The Princess then skipped to a window to hear a dog barking. There was no difference, I decided, between a little empress and a little brother. I sent for the King's mastiff, Amadeo.

But the instant the golden dog arrived, offering paws, hind-legged, the Princess accelerated. And all of us weaving, leaping, bounding; maids and *duennas* (chaperones) lunging—none of us had authority to grasp the Infanta's tiny hands. Nicolasito, arms as windmills, had no better luck.

Don Diego, mopping his brow again, ordered don Bautista to conclude our session.

Tadeo stopped polishing the Moorish mirror and turned to me from across the studio. With the new difficulty in his movements, he made a tight pantomime of a minstrel and mandolin. I understood at once.

Inhaling as deeply as my lungs allowed, I began to sing. Out of my mouth, surprising me, came "Greensleeves"—the English ballad sung by our mother before she vanished on an errand for her Queen.

The song's haunting sharps suspended the Infanta as if in mid-air. She became regal in her stillness. And her look of enchantment erased all ranks as I sang—and singing, I saw relief and gratitude in the faces of maids and dignitaries.

The artist took up his paints; the studio resumed its rhythms. I was congratulating myself, when I heard a deep voice behind me say in English: "Interesting song for a child."

I turned to find the English ambassador's nephew, the *heretic* Sir William Saint James, tall, redheaded, *Protestant*.

It was William Saint James who insolently hoisted me out of our church during my last breathing fit near the Duke. He deposited me on a grassy mound for all Madrid to gawk. Then he turned and fled, having paid a water boy to drown me.

Ruffled, I found myself looking too long at his eyes, the color of olive trees. There was a silence that swelled—until Sir Will decided it was his turn to speak.

"Greensleeves' is about Anne Boleyn, second wife of Henry VIII." This implied my ignorance of history.

Hapless, conniving Anne Boleyn: she stole a King and husband from our Catalina of Aragón. And was beheaded. Quite justly. But at this moment it was all to my mortification.

"Greensleeves' is no nursery rhyme," I conceded primly, turning my back on the heretic Protestant.

Don Diego was clearly generous to allow the English into his studio.

But artists were unpredictable.

Where was the Duke?

# The artist took up his paints; the studio resumed its rhythms.

Don Diego labored at a vast canvas of three stitched panels, standing back now and then, dark eyes abstracted. Tadeo passed him palettes and brushes, stopping to gauge us in the Moorish mirror. With brush strokes true and light, Diego de Velázquez explained life to our eyes.

I began to sing again—this time in Spanish. I chose my grandmother's favorite ballad: St. Peter and St. John on a New World galleon, facing a decision the Devil asked them to make. I found myself glancing involuntarily at William Saint James, still and pale as the marble of Michelangelo's *David*.

All of a sudden, the air in the studio seized, as if a cold wind had visited: Queen and King had suddenly arrived. Don José, the Queen's Chamberlain, was still descending the back steps to announce them. No one saw the monarchs at first: not Agustina, kneeling with a red clay bucaro of water for the Princess or a gossiping duenna by our *guardadamas* (royal guards) or Nicolasito with Amadeo.

King Phillip bowed to us, meninas, our custom, honoring maids first, before we returned his greeting. Menina Isabel, behind the Infanta, was the first to curtsy in reply. The Princess looked to her parents as a child interrupted at play might: without the enthusiasm one would wish.

"Doña Sol, you have done well with our Infanta," said the Queen. Mariana of Austria was paler than usual. She had the fair features and golden hair of her daughter, the same cerulean eyes—if without their light. I noticed how young our Queen looked right alongside the King, who was near the age of my father.

Before I could curtsy in response, Nicolasito roused a tired Amadeo (whose ancestors were sent by England to keep peace). Only when the Infanta asked if she might add a dog



Diego Velázquez, Las Meninas, 1656, oil on canvas, 10' 5" x 9' 1"

to her only palace pets, the *cucarachas* (cockroaches), did the King, ever wooden, put up his hand to mask a smile.

After their Majesties had departed, the Infanta pointed to the Moorish mirror on the back wall.

"Magic!" she pronounced. "They are still here!"

Though the monarchs had retired, the mirror had not released them. There they were, framed in Peruvian silver: the King of blue eyes and long jaw; the Queen, of sad eyes and bejeweled wig.

"Bautista?" Velázquez investigated. "Did you replace the mirror with a portrait?"

Don Bautista had not. Master and apprentice inspected the art in question, perplexed, eyes widening. Then don Diego let loose his resonant laugh.

All turned to discover the Moorish mirror that was no longer a mirror but rather a portrait *mirroring a mirror mirroring monarchs!* 

Awe and laughter rippled through us all—most of all from the ambassador's nephew. "A wondrous prank!" said the redheaded Englishman, William Saint James.

That day my star in court both rose and fell. The future will reveal the reasons.

I can tell you now that when you visit Diego de Velázquez's masterpiece you will see in the painting the artist himself in his Spanish black, the red Cross of Santiago on his breast added after death, signaling he had been knighted. And if you look over the Princess' shoulder, you will find my brother's handiwork in the "mirror" of King and Queen. Tadeo himself painted his "prank" into the canvas. This image made Velázquez the first artist in history to assert equal footing with a King and a Queen by appearing alongside them.

But you will not see me in the first titled *La Familia de Felipe IV*. I was erased by order of the King. For reasons I cannot explain now. So the Duke with the Mexican mines I planned to marry never again took away my breath—nor did I gave him my hand.

After we fled Spain for the New World, my father and I learned of "Stone Man's Disease" wakened by injury, turning my brother's muscles to bone, signaled by large toes *missing* a bone.\* His body continues to slow, most painfully—but his eyes ever sharpen.

It was Tadeo's "right wondrous" works of art that saved fortune and future.

Here, in the open air of the New World my brother paints rivers of olive trees and oceans of vineyards. These, I have planted—and tend and harvest—alongside a man with fiery red hair, the Englishman I love.

And whenever you see Velázquez's gift to the future, unveiled in 1656, later titled *Las Meninas*, you will find the Princess and her court alive as ever. And you may wonder what, exactly, the artist is painting as he stands at the vast canvas with its back to us. I say he was painting what we see before us. And you may feel for a moment that Diego de Velázquez, facing us, pausing with palette at unseen canvas, is painting *you* and all your God given challenges and gifts. •

\*It was a French physician in 1644, Guy Patin, who first diagnosed "Stone Man's Disease," expressing: "A young man came to see me today who had turned entirely to wood." www.ifopa.org

This story is an excerpt from the author's forthcoming novel, Sol & Sarafina & A.I.R., to raise disability awareness.

## LI-BEAR-IAN

JUDY LUNSFORD

It all started in the library.

It always starts in the library.

But this time it was different.

It wasn't a book that triggered all the weirdness, but when I found the necklace in the book about spirit animals, I should have known better.

The library I work at is very different from other libraries. Where I work, the books come to life. I'm not kidding.

We have living, breathing fictional characters that wander around freely inside the building on their designated floors. Dead authors and people from history seem to appear and disappear randomly up on the second floor, where we keep the nonfiction books.

I was checking in some books about astral projection and spirit animals when the necklace slid out of the book. I thought maybe someone had been using it as a bookmark. It is very surprising what people use as bookmarks. So, I set it aside and looked up on the computer who had the book last.

The strange thing was that no one had ever checked the book out. Same for the other books that came in with it. No records of any kind.

I was going to put the necklace in the lost and found, but I got distracted by a patron and had to help them find something for their research paper. I slipped the necklace into my pocket and told myself I would go to the lost and found after dealing with the patron.

I waved to Jane Austen and her main characters, Elizabeth, Catherine, and Marianne as I walked past them. The patron couldn't see them. Not everyone could. In fact, only a select few people could see them.

Rachel, the head librarian, always had a private meeting with those of us who worked here and showed signs of being able to see the strange things that happened. We were not to let on that we could see them. We were not to tell anyone about them. And we were not allowed, under any circumstances, to interact with them.

Some of us ignored that last rule. We thought it was very rude to ignore them, and when ignored, sometimes, they got mischievous. It was honestly better to interact with them. Especially the Austen girls. They had an insatiable curiosity and tended to try to find things out for themselves if they were not kept in the loop.

I rather liked them anyway. The Brontë sisters were pleasant as well. As was Sherlock Holmes, although he was always busy trying to solve mysteries that may or may not exist and was sometimes rather rude about it.

When I finished showing the patron where the books she needed were located, I went back downstairs and was immediately greeted by the Austen girls.

"It's rather quiet today, isn't it?" Elizabeth asked.

"Yes," I nodded. I glanced around to make sure no one was watching.

I put my hands in my pockets and felt the necklace. I pulled it out and showed it to the girls.

"I found this in a book," I said.

I held it up for them to see. It was the first time I really got a good look at the necklace. It was just a thin strand of leather with a green stone dangling from it. Possibly jade, but I wasn't completely sure. I would have to find a book to help me to identify it. The stone was in the shape of a tear drop, beautifully colored (a shade of deep light green), and smooth to the touch.

"Pretty," Marianne squealed.

I looked around to see if anyone else heard her before I remembered that most people couldn't. One of the other clerks did, and he dropped his head down to laugh after we made eye contact. It was Derek. He was extremely hard of hearing, but even he heard Marianne's shrill squeal.

He knew as well as I did that Marianne could sometimes get a bit overzealous.

"Put it on," she urged.

"It's not mine," I said.

"So?" Marianne looked at me with her wide eyes. "Just for a moment, it won't matter. The green would be so pretty with your eyes."

I knew I would never hear the end of it if I didn't, so I slipped the necklace on over my head.

I felt the changes right away. I grew taller and everyone around me looked shorter.

I watched as my hands grew claws and dark brown hair. It didn't hurt. I didn't feel the need to scream or make noise like I'd seen in the movies. It was just interesting.

It was interesting until Marianne started screaming. Then the noise filled my ears and it seemed much louder than it should. Jane and the girls scattered, screaming as they ran through the quiet library. A couple of people here and there looked up and around, like they felt a sudden breeze from nowhere, but then went back to what they were doing.

I turned in time to see Rachel coming up the stairs. Her face said everything—absolute disapproval and horror.

She very carefully approached me and stared into my eyes.

"What book are you from?" she asked.

Derek, the clerk who had been trying not to laugh, came over and looked at Rachel.

"Not from a book," he said, half signing as he talked. "That's Allie."

Rachel eyed me closely.

I lowered myself onto all fours, which suddenly felt more comfortable.

"How on earth did you become a bear?" she asked me.

I tried to speak, but nothing came out but a growl that seemed to startle a few people.

Rachel looked around with dismay.

"Come with me," she instructed.

She headed to the staircase and down to the basement, where the librarians' offices were located.

I followed her, feeling the strange movement of my new body. It felt strangely comfortable but extremely awkward at the same time.

I almost tripped and fell down the stairs as I tried to navigate my large body.

Derek followed closely behind me, apparently too amused to let things unfold without his presence.

I'm not sure how many could see me in my present form. My mind started racing as I remembered the book that held the necklace. It was about spirit animals if I remembered correctly.

So, was the library bringing out some new facet of its magic? I shuddered to think of what else could happen with books that were classified as nonfiction.

Were spirit animals even real?

I followed Rachel to the basement and down the hall to her office. It was a small room with a narrow door, and I wasn't sure I could fit. I sat down in the hallway with Derek standing beside me, a bemused look on his face.

"Now tell me what happened," Rachel turned and looked at me and spoke with a demanding tone.

I growled. She jumped backwards and almost landed on her desk.

I mean, I'm a bear. What did she expect?

She looked at Derek, who looked even more amused at the fact that I scared Rachel.

Derek looked at me.

I tried to remember the sign language that Derek had been teaching me. The best I could manage was, "Necklace in book."

I gestured at my neck, hoping I wouldn't slash my own throat with my newly acquired claws.

Derek reached up and pulled the necklace from around my neck. As it slid off, I could already feel myself returning to normal.

I changed back from a bear to a human and stood there staring at the angry face of my boss.

Derek looked at the necklace thoughtfully and then handed it over to Rachel, who was standing with her hand outstretched to him.

"I found it in a book," I said meekly.

I was seriously glad I still had my clothes on at that moment. Otherwise, hello to nightmares coming true.

"You should know better than to mess with anything you find in a book in this library," she said. "Anything else I should know?"

"The book was on spirit animals," I said. I tried my best to sign for Derek's benefit, but my signing was choppy in the area of vocabulary. But he read my lips to get the gist of it.

"Who had it last?" she asked. "Did you at least look that up?"

"That's the weird thing," I said. "No history of checkout, but it was in the return bin."

"Then this necklace should be locked up, not worn," Rachel said. Her red hair was coming out in a messy splay around her tight bun. The angrier she got; the more hair stuck out. "I will take care of this," she said. "You two need to get back to work."

Derek and I both turned to go back upstairs, he turned at the bottom of the stairs and signed to me.

"You OK?"

I nodded. "Just a little shaken up," I said.

He smiled.

"Your spirit animal is a bear," he grinned at me. "I wonder what mine is."

"No," I shook my head at him.

"Rachel goes home in an hour," he said.

"Seriously?" I asked.

"It's just in her desk," he said.

I shook my head. "Not until after we close."

Derek grinned at me broadly, "Deal."♦

#### THIRTY WORDS

Your speech therapist predicts you will have thirty words in your lifetime, thirty words that your own voice can say, all your other thoughts to be spoken flatly by your iPad, the way you order breakfast from your high chair, tapping the picture boxes we loaded onto your screen.

I. Want. A. Bay-gull. Smoo-thee. Please. I turn from the counter where I'm already spreading your cream cheese, one step ahead. Some things go without saying. Your bagel. My anguish.

Right now at twenty-eight months you have one word and it's my name. You make *Mama* mean *everything*.

