

KALEIDOSCOPE

EXPLORING THE EXPERIENCE OF DISABILITY THROUGH LITERATURE AND THE FINE ARTS

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GLOBAL PERSPECTIVES

"Be Still" by Chris Pellizzari

"Losing Time—And Finding It" by Kimberly Roblin

"The Brightness of Neurology" by Carrie Jade Williams

Contents

◆ FEATURED ESSAY

Losing Time—And Finding It 4

Kimberly Roblin

◆ FEATURED ART

Any Body on the Planet 32

Diane Reid

◆ FICTION

Recycle 11

Joyce W. Bergman

Living with Peggy Sue 16

Jay Merriman

Be Still 26

Chris Pellizzari

Skinned 50

Keletso Mopai

Proud 61

Marc Littman

Blind by Fate 64

Connor Sassmannshausen

◆ PERSONAL ESSAY

Into the Forest 48

Mariana Abeid-McDougall

◆ CREATIVE NONFICTION

Lament for an Altered World 8

Dylan Ward

The Brightness of Neurology 13

Carrie Jade Williams

Like Being Afraid of Beauty 28

Tobie Helene Shapiro

My Friend 41

Shannon Cassidy

Sterile Rooms: A Memoir 42

Cheyenne M. Heinen

The Last Threads of Denial 58

Catherine Shields

Prime Time or Off-Peak? 62

Wendy Kennar

◆ BOOK REVIEW

Finding the Light in the Dark 56

Sandra J. Lindow

◆ POETRY

Robotic Pancreas 7

Sarah-Lizz Myers

Unaware 12

Sravani Singampalli

In Egypt 12

Madeleine McDonald

How I Have Been Touched 15

Marilyn McVicker

Done 24

Safe Travels 25

Gerri Leen

These Hands 25

Glenda Barrett

Weather of the Heart 40

Toni Ortner

My Bones and Winter 40

Kirsten Deane

Quilt 49

Watching Jordan's Fall 49

Allison Whittenberg



Seth Chwast, *The Big Pink Flower*, 2013, acrylic spray paint on canvas, 36" x 36"

Chwast is one of nine artists featured in *Fierce Love and Art*, a film about autism and creative genius. More information about the film can be found on page 32.

Hourglass 55

Kathryn Dalley

Nesting 55

Emily Uduwana

Diversity 68

Donna Springer

◆ BIOGRAPHICAL NOTES 70

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Kaleidoscope, beginning in 1979, pioneered the exploration of the experience of disability through the lens of literature and fine arts. Fiction, personal essays, poetry, articles, book reviews, and various artistic media including two-dimensional art, three-dimensional art, drama, theater, and dance are featured in the pages of various issues.

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



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LOSING TIME—AND FINDING IT

KIMBERLY ROBLIN

We may measure days with hours, but we measure life with memories, the true timekeepers.

Mathematicians see numbers and formulas. Artists see colors and patterns. I see the past in the present—or, more accurately, the present *through* the past.

Glasses correct my astigmatism, but history is my true lens. Like objects in a rearview mirror, history is always closer than it appears. Most people look over their own shoulder; as a historian, I look over mankind's. I skip across decades and centuries, establishing context and connections between people, places, and events. I ask questions. I compare and analyze. *Why* and *how* have always interested me more than *what*.

Something else traffics in time and memory, but with far different aims. It works against historians. It unravels connections. It dismantles and disorients. It is devastating and, for me, painfully personal. Dementia targets not only what I love, it targeted someone I love. My grandmother has been gone five years and would have turned 100 today (February 16, 2019. Happy birthday, Grammy.), and I'm still trying to make sense of what she endured.

Grammy knew before any of us. She called it “losing time.” Seconds, minutes, here and there, misplaced like a set of car keys. Doctors call them transient ischemic attacks or ministrokes, names that bely their permanent and catastrophic potential. Though manageable as isolated events, ministrokes often come not as single spies, *but in battalions*. Their cumulative damage is catalytic. Grammy had seen them as both a nurse and as a daughter. Her own mother once lost time while they were talking, head dropping softly, mid-sentence, into the reflexive posture of a cradle Catholic. Before Grammy could cross the room, she had returned. Ironically, dementia needs time to progress, and her mother ultimately passed before vascular dementia took hold.

The same was not true for Grammy. Apart from losing time and a troublesome hip, she was healthier than most her age. She gardened, walked to the local grocery, knitted and purled blankets for preemies, solved crosswords and cryptiquips. But when dementia began, it was patient and methodical, sanding the hard edges between morning and night, hours, seasons, and ultimately years, as Grammy's grasp on time grew tenuous. She spoke increasingly of the past and showed little concern for the present. We all reminisce, use memories to retrace our steps, but her dementia was not a stroll down the proverbial lane; it was a forced march that sought out the people and places dear to her and swept them away like breadcrumbs until only a few remained.

Normally, memories fade over time, grow hazy with age. But dementia plays by different rules. Grammy forgot people and places relative to when they came into her life, starting with the most recent. As she followed the trail of progression, her short-term memory failed entirely and conversations became cyclical. Then she started losing people. Her neighbor down the hall who made birdhouses? Gone. Sweep-sweep. People she had met in the last five years? Sweep-sweep. The last ten? The same. The pattern became clear: she was not simply looking back in time, she was working her way back in time.

I WANTED TO BELIEVE I WAS SAFE, that someone who had known me my entire life could not forget me. Emotionally, I could not conceive of it; rationally, I knew it was inevitable. She would find me on that trail. It happened incrementally. Some days she knew me as soon as she saw me. Other days, uncertainty in her eyes would spark to recognition as she said my name. Sometimes my age surprised her. I never asked, but I think she still expected the younger me, ponytailed and playing soccer. Until one day the spark never came. I hugged her goodbye after an afternoon of Animal Planet's *Too Cute* and wasn't ten feet from the door when I heard her tell the nurse, "That was a nice young girl."

Even on paper the words catch in my throat.

I don't remember stopping in the hall and dropping my gaze, but I can still see my sandals against the hospital-grade carpet. She found me. Sweep-sweep.

Grammy moved farther down and often narrated the trail, giving clues to where she was and when. She flitted between decades before leaving one entirely: Grand Lake in the 1970s. Columbus, Ohio, in the 1960s. She never mentioned dates or years. Places, people, and emotions defined her memories, not numbers or orbits around the sun.

It's the same for all of us. I can't recall the exact day of the Mumford and Sons' *Gentleman of the Road* stopover in Guthrie, but I can recall the triple-digit heat and crippling humidity, the train whistling somewhere to the east during

the opening song, the pulsing field of thousands, and the pure joy of music and family. Every time I hear a train I think of that night. I also think of Grammy's father, Lowell, an engineer for the Wabash Railroad.

Lowell (one syllable, not two) was, in a word, big. He had big hands and big forearms from shoveling coal as a fireman. He had a big personality, a big laugh, and a big heart. People Grammy had never met came to his funeral with stories of how he had helped them. I grew up hearing about him, Grammy's mother Mary, and her older sister Weisie. Even when I was little I could tell how close she was to them. As she moved down the trail, she spoke of them more than anyone else.

She talked about my grandfather and their walk-up apartment in post-war Los Angeles, how he surprised her with flowers (often gladiolas), how they "played the ponies" at Santa Anita, and spent days at the beach. She talked about my dad and his two older brothers. But she talked about her parents and her childhood most of all.

I learned her mother loved popcorn, bingo, and her Boston terrier, Mitsy; that she wrapped her long hair around the bedpost at night to keep it from tangling; and that her last words were, "Open the gates, Lowell. I'm coming to join you." I learned that Grammy's father called her Bugs and encouraged her tomboyish tendencies. I learned that she despised shoes and the indoors, that she played the violin in elementary school, that her first job was at a soda fountain (finally solving the mystery of her perfectly scooped ice cream), and that she hit the books and the town while at nursing school in Kansas City.

And then one day I noticed a distinct shift. Grammy didn't tell me about her mother, she *asked* about her—in the present tense. There was no mention of year or month, I don't think she could have given me one, it was unimportant. I knew then where she was headed and where the trail led—to a farm in northern Missouri.

Now the sequence made absolute sense and I felt foolish for not seeing it sooner. She was in a time when her parents were alive. How could she ever forget those first relationships, the foundation for everything else? She wouldn't. The

people and places she had known the longest—her parents and her sister—were not on the trail, *they were the destination*. They were with her in the beginning and would be with her in the end—her alpha and omega.

I knew Grammy was a daughter, but that was the first time I thought of her as someone's child. She was ninety-five years old and still remembered the way home. She was Nina (pronounced Nī-nə), child of Mary and Lowell, sister to Weisie. Dementia could never diminish that—it distilled it.

* * *

MAN HAS ALWAYS LOOKED UP AT THE STARS, but we have also always looked back at the past. It is a primal instinct. The past pulls at us all.

But why do we look back? Why do we replay, revisit, and recollect? For the oldest of reasons: life and death. In the beginning, it was about survival. Memory is the keystone of problem solving, risk assessment, establishing cause and effect. I'm talking old school, prehistoric. Our ancestors had to remember which trails led to water, which plants were lethal, how to spark fire, and how to carve spear points. Without the ability to make memories, they would have died.

Whether a failed mammoth hunt or a grandmother's struggle with dementia, it's in our DNA to process experiences and events through memory. We build on earlier knowledge to better understand the present and determine the best path forward. Advancement—scientific, technological, and personal—is the result. But memory serves more than the practical. Although our instinct to look back was born of necessity, it expanded and evolved as lives stabilized and life expectancies increased. We had time to tap into our philosophical nature: retrospection begets introspection.

The less time that lies ahead, the more inclined we are to survey what lies behind. The biological clock ticks louder each year. We drive by old homes, flip through photo albums, reminisce, analyze decisions we've made, good and bad. We may hate daylight saving time, but sometimes we do wish we could turn back the clock. If death did not exist, would we spend so much time looking back? Perhaps, but I'm fairly certain nostalgia is a luxury our early ancestors did not enjoy.

But there's something else behind why we hold on to the past. Something at the core of why we create memories and revisit them—a common denominator among the variations. We make memories and look back to establish connections: between cause and effect, the past and the present, the living and dead, our older and younger selves, to simpler times, happier times, different times. Sometimes the memories remain personal and private; at other times, we share memories through stories. Long before stories could go viral, they

went social. We've told them for millennia. We painted bulls in Lascaux caves. We sang of Odysseus and Beowulf in epics and sagas. We celebrated origins and mythologies in oral histories. We embroidered the Norman Conquest on tapestry. We built monuments, museums, libraries. Wrote plays and made documentaries. We even sent stories into space aboard *Voyager*—golden records of our music, imagery, and language.

We are a species of storytellers. Stories help us find meaning in our time, and transmit customs, culture, knowledge, and morals. As we tell them or hear them, we laugh together, cry together, and learn together. Our connections grow stronger. I never hugged my great-grandfather, never attended mass with my great-grandmother or scratched Mitsy's ears, but I feel like I have. Grammy's stories connected me to them. She helped me travel time and space, to see the past through the present. No DeLorean. No TARDIS. Just memory.

Memories record the past and ensure something of us will reach the future, as Grammy still lives in my mind today. I've told a small part of her story, just as she shared part of hers with me. I think about her all the time. Her warm hands holding mine. Her laugh. Her voice. I think about her as a young girl, her dark hair tangled, her bare feet dirty from climbing trees and walking creek beds.

Most of all, I remember the short drive between my parents' house and Grammy's apartment, when I would drop her off on the way home from dinner. She knew she was losing time, but was still in the early stages. I'd pull up in front of her building and put the car in park. She would ask me how work was going. Did I like my new place? Was I dating anyone? Did I need anything? And, most importantly, was I okay? Sometimes we sat there for only a few minutes. Sometimes it was closer to twenty. But each time ended the same. We'd meet across the console in a hug, she'd hoist herself out of the Tercel, and, right before shutting the door, she would look at me, smile, and say, "Remember. Grammy loves you."♦

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SARAH-LIZZ MYERS

ROBOTIC PANCREAS

“Miss Myers, detention!”
a substitute teacher yelled
above the hullabaloo. Face goes fire-engine
red as I explain that my pump is
not a cell phone. Again.

The man sitting next to me on the plane to Boston
stares appalled as I pull the beeper-looking
object from my bra. Quickly bolus
for the gross airplane food.
Stuff my pump back in the hideout
of my breasts.

First date in months,
I pretend not to feel the warning vibrations
through my dress. Excuse myself and hide
in the privacy of two stall walls and the door
that won't properly latch. I fib my blood sugar
to my pump and return to my concerned date
who knows I was gone for too long.

Body,
I did not ask for the ignorance of others.
I did not ask for these pointed stares.
I did not ask for concerned suiters.
I did not ask for this robotic pancreas.

LAMENT FOR AN ALTERED WORLD

DYLAN WARD

While the world braces for the onset of a global pandemic, my world goes silent.

A nervous energy had permeated everything for several days just as trees were turning back to their former green and leafy selves, heralding the arrival of spring. Schools began to close down; restaurants and businesses soon followed. Soccer games and practices were put on hold. My son's seventh birthday party was postponed and my sister's wedding and our travel plans were upended. Of course all this saddens us, but we understand its necessity in an unnerving time. Our determination is not to let it upset us, that all we can do is ready ourselves for what's coming. Our commitment is simple: to keep a semblance of normalcy within the confines of home.

But with the upheaval of this altered reality and tailoring to new schedules, there is a moment of carelessness. It's scary how much damage a simple slip of a two-by-four piece of wood can do when you least expect it. In just under an hour following the injury to my head, the limited hearing in my left ear is gone. I'm already deaf in my right ear and now my trusted hearing aid no longer functions for my left ear the same way it has for more than thirty years. While my son continues to play happily outside, I am lost in the kitchen in the fading daylight. I tap away on my phone, researching head injuries and concussions and hearing loss, and a childhood memory surfaces. Of another accident, of a heavy rock thrown in an innocent game played between children. The severity of that rock's impact to my seven-year-old head comes hurtling back to me as clear as day.

In the hours and days that follow, I walk in and out of the urgent care and medical offices, stern warnings papering the doors and windows, bottles of hand sanitizer at every turn. Some nurses wear masks and I am crestfallen. They need the mask for safety but mask-covered lips are impossible for me. Without my husband, I would not be able to understand them. I couldn't ask them to remove protection and risk our health, could I?

Suddenly, for the first time in my life, I truly feel like a person with a disability. I'd never thought of myself as disabled before, functioning just like anyone else except for insufficient hearing. Now I am unable to lift anything heavy or move around for any length of time. The vestibular imbalance makes me wobbly, and I tire quickly. I can't really engage in conversation with anyone and I am lonelier than ever. So I wait. I wait each day as time inches forward. I wait as everyone busies themselves with sheltering or not sheltering. I wait while tests are administered and diagnoses are made. I wait while numbers of the sick and dying rise around us in other parts of the world. I wait with small glimmers of hope for a simple fix. I wait with prayers for an end to this chaos. I wait for my hearing to make a miraculous return.

In the midst of all this, it is my son's voice that I miss. While I was absorbed with protecting him and shielding him from the coming horror of a viral infection, I let myself become damaged and vulnerable. We'd been excited at the prospect of learning at home together, me as teacher and he as student. With my hearing gone, I am no longer able to give him what he needs. How can I help him when he

has questions? How can I listen to the new, exciting thing he's learned and wants to share? We don't know enough sign language to communicate effectively. And lip-reading a child's energetic mouth is challenging. My husband helps where he can, especially when my son practices reading out loud. I hold my son in my lap as he reads stories and my husband listens.

My hand rests upon my son's back. And I feel his voice.

By Friday, thick whiffs of pollen lather our city in yellow. My husband and I travel in the morning to see a highly recommended otologist. I was informed how lucky I am to see him so quickly. I wonder if he'll be able to fix me. The office cautions us with similar warnings papering its windows and doors. Bottles of hand sanitizer await outside each entrance. Chairs in waiting rooms are reversed and marked with an x, purposefully situating available seating to keep ample distance. A variety of faces greet me: anxious faces of receptionists, happy faces of audiologists, concerned expressions of nurses, puzzled expressions of the otologist. A series of hearing tests is conducted inside soundproof booths. Results and options are presented. Through all of it, I am apprehensive, both for the epidemic to somehow breach the walls of that medical office and for the personal situation in which I now find myself. The idea of surgery disturbs me. The otologist isn't giving me the option I'd hoped for, and panic sets in.

At home, my son's excited expression and hug welcome me and melt away my worries. For the rest of that warm, sunlit afternoon, I sit with my parents and my husband and we consider the options. We share concerns of what I face in the time ahead. For my son's sake, I keep a cheerful appearance with smiles.

Nestled in my arms that night, my son falls asleep across my chest. I feel the weight of his small body, the rise and fall of his lungs. In the darkened bedroom, I grow sad for him. I am sad for his not getting to celebrate turning seven with a birthday party and friends. I am sad for his missing normal routines, his teacher, his classmates. I am sad for the loss of our daily walks to and from school, watching him run carefree to home. I am sad for his canceled swim lessons and soccer practices on the field with his teammates.

Then I ponder a future of silence. Of nothing but silence. I wonder what this would be like, what it would mean to parent a child I can't hear. Everything else about me is still the same, for which I am grateful. I know there are far worse atrocities. But at that moment, I want most what I don't have anymore: I want to hear my son. With this comes shame and guilt intermixed with other emotions. And I grieve for my loss.

The second visit with the otologist is less worrisome. Warning signs and bottles of hand sanitizer remain. When we enter the waiting room, I see immediately a young man with a mask and gloves on and this sends a small current of alarm through me. I stand away to the side, trying my best to appear casual. But I keep thinking about him and the mask and his gloved hands. Is he sick? Could I get sick just being in that shared space with him? Should I be afraid? How terrible this is, to live with this kind of fear among one another.

A second round of hearing tests reveals little to no change. The otologist encourages me with my best option of a cochlear implant. But my husband and I have little time to contemplate this as we head to our next destination for a CT scan. The hospital is an eerie sight. Masked security guards wave us through at the parking lot gates. To the left I glimpse a makeshift testing site with doctors fully dressed in gloves and gowns and face masks. This is chilling, like unexpectedly coming upon the periphery of a biohazard zone.

Strict protocols are implemented to enter the hospital. Questions are asked, of which my husband interprets, and spacial distance is carefully maintained. For a moment, I think I catch a look of disbelief from someone, a look that says, "Why are you here at a time like this?" As if everyone has more pressing matters to worry about. I feel guilty again.

Inside a waiting room, away from the tension of the main lobby, I sit still with my hands folded in my lap. This part of the hospital seems quieter and cleaner. There is little evidence of the drastic measures taking place beyond its walls, save for a few warning signs and the news broadcasting on the TV behind us. Near the window, two elderly women sit, one wrapped in a blanket the color and texture of snow, the other wearing a mask. I worry for them, for what could happen if that devious virus finds them. A conjured image of

the hospitals in New York City, and the horrific scene inside them, sends an abrupt fear rushing through my chest. How dreadful and sad and lonely it must be in that forlorn place. Then guilt returns and I reproach myself for letting this accident happen amid this awful hysteria surrounding us. I'd been so careful. I'd followed the rules and stayed home. I regret careless mistakes, obsessing over what ifs, wishing I could reverse time.

Coming down the fluorescent-lit hallway behind the radiologist, there is a sliver of panic at the sizable X-ray sign above the door. Inside the room is an abnormally long table vertical to the opening of a substantial, donut-shaped apparatus. I'd prepared myself for this and I hand over my phone, wallet, and ring to my husband. The radiologist shakes her head and says I don't need to take off my ring, which genuinely surprises me. After replacing my ring, I lie down on the table which lifts me up toward the donut opening. Staying still as stone, a red light marks me and the mechanism begins working, rotating around me like a washing machine. The process is over within minutes. The radiologist notes my relief and says, "It's MRIs that are difficult."

On our way home, I try on the hearing aid, just to see. Hope buoys me when I hear my husband's voice. As quiet as it is, his voice is still there. I wonder then if maybe I am rushing into things. That perhaps my prayers for a speedy recovery are being answered. Perhaps I could avoid unnecessary surgery.

My mother texts me, telling me that my son has gone to lie down and they are concerned. This is unusual for him, and it worries me too. My husband reminds me that our son is probably nervous and worrying for me, for Daddy. I grow quiet for a bit, concentrating on the small, distorted sounds I can discern. I hadn't thought about how all of this would affect my son. How he might not be able to articulate his fears and feelings into words. The sounds inside and outside the car become funny. It isn't long before my husband's voice turns into a garbled mess and I can't make sense of him. I remove the hearing aid and allow the silence to return.

During those two weeks, when I'm not constantly checking in on the mounting uncertainty everywhere, I am learning about myself, about the history of my hearing. I am learning how it's evolved and changed through the years. The medical science of the brain and the ears fascinates me. I am intrigued by what makes me different, exploring the otherness of my internal anatomy.

I am also absorbed by the wildness inside my head, of strange and alarming sounds and sensations. They are auditory hallucinations. First it is the phantom ringing of tinnitus, much like the annoying shrill of Internet dial up many years ago. Over time, the tinnitus morphs and merges and changes into sounds of rushing water and howling winds. Following this are the high keys of electric organs, or the pure timbre of bagpipes, sometimes bold angelic choirs, and Gregorian chants. I hear birds tweeting and the music of symphonies. The weep of violins and mournful tones of bassoons.

These sounds concern me at first. But I learn this is an after-effect induced from sudden hearing loss. I wonder what my brain is doing. Is it lamenting the loss of sound? Is it giving me memories of its beauty, of what I've irrevocably lost?

Through all of this, I gradually adapt to a world that cannot be together. I connect with family and friends virtually and by text. My son embraces writing letters to his friends and gleefully receiving them in return. He joins his first grade class and teacher once again by way of video chats. Seeing his and all the children's happy faces is wonderful and touching.

What comes next for me is uncertain. There is an option available and the technology is marvelous and promising. I will confront new challenges in the days and months and years ahead. But just as the world will persevere and learn to adjust from this pandemic, I will learn to adjust with a new way of hearing. Most importantly, though, I've promised to keep my son safe as much as possible, no matter what happens to me. And I look forward to when I'll hear his voice again. ♦

RECYCLE

JOYCE W. BERGMAN

I find it in the dishwasher. But I don't confront Jake. Instead, as it happens, he ambles into the kitchen just as I pluck it from the spot in the top rack where it was nestled between our dirty soup bowls from last night's dinner and the complementary coffee mugs labeled "I'm Yours" and "You're Mine" that I bought for us at a seaside gift shop fifteen summers ago.

