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THE ART OF LIVING

"The Tree That Reminds Me" by Rhonda Zimlich

"The Dissection of Joan Giles" by Kelsie Bennett

"Kathryn the Great" by Tim Campbell

**CREATIVE NONFICTION** 



**FEATURED ESSAY** 

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Dave Wisniewski, Doc Elliot, 2010, oil on canvas, 48" x 48"

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



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## THE TREE THAT REMINDS ME

### RHONDA ZIMLICH

The crisp fall air stung my right ear, reminding my left ear of its numbness. My legs begged to stretch. I drew circles in the air with my feet, awakening them to the coming task, and felt my ankles warm. This is how I prepared for my regular distance of three miles. I windmilled my arms and rolled my head and neck along my shoulders. My body begged to run.

In went the earbuds to waves of "Something in the Way She Moves" that stirred my feet with a slow rhythm and pulled me forward, a mere trot in the beginning. As I moved, I scanned my body, greeting the soles of my feet, feeling them kiss the earth with each step. *Hello*, I thought, to the swing of my arms; each elbow pulled back in stride like a locomotive's rocker-arms. My shoulders spread and the breath in my lungs extended deeper and deeper, expanding my ribs and bathing my heart in rich oxygen. *This is the way the body works*, I thought.

During those early runs I didn't have fatigue. I didn't have doubts. I didn't even have multiple sclerosis—I did, but it was easier to forget back then. I arrived in the run with my mind on my strength, observing my working form. As my legs pulled and pushed at the earth, my attention went outward to my surroundings.

The route took me through my West Eugene neighborhood, past a collection of eclectic homes adorned with front-yard gardens and "Free Tibet" flags. Rain had darkened the asphalt of the street and puddled the sidewalks but let up for

the morning. I could smell a storm distilling nearby, perhaps along the coast range, typical for Oregon. The soft, gray sky hovered above. A pause in the music gave way to a shush of breeze described by the canopy of branches overhead, a standard refrain for autumn in the Pacific Northwest. Great trees framed the sidewalk. The neighborhood had yet to awaken as I stole away on my private endeavor, my solace, those few miles of solitude.

A quiet voice within me coaxed my body to keep moving in ways that most people do not, to get up and go, to run. The cool breath of morning filled my lungs. Cold nipped my cheeks. And I ran like a Shakespearean angel, express and admirable, a miraculous feat which denied the disease in me. Early on, I ran for clarity and not speed, ever stretching my breath, emptying my thinking mind. I ran to feel the body of me, to become my physical self once more. I ran to outrun the encroaching numbness. For joy and breath, and a hundred different things, I ran. Mostly, I ran because I could. I crossed a narrow alleyway, then turned at Taylor Road. Cherry trees lined the sidewalks, shedding their leaves in the morning breeze. They cascaded like ticker tape, championing me on. Their falling beauty pulled me in and, at once, I became a part of the show unfolding.

This morning's stage welcomed me to the scene. A cat waited on its porch, eager for access to its warm home. Pebbles filled a driveway which led to a house adorned by Halloween décor. A silly witch stirred a cauldron. A ghost peered out the window frame. And now, a great black bird moved from a

wire to a branch, an effortless-looking motion that seemed more like a hop than flight. I envied its ease of movement. A lone car glided past, puffs of its white steam issuing complaints against the cold. I watched it turn the corner ahead and then I was alone again.

I turned left; the pavement turned to bark-mulch, the music turned to a woman holding her tongue knowing silence would speak for her. Steady, unlike my left hand when it trembled with nerve damage, I strode the length of the path. Rhythmic, unlike the courage I held against my fearcourage that waivered when my symptoms flared—I held my head high. Fast, so unlike my typical movements, carefully measured, clumsy despite my efforts, I flew. Balanced. Gliding through the morning, my mind along for the ride; my body surprised me, mocked the disease that threatened me, a silent and abiding menace. I came around the bending path, through the trees, mist clinging to their exposed roots. Then I saw the tree, the tree that reminds me. I see her still in my mind's eye, both harbinger and helper. If I close my eyes, I see the silhouette of her etched against the void. I almost forget her until I don't, until she comes to me or I to her. That day, I had returned. Since then, a thousand times she's come to my memories, to my waking dreams.

The tree stood at mile two, a great and old maple. That time of the year its leaves were all but gone, having drifted off to become the soil and other things. Yet even without her grand foliage, she reminded me of disease, with her exposed innertrunk stripped of its protective cambium layers, like delicate nerves stripped of their myelin. The scar along her neck laid plain the damage she knew, showed where the lightning had traveled as it attacked. The tree leaned in the direction of her injury, curled around the damage in a protective gesture. The mutilation along her trunk and bark a telltale sign of how her life changed once the strike occurred.

When lightning strikes from cloud to ground, a billion joules of energy detonate in a flash. The moment of detonation itself is significant. Energy always accompanies a time component. If that same billion joules of energy were spread across the lifetime of the tree it would photosynthesize its entire livelihood. Instead, the abrupt discharge of energy ripped its bark from its trunk and laid open a vast wound. It seared her length rendering a deep, interminable scar, now

as much a part of her as her canopy, branches, and roots. The attack, a singular event in her life. Disease, for me, recurring.

The bark of my nerve's branches, myelin, had been struck by my own immune system. These attacks occurred many times, and would occur again. Myelin stripped and scarred. Without this protection, my nervous system short-circuited. Numbness crept up my limbs. The largest scar between my C3 and C4 vertebrae the size of a dime—a dime! No other scar on my outside body was as large. Yet, there I was running, working as properly as I ever had. And there she was, too, that great maple squared off at me upright and proud. She did not lay down after that lightning strike. Each spring, she reawakened and filled her working branches with budding leaves. Each summer she turned sunlight into sugar deep within her mighty veins. Each fall she cast those leaves off again contributing to the nutrients of the soil around her. She reminded me that morning, and every morning I passed her, that life persists. We make choices to ensure that it does.

This life of mine moved me past the tree. By then, I felt tired. The tree had also reawakened the staggering memory of my limitations, of my body's own strike to attack itself, mistaking healthy tissue for disease. I rubbed the spot on the side of my thigh where I last injected my medication. A lingering pain and a lump under my skin hosted a spiderwebbed contusion, the bruise benign and necessary but reminding me nonetheless. By then, I felt my heart thump in my chest, and I heard it as well, heard it over the song reverberating through a long fadeout. By then, I knew more about MS than many doctors. Each manifestation of disease, its minor and major difference for everyone, how it impacted me. By then, the tree was behind me, though she remains with me still.

Recent talks about trees include their cognitive ability to communicate in a language we cannot understand. I am not sure I endorse this theory entirely; as humans, we are prone to anthropomorphize in order to assuage our own position in nature. But I do believe in the message I received from that tree. If cognizant of her own damage, she chose to persist. Even if not cognizant, she persists still. Whether I am thinking about the disease that ravages me or not, it's still there. And I can make the same choice: to persist. How infinite in faculties, in form and movement, how express

and admirable is the miracle of our bodies, is this miracle of the beauty of nature around us, too, ever reminding us, ever teaching us.

The final push moved me back to the pavement, through the neighborhood streets, down the familiar road where I lived. In the end, I had fatigue but I ran anyway; I had doubts but I pushed at them with each new stride; I had fear but I pressed on. In the end, I finished the run, but it was my courage that won the day, that incessant competition between fear and faith that exists beyond my myelin. In the end, I pushed back at the disease. I couldn't allow MS to be a factor in the equation or else it would have stopped me in my tracks. •

## THE ART OF JORDAN WILSON-DALZELL



Jordan Wilson-Dalzell, Distorted Vision, 2023, digital art

### **Artist Statement:**

I am learning my body in new ways, learning to listen. Many nondisabled people see disability as an Ending; disability justice means that where they see a wall we see a canvas waiting for our voices too.

## THE DISSECTION OF JOAN GILES

### Kelsie Bennett

orpse, cadaver, carcass: death relies on one person equating to one body. In hospitals along the east coast, Joan's body has been taken apart and copied. Doctors are better at dissecting than mending.

\* \* \*

"They're meant to be X-rays?"
Harrison asks, poking Joan's collages with the end of his pen.

Standing next to the easels that display her work, Joan shifts on her feet to alleviate some pressure on her spine. She still aches from meticulously gluing together the collages. They had to be perfect. Harrison has a reputation on campus for being extra harsh on undergraduate artists who apply for showcases; he thinks they should wait to be master's candidates. But in two years when Joan's old enough to consider a master's, she may not have the strength to get out of bed, much less make art. "One X-ray, one MRI."

"Intriguing. I appreciate unique subject matter." Harrison's eyes skate

over the hundreds of black and white photographs of Joan patched together to mimic the angles of her spine. The photos' edges are torn, giving the portraits a sense of decay. "And who was the photographer?"

Joan clasps her hands behind her back to hide shaking fingers. "All two hundred and eighty images are selfportraits. I didn't involve any outside photographers."

He looks at her over his glasses. "Why's that?"

"I wanted to center my perspective."

Harrison turns away to the clock ticking on the wall. "Right now the only perspective I'm seeing is a lot of your face."

If Harrison thinks that's an insult, it means he's missed the point. Joan has spent too much of her life describing her body's failures to people who weren't listening, explaining the obvious to those who will never experience it. She wrung out every last drop of her energy to construct collages

that illustrated her pain. A visual aid to make someone finally *understand*. If she can't get through to Harrison, she won't have any way left to speak.

"My disabilities set in during my early teens. I spent those years in doctors' offices. Being under medical scrutiny for so long made my body into more of an object for doctors to examine than—" Joan can't recall what her body was before it was medicalized. "I don't know, however it's supposed to feel. I'm the subject of a lot of X-rays and MRIs, so my spine is in hospitals all over. It's hard not to feel like I am those X-rays. Those objects. Because I do feel split between twenty-some X-ray sheets instead of like one whole body."

Harrison half-turns back on his heel. "And?"

"I used only self-portraits because I wanted to put myself back in the picture. To . . . reclaim that space."

She must have hidden her beating heart behind enough jargon from her Art and Politics course, because Harrison nods. Having her life critiqued alongside her art is better than usual: usually, just her life is judged.

Harrison says, "Tell you what, Miss Giles. Make me one more collage, write that spiel into your artist's statement, and I'll add you to the spring exhibition."

Joan's eyes widen. In the unexpected rush of ecstasy, she wants to hit Harrison, make him feel an emotion as intense as hers. Years of Joan trying to communicate her pain, and Harrison is the first professional to say, *Yes, I see*. "I can definitely do that. Thank you, Dr. Harrison. Thanks."

He smiles without teeth. "I look forward to seeing what you come up with. Have it done by Friday."

Joan is going to need more decoupage.

Sliding her collages into her portfolio bag, she hustles out of the fine arts building to meet the traffic of Sixteenth Street. She was up late last night from her usual headache, the one hundred thirty milligrams of caffeine needed to suppress it keeping her awake until four in the morning, and her late start forced her to skip her morning spinal stretches to make her meeting with Harrison on time. She'll go back to her apartment and stretch after she hits the art supply store.

The crosswalk sign's orange hand blinks at Joan. She launches herself off the curb to make the light. Halfway across the intersection, her bag's strap slides off her shoulder. Her work, her life, her breakthrough: she can't let it crumple. She bends to save the portfolio before it hits the street. A muscle low in her back seizes.

She tries to straighten, but the movement jolts a vertebra out of place. The misalignment shudders up the column of her spine and her nerves spark like ripped wires. When it reaches the top, her neck locks, and the pain pitches Joan forward. She's forced to

watch her elbows hit the asphalt in the reflection of an MTA bus's front window, unable to turn her head away. The skin on her palms rips as they fail to catch her.

She tries to army-crawl forward but cries out. Her reflection grows larger. The bus doesn't slow down. From the sidewalk, a stranger yells at her to move. If she could, she'd scream back, *Don't you think I'm trying, idiot?* 

Joan sees her back contorted in the bus's warped glass, as ruined as it's always felt inside. She curls her arms tight around her portfolio bag.

\* \* \*

"It's because she's always hunched over drawing," Joan's mom says.

Having her life critiqued alongside her art is better than usual: usually, just her life is judged.

Dull green walls. A yoga mat on the floor like a rug. An examination table covered in holes. Next to Joan, a picture of a perfectly straight spine. Her orthotist's office looks exactly as it did when she was thirteen.

No, she refuses to be here again. She opens her mouth to tell her mom she's leaving, but no sound comes out. She can't feel her lips. She can't feel any of her body, actually, besides the throbbing ache of her back. But that pain is so familiar it may as well be a heartbeat.

Joan's mom says, "She draws on her floor. I bought her a nice desk and she won't use it."

Thirteen-year-old Joan whines, "That chair hurts my back. It's got lumps."

"Because you don't sit up straight in it!"

Hearing her younger self speak is as disorienting as listening to her own voice on tape: a recognizable stranger. Joan doesn't know how they're in the same room together but doesn't want to stay long enough to find out. The art supply store closes in an hour. Despite her loss of legs, she attempts to move forward.

She can't leave the wall. It's like she's as flat as the photo of the perfect spine next to her. That photo that always came in a pair: it was meant to be next to Joan's X-ray, to highlight how crooked Joan's vertebrae were compared to—

Joan may have died, she realizes, but she's still attached to part of her body. A version of it.

She's trapped inside her old X-ray.

She should have known that once her flesh-and-blood body failed, her X-rays are what her soul, spirit, *Joan-ness* would inhabit next. When doctors made X-rays of her back, it always felt like fragmentation—her spine becoming a separate piece from the rest of her body, that part of her leaving to exist elsewhere. The irony: she's finally an object, just like how her doctors always saw her.

"This brace will certainly help with posture," comes the smooth voice of Dr. Logan. He wears his lab coat open over a graphic T-shirt, which isn't as cool as Joan remembered it being. "Why don't you get up on the table here and we'll take your measurements, Joan?"

The examination table is several feet off the ground, and young Joan has to use a step stool to get up. It's cold plastic littered with holes the size of quarters. The same size as the pegs Dr. Logan holds. If older Joan had arms, she'd smack those pegs out of his hand.

She can't relive this. She tries to go back to before the bus hit her, to remember how to take a breath, but the X-ray is so compressing she can't imagine how her lungs ever inflated.

"I'm going to place these around you to figure out how wide your brace needs to be at each part of your body," Dr. Logan says. He plants the first peg by young Joan's right hip. "When we get to where your two spinal curves are, I'll use the pegs to adjust your body to the position the brace will hold you in."

Dr. Logan reaches toward the wall and touches older Joan with his index finger. Older Joan puckers under the force with the sound of warbling plastic. The perfect X-ray next to her is left alone. Joan always wondered if that spine belonged to anyone or if it was computer-rendered, an impossible ideal for doctors to point to and say this is why this hurts, this is where you went wrong, this is how broken you should think of yourself as. Maybe the perfect X-ray would be less intimidating if Dr. Logan had touched Joan's actual back instead of acting like it didn't exist, like the cropped scans—cut off at her clavicles and hips—were all that mattered.

Dr. Logan says, "As you can see on your scan here, your lower curve is more pronounced than your upper. We'll find a happy medium to help them both."

"Okay," young Joan says. No reason yet to not believe him. Dr. Logan walks away from older Joan and back to her younger self.

Pegs are driven into the table, snug against young Joan. She squirms as she's enclosed. Her chest heaves. Dr. Logan puts a hand on her stomach to keep her still. She didn't understand at thirteen: if Dr. Logan was a professional, why didn't he notice something was wrong? Stuck to the wall, older Joan is as helpless as she was the first time she lived through this.

"Give me a second. Give me a second," young Joan says.

Her mom touches young Joan's cheek with the back of her hand. "What's wrong, Joanie?"

"It hurts."

"How could it hurt? He's just taking measurements."

"And only a few more," Dr. Logan coaxes.

# Stuck to the wall, older Joan is as helpless as she was the first time she lived through this.

Young Joan clamps her eyes shut. Maybe to her mom and Dr. Logan, it looks like she's zoning out. Older Joan knows she's trying not to cry from claustrophobia and the pressure on her spine. They were hot tears, embarrassment, and pain.

"There, done. Go ahead and sit up."
Dr. Logan offers his hand. Young Joan takes it not because she wants to but because she's still shaking. He leads her over to his computer monitor, where he inputs measurements before he switches to a screen full of different back brace designs.

"You get to pick whatever pattern you want on the outside," he tells her. "I'll scroll through."

There isn't even anything good. Dinosaurs, fluffy kittens, cartoon fire trucks. If Joan were designing it, she'd have drawn an undersea scene or the sky, to make the world seem bigger even as she's trapped in the confines of the brace.

Young Joan picks the blue and brown tartan print. Being thirteen means she's in a rush to grow up.

She doesn't know that time doesn't always equal healing.

\* \* \*

With a swish like a paintbrush flicking back and forth over canvas, a projector comes to life. Older Joan shines onto the wall as a force of bright light. Gesturing to older Joan, Dr. Martinez says, "This X-ray shows her curve has only worsened by four degrees. That's good news."

The pediatric orthopedist's office was never a place of good news. Joan's mom crosses her legs in the scratchy examination room chair made for onlooking parents and spouses. The lucky chair, Joan had coined it. The sick, unlucky person didn't get to sit in that chair. "She promises me she does her exercises every night before bed, but she won't let me watch. I don't know."

Sometimes Joan did her spinal stretches. Sometimes the pain was so intense that the idea of a Superman, lifting her arms and legs while lying on her stomach, made her nauseous.

Sometimes instead of stretching, she laid on her floor and sketched the murals she wanted to paint on her bedroom walls. Joan's walls were sterile like a doctor's office. Months after this appointment, she would defy her mom and put up chalkboard wallpaper to draw on.

"Kids don't always understand why caring for themselves is important," Dr. Martinez says. "Try to get more involved if you can."

Joan's mom's forehead pinches. "I'm not uninvolved. Don't insinuate that."

Sixteen-year-old Joan pushes aside the curtain separating the examination

room from the changing room and steps in. No matter how many precautions Joan took, wearing bras without metal in them and pants without zippers, X-ray technicians always made her put on a hospital shirt and shorts made of baggy blue paper. Few things were more embarrassing as a teenager. Now young Joan is back in leggings and a T-shirt, the paper hospital garments draped over her arm.

"Am I any better?" young Joan asks. Her eyes pierce the projection of older Joan on the wall, unwavering yet unseeing as she takes in what must seem like any other X-ray. Another copy of herself to leave behind at a hospital. It's her, but it's not; she recognizes it the way she would an anatomy illustration in a textbook.

Everyone's attention is on older Joan. All eyes on the crooked spine. If she could just wriggle, show them she's stuck in here, maybe—

Dr. Martinez presses the blunt tip of a pen to older Joan. The pen guides young Joan and her mom's gaze as Dr. Martinez explains, "Your lower curve is at thirty-eight. That's only a few degrees higher than when you were first put in the brace. Your upper curve's stabilized at twenty-seven, too."

Forty is the magic number, one lorded over Joan for years. At forty degrees, doctors prescribe surgery. They shove a metal rod in the back to forever hinder airport security and totally unnecessary movements like, oh, twisting to the side and standing up.

Softly, young Joan says, "Oh."

Her last doctor said there was a slim chance her numbers would go down. The brace was primarily a preventive measure, Dr. Logan emphasized, to stop her from getting worse while she was still growing. But she thought young bodies were supposed to bounce back.

In the waiting room, Joan met a man in his forties. He'd had the surgery and was in for post-op. She didn't ask him if the surgery hurt; that was obvious and irrelevant. She asked how he felt after.

The man looked at her, thick eyebrows furrowed. "I had no other options. I bought myself time."

It hurts older Joan to wonder: if she'd qualified for surgery, would the bus have missed her? Could she have traded one life-ending pain for another? But even at sixteen, Joan was broken into too many pieces for a metal rod to fix.

Young Joan asked, "Is it helping?"

"I stand up so straight now, I can balance books on my head."

Joan laughed. The only other person in the waiting room, another teenager, texted and pretended not to listen. Joan gathered herself and asked her what she was in for.

The teenager glanced up. She slouched in her chair; Joan couldn't help but notice. "Um, I'm just waiting to drive my grandpa home."

Joan checked her phone. The other teenager had so many messages to respond to, so many people reaching out. Joan had no texts. She had a couple of friends, but they only messaged her about homework.

A skate park was built near Joan's neighborhood over the summer. Her school friends hung out there. Joan didn't join, too embarrassed of having to sit on the sidelines. Her peers were worried about road rash—Joan didn't know how to skate, and she'd never learn, because what if she fell off and never got back up?

In the examination room, older Joan wishes for a throat. Not to get herself out of here like before, but to shout to her younger self that she's not as alone as she feels.

Dr. Martinez says, "Based on what we're seeing, there's no need to continue wearing the brace. When did you first get your period, again?"

"Two years ago," young Joan says.

"Right. You're finished growing. I bet that brace doesn't even fit well anymore, huh?"

### Everyone's attention is on older Joan. All eyes on the crooked spine.

Young Joan shrugs and doesn't return Dr. Martinez's smile. Older Joan remembers she didn't want to encourage Dr. Martinez either way—brace or no brace. In the beginning, she hated the brace. She'd wake up in the middle of the night, out of breath, thrashing against the binds. She'd look down, but she wouldn't see herself, only tartan-print plastic and Styrofoam. Over time, she grew accustomed. The brace didn't become part of her—her back became part of the brace. Without its straps tight around her, she feared the pain would shear her into slices.

"If her X-rays are okay, then," Joan's mom says, "why does she complain so much about her neck?"

\* \* \*

Dr. Angler leans in close to older Joan. Older Joan, no longer an X-ray, is trapped inside a buzzing computer monitor. Liquid crystals funnel around her, forming the shapes of her MRI. She's glad she lacks the olfactory senses to smell Dr. Angler's breath.

Dr. Angler turns older Joan around in time to watch young Joan slide out of the MRI machine. Beads of sweat run from young Joan's temple. She must be—nineteen. Not so young anymore. Old enough to finally come to appointments without her mom. A

needed break, because Joan's mom had become a doctor in her own right: monitoring Joan's movement like she was an inpatient at her own home, demanding video evidence of Joan's stretches every night.

The red panic button is clutched white-knuckled in young Joan's hand, unpressed. Joan remembers how loud it was in there, like being buried alive in a white plastic coffin while a demolition crew took down a building overhead. But Joan knew if she pressed the panic button, it would only prolong the burial. She laid there, shaking while the doctor reminded her to hold still, and told herself she'd been through worse. Constant pain meant discomfort was no longer scary in her mind. It was only her body's reactions that got in the way. It was always her body that got in the way.

"You're done!" Dr. Angler says, gesturing to older Joan on the monitor.

Young Joan squints, and in a tired voice says, "I don't know what I'm looking at."

"No, you wouldn't. Let me adjust the contrast." Liquid crystals move around Joan. Dr. Angler says, "This is a side view of your cervical spine. You'll notice the scan captured the surrounding nerves in much more detail than an X-ray could."

"I see that," young Joan says. Older Joan wants to sneer. What does this doctor want, a pat on the back for having a fancy, terrible machine?

Dr. Angler hums, clicks around. "I'm afraid it's just like your pediatric orthopedist said. I don't see any bone spurs in your neck or other blockages that would compress the nerves."