I'm awake, come lift me from my crib. Watch me stack alphabet blocks to knock down. Look what I found in the drawer! What is it called? Can we go outside? I see my stroller out the window . . . I'm frustrated, I'm so frustrated. All I want is to climb this ladder like that other kid. Why can't I? Why? I'm hungry. My knee hurts. My diaper is wet. I'm scared of that horse, that dog. Read me the Pied Piper. I want to snuggle Bla-bla. I want my nap, I want to go home, I don't like the wind. And (I am sure of it) I love you, too.

She says in addition to the rest of your body, Cerebral Palsy affects the muscles in your lips, your tongue, even your cheeks are implicated. She uses straws, bubbles, and candles to show me how weak your breath is. She says you might be able to whisper a dozen or so more words, the way you concentrate to purse out a barely perceptible P sound, like a puff of effort, and then another Puh...puh...so if anyone is close enough to lean in, and knows you, they understand that you said Papa.

In my journal, I keep a list of sentences I yearn to hear your real voice say. My name is Leo.
I am proud of myself.
My life is a beautiful adventure.
I stop because that's halfway to thirty already.
I want to leave room for you to tell me something
I couldn't hope for.

Reading your mind helps a lot. We've spent your entire life together. I am terrified of when we can't. The speech therapist recognizes at least your charismatic spirit. Your smile speaks like a beacon of meaning.

## **Perspective**

#### SANDY PALMER



Katherine Klimitas, Ostrich, 2016, watercolors, 6" x 8"

"I made the rule a long time ago that I don't paint anything bigger than me anymore."

- Katherine Klimitas

s an artist, and in life, Katherine Klimitas' perspective is rather unique. At only 2'7" tall, her gaze is upward most of the time. She lays on her side when she paints, a few inches away from the paper. On her side, her perspective is askew. You would think that what she paints would be representative of the way she sees it from her vantage point. Yet, the perspective of her realistic animal portraits is spot on. "Lying on my right side, stabilizing my left hand on my body, is actually the position in which I do most daily activities. Because it's hard on my back and my joints to sit up for a long time, even in my wheelchair, I've adapted to doing most things from a more comfortable lying down position. When you have constant pain, it's hard to get anything done, let alone something that requires a good deal of concentration. I have less pain lying down, so it's just easier for me to work like that." The artist was born with osteogenesis imperfecta (OI) and describes it this way: "My bones break easily and grow abnormally. I use an electric wheelchair for mobility and have an aide with me

most of the time. It affects literally *everything* I do." She experienced 500 breaks by the time she was ten, and at that point, her family stopped counting. Broken bones and pain are just a part of her life. It is all she has ever known. She is a small but mighty, savvy businesswoman who isn't going to let anything stop her. It may sideline her temporarily, but she is resilient. "I was raised not to feel sorry for myself. My mother in particular just wouldn't allow it, which as a child was frustrating, but now I couldn't be more thankful."

Raised in New Orleans, Louisiana, by veterinarian parents, she has been around animals her entire life. Her dad wanted to own all of the types of animals he treated so he could become more familiar with them so, she says, "It was always interesting. We had dogs and cats, of course, but we also had a tarantula, snakes, ferrets, birds, and even a savannah monitor, which is not a pet I recommend." The cats and dogs lived with them at the house but the more unusual creatures were kept at her dad's office. Growing up around animals instilled a love for them within her. In fact, she rarely paints anything other than animals. She might, maybe, if you're really lucky, paint something for you that isn't an animal, but it is a rare occurrence.



Katherine Klimitas, Lexie, 2022, watercolors, 5" x 7"

While her parents did all they could to make sure she was in mainstream classes, being treated like everyone else, there were many activities she couldn't do. Playing outside with the other kids wasn't an option so her mom was always looking for ways to keep her precocious youngster busy. When she was five, she gave her daughter an inexpensive watercolor paint set. It came in a plastic tray with a brush. She dipped her brush into water, onto the little oval cakes of color, and began painting. She found it was something she could easily do. And she liked it! Private art classes and summer art camps followed. By the time she was a teenager, she had explored acrylics, oils, mosaic, jewelry design, glassblowing, printmaking, and the list goes on.

After school and on weekends she was at one vet clinic or the other, enjoyed seeing what went on behind the scenes, and sometimes even watched surgeries. She also passed the time painting animals in the waiting room, much to the delight of the animal lovers who received the paintings when she was done. By the time she was twelve, people were commissioning her to paint their beloved pets. As a preteen she reveled in the attention her work received and the money she earned, especially since none of her friends were making money at that age. Having parents who ran their own

vet clinics, she was privy to what it took to run a successful business and she became an entrepreneur early. Another advantage to having parents with medical training is that it has saved her a lot trips to the emergency room. After countless fractures growing up, she knows the feeling all too well, and her mom, who is a homeopathic veterinarian, began splinting breaks for her instead of taking her to the hospital each time. She can break a bone by simply sneezing so that medical expertise has been a blessing, especially since heavy casting materials that are traditionally used can actually cause additional breaks in her surrounding bones. They learned that the hard way, decades ago, so her mom uses a much more lightweight, flexible material to mend her broken bones.

Another benefit of Mom's veterinary practice is that it brought Robin Pellegrin into their lives. Pellegrin was a client of her mom's, and also a college professor, who began working with the budding artist to help strengthen her drawing skills. "Up to that point my style was loose and whimsical because I was thirteen. If I drew a dog that was crooked, it was okay because I was a kid. Robin taught me how to lay on my side and look at something and then, in my head, fix the perspective, compensate for it, and draw it on the paper.



Katherine Klimitas, Flamingo, 2019, watercolors, 12" x 6"



Katherine Klimitas, Sheep, 2018, watercolors, 6" x 8"

She would set up a still life, literally lay down on the floor with me, and we would draw. It used to be that if I drew what was in front of me and then picked up the drawing, it would be crooked. She would say, 'no, it is twenty degrees off . . . see how this looks crooked?' I wasn't making the compensation. Now I do it automatically. So, she taught me how to draw and that's really important when paintings are as realistic and detailed as mine. A good base is essential." Klimitas' medium of choice is watercolors because they are a relatively clean medium, dry quickly, no substrates or chemicals are needed, and once someone sets her up with the paints, water, and paper, she can work on her own, without any assistance. Although, occasionally one of her five dogs might lend a paw as she paints because they enjoy laying beside her as she works.

She continued to develop her craft and decided to pursue a degree in fine art at Loyola University. After one year she switched her major to graphic design because, ever the realist, just like her mom, she quips, "They're called *starving* artists for a reason." After graduating, she had job offers from design firms but decided to start her own business, KAK ART & Designs. For practical purposes it is easier for her to work from home. "I do logo design, branding for small businesses and nonprofits, manage social media accounts, and marketing. I use my brain in a completely different way than I do with painting." While graphic design is her day job, she also has a steady stream of commissioned paintings, and enjoys designing jewelry.

Business has been good for Klimitas and a few years ago she was contacted by Adobe because they wanted to capture her story on film and share it at an Adobe MAX Conference. Initially she was wary when she received the call, "I mean, really, was Adobe calling me? Clearly not. I thought it had to be a scam." But it wasn't. A ten-person camera crew filmed her for an entire day and presented her story at the conference which was attended virtually during the pandemic by people from all over the world. In the video, which can still be seen online, she shares that she loves live music more than anything else. An array of meet-and-greet photos with the likes of Blake Shelton, Little Big Town, and Keith Urban adorn her walls, along with all sorts of memorabilia, and even an autographed guitar from Florida Georgia Line that was given to her in the middle of a concert. On her website there's a picture of her enjoying a glass of wine with Sir Rod Stewart and, she says, "I love music because I think it brings people together." She loves being in the midst of a crowd—



Katherine Klimitas, Alligator, 2016, watercolors, 6" x 8"

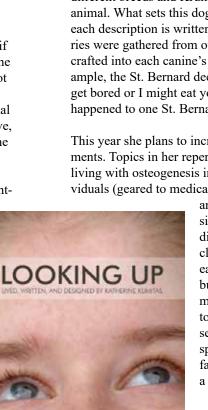
strangers united, singing in unison. Music can have a powerful effect on people, much like art. She believes, in a world where there is so much angst, artists of all sorts should strive to make their impact a positive one.

Music inspires her. Some people say she inspires them. However, she doesn't want to be seen as inspiration simply because she chooses to get out of bed in the morning. There's no reason to congratulate her for getting up the gumption to leave the house. And, please don't pet her head or tell her how cute she is. *Please*, no. "But if they're inspired by the fact that I have a disability and I run my own business and I create art. That's different. I'm okay with that."

She says the eyes are the most important element of her paintings. They can capture the essence of an animal and if they aren't right, there's no point in continuing. There's one piece of work she created several years ago that she cannot bring herself to sell. *Eye-dentity* is a collection of twelve eyes of various animals, close-up. Each eye is an individual painting but the twelve are framed together in one cohesive, mosaic piece that hangs on a wall in her kitchen, where she does most of her work.

In addition to her graphic design business, watercolor paint-

ing, and jewelry design, she is a published author and public speaker. Her first book, *Looking Up*, started as her senior thesis. "The assignment was to do something that only you can do. I chose to write a book about myself, to literally show people the way I live." In the book, she explains what OI is, provides details about her worst injuries, recounts some of the stupid things people have



Cover of Klimitas' book, *Looking Up*, published by Arthur Hardy Enterprises, Inc. (2017)



Katherine Klimitas, White Tiger, 2013, watercolors, 6" x 6"

said to her and shares her general outlook on life. It also includes photos she has taken, revealing her view of the world. The second book, *Breed All About Us*, was a collaboration with her neighbor, author Yvonne Krumins. After numerous requests for various dog breeds, Klimitas painted sixty-four different breeds and Krumins wrote the text defining each animal. What sets this dog book apart from others is that each description is written from the dog's perspective. Stories were gathered from owners of specific breeds and then crafted into each canine's description of themselves. For example, the St. Bernard declares this warning: "Don't let me get bored or I might eat your couch," because that actually happened to one St. Bernard owner.

This year she plans to increase her public speaking engagements. Topics in her repertoire include general motivation, living with osteogenesis imperfecta/treating patients as individuals (geared to medical students/therapists/professionals),

and the importance of school inclusion. "If kids who are physically different are included in mainstream classes as much as possible at an early age, it not only benefits them, but also their able-bodied classmates. It teaches acceptance and tolerance, which in today's world, seems few and far between." Despite the physical challenges she has faced, she says, "feeling left out as a kid was the most difficult. Not be-



Katherine Klimitas, Eagle, 2021, watercolors, 8" x 10"

ing able to join in and do what everyone else was doing was hard." Maybe that's why she loves the immersive experience of live concerts, surrounded by thousands of people. Feeling the rush of energy. Moving to the beat. Singing the lyrics. Connecting with everyone.

She and her family, including five dogs and one cat, survived hurricane Katrina. She evacuated with her mom and the pets, with enough clothing for three days. Dad didn't leave and had to be rescued a week later. They lost nearly everything. "It's hard to lose all of your stuff . . . at any age. An experience like that changes your values. We don't care as much about stuff anymore." There were some irreplaceable things though—artwork from her childhood, family photo albums, gone. Surviving something like that changes your perspective. Her dad passed away ten years ago and she now lives with her mom in a house that is more open and accessible than the one they lived in before Katrina hit. She often travels to various venues across the country with longtime friend, Christy, in search of their next live music fix. Klimitas has a big heart, unwavering sense of humor, and a stubborn streak, when warranted. She takes great pride in her craft but she also likes to have fun, which might include a good shot of Fireball Whiskey, good food, and good times with friends and family. To learn more about her, follow her on social media (@kakartnola), or visit her website, kakartnola.com, where you'll find information about her design business, pet portraits, public speaking, and so much more. Her incredible talent, unique perspective, and passion for life prove that big things really do come in



Artist Katherine Klimitas at work

small packages.♦

## **DATING MY DOCTORS**

### STEPHANIE HARPER

nce, my neurologist at the time came up in the "people you may know" section on Facebook. This creeped me out in the same way as Tinder matching with a guy from my church (who had a girlfriend). I did not friend my doctor (I also did not swipe right, in case you were wondering). The doctor/patient relationship is strange. It's intimate. My doctors know more about me than a lot of my acquaintances. But it's only in a small space within the whole of my life. Only in exam rooms or hospital beds. It's almost as though these doctors don't actually exist once I get out to the parking lot after my appointment. Then, I'm reminded they have things like Facebook.

#### **Blind Dates**

I went on a date once with a reptile-obsessed amateur zoologist who wore socks with his sandals and spent the entire date talking about his female friend whom he was very clearly in love with. Meeting a new specialist is kind of like that.

It's hard for me not to enter that first meeting with a sense of foreboding. I don't know this person, if they will like me, if they will believe me, even listen to me. Anytime I enter a new exam room, I have prepared myself for frustration and disappointment. Also, it's probably going to be awkward as hell.

I've had a few first dates with specialists that ended there. Once, years before my headache started, when I was just a college student with unexplained aches and pain, a rheumatologist reached his hand down my pants to push on pressure points near my butt without telling me what he was doing first. He was an older, abrupt man with dry, chapped hands and I was nineteen and incredibly shy. It made me so uncomfortable I asked my primary care physician (PCP) for a referral elsewhere.

A few years ago, I met with an urologist who told me I was too young to have "real" kidney problems (even though I'd had two full blown kidney infections in as many months) and I probably just had an overactive bladder. She gave me some pills to try, which made my headache worse, and I blew off the follow-up appointment. I was especially disappointed because she had a fountain in her waiting room of a little cherub boy peeing into a pool. I loved the cleverness of this and thought we'd be fast, witty friends.

There have been others. Those ER doctors you only see once and sometimes hope you never run into again. A physical therapist who wanted me to do exercises to help a bulging disk in my back, but quickly realized he couldn't help me until the unexplained fracture in my sacrum healed first.