"Those are dirty," he offers, indicating the items still aligned on the open dishwasher's racks. "It wasn't full, so I didn't start them."

"I know. But this doesn't belong in there. It goes in the recycle bin." I hold it aloft: an empty Dr. Pepper can he's inserted along with the cups, plates, pots, and utensils when he loaded the appliance after dinner last night—the same as he's loaded it every night for the past twenty years, ever since he retired from his government job.

Jake stares blankly, as though only vaguely aware that the hollow aluminum cylinder is something he should recognize.

It's getting worse, I think. He takes the can from me, turns it slowly in his arthritic grip, finally asks in a voice of unfeigned wonder, "Why did you put that in there?"

I speak slowly, too. "I didn't. You put it there yourself when you loaded the dishwasher last night."

"When I loaded . . . what . . . when . . . the dishwasher? . . ." He trails off, searches for a clue and, finding none, gives in to querulous anger: "Don't try to confuse me!"

I don't answer right away. I'm thinking of a time when I couldn't see clearly, either. A time when I was uneasy in the environment where I found myself—when Jake and I

first vacationed together at the sea. That was nearly half a century ago. At the edge of the murky water, I'd been afraid of going out into the ocean and putting my feet on the sandy seabed; afraid of jellyfish, afraid of crabs, afraid of sharp broken edges and shadowy shapes I couldn't identify. Thoughts of grittiness under my feet and of seaweed that might wrap around my ankles and pull me below the swirling tide overwhelmed me as I'd stood ankle-deep in trepidation. Finally, I'd told Jake I couldn't go on.

He'd said nothing of my fear, had simply picked me up and cradled me against him. From the safe edge of the surf, he'd pushed forward in the direction of the horizon, carrying me in his arms through the tumultuous white foam all the way out beyond the breaking waves to where the surface was smooth. He had waltzed me along the top of the shimmering waters in a dance of laughter and light that chased away my fear.

It hadn't mattered what lurked below because I didn't have to touch down. Oddly enough, from the safety of his embrace, it was easy to believe only beauty existed where my sight could not penetrate.

Now I look at the empty drink can he is holding. He watches expectantly.

"You wanted this in the recyclables?" I ask quietly, as if it's a real question, while I gently pry the can from his fingers and, hopefully, the desired correct solution from his tired memory banks.

He nods, satisfied, as I lightly toss the empty container into the bin with the others. ♦

SRAVANI SINGAMPALLI

UNAWARE

An intense cyclone has hit a city
 Heavy downpours, floods and
 Loss of lives
 All come in bonus.
 Trees have fallen down and
 Birds have lost their home.
 Somewhere in another city
 My friend prays for the safety
 Of her relatives
 After watching the news
 On the television and
 I stare at her from my window
 Unaware of the danger
 Unaware of the loss
 Unaware of those lost birds.
 I drink a glass of warm milk
 Mixed with my favorite chocolate syrup
 And go to bed as usual.
 In the morning
 As I open my eyes here
 Many have closed their eyes there forever.
 I complain of being unlucky
 After my mother wakes me up so early
 Unaware of my fate
 Unaware of how fortunate I am.

MADELEINE McDONALD

IN EGYPT

Suddenly I have choices
 Free time bewilders me
 You are gone
 So too my job of care

For you, for us
 I book the trip we planned
 Before illness consumed our lives
 Before you forgot my name

In the rich jumble of Cairo museum
 We will marvel at sumptuous grave goods
 I will hold your invisible hand
 Feeling the wedding ring
 On your finger still

We will seek out depictions of Ma'at
 Goddess of justice and harmony
 Whose feather of truth
 Would have tipped the scale
 When your generous heart was weighed

Hand in invisible hand
 We will trace the hieroglyphs
 That recorded the victories and power
 Of kingdoms long crumbled in the sand

Egypt was the mother of the world
 In Egypt we will say goodbye
 By the lazy, life-giving waters of the Nile
 I will uncouple our hands

The current will carry my words
Wait for me
I will come and find you

THE BRIGHTNESS OF NEUROLOGY

CARRIE JADE WILLIAMS

I have a secret addiction. Not to drugs or drink. There's no rehab for a girl who spends all her time online looking at holiday destinations, researching trips. Exotic places full of mystery and possibilities. Hours ogling the tempting photos, which with a simple click a fix can be bought. With fentanyl and oxycodone, the media always questions: When did it all begin? Well, I know the exact time and date this seed of addiction was planted. The neurologist had handed me a pen and told me to write a bucket list.

The appointment started out as usual, MRI results, blood tests, my reflexes being tested. Since the eye test which resulted in the optometrist sending me to the hospital, and admittance to the neurological ward, I'd adapted to the drill. After years of being told and treated for mental illnesses that never made sense to me, seeing a doctor who performed tests with results I could physically see was a bizarre experience. No more, *in my opinion*, but hard facts, based on collated data.

"You've been misdiagnosed. For years," the neurologist says as he passes a light in front of my eye. "This isn't in your head."

This isn't in your head. I roll the words around on my tongue. The lightbox above his head shows two images, one a neat, smooth brain next to another that I can tell has something wrong with it. Cracked and damaged. If I were a betting girl, I'd put odds on the latter being mine.

"Well it is technically in your head, your brain to be exact," the doctor says, as he points at the image that he has identified as the organ housed inside my skull. It's as though God or someone planted a seed in my head that instead of sprouting out has curled in on itself.

"So, what is the matter?"

"Do you remember the genetic testing we did?"

I nod.

"Unfortunately, you have something called Huntington's disease."

I'm relieved. I've never heard of this Huntington's so it can't be that serious. The doctor, sensing the positivity emanating from me, snuffs it out.

"Imagine Parkinson's, meets ALS, meets Alzheimer's. In one disease. That's what you have."

There is no cure. I learn that a moment later. Few treatments, as I refuse stem cell on principle. And I've been misdiagnosed for eight years by a psychiatrist who didn't bother to run any blood work before handing out diagnoses like sweets. My optimism, stretched paper thin, cracks as the question demands an answer before I've recognized its need.

"How long have I got?"

He fudges the answer. Won't commit to a time scale. Nothing exact. But he encourages, strongly, that I use the next three to five years wisely.

At some point another doctor comes in, with glasses that sit on his head the entire time, who explains the progression of a degenerative disease. The one I now have. He moves on to systematically removing my independence. No driving. No rowing. No rock climbing. My world shrinks as the genetic code in my DNA expands. Not that I'd ever really thought about dying or death, not in a real tangible way, but this wasn't dying by degrees, it was giving up by degrees.

"I am sorry," he says, but instead of referring to the news, he means my misdiagnosis.

"All of us on the neuro ward dread cases like this. Even six months ago we could have started treatment, but the psych team acts as if we don't exist."

I nod, because I'm not ready to be enlisted into a fight. The life I worked so hard for had been extinguished. I would never marry, never accomplish goals I presumed I had time to achieve. I would slowly forget who I was, what I loved, and end up . . . I realize I can't finish that sentence. *Not yet.*

Up until this point I've considered my doctors as a batch of people, some taking blood, others writing notes. Now they are my team. Here to serve my brain.

The doctor, the one with the good hair, laid the foundation for better things to come by handing me a pen with a sheet of paper.

"Go, write a bucket list and I'll see you in a few months," he says, a wave and a smile to dismiss me.

A neurological illness with psychiatric elements that neurologists refuse to treat with medication and psychiatrists refuse to study. I hold this concept, a pearl in my mind, pleased that I still

have the brain power to hold this idea. I learn in the days that follow that as a female in my late twenties I am high risk of falling in to the neurological misdiagnosis trap. I report symptoms that my GP puts down to stress, that a psychiatrist puts down to anxiety, that the pharmacist treats as depression. My brain, already dying by degrees, treats these attempts as an assault and accelerates my symptoms, which no one in the psychiatry department is even considering as having any other root cause than a psychiatric one.

Though I know me best, I'd been shut out of my own treatment by a label handed to me by a doctor who wasn't trained to look at my symptoms in any way other than psychiatric.

I'd noticed the words vanishing. The way my fingers stopped being able to type on the keypad and the jerking movement that had crept from my knee to my feet. The psychiatrist, rarely glancing up from my file, had excused them all away.

"You've had a bereavement, a shock. Depression and PTSD are to be expected."

Why hadn't I asked for proof? Demanded an MRI? Insisted I see my blood levels? At my next appointment I came armed, carrying the research I'd gathered like a shield, I was on a mission. This time shock wouldn't silence me. I needed answers.

"How many other patients are misdiagnosed?" I asked the neurologist.

"There is no fixed data," he said.

"A guess?"

"We work off the assumption that in the vast majority of psychiatric settings there is no toxicity testing, no MRIs and assessments are based on anecdotal judgements. A neurological patient who ends up under a psychiatrist has a 90% chance of being misdiagnosed when assessed by a psychiatrist, because they

are looking to make the symptoms fit the DSM." When the story a patient tells about their experience of symptoms is viewed through the lens of psychiatry, suddenly chorea is viewed as difficult or attention-seeking behavior, seizures are an attempt at maligning, brain cell death excused as a depressive state. The treatment given by psychiatrists then compounds the neurological patients' issues, as this treatment usually rules them out of any studies which could prolong their life.

I brought the sheet of paper with my bucket list typed out, bullet points highlighting the hours I'd spent deciding what mattered to me and how I'd define my time from now onward.

"Can we force them, the psychiatrists, to conduct neurological assessments prior to diagnosis?"

"We can't, but a court can," he said, as I folded my list in half, accepting that there are things to be done before I plan my next trip.

* * *

When you watch movies about women who change the world, they storm into a court room where the judge asks a few questions until they whip out the one piece of life-shattering evidence that turns the case on its head. That is not my story.

In real life, these types of actions take decades, cost tens of thousands and require hundreds of pieces of evidence. As a terminal patient, time is already limited, adding a lengthy court battle to try and set a precedent is not a process open for us. Instead, complaints are made to medical boards with the hope that change will come in time for the next generation.

For me, I wrote my complaint and returned to deciding how I would spend my time. Portioning off some to write

to government officials, doctors, lawyers, researchers, professionals. Most politely decline to listen. This is not a fight anyone has time to care about at the moment and perhaps I only selfishly do now due to its direct impact on my own life, but times change. We evolve. Progress. Look at Monica Lewinsky, once abused by the press for making a bad choice and being manipulated by a man in power who really should have known better, now the outspoken, confident woman addressing slut shaming and bullying within the very culture that destroyed her reputation.

Research became my best friend. In between the globetrotting and the writing, researching treatment options for Huntington's disease became an obsession—functional medicine, stem cell treatment. I read about neuroplasticity in bed, during one of the late nights where sleep evaded, and obsession snuck in. That balance between the need to cognitively fight my way out versus the emotional acceptance is a tightrope I still walk. I've accepted my diagnosis but haven't given up on the possibility of a cure.

Neuroplasticity was what first convinced me that the action of writing, of documenting thoughts, recording memories I feared would float away into the abyss, simply holding a pencil and marking a page, had a benefit. It was inexpensive. Non-invasive. Therapeutic. So, I started. To write, to journal, to jot, to doodle. When my left hand became too weak, I taught myself to use the right. What I say may not change the world, but it changed mine. So why do I write? Very simply, we all love something more in the moments before we grieve its loss. ♦

MARILYN McVICKER

How I HAVE BEEN TOUCHED

In one week
Twenty-five intravenous needle sticks
Three blood draws
Cold disc of stethoscope
Nurses prep and pressure pulse points

Ministrations to infected shingles
Twice daily ointment
Replacing bandages

Today
The chiropractor
Manipulated my spine
Rubbed my back
Head arms
Up and down the length
of my entire body

I felt skin ripple
Muscles relax
Felt all of one piece
One whole person

Not a series
Of broken parts

I cried face-down
On the examination table
Cried at the tenderness
Of one who would merely
Touch

LIVING WITH PEGGY SUE

JAY MERRIMAN

Joanna could hardly believe she and Henry had been trading e-mails for less than a week. She had been anxious at first when she heard from someone she invited to a Sadie Hawkins dance in high school more than thirty years ago, but now she couldn't wait for his next e-mail. Even so, all it took was an unexpected question to make her feel more anxious than ever.

Dear Joanna,

From what you've shared about Leona, she sounds like a great friend. How do you feel about the possibility of meeting in person? There's no hurry but it's something I've been thinking about. Would a phone call be okay? It would be great to hear your voice.

Henry

Joanna would have called Leona if it hadn't been so late. She decided to send her an e-mail instead. It was time to tell her about Henry.

* * *

After Leona silenced the alarm clock, she shook Rob's bare shoulder and told him it was time to get up. Rob mumbled something and rolled over to reach for her.

"Another time, lover boy," Leona said. "If you're lucky, what you'll get from me this morning is coffee and breakfast. Don't push your luck, and don't be long."

Rob rolled back over and pulled the covers over his head.

Leona laughed out loud as she got up to put on her robe. She sat down at the kitchen table with her laptop for a quick look at e-mail before starting breakfast. There was a new message from Joanna with the subject line "Not sure what to do."

Hi Leona,

Last week, I heard from someone I knew in high school who is now living in Louisville. We had one date when we were seniors and it didn't go very well. Nothing bad happened, it just wasn't much fun. The memory bothered Henry, especially since he thought it was his fault.

We've been trading e-mails and it turns out he's divorced, has a daughter, and works at a public library. I've enjoyed getting to know him, but Henry has brought up the possibility of meeting in person. In the meantime, he would like to get in touch by phone. I'm okay with the phone idea but not so sure about meeting in person.

It's not urgent, but let me know what you think.

Joanna

Leona typed out a brief reply.

I know it's a big step. Let's get together and talk about it. One thing I can tell you right now, if Henry is worth getting to know, Peggy Sue won't be a big deal. I'll call you when I get home from work.

Joanna didn't sleep well. She stayed in bed longer than usual and tried not to think about how she would respond to Henry. When she was finally out of bed, she didn't bother getting dressed before making a mug of tea. She considered going out to the patio, but ended up staying in the kitchen. She was about to warm up what was left of her tea when she remembered writing to Leona. She opened her laptop and found Leona's reply referencing Peggy Sue—the name her best friend came up with a long time ago. Joanna looked down at the prosthesis attached below her left knee.

* * *

It was the middle of the week and Joanna was out for a morning run before breakfast. The path she followed was separated from the street by a good ten feet and she was moving in the same direction as the cars on her left. The air was suddenly filled with the sounds of cars honking. That was the last thing she remembered before waking up in the hospital. When she opened her eyes, Leona was there with Joanna's mother, Nell, who had taken the first available flight from Cincinnati to St. Louis. It was two more days before Joanna was fully conscious and able to understand what happened. A seventy-three-year-old man driving a big sedan had a massive heart attack. His car veered off the street and continued past Joanna after knocking her down. Her left foot and ankle were mangled and had to be amputated, along with part of her lower leg. Her right arm was broken and required a cast that covered the entire arm, and doctors in the emergency room confirmed she had a concussion. The driver of the sedan was dead by the time police and medics arrived.

Leona and Nell both noticed that Joanna seemed uninterested in anything having to do with the loss of her lower leg. A doctor explained that this was due to her current medications and that she would soon need a lot of emotional support.

When it was time for Joanna to leave the hospital, she sat in a wheelchair while an orderly pushed her out to Leona's car. Leona took emergency time off from her job so she and Nell could both stay with Joanna. For the next two weeks, Leona took Joanna to appointments and sat with her for hours. Nell did the cooking for all three of them and kept track of Joanna's medications. Day and night, Joanna was never alone.

When Leona had to return to work, Nell arranged for a full-time private nurse and stayed until she was confident that the nurse would take good care of her daughter. Leona continued to spend time with Joanna after work and on weekends. When the cast was removed from Joanna's arm, Leona watched for signs of improvement in how Joanna felt about herself. It wasn't hard to understand that Joanna needed to recover a sense of control over her own life. Regaining the use of her right arm would allow her to be less dependent on the nurse.

When Joanna got her first prosthesis, she made slow progress with the help of a physical therapist. She refused to leave the house except for appointments, but Leona kept trying. Joanna was still using a cane when Leona finally persuaded her to go out for a short walk. It was early evening on a Friday, and by the time they got back to the house, they agreed that Leona would stay over and the nurse could take the night off.

After the nurse was gone, Leona went to the kitchen and poured two glasses of wine. She lit one of Joanna's candles and moved it to the kitchen table. Joanna was half asleep in the living room.

"Come and sit with me in the kitchen," Leona called out.

They sat together quietly for a while, drinking their wine. Leona was the first to speak.

"Have you thought about when you'll start teaching again?"

Joanna shook her head.

"You're doing fine with the walking," Leona said. "How about setting a date so you can have some time to get used to the idea? We can take walks to your office and around the campus, just so it can start to feel familiar again."

"Too soon," Joanna said.

Leona reached a hand across the table and held one of Joanna's hands. "Listen, honey. That god-awful accident should never have happened, but it did. I know you'll get through this and be okay, but you've got to push yourself a little at first. Baby steps. Once you start it'll get easier."

Joanna stared at the candle. "I'm scared, Leona. Scared and angry and tired. If the nurse didn't keep pestering me every morning, I'd probably stay in bed all day."

Leona squeezed Joanna's hand. "You're my best friend, Joanna, and we've got lots of good years left to raise hell and misbehave. Let me help you. We'll get through this together, I promise."

* * *

So many years ago. It had taken Joanna a long time to finally make her peace with Peggy Sue and the accident, but in most respects, she had reclaimed her life. Or so she thought, until Henry came along and stirred things up.

It seemed like ages before Leona called and they were finally sitting together on Joanna's patio. Leona didn't waste any time.

"How long has Henry been divorced?"

"It's been at least six years," Joanna said. "That's when his ex-wife moved to Chicago."

"Do you trust his reason for getting in touch with you?" Leona asked.

"Yeah, I do," Joanna said. "Maybe he's lonely. I don't know. He's definitely someone I'd like to meet if I didn't feel like damaged goods."

"Peggy Sue, I'm sorry you had to hear that," Leona said. "You've been faithfully supporting this peach of a woman all these years and what do you hear? Damaged goods!"

"Come on," Joanna said. "You know what I mean."

"Let me expand on what I said in my e-mail," Leona said.

"If Henry can't deal with your accident, he can kiss my ass. Go for it, Joanna. If it doesn't work out, good riddance, but don't miss out on a chance to meet someone who may turn out to be a keeper."

It had taken Joanna a long time to finally make her peace with Peggy Sue and the accident, but in most respects, she had reclaimed her life.

Soon after Leona left, Joanna opened her laptop and stared at Henry's e-mail. When she began typing, the words didn't come easily. She finally saved what she had written and got ready for bed.

That same evening, Henry checked his e-mail for the last time. Nothing from Joanna. Maybe it was too soon to talk about getting together.

The next morning, Joanna went to the kitchen and opened her laptop. She would finish her e-mail and send it, no matter how long it took.

When Henry got home from work, he went straight to his computer. He was relieved to find Joanna's e-mail.

Dear Henry,

You are right about Leona. I can't imagine a better friend. She has truly been a lifesaver, a wild woman with a heart of gold.

A few years after I began teaching at the community college, I was hospitalized after a bad accident. I was hit by a car and could easily have been killed, but I didn't feel very lucky when I regained consciousness. My left leg below the knee was too badly damaged to be saved and had been removed by the time I woke up in the hospital. Leona was there next to my bed, and she was the one who told me about the accident. She and my mother stayed with me after I was released, and when Leona could no longer stay full time, she still came to see me every day. It was quite a while before I started to care whether I woke up in the morning. Leona wouldn't let me give up and I feel like I owe her everything.

If you still want to meet sometime, first make sure it has nothing to do with what I've told you about my leg. I won't hate you if you feel like this is something you can't deal with. Much better to think about it and be honest with yourself.

Joanna

Henry stared at the screen. He went back to the beginning and read through all of Joanna's e-mails. There was nothing more to learn from them and he knew how he felt. He began typing. When he was finished, he read what he had written and pressed "*Send*."

* * *

The next day was Friday, and Joanna spent the entire day at her office, preparing her courses for the new semester. She felt certain Henry would write. If he didn't mention getting together, maybe they would continue writing for a while. The e-mails would slow down and finally stop when there was nothing else to talk about. She would be busy with teaching soon and that would help.

On the way home, she ordered Chinese carryout at a little place on the edge of campus. She had been sitting most of the day and the walk home felt good. There were no messages on the answering machine. She emptied the carryout containers onto a big plate and used a tray to carry it to the patio. She made another trip to the kitchen for a glass of wine. Her life was pretty easy. She would be fine without Henry.

When she was finished with her meal, she spent some time reading in the living room. Last thing before turning in, she checked her e-mail and found Henry's reply.

Dear Joanna,

I hope I have a chance to meet Leona someday. That is, if you and I are able to meet and you're not too disappointed. Do you have any free time before your classes begin? No pressure, but if it's not too soon to make plans, we could meet here or in your town.

Henry closed with his phone number and said he would love to hear her voice, if she ever felt like calling. Evenings, he added, were almost always a good time to reach him. Joanna thought about picking up the phone, but it was an hour later in Louisville and she was too excited at the moment anyway. She decided to call Saturday evening and send a reply in the meantime.

Friday evening, Henry checked his e-mail and wasn't surprised to find nothing new from Joanna. Meeting in person would be a big step, no matter how they arranged it.

Henry closed with his phone number and said he would love to hear her voice, if she ever felt like calling.

First thing Saturday morning, he found her reply.

Dear Henry,

I'm not going to question whether you've given yourself enough time to think about my e-mail. You say you're ready to meet and I believe you. If you're sure you don't mind, I think it would be easier for me if we meet here. Since you'll be doing the traveling, I would like to pay for your room. I may be able to reserve one of the guest rooms at the college, but in any case it won't be hard to find something nearby.

Thanks for sharing your phone number. I'll call Saturday evening at eight o'clock your time. I've attached a fairly recent photo, taken by Leona. We had just gotten back from an outing in a rented canoe.

Anytime between now and next weekend would be fine for a visit. Classes begin a week from Monday.

Joanna

Henry stared at the photo. Joanna was wearing sunglasses and smiling at the camera. Her hair, an attractive mix of brown and gray, was shorter now—too short for the ponytail he remembered from high school. She held her paddle out to one side like a walking stick. In her right hand was a wide-brimmed sun hat. She was wearing an unbuttoned long-sleeved blouse over what was probably a tank top, judging by the neckline. Athletic shoes were visible below her loose-fitting pants.