"It has to be something," young Joan says. "Something in my neck is wrong. I wake up and I can't move it. I get a headache every afternoon, and then I can't get off the couch. I can't walk in the evenings because my head pounds

too hard. It happens every day. I think it's related to my scoliosis, and I—" Listing her symptoms felt like the complaints of a petulant child. Young Joan stops as Dr. Angler turns away.

"The MRI is a clear picture," Dr. Angler says. "If something were out of place, we'd see it."

Now that her younger self's shakiness is starting to subside, the pinch of her face reveals she has a headache, is fighting through pain and brain fog right now. Even her mid-range headaches made it hard to string together sentences. As if doctors didn't dismiss her already, seeming slow just made it worse.

Young Joan manages, "Can't I get a second opinion?"

Dr. Angler pinches her mouth and clicks around the scan some more. Older Joan moves with the shifting display, helpless.

Dr. Angler says, "Kids your age are under a lot of stress. It's your first year of college, maybe you have a part-time job, not to mention the pressure of figuring out what to do with your life. Have you heard of tension headaches?"

Older Joan puts her whole will into trying to lunge out of the computer monitor to bite Dr. Angler's hand. Being this sick—it was not just tension headaches. She wished she was stressed about what to do with her life, because that implied she had options. She'd mourned what her body cost her. There would be no backpacking through Europe, because she could no longer carry a backpack. No beach days, because it was too easy to lose her footing in a sand dune and throw her back out. No roller coasters at theme parks. No road trips over an hour and a half, no roller rink dates, no car sex, no youth. Joan's peers headed onward without her, so far past Joan they were specks on the horizon.

But doctors hate to be told they're wrong, and they never listen to an

angry patient. Young Joan carefully says, "I had to take the year off college because of this."

Weeks before, she walked in on her mom crying over that decision. Her mom clutched a copy of *Modern Parenting* and asked, hoarse around a lump of phlegm, "Where did I go wrong, Joanie?" She helicoptered in Joan's late teen years, giving Joan no excuse when she still wasn't healthy enough to be the daughter her mom expected.

# Constant pain meant discomfort was no longer scary in her mind.

Older Joan gets turned back around by Dr. Angler so her younger self is out of view. Young Joan's hopeless face was hard to look at, but not seeing her at all is worse.

Dr. Angler says, "I could ask your general practitioner to refer you to a therapist. You might make progress via that route."

In older Joan's mind's eye, the bus hurtles toward her.

"Could you just look at my X-rays and MRI together? Please?"

The chair creaks as Dr. Angler leans forward, shaking her head. She must think Joan is so young and inane. She must think Joan has all the time in the world. "Neurology and orthopedics are entirely different disciplines. I promise, if there was anything to find, we would have spotted it."

\* \* \*

Gripped tight in the hand of twentyyear-old Joan, older Joan blinks out at the world as the on-and-off flicker of a phone screen. Young Joan says to the receptionist at the Midtown X-ray lab, "No, I won't be filing. My insurance refused to cover this. They thought another exam wasn't necessary."

With uncooperative insurance but a high credit limit, Joan went into debt for one more scan. She asked the technician to take it at the same angle as her MRI so the two could be superimposed. She did the usual, stood still over the mark on the floor and held her breath.

The technician showed her the X-ray after. The angle of the screen caught the overhead lights, casting a pearly sheen over the display. It made Joan's reflection bounce back. For a moment, Joan saw her face in the image of her spine: one person, whole. A view she'd never seen before. Doctors always kept her on one side of the room and her X-rays on the other.

She pulled her phone out of her back pocket. "Could I take a picture of this?"

The technician shrugged. "Sure."

With a shutter click, older Joan went from the technician's screen to her young self's camera roll.

At the entrance of the lab, the receptionist runs young Joan's card. Older Joan is turned on and off again as young Joan replies to her bank's text to authorize the payment. "Did the doctors find what you were looking for, honey?"

"I don't know yet," young Joan says. She puts older Joan down on the counter to sign the receipt.

"I have to wait for my doctor in Virginia to mail my MRI disc." "They don't have any ideas?"

The concern in her voice, it splinters Joan. She asks—doesn't suggest. "Listen," young Joan says. "I know there's something wrong with me. They can't see it because they're not looking at the whole picture. I'm pretty sure I'm not crazy."

"I believe you, honey. Who made you think you were crazy?" She asks, "Can I pray for you?"

On the subway ride home, young Joan opens her phone's camera and takes a photo of herself sitting in the disabled persons seat. At her apartment, she snaps another as she does her spinal stretches.

Images populate over a week. Young Joan takes photos of herself when she gets a call from a friend, half-asleep in class, while she studies in the library, as she replenishes her painkiller stock, every evening when her headache is so excruciating she can't get out of bed. She takes a screenshot of a video call with her mom, both of them in frame, while her mom is barely frowning. The photos young Joan takes surround the photo of older Joan, reminding her of a version of herself that is more than an X-ray. It's the longest older Joan's spent as one scan. She's not ramming against the walls of the phone to try to leave. Her own hands can look after herself best.

The photos are printed out. In the kitchen of her apartment, young Joan gathers decoupage and sponge brushes. She zooms in on the photo of the X-ray. As young Joan leans in close to study every detail, her breath puffs onto older Joan, warm with life.

Young Joan tears, organizes, rearranges, and glues photos into the shape of older

Joan. She doesn't use scissors; she needs to feel the power in her hands, her body. The angle she leans over the table to brush on glue is killer, older Joan knows, but young Joan grits and bears it. Afternoon sun flits through the window and disappears. The act of creating burns through her, lets her feel how each nerve extends and connects—until her headache becomes a knife between the eyes, her back spasms, and she collapses into a chair. She comes back to older Joan as soon as she's able.

With extra pictures, young Joan roughly collages her MRI from memory with plans to double-check it when the disc arrives. She finishes her pieces two days before the spring exhibition deadline. She types out a frantic email on older Joan's screen to Harrison.

Morning of her meeting, she wakes up late with a sore back. Dots of last night's headache swim. She needs painkillers and her heating pad. But she's put her back, neck, and self together again, made something to outlast her body's failings, and she'll crawl through the Manhattan streets to show Harrison if she has to.

In the kitchen, with the mouth of her portfolio bag open, she stares for a long moment at her work on the table and at older Joan on her phone.

They're holding each other, older Joan realizes. And they're only moments apart. They will be one again.

Alive Joan tucks her collages in her portfolio bag. Dead Joan is powered off and tucked in her back pocket. Two collages, the phone photo, and Joan: four bodies headed to an intersection.

### AMY DEBELLIS

### LIFE LOST

Some of my hairs are white now like paling ashes when the fire's done, the color burnt out.

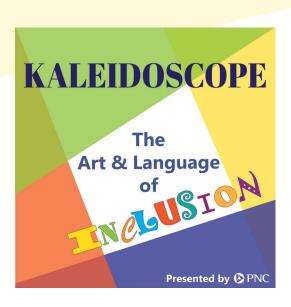
The memories of my old life are burning out.

Every day is an echo of a life that should be lived, my years vanishing.
Just try to make it through the next hour, the next week, the next month.
Just try to make it through the rest of your life.

My dreams shiver and drip and dissolve into pools. I submerge myself in them for hours and awaken with the silver taste of panic in my mouth.

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## A BOOK, A BEREAVEMENT, AND A BETRAYAL

### AISHA ASHRAF

was nine when the best book I ever read came into my hands. Clutching the Puffin Book Club flyer at school, I was mesmerized by the tantalizing blurb and squinty image and, later that evening, not holding out much hope, asked my mother to buy it. It was fiction after all, nothing "educational." When she agreed I couldn't help wondering, had the book already begun to weave its magic? The title alone held unquantifiable promise: The Neverending Story.

Even at this tender age, I well understood the power of books; how they could be a magic potion for your fears. The previous year, while my parents boxed up the contents of our ancestral farm, selling off machinery and animals, I read as though my life depended on it. When winter's early dusk curfewed my outdoor roaming, I could be seen huddled beside the dresser in the warm, bright farmhouse kitchen, nose in a book. But really, I was off gallivanting with The Famous Five, smothering my rising panic by grafting myself into a new reality of mysteries and secrets in the English countryside while the only page I'd

ever existed upon was erased around me.

Those first months in an eighties England wintry with IRA hatred, when my Irish accent earned me a brick to the head from the local kids, I sought sanctuary in the books gifted to me by my teacher before I left. I recognized the displacement felt by Bobbie, Phyllis, and Peter in *The Railway* Children, and Mary Lennox in The Secret Garden. They understood what it was to be unmoored by the actions of adults, swept like flotsam on a current impossible to swim against. The autism diagnosis that might have provided insight into my experiences was still decades away. Who's to say it would have made any difference anyway? Adults ran the world and children were expected to conform. The one good thing about moving to England was they couldn't cane you in school—it was against the law.

Weeks crawled by like years as I waited for the book orders to arrive. It was a gray October day, unmistakably tilting toward winter, when I came in from afternoon break and saw them

stacked on the teacher's desk. I couldn't concentrate after that, stumbling over the words when it was my turn to read aloud from James and the Giant Peach, raising a titter that had Mr. Jones shooting laser-beams over the tops of his glasses. When he finally handed the books out shortly before hometime, I could scarcely bear the last few minutes. As soon as the bell rang I dove straight in, eager for the instant sweetness of hurt dissolving away. Words closed about my head like water, muffling the world around me, and I was submerged in a place accessible only to the deepest, most tortuous of imaginations.

Like the fantastically named loner protagonist Bastian Balthazar Bux, I spent every spare minute in this alternate reality. Offered the chance to live out my life there I would have clasped it without a moment's hesitation, for Bastian was someone isolated and suspiciously different, just like me, who had found the friendship and belonging I coveted in the most unexpected of places—a book.

That autumn was my first in England, in a strange bedroom in a rented house filled with someone else's furniture, at my second new school within a year. Desperately missing the farm, the book helped me adjust to this new suburban life without feeling it all quite so painfully, sort of letting it unfurl quietly in the background. It didn't matter that I hadn't a clue what plimsolls were, didn't know any swear words or what "migrant," "paddy," or "mick" meant. Bit by bit, I learned. My Irish lilt dissolved in the caustic spite of the schoolyard and I befriended the gypsy sisters, Imogen and Irene, because outsiders stick together. At her insistence, Mammy became Mummy. Perhaps it was her way of learning to belong in this new place, but it felt as if I'd left my real mother back in Ireland.

In time, my legs learned to navigate a lightless landing from bedroom to bathroom and my hands found the biscuit tin (even that was someone else's, a great black thing splotched with red and orange blooms), high in a cupboard that Mummy said reeked of Indian spices, without having to check the blueprint in my head. Soon I could wander the house with my nose in a book and not bump into anything.

In spite of its title and comforting thickness (the longest book I'd yet read, easily equal to four Famous Fives piled on top of one another) it was inevitable I'd reach the end of *The Neverending Story*, and when that happened the only way to keep from falling into my own emptiness was to read it again. And again. And again. And again.

The book came with me everywhere: school, the garden, something to read in the car while my mother shopped in a faceless superstore with automatic

doors instead of friendly grocers in an Irish market town where the shopkeepers all knew my name. My constant companion in a wholly altered world, it was a refuge when I lacked words to bridge the isolation inside; for who else would have, could have, understood? In the midst of all this strangeness, it was the only place I now belonged. After a few months its curled cover was soft with the white fur of a million creases; its contours, the weight and feel of its pages, were as much a part of me as the curls on my head. Until the day I reached for it and it was gone.

I didn't know how long it had been missing, by now it was an occasional retreat. The Silver Brumby series in the school library fed the pony-shaped hole left by Twinkle and Tiny back in Ireland, but couldn't replace the soulhold of something that's been with you through thick and thin, a bond smelted in the fires of experience, a friend you would never, ever desert; my portable place to belong.

I searched my room—wrestling open unwieldy drawers, ignoring the plywood squeals, rifling through the half-empty cupboard, even dropping down to squint under the bed. I went downstairs, eyes raking surfaces for the familiar outline.

Nothing.

Swallowing hard, dread sticking in my throat like an expanding cotton ball, I found my mother in the kitchen.

"Have you seen my *Neverending Story*?"

"Your what?"

"You know—my book from the Puffin Book Club." I paused, never sure now if I was talking to Mammy or Mummy. Her gaze drifted upwards, searching some mental bookcase then . . .

"Oh yes, I remember. I threw it away." Satisfied with her powers of recall, she turned back to the counter.

I almost choked.

"You what?! Why?" I demanded of her back.

"It was so tattered, it looked ready to fall apart."

"But..." Incapable of translating the howl of anguish inside into words, a small, pathetic "... I still wanted it," was all that came out.

"You've read it lots of times anyway" she continued as if she hadn't heard me. Then, glancing over her shoulder, "Once I've read a book I can never go back and read it again."

I've never stopped wanting to go back. Being transplanted tore me in a way that never mended. For decades I was ambushed by long melancholy nights when the faraway fields and hedgerows of home filled my head—sleep, when it came, claimed a sodden pillow.

I've kept running from it, hiding it from myself and everyone, because that's what you do when you move forward. You craft a new narrative, one of pioneering bravery, surmounting difficulties, and "making it work." What came before is simply a notch on a post you've grown past, memories of a childhood bedroom, marginalia in a story you no longer inhabit. A string of places you no longer belong.◆

### THE VIEW FROM HERE

### WILLIAM CASS

ur school district's special education director told me before the annual IEP meeting for John Manor that his parents had been a nightmare to deal with for years. He said Mr. Manor was an attorney who headed a firm that represented parents of special needs students in lawsuits against districts they felt weren't supporting their children adequately; they'd already gone to due process hearings twice with our district over what they deemed lack of services for their own son. The director rarely attended IEP meetings at the district's sites, but always made a point of presiding over theirs. Although I'd be there as the administrator of record, he advised me to stay as quiet as possible, especially since I'd just started in my new position as assistant principal at the high school.

The meeting took place one afternoon in mid-September after dismissal, and I said hello to John on my way through the school's main office to it. As usual, he didn't reply, but just gazed off in space and flapped his left wrist in his regular rhythmic pattern. He was in his daily outfit of khaki pants belted high on his waist with a golf shirt tucked in, dark socks, and sneakers with Velcro straps, and sat on the edge of a chair outside the conference room. I'd tried to engage him several times on campus and in his self-contained classroom those first few weeks of school to no avail. His teacher told me that although he was nearly eighteen, towered over almost everyone on campus, and only had a disability designation of autism, his developmental level was that of about a four-year-old.

We all sat around a big rectangular table in the conference room. Mr. Manor wasn't there, but Mrs. Manor had brought an advocate from his firm. Both the advocate and our director turned on tape recorders as the meeting began. The director quickly led us through generalities—progress on goals, special factors, assessment results. As he did, the stony grimace on Mrs. Manor's face never changed. Nor did the weariness, which was something I recognized well, although hers was almost fifteen years further along.

When we came to the portion of the agenda regarding new services, Mrs. Manor spoke for the first time. Her voice was hard and clipped. She demanded the district pay for outside vision therapy, music therapy, and a one-on-one aide in the classroom hired from a company specializing in behavioral data collection. The discussion heated up quickly, with the director and advocate doing most of the talking in increasingly loud voices.

At one point, when I interjected and asked if one of our own instructional assistants couldn't be trained in data collection, Mrs. Manor turned to me with her eyes narrowing and hissed, "You know nothing about my son's needs!"

"Actually," I said quietly.

But the director and advocate immediately began talking over me again. As I sat back, I could feel my color rising. Mrs. Manor had begun scribbling furiously on a legal pad. When she finished, she shoved it in front of the advocate and folded her arms across her chest.

\* \* \*

I went home after school, took a short run, showered, dressed, and headed up to the convalescent wing at the children's hospital. My son, Ben, had been there since I'd moved us down from Bakersfield to San Diego after the school year ended in June. It was the only facility for severely disabled/medically fragile children in the southern portion of the state. He'd just turned five and had tracheotomy and G-tube surgeries on the acute side when we first arrived to help control his secretions and prevent further aspirations; by that time, he'd had at least thirty pneumonias, most requiring lengthy hospitalizations. My wife had moved at the same time, too, but not with us; she'd returned to Ohio where she was from. She said she was done being a martyr and just couldn't do it anymore. I guess I'd been oblivious because it was a complete surprise to me. I hadn't seen it coming at all.

I'd been the head of curriculum at my district in Bakersfield, but took the first administrative job I could find near the hospital in San Diego, and felt fortunate to get it. I'd felt lucky, too, to find the little house to rent just up the street from my school that already had a wheelchair ramp. Ben was recovering slowly but surely from the surgeries, and was gradually having his formula feeding titrated down from twenty hours daily to several bolus feeds. The neurologists had also found a better cocktail of meds to control his seizures; he was averaging only two or three short ones a day. This combination of factors meant that I could bring Ben home later that month. I'd arranged home nursing for while I was at work, as well as five overnights a week, which would help with sleep. I couldn't wait for his discharge.

When I came into his room that afternoon, he was asleep in his usual position, lying on his back in bed. I wiped the drool off his chin with the bandana tucked into his collar, stopped his feed, unhooked his G-tube and sat monitor probe, and lifted him into his wheelchair. I pushed him down the hall past the charge nurse's station. When I pointed outside; the charge nurse just smiled and nodded. I hit the switch on the wall to open the double front doors, then pushed Ben down the ramp and up the walk to the Healing Garden that sat between the convalescent wing and the acute hospital.

The garden was empty. It was a warm afternoon, so I started by dangling Ben's fingertips in the fountain, but that didn't wake him up. Neither did the tinkle of the wind chimes in the tree branches or the freckled shadows on his face when I tilted him back under them. I scooped him out of the wheelchair and held him on my lap on a bench. Like always, he nuzzled his face into my chest, but didn't awaken. Although no one else was around, I used a soft voice to sing the same three songs I did every afternoon, the ones I used to sing to him at bedtime. Then I sat rocking him a little back and forth and thought about my wife, the divorce papers I'd received from her in the mail earlier that week, and the future

A little while later, I reversed our walk and got Ben back in bed, changed his diaper, and got his feeds and sat monitor started again. He still hadn't awoken when I kissed his cheek, smoothed the hair on the flat part of his head, and headed home.

\* \* \*

I saw Mrs. Manor and John go by on the sidewalk in front of my house almost every evening. She had a small dog on a leash and walked about ten steps ahead of her son. The expression on her face was always identical to what it had been in the conference room. Whenever she stopped, John would do the same, until she moved off again and then he'd maintain the same distance between them. He walked in his halting fashion with his left wrist flapping.

My house was on a corner, and Mrs. Manor would pause at the crosswalk there, glance behind her at John, then turn right and head up the sidewalk toward the library. He'd follow. I was usually eating dinner at the dining room table when they came by, and I'd watch them through my front window make their gapped way up the street until they disappeared into the gloaming.

\* \* \*

Ben's discharge went smoothly and on schedule. I'd equipped his room at home with a hospital bed, oxygenator, feeding pole, sat monitor, suction machine, nebulizer, vibrating vest, and other necessary medical equipment like the mister with its tubing leading to the opening in his trach to keep his secretions moist. I'd also strung a mobile of

butterflies from the ceiling over his pillow, had a boombox for music, and a small television for the animated shows he sometimes seemed to respond to. A small bureau held his clothes, diapers, and the like, and his meds, syringes, gauze pads, rubber gloves, tissues, and free water were organized on top.

His overnight nurse was nice, and his day nurse was particularly competent. She came to the house at seven each morning when I left for work, and did his morning vest and suctioning treatment, bathed and dressed him, and pushed him up the street to his elementary school, which wasn't far from my own. She brought meds, his portable feeding pump, and other necessary supplies with her and performed all his care needs there in the classroom during the school day.

For Ben's IEP at his new school, I felt a little strange to be sitting at their conference room table as a parent rather than an administrator. I sympathized with his teacher as she struggled to articulate appropriate learning goals for him and readily agreed to phrases like "meaningfully interact with his environment" and "demonstrate occasional cause and effect using switch toys" even though I knew they weren't measurable and never would be. I was just happy that he was in a place where he'd be loved, well cared for, and around other kids his age. A place where he could hear their voices and laughter; since he was unable to communicate and it was unclear to ophthalmologists how much he could see.

\* \* \*

I didn't cross paths with Mrs. Manor again until shortly before Thanksgiving when there was a message from her on my office phone at school. On it, her short, sharp voice said she wanted to observe in her son's classroom. She said that he was having recent outbursts at home, and she was concerned that the behavioral goals in his IEP weren't being implemented correctly. She said she was available Friday at nine and trusted that would be convenient.

I called the director, explained her request, and asked for his direction. I heard him blow out a long breath. "Well," he said, "it's nothing new. She's been doing it forever. She knows the district's policy allows two thirty-minute observations a year and that she has to arrange those through a site administrator. But, have your school psychologist accompany her . . . don't let her go alone."

I said, "All right."

"Oh, and don't let the psych or teacher mention anything about speech/language services. The SLP is on maternity leave and we haven't been able to find a replacement for two months, so we're way out of compliance there. Fortunately, her son is basically nonverbal, so I'm sure he hasn't given her any indication of that."

I cringed a little. If he felt uneasy disclosing that to me because of my own son, he gave no indication of it. "That's it, then?" I asked.

For Ben's IEP at his new school, I felt a little strange to be sitting at their conference room table as a parent rather than an administrator.

"Pretty much, unless she contacts you afterward to complain. But she'll probably go straight to me to do that."

After he hung up, I found our school psychologist, and he cleared his calendar for Friday at nine. Then, I called Mrs. Manor and got her voicemail; I left a message confirming the details of the observation.

My office was just off the front counter in the school's foyer, and I could see and hear the psychologist greet Mrs. Manor pleasantly when she came that Friday morning. I watched her ignore him while she signed the visitor log. When he remarked on the rain that was expected, she dropped the pen on the clipboard, glared at him, and said, "Let's go. I don't have time for small talk." She almost spat it out.

\* \* \*

Things were pretty manageable at home with Ben. Without nursing on the weekends, I had to get up to care for him a half a dozen times each Friday and Saturday night, so that was a bit of a challenge, but I was usually able to catch a nap the next day. I juggled his care needs on the weekend days and after I got home from work, and we had our routines together. I'd snuggle him while I watched television in the evening and still sang him his three songs before bed. I took him to the library, to movies, things like that. I even got one of those jogging strollers, so I could take him on my runs. He had only two brief hospitalizations during the winter for respiratory infections they didn't even term pneumonia. My new job was okay, too; less work to bring home than my old position, which helped with my responsibilities with Ben. There wasn't time for much of a social life, but after what I'd been through, I didn't have much inclination for one either.

I got the paperwork finalizing the divorce in the early spring. It hadn't been contentious; she didn't want anything from me and asked that I have full legal and physical custody of Ben. I put the paperwork in a file with other related documents along with the photo I'd kept there of the three of us shortly before she left. In it, Ben was in his wheelchair and we were both smiling behind him with our arms around each other

and a hand on his shoulder. Beyond the divorce paperwork, I had no further contact with her except for the birthday and Christmas cards she sent to him that included a fifty-dollar bill and a message asking that I buy him something special.