Some specialists come by way of friendly recommendation. I've never been set up on a date by a friend, but I have been set up with doctors. I met both my immunologists that way. The first one was a recommendation I actively sought. I'd been following the health journey of an acquaintance from my undergraduate years and started to see a few similarities between the complexities of our cases. I was growing in-

creasingly frustrated with my current medical team and felt like I just needed a fresh take. So I reached out and asked her. And, that's how I came to Dr. V. She raved about him and I thought if he had helped her so much, maybe he could actually help me.

My first appointment, in a little office in a giant office park near the Denver Tech Center, he ordered a long list of blood tests and sent me off to the lab. It took three lab techs several sticks each to acquire the forty tubes of blood needed to complete everything, but we made it happen. We even high-fived at the end. Several weeks later at my follow-up, he sat me down and talked through the results—some elevated numbers that suggest inflammation somewhere in my body, nonspecific of course. But he looked at me with kind eyes over the rims of his glasses and said, "I am going to assume that someone, a doctor or family member, somebody has had a hard time understanding or believing you. This number tells us that you are not making this up. I thought you might like to hear that." I broke down. He handed me a tissue and continued talking through the next steps while I blotted my tears away.

The other immunologist is a different story. I don't even know why I go because I'm happy with Dr. V and while we haven't exactly gotten to the bottom of anything just yet, he's working to help identify my immunodeficiency (which seems to only effect specific antibodies) and he never seems out of ideas for new things to try. But he's also patient and knows I'm working with several other specialists so we've gotten into this holding pattern of waiting to see what the other doctors say first. I think more than anything, I'm just restless, need to feel something new is happening. It's how I stay hopeful.

So, when several people in my local chronic headache circle start talking about Dr. M, I decide to give him a try. I've heard of him before. He worked with another doctor, a woman with a sort of miracle worker reputation who decided to open her practice and make it cash only. I had an appointment with her that was canceled in the shake up and I decided not to pursue her because of cost and principle. But Dr. M had steadily been absorbing many of her former patients, the ones who couldn't afford a \$2,000 initial consult and \$600 for every hour after that.

At my first appointment, I was struck by the difference in the offices. Where Dr. V's office was small and basic, Dr. M worked out of his own building, with several providers. Everything was heavily branded in orange and purple. The walls around the waiting room held several accolades for the practice and the providers. This was supposed to be an impressive place. It felt corporate from the get-go. Everything was busy. The waiting room was full and the front desk ladies seemed frantic. I thought, perhaps it was just a bad day. I would learn after a few subsequent appointments that this was status quo. There seemed to be a constant struggle to maintain the caseload.

Two things struck me about Dr. M. His confidence, or arrogance even, when he said, "You don't need to see that other doctor. I can fix you." Five years in with my symptoms and no relief yet, this seemed bold, to say the least. I was also struck by how little time he actually spent examining me. At the first appointment he was in the room for ten minutes, maybe, where he pushed around on my stomach briefly, felt my throat, and ordered CT scans of my thyroid and abdominal region along with a list of additional bloodwork. This was the only time he touched me. In subsequent appointments, there was no physical interaction.

I was immediately put off by his persona, his methods, his office. But I went back a few times because he had ordered tests and I wanted to see it through. When he ordered out-of-pocket allergy testing that is not supported by many of the major medical institutions and regulatory bodies, I finally gave up. I made an appointment to see Dr. V as soon as I could and returned to his office, a bit embarrassed, and a great deal more patient. I haven't looked back.

#### **Online Dating**

With Medicaid, finding a specialist is often exactly like perusing online dating profiles. There are so few specialists who accept Medicaid that I'm often unable to see the person my doctor recommends. I have to go to the Colorado PEAK website and find someone who might work. I go to their websites and read their biographies. There's always a headshot-type photo. If I like what I see, I'll get a referral and make an appointment. It's not at all uncommon to wait three to six months, sometimes longer, to see someone new. But in the lifespan of a chronic illness, where every day is more of the same, what difference does it make really? I've

gotten very good at waiting and hoping this next person will have something new and different and helpful for me. It turns out, in medicine, as in dating, there is often no such thing as "The One."

One of these first dates comes two years after my headache has started. I land myself an appointment at the University of Colorado Hospital Headache Clinic. This feels significant. Like I am taking a step up in the medical world. A research hospital.

My previous neurologist's parting advice was that, in his opinion, the only thing left for me was to consider a surgical option—a neurostimulator. He made it seem dire, as though this was my last chance at any kind of relief from the constant pain. But surgery is scary and permanent. The idea that a pacemaker-type device would be put inside my body, that wire leads would be inserted into my occipital and/or peripheral nerves, is terrifying. But the idea is also action-oriented, and I so desperately crave something to be done to help alleviate my pain that I am willing to try anything.

When the day finally arrives, after four long months of waiting, my mom and I make the forty-minute drive out to the big medical campus in Aurora. The busyness of the place is overwhelming. Traffic is heavy and people are honking at one another, racing each other to parking spots. The parking garage is so full that we park on the very top, out in the open. It's a March day so it's chilly but the sun is shining as I walk inside and find my way to the headache clinic on the fourth floor. I think about all the people here, looking for answers. A hospital with valet parking. This place has to make a difference—has to get things done. I'm confident that I have found what I've been searching for.

Then, I meet my doctor. Or I should say, my fellowship resident. It is a teaching hospital after all. I go through the complete history of my headache saga, which feels so rehearsed I could be performing a soliloquy.

I tell him how and when my headache started, what it's been like since.

He scrolls through my chart on the computer. "I see that you've had MRIs and they've come back normal. Any other tests?"

"I've also had an MRA. And an EKG and heart ultrasound. And a lumbar puncture. Plus, all the blood work."

"All normal?"

I look down at my feet. He has the answers right there in my chart already and asking me feels like he's just rubbing it in.

"Yes."

He writes a few things down on the paper I handed him when I came in, the back of the survey I filled out about my pain levels. "Can you give me a list of the treatments you've tried?"

Maybe it's just helpful for him to hear me list it all out instead of digging through months and months of medical history. I try to see if I can remember them all.

He takes more copious notes and I feel less like a dramatic actor and more like an eyewitness for some terrible crime. When we finally get to a stopping point, he asks me, "What do you hope to get out of today's visit? Are you just looking for a second opinion?"

My stomach drops. "I was under the impression I was here for a surgical consult on an occipital nerve stimulator."

"Oh," he breathes, and his eyes widen. This is *not* why he's here. "I don't do that procedure. I'm not sure anyone here does."

## It turns out, in medicine, as in dating, there is often no such thing as "The One."

I feel the tears welling up in my eyes and I bite my lip. I don't want to cry because once I start, I'm not sure I can stop. Also, he's young and I like his red beard and black-framed glasses and he's not wearing a wedding ring. Now, I just feel worse about making a scene in front of this potentially eligible, wrong doctor bachelor.

So, I don't cry. And I don't explode at the absurdity of this situation, even though this was on my referral and is what I talked to the scheduling department about. I take a deep breath and explain how long I've been waiting for this appointment, how much hope I've pinned on this day. I can tell he's sorry, and perhaps a little embarrassed. He tells me it was probably a clerical error somewhere in the referral process. Then, he exits to discuss the situation with his supervisor.

He leaves the door cracked open. I sit for a few minutes in silence, texting my mom, who's sitting in the waiting room, explaining what has just transpired. I can feel her anger the way you sometimes can, even in a text, no exclamation points required. I am shaking with disappointment and the considerable physical effort it takes not to cry. The fluorescent lights of the exam room bear down on me, as they

always do, and I can feel my headache pain begin to flare under the overwhelming stress of it all.

Then, I hear them in the hallway. It's almost an out-of-body experience, hearing him recite my story. *Twenty-six years old. Debilitating headache. Almost two years. Quality of life greatly reduced.* This is what I look like on paper, how my very complex situation, my life, is summarized in my chart. It makes me squirm. I'm a child listening to her parents talk about her behind a closed door. More than that, I am, once again, my headache. No name, no distinguishing features, just a list of symptoms.

When he returns, I can feel my face and chest flush with an awkward sort of embarrassment, as though I've been caught peeping. It turns out there is a doctor who knows something about the procedure, who might be able to help me, or at least provide me with some information. He tells me he will refer me right away and I should go ahead and make an appointment, pending insurance approval.

It turns out I can't make an appointment. I have to wait for my referral to be processed once again. They'll call me. After a week of hearing nothing, I call them. The earliest I can get in to see this new doctor is another three months away. So begins another season of waiting.

### One-Night Stand

When you have tried as many drug treatments as I have, you spend a lot of time at the pharmacy. I like my pharmacy a lot. It's at my local Safeway, making it easy to shop for groceries while I wait for my prescription. My whole family has been using it for years and everyone knows us. I appreciate the familiarity, even if it also points to the fact that, as a frequent flyer, I have a reason for everyone to know me by name. I take a lot of medications so I have multiple prescriptions that I refill regularly. But there are also always those prescriptions I need for an acute illness or just to try out, the one-timers.

Once, my neurologist prescribed me antivirals, just in case my headache was related to some kind of latent viral infection. It turns out that, more and more, research is suggesting that many chronic illnesses perhaps begin with some kind of infection. I learn all about this later when I test positive for reactivated Epstein-Barr virus.

After working my Google magic, I find out the antivirals I am about to start taking are used to treat shingles, chicken pox, and genital herpes. This isn't a shock. I vaguely understand the relationship between all of these viruses. But reading about it makes me a little uncomfortable.

My first thought is, *What will my pharmacist think?* The head pharmacist is an incredibly nice and handsome middleaged guy with the perfect amount of silver in his hair and

lovely, compassionate blue eyes. He always has my prescription ready as soon as he sees me. I actually get a little excited to go and see him, knowing he'll ask me how I'm feeling, what my plans are for the weekend.

So, I just don't really want him to think that I have herpes. It's silly, because I get medications for off-label purposes all the time, and, also, I shouldn't be propagating the stigma around genital herpes in the first place. It's shortsighted and uninformed. But I just like him so much. What's more, he knows my mom and lavishes her with equal attention and concern when she comes to pick up prescriptions. Will he think, I wonder if she knows what her daughter's been up to? Now, I'm digging into my own psychology, unearthing loads of sexual shame I didn't even know I had. Thanks, doc.

## ... I am, once again, my headache. No name, no distinguishing features, just a list of symptoms.

How do I act when I pick my prescription up? Do I look him in the eye? I should. There is no shame in my headache treatment and there is no shame in herpes or having sex and who cares what he thinks anyway. But I feel flushed just thinking about it and I know I am going to get those red blotches under my chin and across my chest, the ones I always get when I'm anxious. Maybe I can casually work it into conversation that this is for my headaches. It might clear the air. Or at the very least make me feel less awkward. I start to plan out conversational scenarios that might work. I will not upset the pleasant balance of our relationship. So steadfast in my life of ever-changing medications.

When I finally go to pick up my first prescription, after three weeks of battling Medicaid for pre-authorization, he's not there. Instead, a pharmacy tech who recognizes my face but doesn't know my name fills it. He doesn't even blink. This is my lucky one-night stand. I get red, not over the antivirals, but because I feel ridiculous. But I'm also relieved. I've got thirty days before I'll need a refill. No use worrying until then.

### Meeting the Parents

It seems like everyone has their own rule on when it's the right time for a significant other to meet the parents. This is true for my doctors also. I always bring my mother to the emergency room with me. Since my New Daily Persistent Headache began almost five years ago, I've felt the need to always have someone in the room with me. In fact, I usually

bring someone, usually my mother, along when I meet a new doctor. It makes me feel more secure in my being there, as though an outside witness is required in order to make my case seem more believable. They don't even have to speak: just their presence seems to add legitimacy to my chronic illness history.

# This is my quality of life we are discussing, my everything. This is not a game.

"She has a really high pain tolerance," my mother told the emergency room doctor. "Like really high." He had just asked me the level of my headache pain and I had told him a nine. He must have made a face, raised a skeptical eyebrow at my perceived calm, because my mother felt the need to jump in and come to my defense, to attest to the validity of my reported symptoms. This was why I brought her, for added support.

Sometimes, I even bring someone with me to a doctor I've had for years. I asked my father to come into the room with me once when I was consulting with my neurologist because I'd begun to sense a growing frustration in my doctor's attitude toward me, or at least my lack of responsiveness to any of his prescribed treatments. My instinct was that my dad should be there. When my neurologist entered the room, the first thing he said to me was, "I see you've brought your backup."

### Breaking Up

Sometimes, you have to break up with your doctors. It's okay to get to a point where you have to admit to yourself that you're just not a good fit, or that things aren't working anymore. Most doctors understand there are limits to what they can do for you and sometimes the best thing you can do is take your care elsewhere. People leave their doctors for a number of benign reasons too, from a change in address to new insurance. It happens. And sometimes, your doctors break up with you. When this happens, you'll try not to take it personally. But you will grieve anyway.

I've been seeing this particular neurologist for somewhere around a year when it happens. We've tried several treatments and nothing has helped with the pain. It's frustrating for both of us. But I've been good and vigilant about trying everything he suggests and keeping a positive attitude. I haven't even cried in his office, as I have learned that sometimes this scares doctors away or just renders a suggestion for antidepressants.

We are sitting in his office. I know he's grown increasingly frustrated with the lack of progress in my situation. He has suggested a few other specialists, all things that would send me elsewhere. I've certainly sensed a shift in his attitude toward me and my case. But I still want to believe he'll have another brilliant idea. I look at all his degrees and certifications on the walls. My favorite is the certificate of completion of a headache fellowship at Mayo Clinic. Every time I see it, I think, *This guy knows his shit*. It's been a comfort through months of pain.

Today, he is somber. Unfeeling even, as he rolls his stool a little closer to where I'm sitting in a chair against the wall. He's been silently reviewing my chart for a few minutes now. I shift in my chair. This silence is awkward, especially because his medical intern stands and stares at me from the corner. Finally, my doctor looks up from my chart and sighs. "I am completely out of ideas. We have literally gone through everything in the playbook."