He could hardly believe it—they were actually going to meet. He opened his Pictures folder and looked for a photo he could send in return. There weren't many choices. He found one taken by his daughter Annie earlier in the sum-

mer. He was relaxing on the deck, sitting with his legs stretched out on a lounge chair. His head was turned toward the camera with an expression—rather serious with one eyebrow raised—that suggested he was not an entirely willing subject.

* * *

Saturday morning, when Joanna didn't find a reply from Henry, she decided to wait until early afternoon before checking again. If she hadn't heard from him by then, she would check again shortly before she called. It would be a shame to spend the day worrying about it. She thought about Leona's last visit and smiled when she remembered how her protective, tough-talking friend had put things in perspective. Around mid-morning, Joanna decided it was time to give her a call.

Joanna had begun to leave a message when Leona picked up.

"Hey, it's good to hear your voice. How've you been?"

"Much better," Joanna said. "How about you?"

"Doing all right. Just taking it easy this morning, enjoying the quiet," Leona said. "Rob left a while ago to help a couple of friends with a project."

"I wrote to Henry and told him about the accident," Joanna said. "I told him to think about it and be honest if he had trouble dealing with it. He wrote back asking if I had any free time before classes begin and said it was fine with him to meet here or in Louisville. He made me feel like I could take my time, and whatever I decided would be okay."

"Have you decided?" Leona asked.

"I have. I wrote last night and said it would be better for me if he could meet me here and to think about a time this coming week so we could arrange something. He included his phone number when he wrote and I said I would call tonight.

"Where will he stay?" Leona asked.

"I told him I would reserve a room for him. I was thinking we could meet somewhere besides my place when he first arrives, maybe a restaurant or a coffee shop, just in case it doesn't feel right."

"Good idea," Leona said. "Very good idea."

When Joanna checked her e-mail a few hours later, she found Henry's reply.

Dear Joanna,

I can't tell you how happy I was to see your photo. Thanks so much for sending it.

I called my supervisor this morning and said I needed a day or two off next week if someone could cover my hours on short notice. She said to let her know which days and she didn't think it would be a problem. So here's what I'm thinking: I'm off tomorrow and could head your way in the morning and leave Monday afternoon, or we could do the same thing any two days during the week. I thought it might be easier for our first visit to make it a short one. I'll be here for your call this evening—looking forward to it!

The attached photo was taken by Annie earlier this summer. She caught me before I could talk her out of it.

Henry

She thought about Leona's last visit and smiled when she remembered how her protective, tough-talking friend had put things in perspective.

Joanna checked on room availability and sent Henry a quick note before showering.

Henry spent Saturday afternoon at home. He started a load of laundry, paid some bills, did some reading. After an early supper, he checked to see if Joanna had written back.

Dear Henry,

I know what you mean about being photographed, but I'm very glad Annie got away with her photo. I've got a guest room on campus tentatively reserved for tomorrow night in case you can get Monday off and arrive tomorrow. No problem changing the reservation if you visit later in the week.

Talk to you soon!

Joanna

Henry e-mailed his supervisor to make sure Monday would be okay. He hoped he had an answer by the time Joanna called.

A little before seven, Joanna opened her e-mail and the attachment with Henry's photo. She was a little nervous and reminded herself to relax. Easier said than done, but she was glad for the reminder.

Henry was looking at the photo of Joanna when the phone rang.

"Joanna?"

"Hi, Henry. Can you hear me okay?"

"Like we're in the same room. I'm looking at the great photo you sent."

Joanna smiled. "I'm glad you like it. I didn't have many to choose from. Did you find out when you can visit?"

"I've got Monday off, so I can get an early start tomorrow morning," he said. "With the time difference, I should be there around lunchtime."

"That'll be great." Joanna said she would send directions to the campus guest rooms. In the meantime she gave him her phone number and asked him to call when he arrived. She said she would meet him there and they could go out for lunch before returning to her house.

"Sounds good to me," he said. "Anything I can bring along?"

"Just yourself and some comfortable shoes for walking," she said. "Have a safe trip and I'll see you soon."

Their conversation had been short but Joanna felt good about it. Even sending Henry to the guest room rather than straight to her house hadn't felt as awkward as she thought it might.

She called Leona's number and Rob answered.

"Hey, Rob, is Leona around?"

"Yeah, unless she sneaked out on me. Lee-O-O-O-na, it's Joanna," Rob yelled. Joanna brought the phone back to her ear in time to hear Rob continue. "Hold on a minute. Here's Leona."

"I just got off the phone with Henry," Joanna said.

"How did it go?" Leona asked.

"Really well," Joanna said. "Turns out he'll be heading this way tomorrow morning. I reserved one of the guest rooms on campus. He'll call me when he gets there so we can meet for lunch."

Even sending Henry to the guest room rather than straight to her house hadn't felt as awkward as she thought it might.

"At your place?"

"No, I didn't chicken out on that one. I told him I'd meet him on campus and we could get some lunch before going to the house."

"Good girl," Leona said. "We can laugh about it later."

"It'll be a short visit," Joanna said. "He's leaving Monday afternoon."

"In that case I'll forgive you if I don't get to meet him this time. Just be sure to say good things about me," Leona said.

"He's already said he'd like to meet you sometime," Joanna said. "We'll see how it goes. Maybe we can get together for lunch on Monday before he leaves."

After they said goodbye, Joanna went to the grocery to pick up a few extra supplies. Later, she tried some reading but her thoughts kept wandering. When she was finally in bed, she lay awake for a long time.

* * *

Sunday morning, Henry woke up ahead of his alarm clock, set for seven. After breakfast and a shower, he filled his stainless steel water bottle. His backpack, sunglasses, and road atlas were already in the car. He locked the front door and was soon on his way.

Joanna slept in later than usual Sunday morning. After breakfast, she decided to walk to campus and take a look at Henry's room. It occurred to her that she should have looked at the guest rooms before reserving one. No sense worrying, she told herself, and the walk is just what I need.

With Henry in mind as she entered the campus, she saw it with new eyes. There were many mature trees, and care had been taken with the landscaping. Walking paths meandered among the trees and buildings. The unpretentious brick buildings didn't overshadow the pleasant surroundings. All in all, it was an attractive campus.

Joanna walked into the Union Building and up to the second floor. She spoke with the young man at the check-in counter and asked if she could see the room she had reserved. Key in hand, she walked down the hall and unlocked the door. There was a small table with two chairs next to a window that looked out onto an open space with a fountain. The large bed was covered with a quilt. She sat down on the bed and closed her eyes. The air conditioning was quiet and the room had a pleasant smell. She smoothed out the quilt and took a quick look inside the bathroom. Satisfied with her inspection, she returned the key and walked back home.

* * *

Joanna's town was just beyond St. Louis. Henry stopped at a gas station in St. Louis to fill the tank and stretch his legs. He spent some time cleaning the bug-smeared windshield before reviewing Joanna's directions to the campus.

Joanna took a shower when she got back from her walk. She always sat on a stool when she showered, and today she wore a shower cap so she wouldn't have to dry her hair. Other accessories included sturdy wall-mounted hand rails and a showerhead with a handle and flexible hose that could easily be removed from its wall bracket.

After she washed and rinsed herself, she sat with her head down and let the hot water relax her neck and shoulders. She looked at her breasts, her belly, and the stump of her leg. As she got older, she was grateful for breasts that had seemed on the small side in high school—less for gravity to work with. She sat up straight for a moment and put both hands on her stomach. Not bad for a woman her age, she had to admit. And her stump—it had been part of her life for a long time. "Hello, old stump," she said out loud.

When Joanna had dried off and put her artificial leg back on, she went to her bedroom to get dressed. A casual pair of khaki pants and a lavender-blue top were already laid out on the bed. Pants took the longest. She sat on the side of the bed and removed the prosthesis. Next, she worked the left leg of her pants far enough down over the prosthesis so she could reattach it. When she had pushed her right foot all the way through the other leg, she got up and pulled her pants the rest of the way up.

By the time Henry reached the campus, it was almost noon.

There was parking near the Union Building reserved for guests and Henry found a spot in the shade. He shouldered his backpack and headed for the building to find the check-in counter.

When he had his key and opened the door to his room, he sat down in one of the chairs next to the window. The view of the fountain was relaxing, and he was glad to be above the ground floor. His next stop was the bathroom. He looked in the mirror and rubbed his face with cold water.

After stretching out on the bed for a few minutes, he pulled out his wallet and found the piece of paper with Joanna's phone number. There was a phone on the bedside table with instructions for making a local call.

With Henry in mind as she entered the campus, she saw it with new eyes.

Joanna had the portable phone with her when she sat down in the living room to do some reading. She didn't wait for the answering machine when the phone rang.

"Hello?"

"Hi, Joanna. Thanks for the great directions. They took me right to the Union Building and I'm in my room. It's really nice, by the way. Is now a good time to meet for lunch?"

"Sure," she said. "What kinds of food do you like?"

"Most kinds," he said. "I don't eat out very often but when I do, it's usually Asian or Italian. What about you?"

"Pretty much the same," she said. "I've been to a Thai restaurant that has a buffet on Sundays. Does that sound good?"

"Sounds great," he said. "Is it near the campus?"

"An easy walk," she said. "I'll meet you at the Union Building and we can go from there. Will ten minutes or so be too soon?"

"I'm ready now," he said. "I'll wait outside for you."

Joanna brushed her hair and checked herself in the full-length mirror on her bedroom door. Taking her purse, sunglasses, and a hat for the sun, she locked the front door and made the short drive to campus. As soon as she got out of her car, she saw Henry standing near the entrance to the building. He waved and she waved back. She walked toward him, wearing her sunglasses and holding her hat in one hand. Henry smiled and was the first to speak.

“Would a hug be okay?”

Joanna smiled back and they shared a brief hug.

“How was your trip?” she asked.

“Not bad at all,” he said. “I stopped for a while about half-way and there wasn’t much traffic until St. Louis.”

“Let’s go get some lunch,” she said.

They walked a few blocks beyond the edge of campus. The restaurant was fairly busy but they had no trouble getting a table. A waiter brought water and menus and asked about beverages. Joanna ordered iced tea and Henry chose one of the beers.

“Would you like to see the buffet before we look at the menu?” she asked.

“Definitely,” he said. “Lead the way.”

In addition to steaming trays of entrees and rice, there were appetizers, a salad bar, fresh fruit, and other desserts.

“I’m sold on the buffet,” he said. “What about you?”

“Same,” she said. “Seeing all the choices makes me feel like a kid back in the cafeteria days.”

“Those were fun outings,” he said, “except for seeing all the desserts and knowing I could only choose one.”

Joanna smiled. “So unfair.”

They didn’t talk much while they ate, but neither of them felt uncomfortable. From the time they left the parking lot on the way to the restaurant, they noticed how easy and relaxing it was to be together.

“Now that was a lunch,” Henry said when they were finished. “I think it will last me the rest of the day.”

“I’m not quite *that* full,” Joanna said.

“Lunch and dinner,” he said, patting his stomach. “Maybe we can do some walking later. Right now I feel like the walk back to campus is about my limit.”

Henry signaled to their waiter and asked for the check.

“It was nice of you to get the room for me,” he said. “You didn’t have to do that.”

“My pleasure,” she said. “It was nice of you to drive all this way, and thanks for lunch.”

On the walk back to the parking lot, they held hands as if it were the only way to walk. ♦

GERRI LEEN

DONE

Years of routine. Get up
Get dressed, outfit picked
The night before
Fight traffic, always guess wrong
In late

Nothing new. I'll be there when
I get there. Until the
Headaches got worse
And the days started later
And later

Until I stopped having to get up
At all. Disability. I am...disabled
But I'm young (relatively)
I'm strong (sort of)
I'm healthy (ha!)

That work routine, like it or not
Sets the course of the year
Days mean something
Weekends matter
Time is substantial

Holidays? Now that means people
In the grocery store during
My time, the quiet time, when it's just
Moms and the retired folks
Wait—I'm retired now

It was sudden, you see
One day there, one day "You're done"
Not done as in fired. Done as in
You're not able to work
Dis-abled

But that's for big things
Things that require accommodations
There is no work-around for pain
For this all encompassing weariness
For trying to work when you're sick

I'm carving out a life from the
Rubble of a quiet explosion
No one heard it, but it leveled me
"You're done" should have translated to
"You're free"

It didn't. Instead
I heard: "You're useless"

It took time, time alone
Time asleep, time dreaming
Of all the things left undone
Time reading, and writing
So many poems, feelings poured
Out in free verse

Before useless turned to resigned
And that turned to resilient
And done became a door to
A world of things to do between
Migraine episodes instead
Of a jail cell that never opened

But it took time
It still takes time
Migraine doesn't let go
It's never done
But neither am I

GERRI LEEN

SAFE TRAVELS

An egret on a beach at Halloween
Soft winds and water beckoned me to sleep
Most gorgeous sunset that I've ever seen
The colors drawing memories I would keep
I feel the sun; I hear the sound of waves
Imagine stingrays shooting through the sand
Cabanas held up strong by wooden staves
My skin becoming increasingly tanned
It feels so far away from where I am
Much farther than the miles in between
The pain inside me rises like a dam
Keeps life a thing that's not lived, only seen
I want to break the surface of this pain
And swim away, a traveler once again

GLEND A BARRETT

THESE HANDS

Even though the progression of my disease
is slow, each year brings a more pronounced

loss of muscles in my hands. I have no reason
to whine or complain, because I have had more

time to use them than most. For seventy years
these hands have allowed me to bathe my babies,

hug my husband and family, pat my friends on
the back, play a piano, paint a lot of landscapes,

write two poetry books, cook many meals, wave
goodbye to friends, plant flowers in the dirt and

at night to reach toward the heavens in a prayer
of gratitude.

BE STILL

CHRIS PELLIZZARI

Larry was not prepared to see his father dead inside a coffin. At thirty-six, he thought he was *somewhat* ready for it, but the minute he saw the face, the face he had known his entire life, the face he had trusted over all others, the tears came.

His father's sixty-three-year-old face was just so . . . dead.

He'd seen photos of dead people, Civil War soldiers, saints, Holocaust victims, some of them looked just a little dead. Some looked unconscious, others even asleep. Saints looked like they were sleeping. But his father looked very dead. His eyes were small and sunken deep. His mouth was almost invisible. The only thing that looked like it once had life was the large Irish nose. His hair, thick and curly black in life, was reduced to a few patches of white. Such are the ravages of stage-four pancreatic cancer. He would be cremated in a couple hours. The cancer had already cut him down to nothing, and fire would devour that little nothing that was left. The devouring of nothingness on Sunday morning was what brought Larry to tears.

Larry was angry, too. This farewell was unnecessary. He said his goodbyes when his father was still lucid in the hospital, before the full effects of cancer and chemotherapy. Larry told him he was the best father any son could have.

He gave Larry one final handshake—still firm, like the day Larry graduated from high school, when he said he raised him well.

Larry told his high school principal on graduation day his father was the only person in the world who saw him as more than just someone with Down syndrome.

He didn't want to say goodbye to the mannequin inside the coffin. He didn't want the wooden replica to be the last thing in the world he saw of his father. But he would have to bear it. He remembered when he was nine, sitting in church with his mother and father, feeling restless, wanting mass to be over so he and Dad could go home and watch the Bears game. Dad would drop Mom off at the mall for a few hours. She didn't like sports. They would have the whole house to themselves.

"This priest doesn't know when to shut up," Larry would whisper in his dad's ear during the sermon.

"Just be still for a little while longer. We'll be home before you know it," Dad would say.

Larry sat down next to his mother in the front row. He was so close to the coffin, he could have reached out and touched it.

"I love you, Larry," his mother said, kissing his cheek.

"I love you too," he said.

Ecce homo, behold the man, Larry said to himself. He heard those words every Easter. He knew they were Latin words. But they made more sense today, he thought.

But this wasn't the man. Where was the man who welcomed him into the world on January 18, 1982? Outside of Mother's womb for mere seconds, his was the first face Larry saw. He told Larry the moment he burst out into the open, he cried, as infants naturally do, but stopped crying for five seconds and stared at him with a puzzled look. His father said he never forgot those five seconds. He told Larry he felt both the weight of the responsibility that awaited him and the unconditional love of a father being born in those five seconds.

His dead body was too still. Larry wished a breeze from some unknown place would enter the funeral parlor and at least tousle his hair a little. The stillness of his father's body was breaking Larry down.

Get up, Dad! Get up, Dad! Larry said to himself, trying not to open his mouth as he stared into the coffin.

"Halftime is over, the third quarter is starting," the boy would say.

It had been a boring game. It was 3-0 Bears at the half and Father had fallen asleep on the couch.

"I don't know why your mother wakes us up so early to go to church," he would say, yawning.

Larry examined the prayer card he forgot he was holding. On the front of the card was Joseph holding toddler Jesus in front of a bed of roses. Jesus was looking out at the card holder and his little hand seemed to be presenting the roses. There was a little wooden writing desk next to them in the garden. On top of the desk was a book. Larry tried to figure out the symbolism. He couldn't. He flipped the card over.

In loving memory of Sean Murphy. Born January 17, 1955. At Rest . . . Funeral Services, Modell Funeral Home. Friday . . . 2018 at 7:00 p.m. Officiating, Fr. Mike O'Keefe.

You are not forgotten, loved one
Nor will you ever be,
As long as life and memory last
We will remember thee.
We miss you now, our hearts are sore
As time goes by we'll miss you more.
Your loving smile, your gentle face,
No one can fill your vacant place.

Father O'Keefe started to speak.

"I first met Sean when we were both ten years old. We were on the same little league baseball team," he said, loud enough over the sobbing.

Baseball. Baseball. Forget baseball, Larry thought. The Bears were playing a game against the Packers today. It was the biggest game of the year. Larry didn't want to miss it. He knew Dad didn't want to miss it either.

He knelt at the coffin as the priest talked. Nobody seemed to notice. The priest continued to talk about baseball.

"This priest doesn't know when to shut up," he whispered in his father's ear.

He thought he heard his father whisper back, *Just be still for a little while longer, Larry. We'll be home before you know it.*

He saw how still his father was. He was far more still than other dead men. He would have bet the funeral parlor they had never seen a body so still.

He kissed the top of his father's forehead and returned to his seat. He sat through the rest of the sermon without moving a muscle. He had never sat so still in his life. ♦

LIKE BEING AFRAID OF BEAUTY

TOBIE HELENE SHAPIRO

DSPS stands for Disabled Students Programs and Services. It was DSPS until suddenly they reorganized the letters into DSSP. So I suppose anything goes, or everything is meaningless, at least where acronyms are concerned. The DSSP at City College was supposed to offer Meyshe accommodation services because he's autistic, and with autism he just couldn't do this alone, yet.

"Can you give him an aide to go to classes with him, guide him, keep him socially aware, remind him to stay on topic, and . . ."

I was hollered at by the DSPS employee in her wheelchair who nearly rose up on her feet to defend the DSSP against my outrageous demands.

"NO! We can't do that! We don't do that! We're not prepared to do that!"

I backed off, flummoxed. She continued from her chair, herding me out the door.

"We could offer you a notetaker."

A notetaker—my son knew how to take notes. That wasn't his problem. What about this notetaker? Was this going to be someone to sit there in class and take neat, accurate notes for students who hadn't the facility? No. As I found out, on the first day, the teacher would address the class and say, "Whoever wants to earn a hundred dollars a semester taking class notes, come see me." The notes could be good or hap-

azard, the handwriting illegible. Sometimes the notetakers showed up; sometimes they didn't. They were students who just happened to be taking the class. They were untrained, unmonitored, and very young. The pay was damn good for such little effort.

A notetaker wasn't what I asked for, nor what Meyshe needed, but I accepted anyway. Why not? Or what the hell. Give a student an extra hundred bucks.

Why did I think I could ask for an aide? Maybe it was the word "services" in the DSPS acronym. So I'd alienated them before school even began. *Auf en lung auf en tsung*. (From the lung to the tongue.) Whatever I was thinking got blathered without censor. So, I'd have to be the aide, infantilizing my brilliant and charmingly weird son. I would be the mommy going to school with her autistic boychik, silently prodding him, reminding him:

"Meyshe, this is an English class. What they do in the Han dynasty is off topic." "Meyshe, your pants are on backwards."

All the teachers fell in love with Meyshe. His hand was always up waving while he simply blurted out his thoughts, not unlike his mother, the *auf en lung* kid. His commentary was always surprising. The English teacher was a lovely young woman from Romania, full of observations, not too complimentary, on the shallowness of American society.

“You Americans are too afraid of death to want to read deep books. You want happy, happy, happy. All good endings. No death.”

The class mulled this over. Meyshe had a terrible time getting words out, but when he did it was something like this:

“But that’s absurd, Dr. Dascalu. Being afraid of death is like being afraid of beauty.”

Around the room the students’ jaws dropped in unexpected contemplation. The professor awarded my man the monthly counterculture super-depth commendation.

Meyshe was so excited, invigorated, that he brought his proud poetry to his specialty therapist, who is an expert on adults on the autism spectrum. But he came out of his session frowning, confused, and not a little insulted. The doctor called me later.

“Meyshe is expressing suicidal ideation.” I think he felt sorry for us. He mentioned how hard they’d been working together to lift his self-image, defuse the endemic paranoia.

He didn’t say, “You poor thing,” but I felt it in his voice. He’d been well aware of my overwhelming responsibilities: twins with special needs, the ugly divorce, living with an aging mother, kicked out of our family home, under assault by an angry and litigious ex-husband. He was adding a suicidal son on top of that.

I tried to correct the therapist’s notion. “No, no, no, no. It’s poetry. Think of it metaphorically.” Silence. “Death is inevitable,” I said.

“Yeah.”

Okay, good start. He’d concurred. “Meyshe is dealing with the programming of cultural dispositions, universal concepts. Death is a universal concept. It can’t be avoided—(pause)—and beauty is also inevitable,” I urged. “See? It’s a positive statement. And the juxtaposition is achingly ironic.”

Hmm. I shouldn’t have said that. He’d think we were going to off ourselves together.

“I think he’s equating death with beauty,” gravely, psychiatrically.

I could hear him shaking his head. He’s German born, so I was extra Jewish careful not to stereotype—which I did anyway.

“I don’t think so, Dr. R. No. We’ve spoken about this. I know Meyshe; this is how he thinks. It’s a good sign. He is not broken here and we don’t need to fix this.”