Shortly after I filed away the divorce paperwork, I got permission from my landlord to dig up a section on the side of my little front yard for a garden. I worked the soil, put in a brick border, and planted it with a variety of flowers. Almost every day, I spent a little while in it weeding, watering, or changing out dead flowers with new seasonal ones. Ben sat in his wheelchair under the maple tree next to me as I worked. My ex-wife and I had kept a garden like it in Bakersfield. Aside from that, I'm not sure why I bothered with all the work and upkeep. I did look at it often, though, and admired it.

\* \* \*

I didn't attend John's IEP that next fall because he'd technically completed his senior year at our high school and was entering the transition program for eighteen to twenty-two-year-olds, which was housed in a special classroom at the district office. The director coordinated that meeting again, and told me about it afterward. He said that neither an advocate nor Mr. Manor attended, and that he wasn't even sure the two of them were together anymore. He told me he'd agreed to Mrs. Manor's request for a teacher to come to their home ten hours a week instead of having John attend the transition class. He said that in the long run, the cost would be a wash, and they wouldn't have to put up with her observations anymore.

# Mrs. Manor's posture and expression were almost statue-like, and she still clutched books in her lap.

I continued to see Mrs. Manor and John go by on their walks most evenings until December when they seemed to stop abruptly. I rarely thought about them again until an afternoon in May when they went by in a different fashion. It was about five o'clock, and I was using my laptop on the couch in the living room when I saw John pushing his mother in a wheelchair up the sidewalk toward our house. No dog. She sat very still and erect in the chair with a floppy cap on her head and her hands clasped on top of a stack of books on her lap. From where I sat, I could see that the stony expression on her face hadn't changed. At the corner, John paused, then turned and pushed her across the street in the direction they used to take. He walked slowly and deliberately. I found myself leaning forward to keep them in my sight as long as possible.

A half-hour or so later, I saw them approaching from the other direction. Mrs. Manor's posture and expression were almost statue-like, and she still clutched books in her lap. They passed my window in their steady manner and disappeared down the sidewalk toward where they'd first emerged. It became a new routine that repeated itself every few afternoons.

\* \* \*

About a month later, we were experiencing a heat wave, so I pushed Ben up to the library once I'd changed clothes after work to get us into some air conditioning. I sat in an easy chair near the fiction shelves with Ben reclined in his wheelchair next to me and started reading my way through a stack of magazines. After we'd been there an hour or so, I saw John pushing his mother our way through the center of the library. Her blank stare was aimed right at us, but I was dressed in shorts and a T-shirt with a ball cap, so didn't present an image she might remember, and she gave no sign of recognizing me. John turned her before he got to us, but continued into the aisle of shelves immediately to our right and stopped just a few feet away. From the corner of my eye, I watched Mrs. Manor lean forward, choose several thick books from a shelf, set them on her lap, and straighten herself again. Then I watched John push her back the way they'd come until they turned up the corridor toward the checkout desk.

I waited a few minutes before getting up and moving into the aisle where they'd been. The gap on the shelf where Mrs. Manor had chosen her books was clearly visible. I looked at the titles. They were all romance novels by a popular female author. There were so many volumes by her that they took up almost three shelves. I looked up the aisle in the direction they'd gone and shook my head.

The heat wave persisted, and later that week Ben and I were in the same spot in the library when John and his mother came into the main section again and started toward us. They turned and repeated the same motions in the shelves of romance novels nearby. After they left, I checked my watch and saw that it was time to give Ben one of his meds, which I'd left at home.

I replaced the magazines and pushed Ben toward the exit. John and his mother were in line at the checkout counter. As we passed them, a book Mrs. Manor was holding fell from her lap onto the floor. It had a picture of a man and woman in passionate embrace on its cover. I stopped with Ben next to her, picked it up, and handed it to her. Our eyes met. At first, hers remained coldly impassive, and then recognition crept into them. She said, "Thank you."

"Hello," I said. I looked at John. He stared over my shoulder and began flapping his left wrist. I asked, "How have you both been?"

She made a slight shrug. Ben coughed, and I used his bandana to wipe the secretions that had escaped his trach off the gauze under it. She watched me and said, "So, this is your son?"

I nodded. I watched her study him. She looked even more worn than before. I guessed she was nearly sixty, perhaps twenty-five years older than me. She clutched the pile of books tightly with both hands. I didn't know what her circumstances were at home, but I knew they had to be far from ideal; not unlike my own. Like me, I supposed she chased away thoughts about what would happen to her son after she died. A space leading to the checkout counter opened in front of them and John inched her forward.

"Take care," I said and pushed Ben ahead, too, up the corridor, out the side door, and down the long ramp.

\* \* \*

The two of them next passed the front of my house again later that week. I waited about twenty minutes, then got my kitchen shears and pushed Ben out under the maple tree next to the garden. I took time choosing the freshest flowers to cut and included several roses that had just begun to bloom. Afterward, I twisted a rubber band around the stems, set the shears on the ground, and stood in the shade with Ben to wait.

John and his mother reappeared not too long afterward and made their slow way in our direction. She seemed to be watching us as they came over the crosswalk and turned onto the sidewalk in front of our house. I walked across the grass a little ahead of them and stood in the center of the sidewalk. John stopped the wheelchair when he came to me, and his wrist began to flap.

I looked at Mrs. Manor and said, "These are for you. I just picked them."

She lifted a hand off her pile of books and took the bouquet from me. Her flat expression didn't change, but she looked from it to me and said, "I can't remember the last time anyone gave me flowers." She turned them in her hand, then continued, "Maybe never."

I gave her a small smile she didn't see and moved out of their way. I stood watching the back of them go off down the street. It had cooled a little, but was still hot. It would probably stay that way throughout the summer and into the early fall. Another long stretch of time to try to make the most of. Ben made one of his squawks from under the tree, one of his happy ones.

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## **ANOTHER COUNTRY**

### CONNIE HAROLD

This is another country.

It is not labeled on any map. There are no road signs or directions, no clearly marked access ramp, roundabout, or entry. There is only a crooked, narrow lane leading to an empty one-way street.

This is an invisible country. This is a place of abrupt detours, of dead ends without warning. The curious glance stealthily in its direction then hurriedly rumble pass.

This is an impoverished country, the land of the immobilized, the inoperative, the crumpled and the fallen. There is no returning passport or reprieve at this border. There is no able conveyance willing to cart one back.

This is deleterious country, a thieving thoroughfare pitted with rust, and ruts, and ruin. This is the place of the unwilling exile, the sudden outcast, the stranded sojourner careening to the curb without forewarning. This is another country, a place of lost landscapes and truncated horizons.

I have landed in another country, disabled in America.

The first time I remember not being able to see, I was in junior high, seventh grade. It was one of those hazy August days where the sun's glow seethed so brightly it was almost radioactive. I was skipping down Linwood Avenue in Detroit in the middle of the afternoon, a half a block from the flat where my mother, sister, and I lived on the west side. I was clutching a white pharmacy bag containing my hoped for remedies, aspirin and a quickly melting KIT KAT bar. A cooling shower had momentarily sprinkled the sidewalk. It speedily condensed into thin ribbons of steam and pressed against the pressure in my head that had been nauseating me for two solid days. It was 1965, the beginning of the terrible "long hot summers," and this one was about to live up to its name. In a week, Watts would be the first major city to go up in a flaming riot. But that afternoon it was just me walking unassumingly

down a busy street about to confront a disturbance of a totally different kind.

Sunlight blazed off a passing cherryred Mustang and struck my eyes with
a blinding lightning-like flash. An
electric shock wave zapped through
my nerves down my left side, forcing
me to stop on the edge of the curb.
Day was instantly denser and darker
than midnight. The colorless form of
a pickup truck raced by, a shadowy
silhouette reflected bleakly in the plate
glass windows of the Five and Dime. I
shut my eyes against the stabbing pain,
threw an arm up to shield my eyes,
threw a prayer up to jump start my
breath and my panicking heart.

I blinked, rubbed my eyes furiously trying to burnish the world back into color. But I couldn't see. There was nothing in front of my eyes, no hazy cracks of light, nothing but black. I wasn't sure how long I stood there teetering on the edge of the street, a minute, or ten, or two. It felt like forever. I stood in utter darkness unable to breathe and afraid to think about what would happen if the world never came back to light.

As far back as memory would take me, my eyes had done strange things, mostly sudden flashes of intensely blinding light. Or everything would lose its color and then return in a radioactive green haze. Sometimes my eyes would refuse to focus. I would be reading or drawing and suddenly it was as if I was looking through a lens smeared with Vaseline or blind spots would appear without warning, and disappear just as fast. It seemed to happen in the dreaded humidity of summer when the temperature stalled in the nineties, guaranteeing my body would be on the verge of collapse as if it wanted to go on strike.

I couldn't tell how close I was to the street but the nauseating gasoline fumes rising from the gutter made me step back. I missed the edge of the curb and my knee hit the concrete hard. The swish of cars rushing past was close, too close. There was a roaring like waves crashing on the beach filling my ears, a snap, and then no sounds at all.

Then as if a switch had been thrown, a spot of light flashed and crackled in the middle of my forehead. Pain opened my eyes. Daylight's colors snapped gloriously back and I could see. I wasn't even thirteen yet but it felt as if what was left of my childhood had been tossed away like a mangled carcass abandoned on the side of the road, and I was falling down a long tunnel leading to a place I didn't want to go.

For days I thought I might have been dreaming, but it happened again one morning, a flash of brightness then no light. This time it clearly only lasted for seconds but it was also clear that nobody else was waking up in the morning with everything blurry and washed out. Nobody else was having lightning flashes in front of their eyes. Nobody else was praying that if they kept blinking the world would snap into focus except maybe the people on TV staring at a city in flames.

Finally, I took a chance and told my mother. For once she took my

complaints seriously and made an appointment to see the eye doctor. I actually thought the optometrist might know what I was talking about. It would be the first of many mistakes I'd make trying to explain what was happening with my sight.

Maybe I should have told him about the time the colors shimmered so brightly and so beautifully I thought I was in heaven.

I could barely see the cool brown doctor or his cool brown hands as he fiddled with his instruments. It was just a watery, tanned haze. He walked out of my line of sight as I swiped my eyes on my sleeve, and when he came back in front of me he was frowning. Then he smiled the way adults do when they want you to stop making them feel uncomfortable.

"There isn't any reason to cry," he said patiently, holding out a box of tissues. It took him a minute to realize I couldn't see it before he stuffed them into my hand.

"I'm not crying."

Dr. Ellis raised the examining chair so I was eye level with him. "Put your chin up here," he said pointing to the black, plastic headrest. "We're almost finished." He adjusted the knobs and swung the machine with the lens back over my face. "Tell me when you see the two lines come together." He moved close, looking deep into my eyes as if he was trying to decide about something. "Your mother tells me you're quite an artist. Didn't you win the art contest here at the hospital?"

I was stunned. Who paid attention to stuff like that? "Yes... my picture was

in the Free Press." And I'm going to be an artist, and I need to be able to see so you've got to figure out what's wrong with me.

The doctor's white coat floated back and forth in front of me like a ghost. The pain in my eyes was spreading to the top of my head as he leaned in close with a tiny flashlight. I jerked away.

"We'll take a break for a minute," he said. The ceiling lights came on and I quickly shut my eyes and covered them tightly with my arm. I thought I was going to throw up.

The doctor turned off the lights, lifted my chin, and flashed the pinpoint light in my right eye again. I wanted to punch him. From close behind me Mom thundered, "Stop fooling around. I have to get back to work." Her Jean Naté body powder hung thickly in the air above me.

"This is giving me a headache."

"You are a headache!" Mom bellowed as if she was ready to punch me. "If you don't stop complaining and cooperate . . . "

"I am cooperating! My eyes are just tired." I hesitated, thinking fast for some way to make the torturous exam finish quickly. I just wanted to go home and lie down, and not get back up. "I don't think I really need new glasses." I said like I meant it.

"So go blind then," she hollered and flung the examining room door open with a heavy thud. Tears were running down my face like Niagara Falls from eyestrain until my blouse and training bra were soaked. I heard doors opening, doors closing, and the clicking of her high heels echoing down the hall.

Dr. Ellis asked me again if it had happened before and I shook my head. Maybe I should have told him about the time the colors shimmered so brightly and so beautifully I thought I was in heaven. Or about the time I ran into

the wall in the school gym. But that had been different. I was dribbling the basketball toward the hoop when everything went blank and a second later I was watching a sharp corner bearing down inches away from my face as my forehead slammed dead into it. I could have told him, but I didn't. I knew he wasn't going to believe me. Nobody ever did.

"And you have light eyes. What color are they?"

"They change." *God, not that.*Sometimes they're blue . . . or green, or gray." I had a teacher in elementary school who would announce to the class whenever they changed colors because even for a light-skinned Negro kid it was pretty unusual. It set me apart, the same way drawing and painting did, and not being able to see.

"They're very pretty, but it also makes them more sensitive to the light." He patted me on the shoulder. "I can order a tint to put on your lenses that should help with the glare you've been experiencing," he said trying to be reassuring. "I paint a little, too. Landscapes. There's one hanging in the reception area. Let me know what you think."

You want to know what I think? I think you're not telling me what's really going on. "If this is glare then I'm going to be wearing sunglasses at midnight."

He chuckled. "We'll order you a pair of sunglasses too." And I knew as I stared up into his grandfatherly face, knew without asking what he wasn't going to answer: *Am I going to go blind?* 

There were no more episodes of blindness for many years but a shimmering, shaded momentary blankness of vision often came and went without warning. But, so too, did its opposite, a stunningly radiant, expansive light. I looked everywhere for an explanation—in paintings and books, in Sunday school sermons, and TV science shows. I would spot a glimpse of it in the effervescent brushstrokes of a Monet painting or the biblical description of a saint being thrown to the ground by an overwhelming light.

I was walking between two worlds, one of light, one of darkness, the secret winding bypass erected by an inconstant, unconditional malady. And I was looking for something, something which seemed forever out of reach. I lay on my narrow bed for days staring at the minute detail in the silky threads of the pillowcase, the unlined skin of my tawny hands, the rainbow refraction of morning light glazing the window so brightly it was as if a nuclear sun existed in each fleck of rain, each rainbow color arching over the clouds. I was trying to create a library of visual memories to tide me over in case my vision decided to go out again.

Hiding became a way of life, hiding what was important, who I really was, and what I wanted to be. Like layers of an onion, there were layers and layers never to be peeled away, not to be seen, even by me.

### I was walking between two worlds, one of light, one of darkness...

Other people's criteria of what was real quickly became meaningless; my experiences were my own. Laughter and blank stares from my classmates, and a dismissive shake of the head from my best friend were all it took to shut me up. My unnamed, undiagnosed infirmity may have seemed unreal to everyone else, or simply my artist's imagination working overtime, but it was becoming as real and dire an omen as an eclipse to me.

Blindness comes in many forms.

Darkness descends. Light cannot be found. How do you find your way out?

\* \* \*

*Show no weakness* became the secret compass of my every move.

I was nineteen, working part time for a Midtown Manhattan-based magazine while grinding through art school when I began to realize that being able to see was becoming a more dicey proposition. I came up from the subway at Lexington Avenue and 59th like a tourist distracted from the brilliant majesty of the skyline by the mesmerizing shadow of a Styrofoam cup swirling through the gutter. My eyes were playing tricks on me again, going in and out of focus. I squinted, rubbed them, dashed cold water on my face but still my sight wavered making the pen and ink illustration I had just finished look like an acidinduced hallucination. I gazed out of the majestic office windows as if the answer could be found in the herd of yellow taxis battling up Madison Avenue twenty-two stories below.

There were times when my eyes would simply not snap into focus. It was happening more often—like right now. And allergies to the toxicity of the art materials, diarrhea from eating almost anything, and pain that radiated from the center of my head and down my back were making my chosen profession, a visual artist, a quickly receding dream. What would I do if I couldn't draw, couldn't be an artist? It was the only thing I'd ever wanted to do and had driven me to battle the uncertainty and the infirmities that plagued me when I might have capitulated, crawled into a ball, and given up.

"Those layouts going to be ready soon?"

Oh, shit. Norm.

Norm, the production manager, and I were the only ones still hanging around. The editor and art director had abandoned the magazine's office hours ago. I lined up the illustrations and photos on my desk, pulled out the loop as if to study them more closely, trying to get control of the thoughts that leapt up screaming like monkeys running from a cobra. By the time Norm peeked in, I had zipped through every last one of my mental exercises and was a study in perfect control. Had the devil himself come to offer me complete dominion over the earth I would have barely blinked.

I had less than fifteen minutes to come up with a solution and my eyes were crossing with fatigue as I stared at the illustration.

He peered obliquely over my shoulder.

"I'm almost done." I had been working on the last page of the magazine's layout for at least three hours, which was two hours too long.

"I need to see them one more time before the courier gets here. You've got about twenty minutes tops," he said pointing at his pocket watch with a friendly scowl and schlepped into his cavernous office to wait.

All I had left to do was wrap some text around a headline. That was all. I had finished silhouetting the last photograph and laying down the last copy. My thumb and right index finger were numb from gripping the single-edged razor blade as it sliced through the slick, coated paper into the cutting board underneath. I couldn't feel the blade anymore. And since my eyes weren't focusing too well either, I bent

closer to guide the blade's progress, pressing down harder. Then the phone rang. I jumped. The razor's edge was sharp, so sharp it sliced off the corner of my finger without me sensing anything had happened. I didn't realize it until I saw the blood pooling on the page under my hand.

The illustration board lapped up the blood with each thirsty fiber. In less than a minute it would be permanently blood-brown. I looked around frantically. There was nothing to sop it up with, only a pad of slick, vellum paper, a box of non-repro blue pencils, a bunch of technical pens and ink, rubber erasers, rubber cement and thinner, and more razor blades still wrapped in their cardboard sheath. I pulled down the bottom edge of my shirtsleeve and blotted the spreading blood. A faint discolored stain remained on the board. I wrapped my finger with masking tape, and with a #2 sable brush and white gouache I painted over the discolored area until it couldn't be seen and the ink wouldn't bleed through. Glossing over imperfections had become a way of life.

It shouldn't have been a big deal. But the fumes from the rubber-cementladen typesetting had made me lightheaded and slightly groggy. All of the photos were sized and in place with only one final page to finish. I snatched up the pasted-up boards and photos, and grabbed my illustrations. There was a large line drawing with a portrait in the center which was slated for the opening spread. I was checking the pagination at the bottom and there, in the middle of the main subject's left cheek, was a small but unmistakable splotch of blood. It looked like dried blood too. not an artistic embellishment.

I looked up at the clock in a panic. There was no time to redo it, nothing to replace it with. Worse, my eyes were still bleary. I wasn't sure I could see well enough to redraw it even if I had time to try as I leaned over the drafting desk to reposition the slightly askew image, intuitively lining it up with my stainless steel T-square and triangle.

"Norm," I called out meekly, "I think I'll have to send one of the illustrations to the printer tomorrow." I was trying to scrape off the stain off but it had discolored the paper all the way through.

"You can't do that," he hollered.
"Everything has to be packaged together or it will hold up printing."
The rustle of papers meant he was searching for the schedule on his disaster of a desk. "It'll cost a fortune."

Dammit. I needed time to redraw the illustration. But then it wouldn't be picked up by the evening courier which meant the boards would be late to the printer, which would make us lose our spot on the printing schedule, which would cost tens of thousands of dollars in overtime and setup fees, which would mean the magazine would be in the red, which would cost me my job.

"What's the hold up?"

"Nothing." Or I could let it go out as it was. I pulled out the tube of gouache and applied it liberally over the quickly darkening spot. "Just a little change." I watched as the stain bled right through it. The portrait was the central focus of the montage-type illustration. My eye went right to the three-quarter profile just as it was supposed to, right to what was now an unmistakable bloody spot.

I had less than fifteen minutes to come up with a solution and my eyes were crossing with fatigue as I stared at the illustration. I remembered the last time something like this happened. I'd been up for thirty-six hours straight and was having trouble seeing when I bumped into the drafting desk and spilled coffee across my drawing.

And what did I come up with then to save my butt? I made it look intentional, made the imperfection look as if it was supposed to be that way. I had made my mistake look beautiful.

My eyes were wavering but my hand was rock steady. I took out my thinnest

crow quill nib and slipped it into the pen holder. Holding my breath so my hand wouldn't jiggle, I drew a slender line to indicate the contour of a cheekbone just above the stain. Under the cheek I lightly crossed-hatched a soft shadow. It looked natural. It hid the infernal spot. I added a similar shadow to a smaller figure on the other side to balance it out. Visually it looked as if that was what I had intended all along.

Norm didn't notice. Neither would anybody else. But I knew it was there. I knew where all of my flaws were hiding. I had crossed over into another country where no central sun or starry light illuminated the way. I had become a sojourner in the thickets of a perilous landscape. My eyes, my hands, my life were disintegrating like watercolors in a thunderstorm, and it seemed as if there was nothing I could do to stop it. It would take more incidents and many more years but one day the sun would refuse to rise in my eyes, and then I was blind.

It had been more than four decades since my first terrifying bout with blindness as a child when I opened my eyes one bright December morning to the bleak discovery that I was completely, and totally blind in my right eye. No light was getting through.

I'd lain on the bed most of the previous night afraid to close my eyes, focusing instead on the sweaty wrinkles in the cotton sheet, the intimate lamp light trembling across the fading pages of the thriller I was fighting to read. It was as if an electrical wire had gnawed at its own insulation causing a short circuit in my optic nerve. This stealthy ambush was the latest manifestation of my newly disabling, and newly diagnosed adversary, multiple sclerosis.

This is an undiscovered country, an unexplored land, sans stars, or moons, or sky. Here night darkens quickly, light changes imperceptibly, an empty shadow rising beneath the sun.

Ten days before, I had awoken to nothing but gray heaviness in the center of my eye, like viewing the world through a plugged up donut. The neurologist had prescribed steroid pills for those ten days and expected it would resolve quickly. I found myself careening around the space between my eyes. My left one was swimming with a million colors and subtle sensory details, like clues to the soul of the universe. My right eye was fuzzy, grayed out and inhabited by amorphous shapes floating across an indistinct universe. They were like two warring worlds, two distinct countries separated by a chasm as long and deep as an uncharted sea. On the morning of that tenth day, I awoke to a deep black hole in the right eye, a noir of nothingness similar to the empty stare of a blank television screen only reflecting nothing. After another batch of pills and three rounds of intravenous steroids the lights still stayed out.

My weakened eye ached with gritty pain as if ground glass was scraping its orb. Other times it was so heavy it felt weighed down with a bowling ball. It tried to follow the path paved by my sighted eye but it was a transverse, rocky, meander. After a while I stopped looking.

I could feel myself losing the battle, beginning not to care. It took ten minutes for me to gather my limbs for the journey out of bed, to get up the courage to find the floor and stumble with arms akimbo around the corner into the bathroom wall. And still I would inevitably bang my head on the door frame, bruise myself against the knob.

The chasm between my doctor and me was as deep and endless as the Grand Canyon on a foggy night. He asked me what I could see. I told him nothing. It was almost a lie. What I could see wasn't to be found on any of his eye charts. I compared it to the complete solar eclipse whose shadow was then passing over the earth. Religious crowds had gathered throughout India

to hail the phenomenon as a worshipful sign. As the whole world was obscured in dimmed celestial light, I held my breath and prayed in that moment they were right.