The first thing I think is, *I despise sports analogies*. They are completely lost on me. I resent that this is how he chooses to phrase the reality of my predicament, as though my headache disorder is comparable to a bad football game. And, what is this playbook anyway? Who writes it? Is it his personally or is it the sacred playbook of neurologists everywhere and I am doomed across the board? I want to chastise him for giving up on me, for throwing in the towel. This is my quality of life we are discussing, my everything. This is not a game.

I also think that I don't like the way his medical student stares at me. There's a light in his eye, a brightness, a buzzing energy like he is excited to be in the room with me, hearing about my intractable headache, my medical mystery. Maybe he hasn't yet taken the course where they teach you about bedside manner.

"So, where do we go from here?" I ask.

I say "we" because I want to reassure myself that he's still my doctor. That we are in this together. I'm testing him a little, I guess.

"I think you should see a neurosurgeon. I'll pass her information along."

Okay, I think. I'll go talk to this woman and then come back to him and tell him what she says.

"So, when should I schedule a follow-up with you?"

"I suggest you just see how it goes with her first."

So, there it is. The real breakup. He goes on to tell me that he just can't do anything more for me in the same breath

that he describes my "debilitating" headache, as though I'm not the one who's living with it every single day. I want to cry. I almost do. I feel the tears welling up and I think of the face of a cartoon child, eyes filling with blue cartoon waves. What does that mean for me? My doctor is giving up. I must be hopeless. I want to crawl into my bed, pull the covers over my head, and never come out. But, I'm still in his office and he's looking at me, and his medical student is looking me, and I have to at least make it to the waiting room and out to my car. So, I take a deep breath and thank him for his time. Then, I wait for the nurse to provide me with the proper referral information. Then, I make it to the parking lot. At this point, I'm too exhausted to cry.

On the drive home, I think, Maybe he's just an asshole. Maybe all doctors are assholes. It's a requirement of the medical community. Too much knowledge, too much power over people's lives. It's bound to give you a complex. And his medical student, just an asshole in training, right? Then I think, Maybe he thinks I'm an asshole, coming in with my list of questions inspired by articles found on the NCBI and Mayo Clinic websites like I have any idea what I'm actually talking about. I throw around acquired medical jargon like basic vocabulary. I am relentless in my desire for him to fix me, even after he tries everything he can think of, even after he doesn't, he can't. That can't be easy for him, the disappointment on my face, the frustration in my voice after each failed treatment. It must be hard for him, looking me in the eye, knowing he hasn't helped me at all. It turns out that when it comes to this headache stuff, we're all assholes and nobody wins. So I call to make an appointment with a new doctor, hopefully with new ideas and possibilities. All I can do is start again.

### My Longest Relationship

I don't mean to sound like all of my experiences with doctors have been negative. They haven't. The person I really want to talk about is my PCP. He's been my doctor for somewhere close to fifteen years at this point—the longest relationship with a doctor I've had. He's been unwavering in his support of me and my situation, a major advocate. He's also just a genuinely nice human being. He says, "Oh, shoot," when I describe whatever symptoms have brought me in. And, he likes to jokingly refer to me as his "challenge."

Once, when he was doing a neurological exam, he said, "squeeze my fingers and show me what you can do."

I took his fingers in my hands and squeezed as hard as I could, or at least until the joints in my fingers hurt.

He looked at me over the rims of his glasses. "That's it?"

I gave him a sheepish grin. "Yes?"

"Maybe you should make like Popeye and eat more spinach."

I laughed. "I'll get on that."

At the end of another appointment, after we agree that there is cause for some concern with my newest symptoms, mainly extreme weakness in my arms and legs, and we begin to discuss next steps, my doctor says, "You apologize too much."

"I know," I say. I started our visit with my usual preamble of "I know I'm overweight and I have some deconditioning and I am sorry, but this is different . . ." But I do have this habit. It comes from being dismissed (whether intentionally or not) by healthcare professionals, by friends and acquaintances, by family. I feel like I have to be preemptive, defensive even, anytime I talk about my illness.

"I know it's hard," my doctor says. "And I know that people don't always understand your symptoms the way I do, but you have to advocate for yourself. I won't always be around to advocate for you."

I've thought about this a lot. It's a little ominous, like Mufusa foreshadowing his demise with a line about the rise and fall of the sun. I don't think this is what my PCP means. I don't imagine him having any plans to go over the side of a cliff anytime soon. But he's older, in his sixties, and he's begun to reference his retirement more and more often. Which is wonderful for him. But I am afraid.

I am afraid of what will happen when I have to start the process over again, build a relationship of trust and respect with someone new, another PCP, someone who doesn't know me and my family, who hasn't walked alongside me through all of this. What will I do then? Will I be left floundering in a sea of people who just don't know what to do with me, what to make of my condition? Will I be hurt? Will I be doubted? Or will I find someone else with compassion and understanding, another person to count in my corner. Because the corners are small in this land of chronic illness and I need as much support as possible.

Portions of this essay have appeared in Folks Magazine and HelloGiggles.

### THE WINGED VICTORY OF (INSERT YOUR NAME)

These are legs

arms

hands

feet

that move like stone,

creating a marble statue

of a long-forgotten being

that now exists as hardened flesh and muscle

with limbs of pain

like the sharp chisel that cut them

into this new creation.

A statue of the likeness of a once

mobile, living existence

now frozen in this new form

of marble to shield

the destruction inside

and the struggle of living

beneath hardened muscles and a blank expression.

This is the final art form

of an existence

cut and formed

from Marble and Stone.

And the Grecian creation asks why

she could not be

a watercolor painting of

easy, flowing movement

or stained glass of

ever-changing bright color

to see the sun without ache.

But we subject matters

have no say in

our composition

our medium

our final form.

We can only exist as we were meant to exist:

as art.



Chelsea Malia Brown, The Statue, 2022, water-soluble graphite, ink, and acrylic paint, 17" x 14"

Is the *Venus de Milo* affected by society's demands for

fully intact art?

Does the Winged Victory of Samothrace not rival

all marble creations

despite its missing parts?

Then are we not the Winged Victory of (insert your name)?

Are we not beautiful rivals of "perfections" like *David*?

Because of our Marvelous Strength

in Marble and Stone

we keep existing

through the freezing and

through the loss of pieces

that crumble and leave us

with little left of our heads.

We are art capturing pain

but art, nonetheless,

that captures gods and goddesses

in their own right.

And there is a beauty in Marble and Stone.

The Winged Victory of Samothrace is beautiful for its missing parts.

The Venus de Milo is beautiful for its missing parts.

Thus we,

my fellow art pieces,

are beautiful for our missing parts.

For the Marble and Stone

has made us the most formidable

form of art.

Because we know battle

and we know sharp edges

and we know what it is like

to fight for existence.

For watercolors

and oils

and clay

do not know what it is like

to be chiseled down

from what they once were

with tools of pain

and look even more beautiful

in their final form.

We, marble and stone, do.

Previously published in BS Lit (2022). Reprinted with permission of the author.

### LOST IN THE CHAOS AND THE CALM

Today I let my mind wander. This time, I didn't stop it as it tried to slip past me. I didn't wrap its strings around my fingers, I let it tug the rope and unravel. I let it sail away.

ROBIN KNIGHT

### SHOALFISH

I swim with others. Some are dolphins, some are sharks. Which is which depends on the temperature of the water or the weather. Something: it's not clear. From whale song to hammerhead thrash they change their tune at the drop of a mask over the side, pulled deep by invisible cable to pressurized obscurity. Before I know it the warm, blue shallows shelve into coldness. Gloom wraps me in panic. I pray. My prayer says: "Even turtles nip if they think you're edible." Overwhelming, but it's either that or swim alone.

Previously published in Rattle (May 2021). Reprinted with permission of the author.

## ALEIDOSCOPE

## 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.



## WAKE

### Vesper North

he ravens are circling."
Rose watched through
the barred window as a
slurry of black birds soared around
one of the maple trees that speckled
the outer grounds—cawing, one
over the other. The six-by-six hole in
the wall made the twelve-by-twelve
room, occupied by eight women,
seem just a little bit larger.

"They're crows," Genny corrected from her corner of the upper bunk she shared with Rose. Genny sat hunched over crossed legs, her frizzy dark hair spilling out from the rubber band—she didn't need to see the creatures to know them. She'd been listening to them for days and then weeks and, now, months. This was her home now.

Rose kept her hands flat on her knees, which were pressed tightly together, putting strain on the open wound beneath the bandage on her right wrist. "They're annoying," she griped. Though she wore the clothes of a transient, Rose worked tirelessly to maintain the air of a lady—even the

sound of her displeasure had a polite air to it.

"A hawk took one of their own," Genny said while running her fingernails over her knees, scratching them until they turned red—if she didn't stop, it would be the jacket for her again. "They're mourning their lost companion."

Rose watched as the crows swooped through branches—up, down, around—in a procession. Her lips moved as she whispered to herself:

Ding, dong, bell.

Pussy's in the well

Who put her in?

Little Johnny Green

Rose relaxed her palms, bringing her hands to fold in her lap as she continued to hum. A tiny blot of blood seeped through the bandage—it would need to be redressed, and she would have to see that doctor again.

\* \* \*

From the fullness of her cheeks, sheen of her dark honey locks, and unblem-

ished skin, Rose had never gone hungry a day in her life. As she stared at the tin plate of prunes with its juices soaking the lukewarm scrambled eggs, she considered now would be a good time to start.

Rose took a sip of her black tea. Her new diet of Earl Grey didn't help to build a traveler's constitution. She'd considered escaping in the night, but even if she managed to slip past the nurse's station and avoid notice from the athletically built orderlies, she didn't know this part of Georgia well.

Barb, one of the middle-aged patients, set down two more tin plates in front of the women to the left of Rose; she was one of the few tasked with serving the others because she didn't shake, twitch, scream, or claw. To Rose, Barb didn't appear to be insane at all; even in the confines of the bedroom they shared, she never indicated being afflicted by illness. The middle-aged woman kept her hair in a tight bun and stood straight—not hunched like some of the whisperers. Rose had already spent one too many days here—she'd expected

she'd be out by now, and someone like Barb didn't give her hope.

From breakfast, she went to the nurse's room (a small space designed to treat minor injuries) to have her bandage redressed.

"It's healing fast," the nurse remarked, subtlety gauging Rose's reaction. Rose thought it a pity the woman sitting across from her ended up in a place like this. From the right, she was a pretty young woman. On the left, a webbing of scars stretched across her cheek. Who would marry that? Rose wondered. "Shouldn't need to wear the bandage much longer," the nurse went on, lowering her head.

The hole in Rose's wrist was too small to need stitches and wasn't deep enough, it seemed, to cause any severe damage. She smiled at the nurse, "Thank goodness."

After receiving the usual warnings about aggravating the wound, the orderly waiting outside the nurse's room escorted Rose to see Dr. Marshall. She'd seen a few doctors since she arrived, but none of them made her speak as much as this one.

The mood of Dr. Marshall's office reminded Rose of the doctor she saw as a child—only for a brief period. That's when Rose became a true lady, learning how to be mindful of what she said when presenting herself to others. Rose was an accident-prone child—her family knew that—setting "reasonable ground" for her internment in an asylum.

Dr. Marshall took a seat behind the desk, opening her leather-bound note-

book. Rose had never seen a female doctor before, which only added to the absurdity of the situation.

"Do you have children?" Rose asked.

"No," the doctor responded without looking up.

"A husband?"

"You know the answer to that." It's true; Rose never spotted a ring on the doctor's left hand.

"Why not?"

Dr. Marshall smiled. "It wasn't in the cards. Now, let's—"

"When do I get to go home?" Rose interrupted, failing to suppress her impatience.

"When you're better." Dr. Marshall lifted her gaze to meet Rose's. "The surgeon mentioned that the chloral hydrate may have had adverse side effects."

"I feel fine," Rose asserted, raising the pitch of her voice just a hair.

"Can you tell me what year it is?"

"1939," Rose replied confidently as Dr. Marshall scrawled across the page.

"The month?"

"February."

"And the date?" Dr. Marshall's pen hovered, waiting. Rose lowered her head just a hair, unsure. "What day of the week is it?"

Rose parted her lips—pausing.

Dr. Marshall made a note. Rose's brow crinkled. Mindful of her appearance, she quickly relaxed it. "It'll come back to you in time," the doctor assured her.

There were two quick raps at the door before the heavier set and hard-faced Nurse Cafell opened it. She lifted a fine silver tray off the cart in the hall and carried it in.

"On the desk," Dr. Marshall instructed, "if you please." Cafell set the tray down and proceeded to pull off a large polished French cloche with a fleur-de-lis engraved on the tip. Rose nearly drooled at the sight of the sandwich, piled with bright crimson cuts of roast beef and crisp lettuce, complete with a side cluster of Concord grapes. She caught sight of her reflection in the cloche, recoiling at the ghoul staring back at her.

"Miss Cafell tells me you've been complaining," Dr. Marshall spoke.

Rose shot a glare at the nurse as she carried the tray out. "Many of the girls complain."

"Not to Miss Cafell."

"It's just—well, I'm not accustomed to this place," Rose said as Nurse Cafell closed the door behind her. "It's different."

"Tell me about your home."

"It's lovely," Rose responded with a close-lipped smile.

"It's quiet where you live?"

"Yes."

"Does that bother you?"

Rose shifted her weight in her seat. "My home is perfectly pleasant."

"Do you leave the house often?"

Rose shrugged her shoulders slightly. "I accompany Mother on social visits."

"What about your friends?"

"I have a perfectly happy life," Rose spoke each word carefully, remembering to smile at the end.

Dr. Marshall made another note in her book.

Rose found it difficult to focus with the sandwich sitting just mere inches from her, untouched.

The orderlies had bound her with the padded shackles hanging against the tile wall; her toes barely touched the wet floor.

"That was a lie," Rose said. "My life can be," she paused briefly before forcing the words out, "difficult sometimes."