“I’d keep my eye on him,” he said, seriously. Very seriously. Ploddingly serious. Deathlike serious. And not beautiful.

“Meyshe is a poet,” I pointed out. “His language dysfunction is, in this case, a boon, a strength, a lovely quirk.” I left out “miracle.” Dr. R may look askance at miracles, both large and small, unless they have some bearing on the frontal lobe and executive functioning. I tried to think of some other way to express the passion, affection, and life joy in statements like, “Being afraid of death is like being afraid of beauty,” but I couldn’t. He warned me again, politely.

To this day I think of all the people who don’t understand Meyshe, who assume as they observe a twitch or a wordless utterance or his trained and awkward eye contact that what is truly needed is a notetaker because more effort would be too much trouble and there is no emotional budget for it. And then I have to think of all the people Meyshe cannot understand and the rift Meyshe would need wings to cross over. This mission is all on him, except for me. But there I was trying to explain Meyshe’s metaphor about the incapable nature of beauty and death to a decorated expert in the field, and it wasn’t working. I thought in trite ironies: Deadly. Beautiful. We hung up.

In an act of reckless bravery, Meyshe selected “Introduction to Speech” to satisfy the English language requirement—one more attempt to traverse the breach.

At the first meeting the professor assigned the students to prepare a simple five-minute talk to introduce themselves. There would be three class sessions dedicated to giving

these speeches. The neuro-normals threw words and sentences and paragraphs among themselves without thinking. For them, the thought was the word. For Meyshe, putting together one expressive sentence was labor.

He was three years old and not speaking in phrases. Labels, he could do. He could name hundreds of objects, maybe even attach a “the” to them. But to string several words together seemed an impossibility. I watched him wrestling with himself, wringing his brain out for a pair of words that would never come. I sat him down at the breakfast table and placed a glass in front of him.

“Glass,” he said.

I filled it with water.

“Water,” he said.

I dropped a bead of blue food coloring into the glass.

“Blue,” he said.

I poured a clear glass of water and set it down next to the first. “What’s this, Meyshe?”

“Glass.”

“This is clear water. Clear.” I showed him one then the other, giving them their names. “Clear water. Blue water. Clear water. Blue water.”

He could say “glass” and “water,” “blue” and “clear,” but he couldn’t say “blue water” or “clear water.” Not to save his life.

I wrote it down, one word per line, on a piece of yellow notepaper. He’d taught himself to read and write by the time he was two and a half watching *Sesame Street* and using refrigerator magnets that he would line up on the floor in front of him.

“SOUTH AMERICA”
“ELEPHANT”
“COOKIE”

This was easier.

Blue
water

Clear
water

He read them. “Blue water. Clear water.”

But if I took the writing away, the words were gone.

How was I to know my son? The words went in and disappeared, the syntax falling apart, the order lost into a whorl of comprehension without words. For lack of the professional lexicon, I called it “auditory dyslexia.” The speech/language therapist called it a language processing dysfunction.

Nearly twenty years later, he was sitting in a college classroom in Berkeley, California, waiting to devote an entire five minutes on a talk about himself.

The words went in and disappeared, the syntax falling apart, the order lost into a whorl of comprehension without words.

The members of the Introduction to Speech class were fidgeting in their seats. It was the third and final day for classmates to perform their “This-is-about-me” speeches. Meyshe had rehearsed his four-minute talk many, many times. I’d sat there with the timer, and it was “Ready. Set. Okay!”

“Hello. My name is Meyshe,” and he scanned the ocean before him without focusing on anything or anyone, back and forth for good measure.

“You may be wondering why I act so bizarre. That is because I’m autistic.” A pause. “No, I’m not a headbanger. Nor am I a savant.” He hit his head with his fist to demonstrate headbanger, and painted a halo over his corona of hair for “savant.” “Nor am I void of a sense of humor or emotions. We autistic people call you people ‘neuro-normals.’ Being autistic, I don’t learn social skills like you do—by osmosis. I have to be taught with social lessons.” And he went on to explain how he leaps off topic in conversations and illustrated by jumping from one spot on the floor to another and to another, physically, hop, hop, hop. All this time, his eyebrows were in full arch as if he were suddenly surprised or awestruck. “Then I’m entirely off topic, and I have to yank myself back to the conversation and say something that confuses everyone and embarrasses me.”

He explained that he had no ulterior motives. Never. “With neuro-normals, a man might give flowers to a lady because he really wants to jump her bones,” (laugh, laugh—they laughed), “but when I give flowers to a lady, it’s because I want to give flowers to her. I don’t want anything else. So you can trust me.” All the women sighed with an exhausted yearning, and the men sighed too while quietly crossing a favorite stratagem off the docket.

He told them how language was both his strength and his weakness. Extemporaneous speech was very hard for him, because the words didn't stay inside his head. But his strength was in the written word, because he had time to organize his thoughts and the words stayed there on the page where he could freeze them. He told them how he taught himself to read and write when he was two and a half, but didn't speak in sentences until he was six years old. He told them he was a musician, an artist, and a writer and was studying languages, which fascinated him. "Chinese, Tibetan, Russian, Korean, Japanese, Latin, and hopefully," he said, "Hebrew." So far and for the remainder, he had them charmed thoroughly with his courage, honesty, and complete vulnerability.

His last words were that he likes people. ("Awwwww.") People are a mystery to him. ("Awwwww.") He wants to be friends and he hopes "that you will please not hold my autism against me." ("Ooooooooooh!") "I mean you no harm."

Then he bowed. Awkward, clueless, bizarre, and thoroughly lovable. He got the loudest round of applause of anyone. My son.

Afterward, other students were slapping him on the back telling him he was awesome. One student walked right up to Meyshe, seemingly speechless from admiration, and boldly hugged him, nodding his head on Meyshe's shoulder.

When the last student had finally left the room, he was still standing there, perplexed. He didn't know what to do with the acceptance, nor the human contact. There was no precedence, no experience. What instructions are there on being seen when you've been invisible all your life?

On the way out the door, a messenger from the DSPS caught up with us, handed us the outline from the notetaker. It was an effort to parse the handwriting.

The regular notetaker is sick today. This is Zack. I'm the substitute. I hope this helps.

Intro to Speech 1

1. Mayshe is Autistic

He calls us "Nuro Normals"

Needs social lessons, not us

Off topic confuses us, embarrasses him

N/Normal floers lady jump bones

He flowers to lady—just flowers. You can trust him

Speech hard, writing better—learn to read/write

2 ½!!!!???

Interests: music, art, writer; languages

"Wonder why I act so bizarre" (that belongs up top)

P.S. Thanks. We did wonder. Beautiful ♦

ANY BODY ON THE PLANET

DIANE REID



"Joy Lab Research" dancers: Neca Zarvos and Ticiane Duarte. Photo credit: Gil Grossi

Soft, melodic instrumental music plays on a stage lit with a red hue—warm and vibrant. The sound is ambient—promising to stay quiet and low, without lyrics to suggest any narrative. You have been invited into the heart and hearth of this dance. There is a wheelchair facing sideways, with a woman sitting in it. Another woman stands directly in front, close. Slowly, she eases back to sit in the lap of the seated woman. She reclines casually, stretching long legs out, relaxing, her face blank, peaceful as the seated woman gently embraces her.

The dancers move to the floor. One dancer's legs raise the other dancer in the air, her feet lifting the pelvis of the fully-extended flyer, who wears no prosthetics. For the first time, you have a clear visual of the woman's body—a body condensed by legs that end at the knee. Elegantly, the lifted dancer is rolled down, the two catching and circling each other until they lie side-by-side. There is an intimacy in this moment that suggests this could be you and your sister, you and your friend.

If you want to tick off Alito Alessi, tell him how marvelous it is that he works with “those people” who have disabilities. I wouldn’t have said it, though he was clearly poised to hear it. As the artistic director and cofounder of DanceAbility International, based in Eugene, Oregon, Alessi—whose accent is more New York than northwest—bristles at the notion that his work is for people with disabilities. “It is work for people, for *all* people,” he says emphatically. It’s clear this explanation is one Alessi has needed to articulate many times before. “You know, when we think, *Oh, it will be so good for ‘them’*. . . . The problems arise when people get separated and isolated from each other, which is what society does to ‘those’ people,” he makes finger quotes. “And whenever you isolate someone, guess who else is isolated? You.”

A Guggenheim Fellow, an Ashoka Fellow, a Fulbright Senior Specialist, among other honors, Alessi has been practicing what he preaches for more than thirty years, receiving international recognition, training 750 teachers in fifty countries to be truly inclusive in their instructional practice. It started in 1987. Alessi and his dance partner at the time, Karen Nelson, produced a workshop for people with mixed abilities, through their work in Joint Forces Dance Company. This exploration inspired Alessi’s life work, and his passion for providing opportunities for people of all abilities to dance, led to the development of a methodology he has since used to teach, train, and inspire countless dancers in Oregon, across the United States, and internationally. Through workshops, classes, and his choreographed performances, Alessi is continually expanding the vision of DanceAbility International, reaching out to communities around the globe.

The basic philosophy of DanceAbility’s work is similar to the Bodhisattva path of Tibetan Buddhism. Alessi explains, “. . . you don’t go anywhere unless you all go together.” This belief anchors his fundamental practice of fostering connectedness through artistic expression. To Alessi, the work is all about building relationships. “A person’s condition, I always say, is not a problem. The fact that you’re alone in it is the problem. Relationship is the anecdote—a homeopathic solution to isolation.” Clearly, the mission of DanceAbility goes beyond movement to a much larger ideal.

Alessi speaks with the conviction that comes from experience whenever he discusses his work—even as he adjusts his salt-and-pepper ponytail—his enthusiasm and energy underpinning each statement. The DanceAbility methodology, he explains to me, has many elements, but the starting

point in any class boils down to one logical question, the common denominator: “What is it that everybody *can* do?” Finding that common denominator involves answering the following questions about every person in the room: *Is someone totally blind? Is someone totally non-mobile, cannot move their body from one place to another, whether in a chair or not? Does everyone understand cause and effect—that an action has a consequence? Are there people in this class who are totally unresponsive to the world around them?* Alessi explains that answering these questions allows the teacher to alter the teaching and adapt, rather than trying to “fix” a student.

**If you want to tick off Alito Alessi,
tell him how marvelous it is that
he works with “those people” who
have disabilities.**

Wait, surely that comatose person lying in a hospital bed, unresponsive to the world around them, cannot participate in a dance class. Alessi anticipates this type of skepticism, “The hospital bed happens to have wheels on it If I had a comatose person in the class, I’d say, ‘You can move whenever you want, or you can be still, whenever you want, and you’re dancing with the people in your group.’” The multiple elements in the method Alessi uses is designed to work for the full range of abilities simultaneously, primarily through the collaborative movement of the group and through touch. He shares how the teaching method uses a “common language,” eliminating wrong choices. “So, the person who can’t move is always doing the right thing by being in stillness. And the other people are learning how to make relationships with that person, make images, or photographs.” Further, Alessi explains that part of the method focuses on touch as a possible modality, “. . . the bed can be moved through the room by touching that person’s body.” Touch, when accessible for everyone in the room, can have a genuine impact for making connections.

Alessi asserts that identifying “the ‘common denominator’ between *any* population of people who might exist, *any person on the planet* can be in the room including them as an equal participant of society, belonging, involved—whether we know how they’re involved or not—participating both creatively and practically.” The concept of “common denominator” allows the class to build from what everyone

can do, as opposed to teaching what they cannot do. “I learned from the mistakes,” Alessi says, “. . . teaching many things that people could not do, which made me feel like shit to tell you the truth.” The focus shifts from the perception of disability as a problem, to work with a person’s capability. “This is not,” he says with a hint of practiced derision, “therapy.” He explains that the exercises used in the DanceAbility Method create a profound educational and healing environment for teachers and students alike. “Am I healing you? No. Am I your therapist? No. Are you healing yourself? *Yes*. Are you your own therapist? *Yes*.”

I’m curious how Alessi came to realize this paradigm shift would actually work. He shares a story of a mother who wanted to learn how to communicate with her daughter, a nonverbal child about nine years old, who had cerebral palsy. “The little girl just laid on a very soft carpet in the living room, and I’m talking to the mother . . . and in the kitchen, in the other room, there’s a parakeet, a bird, singing, now and then. And every time that bird sang, that little girl laying on the floor would roll over and look in the direction of the bird. I said to myself, *Oh, she understands cause and effect*. I told the mother, ‘It’s interesting about the bird. Could I come back tomorrow?’ I went back to my hotel . . . that was in the days of those small cassette recorders—I got about five or six of those little recorders from my friends, took them back to the house and I recorded that bird and then I put them all around the room. The little girl started to go like this: she rolled to one side when she heard the bird, she rolled to the other side,” he says, demonstrating, “when she heard the bird, she looked the other way.” He explains how that experience morphed into the concept of Teach the Reach. “I would reach toward her and wait for her to go like this,” he says, moving his fingertips slightly. “When she went like that, then I would touch her. She learned, that instead of me touching her, whenever



“Wheels of Fortune” International Dance Day, Shanghai, China, dancers: Alito Alessi, Emery Blackwell, and Jana Meszaros. Photo credit: Steve Christiansen

she wanted to communicate, I taught her mother, just reach toward her, wait for an impulse, an initiation from her body, that’s saying, *yes, let’s do something*.” I am struck by Alessi’s uncanny ability to attend to sensation in the present moment and to teach others how to do so as well.

After my initial conversation with Alessi, I’m wondering if this unique perspective is why the DanceAbility Method has caught on with dance instructors both nationally and internationally. Michaela Knox, Director of Spark Dance Program, across the country in Maine, describes how, after fifteen years of teaching, she had a student come to her class who was blind, motivating her to research methods for children with disabilities. Knox describes this turning point in her career. “I went to a five-day DanceAbility training and knew pretty early on that I wanted to continue on.” In 2017, Knox attended a month-long certification training in Lisbon, Portugal, that she describes as “an incredibly intense, rich learning experience.” I ask what Alessi is like to work with. Knox responds, “The first thing I noticed is

that he really is very present with everyone he's with, and he's able to meet each person where they are. There's just total acceptance. Training with Alito has changed the way I experience the world around me, how I experience dance and movement, the way I experience being together with my students. It really cracks open the possibilities." She gives an example of working in a school. "One student had Pitt-Hopkins syndrome—no cause/effect, unintentional movement. We had four students lined up, and each had a turn. Alex is third. She is still, in a wheelchair. She doesn't understand verbal language. Eventually, she'll make a movement. We'll wait until she does. As soon as she makes a movement, we say, 'Great,' and move on to the fourth. She's included, it's normalizing, and attention is not on her beyond that. The staff person who is the helper will want to assist, may lift her arm. I'll say, 'Thank you. Now let's try it a different way; you just watch with me.' The staff is learning and more importantly, there's learning for the group. We pause, we reframe for success, we integrate naturally." I want to see this in action, so when I get an invitation from Knox to join a Zoom class, I eagerly accept.

When it comes to defining dance, Alessi feels his work doesn't fit in the mold of what many high-level, classically-trained dancers do.

Before the pandemic, she had classes in six communities stretching across Maine; in March they shifted to remote learning. In this adult class, as students join, it's clear they range in ability and setting. Some students take class from home, some are in group homes, and one woman enthusiastically joins from a parking lot next to her car, having found a hotspot to access the Internet.

To begin the class, Knox leads the students in a brief game before the warm-up, acclimating them to communicate non-verbally over Zoom. In the warm-up activity, she explains to me as students listen, "No one ever has to do anything they don't want to do. We are always trying to focus on sensation—how your body feels when you're moving." She asks the class to make a big movement, "any part of your body—what would that look like?" Small movement. Fast movements. "Whatever fast means to you." Now slow

movements. "What does it look like for you?" As I watch how these concepts are presented, I realize I'm seeing the common language Alessi spoke about. The students understand there are no wrong choices. They are engaged, each interpreting movement and language within their own ability. To foster relationships, Knox asks them to "choose a shape you want for your ending; stay in that shape. Now look at someone else on the screen and notice their shape." Students now have to work in partnership. She transitions to "follow and lead," guiding students to observe another leading, the others following the movement. "I might interpret it in my own way." Back to the concept of no wrong choices, Knox reminds them, "Kea might use big arms, I might use just my hands." Marie, a student with Down syndrome, volunteers with enthusiasm to lead. The music begins—"Dancing Queen"—with Marie moving her arms, her body swaying, smiling with abandon. The others follow, each in their own way: Josh using intricate hand movements, Vicky swaying ever-so-slightly, a grin spread across her face, and Donald, in a wheelchair, pumping his arms with enthusiastic rhythm. "Awesome," Knox calls out, keeping the momentum going, "find your energy!"

The activities that follow involve more connectivity, having students watch each other, mirroring, building awareness through sensation of their own movements and attending to their partners. The girl in the parking lot could care less who's around to notice her as the Talking Heads "Days Go By" plays. In the final portion, having built on success, everyone has the opportunity to share a movement with the group when Knox calls their name. Neil Diamond's "Sweet Caroline" plays as the students share. Observing this class, I realize the genius of Alessi's method is its deceptively simple language of acceptance. I become a little choked up. I feel like Alessi is saying in my ear, "This is not therapy! It's building relationships through artistic practice!"

When it comes to defining dance, Alessi feels his work doesn't fit in the mold of what many high-level, classically-trained dancers do. He says, ". . . it's not only how good you can do something with your body, but how to teach people to be in their body *as it is*, not how can you make your body like someone else. How can you find your body, get in it fully, appreciate it, accept it and then develop relationships that get what you need, get what you have to offer. That's dancing to me." To Alessi, dancing is not about the perfect leg extension. "I mean, I love watching those things, I don't want to put it down, but to be able to mechanically move your body, that's not a dancer to me. Dancing is a lot more." Clearly, his definition of dance is as inwardly focused as outwardly.



"Tango Tangle" dancers at Kennedy Center, USA: Alito Alessi and Emery Blackwell. Photo credit: Scott Suchman

I get the sense there has been resistance in the dance community. "Oh yeah." He describes how many of his friends were shocked he was "giving up" his career in dance to work with people with disabilities. Alessi shrugs, smiles, as he shares that he considers his work as leading the way in dance, eliminating isolation through artistic expression. Alessi, though, is not a stranger to groundbreaking ideas in dance; he cut his professional teeth on Contact Improvisation.

Contact Improvisation is a genre of dance developed by the brilliant Steve Paxton in the 1970s—a man Alessi knows and admires. The genre's hallmark is how it creates a landscape of problem solving between dancers in proximity, touching, working toward a common goal. Decisions are spontaneous as dancers enter and exit contact together, with no boundary. It is intimate without being sexual. The idiom broke movement boundaries for dance at that time.

In the seventies dance culture, Alessi explains, "It was basically a revolution against the institutionalization of dance that happened predominantly from ballet, which started to separate and isolate people based on the kind of body they had, and if they had a perfect body they would be able to be called a dancer." Alessi was interested in teaching dance for any body. "It was a sign of the times, the early seventies . . . I'm saying everyone can dance, I look at my students, everyone isn't in my classes. I think, *Okay, what would happen if we have a class where any person on the planet can come?*" I see now where his favorite phrase was born.

A video from 1987, "Common Ground," shows what happened when any person on the planet came to Alessi's very first workshop. The film of the early DanceAbility days, called *Dance for Any Body*, shows a young Alessi with his able-bodied colleagues rolling, stretching, balancing, sharing weight, partnering with 100 participants in a Contact Improvisation class. His athleticism and energy are apparent

as he rides the back of wheelchairs, legs aloft. In this film, one participant is lifted from a wheelchair and stretched across a group of dancers lying face down on the floor, side-by-side. Gently, they roll. As they roll, he moves across the group, a look of wonder on his face. I am reminded of the freedom of a mosh pit, but without the substances. “I am much less inhibited,” the participant shares after this exercise, “my inhibitions wash away.” From this workshop, the basis for the DanceAbility Method evolved.

“... he doesn’t necessarily filter his critique, he spews it out and that’s not necessarily easy to hear. . . . He’s like spice, he’s like cayenne pepper.”

Alessi’s dedication to eliminating isolation isn’t all for other people, though. Originally from Buffalo, New York, his family moved around—a lot. When he was seven, his mother became quadriplegic, the result of an automobile accident that occurred in front of his house. “My sister was also quite injured in that accident,” he shares. Following that tragedy, Alessi, his four siblings, and his parents lived a nomadic life, shifting from state to state all over the country, as his father, an Italian immigrant, struggled to manage financially. As he was about to become a teenager, Alessi stopped moving with them and went to live on his own in Buffalo. He learned to function alone, at a cost. “I could make things happen, but I couldn’t let people get close to me. I lost my ability to feel, and communicate, and establish close intimate relationships.” He is quiet for a time, looking away. “Yeah.” The weight of his averted gaze feels heavy.

Two things kept Alessi going: street dancing and running. He describes those early days in the inner-city streets of Buffalo with James Brown the backdrop to the freestyle social dancing. “We made circles,” he gestures, “and people went in the center and danced, and then you came out and someone else went in, you know?” Street dancing gave Alessi “a little bit of self-esteem, and, also, recognition by my peers.” Because he was recognized as one of the best dancers in his community, he found connection to others. In addition, he was a runner in high school, with heroes like Steve Prefontaine. Receiving recognition (“I was in

the newspapers!”) for running—which eventually brought him to the University of Oregon—was the second step on Alessi’s path to connection. He was not, however, content to sit in this recognition by himself. He wanted to feel value and purpose, and after moving to Eugene, Oregon, he found it again, in dance; specifically, teaching and choreographing dance for any body.

In addition to his teaching, Alessi is a dance artist whose choreography is distinguished by collaboration, diversity, and physicality. Shannon Mockli, associate professor of dance at the University of Oregon, has worked artistically with Alessi since 2009. She shares that Alessi, “really operates as freelancer” in the UO and Eugene arts community, using venues such as the public library, music groups, the Lane Arts Council, and different types of organizations, seeking interdisciplinary connections. All of Alessi’s choreographies, according to Mockli, are collaborative. “Because he uses improvisation so heavily, all the dancers are contributors to the work, on the deepest level, from the first movement that happens . . . He usually enters with a vision, whether it’s an image, a tone, or a quality, a vision quite specific, but within that the dancers are always making choices about how that is expressed.” She admits, though, that Alessi has high expectations. “He’s very specific and very opinionated, and, you know, sometimes that’s challenging, for sure. And he doesn’t hold back, no matter who the person is, their ability, he works to challenge everybody in the room . . . When [Alessi] invests in a project, he invests all of his being all the time, always comes to rehearsal prepared, always comes with new ideas.” She goes on, “I won’t say that there aren’t times when that doesn’t come with frustrations . . . he doesn’t necessarily filter his critique, he spews it out and that’s not necessarily easy to hear. That’s kind of what you want to be ready for when you work with Alito. He’s like spice, he’s like cayenne pepper.”