Things happen for a reason. Empires fall. The lights go out. You wake up one day and can't see. It makes you focus. It made me see.

My eyes, my hands, my life were disintegrating like watercolors in a thunderstorm . . .

As much as I thought I knew about light, the reality of its form and notform was infinitely different from my previous experiences. Here was the missing path. I had seen and painted the intricacies of color since I was four and had repeatedly experienced light as a presence. That glowing expansion into infinite light was totally different from ordinary seeing. This, however, was something else again, an experience of light as darkness pulling inward instead of expanding out.

Both black and white contain all of the colors of the rainbow's spectrum and slowly I began to realize how much form, and volume, and depth were shaped by the perception of those sensations. For I could see and feel how people and tables and televisions radiated light even if I could not receive it in a normal way through my right eye. It was reminiscent of swirls of water, a pattern of waviness that didn't quite extend to me as if held back by an opaque barrier. Each day the barrier became a bit thinner, less intrusive but it was there. It would not lift. It would not fall. And each time I crashed into a bookcase or stumbled into a chair, I had to stop my thoughts from tumbling to the floor.

I backed off from all the emotions and put aside all projections of what shape the future would take. I rounded up the pain, categorized its variations and manifestations, pushed them into the corner of my consciousness, and told my fears to shut up. And then I meditated as best as I could, let my body float away, and focused on what I was actually able to see.

The body is a treacherous companion. I don't pay much attention to it anymore. I have learned to close my eyes, to still my thoughts. I have learned to leave the body behind. Slowly, I mend all the flowers of my senses by concentrating deeply, intensely on the sun that rises behind closed eyes. My sight has inched back through the mist, shifted the wavy grayness as it recedes. Like the faint remains of a half note reverberating through the air, or positive and negative space twisting together in a work of art, what was once a diminished state is now a different state, aglow.

The art critic, John Berger, once asked, "What is art but a way of seeing?"
Perhaps, seeing is the art.

I close my eyes on another country, a land of truncated vistas, an endless terrain of night. My eyes open. I see a straight and narrow highway, and watch as the undulating spherical hole moves from the center of my sight, from particle to wave, from matter to thought, from darkness to body to light. •

### **M**ETAMORPHOSIS

When my mother was diagnosed with lupus, she sank down in relief. Finally, her prayers had been answered to form more questions than answers. Support in the shape of textbooks and doctor appointments looming on our dining room counter, wall calendars. As children, we didn't know any better and traced rashes on her face. She said butterflies, so we pictured monarch ones coming and returning more frequently than migration season. We didn't question when she no longer took us to the park, grocery store, picked us up after school. Only later did we realize her aching joints, her body attacking itself, pain she carried throughout the days. Later, she told us that our naivety was her protection that she tucked into her pillowcase after afternoon naps, folded into her tired evenings, soothing her when awakened from sharpening discomfort. We didn't really understand how serious it was until we were teenagers spending the holidays in the hospital where we learned about bacteremia, steroids, autoimmune conditions. Your body was attacking itself as you closed yourself inwards. Your disease is all uncertainty and fluttering curiosity. Now, I am the one wearing the white coat, answering prayers, inviting questions. Every patient has your face. Still, more questions than answers linger through the days. So far, I have migrated with my wings fluttering and you are the warmth to which I return.

## HEALING FOR THE SOULLESS

### WAYLON HENGGELER

Then I asked my physician about my soul, she equivocated. She was the one who had diagnosed and cured me, a woman I held above all the others, so grateful was I to be alive.

"And how long has it been gone?" she asked, face kind like it had been when she passed me a tissue all those months ago, the first time I came into her office. I had been a shell then, hunched and shivering, resisting the urge to lay down on the floor and never get up. Now I was a different kind of shell, resisting the impulse to start moving and never stop. I fidgeted. I tried not to stare at my doctor's lemur-soul as it craned toward me in unabashed interest, stretching the skin of her chest taut against its simian outline. These days other people's souls made me uncomfortable. Resentful.

"March, I think? Maybe April?" I couldn't really remember the date—when the wolf-soul clawed its way out of my chest, bloody, I had already been bedbound for so many months that time had lost its meaning. Despite the pain, I had been grateful that my soul had finally decided to leave me and fend for itself. I was clearly dying, and I was tired of grieving this loss, of fuming at the injustice of dying from an unidentifiable disease at twenty years old. It was a relief, then, to be soulless. To imagine it running through the nearby forests, wind against fur. To listen for its howls each night while I mindlessly watched television and pretended to be apathetic toward my own impending death.

Now I was cured, able to walk and talk and remember names and recognize the landmarks of my small, island community. I could read books, go on jogs, spend the entire day out of the house. I was no longer crushed with fatigue, no longer subject to dementia, no longer stripped of all coping mechanisms.

And yet despite this boundless blessing, all I could feel were the thick reverberations of a deep, endless grief. I was not me; life was still not worth living. Maybe my soul could save me.

"Hmmm. That's a long time ago. And I have here that it's a wolf-soul? Well, as I'm sure you know, it's difficult to return the soul to a body it's decided to leave. That being said, people do it. However, this is outside the practice of medicine. Have you seen a therapist? They are better trained in souls. Patients have also used self-help books."

I decided to take this as a call to action. I went home and immediately placed myself on a few different waiting lists for a few different therapists. I also ordered both self-help books the physician had mentioned.

As I waited for the therapists and the books, I continued to try to pretend to be myself despite the devastation of my empty chest. After spending months regaining the ability to be upright and go on walks, I was now spending an hour every morning at the pool and an hour every afternoon walking along the forest and seaside trails by my home. I remembered how to read and started reading novels again. I watched TV shows that promised a happy ending. I never stopped moving, as if this alone would protect me.

All the while, I listened for the howl of my wolf-soul, thankful that I lived on an island and the wolf would have to throw itself into the freezing salt water before it could be truly lost to me. I would hear it sometimes, at dusk, its mournful cry echoing off the mountains. I would run after the sound or gun my car in its direction, but the mountains echoed in a way that distorted sounds, and I never seemed to get any closer to their source. I never even found footprints.

At the pool and around town, people would whisper behind their hands about me, the local girl who was missing her soul, poor thing. She had been sick, but she was now well. Lucky girl. But still, poor thing, no soul. The ones I knew and the ones who knew my parents would come up to me, eyes glittering, and would try to get the story firsthand. My ineffable sickness, which had no cause or counterpart. My cure. Their souls would press their heads against the stretchy skins of their chests to get a better sense of me, revealing the outline of a lizard, a dolphin-head, a squirrel. Early on, I didn't know what to do, so I told them everything, all the gory details minus the fear. The nausea that followed was unbearable. After that, I said as little as they would let me get away with.

# Now that the therapist had heard my wretched story, I hoped she would actually help me.

The closest I came to peace was when my body was moving and my mind was occupied with a podcast or audiobook, turned down low so that I would be able to hear my wolf-soul howl. But even with this constant movement, the emptiness of the space in my chest where my soul should have been hollowed me out and collapsed my lungs. I felt like I wanted to tear my skin off. I screamed in the woods, and it didn't help. I cried all the time, and it didn't help. I thought about the people who were sick like me but didn't get better and how lucky I was to be better and how grateful I should be to be alive, and it didn't help. I thought about dying, the cool release of it. How funny it would be, to be so terrified of death when I was sick that my soul clawed its way out of my body, only to get better and then kill myself. The irony. I almost laughed, for the first time in over a year. Almost.

After waiting for weeks, I finally saw the therapist for an exorbitant fee. I drove an hour off island to her office, sat in a chair across from her, under a lamp that cast most of the room in shadow. She made me tell her everything, and in a dull voice I explained about the sickness, about how I had heard my parents sobs echo in the house, about how physicians had called me an attention seeker and a liar, about how my friends ignored me while I was sick and now talked

to me like I was still the person I was before, pretending they couldn't see that my soul was no longer there. The doctors' appointments had made me well-practiced at dissociating while talking about myself; to my pleasure, I managed not to cry. Now that the therapist had heard my wretched story, I hoped she would actually help me.

"How do I get my soul back?"

"My biggest suggestion is mindfulness. Sometimes finding peace in your mind and body will lure a soul back. Think of inner peace as the bait and your body as the trap."

"I've already tried that. Meditating causes me to have a panic attack." This had been one of the first things I had tried, after the cure. But I had spent so much time alone, with only myself and my Death for company, that stillness made me feel like I was back there again, like I was still trapped in the quicksand of illness.

"Strange. Maybe build up to it?"

"It's just really hard for me. Is there anything else? Anything evidence based?"

"A few things, but I'm not trained in them. I can tell you though that meditation can work wonders. Also art therapy."

I scheduled my next appointment with her and left. That night, I tried art therapy. I painted a picture of a wolf, blood dripping from its teeth, that looked like it was drawn by a talented but very disturbed child. I drew a tree on fire. I drew myself swaddled in seaweed, drowning in the ocean. I waited, but I heard no howl. The next day, I cancelled all future appointments with the therapist.

I didn't like the idea of baring myself to another therapist, so I was relieved when the self-help books finally came in the mail.

The first was called *Soul Food* and recommended eating the diet that your soul would eat if it were a real animal. It sounded ludicrous, but I had so little to lose that I loaded up on venison, chicken, and sausage at the local specialty foods store and ate only meat for two weeks. Nothing.

The second book was called *Body, Mind, Soul* and recommended eating a human-healthy diet, doing crosswords, and exercising out in the open air. It especially stressed the importance of yoga. So, I bundled up and did yoga every morning in the freezing winter air in a field a few minutes from my house, near where I had once heard the wolf-soul's howls. Nothing. The book also suggested finding meaning in the meaningless trauma I had experienced, of finding silver linings in the devastation everyone pretended not to see. I gave up on the self-help books.

I thought about death and dying, of slipping out of my skin, of release. It was a relief to no longer be afraid. Death is different when you choose it. When I was sick, I would think that even death was better than the hell I had found myself in, the dementia and bone-crushing fatigue and pain nearly overwhelming my will to survive. I would think, *I want to get better or die*. But then, I would feel Death's cold breath on the back of my neck, its fingernails tracing my spine, and I would panic, struggling to inhale. I would be shot alive with the knowledge that even though my life was hell *I did not want to die*. Now I looked at Death in its blank face, contemplated taking its fetid hand, and felt no fear. It was strangely comforting.

Still, it felt evil of me to be given this chance at a life that so many other sick people dreamed of and then throw it away, like it was nothing. Sure, I couldn't feel joy. Sure, the moment I stopped moving and sat alone with my thoughts I was overwhelmed with panic and the belief that I was sick again. Sure, I was so lonely that I no longer had any idea how to interact with people. Sure, my parents were maybe going to get a divorce because of the stress of caring for me. Sure, I was so angry at my friends for abandoning me that I dreamed of retribution, their own descents into illness. Sure, life wasn't worth living; but it was a gift given to me anyway, and to cast it aside like it was nothing would be unforgivable.

I had searched the Internet already, but it had been cursory, so sure had I been that physicians and therapists and professionally recommended books could help me. Now I focused on information gathering.

I combed through the scientific literature on soul-loss. Almost everything focused on the military. Until recently, the US military had rounded up the souls of surviving soldiers in giant, costly operations using helicopters and men on horseback and giant herding dog breeds, like rottweilers. However, a few decades ago, the military had come up with a special procedure that chained your soul to your body, so even if your soul clawed its way out of your chest, it was forced to stay nearby, thrashing and writhing in panic and pain. It was said that people were changed after these chained soul-losses, that they skittered through life like a beaten dog. They were worse off than they would have been if the souls hadn't been chained, but it was deemed too expensive to always be rounding up souls after every little war. Soldiers were now required to have soul chaining procedures upon enlistment. These procedures weren't generally done on civilians. The exception was prisoners, who were said to forfeit consent upon committing or being suspected of a crime. It was again considered too costly to always be hunting down the smaller souls that would birth themselves into cells and then escape. The chaining procedure was deemed extremely cost effective by quite a few public health publications.

There was little scientific information on tracking down a rogue soul without helicopters and dogs, so I turned to the anecdotal. Eventually, I found a number of Internet forums where people talked about losing their souls, and, in some cases, tracking them down again.

A man whose son had died and whose chipmunk-soul had lived in the stone wall near his house until he caught it in a live trap baited with peanut butter.

A woman whose sister was murdered by her husband and whose porcupine-soul had been extremely difficult to locate. It had eventually been found high in a tree near her sister's old house.

A young boy whose mother had died and whose owl-soul had taken the bereaved father years to track down and capture.

A woman, recently diagnosed with schizophrenia, whose mouse-soul had required the woman to rehome her cat until it was caught.

A rape survivor whose dog-soul stayed close, walking next to her for years while she ignored the soul, punishing it and herself, until she eventually let it climb back into her chest.

There were also reports of people who never caught their souls, people whose souls were arctic terns that flew away, were whales that dove deep, were ants that crawled into cracks. These people sleepwalked through life, empty, bereft, haunted, hollow. Sometimes they lived long lives. Sometimes they killed themselves within months.

# Now I looked at Death in its blank face, contemplated taking its fetid hand, and felt no fear.

There was a consensus on these forums that catching the soul depended a lot on what animal it looked like. Domestic animals were the easiest, birds the hardest. Anything that migrated was nearly impossible. Wild predators, like my wolf-soul, fell somewhere in between. While they couldn't fly away, they could be difficult and dangerous to apprehend. Once they left your chest, they were more wild animal than soul.

Reading these posts, I finally realized that no one was going to help me; I had to do this myself. I waited until the next time I heard my wolf-soul. The following morning, I set out early in pursuit. The day was cold and bright, the sun reflecting off the snow. I crunched along paths of packed-

down snow and picked my way over large sheets of ice, feet moving in tiny steps to keep from slipping. In my bag was food, a water bottle, and a thermos of sweet coffee. For the first time in a long time I walked without distraction, listening to the still air and the occasional cawing of crows.

I decided to take a trail that ascended a nearby mountain. I had always enjoyed this hike, had loved to run up the mountain in the dark in order to catch the sunrise during the time before my illness. Maybe my wolf-soul loved it too.

The air felt clean in my lungs. My body was weak, but the strongest it had been in a long while. I traveled up the stone steps built into the mountain, pausing only occasionally to sip my coffee or drink from my water bottle.

I couldn't hear howling, but then, the wolf-soul only howled later in the day. If it was summer, I would have left closer to dusk, but it was winter, and cold; I hoped to get a head start. I was near the top of the mountain when I noticed the tracks. I stared at them for minutes, in disbelief. I had not thought that my plan would work, but here they were, giant paw prints in the crusty snow.

I left the hiking trail to pick my way through the trees after the paw prints. I followed these tracks for a long time, walking through the underbrush, skirting around cliffs and trees, losing the trail in icy sections, and finding it again in the snow on the other side. The day passed this way until I had only the vaguest idea where I was. The sun had sunk low enough that it was behind one of the other mountains. I hoped that the wolf-soul was close, acutely aware that if it came to stamina, I would never win, that I could follow this wolf-soul forever without it tiring or even knowing that I was on its trail.

And then I heard its beautiful, mournful cry. My heart leapt in my throat—it was nearby. I struggled to pinpoint the location, panic rolling through my body in a wave. Finally, I decided that it seemed to be coming from further up the mountain. I began to run, attempting to breathe evenly and land quietly on my feet, even as I struggled up the steep, icy granite. I needed to sneak up on it, and God knows how I could possibly sneak up on a wolf.

I crested the mountain. The island lay out beneath me, mountains foreboding under their masks of ice, sky pink, ocean a deep velvety black. Against this all I saw my wolf-soul, huge and thick furred, singing itself into the sky. Even though I knew it was my soul, not a true wolf, I hesitated at its fearsomeness. The animal part of me awakened an instinct to run. I wondered for the first time who it was singing to. Me? Itself? Or maybe it had forgotten it was a soul and was only in search of a pack.

The wolf hadn't seen me. It occurred to me that its howling might give me the opportunity to sneak up on it. I crept forward, trying to stay out of sight, trying to walk quietly. Almost . . . almost . . . it paused its howl, ears perking, and swiveled its head toward me, holding me still with its deep honey eyes.

I sprinted toward it as my wolf-soul jumped to its feet, hackles raised, growl in its throat, teeth gleaming. I had expected it to run away, but instead it lunged at me. I screamed.

We collided, and my breath was knocked out of me. I fell on the ice, hard. Coarse fur, teeth around arm, claws slicing into chest. Ripping flesh, ripping clothes. Burning wounds, stinging cold air on exposed skin.

I feel my chest ripping open and I remember what it was like, lying bedbound, too fatigued to read or knit or talk or do anything, unable to accomplish the simplest of tasks, unable to think, unable to run or even really walk, too tired to shower, feeling like a stranger with another person's memories, feeling so fucking scared all the time, feeling so betrayed by physicians, feeling so confused and horrified that becoming suddenly, mysteriously, pointlessly bedbound at the age of twenty was a thing that could happen to a person, feeling *too much*. I was so relieved when the wolf-soul had clawed its way out of my chest because I didn't know if I could survive another minute of living in that terror and pain.

And now my chest is ripped open again, and the wolf is not on me anymore, it's inside of me, and the weight and pressure of it against my heart and lungs are both familiar and foreign, both heartbreaking and wonderful. I lay in the snow as the ice slowly melts into my back, and blood seeps from my cuts, and tears and snot trace salty paths down my face. And together my wolf-soul and I sob and cry and howl at the evening sky, bound once again within my fickle, fragile body. •

### **ARTHRITIS**

**arthritis**, n., degeneration of one or more joints, with accompanying inflammation, stiffness, and pain; often presents with weakness and reduced range of motion

```
Good thing I've got two shoulders
                     on a bad day
       when my right arm
              can't pick up a towel
       Used to be easy to wash a pan
brush my hair
              pull on a sleeve
              Used to be applying deodorant
didn't turn me into
                                           a contortionist
Never thought twice about turning
       a doorknob
              carrying
                     a cup of tea
                                    walking
                             downhill
                                           rolling over
       Always thought I'd want to go on forever
but if the worst days become my every day
              Ι
       don't
                     know
Never thought anything would stop me
but
              the right shoulder
       the left knee
                            my hips
                     both hands
```