Dr. Marshall set her pen down and closed the notebook, setting it aside. "What can we do to make you more comfortable here?"

"You could allow me to leave."

"Do you want to go home?"

Rose shifted her weight in her seat. "I don't even know why I'm here."

"What happened to your wrist?"

"I told you; it was an accident."

"Yes, you accidentally fell on a knitting needle."

Rose sighed. "Yes, I was putting the needles away when I tripped on Daddy's bearskin rug and fell."

Dr. Marshall stared at Rose, not moving, not blinking.

"It was an accident," Rose repeated. "I told you I—" Rose shot up out of her seat. "This is ridiculous! I'm not insane! I don't belong here!"

"You can leave anytime." Dr. Marshall told her, perfectly calm.

"No, I can't!" Rose screamed. "I'm trapped here! Why won't you listen to me!"

Nurse Cafell opened the door—two strapping orderlies hurried past her, taking hold of Rose, who thrashed about, failing to escape their grasp.

"It was an accident!" she hollered. "It was an accident!" The taller orderly wrapped his arms around Rose, pinning hers. She kicked her legs out, knocking the roast beef sandwich onto the floor and sending the grapes rolling about like marbles. "It was an accident!" Her voice faded as they carried her down the hall to the hydrotherapy room.

\* \* \*

Ding, dong, bell
Pussy's in the well
Who put her in?
Little Johnny Green
Who pulled her out?
Little Tommy Stout
What a naughty boy was that
Tried to drown the poor cat.

The water from her hair soaked through the pillow, so Rose scooted down to the center of the mattress.

"I have a silk dress," Rose whispered, "a deep sky blue with a wide V-neckline that stretches to my shoulders. Daddy gave it to me for my eighteenth birthday; it was perfect. He filled the back section of the house overlooking the plantation with hundreds of people, all admiring me in my blue dress."

Rose pulled her knees tighter with her left arm; she'd been shivering so hard she didn't feel the soreness in her bruised wrists. The orderlies had bound her with the padded shackles hanging against the tile wall; her toes barely touched the wet floor. She pushed that memory from her mind, remembering the home she'd been pulled from. "The servants made a feast—much larger than we needed—and there were all my favorites: lavender mousse, ginger crumble cake, and apple brandy."

It seemed like a lifetime ago rather than a couple of weeks. At home, she was dressed in fine fabrics, fed exquisite food, and adored by all. Here, she wore secondhand rags, ate revolting food, and was bound and hosed down with icy water.

"It was really something," Rose said to Dr. Marshall as she stood by the bed-side, monitoring the IV pumping insulin into Rose's system.

Rose focused on the party, on that blue dress, on that moment before he came.

\* \* \*

Rose waited in the front hall with some of the others. She tried to keep her eyes open as she yawned; she thought she might fall over if she closed her eyes. The insulin therapy threw off her sleep schedule and her sense of time.

Nurse Cafell stepped to the front of the group, flanked by orderlies.

"Grab a pair of gloves," Cafell ordered, "and follow me single file out to the garden." She turned on her heels and headed outside. The women filtered between the two orderlies, taking a pair of gardening gloves out of the crate on the floor as they went.

"Where's Genny?" Rose asked Barb.

"Jacket."

The weather had been fair—refreshing even. Though the sun hid behind cover, a cloudy sky was preferable to none at all.

Elaine always aided Nurse Cafell with gardening hour, keeping an eye out in case someone wandered or took a trowel without expressed approval. The two orderlies accompanied them outside, walking the perimeter of the garden, keeping an eye out. She reminded Rose of Barb, though Elaine had a warmness to her, seemingly immune to the harsh effects of this place. Rose thought her simple—that Elaine might be better off here than in her previous life, whatever that might have been.

Rose was tasked with planting some fresh herbs—not that she'd recall any in the food they fed her. The chilly air brought on another yawn, so she brought herself to her feet to take a turn about the garden, hoping to stave off the sleepiness.

On the south edge of the premises, behind an iron fence, was the rose garden—off-limits to all patients. Rose admired the blooms from between the ebon rods. What a shame, she thought, to see such beautiful things hidden away. Her hand tightened around the grip of the trowel.

"Rose!" Elaine called as she came through the thick sea of trees. "Have you completely lost your head, dearie? They'll put you in isolation if they find you out here."

Elaine took her by the arm and led her back to where she belonged.

The orderlies didn't notice Rose had slipped off; she filtered back into the group (Elaine keeping an eye on her.).

Toward the end of the afternoon, Nurse Cafell and the orderlies guided the girls

back to the building, up the stone steps, and past the colonial columns into the main hall.

# What a shame, she thought, to see such beautiful things hidden away.

Dr. Marshall stood outside the door to Rose's room, hands tucked in her pockets, head lowered. Barb stood in front of her—arms crossed and inconsolable.

"Poor Genny." Barb touched her forehead, sternum, left shoulder, right shoulder—sending a short prayer.

Rose peeked into her room: Genny hung from the bed, her straightjacket caught on the corner of the frame, strangling her.

\* \* \*

Rose sat in the dining hall with Barb and her other roommates, waiting for the orderlies to remove Genny. She sat far from the others, resting her chin on her folded hands, hesitant to fall asleep.

The chair next to her dragged across the floor. "How are you doing, Rose?" Dr. Marshall asked.

Rose blinked her heavy lids in response.

"I have a letter from your mother."

Rose sat up, looking from Dr. Marshall to the envelope on the table tucked under her hand. "It's open."

"It's policy," the doctor replied.

"Is it policy for you to respond?" Rose spat.

"You can invite your family to visit. Maybe even your fiancé."

Rose shifted her weight in her seat.
"It's best if they don't see me like this."
She reached for the letter, but Dr.
Marshall's fingers remained pressed
firmly on the envelope.

"I see they took your bandage off," Dr. Marshall said, looking at Rose's wrist.

Rose rubbed the round pink scar with her thumb.

"Are you ready to talk about it?"

Rose paused—she parted her lips and closed them again. "I was putting the needles away when I tripped on Daddy's bearskin rug and fell."

Dr. Marshall restrained a sigh, swallowing it instead. She tapped her fingers against the paper—thinking—then slid the envelope over to Rose. The doctor walked away, leaving Rose to read. Her mother expressed distress over her absence, asked Rose how she was doing and when she'd be home. Her mother tucked a photograph into the folded pages of the letter; in it, Rose and her fiancé, Ewan La Voliere, stood in the parlor, his arm wrapped around her. While he smiled directly at the camera, Rose peered down, quite demure, at the bearskin rug at their feet.

\* \* \*

The La Volieres were positioned just shy of royalty—any girl would be lucky to marry into a family of such wealth and influence. Rose's parents prearranged for her to meet him at her eighteenth birthday soirée. He was taken with her, as many other men had been, and proposed a week later. Her parents were thrilled, especially because of Ewan's political ambitions. While he was off rubbing elbows and raising funds for his current campaign, Rose planned the wedding with her mother and Mrs. La Voliere. They were

to be married that fall, then the accident happened.

\* \* \*

Rose peered through the round window in the door of her room. She couldn't see anyone but could discern the direction of the voices, thereby pressing herself as hard against the door as possible until her right ear was situated firmly between the glass and her head.

"I don't care who he is," Dr. Marshall growled.

"The matter has already been settled." Rose recognized the voice as belonging to the head of the hospital, a wiry fellow who had lost most of his hair and admired tweed above all other fabrics. She couldn't remember his name.

"She's sick," Dr. Marshall argued, softening her tone.

"Only to you."

Rose heard shoes beat against the floor as one of them hurried off. She ducked down as the man passed. Once clear, she returned to bed but could not sleep—at least, not now.

\* \* \*

At breakfast, Rose ignored her plate of leftover raisin bread from yesterday, runny eggs, and black tea.

"Miss Bryans." Nurse Cafell called from behind her.

Rose took a breath, closing her eyes: "Ding, dong, bell." She exhaled, opened her eyes, and rose to follow.

Nurse Cafell led her to the main hall where Ewan paced, his hands in his pockets. On his next turn, he spotted Rose. Ewan rushed to her, pulling her into his arms. "Look what they've done to you." She spotted Dr. Marshall coming toward them from the administra-

tion wing, a crate in her arms filled with books and journals; she wore a long dark gray coat instead of her usual white one. They made brief eye contact before Dr. Marshall exited through the double doors.

"It's time to go home," Ewan told her.

\* \* \*

A handful of years after she left Georgia, Dr. Marshall found work in New York state—the weather suited her, and the hospital was less crowded, making the work less taxing. She hadn't made many friends here, though she didn't have many in Georgia either. The people were, in her opinion, more agreeable, and she could see herself living out her days here.

She sat in the lunchroom, alone, as she did every day: a book in front of her, tea on her right, and a roast beef sandwich with a side of grapes on her left.

Two of the male staff members took a seat two tables over from her. She didn't recognize their voices as they came in—must be the newly graduated medical students the receptionist warned her about.

"Did you hear about that young senator from Georgia—La Voliere?" the blond, baby-faced doctor asked his dark and chiseled lunch companion.

"Mm-nn," the friend shook his head, mouth full.

"Dead—went right off a bridge."

Dr. Marshall listened as the dark-haired doctor swallowed, "Good riddance. Did you read he was making a bid for the presidency?"

"He never stood a chance," the blond one scoffed. "They said the wife was driving."

"I don't let my wife drive."

The blond laughed in agreement.

Dr. Marshall didn't need to be facing them to know they looked at her. She continued to eat her lunch in silence, thinking about the newly late Rose Bryans La Voliere.

## MEETING RYAN

COURTNEY B. COOK

see things clearer—or at least more logically—than most people. That may not sound like a big deal, but it's frustrating. Very, very frustrating. Mostly because I'm not as blinded by emotion as other people. I have an objective perspective of most situations, but people . . . they just don't listen to me.

"Are you listening to me, Natalie?" my best friend Destiny asks, her voice pitched higher than usual in annoyance.

I shake my head, clearing away my intrusive thoughts. "I'm sorry, I got distracted," I admit. "It's so loud in here."

That's not a lie. People's conversations and shouts echo in the school cafeteria, a messy blend of voices screaming, yelling, and hollering. Dishes clank against each other, and every once in a while, there's a screech as someone scoots their chair back from a table. The noise is overwhelming, and I can't help but feel a little claustrophobic.

"So I think you should meet Ryan." Destiny's raised voice brings me back to our table.

I sigh. "Your new boyfriend." Of course that's what she was talking about. "I mean, are you sure? You don't think it's too soon? You guys just started dating, what, four weeks ago?"

"Of course!" She grabs my hand. "You're my best friend, and your opinion really matters to me." She hesitates. "Plus, you always have a good sense about people, and you always look at situations objectively."

I smile, a warm feeling rising in my chest. "And besides, talking about boys is what best friends are for, right?"

She laughs, high and clear, and I can tell it's a genuine laugh. "So, do you want to meet him tomorrow? We could meet up at the park after school, at our usual table."

As much as I don't want to meet Destiny's boyfriend, I do want what's best for her. And if that means meeting her boyfriend and judging him for her . . . "Okay, sounds like a plan."

"Awesome!"

The bell rings, making me jump. Destiny's chair scratches backwards as she leaps up and gathers our dishes. "Come on, let's go to class." She grabs my hand and drags me through the crowd of people that are stampeding to the exit. I hate being among the crush of bodies, with all the yelling and the smells, all in close quarters. Luckily, Destiny is an expert at maneuvering us through the crowd, and before long, we've escaped the masses and are on our way to class.

The rest of the day goes by as usual, same old boring routine, except that I can't get my mind off meeting Ryan. I honestly don't know what Destiny has told him about me, and I just feel like no matter what, it's going to be awkward.

Who am I kidding? It's always awkward for me when I meet new people.

Destiny comes and finds me after school the next day, and by that point, my anxiety is jumping through the roof. I slip on my sunglasses and try to play it cool as we walk over to the park. She squeezes my hand way too tight as we walk, but I know she's just excited. I can practically feel the energy radiating off her as she blabbers on and on. Finally, I manage to get a word in edgewise.

"What does he look like?" I ask her.

She lets out an excited squeak that sounds like a mouse. "Well, he's about the same height as you, and he has longish brown hair. He has these beautiful green eyes . . ." She squeezes my hand tighter, making me wonder whether or not my hand will still be attached to my arm when we get to the park.

We walk a little farther and turn into the park. The path changes from hard concrete sidewalk to gravelly dirt that crunches underfoot. Birds tweet overhead in the trees, and I can even hear squirrels chittering at each other and scampering around. I inhale, enjoying the scent of freshly cut grass and a cool afternoon breeze.

I inhale again, sniffing the air. "It's going to rain."

Destiny sighs. "Ugh, of course." She stops. "Okay, you stay here at our picnic table and I'll go see if I can find him. That way we have it covered, whether he comes here or I run into him. Maybe we can go to the ice cream shop or something so we don't get rained on. Sound good?"

"Yep," I reply and slide onto the bench of the picnic table. I freeze. "But how will I know it's him if he comes by?"

"Oh, I've shown him pictures of the two of us together, so he should be able to recognize you." Her footsteps crunch on the gravel as she walks away. "Oh yeah, and you can ask him what my middle name is, he knows," she calls, her voice fading as she leaves.

"Wow," I murmur, picking pokey wood splinters off the table. Destiny must really like him if she already told him her middle name. It took her forever to tell me what her middle name was. It's not like it's super embarrassing . . . just weird.

It's kind of nice to listen to the sounds of the park without Destiny talking so much. Children laugh nearby and I can pick out different bird songs, separating them from each other in my mind. A dog barks somewhere in the distance. The most prominent sound is probably the wind rustling the trees—either that or footsteps crunching on gravel as people walk by.

I start to hum as I pick at the splintering wood on the picnic table. The *crack* as I break off the bigger splinters is really satisfying. The wind brushes against me, pushing my hair in my face, and I can't help but smile.

"Hey, you're Natalie, right?"