When I jokingly share this descriptor, Alessi says, smiling, “I’m much nicer than I used to be, you know.” He’s aware he’s rubbed some people the wrong way, noting, “The difficulty is that people don’t understand *why*. You know, my history, it’s a little bit to do with the *why* . . . some of the demanding is good, and some not, not all of it . . . I still work on those things.”

Some of that temperament emerges because Alessi is always determined to make highly-acclaimed choreographic work. “People think you can’t make great work with disabled people, that it’s just therapy.” He made a plan to widen his audience through innovative work, such as working with the full orchestra of the Eugene Symphony, and a project with Frances Bronet of the Pratt Institute in New York City, to promote this ambition. Alessi often finds venues through demonstrations, street performance parades, or community events. I can sense the pride he takes in the versatility of his collaborations.

Alessi's process is varied, depending upon the project, depending upon the people and their varied abilities. For example, in the "Bach in Motion" festival, against the intensity of the music, Alessi used crutches in an exercise to find the expression of suffering he was looking for, exploring the symbolism directly with his dancers. He often choreographs in silence, "with no music whatsoever, and the music arises out of the bodies of the people I'm working with . . . The most important thing is identifying what the expression of a person's body is, what wants to come out, and then trying to find a way to liberate that body into its expression in ways that are possible rather than in ways that are not possible."

The work, though, is more than defying the physical limitations; it's about showing people something they haven't seen before, something they didn't think was possible.

Alessi explains that selecting dancers involves auditions, "One of the most important things to me is not so much how great they move, but the quality of their presence. Can you not move at all, but you *shine* on stage? You know, it's possible," he smiles. "A lot of times choreography creates itself," Alessi grins, ". . . we do some crazy things in the dance disabilities world."

The work, though, is more than defying the physical limitations; it's about showing people something they haven't seen before, something they didn't think was possible. "Every person can make every movement, and any one part of the body can both experience and express every emotion." I'm still processing that statement when Alessi takes it further, "Every body can interpret every movement in their own way, and every person can do every movement in a way that's relative to them." This is clearly not the first time he has said it, but, for me, I'm still wrapping my head around how he takes the profound nature of these ideas and makes them a reality.

I want to know what dance gives him that nothing else does. Alessi shares that he's learned "how to arrive in the present

moment, to value relationships, to value every relationship . . . how to experience pure pride—which is something I didn't have access to in my life—at other times in my life. I didn't know how to be proud of myself." He pauses, looks at me. "Now, sometimes, it just happens to me . . . sometimes that feeling wells up in me when I'm watching some beautiful dance happening or watching some group of people transform themselves. Yeah." *One dancer's legs raise the other dancer in the air; her feet lifting the pelvis of the fully-extended flyer; who wears no prosthetics.*

Ultimately, Alessi would like to see his method of advocacy and teaching continue to expand as a living formula. "There's a method that works, that if you follow the directions it will work for you, but you don't have to stop where I stopped. Hopefully it will go further than me. It's got to, because I could only take it where I did. Now, people can get to where I am in five years. It took me thirty years to get here." He feels the most valuable way he's contributed is through developing tools, practical tools that he's been able to share, watch, critique, and develop further.

Like owning any company, the business of running a dance company involves administrative aspects, trainings, and finances. Clearly, COVID-19 affected the in-person classes for DanceAbility, the international trainings, and the Joint Force's touring has been put on hold. Alessi spends each day at the office working with his Board to tighten the infrastructure of his organization to the standard he wants as an international enterprise. He does trainings online—four two-and-a-half-hour Zooms a week—and works on the book he's writing about the DanceAbility Method.

Alessi's goal of furthering the mission is clear, but I'm wondering about the bottom line. In order to be sustainable, it takes resources, and those resources come from the advocacy of people who deeply understand and value that mission. This topic hits a nerve with him. With exasperation he says, "I think not enough people know the value of this work." He throws his hands up as his voice rises. "We're doing really important work in the world. But we struggle to survive." Nevertheless, it is clear Alessi is determined to perpetuate the vision that all bodies speak, all bodies can dance, and all bodies have something to offer.

There's a fearlessness to Alessi's approach that I find fascinating. How did this man, who is an interesting blend of street-smart savvy and sensitive, reach a point where he had the ability to connect in any situation he encounters, to find total acceptance for others without hesitation, *ever*. Is the man a saint who smiles benevolently down upon all creatures? On the contrary, Alessi blisters at the thought that this work is all warm and fuzzy. "It's not only happy, disabled people, you know. There's a lot of grief, there's a lot of suf-



“Wizard of Odds” dancers: Alito Alessi, Emery Blackwell, Jerry Maxwell, and Laura Hiszczynsky. Photo credit: Brian Lanker

fering, there’s a lot of people who become disabled, a lot of people who have eating disorders, or were sexually abused. I think my personal experience really trained me and gave me quite an ability to sit *in the presence* of severe trauma or severe disability or severe grieving because I also had a lot of loss in my life. I stuck with it because I got something out of it. I wasn’t doing things for other people; I stuck with it because it gave *me* something.” His dark gaze direct, I recognize that he stopped flinching at obstacles a long time ago.

Alessi resists the idea of being dubbed a hero. “Let’s not be too woo-woo about it,” he says, “making a living motivates me also. Making money by doing something of value and purpose. It’s not about how lovey and beautiful it always is, because it’s not always that, it’s hard work, to face reality and figure out how to keep moving.” Some people are jealous of his success, he admits, others think he’s taking advantage of people with disabilities. “You know,” he says, shrugging, “people think everything.” He gets frustrated, too, by “able-bodied people’s paralyzed minds.” In Alessi’s view, prejudice is something learned that can be unlearned. “I think through my work I have unlearned many of those

things. I learned to love any body. You know, as a man you’re taught to love a particular kind of body, or to touch a certain kind of body, but I can say I’ve loved, *sincerely*,” he laughs, “an extreme physicality.” There is true amusement in that laugh.

When I asked how he’d like people to think of him, Alessi becomes serious. “I would like people to see me as a person who is really in pursuit of eliminating some of my own suffering that causes me to not be nice sometimes.” He shrugs. “I guess I would like people to see me as a person who really devoted my work to something I could give to someone else. Something they could use to help someone else and that they could then pass on.” I’m thinking of another moment when Alessi suggested his living body of work continues to grow with each new person’s input. “You know, if you learned how to make soup, but you have a particular taste, you add your own spices.” Though I’m thinking, in this case, every body needs a little cayenne pepper. ♦

TONI ORTNER

WEATHER OF THE HEART

You cannot chart the weather of the heart.
You cannot burn memories like leaves.
You cannot wipe away the stain of grief.

KIRSTEN DEANE

MY BONES AND WINTER

Summer's almost over
and I never loved the sun but winter's
coming and my bones
will ache and my arm will stiffen
and my mother will ask if she can massage my muscles
and I will say no, I'll do it
myself. I won't,
it will hurt
so I pick the first hurt over the second.
I will cry because sleeping will hurt and waking up will hurt too.
I will cry because I'm crying and my bones are hurting
and I will fall asleep
and say *Hello* to winter tomorrow.

MY FRIEND

SHANNON CASSIDY

Pain is my friend. Not the kind of friend who invites you for a hike after you've lost your job. Not the kind who offers to shuttle your kid to school when you're sick. She's the lab partner you have when you're struggling in chemistry class. The kind you have to work with or else you fail. The kind where you do all the work, but you are nice to anyway, because it's just plain easier.

I can identify her, describe her, point to her. When I share this with my doctors, sometimes they can make her go away. Treat her, excise her, tame her. Even when they can't, she's still mine to tend. I tell her to hang on already, I'll give her some attention. Then I guide her to the oversized oak chest, heavy and warped from age. I fold her inside and tell her to keep still and quiet. I secure the latch and leave her there. She's not gone. In fact, she reminds me frequently that she's still there. But she's in her place.

On good days, I visit her in her chest, in appeasement. I know, you're still there. That's very good. Pat her on the back. And resume my day. On bad days, she screams and beats against the inside of her box for hours on end, the thumping and shrieking scraping raw the insides of my ears.

This friend, she's hard to shake, a clinging mass of need. A wounded creature, cowering by my protective limbs. I'll speak softly to reassure her, though I know my voice can't reach her core. My patience wears ragged, but erupting at her has a similar non-effect, so I swallow my reproach.

The other issues aren't so simple. The dizziness, tilting of the world on its axis, with no mind to gravity, the laws of physics. The nausea that sweeps over me in pulses of misery. I try to explain these things to the ER doctor, my specialists, the nurse. They frown and look at me for a second too long. And then look away. These beasts are perhaps the opposite of my friend: elusive, changeable, a glissade away and back again.

Occasionally I'll ask the teacher if I can change lab partners. Maybe I've had a flash of a different future, a photo in the negative. I'm told no, assignments are set. I stop asking.

Once in a while, my friend will fall asleep in her box. Or she will find some other distraction. But she likes to return under the cover of darkness. I sense her presence even before I wake. It's a Tuesday in late spring, a Saturday in early winter, a Thursday in mid-summer. There's no telltale change in barometric pressure, no prognostic of dampness or storms to come. She simply returns. And the next time I turn over in my sleep, without waking to any discernable level of consciousness, I know she's there. Enveloped in my warmth, sharing my room, my bed, my body, my air. ♦

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STERILE ROOMS: A MEMOIR

CHEYENNE M. HEINEN

“I love you,” I said on August 31, 2017. I said those words before I could make out who was in front of me. “I love you too, sweetie,” said a kind, unfamiliar voice. She laughed as she said it, but what I said wasn’t funny. I really loved her. I was certain she was my mom. The unfamiliar voice wore navy blue scrubs and she had an old face. Her hair looked like she stuck a fork in a power outlet, reading glasses hung on her nose, and she smiled nicely at me. A cold thumb grazed over the surface of my hand where a long needle slid into a protruded vein. There was something maternally comforting about her touch and presence, even though I could barely see the details of her face.

“Can I hug you?” I asked the lady in blue scrubs. She excitedly yet so gently, hugged me without wrapping her arms around my neck. Her perfume confirmed that this wasn’t my mom, but her kindness was allusive. I laid at an angle on a stiff twin-sized bed and the room looked white and foggy. I could make out other people sitting upright in their beds, too. I had just laid down for a medically-induced nap after an argument with a technician about my tattoo of serotonin. It had occurred to me, long after the age of eighteen, that my serotonin tattoo could be controversial in this way. I realized that people may think I liked tripping out on drugs so much that I had it tattooed on me when it was a symbol of happiness. I realized that people like this technician would argue with me over it, but I still wonder why he chose a time when I was actually tripping out on drugs to argue about it.

“You have to have some professional approach to serotonin,” he said while I was getting tired under big lights. His assertion compelled anger out of me, but my body was too weak to have a full argument with the guy.

“Well, I’m not a drug addict,” I snapped at the technician while he hooked prongs into my head and different parts of my body. Before asking me about my tattoos, he’d told me he was there to monitor my brain activity while I was under anesthesia and he’d monitor my neurological responses through prongs stuck into parts of my body.

“I didn’t say you were a drug addict,” he said with an uncomfortable laugh. The room went black after that and I never saw that guy again.

* * *

“Patient is a twenty-year-old female with Chiari I malformation,” I overheard a voice say from behind a curtain. I’m not sure if it was the first curtain or the second curtain, but I usually heard that rehearsal of words from behind a curtain. “Patient had a decompression this morning with Dr. Feldstein,” the first curtain.

I was too sedated to comprehend if the voice was speaking to me or to someone else. My limbs were too heavy to move, and my mouth was so dry that I didn’t make an effort to ask who was there. Dr. Feldstein was my neurosurgeon,

but I was unsure of where he'd put me. After a few moments of going in and out of coherence, a figure slid back the curtain surrounding wherever I was.

Through the fog that still hung in the room, a younger lady in seafoam green scrubs and a mouth full of braces exchanged words in hushed tones with the nurse who I'd thought was my mom. The lady with braces said hello to me and asked me how I was doing, but I didn't say hello back and I didn't tell her how I was doing. My body was too heavy to respond to questions.

I met this woman before my argument with the technician; she had put me to sleep and I liked her for her braces. I usually never trusted young doctors; I thought they didn't know enough despite how long they'd gone to school. I especially didn't trust the doctors who I sought to put a scalpel to my head. This one was young and friendly, but knowing she was an anesthesiologist was freaky to me. If she wanted to, she could turn a dial just a tad too far and kill me. But this one was nice, didn't seem murderous, and she had braces. For some reason, I have a lot of respect for older women who decide to get braces.

Two people appeared in front of me through the fog. They *could've* been my parents, but I already thought the nurse was my mom and she wasn't. I wouldn't let my eyes fool me. The woman in front of me had a stream of tears coming down her face and the man next to her was expressionless and seemingly ignorant of the circumstances.

"I love you," I said to these people, who I was *almost* sure were my parents, and the lady cried even harder and reciprocated my emotions with, "I love you so much!" Her booming emotions made me laugh hard, and it hurt. It hurt so bad that I stopped laughing and went back to silently loving The Strangers in this unfamiliar room. I told The Strangers that I loved them again as my body felt heavy, and I went silent with sleep.

* * *

When I opened my eyes, I was more aware, and I could tell I had been moved to a room by myself and The Strangers were gone. In front of me was a glass window with two nurses sitting behind computer monitors, typing and talking and occasionally smiling at each other. The nurses were

young women, maybe a few years older than me, skinny, with clean hair and friendly attitudes. One nurse had darker skin, I'd say she was Latina, and the other nurse was thin and white with a long, blond ponytail and white headband. They both wore sparkly wedding bands and talked about their kids.

"I'm sorry, honey, but this is probably going to burn," the brown nurse told me. "I'm going to count back from three, okay? Three . . . Two . . ." She didn't even get to one and an intense burning sensation that I've never felt before ripped through my lady parts. I was angry that she told me she'd pull at one but pulled at two. The catheter removal felt like having a half-lit match pulled out of me. A scream that came from my gut made the nurse frown and I slapped my hand against the stiff mattress and tried to catch my breath. The fire in my lady parts lingered for days, especially when I peed. I'd ask the nurse to turn around and face the door when she followed me into the restroom. That way I could preserve some dignity and she wouldn't see my scrunched-up face as I urinated what felt like a stream of fire behind her back.

Her apology was as genuine as her career. As the catheter snapped out of me, it made the snapping noise you'd hear when you stretch a balloon before filling it.

"It's fine," I lied through the pain.

When the same nurse took off the blood-soaked gauze that covered the small incision on my neck, I was surprised to find out that my surgeons decided not to use staples when they sewed my neck back together. I'd already imagined trying to sleep with this big incision on the back of my head, but I would have to sleep on staples, too? I thought that would've been torturous and something I've seen in a horror film. I was pleased that the spidery stitches would dissolve over time and fall out, and there would be no sleeping on a row of staples.

The brown nurse presented me with a small medicine cup with several pills in it. I didn't know what they were for, but I had a *raging* headache and a stiff neck; I'm sure something in the cup would numb the pain but I was afraid to ask. She rattled off some words that sounded like they could be medications, but what did I know? The only word that I remember standing out to me was *Colase*. Every other word

was foreign to me. A lot of what was happening was foreign to me. I'm not a nurse nor was I familiar with anything in the medical field. But I was firm with my surgeon that I did *not* want any controlled substances, so I told him not to try.

"This is where it starts," I said to my surgeon as if substance addiction had been a foreign concept to him in his thirty years of being a neurosurgeon. "You have this major accident or surgery and then you get hooked on pain meds. I don't want them." Maybe my adamance was annoying, maybe it was slightly respectable, but I was far too scared to take hard drugs.

I stared at my feet and begged my brain to wiggle my toes for me as if I'd been trying to cast a spell on them.

"But, Cheyenne, you're not a drug addict. It's only 5 milligrams of oxycodone and trust me, you're going to want to take it." And he was right. I wasn't a drug addict and I definitely needed something to ease the pain because Tylenol wasn't helping. I felt like someone had taken a baseball bat to my head a few times. The back of my neck started to swell, and I felt a heartbeat behind my eyes. Turning to look at someone was not an option (and it wouldn't be an option for weeks), just small shifts in my bed and straining my eyeballs to look through my peripheral vision.

My surgeon and a young Indian lady in a white coat came to talk to me bright and early, I'd say around seven the next morning. The Indian lady introduced herself as a resident physician. I'd been asleep and woke up to both of them hovering over me like new parents hovering over their baby in a crib. I remember I'd snapped out of sleep quickly and pretended like I'd been alert and waiting for them to come. He said they would move me down to The Floor, wherever that was. I liked the ICU, though. The nurses were nice, and they told me they would try to get me to stay there for as long as they could because I was "the youngest and nicest patient they had." They said how much they enjoyed having young people in the ICU, because the patients are usually old and senile, losing their shit. I guess I was a nice neutralizer.

I made it to The Floor and hated it. My roommate spent the whole night crying, loudly. She boo-hooed for hours, but my surgeon gave me a pill that made my eyes heavy and I drifted into a deep, undisturbed sleep. After a while, her boo-hoos faded away and she slept all day with her television on a low volume (I was thankful for that). One of the nurses told me, in passing, that she was crying because she had a rare disease that needed some special surgery and no surgeon would take her Medicaid. I bet that nurse legally shouldn't have told me that, but the nurses and I were in cahoots.

* * *

I woke up on November 26, 2018, in a room like the one I woke up in on August 31, 2017. This room was dim, though. I think it was late in the evening. This time, I knew who was in front of me. My mom sat closest to me and my dad sat next to her; my mom crying for the same reason she'd cried last year, and my dad expressionless and selectively ignorant as usual. I didn't wake up saying "I love you" to any strangers and I didn't laugh this time. I remembered this feeling too well and was angry that it happened again. As soon as I woke up in the Dim Room, I wondered why I couldn't feel my tongue and half of my face. It felt like someone punched me in the mouth. It was so dry that it was hard to swallow and any muscular movement of my mouth or tongue gave me a wincing pain. There was also something that felt like a chewed piece of gum in my throat; it made me gag.

"Did someone drop something on my face? And there's something stuck in my throat," I asked a nurse who I couldn't really see.

"No, it's probably from sleeping face down on the tubes," she said. I opened my mouth for her to look at what was in my throat. She said it was a lymph node that had gotten caught during intubation. After that, she ran her fingers across my shoulders and down my arms and asked, "Can you feel that?"

I couldn't feel it. I saw she was touching me, but I couldn't feel her fingers running over my arms. She asked me to wiggle my toes and I just couldn't do it. I stared at my feet and begged my brain to wiggle my toes for me as if I'd been trying to cast a spell on them. But the magic in my toes didn't happen that night. I knew this neuro exam well, at this point. I remember thinking about how my second surgeon prepared me for this. "You could become paralyzed," he said to me after being two hours late to my appointment. "You could get hydrocephalus and that could be life threatening," he added. All I could say was "Okay," since I didn't know what else to say. So, I thought I was

paralyzed and that's why I couldn't feel her touch. I had mentally prepared for paralysis, especially after my new surgeon included the word *death* in his rehearsed list of risks prior to my now second operation.

This time I didn't care how hard the drugs were, since I already knew the intensity of this familiar pain.

"Look in this mirror," the nurse held a mirror to my face, and I opened my mouth to look at what hurt so bad. A nickel-sized black and blue bruise on my tongue was what made everything in my mouth sting. "You have a bruise on your tongue, probably from the tubes or your teeth."

"Are you sure no one punched me in the face while I was sleeping?" I asked her again, knowing those doctors and nurses wouldn't have punched me while I was out cold.

"No," she laughed, "No one punched you."

On the first night, a nurse around my age took care of me and looked like an old friend of mine. She had brown hair that was held high in a ponytail, a headband pressed to her hairline, glasses, a nice small smile and an engagement ring on her left hand. I remember she referred to her man as her fiancé. She often said *my fiancé this* and *my fiancé that*. I looked down at my phone that told me it was late evening. The Big Room I was now in was darker than the Dim Room and I heard subtle beeps of other peoples' monitors; I shared a room with three people who also had neurological ailments.

I'd started to feel that familiar pounding in my head, much worse this time and the laugh I shared with the nurse intensified the pain.

"Your medication is probably wearing off, I'll give you something," the nurse said. This time I didn't care how hard the drugs were, since I already knew the intensity of this familiar pain.

I had drifted in and out of sleep for a while when I jerked myself awake to a man shouting. He had been yelling incoherent sentences and I heard a woman yell, "Stop hitting me, Nathan!" and "Your savior is coming!" whatever that meant. The man next to me tried to escape a few times throughout the night. He ripped out his IV and started walk-

ing toward the door until the nurses stopped him. I never saw exactly what he looked like, but I imagined this tall, slim man with gray bedhead. In my imagination, he looked like my grandpa, mostly because he sounded like him, too. This man yelled all night and the nurse who had been taking care of me told me he had a traumatic brain injury and dementia. What a fucking mix.

"Do you know what year it is, Nathan?" his doctor, I presumed, asked him.

"1974," Nathan answered.

"Do you know where you are right now?"

"Oneonta."

It was 2018 and we were in Albany. I heard that same conversation three times a day for four days straight. I heard this conversation over and over again, since the only thing dividing us was a curtain. Nathan gave the doctors and nurses the same answers before they decided to fly him somewhere else. Nathan's screaming kept me up for three nights and by the fourth day of little sleep, *I* was screaming at my surgeon and his antisocial resident physicians to get me out of there. My surgeon's residents stood before me with notebooks and only a few of them smiled and gave me a half-wave when I made eye contact with them. The rest of them just stared while I wailed angry, exhausted words at my surgeon. I wasn't angry with him or his residents, but I was exhausted and pissed off that Nathan wouldn't stop yelling once the sun went down. Plus, I had become sick with some sort of cough that amplified my headache, my appetite disappeared, and I could feel the bags under my eyes from the few hours of sleep during the past four days.