Moderate to severe degenerative changes said the doctor you can see it on the X-rays

```
I can feel it in my days

don't want it

can't change it

and here it is

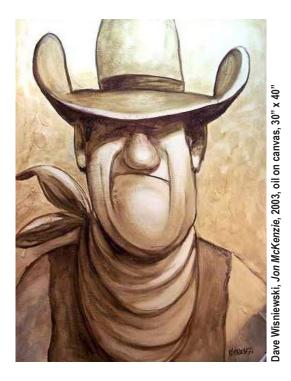
My beloved weaves his fingers through mine

drawing me close

my heart welcomes him
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but my fingers cannot

and we have to find another way to intertwine



## **BRUSH SLINGER**

### SANDY PALMER

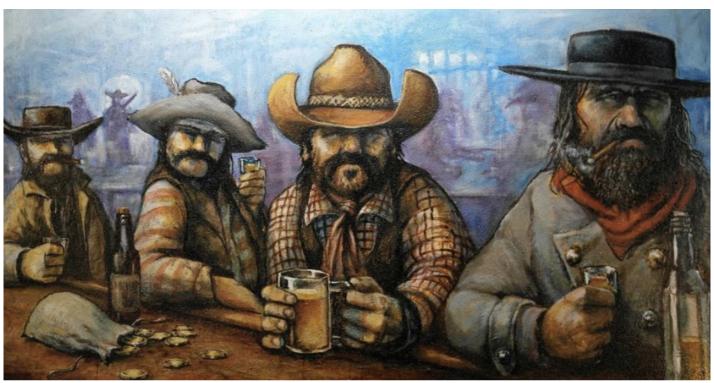
"My drawing, painting, and sculpture teachers taught me to see again."

- Dave Wisniewski

s a young boy, Dave Wisniewski watched the Western television drama Gunsmoke. Tough as nails, yet empathetic, US Marshall Matt Dillon maintained law and order in his frontier town and made an impression on many people who watched the show during its twenty years on the air, including Wisniewski. As an adult, armed with an active imagination and some paintbrushes, he created his own fictional characters of the west, like Doc Elliot and Harry Morgan, among others. Characters who came to life on the canvas as he painted them, dreaming up the kind of life they lived with each brush stroke that shaped a

prominent nose, square jawline, or even a disparaging sneer. Pensive and weathered, Doc Elliot peers over a pair of cracked spectacles. After patching up men who were injured in the Civil War, he moved to Colorado where he found a small ranch in the wilderness and spent the rest of his days fishing and caring for local folks who came to him with their ailments in search of healing. When a character, like Doc, was fully formed in his mind and completed on canvas, he would pen the fictional story of the person he painted and add a photo of the painting along with the story to his website. Once demand for his work increased, he no longer had time to write the stories but, make no mistake, each one has a story. Every painting is a member of his everexpanding family.

"My earliest memories are of living in a trailer on my grandparents' five-acre farm in Michigan. I used to hang out with the chickens and pigs, and play in the crick that ran through the back of it, falling into it quite a bit." His dad was a musician who traveled around the area playing at different venues and imparted to him the gift of music, which always filled their home. His mom had been a model and was Miss Toledo prior to marriage, but she was also a talented artist. "Mom enjoyed painting with oils and I would sit



Dave Wisniewski, Four of a Kind, 2018, oil on canvas, 66" x 36"

alongside her and she would set me up one of those cardboard canvases and help me with the paint. I enjoyed it."

By the time he entered second grade, the family, which now included a younger sister, moved to Toledo, Ohio. After completing the painting of a landscape, he asked if he could bring it to show-and-tell at school. The paint was still wet but he took it anyway. Impressed with his work, his teacher placed the painting on an easel at the entrance to the school where everyone could see it. He realized at that young age he may have talent. The realization took root, and confidence in his abilities as an artist and musician flourished as he got older.

At sixteen, the drummer in his dad's band retired and he joined the band as its drummer. Shortly after, he was diagnosed with type one diabetes and learned how to manage his blood sugar levels, which, in 1973, was more complicated than it is now. After high school he worked odd jobs for a few years before being hired as the store artist for Peaches Records & Tapes.

With a passion for both music and art, this job was a perfect fit. He created displays in the windows, a variety of signs, and even airbrushed portraits of musicians.

In his early thirties, the store closed, so he and a friend decided to open a sign shop, and business was good. "It was around that time I started to have problems with my eyes. I just couldn't see as well. Driving became difficult and I made an appointment for an eye exam because I figured I needed glasses." The technician discovered his retinas were hemorrhaging and he was later diagnosed with diabetic retinopathy. Blood vessels were bursting in his eyes and littering his vision with debris. In 1987, laser treatments were the only option. While it treated the blood vessels, it also burned holes in the retina, resulting in vision loss. He received a dozen or more treatments in each eye. Within a month he was legally blind. "That wouldn't happen now. There are new treatments. Back then, that's all they could do, otherwise I would have lost all of my eyesight."

He received intensive rehabilitation. low vision evaluations, and aptitude testing through The Sight Center of Northwest Ohio. With their support, he decided to pursue a degree in art at the University of Toledo because, sight or no sight, he was still an artist. They provided low vision aids to help in the classroom, including a closed-circuit TV (CCTV) on a cart that was used to zoom in and see the live models so he could draw them. Instructors were intrigued by the blind student pursuing visual art and everyone was very accommodating. As he used the CCTV and enlarged the subject to be drawn in class, one teacher said, "I don't want you to use any of this. I just want you to draw what you can see. Don't try to see." He began sketching shapes and shadows, avoiding the detail that was not discernable. As a result, instructors found his work more interesting.

His mom drove him to school and went to the lectures as well. He would sit in the front row, not wanting to miss anything, and she would be one row behind. They would discuss the lectures during the drive home. He proudly



Dave Wisniewski, *Thunder Hawk*, 2012, oil on heavily-textured canvas, 48" x 41"



Dave Wisniewski, *Doris on Holiday*, 2002, oil on canvas, 36" x 48"



Dave Wisniewski, *Dead-Eyed Dixon*, 2022, oil on canvas, 38" x 42"



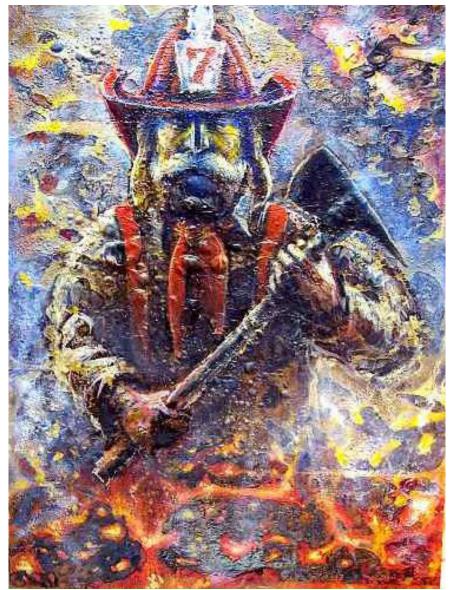
Dave Wisnewski, Got to Know When to Fold 'Em, 2018, 40" x 42"

graduated summa cum laude. As he walked across the stage and received the purple and gold cord he turned to the audience and, unable to see her, waved in the direction where his mom was seated, confessing, "I received that more for her than for myself. I owe a lot to her."

The following year she passed away suddenly after surgery, and the family was left reeling. "Then my dad got a call from a furniture store saying that a couch my mom ordered was ready to be picked up. We were still suffering, and I said I'd go with him to the store. Dad told the sales lady Mom had passed. I introduced myself and she said my mom talked endlessly about what a great artist I was." During their conversation, she suggested he take his work to a local art gallery in Sylvania. Wisniewski went to the gallery with a Polaroid of a cowboy he had painted. The manager of the gallery told him

to bring the painting in and she would hang it to see if it would sell. There was a message on the answering machine when he arrived home. Someone purchased the painting for \$700 after seeing the Polaroid. He was stunned and elated. He delivered the painting to the gallery and she asked for another one. He went home and painted another cowboy. Chrys Peterson, local news anchor for WTOL in Toledo, purchased that one and then followed up with a news story about him which can be seen on his website.

Many of his paintings are monochromatic with rich brown tones, texture and grit, depictions of characters from the wild west wearing large-brimmed cowboy hats that cast shadows on the eyes of the subject. "I take it a step further by shading the eyes where you can't see if they are looking at you or not. I experience that. Someone looks and waves my direction



Dave Wisniewski, Ol' No. 7, 2009, mixed media, 30" x 40"

and I'll wave back. Then my wife tells me they aren't waving at me after all. They're waving at someone else." He releases a hearty laugh at the thought.

He makes every canvas from scratch—cuts the wood, miters corners, glues, nails, and stretches canvas. "I used to work construction so I know how tools work but it scares my wife to death when she hears the saw running." He begins with four-foot pieces of wood and then cuts them down. "I don't measure, I just do what feels right for the piece, but I need it large because of my eyesight. Once the canvas is ready, there's a layering process that occurs. One coat of paint—any color or type—

maybe two, and then some canvases will receive a sprinkling of sawdust, coffee grounds, or bird seed for texture. One time he scraped peeling paint off a house and collected it in a can and used that. He chuckles at the thought that someone may have seen him and wondered what on earth he was doing. Another coat covers everything and then a layer of white or beige is added before painting of the actual subject begins with oils.

In addition to the characters who spring from his imagination, he receives commission jobs to paint portraits of people from photos and has collaborated with interesting

community members to create artwork for The American Diabetes Association's Celebrity Art Auction Gala. One collaboration was with Toledo's Fire Chief (now retired) Michael Wolever. Since the fire department covers such a wide area, they used white pages from the phone book to represent the many people firefighters are there to serve. The pages were affixed to the canvas and coated with a clear sealant. Wisniewski was armed with a torch and Wolever relied on a spray bottle of water to control the burn. Emerging from the charred pages is an early American fireman sporting muttonchop whiskers and red rescue helmet with an axe gripped securely in his hands. Ol'No. 7 went to the highest bidder at the auction and raised money for an important cause.

"The vision impairment is a hurdle. I try not to think about what I'd be doing if I wasn't visually impaired. Would I even have the intention I have because I'm able to do what I can with what I have? That is quite the question." He loves all of his paintings because they are an extension of himself, and would never be able to choose a favorite. "That would be like asking which kid I like best. I put the same amount of effort into all my paintings. I wish some might have turned out better but it doesn't mean I don't love them."

As most artists do, he's completed a few self-portraits. He's the sheriff in one painting and a clown in another. "I'm a Polish guy from Toledo painting western cowboys," he says with a chuckle. "I'm kind of a clown to get away with it."

His work has been featured in solo and group exhibitions and in 2019 he was honored as the City of Sylvania's Hall of Fame Artist. That recognition was followed by induction into the Roy C. Start High School Hall of Fame, his alma mater. With all the accolades, he says his children are his greatest accomplishment. He has a son and a daughter who are doing very well in life. He also has two grandchildren and shares his passion for music with them. With a man cave/music studio in his basement, they play drums, create tunes, and belt out lyrics into microphones. "Their parents promote sports activities and I promote music and buy the equipment for them to use when they come over. We have a ball together!"

Wisniewski just completed a commission painting and is flirting with the idea of getting the airbrush out again. The precise detail work he once did will not be possible but he wants to experiment with it to see what he can create. After decades of painting and promoting, the artist has reached a place where he says, "I don't push the cart so hard anymore. I just try to ride in it now. I'll even take a hiatus every so often . . . long enough to get the urge to paint again and then I fluff the brushes and pull out another canvas."

You can see more of his work on his website www.davewisniewski.com, by following him on Facebook at Dave Wisniewski Artist, or in person at Fuller Art House Gallery in Sylvania, Ohio.◆



Dave Wisniewski, There's A New Sheriff In Town, 2011, oil on canvas, 46.5" x 38.75"



Artist Dave Wisniewski working on one of his larger-than-life cowboy paintings.

## PAX ADAMS

#### CARRIE HINTON

think that green one's for us, pal," I say to the excited little cherub clinging to my pant leg. Just seven years old, Derek is all cheeks and tummy. He lives with his parents in an apartment complex on the outskirts of town. His parents are kind and sincere but permanently exhausted. The world and its demands frequently push Derek into a state of explosive overwhelm, and although he can talk, he has a language delay that makes every aspect of functional communication a challenge.

Twenty years old, I attend the local university and work part time with Derek and a handful of others. I was offered the position by Derek's lead therapist, who is also a family friend. She hired me for my empathetic nature, but also because she knew I needed a job. I know little about autism, meaning I have very few big ideas about how to "fix it." Ready to embark on an outing, as we often do, I clutch Derek's hand, and we approach the neon-green taxi that's arrived to pick us up.

The driver's name tag posted on the dashboard silently introduces him, *Jerry Baker*. I slide over the rough Navajoprint fabric covering the back seat. The smell of stale cigarette smoke paints the interior of the cab, and dust particles left behind by fellow travelers hover in the air, illuminated by the late afternoon sun. Appearing to be about sixty, Jerry has messy gray hair that frames his jarringly hazel eyes and bulbous, red alcoholic's nose. He turns to us and says, "Hello guys. Where are we heading?" in the husky voice of someone who has smoked a pack-a-day since he was fifteen.

Derek looks at the driver for the first time since entering the cab and squeals with glee. "It's Pax Adams!" Derek's family adores Patch Adams, the doctor famous for bringing comedy to his medical practice by wearing a red clown nose while treating patients. Robin Williams portrayed him in a movie. Derek's family met the real Hunter "Patch" Adams once, and they reminisce about it often.

Derek excitedly lunges forward and pats the back of Jerry's head. "Hi Pax," he coos. Jerry looks at me, obviously confused, but he seems to welcome Derek's energy. I smile nervously and shrug, and will him to be kind. Jerry places his large hand on Derek's pudgy fingers. "Hey kid, how ya been?" And we're off.

My outings with Derek, as with many of my neurodivergent clients, are peppered with moments of system overload, usually theirs, occasionally mine. Derek and I move slowly, in fits and starts, because we are traveling at his processing speed. That is not to say that Derek or any of the others have slow processing speeds. On the contrary, I believe they actually process the world at warp speeds. Derek takes in the environments around us faster than I can, and I sense he has far more to say about what he sees than his speech-producing systems allow.

I glean insight into Derek's experiences by paying close attention to his body language and the sporadic comments he makes, his broken phrases, occasional questions, and loud hollers of either tremendous delight or abrupt frustration. I believe it is all intentional communication. When I ask

clarifying questions, Derek becomes stressed, so I try my best to join him as an observer. All I can do is be present and bear witness to the grand adventures of a vulnerable little guy out in the big, weird world.

\* \* \*

One day I arrive at Derek's apartment to find everyone screaming. Derek's parents are frustrated, and he is wailing. "Let's stay on our plan, buddy. I'll call for our ride," I say, not sure what else to do. Jerry rolls up five minutes later. Derek tries to hide how upset he is, but his sobs are audible as he huddles next to me in the back seat. I wrap my arm around him and look at Jerry in the rearview mirror. His eyes are on Derek. He puts the cab in gear and drives a few blocks before pulling over. Derek doesn't seem to notice that we've stopped until Jerry turns and taps his foot.

"Hey kid, you having a bad day?" Derek buries his tearstreaked cheeks in my side. "Listen here, pal, Pax doesn't
like to see you so upset. Here, check this out," and Jerry
squeezes his own nose. "Honk!" Derek looks up. "Honk!
Honk!" Jerry leans closer, "Now you try." Derek springs
forward and gently squeezes Jerry's red nose. "Honk!" Jerry
belts out his biggest baritone honk yet. Derek lets out a
howling, cathartic belly laugh and throws his arms around
Jerry's neck. "That's it, kid. You're gonna have some bad
days. You will. We all do, but you gotta keep laughing, kid,
cuz you got a hell . . . heck of a laugh."

\* \* \*

After working with Derek and my other clients for a few months, I decided to dedicate myself to human services. Twenty years later, I am still dedicated and, incidentally, still as much a student of neurodivergent humans as I was in the beginning. I am still learning from the way they experience a world some may never get to express in their own words, in a way others will understand. I am still learning from characters like Jerry who have enough courage to dive into someone else's story without question or judgment.

Isn't that what we all want? Someone to come alongside us? Someone to fill the empty spaces in our stories? If we pay attention, our most vulnerable fellow humans are teaching us how to bear witness, how to join, how to show up. These are not easy skills to master, especially when we allow ourselves to be seduced by what we think we know. If we are lucky, we'll come across a Jerry, an unassuming sage, who will make it look effortless and who will remind us to keep laughing, no matter what.

Previously published in You Might Need To Hear This (October 2023). Reprinted with permission of the author.

#### HAREENDRAN KALLINKEEL

#### Knowing Him, Knowing Her

He knows spring by fragrance of flowers chirping of birds

She knows spring by colors blooming in gardens blue sky greeting birds in flight

He feels winter through his dry skin pinpricks of chill that freeze flesh beneath

She collects falling snow palms pale, yet warm pieces of white cotton spill out from her hands

Chaotic rustle of banyan leaves swooshing of wind in the foliage alert him of approaching storms

She takes her cue from frantic shadows of fluttering leaves film of dust veiling horizon

He perceives rain's ferocity by its lashes against windowpanes gurgles of choking drain

She experiences it by the blackening sky drops falling in slanted patterns

To him, a thunderbolt is deafening rumbling that echoes in his ears

To her, it's lightning splitting through a dark sky flashes dazzling her eyes

He never sees her smile knows she always does She never hears him call her name knows it's his mantra.

## BORSCHT WITH A CHERRY ON TOP

#### CLAIRE IBARRA

The apartment was draped with melancholy, and Margaret had let herself fall into a sullen mood. She sat propped by pillows on her bed, looking through a photo album. She stared at an old photograph of Richard and herself—they were in their thirties, smiling, both good-looking she thought. Richard had died nearly a year ago from a heart attack, and since then she often found herself alone, talking to the photographs of him in whispers. He lingered everywhere all of the time. It was so generous of him to go in his sleep like that—quietly without a fuss. He was always so civil and stoic, even at his own death. He just fell asleep and never woke up.

The knock at the door shook Margaret out of her slump. She forgot she was still wearing her nightgown when she answered the door.

"Hello, neighbor," Margaret said, as she gave Yvonne's shoulder a gentle pat.

"Hello, I wanted to—oh, are you ill?" Yvonne tilted her head as she examined Margaret from head to toe. Yvonne

wasn't the kind of person to stay in her pajamas, especially past noon.

"Heavens, no. I'm just taking the day off. Would you like to come in?" Margaret offered while saying a little prayer that Yvonne would decline.

"I have to get down to the store. Franklin is waiting. I want to ask you to check in on Sarah later. She's not herself." Yvonne spoke abruptly, always to the point.

"Can she come here, to my place?"

"I'll tell her to come in an hour. Is that good?" Yvonne said with her accent, which made her sound decisive and tough for a 5'2" old lady.

In her chunky gray sweater and wool skirt, Yvonne limped down the hallway and disappeared into the shadows. Margaret suddenly felt young. She glided and swayed with panache, while wearing her nightgown with lace and ruffles. She went to her closet and found a cashmere silk blend shawl in powder blue and opened her jewelry box, where she found sparkling chandelier earrings.

Shimmers of light from the earrings bounced off her auburn hair and all around her face while she modeled poses in front of the full-length mirror next to her bed.

By the time Sarah rang the doorbell, clothes were scattered all over. She led Sarah into the room, and before the girl had a chance to say a word, she was draped in scarves and jewelry, wearing high heels and a knit hat. Standing in front of the mirror, Margaret twirled her around and Sarah clapped her hands.

"Can you do my makeup, too?" Sarah asked gleefully.

Sarah was nineteen years old and had mild Down syndrome. Yvonne had never spoken to Margaret about Sarah's condition. Only once Yvonne skirted the subject by saying that Sarah was born "different." The term most people thought to use was "special" but Yvonne didn't think that way. The whole notion of political correctness escaped her.

Margaret had watched Sarah grow up. When she was little, Sarah sometimes visited their apartment to watch TV and eat cookies. Once in a while, Yvonne needed a spur of the moment babysitter, and Margaret had been happy to oblige.

## Margaret noticed how vulnerable Sarah was just then, and wondered how she could help her.

Now Sarah's blue eyes looked into Margaret's with such innocence that Margaret got a lump in her throat.

Sarah sat at the edge of the bed, while Margaret leaned toward her, putting blush on her already pink cheeks. Sarah had a full face with no apparent cheekbones. Margaret used a big, soft brush that tickled Sarah's face and she giggled. Sarah didn't have much of a brow line either, but Margaret carefully dabbed bluish-gray eye shadow on her lids. "This is a very sophisticated color," she told Sarah.

Sarah put her hand up to her mouth, and giggled some more.

Margaret brushed Sarah's fine, light brown hair and said, "The color of your hair is lovely, Sarah. It reminds me of where I grew up. In the summertime, the long grasses on the plains glittered like gold in the sunshine."

"Where did you grow up, Miss Margaret?" Sarah asked. Why Sarah called her Miss, Margaret could never figure out. Somehow the girl got it in her head and the way she said it sounded folksy. Maybe she heard someone say it in an old Western movie.

Margaret hadn't always lived in New York. She and Richard both lived out west before they were married. Margaret grew up in Broomfield, Colorado, where she had been crowned Miss Broomfield when she was seventeen. It didn't sound so glamorous anymore, it almost sounded obscene. A year later she became a hippie and was embarrassed by the year she spent wearing the crown to the county fair, visiting middle schools where she talked to kids about working hard to make their dreams come true, and attending social clubs. Maybe that's what bothered her about Sarah calling her "Miss" Margaret.

"There now, let's have a look,"
Margaret said as she stood with Sarah
in front of the mirror. "You look
beautiful."

The look didn't quite work with Sarah. It was too much makeup—she looked better without any at all. And the hat and scarf overpowered her. But Sarah grinned at herself and tilted her head, taken by her own coquettish girlishness.

"I look beautiful," she imitated Margaret's inflections.

"Your mother told me you're not yourself these days. Is there something bothering you, Sarah?"

Staring at herself in awe, she replied, "My mother treats me like a baby."

"Your mother cares about you very much."

Sarah sat down on the bed and said, "Did you know I have a boyfriend?" Sarah suddenly got embarrassed and giggled into her hand. She did this to express most every emotion: joy, nervousness, embarrassment, and relief were all denoted by giggling into her cupped hand. Sarah attended an Adult Matters program, which was also called a life skills school. She went three days a week, and participated in educational and social activities for young adults with special needs. She even took the bus by herself.

"That's wonderful. Is he a nice boy?" Margaret asked.

"Oh, he's very nice. He goes to my school." Suddenly Sarah looked

defeated. "My mom and dad won't like that I have a boyfriend."

"Have you told them?"

"No."

"Then how do you know they won't like it?"

Sarah looked up at the ceiling and thought for a moment.

Then she told Margaret that Darren was the cutest boy at her school. She went on to tell about how they held hands during lunchtime, and he always walked her to the bus stop after school. He kissed her once—pecked her lips so quickly she didn't even realize what had happened until she got home. Then at the dinner table she kept giggling into her hand, and her parents kept asking, "What's wrong, Sarah? What's wrong?" And they looked so worried that she felt guilty and started to cry. She had to tell them something, so she said that a boy punched her in the arm. Yvonne said she would have to talk with the director, and Sarah hadn't been sleeping well the entire week.

Margaret noticed how vulnerable Sarah was just then, and wondered how she could help her.

"How would you like to have a parttime job, Sarah?" Margaret was surprised by her own question. "I need someone to run errands for me—like go to the dry cleaners, the grocers, maybe even go across town to the Design Center. You would be like an assistant."

"Really? Would I get paid?"

Smart girl. Always think finances first, Margaret thought. "Yes, of course. I mean I can't pay much but let's see—"

"Sometimes I work at the shop. My mom and dad pay me five dollars an hour."

"Well, I'll pay you ten dollars an hour—but it's only part time, okay? You have to ask your mom and dad if

it's all right with them. Do you think it will be all right with them?"

"Yes, yes, yes! Well, I don't know but I'll ask them."

"And Sarah, maybe you could bring your boyfriend over here sometime, so I could meet him."

"Oh, Miss Margaret, I love you!" Sarah hugged Margaret so tight her back cracked.

\* \* \*

Margaret had a rough few days. She was having trouble leaving her apartment. Every time she tried to leave, she felt on the verge of a panic attack. She would get short of breath and her palms sweated. She remembered the lights of the ambulance flashing through the window on the night Richard was taken away. A crowd had gathered around the truck on the street below. Now Margaret was afraid she was developing a social anxiety disorder.

It was Sarah's first day of work, and Margaret was surprised when she showed up at the door with her boyfriend Darren. Margaret worried that Sarah had misunderstood and took her new job as merely a ruse to rendezvous with her lover. Then Margaret imagined the two requesting to borrow her bed for an hour, after which Sarah would tell her parents all about the "errands" she did for Miss Margaret.

Instead, Sarah very shyly introduced Darren to Margaret. He was polite and shook Margaret's hand, and asked if she had any pets, and if she liked cats or dogs better, and what her favorite color was. They had strolled into the kitchen, and Margaret offered them each a seat at the dinette table.

Once they were settled, Sarah and Darren sat at the table like they were at a restaurant waiting to be served. Margaret had the urge to give them menus. She regretted that she didn't have something to offer them—something that kids like. When her two grandsons, Jack and Tyler, visited she stocked up on juice boxes, Goldfish crackers, oatmeal cookies, apples, and peanut butter. Now the fridge only had fat free milk, half a bottle of pinot grigio, an asparagus bunch, and mangled wedge of Brie.

"I'm very sorry, but if you'd like a snack, I can only offer you asparagus and Brie."

Darren's elbows rested on the table and he cupped his chin in his hands. He looked like he was twelve years old. "What is asparagus? What is Brie?" He asked in a monotone.

"Asparagus is a green vegetable that grows as a stalk, and Brie is a cheese from France." Sarah and Darren both made faces and giggled.

"Darren, may I ask, how old are you?" Margaret wasn't sure, he looked twelve but he could also be twenty-five.

"I'm almost the same age as Sarah."

"Does that mean you're older or younger than Sarah?"

"It means we're not the same age, but almost the same."