The deep voice next to me makes me jump, pulling me out of my thoughts, and I turn toward him. I hadn't even heard his footsteps as he approached. "I am. Are you Ryan?"

"Yep, that's me!" The bench creaks as his sits down. "It's nice to meet you, Natalie. Where's Destiny?"

"Looking for you," I answer, fiddling self-consciously with my sunglasses before going back to picking at the table. A sharper splinter stabs me, and I wince. I tilt my head. "Destiny said I could ask you what her middle name is, to prove it's actually you, and not some random weirdo."

Ryan laughs, and it's a deep, full laugh. "It's Allegra. Her parents chose it because of its Italian meaning, without thinking about the medicine."

I nod and grin. "Poor girl."

The bench creaks again as Ryan leans forward. "So why is Destiny looking for me? I thought we were going to just meet here and hang out."

"It's going to rain," I explain. "We were talking about moving to the ice cream place, just in case."

He hesitates. "But the forecast didn't say anything about rain."

"Smell," I tell him, and I hear him inhale and exhale. "Do you smell that dampness in the air? It's definitely going to rain."

Ryan sniffs again. "I can smell it, barely. That's so cool."

"Ryan!" Destiny's voice carries across the park, as does the sound of her running feet. She stops next to the table, out of breath. She spoke between huffs. "I've been . . . looking for . . . you!" She puts a hand on my arm as her breathing grows closer to normal. "I'm glad you guys are doing good. Let's head over to that ice cream shop."

The table creaks as Ryan gets up and I slide off my side of the bench. "Lead the way, Destiny." Now I get to judge Ryan and see if he's right for my best friend.

Destiny hooks her arm in mine. "Rock on your right," she tells me, and I sidestep neatly out of the way. "I'll get your cane out of your backpack in a second," she adds.

"Wait, what?" Ryan asks, his confusion evident in his voice.

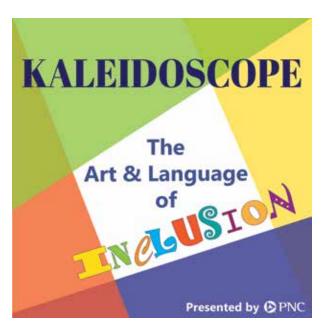
I laugh, hitting Destiny's arm. "You didn't tell him!"

"You must have done a good job being subtle," Destiny says, and I can hear the grin in her voice.

"Tell me what?" Ryan asks impatiently.

I raise an eyebrow and turn toward his voice. "Tell you that I'm blind."

♦



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# You're Going to Take the Poodle to See Macbeth?

### HANNAH SWARD

was in Santa Cruz visiting my father and stepmother, Gloria. We were on our way to a neurologist's appointment for Gloria's fading memory after taking a walk along the cliffs overlooking the ocean, stopping at the lighthouse to listen to the sea lions and watch the early morning surfers ride the waves.

I was driving. Gloria in the passenger and my dad in the back seat. In the rearview mirror I could see Dad with a moleskin pad on his lap. This was not unusual. There was rarely a time I ever saw him without pen and paper scribbling. He was a poet.

"Why aren't you married?" Gloria asked me.

She'd been asking this for the past twenty-five years including six times since we had left the house twenty minutes earlier.

"I have a husband," she said. "I've always had a husband. I don't always know where he is though."

"Well," my father said. "Right now he's in the back seat."

She turned to look at him. "Oh! Aren't I lucky. He's very handsome."

"What was that?" Dad asked.

"She said she's lucky, Dad, lucky to have a handsome husband."

It was at that moment on Highway 17, driving Gloria's 1998 gold Honda that I sensed something within Dad was shifting. It was subtle. Looking back I see it as my father, five years after Gloria's diagnosis of Alzheimer's, finding a way to respond as the writer he is. In turn, Gloria's experience also began to change. For the first time she felt he was really listening to her in a way that he never had. She felt heard.

"Compatibility Plus, a dating service, that's how your father and I met?" Gloria asked.

She loved hearing the story of how they met, and I loved telling it.

"Yes," I said. "But I had to push him to go, 'It's just a date' I told him. I could tell something was missing. He was withdrawn, lonely."

"You didn't want to go?" Gloria asked, turning to Dad. "I don't see why not, I'm a catch, a beautiful woman. I've always been a beautiful woman."

"But he did go, Gloria. He went off in his old avocado green Volvo with pink roses, chocolate-covered cherries, and his latest book, *A Much Married Man*. I told him to leave the book but he took it anyway. And you know what, when he

got home that night he told me, 'You playing Cupid paid off."

"What did you pay to meet me?" Gloria asked my dad, not waiting for a reply. "I got you for half price, I bargained with the match-making man."

\* \* \*

Sometimes he'd miss what she said and ask her to repeat it. But she couldn't remember. She couldn't backtrack in time. I watched as he listened, sometimes writing down what he heard. He was *all* there with her in a way I'd never seen during their thirty years together. I mean with her, in the *here and now*. His hazel eyes alive, looking into hers and hers looking into his. I could tell she felt heard. She was heard. Isn't that what we all want? To be seen and heard? I mean *really* seen and heard.

"Gloria?" I'd ask. "Do you know you have what every woman wants in this world?"

"I do?"

"Yes, you have a husband who listens."

She'd smile, almost mischievously.

"I know I do, honey. I am and I've always felt I'm the luckiest girl in the world."

\* \* \*

It wasn't always this way. In the beginning it was hard. Very hard. Seeing my dad try to cope with her diagnosis, her phases of forgetfulness. Getting lost on her way home in the car, having her license taken away, her anger. One time I was visiting and staying in Dad's writing studio. Early one morning she swung open the door and said, "Why the fuck are you here? Get out of my house."

I was terrified. What was this going to be like for my dad? How was he going to cope? For the first time in his life at the age of seventy-five he experienced writer's block. Words had been his world. Gloria had been his world. Now both as he had known were gone. He sought therapy. His therapist suggested a support group.

He went one time. It was too much too soon for him to hear all the experiences of husbands and wives forgetting who their kids were, how to eat, to shower, the need to wear and have their diapers changed, having to put their loved ones in a home. The isolation and day-to-day copings of the one you love going away. He was very clear that he would never put Gloria in a home.

He withdrew more and more into himself. On our long walks on the wooded trail he didn't say a word. We walked in silence. It wasn't a shared silence though. Not like how it used to be between us. He was somewhere else, almost as if the towering redwoods had swallowed him deep into the forest and he was gone. I missed having him with me. I missed Gloria too. The Gloria and the father I had known.

I loved and love my stepmother. My heart broke. I went through anger, resentment, fear. And most of all, fear for Dad. How, how would he cope?

\* \* \*

I never would have suspected the change that would occur not only with Gloria but also with Dad and their relationship.

I return to that moment in the old Honda Accord. An ordinary day on the freeway going to a doctor's appointment. Visiting and trying to be a good daughter, a good stepdaughter, showing up for those we love.

My father scribbled trying to get down the essence of Gloria's amusing, often startling words. Once we had gotten tickets to Shakespeare Santa Cruz.

What do you mean she's coming with us? You're gonna bring Cosette to see Macbeth? I know she's a service dog, but she's not gonna like it. She doesn't know the play. She'll be bored. She'll be so bored!

They became part of his book, Love Has Made Grief Absurd.

It's been two years since Gloria passed. She still speaks as strong as ever. And my dad, in the true nature of a poet, still listens, savors, and writes. ◆

Previously published in Red Wheelbarrow. Reprinted with permission of the author.

Hudson P	LUME
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### AT THE RIVER, REMEMBERING

Smoke disappearing into water is how we remember her, finally. Gray confetti in the breeze, when we let go of her.

The blue-ridged topography of the backs of her hands. The fingerprint of her voice still pressed against our ears.

We try not to remember her in the red velvet room, bruised by the air like a peeled apple, and her leaden arms filled with ice water. Forced to endure the carpeted wing of a way station,

with Muzak spinning like cotton candy around the walls, and manicured angels murmuring "arrangements" down the hall. Until, at last, we come to remember her here

by cupping her ashes in our hands, and leaning over gingerly to release the dust of her minerals. What more can we hold?

## THE CALIFORNIA RETURN VALUE

### KELLEY A PASMANICK

Tive just finished my grocery shopping at Safeway and roll out the double doors. I swivel my power wheelchair toward the trash cans. I put the latex glove on my left hand, and with my right one, I retrieve my empty tote bag from the handle behind me and set it on the sidewalk, although not without purpose. This empty bag will hold my recycling. Prophylactics donned, I've officially entered Phase Two of my time at the grocery store: picking plastic and glass bottles and aluminum cans out of the trash.

I heave myself out of my wheelchair and stand in front of the trash can. Bending my knees, I shove my whole left arm into the trash can, aiming my gloved hand toward its bottom. My fingers touch nothing. I straighten up and step back, lowering my head to get a better view of the inside of the can. I spy a plastic water bottle, its label still on, reading Dasani. Arching myself forward again, I guide my hand to it and pluck it from the trash. I examine the bottle. It isn't empty, and I untwist its cap and dump the remaining water out on the sidewalk. I replace the cap and

inspect the bottle's label once more. It's firmly stuck to the bottle. *As it should be*, I think. Every bottle should include a label around its base. The label is the key, for on it is the California Return Value or CRV.

As my coworker, Sande explained, the CRV is the amount of money paid to consumers when they recycle beverage containers at certified recycling centers. For beverage containers under 24 ounces, consumers are paid five cents. For containers 24 ounces and over, they are paid ten cents. "So, a 16.9 fluid ounce six-pack of water, for example," Sande said matter-of-factly, "would have a CRV of thirty cents."

I chuck the Dasani bottle into my bag. Five cents literally in the trash, I think, staring at the bottle too long, knowing that I've been staring at it for too long, but still unable to look away. I know why I stare. I know exactly why. I stare because the CRV, as the acronym indicates, ascribes the bottle with value, with worth. The CRV renders one man's trash another person's treasure. Mine. The California Return Value is a

paradox of progress, deserving not only of my stare, but my exertion.

I shift my gaze back to the trash can's contents. Something shiny catches my eye. My eye is practiced enough to recognize it at once: the gleam of glass. Without hesitation, I thrust my gloved hand into the bin again, extracting the glass bottle. It's a Snapple ice tea bottle, label intact.

"Are you okay?" someone asks as I drop the Snapple bottle into my bag. I look up, and a pretty blond woman with shoulder-length hair and bangs is looking at me with genuine concern. How I must look to her. I know I don't aesthetically look bad, having just come from work. I'm wearing a white camisole with a black-and-white wraparound striped sweater and blue jeans. My sweater and blue jeans are both designer, but what she doesn't know is that neither are new. Nothing I have is. The sweater is a hand-me-down from my fashionista older sister and the jeans are a Liz Claiborne throwback from 2004 bought new when I was eighteen years old, nearly thirteen years before.

I look at her. "Thank you, I'm just fine! I'm just collecting bottles for pocket money. Napa's expensive."

"It is," she agrees. Standing, I'm self-conscious of my wheelchair cushion, now exposed, with a patch on it, strategically ironed on to cover a rip in the nylon. I wonder if she notices it, hoping she doesn't, wondering if I only notice it because I know where to look. I also know my wheelchair isn't new either. It's nowhere near it. My Quantum 600 Power Wheelchair is as old as the blue jeans I'm wearing.

"I moved here recently, so I'm still adjusting to the difference in prices." Even as I say this, I wonder why I feel compelled to justify this to her. It's none of her business, and I know this, but then I remember the rule: I'm disabled, so I have to justify it. I have to justify me. I am obligated to give her a reason for why I do what I do because I am, have been, and will always be what she is not.

"I just wanted to make sure you were all right," she says. I smile a smile that must reassure her because then she is gone. I sigh, relieved, grateful that she didn't press further. I'm grateful for her restraint because what I've told her is only a half-truth. What I haven't told her is that I collect bottles and cans from the trash for money. Not pocket money, *just* money.

I haven't told her that I am prohibited from having cash *on me* at any time without being able to account for it dollar for dollar and cent for cent to the Social Security Administration. I certainly haven't told her that I owe the Social Security Administration

\$3,184.20 because I work full time and no longer receive disability-related monetary benefits. I also haven't told her that I'm not allowed to save any of my wages from my full time job because doing so would jeopardize my ability to receive state-sponsored healthcare since my employer, a disability-related nonprofit established for disabled individuals and run by disabled individuals, offers health insurance coverage that is too limited to cover the scope and breadth of my disability-related needs, all the while not even knowing if I'll receive state and federal tax refunds the following year while knowing without a doubt that the aforementioned tax refunds would be my savings. I definitely haven't told her that I reuse stamps that aren't canceled by the US Postal Service, reuse bags originally used for recycling for trash even if they are ripped from the glass bottles and aluminum cans, shop at The Dollar Tree—where everything is sold for one dollar—as much as possible, complete multiple online surveys on a daily basis to rack up enough airline miles for bicoastal travel since I can't actually afford to fly. And there's definitely not any way in the world that I would even *consider* telling her about what I view as no small feat which is to have deferred my student loans for another five years under the little known and even more underutilized Vocational Rehabilitation education-related deferment for the disabled. I have already been using it for the last twelve years, grateful that this particular deferment, however unknown and underutilized is also unlimited. And I most certainly have not told her that I only have the student loans because my doctors didn't understand the meaning of the terms, Total and Permanent Disability

Student Loan Discharge, for which I was eligible up until this year since my disability (cerebral palsy is a congenital neuromuscular defect) affects everything I do. It affects me totally and permanently as the name of the official discharge suggests, and for twelve years it kept me below the poverty line because I wasn't working, although not for lack of trying. The discharge only required me to meet these criteria for three years, and I met them four times over, but because my doctors thought that "total and permanent disability" meant that the disability had to be fatal, even though I told them they were mistaken, and they chose not to educate themselves about this loan discharge program, I am now responsible for \$40,000.00 of student loan debt.