My surgeon made more room in my skull for my scientifically proven massive brain, so for four days, the excess flow of spinal fluid drained into a bag. I wasn't allowed to move unless someone closed my drain and lifted me up out of bed. I felt like an overgrown baby when I asked an adult to lift me, a twenty-one-year-old woman at the time, out of bed to use the bathroom or take a walk. But I remember thinking, every time I looked at the spinal fluid in the bag when I wanted to get up, the mix of clear fluid and blood looked like pink wine.

My stomach was nauseous with a rage hunger that couldn't be satisfied with food. The one time I did try to eat, I took my first bite and almost simultaneously, the man across from me started violently vomiting. He had a seizure; vomiting accompanies those. The same way it accompanies loss of appetite. I felt bad for the man as his body convulsed with gagging and dry heaves. He screamed, "Get me the

fuck out of here, please! I want to go home,” and a nurse sat at his side while he hurled his vomit into a blue bag. I’ve never seen a man as weak and sick as this man was. He would wail his violent words at the innocent nurses who were just trying to help and soothe him. He would cry for help, shiver with pain and sickness, and fall asleep. I had no choice but to see and hear this from my bed; if I closed the curtain, I could still hear his wails of pain. Resigned to my hunger, I watched the man cry and vomit. If I was going to hear it, I may as well see it. I watched this man’s rage from my bed. I watched his rage turn into defeat as sickness dictated his body’s response and made it weak. I watched a grown man succumb to his own body.

I stroked my right thumb over the top of an old, soft hand that squeezed mine and said, “I want my mom.”

I needed to go to the bathroom, but a nurse had to come with me. On the first night, I asked the nice nurse who was my age and looked like my friend to help me go to the bathroom after she pulled the catheter out. Like the first time, the familiar feeling of a half-lit match ripped through my lady parts, but this time around, I was ready. I already knew the feeling, so it didn’t hurt as bad. And this nurse actually counted back to one. She walked with me across the room, pushing a long pole with wheels that held my IV fluids and a bag where my cerebrospinal fluid drained. The first few steps were strange, with unfamiliar pangs of pain. My feet didn’t feel like my own. The feeling returned to my toes which made them more sensitive to the cold floor radiating through my socks.

I felt like I was walking around with a film over my skin, since I hadn’t showered for two whole days. I did my business while the nurse talked about an ugly sweater party she was going to with her fiancé. We were talking about where she could find an ugly sweater. I stood up, let her wipe me like the overgrown baby that I was, and told her to check Amazon. I told her my friend bought an ugly sweater from Amazon and I bet she could find something good *one* there, too. I remember looking into the mirror, just about to turn on the faucet to wash my hands, the nurse also facing the mirror, still talking about ugly sweaters. I said “Why is my face so yellow?” and she said, “What?”

The room went black and I felt light. My head fell back first, and the rest of my body followed. I remember not feeling any pain as my fragile head abruptly fell back, just lightness. I don’t remember anything after the blackness came over me, but I was certain I was dying. My eyes were open, but all I could see was black nothing; a loud buzz in my ears hindered my hearing. I vaguely heard a woman shouting through the buzz in my ears, “I need some help in here!”

I counted three voices. All of them female. One I assumed was the nurse who looked like my friend who was just talking to me about ugly sweaters. The two others, I can’t tell you who they were, but I remember the buzzing in my ears amplified and I heard a woman shouting my name. She sounded old. I think it was her hand that squeezed mine.

“Cheyenne, please wake up. Can you hear me?” A voice said.

Hydrocephalus, hemorrhaging, some other medical terminology that I can’t regurgitate from my memory . . . Dr. German’s rehearsed list of risks replayed in my pounding head and limp body . . . *and death.* When I made the decision to have this surgery again, I came to terms with dying. He said the words, and I accepted them. I even processed the words with my therapist, Irma. I’m sure he had to say that word for insurance and legal reasons, but it was a real possibility at that point. I decided I could either live a shitty quality of life for the rest of my existence, or I could try this again and hopefully live a better life, but potentially die in the process. I’d accepted that. I’d accepted that I could be dying on a bathroom floor at Albany Medical Center.

“Cheyenne, can you hear me, sweetie? . . . I think she has low blood sugar . . . When was the last time she ate? . . . Um, I don’t know. . .”

Two people talked through the lingering blackness and buzzing. I thought my eyes were open, but I couldn’t see anything but blackness while my limbs pulsed. The painful pulse in my limbs told me that I wasn’t dead. I was very much alive. I stroked my right thumb over the top of an old, soft hand that squeezed mine and said, “I want my mom.”

I remember feeling small and childlike and helpless when I said that, but I really wanted my mom, who was absent. I know she slept silently in her bed while I groaned in pain and blindness on the bathroom floor.

In a room with three people, I’d never felt so alone. The three women sighed with sadness when I said that. “Oh, honey,” the old lady voice said through the buzzing that was

diminishing in my ears. My right thumb still rubbed the top of her cold, soft, wrinkly hand. "You're not my mom," I said to the lady as the blackness dispersed and the buzzing started to escape my ears and my heart pounded hard in my chest.

I could make out the nurse that took me to the bathroom, she sat in front of me and another nurse sat beside me cradling my fragile head to her chest like a mother would a baby. My body in a tangled position on the floor. I awoke feeling immediately violated since I had no underwear or bra on and nearly all my body parts were exposed to these three strangers. I shoved my gown down between my legs to hide my exposed body parts from the nurses who have probably seen more naked people than I can count.

I remember laying on the cold floor with my head against the old nurse's chest and I started crying a painful cry. I started crying in embarrassment. I started crying because I felt alone on the floor of a hospital bathroom with three strangers, crying for my mom who wasn't there. I started crying because I had to do this again. I started crying because I felt too young for this. I started crying because I was angry. I started crying because my doctors get to go home, and I don't. I started crying because these nurses had no clue what kind of pain I was in, they just felt sorry for me. I started crying for help years before all of this, but I wiped my own tears and tried to forget it. Years of pain, just to end up on a cold hospital floor. ♦

Call for submissions

KALEIDOSCOPE

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

• Double-spaced, typewritten

• 5,000 word maximum

• Electronic submissions preferred

Email submissions to kaleidoscope@udsakron.org or online at kaleidoscopeonline.org.

INTO THE FOREST

MARIANA ABEID-McDOUGALL

The beginning of the trail is as inviting as any walk into the woods: uneven ground, oddly-shaped rocks, and trees in every direction. It starts off level, but the trail quickly changes to a steady and steep incline, with trees growing at an angle to adapt to their environment—just like I’ve always had to adapt to mine. If these trees were planted on even ground, they would look out of place, weird, growing in ways they shouldn’t. Just like others thought I looked when I was a child. But here, on these extremely steep slopes, these trees function just fine, and look like they belong.

Walking alone in the woods, with my cowboy hat on my head and my wooden walking stick in my hand, I have room for nothing else in my mind other than the beauty of my surroundings. There is too much wonder around me to do much other than simply acknowledge that my heart is pounding and my breathing is fast, and I’ve neglected to put on my knee braces or bring my inhaler.

The pain in my knees is there, as always. But I keep climbing. The forest calls me, and the challenge of the mountain dares me to keep going. I’m alone on the trail, but I don’t feel alone. Here in this beautiful place, I’m as much a part of the woods as the deer

that bounds off the minute it hears my footsteps.

Hiking has long been a passion, but it gets more difficult as joints more frequently slip out of place, as more cartilage disintegrates, as pain increases, as darkness approaches when I’m not mindful of how fast I change positions. I have more aches and pains than most thirty-somethings, but most people wouldn’t know it. What they see is someone climbing up mountains, walking into the woods, picking up children when they stumble, working hard so she can enjoy the outdoor spaces this beautiful continent has to offer.

Most people assume I’m healthy, because most of the time, I look it. The braces are hidden under clothing, the pain is pushed to the back of my mind as I deal with daily life. And most of the time, I don’t think of myself as a chronically ill person. I just think of my illnesses as nuisances to be pushed away when there are more important things to tend to: like the view from the top of a mountain.

And here, miles away from “home,” climbing in the beautiful woods of Bridges Trail at Garner State Park in Texas, I have an epiphany. Getting close to the top and seeing the amazing views with which the mountain rewards

me, I realize this very moment is a parallel and a metaphor for my life. The woods don’t care if you can walk in them or not, but they’re always there, waiting for you to enter, to discover, to enjoy. And when you do, the going is often hard, but the rewards are worth it. In the same way, life doesn’t care if you give in to the pain or if you just live. Life is just there, waiting to be lived. And when you ignore what others have to say about what you can or cannot do, and you just keep up the climb . . . you get wonderful returns for your efforts. The road is not without its challenges. In fact, it’s often an uphill climb over uneven ground (without a ramp).

As I question whether or not coming up here without my knee braces was a good idea, I can’t seem to give myself time to reconsider my options. The trees are too beautiful, the incline too inviting. I don’t know what the view from the top will be like, but the hill is pulling me, and its force is irresistible. And when I finally get to the top, the view takes my breath away. When it does, I stop and take in another breath. A deep breath, forgetting my worries for the time being, and letting the view wash clean my soul. Here, in this moment, nothing else matters. And even the pain can be forgotten, if even just for a moment. ♦

ALLISON WHITTENBERG

QUILT

Slaves recognize the metaphor
 Putting odds together with ends
 Knitting scraps into study shape

Manipulating fabric
 Irregular shapes:
 Functional, enduring

Making a way
 Out of no way

ALLISON WHITTENBERG

WATCHING JORDAN'S FALL

. . . God, I hate November
 All the hope I had hoped
 Against hope for Jordan.

Dad beat Jordan, to
 Straighten him out, to show
 Jordan, to silence him.

My brother lived until the next
 Season, onto the next winter,
 Very quiet like a fallen leaf.

SKINNED

KELETSO MOPAI

When Lehumo asked you to meet his father, you were startled but flattered: no man had ever introduced you to anyone. Perhaps it had something to do with your reclusive personality. Or maybe it had to do with your skin; most probably that. You're "too light," as people put it. You glow in the dark. You scare toddlers.

Your best friend, Lolo, said to you: "They're terrified of dating people like us. Samantha, it will never last."

"Lehumo is different," you told her.

You didn't like how she'd said "they," as if he was some extraterrestrial species and not a human being just like you. You remembered his genuineness when he said to you on your first date: "I don't mind. I don't know why anyone would mind dating an albino. My younger brother was born with albinism anyway." You watched his thick lips as he uttered those words. You gazed at his melanin-kissed face and your heart quivered.

Sometimes you thought, *no, Lolo's right; it won't work*. But the two of you had made it together so far, eight months without you sensing any trouble.

At the coffee shop, the same one where you and Lehumo first met, your round blue hat and flowery dress drew attention. Lehumo stood up and waved you over, a huge smile on his face.

His father was sitting at the table. They could almost be twins, if not for Lehumo's tall stature. When you reached out to shake the old man's hand, you noticed a familiar hostility in his eyes.

"Haven't you learned anything from what we go through every day with your brother?" he began before Lehumo could even introduce you. "Now you want to bring somebody like this into our family?"

Your knees weakened. When you opened your mouth, words did not come out. You looked at Lehumo. He appeared even more embarrassed than you were. You knew then that you did not want to be there.

The blackness in your bedroom is almost comforting. It is 8:00 p.m. on the dot. "Sam, open up!" Lolo's squeaky voice pierces the door. "Sam!"

As soon as you open the door, you wrap your arms around her and just weep. You would dig your heart out with a shovel if you could. If it means not feeling the heaviness of your bones. The dryness of your throat. The pain.

"Not out here, Sam," she says under her breath, wiping the tears off your face. She pulls you inside and closes the door. "What's with the darkness in this place?" she asks, struggling to locate the light switch.

“No, don’t. Please, I prefer it this way.”

The two of you lie in your bed in the dusk, staring at nothingness. Your luminous skin shimmers in the room. The air just silent. Lolo finally says into the stillness: “I am sorry.”

“I know.”

“So, what did Lehumo say to you?”

“He said he was sorry . . .” You breathe in as deeply as you can, then add, “He said he loves me and that he didn’t expect his father to react the way he did.”

“That’s a nice thing to—”

“I broke up with him.”

“Oh, Sam . . . I’m so sorry.”

“I love him. I love him so much it hurts, all over. I am so stupid!” You cry again, this time so hard you almost taste blood in your throat.

“No, don’t say that. You are not stupid. Please, don’t cry. I saw the way he treated you; he loves you just like you love him. I should have been more supportive, and for that, my friend, I apologize.” She adds, “The only love I know is my husband’s, and because I can’t see myself with anyone else, I judged you. So I won’t pull an ‘I told you so,’ because you proved me wrong. Lehumo’s father is what went wrong.”

“That doesn’t make me feel better,” you say, wiping the tears.

She holds your hand and says, “Sam, we’re allowed to fall in love with whoever we want. You did that. I commend you for it. It breaks me, seeing you in such pain.”

You imagine the sincerity on her face. It hurts you to hear her say that; for her to acknowledge you are indeed feeling pain. You don’t want to feel this weak.

“If I did the right thing in going for Lehumo, then tell me why I feel like the biggest loser on this entire planet?”

“Because you did lose. You’re still going to lose some more, whoever you love.”

You don’t say anything else to her. You don’t cry either.

Lolo’s hand is still in yours when you fall asleep. Later she will cover you with a blanket and tiptoe out of your apartment, and go home back to her husband and their daughter.

In the following days, you do not call Lehumo. You don’t want him to call you either. When he does, eventually, you ignore him. You lock yourself in your apartment and feel utter shame. It swallows you, makes you want to take a sharp blade and peel your skin off.

Eventually, you delete Lehumo’s contact number, even though you know it by heart. You convince yourself that his father was right. What were the two of you thinking, anyway? After several weeks, you become angry that his father makes you feel this small. That his rejection makes you feel subhuman, not worthy of his son, not worthy of love at all.

After several months, you start dating again. This time, you go for the ones you’re supposed to date. The ones you’re expected to love. So when you meet Kagiso on a dating site for people with albinism, you expect more. You anticipate blue skies and rainbows.

Like you, Kagiso is a primary-school teacher. While you’re having lunch at a restaurant, he says he’d like to settle down soon. He suggests that he isn’t looking for a date, but a wife.

“We’ve only just met,” you laugh.

“Someone like me isn’t willing to dip my feet in little streams, waiting to see which one will flow into the ocean.”

You take a bite of your salad. “Why not? Don’t you want someone good enough for you?”

“I’m twenty-nine. And you are . . . twenty-eight, correct?” You nod. “We’re getting old. I’m old. When we talked online, I felt, this is it. I believe I know a lot about you now. We’ve been talking for weeks, Sammy. Besides, people

like me and you don't have the luxury of saying there are 'plenty of fish in the sea,' because there aren't."

"I don't think like that."

"Then you should. You told me that your best friend is married. Don't you want that for yourself? A husband?"

"She married the love of her life. They grew up together, long before I even met her."

"So you want to take a chance and see where this goes . . ."

"I do, Kagiso. I deserve that luxury."

He does not agree. You can see it in the way he shakes his head and flaps his eyelashes. He wants to get married, and if he can't get that from you, he might as well get it from someone else.

"That's unfortunate. I really thought you were the girl for me."

"I could be," you say, a little desperately. "If you're willing to see if we're a good match . . ."

He shifts on his chair. "No," he says flatly. "I know what I want. Dating for the sake of dating isn't in the cards for me. You're very pretty, I'm sure you'll get any man you want."

You're disappointed, because you'd been hopeful. When you stumbled on his handsome profile picture and read his biography, and after talking to him online, you felt a slight connection. Both of you are educators. Both in your late twenties. And both of you know what it's like, living with albinism. You thought this could turn into something great, but not enough to put a ring on his finger and say "I do," right on the first date. Why must people like Kagiso live life as if it's a perfectly designed machine, where everyone does things at set and particular times or all hell breaks loose and everything shuts down? Doesn't he know that life, your plans, and the future could just collapse at any time? If he'd mentioned before meeting that he wanted to get married quick, like a warlord offering his daughter for a plot of land, then you wouldn't have bothered.

You miss Lehumu; he wasn't this cynical. The two of you knew marriage and babies would eventually come. You were willing to meet his entire family before deciding on the next step. And you thought you knew everything you needed to know about him: that in the morning he liked listening to the radio and catching up on the latest news. Which part of his belly vibrated when you laid your hands on it. That he liked bran flakes with low-fat milk. You knew

that when you spoke, he looked at you and paid attention, not so much because he enjoyed the things you said, but because of how your lips moved, and the way you curled the lower one.

"You talk sexy, you know that?" he'd said to you the first night you spent together at your place. You were lying on the bed, and he was gazing at you with his fists fixed below his chin. "I swear, you do it on purpose. Those lips . . . Angelina Jolie has nothing on you."

If he'd mentioned before meeting that he wanted to get married quick, like a warlord offering his daughter for a plot of land, then you wouldn't have bothered.

"Baby, did you hear anything I said?"

"Not really," he laughed, and you hit him with a pillow.

You find yourself in Benedict's bed again. This is the ninth time you've slept with him. This time, you just wanted to have sex, and he was the first person to come to your mind. The first time was after going through Lehumu's Instagram account and seeing a picture of him with another girl.

This girl's skin was so brown you'd swear she smelled of mahogany. You told yourself you'd look at the picture just once and forget it existed. But you became obsessed with it. You critiqued the smile on Lehumu's face; did he seem happier with her? Did she seem into him? You analyzed her long green dress. You'd never seen anyone wear green so well. But did she not know train dresses were no longer a thing?

You'd met Benedict at Lolo's thirtieth birthday party, three months ago. He'd whispered into your ear, "Sleeping with an albino is on my bucket list . . ."

Surprisingly, you weren't offended. Perhaps because you were hammered. Or because you've heard such things before. "Albinos make you richer," they say. Along with the more disturbing one: "An albino's body parts bring good luck." And so you whispered back, "Fucking a white man's always been on mine."

You grab your clothes scattered on his bedroom floor, preparing to leave. Benedict opens his eyes, lies across the bed and says, "I love you."

"What?"

He sits up, strokes his loose hair with his fingers, "I think I'm in love with you."

"Are you insane?"

"Is it so shocking?"

You don't want to be rude. "I have to go." You pull up your jeans. "I have a class to teach in the afternoon."

"Just like that? Why are you so cold-hearted?"

"Excuse me?"

"I tell you my feelings and you brush them off? I love you, Samantha. I want to be with you, instead of sleeping with you whenever you feel like it."

You don't mean to chuckle. "I'm sorry if you feel used. But you knew what this was from the beginning. This is a tick on our bucket lists. I don't even know why it went on for this long." Then you pause, and add, "Now that you've slept with an albino, what do we taste like?"

"You're more than that to me."

Grabbing your handbag from the floor, you say, "I'm sorry. This is the last time I'm seeing you. Take care, Ben."

He gets up. "Can I at least get a hug?"

You smile, going into his arms. You rub his back. "See you when I see you, white man."

You can feel him smiling into your hair.

"See you when I see you, Samantha."

Outside his front door, when you browse through your phone, there's a text from Lehumo: "May I see you, please?"

The thought of seeing Lehumo again after so long terrifies you; gives you nausea. It takes you more than two days to decide, and more than a week to reply.

"Hello, Lehumo. Where can we meet?"

He texts back minutes later. "Same place we first and last

saw each other."

You have so much to say to him.

You arrive at the coffee shop at 12:00 p.m. Lehumo stands up when you approach his table. The boy beside him looks

"Oh, Lehumo," you say, bursting into furious tears. "You had to wait this long? You had to make me hate myself first?"

almost like him. The teenager's pale eyes are warm and friendly. You put out your hand and he clasps it. "Are you Lehumo's girlfriend?"

Lehumo laughs. "He's forward like that. Samantha, this is my brother."

"Hi. It's nice to finally meet you!"

He giggles. You gaze at Lehumo. He whispers something into his brother's ear, and the boy excuses himself.

You sit opposite each other at the circular table. Now that you're alone, the air between you abruptly changes.

"You look great," Lehumo says seriously.

"You too." He does; he looks darker in his white shirt. "Why did you want to see me?"

"I miss you. I don't know about you, but it's been so hard to move on with my life without you." He looks down at his hands on the table. "You're the one. It's you or no one else."

You cover your face, attempting to hide the anguish straining your cheekbones. This is what you've yearned for months to hear him say. "You have a new girlfriend. I saw the pictures on your Instagram."

"We broke up three-and-half months ago."

"Why?"

"Why? Isn't it obvious? She wasn't you."

"Oh, Lehumo," you say, bursting into furious tears. "You had to wait this long? You had to make me hate myself first?"

"No, that's not—"

"I hate you. I hate your father."

"Sam, please . . ."

"I hate you!" You don't mean to shout, but the anger needs to escape your lungs. "Do you think I asked to be born this way? To be treated like garbage by someone I love?"

"Sam, I know—"

"Lehumo, everything's changed now. You can't just text me after seven months and tell me this."

"I was giving you space."

"Well, I'm pregnant!"

He falls back into his chair. *"What?"*

This makes you cry even more. "I'm four weeks pregnant, Lehumo. I found out a week ago."

"Who is the father?"

You wipe the tears. "It doesn't matter."

"Are you in love with him?"

You shake your head. He's quiet.

You look at him with your reddened eyes and say, "I know. You can't be with me anymore."

He rubs his head. You can't figure if the look in his eyes is hatred, or shame, or something else more dreadful.

And then Lehumo stands up and leaves you there. Like a death, with as little consolation.

You remain seated, not moving a finger, in shock. So this is how you really lose him. There was no finality in the way you ended things months ago. You broke up with him to hurt him. You broke up with him so that when you look at yourself in the mirror, you won't feel like the ugliest girl alive. What's worse—knowing you've lost him forever, or admitting it's all your fault this time?

But then, like the undead, Lehumo reemerges, sits down and says, "I can. I think I can. We can still be together."

"You, you don't mean that."

"We had broken up, Samantha. It could have happened to me. I could have impregnated someone else."

"But you didn't."

"Do you love me? Do you want to be with me?"

"Of course I do."

"Then love me. Be with me."

"You are being unrealistic."

"Being unrealistic was introducing you to the man who basically claimed my brother wasn't his child, just because he didn't come out as he'd expected. Loving you and choosing you is the most realistic thing I can do. So here I am, Samantha. I am willing to be with you and the baby, however she or he comes out—"

"I'm getting an abortion," you interrupt.

He hesitates. "Are you sure?"

You nod. You've been thinking about it, but now you know.

"Okay . . . okay, it's your decision. But please, Samantha, if you don't see a future with me, you should tell me; I would let you go." He pauses. "Like I told you, it's you, or no one else."