Margaret suddenly realized that he was evading the question.

"Well, if you don't want to eat cheese and vegetables, then I guess it's time for Sarah to get to work. I've made a list, Sarah."

Margaret went over the list carefully with her, explaining that in the pharmacy the clerk would help her find L'Oréal Medium Auburn #5MB optimized fade-defying hair dye. The small canvas bag to drop off at the dry cleaners was uncomplicated. And for groceries, she had a small list: yogurt, toilet paper, and orange juice. Margaret added Goldfish crackers, juice boxes, and oatmeal cookies.

"You can have these snacks when you return," Margaret told the two.

## Every time she tried to leave, she felt on the verge of a panic attack.

"Can we have Gatorade instead of juice?" Darren asked.

Margaret felt ashamed that she didn't even think to ask what Sarah and Darren liked. She was selfishly thinking of Tyler and Jack, and their favorite snacks. "Yes, of course, what flavor shall we get?" she asked him.

"Blue flavor."

"And is there anything else you two would like to eat when you're here visiting?"

"I hate oatmeal cookies," Sarah said.

"Well then, we must scratch that off the list." Margaret put a line through the word oatmeal. "How about chocolate chip, or butter cookies?"

"How about vanilla wafers!" Sarah was enthusiastic. "And green grapes—not the purple ones—and chocolate pudding and cheese, but not the French kind, and—"

The list had become illegible, and by the time the two left to do the errands, Margaret wasn't sure what they would bring back with them. But within the hour, all three were seated at the table eating grapes, vanilla wafers, and pudding. They drank blue Gatorade straight out of the plastic bottles.

Margaret watched Darren offer his last cookie to Sarah, and she tilted her head and smiled as she took it from him. Sarah scooted her chair closer to him and Darren covered his face with his hands for a minute to regain his

composure. Sweet gestures went on like that and Margaret observed them with wonder.

As Margaret sat with the two lovebirds, she began to feel warm—a love swelled deep inside her and she felt blessed to have had such a rich life, with a loving husband. Even if it hadn't ended on a perfect note, she had many years of a happy marriage to reflect on and keep close to her heart.

At the moment, it seemed to her then that all of humanity was childlike with its struggles and hopes, and as she watched Sarah rest her head on Darren's shoulder, everything seemed good and wholesome. "Excuse me for a minute," she told the two. Margaret went to her bedroom, laid herself on the bed and closed her eyes.

Margaret was on a boat, sailing the ocean waters with Richard at the helm. The boat swayed over the swells, gliding along at a good clip, but when she looked at the horizon there were dark, ominous clouds rolling in from all directions. Above was clear blue sky, but the black, swirling clouds began to rapidly enclose them from all directions, until there was only one small patch of sunny sky directly overhead. It became dark, and Margaret could see twirling waterspouts and jagged lightning bolts flash and the distant thunder boomed in her chest. Margaret tried to yell across the boat to Richard. He looked over at her, and she pointed at the storm encircling them.

Richard gave her a thumbs-up and began to heave to and come about—but the water was so choppy he lost control and the main sail collapsed and billowed in the fierce wind. Margaret began to panic, as everything seemed out of control and destined for ruin. And the clouds just kept rolling in around them swiftly like the waves on the sea, and when she looked down at the water it was black, like shimmering, thick oil.

She could feel the wind fighting against her and the boat was rocking back and forth with increasing force. Margaret held the side of the boat to keep from falling in the water.

She woke to her daughter shaking her, "Mom, wake up. Are you okay?"

Margaret sat up with a start and had to catch her breath. "Yes, of course, I'm okay. What did you think?" For an instant, the memory of Richard's death flashed through her mind, but she quickly shook it off. Yet, the vivid dream combined with the concern on Joyce's face had Margaret disoriented. She took a few moments to locate her position in time and space. She relaxed when she realized she was in bed. There was still light coming in through the window, and she was not in any compromising position.

"Have you seen Sarah?" she asked Joyce, wondering when she and Darren had left. Hopefully Sarah made it the five doors down the hallway to home without any misadventure.

"Yes, I saw her in the hallway and she told me that you passed out."

"Were those her words, or yours?"

"Well, she said, 'Miss Margaret fell onto her bed and wouldn't wake up.' Does that suit you better?" Joyce was not pleased. "Mother, are you taking something? A prescription?"

"That's ridiculous. I was just tired and I dozed off, that's all. Really, honey, I did not pass out. I took a nap." Margaret pulled herself out of bed and went into the bathroom. There she used the toilet, washed her hands and face, and brushed her hair. She smiled unnaturally into the mirror and examined her teeth. Next time I'll put whitening strips on the grocery list, she thought. She pulled at her roots and noticed the gray, which reminded her that she would dye her hair that very night. When she came out of the bathroom, Joyce was sitting on the bed crying.

"My goodness, honey. You needn't be sad." Margaret sat down next to her daughter. Joyce didn't say anything at first, she just sobbed quietly. Margaret thought about all the things she could say to her daughter to console her, but then something whispered to her, Wait, don't intrude. Margaret understood that not everything revolved around her. Maybe Joyce had her own reasons to grieve.

Margaret held her daughter's hands and let her have a good cry.

"Do you ever miss Dad? Sometimes I wish he was here," Joyce said as she took a tissue from the box on the nightstand. She dabbed her eyes and then blew her nose sonorously, which startled Margaret and made her flinch.

Even if it hadn't ended on a perfect note, she had many years of a happy marriage to reflect on and keep close to her heart.

"Of course I miss your dad. Even if things weren't perfect toward the end, you know I loved him very much." Margaret's mind began to reel back in time, and she shuddered when she remembered the last time the three of them were together, three days before he died. They had met Joyce downtown for lunch. Margaret was hardly speaking to Richard that day, and so she conveyed her thoughts to him through Joyce.

"Remind your father he shouldn't be eating red meat—that's what the doctor said."

"Tell your father to use the Chase card to pay for lunch."

"Please ask your father to hail us a cab."

Now it seemed so immature and petty.

Joyce looked at Margaret with a pained expression: eyes red and swollen, lips pursed and the space between her brows crinkled. "I still can't believe he's gone."

#### Margaret mulled over the predicament: how to be honest and yet not betray Sarah's confidence.

The next day, the doorknocker tapped with short, distinct taps. Margaret answered the door with a wool shawl wrapped around her pajamas, and she wore big, puffy bright red slippers. She had found them in a storage box—Kyle gave them to her as a Mother's Day present when he was twelve years old. He had said, "Mom, I liked these. They looked like cherries and so reminded me of you."

"Why do cherries remind you of me?" she had asked him.

"Remember last summer and we were on the beach, at that ice cream place, and you ordered us a sundae and there was a cherry on top, and then the cherry fell on your shoe. And you looked at me and laughed, and then you ate it, right off your shoe! That was so awesome, Mom." At the time, Margaret was moved to tears by the thought of being awesome in the eyes of her son. If only it could have stayed that easy—as easy as eating a cherry off your shoe.

Now Yvonne stood in front of Margaret with a blank expression. "Franklin has locked me out of the house. He was supposed to leave the key under the mat, but it's not there. Can I use the phone?" Yvonne asked in her thick, Slovak accent.

"But of course." Margaret gestured for Yvonne to come in, but Yvonne hesitated a brief moment, looking down at her feet and then at Margaret's. Yvonne wore brown clunky shoes and black opaque pantyhose. Margaret's red slippers looked like clown shoes.

"Humph." Yvonne grunted and then walked over to the phone. She spoke in a guttural, deep voice and when she hung up the phone, she said, "Franklin's on his way."

"Well, may I offer you a cup of tea? You can relax here, while you wait for him." Margaret went to the kitchen and filled the teapot with water and placed it on the stoye.

Yvonne asked, "Margaret, what can you tell me about Sarah. Her father and I have been worried, has she told you anything?"

Margaret mulled over the predicament: how to be honest and yet not betray Sarah's confidence. She also knew that she couldn't let the secret romance go on for too long, without a possible disastrous outcome. Though they were innocent, their hormones were not.

While thinking it through, she told Yvonne, "She seems very happy, if that is your concern."

"Okay, good. But I get the feeling like she's hiding something. What has she told you?"

"Sarah has a new friend. Isn't that wonderful, Yvonne." Margaret knew she'd have to divulge the truth right then, or come up with a better plan.

"A new friend? Have you met this friend?"

Just then the teapot began to whistle in a frantic, manic screech as if the building were on fire. Margaret busied herself preparing the tea. Yvonne looked straight ahead and drummed her fingers loudly on the table. She perked up when Margaret set down a cup of tea in front of her.

"Why wouldn't Sarah want to tell us that she has a friend?" Yvonne sounded hurt, and for the first time Margaret sensed her tough exterior soften. "Why did she not want to share this with her own parents?" This time it was a personal question, not directed at Margaret. "I just don't understand—"

"I have an idea. Why don't you and Franklin, and Sarah and her friend come here for dinner tomorrow night! The four of you can enjoy a nice, romantic dinner."

"What do you mean, romantic? Is her friend a boy?" Yvonne stood up from the table and now looked directly at Margaret.

"Oh, that's just an expression. You know, it will be very intimate and friendly, that's all." Margaret took a deep breath. "But since you asked, yes, her friend is a boy."

Yvonne pulled her shoulders back and folded her arms. "This is unacceptable. Sarah can't have a boyfriend."

"He's a very nice boy, Yvonne. They met at their school," Margaret explained.

"You met this boy and didn't tell us?" Yvonne glared at Margaret. Margaret noticed the deep creases across Yvonne's forehead, and her eyes became beady slits.

"Isn't it better that she confided in someone?" Margaret was feeling defensive. She knew she had done her best to help.

"Last year, one of Sarah's girlfriends got pregnant. The parents didn't find out until she began to show, months into the pregnancy. What do you think would happen if Sarah became pregnant?" Yvonne sat back down at the table and rested her head in her hands. Margaret sat next to her, and with some hesitation, she placed a hand on Yvonne's arm. Yvonne didn't jerk away, so Margaret scooted in closer.

Margaret said, "I'm sure it hasn't gone that far, Yvonne. They appear to be very innocent. Isn't it better to meet Darren and have some influence over the situation?"

Yvonne took a napkin from the holder and wiped tears from her eyes. She sighed heavily and after a long moment, she said, "We'll come for dinner."

Margaret searched through her cookbooks for Slovak-Jewish recipes. She looked over the ingredients for borscht, cabbage rolls, Hungarian goulash, and latkes. What would Darren like? She wondered. She finally decided on borscht and latkes for an appetizer, baked fish and Russian salad (with lots of mayonnaise, Darren would surely like that) for an entrée. Margaret had always enjoyed cooking. At one time it had been a hobby shared with Richard. They often had dinner parties for friends, most every weekend, and the two of them would work in the kitchen in the afternoon preparing gourmet dishes. They put on music, jazz or classic rock, and cooked while sipping wine. It was even romantic as they fed each other morsels of their concoctions.

She told the two lovebirds about the dinner invitation that morning, and although hesitant, they both gave into the idea with Margaret's gentle encouragement.

Margaret invited Darren to come over early to help her in the kitchen. She didn't want him to feel put on display or have to awkwardly announce himself to Sarah's parents. While she and Darren worked together in the kitchen, Margaret couldn't help feeling rattled. Darren was not like Richard in any way, and was much more like her grandkids, when they helped her bake cookies or prepare snacks. "Okay, sweetie, maybe you shouldn't use the knife after all," she told him after he nearly chopped his finger off. "Why don't you wash these vegetables under the faucet instead?"

Darren sort of bounced around, top heavy and uncoordinated, yet eager to help. "Okay, okay, I can do it," he would say. He set the table in the bedroom and helped put the food in serving dishes, and by the time the knocker tapped announcing their guests, everything was ready. Margaret and Darren stood together at the door to welcome Yvonne, Franklin, and Sarah.

Sarah stood behind her parents meekly, and when Yvonne and Franklin saw Darren they passed right over him. They both glanced around and finally fixed their gaze on Darren. "This is your friend, Sarah?" Yvonne asked her daughter. Her tone wasn't angry, just surprised. Franklin shrugged his shoulders and shuffled his feet.

"I brought an apple kugel for dessert." Yvonne handed it over to Margaret.

Franklin handed her a bottle. "And this is honey wine, from my country."

"That's so thoughtful. Well, now, let's all move to the table, shall we?" Margaret began nudging the tightly nestled, yet awkward, group. The four sat down heavily, while Sarah kept her head down and eyes averted. Finally Sarah said, "Miss Margaret, where are you going to sit?"

"How about if I squeeze in right here, next to you?"

Sarah smiled.

"Well now, real introductions are in order. Yvonne and Franklin, this is Sarah's friend, Darren. Darren, these are Sarah's parents, Mr. and Mrs. Ivanov."

"Hello, Mrs. Ivanov. I see you when you pick up Sarah from school," Darren said.

"Yes, you look familiar."

"I always see you wearing a long brown coat with a red scarf over your head. I always know it's you because of your red scarf." Darren was animated.

"And do I know your parents?"

"You talked to my mom once. You sat next to her at the talent show."

"Oh, I remember her. Hmm, Patricia, was it?"

"Yes, yes! My mom's name is Patricia!" Darren was glowing with this new development. Their mothers were practically friends, and now he looked over at Sarah with an adoring, grateful expression.

During the rest of the meal, Darren grinned from ear to ear; the only time he frowned was while eating the borscht. Sarah kept her head tilted in a sweet, yet curious manner, lifting her eyes to scan the unbelievable scene before her: her parents having dinner with her boyfriend. Franklin was fairly unimpressed with the entire affair and sipped his port quietly, while seemingly half-asleep. Margaret chattered, as she tried to engage everyone in dialogue. Yvonne nodded and grunted.

By the end of the evening, once her guests had shuffled out the door, Margaret was spent. She collapsed onto her bed exhausted, but knowing it had all been worthwhile. Margaret had successfully introduced Darren into the lives of the Ivanov family, and she felt the warmth of a big, ever-present love.

Margaret took a framed picture from her nightstand and stared at it. She and Richard stood together, embracing and smiling with the Golden Gate Bridge stretched out behind them. She traced Richard's face with her finger and whispered, "I miss you."

## **GOOD VIBRATIONS**

Nancy J. Fagan

wake at three in the morning, or thereabouts. I know the general time because my neck is vibrating. Every night, while I dream, my device fires during a randomized minute somewhere in those wee, predawn hours. If I sleep on my left side, the movement is startling and foreign, despite the many months the compact bullet of energy has rested deep against my vagal nerve, adjacent to my carotid artery. It does not wake me—that's my busy mind instead. My device, a vagal nerve stimulator, has released me from the throes of pharmacology costing thousands of dollars in medication each month, millions over a lifetime. More importantly, it has relaxed the grip rheumatoid arthritis has held on my life for over thirty years.

\* \* \*

Rheumatoid arthritis (RA) affects over one million people in the United States alone. RA is not the same as osteoarthritis which naturally occurs with age or after joint trauma. I get the confusion—they both cause joint pain and swelling. But RA brings a bonus: it is a disease that leaks from the joints through the body to the organs. It's autoimmunity at its finest, a body attacking itself in a fit of rage, leaving erosion in its wake.

My husband's friend gave him an article about using vagal nerve stimulators as an experimental treatment for rheumatoid arthritis. The preliminary results were hopeful. "Read this," my husband urged, his voice filled with optimism. "Something new."

I rolled my eyes and scoffed. "Everyone has the thing that will cure me." I thought briefly about the pleas from well-meaning friends and family to try emu oil, gin-soaked raisins, or a line of natural products that would have cushioned my former dental hygienist's pockets with profits from their sales. I received a recommendation from a nurse practitioner to switch to organic meats. She had no idea I had been a vegetarian for nearly fifty years. I had, long before my husband came to me with the heavily thumbed magazine, given up on miracles.

"Read it, please?" His tone was colored with the good, the bad, and the awfully ugly that over forty years of marriage to a person with a chronic illness had brought. He'd seen me at my worst and suffered alongside. The least I could do was read about the treatment.

The article drew me in immediately. It was printed in the magazine section of a well-known publication, with science to back it up. I reached out to the company that manufactured the stimulators and corresponded with them for nearly seven years, outlasting a variety of their staff members and physician leads who moved to other jobs or retirement. I decided to volunteer for their next clinical trial. But they needed funding and government approval, and I would have to qualify for the study, go off my effective biologic medication for months, and undergo neurosurgery. There was a fifty-fifty chance of sorting into the control group where I would not receive therapeutic stimulation for the first three-month phase of the trial. My mind tumbled with the decision.

When the invitation to apply to the official clinical trial appeared in my inbox one day, I accepted.

When you have a chronic disease that is hidden and you don't complain about it constantly, people assume you are fine. After thirty years of adjusting my life to suit the disease, people see the public me, not the patient. Not my early to bed days, afternoon naps, or the strain of folding laundry. They can't feel my ankles burning through the night despite medication and ice packs. No longer do I start the day at 5:00 a.m. in the gym for an hour on the stair-stepper before a twelve-hour nursing shift. Instead, I walk. I started slow. Five steps, then ten, and a few more each day until I got to one hundred. I consistently go one mile now, at least on weekdays. I had tried one drug after another and sometimes three at once for months, even years, until my team came up with an effective treatment that had tolerable side effects. One that allowed me to engage with the outside world. One that provided moderate relief and rest. The curated combination of drugs also gave me low platelets, dwindling white blood cells, and squamous cell skin cancer. And only the inner circle of someone with a forever illness sees the effect of its chronicity on a spouse, a dear friend, or a child. My body is hard to live with.

\* \* \*

I saw my mother in the operating room. She sat in the corner with a quirky smile on her face, like she had a secret to share. I felt her around and within me, and I knew I was safe because she was there amidst the noise of the instruments clinking together, the masked faces above, and the straps that secured my arms. She'd been dead ten years, but death didn't stop my enhanced mind from imagining her. I wanted her there at my chance to rid myself of my pharmacy, and to take a gamble that I might feel mostly whole again. As I was attacked from both sides by mumbling doctors, she perched on a stool overseeing the procedure.

When I woke from the operation, my mother was gone, but her absence did not surprise me. The crisis of playing with my vagal nerve was over, with the device firmly stitched inside where it will stay for the rest of my life. I tuned into the recovery room, much like the one I used to work in before RA helped me leave my job. I understood the lingo, the procedures, the consciousness level of the patients. The normal buzz of conversation and its interruption by ringing phones and patient moans. I smelled the lick of anesthesia on my breath; I was certain I could taste it.

Over the months of summertime, my dosages, in the form of amperage instead of needles, were adjusted. Frequent four-hour round trips to the study center with my husband-chauffeur gave us time to discuss how I felt, though specifics were difficult to qualify and made me cranky. I told him, instead, how I wished to feel by the time the therapeutic dose

reached its ceiling. With each visit, the nurse raised her iPad and controlled me, entering mysterious numbers, testing my blood and my heart.

Pain resumed in small bursts and seared into my joints through June and July. My stiffness and fatigue threatened to overwhelm the way it had thirty years earlier when I begged my rheumatologist for relief. It was clear to me that I was sorted into the control group and was not receiving any stimulation.

At any point, I could have exited the trial, but I reminded myself of the reasons I had chosen to participate. I wanted to avoid the ill effects of drugs. The major pharmaceutical I took each week had been on the market for a mere twenty years—not enough time to predict its long-term effects on my body. What other not-yet-identified dangers would surface and threaten my future? In addition, as I neared Medicare age, my injectable drug cost out-of-pocket shifted astronomically. A change in drug regimen was planned, a pharmaceutical experiment that Medicare covered, thwarted when I signed the papers for the trial.

# When you have a chronic disease that is hidden and you don't complain about it constantly, people assume you are fine.

Instead, my vagal nerve stimulator was gifted to me, endowed by generous benefactors who took a chance with their money instead of their bodies. The study paid my travel expenses and provided yarn money for my troubles. Above all, it carried a guarantee that after three months, when I entered Phase Two, the device would be fully activated to deliver its true therapeutic dosage, regulating my immune system through the vagal nerve, its manager. The fact of a fully functioning device, along with my study nurse's encouragement, came together as an acceptable risk and I plodded on through days peppered with long naps and sighs. The second phase approached: *The One Where Everyone Vibrates*.

\* \* \*

Over a few weeks, the true therapeutic buzz from the stimulator dampened my RA symptoms. "It's remarkable, isn't it?" I watched my rheumatologist pore over my hands, wrists, feet, and ankles. "I have no swelling. No pain." He is cautious with praise. Six months after going off my injectable for the trial, we decided to stop my other RA medicines. Within a year after entering Phase Two, the bottles of pills

and capsules in my cupboard and the prefilled syringes from my fridge were banished. No more increased risk of skin cancers, lymphoma, or the need for medication to work through my tired liver to allow me a day free of pain.

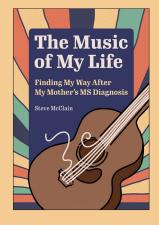
Weeks of continued improvement ensued, without the biweekly shots, pills, and steroid injections that I'd taken for decades. However, the damage that was done before persists in my wrists and hips. And on occasion, a finger joint will be tender or puffy. I'm realistic about the future. We're treading through territory that might have pitfalls, drawbacks, or a day when my stimulation is not enough to hold my disease in check.

\* \* \*

Today, post implant, I work all day, full time at my hobby that is now my new profession as a writer. Though I take most of the credit, my device helped me complete graduate school and allowed the energy to publish essays and stories plus find an agent for my debut novel. But the vagal nerve stimulator did not fix every issue. Aside from random

joint tenderness, I also maintain a level of tiredness that supersedes the usual I-did-not-sleep-well-last-night. It is bone fatigue, felt inside out, like the sense of one's cells dying or reorganizing to mount a revolt. One of the study doctors says fatigue is indicative of my disease activity. Rheumatoid arthritis is still bubbling beneath the surface of my skin but it's no longer erupting. I also consider that my friends complain of tiredness too, so there is the possibility that something else comes along with being over sixty.

Last night when I woke at 3:00 a.m. and felt the buzz, I held a mix of appreciation with an eerie feeling. It was deep night, the windows were covered in blackout drapes, my husband snored lightly beside me. There was a lump of cat at the bottom of the bed echoing his rumbles while a piece of metal encased in plastic shuddered in my neck. In that moment, I wanted the device gone. Why couldn't I be well again without the extra metal inside? It's just too odd, too sci-fi. Then the vibration dissipated. It ebbed so quickly, I'm not sure I remembered what it felt like when it gave me a tune-up moments before. I stretched and wiggled my wrists, then my ankles, and slipped into a dream.



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## KATHRYN THE GREAT

#### TIM CAMPBELL

omething's not right," my wife, Linda, said. "Her breathing is labored." She looked down at our newborn, Kathryn, cradled in her arms. A primitive stress drew Kathryn's tiny face taut. I took her while Linda called our pediatrician, who lived down the street.

Kathryn had been born in two hours flat. After the delivery, I had lain on a gurney a short distance from where Linda was recovering. I called over quietly, a sense of contentment in my voice. "We are parents . . . again."

She murmured a soft reply. "Another girl. And did you see how she looked around the room?"

"Yes, she is another special one." I paused. "The doctor was amazed at her alertness."

We named her Kathryn, after two grandmothers.

Linda and I had been living a dream raising Alana, Kathryn's three-yearold sister, and wanted to extend it indefinitely. We thought the timing of Kathryn's arrival gave Alana just enough room to form her identity and be comfortable with a new sibling.

I had been delirious with the joy of being a father, determined to not be like my dad, who had a sandpaper exterior, was often hot under the collar, and quick to the belt. I cherished my time with Alana on playgrounds, at school, and reading together at night.

A week after Kathryn was born, a friend snapped a photo of the four of us, the only photo we have of the whole young family, healthy.

\* \* \*

Now, waiting for the pediatrician, we sensed something menacing in the air, but it floated out there beyond our grasp. Our throats dried. We felt the tight grip of helplessness. I held Kathryn's face close to mine. Her mouth opened slightly. She gazed up into my face but with the unfocused stare of a newborn. Her breathing grew more strained. Her head was laid back,

mouth open, and airway clear, yet she made tiny gasping sounds. My gut vibrated with anxiety and helplessness. My dreamy foray into parenting was turning nightmarish.

The pediatrician arrived. She took Kathryn with authority, laid her on the dining room table, and examined her, listening intently and pushing her fingers into Kathryn's tiny midsection. She finished abruptly, looked up at me, and said: "Get her to the hospital . . . I'll call ahead." The pediatrician paused. Her face tightened, and her tone changed. Her next words hit me like a thunderclap: "She might not make it."