I haven't told her any of this, but this is what I'm thinking about as I make my way over to the trash cans at the Ross department store, but not before another well-meaning woman comes up to me, thrusting an empty vitaminwater bottle toward me. "I wasn't going to throw it away," this new woman says.

"You keep it," I reply, my face hot with chagrin, knowing all too well that she's seeing on my face what I am feeling.

"I would rather give it to you," she says, to which all I can do is to say thank you and take the bottle.

This was a paradox of progress, a conundrum of consumption, indeed. I'm not harming anyone. I'm taking what others have discarded, what others have decided they don't want or need, so why do I feel guilty?

I sit there feeling ashamed of my resourcefulness—the attribute I admire

most about myself—when the first woman comes back up to me with her hand out.

"Here," she says, thrusting green toward me. "So, you don't have to collect trash just for pocket money."

Suddenly, I'm short of breath, having registered the significance of the green in her hand. I'm taken aback and pounce on her with an immediate, "Thank you so much, but I don't need this. Really, I'm only collecting recycling for pocket money."

She looks at me and says, "There's you and Rico out front. I always give him something when I come."

"I really don't need this," I reply again, having no idea who Rico is and frankly, not caring. "I have a full-time job. I have a master's degree." The irony of her last retort about "Rico out front" is not lost on me. Her mention of Rico is ironic because "rico" means "rich" in Spanish. I know this because I'm fluent in Spanish, having formally studied Spanish from the age of eleven through twenty-one. In addition to my master's degree, I have a minor in Spanish and a Bachelor of Arts in English which is composed of double majors in literary studies and creative writing. Out of the three Pasmanick girls, I am the most formally educated, having more letters after my name than both of my sisters combined. And yet, out of the three of us, I am the one who is paid the least and is collecting trash in an attempt to make up for the fact that one of these things—me—is not like the others.

As I gaze into the pretty face of this woman with shorn blond locks who is genuinely good enough to give me, a complete stranger, a gift of money, I realize that everything I've ever done is an attempt to make up for it. I hesitate to use the word premeditated here because of its close association to crime, so if not premeditated, then *calculated*. Every decision I've ever made has been a calculated one to what I can only hope has and will continue to undermine the fact that I never have been, nor ever will be what she is or what my sisters are.

My reverie ceases with the sound of her voice. "Really, giving you five bucks won't kill me. Fortunately, my husband works for a big company which allows him to do well enough that I can do full-time charity work."

Admirable, I think, honorable. She doesn't have to work, but she does, and not even for herself. This woman is what selflessness looks like, I think as I stare at her in wonder. It isn't often that I get to meet selflessness in human form, stare selflessness in her face. hear her voice and know her wants. Seeing the obvious ethical dilemma by taking from this woman—by literally taking from selflessness—I say, "I'm an independent living advocate at a nonprofit in downtown Napa. I serve the homeless and disabled of Napa." I stare at the five-dollar bill in my hand and stammer, "I know who needy looks like, and I'm not it."

"Keep it," she cajoles, pressing the bill back into my hand. With the other

hand, I remove one of my business cards out of my pocket, evidence to legitimate my words, to justify them. "You didn't ask for it," she continues. I look up at her knowing she's right. I didn't ask for the five-dollar bill, and I didn't ask to be what she and my sisters aren't.

"I'm doing the best I can with what I have," I reply, this time not intending to legitimize or justify anything to her, just simply making a statement of fact, my truth. One man's trash is another person's treasure. Mine, I think, as I very carefully unfold the five-dollar bill to put it in my wallet. •

Previously published in Tiny Tim Literary Review (June 2017). Reprinted with permission of the author.

## POST-POLIO, SLOW WALKS AND THE SEAL BAY BOARDWALK ON KANGAROO ISLAND

### **ALPHEUS WILLIAMS**

To see a World in a Grain of Sand And a Heaven in a Wild Flower Hold Infinity in the palm of your hand And Eternity in an hour

-William Blake *Auguries of Innocence* 

eople wear knit caps, coats, and scarves, frosty breath puffs from lips as they trickle back toward the bus in the parking lot. On the dunes, coastal spinifex shimmies in the onshore wind, long white lacy growth wafts like witches' hair. Connie, the park ranger, watches from the large window overlooking the boardwalk that zigzags out for more than half a kilometer down to the shore of Seal Bay. She can see patches of vibrant colored wildflowers growing close to the ground, sheltered from the wind. Wattle, bottlebrush, gum, grevillea, and banksia. It is their time to bloom, grace and color strutting their stuff and showing off. They herald the onset of spring but most of the tourists have come to see the seals and sea lions. The sky is soft and pillowy with gray-blue clouds lifting and drifting away. The wind carries the barks of the seals and sea lions from the beach half a kilometer away and the sky is beginning to clear. The seals have whelped. The small liquid-eyed pups shelter behind the dunes waiting for their mothers to return from the hunt. The tour bus leader is rounding up the last of his passengers. The driver turns the ignition. The heavy thrum

of the engine, a clarion call for straggling tourists to pick up their pace and board. The tour leader opens the door to the National Parks Shop and checks for dawdlers. The shop has emptied.

"All gone," says Connie. The tour guide smiles, gives her a thumbs up.

An elderly woman enters. Her arms are wrapped around herself. Her face flushed with chill. She and her husband were the first to enter the park this morning, a few hours ago.

"Whew. Cold!"

"You've been out there for a while," says Connie, "did you enjoy it?"

"Beautiful! That boardwalk is just wonderful. My husband's in his element. Can't tear him away. I'm waiting here where it's warmer."

Connie and the woman stand before the picture window. Their shoulders almost touch. A man with forearm crutches and camera appears on the boardwalk from where it was obscured by a dune. He stops, looks over the safety rail of the boardwalk where dunes rise to almost eye level, leans forward, lines up his camera.

"What's he doing?" asks Connie.

The woman squints through the window. "Who knows? Whatever it is I'm sure it will show up in his camera. We've been here for less than a week and he's taken hundreds of photos. A wildflower, driftwood, a rock, a bee deep inside a flower petal, spider's web, a single bird feather. Things he sees that most of us don't."

"What does he do with them?"

"Stores them on his computer."

Connie smiles. Turns her head slightly.

"I know," says the woman. "weird, huh? He says it's about learning how to look at things."

The man stops again, lines up another shot. Connie and the woman face each other and smile. Connie likes her. The man looks up and sees them watching. He waves, his forearm crutch dangles from his raised arm like a pendulum. Connie and the woman wave back.

"Wow! It must take a long time," says Connie.

The woman shrugs. "He's a polio survivor. The crutches protect him from falls. He only started using them a few years back."

"Polio?" asks Connie.

"Yeah. Young people don't know much about it anymore. Polio was a big thing before the vaccine. A children's disease. Sam got it as a baby, left him with a limp and a damaged leg but it didn't get him down. He led an active life.

Skin-dived, fished, hiked, camped. A few years back he was hit with post-polio symptoms. Pain, falls, fatigue. Times when he didn't want to get out of bed because he knew it would hurt."

"That's terrible," said Connie and she meant it.

"Wasn't nice. His GP didn't know what was wrong and neither did the neurologist. We researched it ourselves, Internet, wrote letters, and found it was post-polio and there wasn't a hell of a lot he could do about it. The more he fought it the worse it would get. The wrong kind of exercise would be like mass murder of nerve cells."

"What did you do?" asked Connie.

The woman shakes her head. "I was worried. Afraid it would get him down. He'd always been a fighter but now fighting was dangerous, would make it worse. He fretted. Said what was he supposed to do, sit on his derrière and wait to die?"

"He looks happy enough now," said Connie.

"Sam does things differently. He says when you slow down, see things, think on things, immerse yourself in their beauty, celebrate them, it opens up a whole new world. His only regret is that he wishes he learned to do it earlier. He calls them slow walks and they taught him about what was really important."

"Well," says Connie, "there's some wisdom in that when you think about it, isn't there?"

"Hey," says the woman. "Who am I to argue with it? It's made him happy and really the pictures he takes have a special beauty about them. And I suppose he's just found a different way to stay in the fight."

Previously published in Senior Stories, an anthology (2020). Reprinted with permission of the author.

### PLEASE PAY AT THE RECEPTION DESK ON YOUR WAY OUT

No one is saying that your illness is in your mind. You may well find yourself having all sorts of physical symptoms. But our tests are the source

that we base our opinion on. They are the best of what we have to offer. They should put your mind at rest. The small anomalies are meaningless. I'd like to proffer,

that any serious illness would leave a trace behind. But we haven't found anything. You should be reassured that your test results are so good. Nevertheless,

we would like to recommend a treatment of exercise and therapy; you must avoid becoming deconditioned and depressed. This has been proven helpful in some cases. No,

we are not familiar with the studies you are citing. We have our own evidence that we base our recommendations on. We don't know about any fudging of facts, nor of this new research, except that they have found nothing.

I'm afraid we can't help you any more than we have. Why don't you just go for a walk in the sunshine. Let us know if there's anything else; come back another time—my assistant will take your payment.

Previously published in Blanket Sea (February 2020). Reprinted with permission of the author.

## THE CIRCULAR MORNING

### (Intrusive Thoughts and Short-Term Memory Loss)

### **ERIC WITCHEY**

aints and sinners covered the walls of his apartment, and he hoped they cancelled out. The sinners came first, and he'd never give up his collection of poster women from the '60s and '70s. The saints hadn't become interesting until he was in his seventies, and suddenly a little bet hedging seemed in order.

The nightstand, like all the surfaces in his place, showed the routine of his mornings and evenings by row and rank of amber plastic bottles with hospital-white labels, pink warning stickers, and childproof caps. The morning ranks on the left seemed poised to do battle with the night ranks arrayed on the right, and the empty coffee mug he'd left between them sometime in the last week appeared to be the objective of both armies.

Aspirin no longer kept his joints moving, but he lived in an age of miracles and wonders, so his doctors had prescribed opiates for him. *First among the ranks*, he thought as he vacuumed the carpet, carefully looking out for any expensive tablets or capsules that might have fallen during his morning and evening fumbling.

The vacuum coughed, whined, smoked, and died, and relief washed through him. If that ancient monster vacuum had given up the ghost, could the end of his suffering be far behind? He wouldn't bother to fix it. Hell, he wasn't sure he could get it fixed. Did Kirby still exist? Did their lifetime guarantee still have some power left in it?

Somehow, looking up a Kirby dealer on the Internet felt wrong, like trying to text an old friend you haven't seen for thirty years felt somehow out of place, a violation of some sacred duty to speak in person—a sense of obligation set in place at a time when courtesy was a norm unchanged by time.

Maybe they'd send someone over and he wouldn't have to go out. Maybe they'd even wear a mask and he would let them in.

No.

He'd put the vacuum out on the porch.

But that was putting the cart before the horse. First, he had to know if Kirby dealers still existed.

Except, on his way to the desktop computer he'd kept limping along for ten years, the cat decided it needed his attention and, likely since the damned animal was a self-serving whore only when it was hungry, breakfast.

Harvey dutifully filled the creature's bowl, stroked its back twice, scratched at the base of its tail until it raised its rump and started eating, then stood and tried to remember what he'd been doing when the cat had interrupted him.

Probably making up a story. That's what he was usually doing. If it wasn't a half-assed attempt to put one on paper, it was some rant or another in an attempt to rewrite the past that haunted him, intruded on his moments, raised his blood pressure, and set him to cursing loud enough for the neighbors to occasionally complain about the crazy old man next door.

But he couldn't remember the story. Whatever it had been was gone.

Unless the computer was still on and the file was open, but it wasn't.

He stood over the dark screen and worn keyboard wondering when he'd lost the ability to remember what he'd been doing five minutes ago.

It started in the kitchen. He was sure of that. He remembered walking into the kitchen many times and not remembering why he was there. In a distant thought, he wondered why he remembered not remembering.

That didn't matter. He tapped a forefinger to the middle of his forehead to bring his thoughts into focus.

Surely, the first time had been in the kitchen.

Of course, he couldn't remember which time was the first time, so he couldn't honestly tell himself the first time had been in the kitchen. It could easily have been some other place.

Shit.

He left the little office he kept and headed for the kitchen. If enough memories had left him there, perhaps some of them were still there and he could find one.

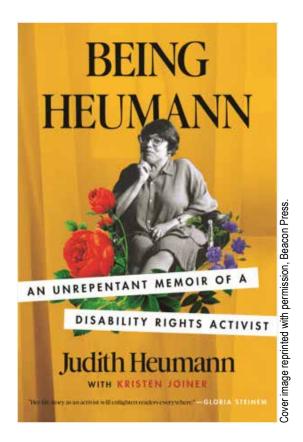
He found the cup of coffee he'd made earlier. Cold, and a thin skim of congealed milk across the brown surface, he loaded it into the microwave and hit the beverage reheat button. While he waited, he rinsed a few dishes and moved them to the dishwasher. Some were clearly a couple days old, and he thought he should really make an effort today to clean the house.

Once he was done with the kitchen, he'd pull the monster vacuum out of the hall closet and vacuum the carpets, starting in his bedroom.

The vacuum was missing. The place where it had stood was empty, and the closet gave no clue as to where it had gone or who had taken it.

The microwave dinged.

He headed for the kitchen, but the cat interrupted him, letting him know it was time for its breakfast and the ritual scratches it required every morning.◆



## How to Make a Fuss

### FIONN PULSIFER

Review of Being Heumann: An Unrepentant Memoir of a Disability Rights Activist by Judith Heumann, with Kristen Joiner, Beacon Press, 2020

eumann's memoir, Being *Heumann*, is a brilliantly told recounting of her determined fight for accessibility. She describes her first experiences with discrimination and segregation, from childhood to her teen years; she explains why and how she sued the New York Board of Education for her right to teach; she details how she moved back and forth across the country, following the fight for the rights of people with disabilities. Judith Heumann was instrumental in the shaping and success of the disability rights movement. She was constantly in the thick of it, constantly the most determined person in the room. Heumann obliterated obstacles and left a trail of accessibility in her wake.