You stare back at him, not knowing what to think or say. One minute you're living your worst nightmare, the next you are shown a staircase with your dream placed on top of it.

And so, without wasting any more time, you grasp Lehumo's hands and say, "I'm in." ♦

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KATHRYN DALLEY

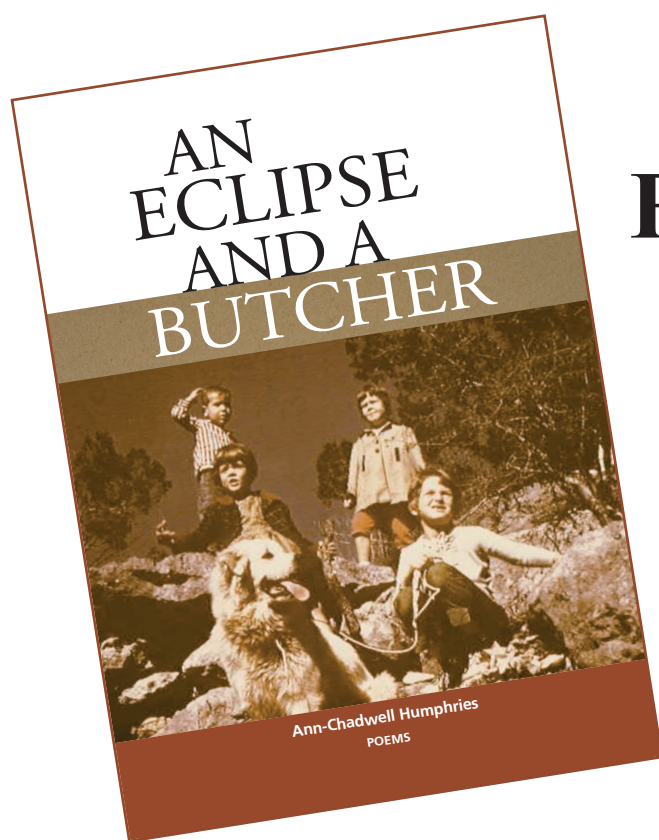
HOURLASS

Leave the shards of shattered dreams lying where they lay
For even the most calloused hand
When cut
Must surely bleed
Instead just let the sands of time
Blown by the winds of change
Erode them down to harmless dust
Which your deserts can reclaim

EMILY UDUWANA

NESTING

There are bird's nests in my hair.
I had hoped to attract hummingbirds,
but no fluttering wings arrived
to provide an adequate excuse
for the monstrosity growing in tandem
with the aching of my arms
and the trembling of my hands,
which don't appear to realize
I am only twenty-two
and should not require help
to brush the bird's nests from my hair.



FINDING THE LIGHT IN THE DARK

SANDRA J. LINDOW

Review of An Eclipse and a Butcher
by Ann-Chadwell Humphries, Muddy Ford Press, 2020

Consisting of thirty-eight poems, and an “Introduction” by Ed Madden, Poet Laureate of Columbia, South Carolina, Ann-Chadwell Humphries’ poetry collection is well-wrought and accessible to any educated reader. As an adult, Humphries lost her vision from a genetic disorder called retinitis pigmentosa. Her website, ann-chadwellhumphries.com, describes the process of her loss “I went from (seeing through) a hula hoop to a donut and then a straw.” Her poem “My Blind Obsession” delineates how she struggled with advancing disease and, at first, tried to ignore it, chase it from her yard:

but it would not leave.

So blindness and I shook hands, became friends.
(website)

Becoming friends with blindness seems a nearly impossible process, but although Humphries admits to drawing “blood” in her fight with the disease, she is convincing when she asserts that her life has become better because of her blindness (website). Her other senses have become stronger, and she claims to have “at least sixteen” of them including “sense of memory, sense of organization, sense of concentration, sense of movement, sense of orientation, [and] sense of humor” (website). Her sense of humor, in particular has been “an asset when forced to change” (41).

Her wry wit peeks from many of her poems, especially when she announces that “love is blind” (41). Scents of Listerine and linseed oil wander into her poems, exemplifying her sensory grounding in the physical world. She feels the vines and flowers gilded on the cover of a rare book as if she is actually seeing them. Her powerful sense of visual organization, part memory, part something else, allows her to “imagine how people look” when she talks with them (41). All these talented senses become apparent to her readers and listening audiences, especially when she recites her poetry from memory.

Humphries is an organized person. Her career began as an intensive care nursery RN and later a hospital facility planner in Clemson, South Carolina. She prepared for becoming blind by taking classes in mobility, adaption to blindness, and assistive technology, becoming adept in the use of Apple Voice-Over and making extensive use of it after her retirement when she began writing poetry. Prior to her blindness, she had been visually proficient at organizing spaces. Now, although she is totally blind except for awareness of light, it makes sense that her poems about her childhood consist of a series of “flashbulb” or photographic moments that have personal, emotional significance, and relationship to her blindness. She remembers watching “the moon slide across the sun” in the gravel parking lot of a grocery store,

(32) and swimming under a floating dock, the sun slanting “its white curtain through green water” (13). In 2017, she goes to a local park to watch another eclipse, not expecting the “metallic light” and “shadows crisp as pencil lines” (7). It is light rather than darkness that dominates these poems; the organization of her adult experience of blindness is suffused and enfolded by the experience of light. “The Virtual Tour” begins:

She counts-off nineteen steps to the porch,
crosses the threshold to plunge into a pool of April sun
planning through the picture window. She feels
its warm gold on her thighs. (18)

“Nine Days” is a series of haiku, poetic emotional snapshots of her life from wedding to funeral planning, including this one, essential to her continuing life as a writer:

I mark my keyboard
with dots, place my fingers there
and begin to type. (26)

“Fine with Blind, A Self Portrait” exemplifies her coping skills, how she looks forward, “not back” as she adapts to change: eating, walking, hiking (41). It is apparent that she is more than a little proud of her successful adaptation:

“Folks can’t tell I am blind / During conversation, I turn to look.” (41)

She concludes:

Blindness provides insight. My sense of touch
becomes my sight, and now, I welcome change.
With hearing and healing, I thrive as blind. (42)

Thus, her determination to “thrive as blind” draws her to describe how “An Artist Renders the 1918 Eclipse” (51). Howard Russell Butler, a physicist and oil painter, blind-folded himself before looking directly as the moon eclipsed the sun, and then after two minutes, “retreated to his impromptu studio onsite” to paint (51). The resulting painting, which is now in the public domain is included below and seems to metaphorically depict both the progressive loss of Humphries’s sight and the blooming elation of what she has found in the corona of talent that replaces it. ♦



Howard Russell Butler (1856-1934), *Solar Eclipse*, 1918, oil on canvas, left panel of triptych

THE LAST THREADS OF DENIAL

CATHERINE SHIELDS

“**Y**our daughter Jessica is *profoundly retarded.*”

The words yank like an invisible chain, back to that moment in 1988 when the doctor made his diagnosis using words that are now considered culturally insensitive. Those six words launched a journey I struggled to navigate for twenty-four years. Today I face what awaited at the end of that passage.

I enter Jessica's room, a room she no longer occupies. Everything appears the same as yesterday—the same, but different. An assortment of posters hang on the wall above her bed, most of them images of the band Backstreet Boys. In one photo, the five boys lean forward, arms linked. They smile, and for a second, I imagine they can hear me. I whisper the words like a well-kept secret.

“We moved Jessica to a group home today.”

I turn my attention to the posters Jessica told me to bring. My fingers tremble as I grab the edges, my heart

about to crack into a million pieces, like the broken keepsakes she has refused to throw away.

If she were here, she'd repeat the same questions she always asked. *Mommy, where we go today? Mommy, what we do? Mommy? Why you no answer me?*

This last thought stops me. I don't have any answers. It was our long-term goal to move her to a group home, but what if we made a mistake? Fear teeters like a seesaw. Maybe we should have waited until we were too old to take care of her ourselves. What if she doesn't like her new home? Or worse, thinks we abandoned her?

“You're making that face again.” My husband, Chip, stands in the doorway. “I can tell what you're thinking. The staff at the group home said they'd call if there were any problems.” He folds his arms across his chest. “We're supposed to wait a few days. You're going to call anyway, aren't you?”

I shrug. “Sorry, I have to.” I grab my phone and dial. Two rings later, Nina, the house manager, answers.

“Hi, it's Jessica's mom. I know you advised us to wait a few days to call, but can I speak to her?” The words leap from my mouth as if they possess a mind of their own.

“Yes, Mrs. Shields, but we want her to adjust to the new environment. Can you wait? I promise she's fine.”

A long silence follows. I'm not sure whether to wait or hang up. When I don't respond, Nina sighs. “Okay, I'll get her.”

Seconds tick by until I hear Jessica's voice.

“What you want Mommy? When you come here?”

“Um, I'll come soon. In a few days.”

“You forget my posters? You say you bring them.”

“No, I didn't forget. I started taking them down.”

“Okay, Mommy. I love you. Bye.”

I hang up the phone and stifle an urge to cry. No one can take care of her as well as I can. The idea of letting go nearly brings me to my knees.

“So do you feel better now?” Chip uncrosses his arms, a tiny smile peeking through his graying beard, his green eyes like beacons calling me home. “Come on, what are we making for dinner? It’s getting late.”

“I’m not hungry,” I murmur. “Go ahead and grab something. I might be a while.”

“Are you still worried? Nina just told you Jessica’s fine.” He waits for me to respond and when I don’t answer, he shrugs. “Okay, fine. Do whatever you have to. I’ll be in the kitchen.”

A rumpled pink bedspread covers Jessica’s mattress. I sit, pull her pillow close to me, and inhale. Faint traces of her vanilla-scented shampoo remain. Chip doesn’t understand. He didn’t spend years worrying about how to make Jessica *normal*. It always seemed easier for him to accept she wasn’t.

Stacks of empty video boxes, loose CDs, magazines, and crumpled pictures are scattered over the top of Jessica’s nightstand. I begin to straighten the hodgepodge of items and spot my favorite picture. It’s a photo of me and four-year-old Jessica smiling at the camera. Her saucer-blue eyes sparkle with childlike innocence. Silky bangs frame her face and her blond hair cascades like a waterfall of curls. People often said she should be a child model. If things had turned out differently, it might have happened.

My finger traces the curly lines of the embossed silver frame. I had insisted Chip take our picture. To mark the occasion. I slide the photo free and turn it over.

In blue ink, I’d written the date. April 5, 1988, the day we took Jessica to the appointment at the Miami Hoberman Institute. Chip and I had met with the neuropsychologist, Dr. Morgan, an expert in the field of childhood neurodevelopmental disorders. Prior to that day, one that marked *before* and *after*, I saw a vision of my life laid out before me. I had a loving husband, three daughters: a seven-year-old, and a set of four-year-old twins. But the universe had a different plan.

My mind reconstructs the scene. Snippets of details: the cold room, the red leather chair, the click of a pen, the pronouncement, the words *profoundly retarded. Destined to remain a child*. The doctor patted the thick file. His monotone voice announced there wasn’t anything else they could do. I sat beside my husband and eyed the evidence before me: the diplomas, the credentials from leading universities, the sparse furnishings, my daughter’s name printed on the edge of the manila folder, the mega-size box of tissues. The doctor clicked his pen. Once, twice, a third time. The meeting ended.

Dr. Morgan rose from his seat, extended a hand, and encouraged us to seek counseling. I ignored the proffered hand. Instead, I rushed into the hallway and left behind remnants of my shattered dream. For a split second, my mind conjured an entirely different scene. Eyes closed, I imagined it. What if I could change the ending?

Then we stood at another door. Chip guided me into the children’s activity room. Jessica noticed us. Her eyes lit up. She pointed and said, “That my mommy.”

The woman beside her, clad in pink scrubs, laughed as Jessica tugged on her hand. “I’m Carol,” she said, “one of the nurses here. Your daughter is so sweet and adorable.”

A second nurse sidled up and stroked Jessica’s hair. “She certainly is. She’s angelic.”

I nodded, barely able to look at Jessica. Perhaps I would never see her the same way again. What then?

Carol touched my shoulder. “Oh, please don’t cry. So many kids come to our center, but your daughter is special. Perhaps she arrived in your life to help you. They say the Lord works in mysterious ways.”

Inwardly, I grimaced. Why did she have to say that? It sounded so condescending.

Jessica held up both hands. “Up, Mommy. Pick me up. We go home?”

“Yes. Daddy and I will take you home.” I held Jessica and pressed my face to her cheek. The fragrance of her skin reminded me of how much I treasured her. How could I live with the fact there was no cure for her irreversible brain damage?

Years later, I would revisit this moment and understand what I refused to understand then; that I could never change the fact Jessica would always remain childlike. But for a long time, I waited

for the *real* Jessica to emerge. I would do anything in my power to *fix* her, to help her be *normal*. Although I enrolled her in therapy, sent her to different schools, and hired numerous tutors, she never learned to read or write.

Jessica and her sisters grew older. I divided my time between the world of special needs and the mainstream world. I drove Jessica to therapy, then drove the other two girls to cheerleading practice. With each passing year, my denial slowly crumbled. Jessica watched her sisters learn to drive, begin to date, and go off to college. Did she long for that same independence, or was I the one who wanted freedom? She was nineteen when I decided it was time. She should be able to stay home alone.

Part of me knew no one in their right mind would leave a five-year-old unsupervised, but she wasn't five, she was nineteen. I devised a safety plan. For months, Jessica and I practiced using speed dial so she could call my cell phone. I laid out the rules. Under no circumstances was she to answer the phone or the door. I started going on short errands. A run to the store. A stop at the post office. The arrangement

worked great, until the day I arrived home and found the police car parked in front of my house. That day, instead of speed dialing *9 to phone me, Jessica accidentally dialed 911. When the operator answered, Jessica hung up. Dispatch sent an officer to investigate. He explained they were required to verify whether the call was an emergency. If I hadn't arrived when I did, they would have broken down the door to gain entry. The chilling image cut through the last thread of denial. That was the day I realized Jessica needed lifetime care.

Recently, a friend asked me if I still grieve losing the storybook future I once imagined. I told her at times, I do, but that there is so much to be grateful for. Jessica's sisters are married, have children of their own, and adore Aunt Jessica. I had made a mistake longing to *fix* Jessica. She was never broken, nor did she need to change.

I did.

* * *

Chip pokes his head through the bedroom doorway. "Hey, didn't you hear me call you? You've been in here more

than an hour. Are you ready now?"

I steal a last glance at the photo before I return it to the nightstand. It might take the rest of my life to learn the art of acceptance. I'm ready. ♦

Reprinted with permission of the author who gratefully acknowledges Levitate Magazine and The Manifest-Station, where earlier versions of this story appeared.

PROUD

MARC LITTMAN

As expected, no baseball team picked my son with autism, Danny, so we sat in the bleachers where he pondered if the ball got airsick when it was hit. Danny then enlightened his fellow bench warmers about how Abner Doubleday invented baseball in America during the summer of 1839. Abner would go on to become a Civil War hero. As usual, no one listened to Danny rant. Suddenly a foul ball rocketed toward the stands and Danny caught it barehanded without missing a beat. He asked me to throw it back, but I proudly insisted my son do the honors. ♦

PRIME TIME OR OFF-PEAK?

WENDY KENNAR

The other night I sat on the couch as my husband stood behind me and brushed my hair. I told Paul I felt like I was slowly falling apart. I was becoming just like one of my Grandma's purses.

"What does that mean?" Paul asked.

"My grandma never liked to get rid of a purse. She'd tape the handles, because the rest of it still worked. It wasn't ripped. The zipper worked. Just the handles were breaking. She'd use a taped-up purse," I said.

"That's who I'm becoming," I said.

"No you're not," he said.

But it's how I felt just then. And it's how I feel a lot of the time. Parts of me work just fine. Other parts, specifically my left leg, is more like the taped-up handles—kind of working, kind of getting the job done.

My twelve-year-old son is baffled when I tell him I can't always remember my age. He never forgets his age, and carefully keeps track of when he'll meet the half-year-older mark.

It's harder for me. Of course, I know I'm forty-four years old. But it's not that simple. Because of my invisible disability, I feel so much older. Sometimes I have to say my age out loud, to remind myself, because it doesn't quite seem possible. In many ways I feel like the same girl I was when my then-boyfriend, now-husband of twenty-one years first asked if he could kiss me goodnight.

I still drink apple juice at breakfast. I still yell at the TV when watching a basketball game. I still prefer sunflowers to roses and silver to gold.

Yet, physically I feel much older than my forty-four years, as if I am experiencing part of my aging process on a specially-designed fast track. After all,

I am a retired elementary school teacher. Retired after a twelve-year career. "Retired due to a disability," according to the state of California. Retired days before my thirty-seventh birthday.

Retirement didn't happen the way I imagined. It wasn't the way my dad retired from his Thirty-year career with the phone company. His retirement was expected, applauded, and celebrated.

I fought my retirement. I tried to ignore the daily tears, the gripping pain in my legs, the sheer exhaustion. I tried to dismiss my rheumatologist's repeated question: "Are you still working?"

I thought I could do it. I thought I could keep chugging along like The Little Engine that Could. But I didn't like the person I had become. As a teacher, I gave the best version of myself to other people's children. I came home and gave my remaining energy to our young son. (He was almost five when I retired.) By the time my husband got home from work, there wasn't much left for him. And there was nothing

left for me. I was disappearing into my teaching obligations, my pain, and my disease.

Ultimately, I couldn't keep up with the physical and mental demands of my career while also trying to deal with the physical and mental effects of living with a painful chronic medical condition. Undifferentiated connective tissue disease is an autoimmune disease. Everything happens on the inside. From the outside, I look "fine." But I don't feel fine. I feel worn-down, slow, and cumbersome.

I'm forty-four years old. But I climb the stairs to our bedroom each night, and my knees creak as if I'm walking on the hardwood floors in my parents' nearly-hundred-year-old house.

I have a disabled parking placard in the car, something my parents (both in their seventies) thankfully don't need.

My life consists of frequent doctors' appointments, bottles of medications, heating pads, and pain.

It's hard to know which parts of my life are impacted by natural aging and which parts have been impacted by my autoimmune disease. Is my lack of energy and lack of flexibility a result of my body simply not being twenty-one anymore? Or have all these changes somehow been sped up, as if I'm rolling along downhill, the brakes have gone out, and not only can't I stop, I can't even slow it down?

I don't know. I'll never know. Because there's no way to separate the naturally-aging me from the chronic-patient me.

In my low moments, when it hurts to bend and reach for a container of leftovers on the bottom shelf of the refrigerator, when it hurts to get in and out of the car, when it hurts to lean over and turn on the garden hose, I am an old, weak woman trapped in a younger woman's shell of a body.

I walk around in a near constant level of pain and fear. They're always there, sometimes at a full-on boil like a pot ready for my son's favorite noodles. Sometimes on a low simmer, like the sauce that gently bubbles on the stove. But always on.

I am terrified of what the next MRI might show, terrified that a shopping trip to Target may leave me in pain for the rest of the day. Because if that happens now, what will happen as I age—when my body is expected to slow down, suffer aches and pains, and generally not be as fast or resilient?

What then?

I was thirty-four years old when this all started. At the time, I thought I was experiencing an isolated medical issue. My left calf was abnormally swollen. It was just the beginning. And as the years go on, multiple body parts and systems are impacted. Autoimmune diseases tend to function like dominoes—starting off with one and then causing multiples to fall.

Now I have digestive issues. Now I have my optometrist warning me that one of my medications frequently causes damage to eyes after long-term use.

Whether you have an autoimmune disease or not, no one knows how the future will play out. Things happen in our bodies that can't always be predicted or explained.

I just don't feel like other women in their forties who may see the limitations of middle age far out on the horizon, but still feel they're in their prime. I don't think my best years are still ahead of me, that I'm just getting started on this grand adventure called life. In fact, I wonder if it's the opposite. What if I missed my chance for adventure and new experiences? What if I was so busy following schedules, checking things off my carefully constructed list of plans, that I have completely missed my chance? What if my physical capabilities become increasingly limited, and it's all downhill from here?

Maybe instead of a taped-up purse, I'll compare myself to one of those time-lapse videos of a stargazer lily blooming. The flower is still striking, the smell still fragrant. But the overall effect is a faster, a shorter bloom. ♦

BLIND BY FATE

CONNOR SASSMANNSHAUSEN

Kat moved around her room with practiced steps. For as long as she could remember, she'd been revered and scorned. Respect was always given, but disgust as well. She never understood why she deserved either.

Four steps to pass her bed, turn right, left hand extended to the edge of her dresser. She let her fingers ghost over the front until they found the handle to the drawer, then lower to the next one down. Opening it, she pulled out her clothes. The stiff, yet soft leather of her leggings and shirt gave her comfort at the mere brush of her fingers.

Once dressed, she felt around under her bed for her boots, nimble fingers tying them quickly. A beep from her watch alerted her to the time. She stood, opening the top drawer of her dresser. She pulled the belts up, lifting twin swords that she strapped to her back.

Nine steps to the wall, along the wall to her staff by the door. At that time of the morning, she wasn't likely to need it, but later, when more people awoke, she would.

She made her way down the corridor of her underground village. The hum of the lights overhead was a white noise she was used to ignoring. She stopped by the kitchen, grabbing a fruit, lifting it to her nose. Apple, a good choice.

When she finally made it to the training hall, she relaxed. Then a shoulder slammed into hers, sending her toppling into the wall and knocking her staff from her hand.

"Why don't you watch where you're—oh, it's you."
Gabriel. One to scorn her.

She heard his steps retreat. "You could at least hand me my staff!" Nothing. Not that she was expecting anything else. Ass.

She felt around with her foot, finding her staff not far from her. With a flick of her toe, she tossed it into her hand. She should get practicing before too many more people showed up.

* * *

Kat sat across from Damien that evening, eating the bland food he'd placed before her. "I don't understand. Why do people treat me the way they do?"

"I don't know if you want to know the answer to that."

She pushed her plate away, and it clicked against his. He blew out a sigh before standing. She heard him move around the end of the table. His elbow bumped her shoul-

der as he offered it to her. She took it, letting him lead her from the hall. For a while, the halls were familiar. Then he opened a door she'd never been through.

"Where are you taking me?" she asked.

"You want answers. There's only one person who can give you all of them."

When they finally stopped, the cool of the room dug into Kat's skin.

"What do you want?" The voice wasn't one Kat knew, and the woman sounded frightened. "Oh, it's you." Those words she'd heard so many times before, giving her scorn and hatred, were now steeped in awe and wonder. "You have grown up. Has it been so long?"