I stared at her, my pulse quickening. Internal alarms built to a clamor. I glanced at Linda. Her face was frozen. The glint of fear we had suppressed waiting for the pediatrician flashed into a panic.

"Go," Linda said.

With that word, I understood that Linda needed to stay with Alana. I swept

up Kathryn in a single motion and was out the door, moving with dumb determination. I strapped her into her car seat, mounted backward next to me in our Datsun, and headed for the hospital. Her breathing grew more erratic. Her infant face craned upward, beginning to contort in distress. She continued to gasp for air.

I was in a race against something dark and foreboding. The world shrank. Speeding through the streets, I raised my voice and spoke to Kathryn with as much calm encouragement as I could muster. "Hold on, Kathryn, hold on. We'll be there in a minute. Daddy's with you, honey." I was pleading with my baby as though she were a warrior in a battlefield ambulance. I didn't know what else to do. "Don't let go. Hold on, Kathryn, hold on." This was all I could do to let her know she wasn't alone.

I pulled up to the emergency entrance and grabbed her out of the car seat, leaving the car sitting in the driveway, doors open, and sprinted through the entrance.

Children's Hospital was a familiar sight from previous visits. I knew exactly where to go. I did not bother to stop at registration or security.

"Baby Campbell," I called out as I rushed past. They had gotten the message and waved me through.

In pediatric intensive care, tiny infants—some under hoods, others strapped onto small tables, still others in small beds—ringed the perimeter of the large room. Each infant patient was heavily shrouded in electro-medical technology. All our earlier visits had been to a pediatric ward where children

moved and cried. In intensive care, the tiny infants lay still, heads turned aside, silently acquiescing to the imperatives of medication, tubing, and wires. Monitors and lights beeped and blinked

In the center of the room stood a small table under a bank of lights, fresh linens draped over its edges. Assorted medical paraphernalia hung from rolling stands and ceiling fixtures. Four nurses moved into position, poised around the table. They were expecting us. I recognized two of them. We exchanged nods, and I laid Kathryn on the table.

Kathryn gripped my little finger firmly as I hovered beside her. The thought that this could be our last connection tormented me. A nurse gently led me aside. My contact with Kathryn narrowed down to her tenuous grip. Then her tiny fingers slipped away. My heart sank into darkness. A heave of fear reached my throat.

Quickly a circle of attendants closed around her table. Groups of nurses and medical technicians appeared, taking up positions, and wheeling in equipment; they executed precise maneuvers, then disappeared. They bore one kind or another of devices: syringes, tubing with sharp insertion wedges, trays of glistening stainless steel, wiring and clips, blood pressure patches, and charts.

A large clear canopy came down over Kathryn's head. The staff asked me gently again to step back, but I could manage only a few paces. Something far down in my core was being pulled apart. I kept eye contact with Kathryn, despite my tears. My field of view narrowed. Nothing else in the world

mattered. Her head was turned toward me, even as the canopy came to rest over her head and onto the table, covering the upper part of her body. Doctors moved in groups of two and three. The table was now surrounded by medical people.

The chief physician began an incision just below her belly button to get fluids and nourishment into her. A nurse motioned me to a chair at the edge of the room. I looked back at Kathryn, now unconscious from sedatives and shock. She had turned a purplish color. I could only get glimpses between the white-gowned bodies and arms. I sat, numb, terrified.

The medical staff began a series of coordinated moves. One inserted tubes into her tiny veins in each arm for nourishment and antibiotics. Others placed lines in her legs and patches to monitor her heart. Each move picked up the pace, accelerating like a gas turbine at ignition, the quiet whir of a medical machine rising in pitch, integral parts building to a fury.

Later I learned that her six-pound body was mustering all it could to hold off a virus attacking her heart. She had gone into heart failure. The technical name for her condition was viral myocarditis, but that told us little other than a virus was attacking her heart and was winning. Her heart had ballooned to the size of a small melon. Seizures showed that the viral attack was impacting her nervous system. A doctor gave her a one in ten chance of surviving the night.

The next day, Kathryn's condition became more complicated. Blood chemistry data, taken every hour to manage the balance of fluids and blood pressure, was contradictory and confusing. Kathryn's intravenous tubes kept pulling free; her small body mass allowed little margin for error when placing the lines. Even experienced nurses had trouble finding her veins and coaxing a minuscule needle into them. She would flinch with each insertion—arms, legs, even forehead. Invariably the lines would have to be removed because the vein had been missed. Witnessing this was torture, an unavoidable concomitant of our support. There was no turning away.

Meanwhile, Alana was abandoned by one parent at a time as Linda and I alternated our visits to the pediatric intensive care ward. The fatherhood project—my inventing a way to be a father that was part dreamy lullaby and part spiritual partner with a rule book and a wink—began to disintegrate. My brief times with Alana, fit in between visits and consultations at the hospital, proved the unraveling. We tried to stay upbeat around her, but inevitably there were fewer trips to the park and pushes in the swing lost their zest. I put on a brave face for her, and she gleefully met my eyes. But inside we both seemed to know that our play had lost its magic.

At the hospital, the physicians described burgeoning complications. Kathryn had suffered an absence of oxygen to her brain, a condition called anoxia, during the initial stages of the illness. The degree of brain damage was difficult to assess, but her frequent seizures signaled trouble. In addition, X-rays showed that her right kidney had decreased in size, possibly due to a blockage of blood flow on that side of her body. And there was the ongoing threat of further heart trouble.

One night in the second week of her hospitalization, the heart monitor flashed erratically. The beat line made jagged spikes and plunging troughs. Each change jerked us along, our spirits riding on electro-technical beats.

The attending physician, one of the cardiologists, called us to his office. We braced ourselves for the news we had been dreading.

"She may not get through this night, and I feel you should know, and be prepared," he said. "When the time comes, if you wish, we can turn off the machinery, unplug her, and you can hold her and be with her to say goodbye." He motioned to a door. It led to the special room just off the main ward where we could have our last moments with Kathryn in peace. Linda and I tightened our grip on each other. I swallowed a dry, empty swallow. I could not even look at the door.

Linda and I were coming up to the summit of the compact we had made for ourselves and Kathryn a few days earlier.

"We both know that she might not make it," Linda had said then.

Now we were confronted with the choice we dreaded most. We sat alone in an empty visitor room. Our eyes locked on one another. The deep creases in Linda's face reflected my anxiety. Her eyes were wet. Her lip folded out as she began to cry, her hands trembling. Then, summoning courage, she drew herself more erect. The trembling stopped. Her eyes bore deep into mine. I already knew where she was headed, but I was shrinking inside, in a futile attempt to escape reality. But the only light was forward, to push back against these feelings of doom and double down on our baby.

"We have to give her everything," Linda said.

"Everything we've got as long as she's alive," I answered.

"Yes. Every single ounce of love we have, we must give. We must give it now."

"Yes," I whispered. "Yes. Everything."

We hugged each other and wept. We felt certain of our pledge. We had reached into the very depths of our being, where soul and identity unite, and refused despair, pushed back against a fearsome threat of fate, gritting our teeth against fear.

The degree of brain damage was difficult to assess, but her frequent seizures signaled trouble.

Besides the torment of witnessing Kathryn's suffering, we faced overwhelming challenges, whether she survived or not. The deeper our commitment to her, the more acute the loss if she were to die. Yet the medical staff had hinted or said outright that long-term prospects were iffy. We knew that Kathryn's epileptic seizures would likely continue, but couldn't know the long-term effects of brain damage. One kidney was seriously compromised. Heart tissue was scarred. Some of the medical staff thought she might never leave a hospital setting, might never escape the dependence on medicaltechnical supports, and might never recover from an unresponsive state. We stood on a knife's edge. On one side life, with the prospect of unending challenges, on the other, death and a black abyss of grief. Either way, we stared into a mountain of emotional debt.

We could have shut down the battle right then and there. We chose to go all in. We entered a phase of dark suspense, an agonizing watch that gave added weight to each capricious flicker and beep of electronic monitors.

That night melted into the morning. A nurse gave Kathryn to me to hold. Hours melted away. The dreaded moment never came. If anything, Kathryn seemed to be a little more stable. Her heart activity grew less erratic. We drew a cautious breath. Sometimes titanic battles are quiet and internal.

\* \* \*

Linda and I settled into a routine. We would split shifts during the day, one of us driving Alana to daycare, the other picking her up, and alternating our time with Kathryn. Being close took on new importance for us. She was effectively in a coma, on a respirator, and filled with drugs. Nonetheless, we felt it was therapy for her, however impalpable, for us to orbit silently around her, to be in her psychic field, in her aura, to hover on the surface of things, to sing and coo to her, watching for any sign of emergence from her deep stupor, at least hope that we might touch her soul.

## "My beautiful world is falling apart," she sang.

At the hospital, our hopes were tethered to the dancing, beeping heart monitor. The hourly news of her blood chemistry samples was a continual reminder of her delicate state: electrolytes too high, with pressure too low, or vice versa. Yet in time, perhaps because of the emotional Novocain that resulted from unrelenting tension, we came to take each bit of news with muted feelings, not assigning too much hope or desperation to upturns or downturns.

Kathryn was heavily laden with fluids and medications—to control seizures, regulate blood pressure, and steady heartbeats—and she was never conscious. We sat for long hours at her bedside. One afternoon I bought a tiny rubber elephant and folded it gently into her gripping fingers. Her involuntary movements gave the appearance of waving the elephant

about. My little baby was doing little baby things. I wept.

Intermittently, I would shuttle back to the house to pick up the most important medicine Kathryn would ever receive: Linda's breast milk. Linda continued to express at home. It was not easy, but she did not give up. Her breasts were sore and nipples raw from the breast pumps. Though we were both emotionally battered and depressed, Linda grew stronger and more determined with each week.

I would take the few ounces of milk in small bottles as though I was engaged in a global pharma enterprise. I placed the priceless elixir in a cooler next to me in the car. I carried it carefully into the hospital and placed the bottles gently between Kathryn's lips. Though she was never fully awake, sometimes the aroma would work its way into her system, and she would suckle instinctively. This cheered me immensely.

Kathryn looked scrawny, tiny, pale, and near death. A heart monitor was attached to her chest, an IV in her head, a tube in her umbilicus, electrodes, and IVs in every limb. A catheter drained her spleen. A black respirator mask covered her face. She wore a knitted hat. I sat on a stool next to her and stroked her head, holding her hand.

Linda adapted the words from a lullaby we often sang to Alana at bedtime during the idyllic phase of parenthood, now in the distant past. The lullaby went like this:

Hey, hey, Kathryn Ariel. Hey, hey, Kathryn Ariel. Everybody loves Kathryn Ariel. She's the special one.

Like a mantra for keeping her alive, we would repeat this over and over. I pretended that the sound of my voice drowned out the monitors and the occasional outcry of infants nearby and that Kathryn could hear my song, even though she could show no outward sign.

When nurses came to attend to Kathryn as I was singing quietly, they glanced at me and smiled faintly, not intruding, but seemingly acknowledging that therapy was underway. The nurses always seemed to know what was needed. Their tacit support cheered me.

But sooner or later, the monitors and the beeping would get the better of me. Spikes and alarms went off as Kathryn went into a spasmodic run of heartbeats. Tense alarms vibrated in my body; I just had to surrender. She would show no outward sign of change, but the monitor would fly into a cacophony of noises and jagged lines, and I would stiffen with apprehension, riveted to the screen. The scenes reminded me of submarine movies with crews trapped helpless, listening for the pinging of an unseen destroyer overhead. We waited for the awful moment when strings of two, three, or more arrhythmias would appear sequentially, knowing that this spelled trouble—or even the beginning of the end. With a heart rate sometimes over 200 beats per minute and blood pressure over 170, Kathryn's heart was losing its integrity, slipping into a flurry of disorganized contractions. A nurse would push the hard copy button, and a small, inked arm would begin tracing the beat pattern on a roll of recording tape until she tore it off and hurried away. My singing trailed off. But I did not give up. I waited for a quiet moment and started my song again.

\* \* \*

We struggled to make time for Alana. One afternoon during Kathryn's sleep time, I saw an opportunity to recapture the fatherhood project for a moment. Relishing our presence, Alana began to dance for Linda and me in the living room. We were her audience, seated on the sofa, giving her our undivided attention at last. She entered the room in her raspberry leotard, one that I had brought back from Brazil. Alana strode in proud and upbeat. She twirled, her head cocked back, dancing a made-up dance, her arms out to her sides. She spun around in lazy circles and began to

sing. The first and only line in her song sent my heart through the floor.

"My beautiful world is falling apart," she sang. She turned repeatedly around the room, singing with a bright smile on her face, with no apparent recognition of the gravity of her words. "My beautiful world is falling apart."

I felt as if the air was sucked out of my lungs. The virus had spread even further than I feared. It was not only threatening to kill Kathryn. Its effects were spreading into Alana's world, in ways none of us could know. Alana's dance and her simple tune came across like a brass symphony playing a disguised dirge. I put on a brave face, but inside my spirit withered in grief. It felt to me as if Alana was being abandoned. There is no more stark illustration of that than my utter inability to recall specific moments with her during this period. Perhaps my memory loss is a companion to trauma. Linda and I focused on the neediest at any given moment, and Alana inevitably came up second. I felt a tear in my heart whenever Alana came to mind. Even today, nearly forty years later, I feel that those times of separation, created a debt I still owe, even though Alana herself moved forward a long time ago. I still feel residual heat in the coals of my grief.

\* \* \*

I spent many nights sitting at Kathryn's bedside and sleeping on a couch in a nearby visitors' room. Linda was at home with Alana. A nurse awakened me quietly at 4:30 in the morning during the fourth week. Kathryn was going into convulsions. This nurse was the epitome of a healthcare professional. She told me from the beginning that

she'd never give up on Kathryn. When the trouble started up again, she came to the couch where I was sleeping.

"I think you should come," she said quietly in the darkness. "Kathryn's beginning to seize." Her eyes were focused on mine, letting the message sink in. She was worried about Kathryn surviving the night.

We both knew the tiny tremors in Kathryn's limbs were a sign that her body was losing the battle. I sat next to my baby and held her quivering little fingers. I gave all I could to her, inwardly opening my spiritual core, exposing the innermost strength of my being, and projecting it onto her, as though I were hurling a magical cape of immortality upon her. It is a feeling that lies behind a deep grunt, the sound you would make trying to move a mountain, except I was silent. It was not mass that I was trying to move. It was an invisible force, a gargantuan exertion, showing strength, showing defiance, showing tenderness, and caring, cradling my baby in my arms. I heard nothing. I had blocked out the chirping electronic monitors. I started a line or two of the lullaby, humming softly, grasping delicately her fingers, the miniature petals reaching out, exposed. I felt quite certain that these were her last moments on earth. But by God, I was there. I defied lightning to strike—take me if you want—but I wasn't going to let that virus kill my baby, not if I could help it. The nurse would not have noticed this. I sat calmly at Kathryn's bedside, a little bit of Buddha hiding the storm inside.

After a few hours at her side, I felt completely wrung out. I had no tears left. Sometime before sunup, Kathryn fell back into quiet. Miraculously, the dangerous moment seemed to have passed once again. The nurse looked up at me, astonished, shaking her head in disbelief. I felt utterly depleted inside.

Kathryn showed us that from deep within her she had a powerful will to live. She fought a titanic battle. Yes, the tangles of technological monitoring and an armory of medications supported her, but Kathryn herself, sustained by her mother's breast milk and our physical presence, won through to daylight. Several weeks later, after she was discharged from the hospital, we began a prolonged struggle, one that stretched into months and years, to protect her from infections, administer medicines, and arrange for physical and speech therapy. Meanwhile, Eric was born, a welcome addition whom we called Mr. Wonderful. After years of keeping Kathryn alive, Eric was so easy. Gradually, I tried to resuscitate my dream of inventing a new kind of fatherhood, but the whole game had changed. The home care routine, plus special education, hearing aids, and social support went on for decades.

Kathryn showed a dogged determination in school, and though not expected to graduate high school, she came close to making it through community college. Alana grew into a sweet mother and creative neuroscientist. Eric blossomed into a twin of Alana after years of shouldering too heavy a load for a younger brother.

Last December, Kathryn, now forty, celebrated her eleventh year of swimming a mile, five days a week. She flexes her biceps and says with a beam, "Look at these guns, Dad." And when she hits the pool, you should see her go.◆

## THE VOICES IN HIS HEAD

EMMY D. WELLS

om, can I have a PRN med, please?" Sixteenyear-old Max asked me. He rubbed the sides of his head. "They won't stop coming."

I handed him one of the pills he took a few times a week when the voices in his head got too loud, and then guided him to the living room to give the medication time to work. Moments later, a high-pitched screech came as Max ran down the hall, toward the outside kitchen door. I slipped in front of him. When Max is in distress, his first instinct is to flee. I knew that if he were to go into the street, not only could he get hit by a car, but as a Black teenager, there could be a violent reaction from neighbors or the police.

Max's dad called 911.

Max melted to the floor and writhed. "They keep coming!"

I wanted to talk to him, but when the voices in his head are loud, they are all he can hear. They tell Max to hurt himself and other people . . . to kill.

One of the most common symptoms of schizophrenia is hallucinations. Some people with schizophrenia have visual hallucinations, meaning that they see things that aren't really there. Others have auditory (hearing things that aren't there) or tactile (feeling things that aren't really happening). Although Max usually has auditory and visual hallucinations, he occasionally gets tactile as well. This was one of those times.

Max's screams sawed through the walls. They went into the yard and pushed their way into the empty street that awaited the ambulance that held the paramedics who would medicate Max... make the voices go away—at least make them stop screaming.

When you adopt a child . . . you don't expect him to come home with other people inside of his head. He smiles and cries and laughs just like other babies do. Something happens while he grows, though. His imaginary friends get angry. They get mean. They take over.

"They won't stop coming." Max punched his head and scratched his face.

I grabbed his hand.

He hit me.

Max's dad was on the phone. With each word Max screeched, the dogs howled. The screaming, the talking, and the howling reverberated throughout the house, bounced off the walls, and pierced my ears. I couldn't think.

"They won't stop coming."

The paramedics backed the ambulance into the driveway. Ten seconds. Fifty seconds. A minute and a half.

Why the hell aren't they getting out?

"They won't stop coming."

In the doorway, a police officer appeared. His night blue uniform was perfectly pressed, and his gun hung from his belt. The scene would have made Max nervous had he been alert. The last time the cops came, the voices told him to attack even though he didn't want to.

#### The staring eyes in the Bangor, Maine emergency room made Max's screams louder.

"What's going on here?" the officer asked.

I yelled my answers because the dogs were howling, and Max was screaming, and my ears were searing with pain.

"Has this happened before?"

When your son is on the floor screaming for the voices in his head to shut up, and the dogs are howling and screeching because your son is yelling at the people in his head, the first thing you wonder is why the hell it matters if this has happened before. Even if it has happened before, it is happening now, you think to yourself but don't say because you know you need their help and you don't want to make them go any slower than they already are.

"They won't stop coming."

The officer left. Seven minutes. Eight. He returned with a paramedic. Then another one appeared with two more officers.

They surrounded Max and yelled about what should be done.

"They won't stop coming."

One of the paramedics came with a needle and vial in his hand. He unwrapped the syringe and held the vial up to the light. I wanted to snatch it out of his hand and do it myself, make it go faster.

"They won't stop coming."

They held Max down; stuck him in the arm. Nine minutes. Eleven.

"They won't stop coming."

"Maybe he needs more," a paramedic said.

Another nodded and pulled out another syringe. Unwrap . . . draw out the liquid.

"They won't stop coming."

He stabbed Max's thigh. We waited. Four more minutes. Fifteen. Nineteen.

"They won't stop coming."

"He needs to go to the hospital," the paramedic told me.

When your son is trying to get away from people that don't exist, people who want him dead, who want you dead, it quickly becomes apparent that your son needs to go to the hospital. You wonder, but again don't ask, why they haven't already strapped him on the gurney and put him in the ambulance. It's impossible to impart this information, though, when your son is screaming, and your dogs are howling. The sounds stab at the back and sides of your skull, like a knife moving around. Back and forth. Side to side. In and out.

"They won't stop coming."

One paramedic brought a flexible stretcher, like a reinforced, Max-length tarp with handles.

Max kicked and swung at them.

Four men lifted Max and took him outside where the fifth man waited with a gurney. Max flailed. They strapped him down.

The staring eyes in the Bangor, Maine emergency room made Max's screams louder. Before I got through security and into his room, they had given him a third and fourth injection. I watched the crowd of people work over Max as he flailed under the weight of their hands.

The doctor asked, "Who is Luke? I thought his name was Max."

"His name is Max."

"But he just called himself Luke."

My mind raced, then it dawned on me.

"Oh! His name *is* Max. Luke is the dominant voice in his head."

The doctor nodded with recognition.

"Luke has never spoken to anyone other than Max before."

The doctor moved rapidly through his questions.

"We may have to chemically sedate Max if these meds don't start working." I knew he meant it would chemically *paralyze* Max—make him unable to move. I nodded, giving permission for something I did not want for Max, but saw no other option.

"Max is such a weakling. It feels so good to be out." Luke spoke in a lower register.

Luke's voice was more sinister than Max's had ever been, I wanted to throw up. This was someone I did not recognize and the thought crossed my mind that I might never see Max again. I wanted to show Luke what I thought about him taking over this almost grown man who knows how people might judge him even if it isn't true—as another Black man on drugs.

Luke's movements were reduced to small waves of squirming aggression. "I want to kill you all," he screamed with an increasingly weak voice. "I will never . . . let Max out . . . again!"

Just as suddenly as it started, he was asleep.

The nurse drew blood, checking for drugs and chemical imbalances. Doctors want to believe parents when they say their child does not do drugs, but they prefer the surety of their machines over fragile parental psyches.

No drugs.

I tried to sleep in the hard metal chair.

I paced the room.

I tried to sleep again.

For fourteen hours, I wondered, when I saw his eyes again, who would be behind them.

"Mom, what happened?"

It was Max. I was sure. Those were his beautiful, loving eyes.

Even though I was sure, I held back my tears. Maybe I wasn't really sure.

Can I ever be sure?

For Max, living with schizophrenia is a daily effort to stay centered in reality. He rarely ever stops hearing the voices in his head, even with his medications. We talk about the voices as though they live on a spectrum. When his meds are working well, the voices are there, but they are quieter. He can concentrate better and have conversations with people without pausing to figure out which of the voices he hears are real. When his regular medications aren't enough, he has to take a little extra, something we call a PRN. It is at those times that Max is most distressed. It comes just before he loses all touch with reality. If we don't catch it in time, it's too late. He needs emergency department intervention. That is what I've described here. For him, the ever-present possibility of going to an emergency department means an ever-present possibility of going to a psychiatric hospital. It is a living hell.

The medications help keep Max from medical emergencies, but hallucinations are a part of his world. He lives with it every minute of every day. Even when he sleeps, the most prominent voice in his head tells him to kill the ones he loves. Every night, he watches us die. Every night he kills us.

Author's Note: Teenage schizophrenia is an insidious disease that needs more research to help those who suffer its effects live as normally and as independently as possible. If you think your child may be exhibiting signs of schizophrenia, seeking help early is the most important thing you can do. Talk to your child's doctor or therapist. Get them the help they need. For more information about childhood schizophrenia, please visit The Mayo Clinic's website. For general information on schizophrenia, you can also go to the National Alliance on Mental Illness.