One aspect of Heumann's memoir I found particularly interesting is her constant and subtle analysis of her own standing in the world. She reminds us consistently that she is a disabled, Jewish woman, and each of these identities influenced her life in different ways. In the prologue to her memoir, Heumann explains that her parents grew up in occupied Germany, and each emigrated to America as children. In what she calls "Hitler's pilot proj-

ect for . . . mass genocide," German doctors "encouraged parents to hand their young children over to . . . pediatric clinics, where they were either intentionally starved or given a lethal injection" (xii-xiii). Heumann believes that, when they were confronted with a recommendation to institutionalize her from a well-meaning doctor, her parents' experience with the Nazi party informed their decision. "They had personally experienced," she explains, "what happens when an entire country chooses not to see something simply because it is not what they wish to see" (xiii). The violent oppression

Heumann's parents witnessed and experienced shaped their characters and their beliefs which, in turn, shaped her life. Their experience taught them to be vocal in the face of oppression. They taught her to value and stand up for herself. Her mother fought relentlessly against the discrimination keeping Heumann from public school. Heumann's mother taught her how to make a fuss.

Heumann doesn't dwell on discrimination. Though her life's work was an anti-discrimination movement, resulting in numerous anti-discrimination laws for people with disabilities, Heumann focused on where she was going, not what was in her way. This is also true of the sexism she faced; though she does not dwell, she does examine how sexism shaped her career. After founding the World Institute on Disability (WID) with two peers, Joan Leon and Ed Roberts, Heumann found herself pushed out of the codirector position she shared with these colleagues in favor of one director-Ed. There had "been no process . . . no discussion with [them] at all . . . The men on the board, and it was mostly men, had simply made a decision." Heumann believes they may have made the right decision, as he was a good fit for the position, but is troubled by the implications. She tells us that she did not "push [herself] forward in the same way Ed did." She did not "presume privilege." She relates the conflict many determined, passionate, and ambitious women face-being raised to be loud, while being raised to be quiet. Heumann spent her life standing up for herself while simultaneously being "deferential to men, even when [she] didn't mean to be" (160).

Adding to this conflict is the fact that the women's movement has, historically, been exclusionary. Mainstream feminism, throughout its history, has ignored disabled women, Black women, LGBT+ women, and, essentially, anyone who did not fall within the tight constraints of what was considered a "respectable" woman when the movement began. As Heumann explains, women with disabilities were "always pushing" to be recognized by the women's movement but were left "basically on [their] own" (162).

I would love to hear more about Heumann's interactions with and thoughts about the women's movement. She strikes me as a powerful voice for civil rights in any form, and I wonder if she ever had the opportunity to focus her energy on the intersection of ableism and sexism—hers is a viewpoint that I believe would be invaluable to feminism's trajectory.

What struck me most about Heumann's character, other than her unending energy and deep commitment to civil rights, was her humor. One can easily tell She relishes the wittier moments in the disability rights movement. An example of this comes from the chapter "The White House," where Heumann recounts the last leg of the push to get Health, Education, and Welfare (HEW) Secretary Joseph Califano to sign the Section 504 regulations which would provide this civil rights clause with some "teeth," so to speak. Heumann and a few colleagues left their sit-in at the San Francisco HEW offices to lobby for the regulations in Washington, D.C. Once there, they met with some sympathetic representatives but found that Califano and President Jimmy Carter were reluctant to face them. In fact, they both literally "slipped out the back" each time Heumann and her colleagues attempted to confront them. Heumann and her colleagues decided to take advantage of the contradiction between these actions and "Carter's 'Open Door Administration' slogan." They would force Califano and Carter to face the choice of "speaking with [the demonstrators] or leaving through the back door." Heumann and her team

wrote press releases pointing this out; she gifts us this tagline from one such release: "We remained 'stymied by the administration's new backdoor policy" (144). I believe Heumann's sense of humor, as well as that of the people she worked with, was part of her impressive resilience. Again and again, Heumann and her colleagues faced discrimination, pity, dismissal—on more than one occasion, they were flat-out ignored. Though her tone is at points somber or enraged, it is never disheartened. Heumann maintains a level of hope and humor that has clearly served her well.

If I were her publisher, I might have encouraged Heumann to focus, at least for a chapter, on her internal struggles. Much of this book gives us a personal insight on a larger movement, but I am left wondering how Heumann surmounted personal obstacles; she must have felt scared, or unsure of her place at times. Was she hurt by those in the women's movement who ignored her, frustrated with the nag of sexism throughout her career? Though she hints at this, her focus in remembering is the same as it was in life: the work. I would have appreciated a more explicit and vulnerable self-analysis.

More than a remembrance, this memoir feels like a handbook on advocacy. Through Heumann's story, we learn about the tactics she and the other members of the disability rights movement used, the ways they came together, the culture they created, and how they not only survived, but thrived. As Heumann tells us, "most things are possible when you assume problems can be solved" (7). Heumann, always a teacher, uses her book to pass on to us the lesson her mother passed to her so long ago: how to make a fuss.◆

**Sharon Hart Addy** is former teacher and part-time writer living in Baraboo, Wisconsin. Her work has appeared in *Whimsical Winter Wonderland* (2021), *Mystery Magazine* (2021), and *Heartbreaks & Half-truths* (2020), among others. "I enjoy writing and I hope my stories expand my readers' experience and understanding as it entertains them."

Evelyn Arvey is a writer and artist who lives in Seattle, Washington, with her husband and six cats. She was editor of *Stories From Our Center: Lives Challenged by MS* (2021), a collection of candid, raw, and heartfelt memoir pieces and short stories, written by people with MS. Her work has appeared in *Pentimento* (2016), *Stealing Time* (2012), and *Pedestal Magazine* (2012). She says, "I write because I have so many stories I want to share. I am an artist because I cannot see any other way of being."

Conny Borgelioen lives in a seaside town in Belgium. Her poetry has appeared in *The Emma Press Anthology of Ill-ness* (2020) and *Atelier of Healing: Poetry About Trauma and Recovery* (2021). She says, "Writing poetry has helped me make sense of my new reality. It keeps me sane in a world where we are constantly judged by our physical appearance and capability."

Chelsea Malia Brown is an artist and poet living in Gig Harbor, Washington, whose work is heavily influenced by her disability. "I create as an outlet for processing physical and emotional pain, celebrating the body, and reclaiming lost power." Her art has appeared in *Al-Tiba9 Contemporary Art Magazine* (2022) and *Strukturriss* (2021), and her poetry was published in *Seattle Erotic Art Festival Lit Anthology* (2020).

Daylyn Carrigan grew up in Washington state and recently graduated with a bachelor's degree in English writing from Pacific Lutheran University, where any time not devoted to writing was dedicated to singing a capella. Her work has appeared in *Saxifrage* (2021). "My disability influences all of my work, even if a piece is not inherently disability centric. My hearing impairment changes the way I interact with the world and how the world interacts with me, which shapes the way I approach my writing."

Dawn Rachel Carrington is a freelance writer, an entertainment journalist, and an author living in Summerville, South Carolina. Her work has appeared in *The New York Times* (2020), *Rooted in Rights* (2020), and *You&Me Medical Magazine* (2021), among others. "After I became disabled, I didn't want to write about it or talk about it, but over the years, I've learned it is important to discuss. People need to know that disabled people are just as good, or bad, as able-bodied people."

Courtney B. Cook is a copywriter living in Abilene, Texas, with a M.A. in English from Abilene Christian University. Her work has appeared in *Kaleidoscope* (2022) and Lubbock Christian University's *Chap Book* (2020). She loves learning new things and teaching others about them through writing. "When I'm not working, I enjoy rock climbing, swing dancing, and crocheting. The most important things to me are my faith, my family, and my friends."

Matt Flick is a police administrative aide for the New York Police Department and lives in Staten Island. "I am a person who always sees the humor in the world around me. My writing is definitely influenced by my disability. Even if I'm not specifically writing about my disability, as a person with a disability, I am naturally more observant of people and my environment which gives me a unique perspective of the world."

Jane Gabriel is a wife, mother, and award-winning author of fiction and nonfiction. She lives in San Antonio, Texas, and is passionate about educating others and advocating for people with disabilities. Her work has been published in *The Writer* (2022) and *Please See Me* (2022). "Disability is a daily challenge for me and my struggles with it have made me far more empathetic and kind toward others and myself."

**Stephanie Harper** is a writer, author, editor, and part-time church administrator living in Littleton, Colorado, with her family. Her novel, *Wesley Yorstead Goes Outside*, was published in 2020. Her writing has also appeared in *Healthline* (2021) and *Living Lutheran* (2019). "I often write about my experiences with chronic illness, both what it's like to live as a chronically ill person and also how it has affected my professional life." Her favorite time of day is brunch.

Robin Knight is a neurodivergent writer of mixed race living in the United Kingdom. His work has appeared in *Poetry Wales* (2022), *The American Journal of Poetry* (2022), *Rattle* (2021), and *The North* (2019), among others. "Writing is an essential urge in me. It's how I communicate with myself and explain what's going on to myself. My brain is like a grandmother's fridge—things long forgotten by others remain there preserved."

**Judith Krum** is a retired teacher living in Sanford, Florida, who describes herself as an educator, a cheerleader, and an advocate. Her memoir, *My MS Journey: Recalculating*, was published in 2021, and her book of prize-winning poems, *Poetic Prisms*, was published in 2017. "My work is informed by my total life experience; my disability is part of that total experience."

Fay L. Loomis was a nemophilist (haunter of the woods) until her hikes in upstate New York were abruptly ended by a stroke. She is a member of the Stone Ridge Library Writers and the Rat's Ass Review Workshop, and her poems and prose have appeared in a variety of publications. "I have candidly discussed and written about my disability which has helped in my healing process and inspired others."

**Judy Lunsford** is a writer living in San Tan Valley, Arizona. Her work has been published in *Disabled Tales* (2022), *Alternative Holidays* (2022), and *Promise in the Gold* (2021), among others. "Brain Surgery, radiation, and chemotherapy for cancer have slowed down my writing quite a bit, but I am determined to keep getting better and keep at my writing." Lunsford is also partially deaf from Meniere's disease.

**Vesper North** lives in Orange, California, and is a teacher. Their poetry has been published in *Meditating Cat Zine* (2022) and *Ouroboros* (2021). "I write because I love to tell stories. It's the unique perspective I have, to see and make sense of the darkness in others, that has influenced how I create characters and write stories."

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

Kelley A Pasmanick is a thirty-six-year-old woman from Atlanta, Georgia. Her work has appeared in Wordgathering, Squawk Back, Praxis Magazine, The Mighty, Loud Zoo, The Jewish Literary Journal, Umbrella Factory Magazine, Breath & Shadow, Kaleidoscope, and Tiny Tim Literary Review. Pasmanick has been a repeat contributor to The Handy, Uncapped Pen and Disabled World.

**Hudson Plumb** is a proud father, husband, healthcare strategist, and lifelong lover of poetry, living in New York, New York. After a lengthy hiatus, he is grateful for the opportunity to return to writing. He has spent a considerable amount of time on a remote river near the border of Oregon and California and says, "My experiences there, and surrounding events, have deeply influenced my work."

Fionn Pulsifer lives in Glendale, New York, and is currently pursuing a degree in justice studies at Arizona State University. "My disabilities directly affect the way I interact with the world—what work I can do, how I communicate, what I prioritize. I believe that an accessible world is one that is equitable, supportive, and safe for all, and I work to help create that future."

Jess Pulver is a mother, clinical therapist, and aspiring gardener living near Portland, Maine. Publication credits include *The Good Life Review* (2022) and *Literary Mama* (forthcoming January 2023). Her son has cerebral palsy, which she says, "has defined our experience as a family . . . I write because I want to open up space for more honesty and complexity in our discussions about our lives."

**Kristen Reid** is a graduate student at Tennessee Tech University, studying to become an English educator. Her work has been published in *BS Lit* (2022), *Broadswords and Blasters* (2019), and *Night Terrors Vol. 19* (2021). She lives in East Tennessee with her black cat, Lestat, and says, "The only way I can work through a bad MS symptom flare-up is to write. I also find that expressing this for others to read gives me joy because I want others like me to know they are not alone in their struggles."

Hannah Sward lives in Los Angeles, California, and is the bestselling author of *Strip: A Memoir*, published by Tortoise Books (2022). Her work has been widely published in literary journals in the US, Canada, and the UK. Sward is also on the board of Right to Write Press, a nonprofit that supports emerging writers who are incarcerated. Regarding the piece in this issue she says, "I wrote this essay to give the families and those struggling with Alzheimer's hope beyond the old narrative."

Alpheus Williams is a retired teacher living in Australia who had polio as a child, which returned as post-polio syndrome later in life. His work has appeared in *Mystery Tribune* (2022), *The Write Launch* (2020), and *Barren Magazine* (2019), among others. He is an activist for the environment, community, and heritage, and says, "As a teacher my aims were to inspire enjoyment and love for literature and learning and to encourage self-respect and critical thinking in young adults."

Eric Witchey is an award-winning writer living in Salem, Oregon. His work has appeared in *Short Story America Anthology* (Vol. II, 2012) and *Realms of Fantasy*, among others. "I am driven to understand myself and others. Writing gives me a mechanism for exploring possible perspectives and providing those explorations to others."

Carol Zapata-Whelan is a university lecturer in Spanish who lives in Clovis, California. Her work has appeared in *Newsweek, Los Angeles Times, The Rotarian*, and other publications. She is married and has five children. "My son Vincent is the world's first M.D. with fibrodysplasia ossificans progressiva (FOP), which turns muscle to bone. I write to raise FOP awareness and give hope by sharing Vincent's adaptability story."



Katherine Klimitas, Baby Orangutan, 2017, watercolors, 6" x 6"



Katherine Klimitas, *Giraffe*, 2018, watercolors, 6" x 8"