Kat let go of Damien, stepping toward the woman's voice. "Who are you?"

"I'm called Mirra. I am a prophetess." A gnarled hand grasped Kat's, fingers misshapen from breaks not properly set. "I know why you have come, child, but you will not like the answer."

"Tell me, anyway."

"Before you were born, I foretold that you would save our people from an invading force that would kill us all, that you would protect beyond the reach of sight and rise triumphant."

Kat pulled her hand away, turning in the direction Damien should be. "That's why you insisted on training me? Because you felt obligated?"

"If you stand a chance against an army, you need to know how to fight. Everyone among our people is trained, so why not you as well?"

"So, it's more than people hating me because I'm blind. I'm supposed to save them from invaders who I can't even see to fight?"

* * *

Many weeks passed since Kat had spoken to the seer. She hadn't spoken much to Damien either, only during training, but her life was becoming lonely. She hadn't realized how much she relied on him for her social interactions. She still trained hard, if not harder than before. If she was destined to save her people, she needed to be ready.

She saw, so to speak, Damien just as often as usual, but always for training. She trained longer, harder, and when he would try to be social, she would raise her blades and attack him with renewed vigor. Today was no different.

She collapsed to the floor, chest heaving from the long hours of training.

"You need to rest, Kat." At least Damien was keeping the conversation to training, this time. "If you keep going like this, you'll hurt yourself. You're burning out. Take the day off tomorrow and rest. We can train again the day after."

"Then I'll find someone else to train with me." She needed to be the best to fulfill this damn prophecy that had people hating her.

"No one else will, and you know it."

And well she did. Damien had fought to train her when she was a child. No one wanted to train her or with her. And that hadn't changed as she grew up. No one had wanted to be the person to hurt the little blind girl.

How was she supposed to save them if no one would train her?

With a snarl of annoyance, she pushed herself up. “Fine.” She skipped dinner, going instead to her room.

* * *

She didn’t come out all the next day. Damien came by to bring her food, but she hadn’t allowed him a chance to speak. The next morning, she didn’t feel like venturing out, even to practice. The time alone had felt nice, despite having been alone most of her life.

In the afternoon, a loud banging sounded on her door. “Kat, you need to come to the Council chamber,” Damien said from outside. “Bring your weapons.”

She shot out of bed, changing her clothes quickly. She opened the door, and her fingers met Damien’s offered arm. They usually just sent someone to watch her train, not summon her to demonstrate, like some of the others.

“What does the Council want?” she asked.

“It’s best we wait until we’re there.”

An alarm sounded through the halls, echoing from the steel of the walls and tearing into Kat’s ears. She covered her ears, dampening the shrill sound. She hadn’t heard anything about a drill, which meant this wasn’t. They were under attack.

They stepped into the Council wing, and the sound died away.

“It’s happening, isn’t it?” Kat said. “We’ve never been attacked before.”

She heard raised voices ahead, Gabriel being the loudest. “You can’t honestly be thinking of bringing her in on this.”

“She was foretold to be the one to save us. We must heed the seer’s warning.”

“She’s blind for God’s sake.”

No one seemed to notice Kat had arrived, and she remained at the back.

“You’re going to leave the fate of every citizen in the hands of a blind girl who can hardly fight.”

Kat had heard enough. If they were under attack, they needed to actually discuss the attack, not whether or not she should even be here. She stepped further into the room, raising her staff. Gabriel was shouting loud enough that she could easily find him. She swung her staff around, slamming him in the stomach.

“I’m blind, not deaf.” Kat turned her back to him. “And I’ve gotten used to it, so . . .” She didn’t need to see. “What sort of tech do they have?”

“None that we can tell, just their blades.”

“Get everyone to the bunkers. Then cut the lights.”

“What’s that going to accomplish?” Gabriel’s heavy steps told Kat he stepped toward her, and she swung her staff again, hitting him across the face.

“As you have pointed out, I’m blind. I know every inch of this place, and I don’t require light. They’ll be just as blind as me. The only difference; they haven’t been trained that way.”

More discussion occurred, all the while, Kat stretched out her muscles.

“Are you sure about this?” Damien asked her.

“Isn’t this what you’ve been training me for?” she snapped back.

“Kat, I didn’t know about the prophecy until five years after I started training you. It’s never been about duty or anything like that. I wanted to train you.”

“Why?”

“Because I understand not being trained for something beyond your control.”

He took her hand, lifting it to his left shoulder. And that was all there was—no arm. But . . . how had she never noticed? He always walked with her, practiced with her. How . . . oh. He’d always made sure she was on his right when they walked, and in training, he only ever used one blade.

“No one wants to train with a ‘cripple,’ so I found you, who no one wanted to train.” He lifted his hand to her cheek.

“You are stronger than you know. You know everything you need to stop them. Don’t pause to think.”

Once the Council came to the conclusion they should listen to The Chosen One—God, that sounded pretentious—Gabriel stormed out. Damien was to coordinate cutting the lights. Kat trusted him. He was the only one she wanted whispering in her ear via the earpiece.

She took a deep breath, leaving her staff behind. She drew her swords, stepping into the hall. The halls were quiet, with only the hum of lights filling the silence. Soon enough, Damien would systematically turn off that buzzing and the lights that accompanied it. They’d decided cutting the

power little by little would give the enemy less time to prepare or flee.

She moved with silent steps until she heard the distant echo of booted footfalls. She ghosted toward them, following the occasional instructions Damien spoke into her ear.

She heard voices around the next corner.

“Alright, Kat, lights going out in three, two—”

The raised voices of the men in the next hallway told her that power had gone out. She rounded the corner and swung her blades. There was very little resistance from the people she met, and once the hall fell quiet again, she waited a moment, listening for the slightest sound. Kat moved down the hallway, and each time she approached enemies, Damien turned out the lights.

When another enemy fell to the ground beneath her blade, she stopped, listening to the silence around her. For the first time in her life, everything was still; not a sound filled the halls, not even the constant hum of the electricity to the lights.

“You alright?” Damien’s voice echoed in her ear.

“Is that all of them?”

“You did good, kid.”

* * *

Two weeks passed since the attack, and Kat walked into the dining area for the first time, next to Damien. Every day since, she’d had Damien bring her meals to her room.

As she stepped into the room, the chatter quieted until only the hum of the lights could be heard. Then someone began to clap, then another, and another, until the entire hall applauded.

“If this is how it’s going to be,” Kat said to Damien, “I think I’ll stay in my room for a while.”

“You’ll have to get used to it. You’re our savior.”

“I think I’d rather go back to how it was.” She smiled, and Damien chuckled, leading her to an open table.◆

*Previously published in the Challenge Accepted
charity anthology (March 2019).
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DONNA SPRINGER

DIVERSITY

The desert holds beauty
But not to people
Who like rainforests
And don't like deserts.

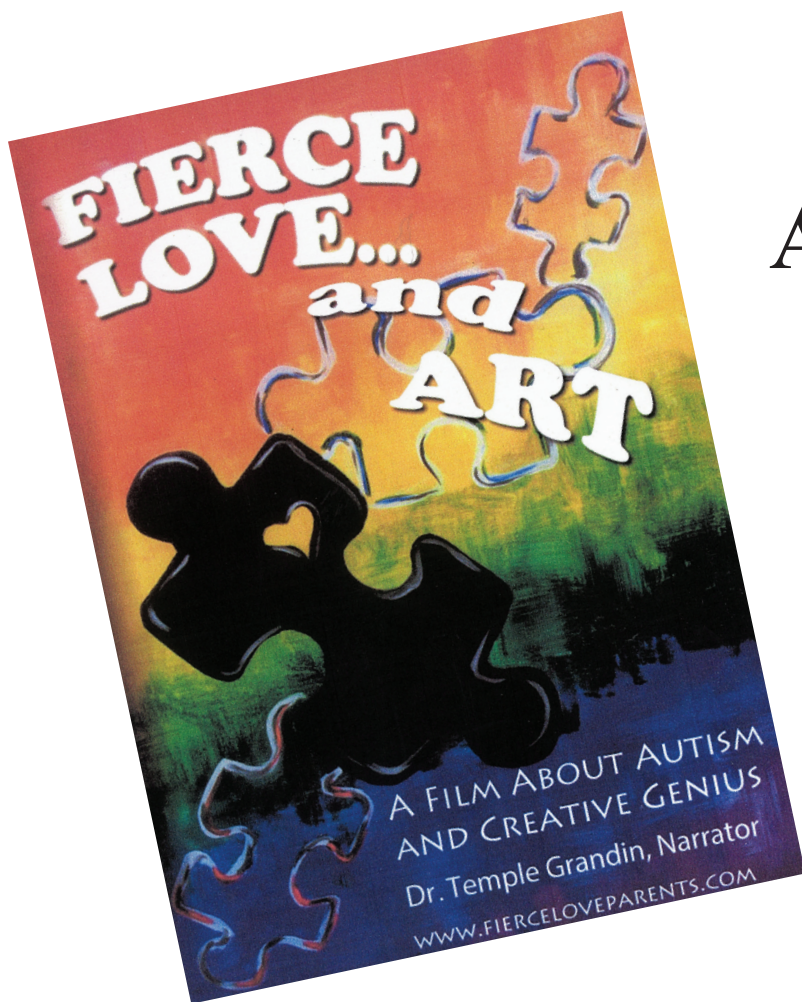
Desert winds sculpt sandscapes
Beneath the sun's strong rays
Rippled patterns soothe the eyes,
Unlike a rainforest's trees
Whose multi-shades of green leaves
And brown winding branches,
Offer coolness and shade.

A rainforest's odorous peat
Softens soles of feet,
Though cradled in boots.
The desert's sun allures eyes,
And whisks hairs of forearms.
Saguaro of the desert hold water,
As does the lush green peat
Of the floor of the rainforest.

Maybe I'm weird—
A desert,
But not a rainforest.

Both can hold beauty.

*Previously published in Perspectives-Poetry Concerning
Autism and Other Disabilities (Volume 2-2012).
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Fierce Love and Art, a WorldFest-Houston International Film Festival finalist, is a documentary film about autism and the transformation that occurs in the lives of nine people with autism, and those who love them, through creative expression. This film provides hope to parents and grandparents, encouraging them to look beyond a diagnosis of autism and see what lies beneath. While verbal expression was limited, or nonexistent, three of these artists found a way to make their voices heard. All of them reveal amazing talents that would have remained hidden if not for the supportive people in their lives.

The original documentary, released in 2018, was nearly three hours long. A reedited version of the film, with narration by Dr. Temple Grandin, was released in 2021 and is less than two hours. *Fierce Love and Art* has been a labor of love for its producer, Dr. Laurence Becker, and Ron Zimmerman, the director, cinematographer, and editor of the film. Music in the film was composed by Tony DeBlois, a talented man with autism who shares his story in the documentary. To see a two-minute trailer go to <https://vimeo.com/479618244>.

For more information about this film visit www.fierceloveparents.com. Contact Dr. Laurence A. Becker at rbecker64@aol.com for questions about the film or to order your DVD.

AVAILABLE NOW!

Brief biographies about the individuals featured in the documentary:

Seth Chwast was diagnosed with autism at twenty-one months and is primarily nonverbal. He took an art class when he was twenty and three years later was on the *Today* show as a featured artist.

Tony DeBlois graduated magna cum laude from Berklee College of Music, plays twenty-three musical instruments, and can sing in eleven languages.

Kimberly Dixon was nonverbal and diagnosed with autism and epilepsy. Her mother began teaching her how to type when she was six years old. Within a few years she was writing poetry, describing how it feels to be nonverbal.

Grant Manier has a penchant for tearing paper, which is a form of therapy for his autism, and creates amazing collages all of the bits and pieces. He was featured in issue 72 of *Kaleidoscope*.

Christophe Pillault lives in France and is unable to talk, walk, or feed himself but paints amazing images using his fingers as brushes on the canvas. His work has been exhibited in France, Italy, Japan, and the US.

Ron Sandison has autism and when he was young his mother used art to teach him to read and write. He is the author of *A Parent's Guide to Autism*.

Erik Warren was diagnosed with autism when he was young. While he struggles to communicate verbally, he is a master with a scroll saw and creates beautiful, intricate images.

Richard Wawro was a Scottish artist who was legally blind and nonverbal. By age three he was drawing with crayons and later became a prolific artist. *With Eyes Wide Open* is a documentary film about the artist by the same director and producer of this film.

Ping Lian Yeakwas born in Malaysia and diagnosed at age four with ADHD and autistic features. He began tracing and coloring when he was young and developed amazing artistic talent.

Mariana Abeid-McDougall is a writer, dreamer, wife, and stay-at-home mom who lives with chronic illness and pain but does not allow it to define her. She has a post-graduate degree in education and her work has been published in *Time Panther* (July 2020), *Story Me* (June 2020), and *Huffington Post* (2016). She says, “I write about what I like, whether disability-related or not, because I’m a multi-faceted individual and there is more to me than my illnesses.”

Glenda Barrett is a writer and artist living “a simple life” in Georgia. Her work has been published in *Woman’s World*, *Now & Then*, *Farm & Ranch Living*, and *Country Woman*. She says having Charcot-Marie-Tooth disease has taught her patience and she writes because, “I believe words can change lives.”

Joyce W. Bergman is a retired attorney turned fiction writer living in Georgia. She received honorable mention in Glimmer Train’s Short Story Award for New Writers (February 2015) for her story “A Woman Close to Fifty.” She says, “A good session of writing is like walking, then running, then being lifted off your feet to fly, and then soaring higher and higher.”

Shannon Cassidy is a California native living in the Oakland hills with her husband, son, and two dogs. Her work has been published in *Wordgathering* (February 2020), *The Smart Set* (January 2020), and *Mothers Always Write* (January 2020), among others. Although she struggles due to illness and fatigue, she remains “curious, compassionate, slightly neurotic, knowledge-hungry, word-obsessed, and always up for a good joke.”

Kirsten Deane is a young writer in Cape Town, South Africa, pursuing a master’s degree in creative writing. Her poetry has appeared in *Best “New” Africa Poets 2019 Anthology*, *ClemenGold Writing Project* (2020), and *New Contrast* (Spring 2020). She says, “My poetry has always been drawn to the simple experience of everyday life and living with a disability has made my ‘simple’ everyday experience different and new every single day.”

Cheyenne M. Heinen is an English teacher, student, writer, and humanist with a master’s degree in adolescent education from State University of New York at New Paltz. Diagnosed as an adult with Chiari malformation, type 1, she struggled, but says, “It has inspired me to empower myself and others through writing.”

Wendy Kennar is a writer, wife, mother, and former elementary school teacher who has lived within one zip code her entire life. Her work has appeared in *Chicken Soup for the Soul: Making Me Time* (February 2021), *Breath and Shadow* (Fall 2020), and *Motherwell* (July 2020). “I write because I attempt to make sense of things around me, including my autoimmune disease. I write for connection, to learn I’m not alone in navigating an unpredictable, chronic medical condition.”

Gerri Leen is a Rhysling-nominated poet from Northern Virginia. Her work has been published in *Strange Horizons* (2021), *Grimdark Magazine* (2014), *Deep Magic* (Summer 2020), and *Escape Pod* (2018), among others. *Dreams & Nightmares* nominated her for a Pushcart Prize in 2020. “I think you have more empathy for others when you are suffering from some kind of pain or distress. And working through it is its own kind of triumph.”

Sandra J. Lindow is a semi-retired teacher and editor. Her most recent chapbook, *Chasing Wild Grief* (Kelsey Books, 2021) is available and her scholarly book, *Nnedi Okorafor: Windseeker’s Guide to Magic, Morality and the Future* (McFarland) will be published in the fall of 2021. Recent awards include the 2018 Blei Award for Poetry and the 2020 Muse Prize for Poetry. Her disabilities are post-traumatic stress disorder from childhood abuse and post-breast cancer lymphedema. Lindow says, “These issues have driven my poetry as well as my scholarly criticism.”

Marc Littman has a son with autism and serves on the board of a nonprofit in Los Angeles that serves adults with developmental disabilities. He says, “I am a vehicle powered by words to drive home a message: there is a road for all to succeed. If I can use my writing to galvanize society to be more accepting, I will have accomplished much.” He’s had about two dozen short stories published in various online magazines and anthologies in the past two years.

Madeleine McDonald is an author, editor, and translator living in the United Kingdom. Her historical novel, *A Shackled Inheritance*, was published in 2016 by The Wild Rose Press, Inc. Other work has appeared in *Love and Loss* (Timeless Wisdom, Book 4, 2020) and *Mslexia* (2020). She worked abroad for United Nations organizations, meeting many people from different backgrounds and says, “Many found their way into my fiction.”

Marilyn McVicker is a writer and retired musician living in North Carolina. Her full-length book of poetry, *As for Life*, received honorable mention in North Carolina Poetry Society's Lena M. Shull Book Award (2020). Her poetry has been published by *Kakalak* (2018) and *The Healing Muse* (2021), among others. Living with several rare diseases that isolate her, she says, "The pervasive, overwhelming issues presented by my illnesses compound my need to speak up and express myself."

Jay Merriman lives with his wife in Southern Indiana, where they share an overgrown piece of land with a fascinating variety of wild creatures that come and go. He has completed his first novel and continues to work on fine-tuning it.

Keletso Mopai is a qualified geologist and author from a small township in South Africa. Her work has been published in numerous journals, shortlisted for various literary contests, and she was the winner of an Igby Prize for Non-fiction in 2017. A collection of her short stories, *If You Keep Digging*, was published by Blackbird Books (2019). She says, "I write about social issues in my work and albinism is one of the issues I am passionate about."

Sarah-Lizz Myers is a poet and M.F.A. student at Vermont College of Fine Arts. Nature, mythological themes and Type 1 diabetes are often subjects of her work. "Poetry allows me to help others with Type 1 diabetes and other medical complications know they are not alone in the fight to live." She has just finished her first chapbook titled *Hanging Flowers*. She lives in Ohio with her dog Duncan.

Toni Ortner is a college teacher of English and a writer who has had twenty-six books published by small presses. Her books include *Daybook I Deerbrook Editions* (2019) and *Giving Myself Over to J.S. Bach* (2018). She says, "I write honestly about the experiences I have and what I observe and hope my words connect with my readers and bring them some measure of joy or comfort."

Chris Pellizzari is a writer and teacher who received his master's degree in journalism from Columbia College Chicago. His poetry has appeared in numerous literary magazines including *Gone Lawn* (April 2021), *Softblow* (April 2021), and *Allegro* (September 2019). He experiences panic attacks and says, "Anxiety has made me into the writer I am today. It has been more of a gift than a curse as far as my writing is concerned. The experience and pain are invaluable."

Diane Reid lives in Maine and has worked as a speech-language pathologist in public schools for more than twenty-five years. "Working with students with disabilities, I have become interested in the topic of disability access in the arts." She is currently pursuing an M.F.A. in creative nonfiction writing through Bay Path University and says, "I am a lifelong learner with interests in history, the arts, and the untold stories of women."

Kimberly Roblin is a writer, curator, and fourth-generation Oklahoman. She received her B.A. and M.A. from the University of Oklahoma and has worked in major museums since 2005. Her work has been featured in *The Journal of Gilcrease Museum*, *True West*, *STATE*, *History Scotland*, and several books, including *Thomas Gilcrease*, the 2009 Oklahoma Book of the Year for nonfiction.

Connor Sassmannshausen is an *American* author who has lived in many places around the world. Her work was published in *Like a Woman Anthology* (December 2017), "Of Damsels and Monsters" received the Servicescape Short Story Award (November 2018), and she was a runner-up in the Women On Writing Contest for her short story "War Beast."

Tobie Helene Shapiro is a writer, composer, and cellist who has also worked as a visual artist, cartoonist, graphologist, and chef. Her work has been published in *American Writer's Review*, *Litbreak Magazine* (July 2020), and *When We Turned Within* (October 2020), among others. She writes about her sons, "about raising them, about the system that makes no room for them, about their bravery and struggles, about my life as the mother of two human beings with disabilities."

Catherine Shields lives in Miami, Florida, where she is a retired educator with an M.S. Ed. in exceptional education. Her work has been published in *The Mainfest-Station* (March 2021), *Uncomfortable Revolution* (January 2021), and *Variant Literature* (July 2020). Her daughter was the catalyst who inspired her to write her memoir, "A Million Ways to Measure Normal." In her free time she enjoys hiking, kayaking, and exploring Everglades National Park.

Sravani Singampalli is a web content writer living in Pradesh, India, who says writing is therapeutic for her. Her poetry has appeared in *Parks and Points* (April 2018 & April 2020), *The Deaf Poets Society* (2019), and *House of Zolo* (2020), among others. "I feel disability comes in various forms and for me, it is important to celebrate and enjoy life to the fullest."

Donna Springer was diagnosed with Asperger's syndrome later in life and is now an adult Asperger's support group facilitator. She says, "I feel that most themes of my difficulties are universal rather than specific to a person with Asperger's syndrome. I write because it helps me focus on issues, sometimes moving me toward progress in dealing with those issues."

Emily Uduwana is an artist and writer living in Southern California. Her work has been published in *Stonecoast Review* (Summer 2020), *FUNGI Magazine* (Winter 2021), *Columbia Journal* (January 2021), and *The Northridge Review* (October 2020). She says, "Struggling with unexplained symptoms has led me to approach art and writing in new ways, from finding more accessible mediums to infusing my poetry with the experiences of my day-to-day life."

Dylan Ward lives in North Carolina and his work has been published in *Adelaide Literary Magazine*, *Split Rock Review*, and *One Person's Trash*. He loves reading good books with strong cups of coffee and being a stay-at-home dad. "I think it is more important than ever to highlight disabilities in writing and to share our experiences as part of the human spectrum."

Allison Whittenberg is a Philadelphia native who has a global perspective. She has received the John Steinbeck Writing Award, New York Library Best Books for the Teenage, and Patterson Prize for Books for Young People. Her published novels include *Sweet Thang*, *Hollywood and Main*, *Life is Fine*, *Tutored*, and *The Sane Asylum*. She says, "The constant joint pain I experience has been maddening at times but writing has always been a solace for me."

Carrie Jade Williams lives in Ireland and is a passionate advocate for improved accessibility within the arts. She received the Financial Times Essay Award in 2020. Living with Huntington's disease she says, "I believe it is important to share my thoughts. I write because I want to be heard. As a writer who relies completely on assistive technology to communicate, I think it is vitally important to normalize writers with unique communication needs."

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