Max was brave enough to let me write this article knowing that he could face judgment from others. He wants people to understand what it is like to have schizophrenia and know there is help out there if you look for it. Can you be brave enough to get to know someone with schizophrenia?

## DARCI AND THE HOOK, LINE, AND SINKER

#### Danielle Krikorian

arci, you're eating fish on a Thursday. You're not supposed to be eating fish on a Thursday. Remember what happened last time you ate fish on a Thursday? You got sick. Stop now.

It's good fish this time.

But it's Thursday. A bad day to eat fish. Stop eating.

Darci paused and looked at her friend, Bree. "I'll be right back."

Bree nodded and Darci left, looking for the bathroom.

Darci, you ate fish today. You're gonna get sick and not only that but something bad will happen too.

She nearly crashed into the door when she found the bathroom. Once she was inside, Darci ran to the nearest stall and was about to get in when the voice returned.

Not that stall. That one is the first stall. Remember, one isn't a good number. Try the second stall.

Darci walked to the second stall in the row, pushed open the door and slammed it behind her once she was inside the white cubicle. She locked the door and rested her forehead against it.

Darci, why is your forehead on the dirty door? Get it off!

She obeyed and took shallow breaths.

Breathe.

But instead of inhaling a breath, she started crying. Warm salty tears started escaping, down her face, ready to fall to the floor and splatter. They were reminders of how weak she was.

"Damn it!" she said, pounding her fist against the door of the stall. She wouldn't be feeling this anxious if she told her friend that she wasn't craving fish today; but that would be a lie. She did perk up when her friend asked if she wanted to go to the Fish Grille with her. It sounded like something good to eat. Plus, she could be doing some exposure therapy by facing her fear. She couldn't limit herself. Darci was already so limited. But this was her own fault. She should have known she couldn't handle this.

When you get home, Darci, you have to shower. Then maybe you won't get sick and you won't be dirty.

Again, the fear of being "dirty" or "contaminated." The demon in her mind always circled back to that main fear and the shower compulsion. Darci had been obeying these fearful commands ever since she started having anxiety problems when she was small.

She was a fish. A helpless fish like the one she'd just been consuming. She was lost and always afraid of being "eaten."

But then a shiny piece of something that disguised itself as relief would descend into her ocean, beckoning her. Calling her with promises of a fearless future and the smell of liberation. Once she grasped onto that shiny something, its true colors would show, and it would be too late. That piece of "relief" was attached to a silver sharp hook that would latch into her fishy flesh and carry her up into the cold air where she couldn't breathe. Everything came with a price. Even relief. There were always strings attached and for Darci, those strings came with silver sharp hooks that would make her bleed.

She was tired of bleeding. She wanted armor. She wanted a sword or weapon. If she was a fish, then why couldn't she be a swordfish? That way she would have some chance of keeping herself safe and uncut.

Footsteps echoed in the bathroom, bringing Darci out of her thoughts. She held her breath and waited. But it was just another woman needing to use the bathroom for her own relief.

Darci unlocked her bathroom stall door and walked out, looking at herself in the mirror. Her face was stained with tears. She needed to clean herself up. Darci started to wash her hands so she could wipe her face. But there was that catch. She had to wash her hands for two minutes or else it wouldn't be done properly. More than that, she had to think of safe and clean thoughts at the same time. It was the merrygo-round from Hell her mind always rode. The scary-go-round.

But no. She didn't have to ride the scary-go-round. Not anymore. Actually, not ever. Darci rinsed her hands of the soap, grabbed a paper towel, and wiped her face. She was about to walk out the door when that anxiety, the one she usually felt when she disobeyed the demon, bubbled up.

### Darci, go back and wash your hands for two minutes. Then something bad won't happen.

Clenching her teeth together and her hands into fists, Darci had a choice to make. A quick one before the woman in the stall came out to find her staring at the bathroom door. She could break free a bit and tell the demon that she had the power. Or she could give the demon more power.

Anxiety bubbled more. Still trying to figure out what to do, Darci heard the flush of a toilet. Her time was up. She needed relief. Darci walked back to the sink.

Hook, line, and sinker.◆

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STACIE EIRICH

#### **Breathing Hour**

Day dampened by chill and gray, she looks tired and worn beside me, her usual chattiness quieted.

I feel the smallest of sighs against me, ask her again if she's alright.

Perhaps this is what she tires of, the constant worry and care, the questions, the way my hands

find hers and hold on as if the wind might blow her away. As if the clutch

of my arm in hers might shield her from the storm cancer brings —

the pain and uncertainty of each tomorrow.

I've told her I would take it all away if I could, told her that her care

is my most important job. But perhaps this too is what she tires of, because

she is fourteen and wants more than anything to be her Self, to get back to being fourteen

like her friends at home taking selfies of their tips dyed purple and green, going to the movies

and dance class, Snapchatting, giggling. Instead, tears fall from her eyes in the bathtub

as she thanks me again for staying with her, for taking care of her.

In the golden light of a Saturday afternoon, she tells me she wants to take a nap and lies down, awash in sleep

the moment her eyes close. I pull the laundry from our basket, folding as she slumbers, tucked underneath

her soft gray blanket. Lights dimmed, I put in my earbuds, listen to poetry readings, my mind wandering by the third.

I switch to instrumentals, pull up my computer, begin to write. A knock delivers our mail; this small interruption

doesn't wake her. I gaze at the swirling colors on her tie-dye T-shirt, watch her breath expand and fall.

Follow the outline of her chin and cheeks, notice the way her mouth relaxes into a small open frown, how her skin

seems to glow against the softened light. How the dark outline of a single hair remains

at the top of her forehead, how her eyelashes curl downward, dark and full

as her eyebrows. How her hand rests atop the blanket, fingers curled into downy fleece.

The hour turns and I consider if I should wake her, if I should take her temperature, or if this is just rest she needs. If this is her body and my mind readying themselves

for the storms to come, if this is the calm settling in to us like the afternoon, long and steady, still and quiet — still shining

on the other side of the shades. The day waiting for us, waiting for her

to heal, the two of us standing together on the other side of cancer — our hearts stepping into tomorrow, free from

what holds us, free from what keeps happiness at bay.

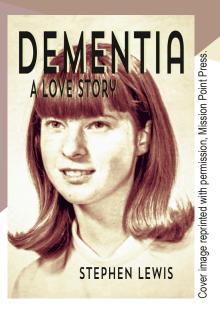
## **CALL FOR SUBMISSIONS**

Kaleidoscope magazine has a creative focus that examines the experience of disability through literature and the fine arts. A pioneer in the field of disability studies, this award-winning publication expresses the diversity of the disability experience from a variety of perspectives: individuals, families, friends, caregivers, educators and healthcare professionals, among others. The material chosen for Kaleidoscope challenges and overcomes stereotypical, patronizing, and sentimental attitudes about disability through nonfiction, fiction, poetry, and visual art. Although the content focuses on aspects related to disability, writers with and without disabilities are welcome to submit their work.

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

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





## GIFT OF THE MAGI IN TRAVERSE CITY

#### GERI LIPSCHULTZ

Review of Dementia: A Love Story by Stephen Lewis, Mission Point Press (2021)

"When I am complimented for my good care of Carol, I want to say, 'But yes, I am doing this for me as much, and perhaps more, than for her. It is possible that were Carol in a facility her care would be as good, maybe even better, than what I can offer. At least, it would be professional. I am taking care of her in our house because I cannot imagine, at this point, being without her physical presence in my life." - Stephen Lewis, *Dementia: A Love Story* 

Segal's novel *Love Story*—watching, knowing how it would end—but still clinging to the possibility of Jenny's recovery as the story of her illness unfolds—they who are so young, so beautiful, and so terribly in love. Released fifty years ago, the film and the book were said to be an unlikely balm for a country wracked by the Vietnam War. And I wonder if a similar effect might be in store for the reader of Stephen Lewis' memoir, *Dementia: A Love Story*. If only there were a portmanteau for hopeless hope! Surely, there must be an amazing German word like *zeitgeist* or *fernliebe* that catalyzes this trope of hope against hope—or even hope combined with dread. How is it that we take in *Hamlet* or *King Lear* and still hope that Ophelia or Cordelia won't die?

And yet—here's the difference. This is life, not the symbolic stand-in, but the real thing that in the hands of this writer holds the reader like art does, by words that succeed—as "true stories, well told"—as described by Lee Gutkind, whom *Vanity Fair* has called "the godfather" of creative nonfiction for his part in bringing the genre back in into the literary canon—and back in vogue.

We are now in a time calling for memoir, for these "true stories, well told"—and we are desperate for hope. And this memoir does offer hope, despite the hopelessness of its story. What slowly unfolds is the story of a man whose wife is irreparably in the grip of early onset dementia, possibly brought on—but definitely accelerated—by chemotherapy treatments for breast cancer. He compares the disease to a

car riding at full speed, whose driver cannot stop it, in spite of the pedestrian stepping out from the curb who is oblivious to the danger. Lewis calls the dementia an "effective, if harsh tutor," and himself a "stubborn, resistant, but ultimately accepting student of its hideous machinations" (364).

Lewis braids the story of his courtship and marriage with the deeply quotidian moments of caregiving. There are photos of his wife, Carol, that show her sitting in a cherryshaker, at the desk where she clerked as a lawyer, and at their wedding. There are descriptions of the various pertinent equipment, and in particular the "tilt" chair that succeeds in providing some freedom, some joy. There are stories of handles to grip, for help climbing the stairs—although all too soon, those handles will become obsolete, as the stairs prove too formidable—and Carol will remain downstairs, as will Steve. He describes their sleeping arrangements, the way their home is transformed to accommodate the changes, the decisions about care. He tethers stories of their former life to meaningful objects that help tell who he is, who Carol is; stories of favorite foods, of the routines he establishes, of the various decisions he is forced to make as the disease pursues its deadly course. And while this is not a young couple in their twenties, but in fact an older couple in their sixties and seventies (Lewis is ten years older than his wife), it's a true story—not fiction—and there is a profound feeling of connection for the reader due in part to writing style, structure—and the very voice of the writer. Lewis has written novels and textbooks; his doctorate is in Puritan American literature, so—no, this is not the first book he has penned; it is, however, his first memoir. Although he claims not to have indulged prior to this as writer or reader in the contemporary explosion of memoir and creative nonfiction, Lewis was an English professor with scholarly familiarity with Melville, Hawthorn, Emerson, and Henry David Thoreau, to whom he occasionally refers in these pages. But this is not a litany of detached, moralistic, or spiritual ponderings or the rebel's philosophies while choosing to follow his philosophic abandonment of the so-called civilized life. It's the record of a man's dedication to his dying spouse, a woman whose mind is deserting her body, a disconnect profound and unstoppable.

At one point, Lewis compares the dementia to the thick layer of snow that covers up every spot of existence as he looks out the window of their home in Michigan. But the analogy only goes so far, he writes, because the snow will melt. He's been told, and he's been shown there's no hope, but

he carries on as if there is. He persists with dignity and love and everything that makes this book an exemplary work of literature, worthy of reading, not just for the story, not just for the clarity of the writing and revelations of both his and his wife's characters and biographies, but for the model he provides as a caregiver, as someone who has the mixture of humility, compassion, and strength to care for another human being.

They were sweethearts, they met in academia. She'd left the family farm—where she was the first girl to manage a cherry shaking machine—to come east to go to school; he was a professor and writer, divorced, ten years her senior—a city boy, born and raised in the Flatbush section of Brooklyn. She—taking writing courses, envisioning herself a writer-would also go for her law degree, and somewhere in the middle of this, she broke up with the boy she'd come east with and met this professor, while sitting in the library of the college that would make him a professor emeritus years later, when he left with his family—this farm girl and their daughter—to move back to the very place where she was from on that thin strip of land, known as Old Mission Peninsula jutting out into Lake Michigan and known for producing something like 75% of the world's tart cherries. It's a love story from beginning to end.

What makes this book so powerful is that it's written in real time—not in retrospect. It's written by someone who had the presence of mind to record the moment—and the tension, the intensity are not lost upon the reader. Every passage in the book, only minimally edited, first found a home in a blog that Lewis shared with Facebook friends. The idea to pursue a journal of this kind originally came from a former student of Lewis, who suggested that writing routinely in the form of a journal or blog, a series of entries, might help to balance his caregiving and offer Lewis purposeful activity when little else could be done—while performing a service for those who might be in a similar situation.

The blog amounted to nearly eighty entries that essentially spun out of a structure that supplied an initial grounding in setting—time/weather—and the planned activity; from this he carved what amounts to extremely compressed essayistic moments. These small blocks of prose are in themselves complete with a title, along with a beginning, middle, and end—very satisfying to set down and pick up again—and perfect for both readers of the blog and of the book.

If the reactions to the blogs serve any kind of indication of how the readers of this book might respond, the suggestion of Lewis' student waxes profound. One of the readers of his blog—most of whom one assumes are friends and associates—writes that she wished she'd known his wife—so compelling is this portrait. As Lewis links a number of Carol's before-dementia stories to the domestic artifacts, he also describes excursions outside of the old north country farmhouse surrounded by cherry orchards and Lake Michigan and more often than not a good deal of snow. Not only do we see the vividly alive, fascinating, interest-laden lovely Carol of many talents, but we also are drawn to the land, the home, the history—and all that interests her. We are compelled by the setting as much as by her character, her life that he, and we, are losing.

There are occasions when she calls for him, when he wonders which "Steve" she is summoning—whether it's the "before dementia Steve," or the current Steve. There are times when she squeezes his hand and the touching moment when Lewis announces that he's going downstairs to exercise and jokingly reminds her to stay put.

This time I added, "And don't party like you usually do when I'm gone."

Her face opened into a wide smile.

And she laughed.

Not a big belly laugh, but a very discernible laugh.

She was with me in that moment, completely and as fully as she used to be (255).

By coincidence, in the middle of all this, Carol's favorite book, To Kill a Mockingbird, makes a retrospective comeback in The New York Times Book Review, which becomes the occasion for Lewis to consider whether an audiobook might hold her interest—and it does. It's a book that never captured Lewis, who tries, unsuccessfully, to interest Carol in the "less than positive" reviews. Of course, as a reader who similarly invested an enormous amount of time and love imagining Jean Louise Finch, better known as Scout, I know exactly why a precocious farm girl might hold onto that book for a lifetime. Another time, Lewis reads one of her own short stories to his wife—and that story delivers—both for her and for him. He marvels at how gifted a writer she is—how her work stands up. It's important to note a few things here, namely that before the transformation of blog to book—and perhaps even before

he ever dreamed of publishing this work—Lewis determined to find a publisher for Carol's stories, which he succeeded in doing; the second thing: I reviewed the book, titled *The Wolfkeeper* for *New Territory Review*; and now in the interest of full disclosure, I must say that Carol and I had become writing friends—friends who write, friends who read each other's work—and I adored her stories. About twenty years before she passed, I'd asked to interview her for my column in a small women's newspaper on Long Island.

And so, I can say that this book succeeds whether you "wish" you'd known Carol, or you actually did know Carol. And while Lewis engages the reader with asides from literature, and while there are a number of themes here, there is an especially powerful idea around the duality, around what he calls the "two Steves" and the "two Carols." He becomes aware early on that Carol does not associate the caregiving "Steve" with the husband "Steve," which certainly parallels his own revelation that Carol before the disease is not the same person as she is after the onset of the disease. This becomes an ongoing negotiation.

One of his readers, so moved, offers up her own very poignant story in the comments. She writes: "One time, my late husband told me I looked just like his wife . . . . I asked if she was pretty. His eyes lit up, and he smiled even bigger and said, 'Oh, yes!"

The reader responds to the clarity of his structure, his careful attention to the details (another one of the commenters of his blog wrote: "It's the little things") and his humility, his so-called internship, with this "hideous" disease as his "tutor." But what is most moving is the dignity of his approach, the evidence of his appreciation and respect for all Carol had wished to accomplish, from her fiction to the work with the historical society of her town, along with her interest in the land, the water, in the flora and fauna, in photography, in music, in history—all of this intelligence funneled into an interior world that no one but Carol had access to—his complete and wholesale loss of the beloved—and his willingness, as he writes, to care for her because he "cannot imagine" a life without her.

That Lewis is able to sustain this space of hope against hope, even when hospice enters the picture, and how he navigates this devastating and dark road with all of its cliffs, as meticulous with the details of his story as he is with the details of his caregiving, is a testament both to his wife and to his own humanity.

Therein lies our hope.◆

Aisha Ashraf is a writer and Irish immigrant living in Ontario, Canada. Her work has appeared in *The Maine Review* (January 2022), *River Teeth* (November 2020), and more. Describing herself as the "archetypal outlander," Ashraf was diagnosed with autism in her late thirties. Outside of writing, Ashraf dedicates time to increasing awareness concerning the difficulties faced by people with autism and those who have suffered abuse.

Kelsie Bennett is a student who will graduate from New York University with a B.S. in media, culture, and communication in 2024. With work appearing in publications including *The Foundationalist* (May 2022) and *Spires Magazine* (November 2022), Bennett states that having a disability has shaped their approach to fiction and their intentions as a writer. Bennett writes "for the disabled community first," opting to portray the reality of it rather than oversimplifications. They also create handmade jewelry and serve as a managing editor of NYU's undergraduate literary magazine.

Cynthia Bernard is a poet and teacher residing in Half Moon Bay, California. A student of the M.F.A. program at Lindenwood University, Bernard's work has appeared in *Multiplicity Magazine* (June 2022) and *Switchgrass Review* (2023) among others. Finding her voice as a poet after "many years of silence," she does most of her writing from her oceanside home.

Tim Campbell lives in Berkeley, California, and his work has appeared in *Catamaran* (2001), *The Smart Set* (2001), and more. After a forty-year career in overseas urban poverty, Campbell decided to establish a voice within creative nonfiction. His essay "Jake at the Dump" was a finalist at the San Francisco Writers Conference and appeared in its 2023 anthology.

William Cass is a retired elementary school principal who lives in Coronado, California. Appearing in *Amarillo Bay* (October 2018), he has been nominated for the Pushcart Prize six times. Cass writes because he has "a need to reflect on and/or try to make sense of events, interactions, and experiences—especially those that move me in a meaningful or profound way."

Amy DeBellis lives in High Falls, New York, and her work has appeared in *Flash Frog* (October 2023), *Pithead Chapel* (June 2023), and *Atticus Review* (August 2023), among others. DeBellis obtained her B.A. in English from New York University in 2019. She often uses writing to serve as distraction from her myalgic encephalomyelitis/chronic fatigue syndrome brought on by a bout of long COVID. She says her dog Lily is her biggest fan.

Stacie Eirich is a mother, writer, and singer who makes her home in Louisiana. Her work has appeared in publications including *Susurrus Magazine* (Summer 2023) and *Synkroniciti Magazine* (September 2023). As the caregiver for a daughter diagnosed with a form of pediatric brain cancer, she says, "I write because it is how I make sense of experiences, emotions, and the world—and because I believe our voices are worth sharing."

Nancy J. Fagan is a writer living in Longmeadow, Massachusetts. Graduating with an M.F.A. in writing from Vermont College of Fine Arts in 2022, her work has appeared in *Fiction International* (October 2022) and *Breath & Shadow* (February 2019), among others. Fagan states that her time as a registered nurse has given inspiration to her character creation and world building.

Connie Harold is a writer who lives in Annapolis, Maryland. She's a published author and playwright with a monologue in *More Monologues for Women by Women* (1996). Harold was originally a visual artist who had to curtail her career because of undiagnosed multiple sclerosis. She believes that "participating in writing, and all of the arts, is essential to becoming a complete human being by accessing, and revealing, the beauty within."

Waylon Henggeler is a M.D./Ph.D. dual degree candidate at West Virginia University. Henggeler loves reading, writing, knitting, and hiking with their dog, Eider. When not writing, they take interest in making the medical system, "more accessible and less harmful for marginalized communities." They also explore the ways medicine can be, "intrinsically ableist and racist and how to fix that."

Carrie Hinton is a human services professional who has spent her entire career working with individuals with disabilities. Her work has appeared in *You Might Need to Hear This* (October 2023) and *The Bookends Review* (November 2023). Hinton's goal when writing is "to do justice to the stories others have told me, the stories they've allowed me to join." Hinton lives with her two teenage children and pets in Ripon, Wisconsin.

Claire Ibarra is an author, artist, and citizen of the world who lives in Boulder, Colorado. Obtaining her M.F.A. from Florida International University in 2015, her work has appeared in *Fragile Saints* (February 2021), *Vortex of Our Affections* (2017), and *Adelaide Magazine* (March 2021), among others. Ibarra believes that "my work is to explore the human condition through characters and the complexities of relationships, hopefully giving insight into our shared experiences and humanity."

Hareendran Kallinkeel is a writer from Kerala, India, whose work has appeared in publications including *Bryant Literary Journal* (May 2020), *El Portal* (Spring 2021), and *Cardinal Sins* (Winter 2022). He recognizes and appreciates all the strengths that are unique to everyone. He also writes to help reach out to his fellow beings while offering a world view through a different lens.

**Danielle Krikorian** is a museum associate living in Irvine, California. She earned a B.F.A. in creative writing from Chapman University in 2020 and says her OCD and anxiety have greatly influenced her work. Krikorian is working on a full-length novel about the character, Darci, who she has written about in this issue, and she hopes to query the novel in the spring of 2024.

Geri Lipschultz is a dreamer, writer, mother, teacher, and lover of music, art, literature, and the natural world. She lives in Huntington Station, New York, and her work has been published in *Ms. Magazine* (2020) and *The New York Times* (1986), among others. Lipschultz says that she writes because "it is a practice that lifts me into a realm where I am forced to confront and wrestle with my thoughts in the attempt to order them."

**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.

Emmy D. Wells obtained her M.A. in English and creative writing from Southern New Hampshire University in 2022. She lives in Hampden, Maine, with her family and says her work is influenced by three of the six members of her family who have disabilities. "The strongest writing I do is when it is about them. I want to help show people, in my own way, what having a disability looks like."

Jordan Wilson-Dalzell is a writer living in Emeryville, California. With a bachelor's degree in creative writing from Pitzer College, she has released several chapbooks, including *Resuscitate* (September 2018) and *Bitter and Righteous* (July 2018). Wilson-Dalzell considers art a compass and writes because, "my soul combusts when I don't . . . . Dance, writing, and the redwoods make this disabled autistic queer feel alive."

Ellen Zhang is a physician and writer living in Palo Alto, California who has studied under Pulitzer Prize winner Jorie Graham and poet Rosebud Ben-Oni. Obtaining her B.A. from Harvard College in 2019, her work has appeared in *Chestnut Review* and *The Shore Poetry* among others. Zhang believes that as a physician, it's vital to understand the roots, challenges, and vulnerabilities of patients. Zhang writes because "I want to share my voice with others."

Rhonda Zimlich is a professor living in Bethesda, Maryland, whose work has appeared in *Sante Fe Writers Project* (July 2021), *Red Fez* (May 2022), and *Brevity* (September 2018). She is writing a memoir about her experiences with multiple sclerosis and running eight marathons since her diagnosis. She states, "I work through my experiences, combing them for stories that might speaker deeper truths and help me to sort out my own abilities and disabilities." Zimlich also loves to teach writing and finds great joy working with young writers to help them share their stories.



Dave Wisniewski, Simple Folk, 2009, oil on canvas, 48" x 36"



Dave Wisniewski, *Hemmingway*, 2016, oil on canvas, 36" x 48"



