

# KALEIDOSCOPE

EXPLORING THE EXPERIENCE OF DISABILITY THROUGH LITERATURE AND THE FINE ARTS

Number 82  
Winter/Spring Online 2021



**WE ARE WORTHY**

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"The Crayons and the Bone" *by sarah elizabeth*

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"Wrap Me Up and Tie It with a Bow" *by Shawna Borman*

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"Rejoice the Archangel Raphael!" *by Marilyn Slominski Shapiro*

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Blur, *Worthy*, digital illustration, 11" x 17"

"The inequalities that disabled communities face, especially people of color, need to be talked of more openly. I created this as a simple reminder that at the core of ableism is the belief that our value lies in what we can and cannot do physically—and I want to say to every able-bodied person: that's not true. We are worthy because we exist! Simple fact."

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



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# WRAP ME UP AND TIE IT WITH A BOW

SHAWNA BORMAN

I never liked doctors much when I was a kid, but when you grow up with a neuromuscular disease, you end up seeing a lot of them. In fact, I still don't like them. Except for her, and the other one, and you. After more than thirty years, I can admit that you three are pretty okay (for doctors). I guess it's only natural that I eventually came to like the woman who delivered me and has been my primary care physician ever since. And the other one had a good thirteen years to hit a nerve as only a pediatric neurologist could. But you . . . you were someone special. An orthopaedic surgeon. You were even more terrifying than the blood-suckers in the phlebotomy lab. You wanted to cut me open.

\* \* \*

I sat in that tiny cubicle of an exam room waiting for you to make your grand entrance (because I was sure you would be like the rest, a self-important jerk who strode into a room like you owned the place). The firm bed/table gnawed at my dislocated hips and the white paper that covered it crinkled as I squirmed to find a semi-comfortable position. The air was chilly enough to raise goosebumps across my arms. Or maybe it was the fear, not that I would ever have admitted that. My stomach did a nervous dance, one that I'm sure was intensified by the slight aroma of disinfectant that lingered in every corner. The quiet repetition of my parents' gentle breaths was marred only by the occasional flip of a magazine page from where they sat on either side of me in the thinly-padded waiting-room-style chairs.

It was mid-January and I was five years and a few days old. Like most kids, I enjoyed drawing and playing with Barbies or Hot Wheels and that kind of stuff. But most of all, I loved to talk. It was nearly impossible to shut me up, unless someone put a bowl of ice cream in front of me or took me within five miles of a hospital. Actually, you got lucky. The first few years of my life, if I had any inkling that my parents were taking me to a doctor, I screamed at the top of my lungs from the time we left the house until we returned. I would scream myself hoarse, then I'd scream some more. It wasn't like the usual toddlers throwing whining tantrums thing, it was ear-piercing shrieks of terror. I had been that way since I was six months old. Ever since an inept blood-sucker had pierced clean through my tiny flailing arm with her needle. But, like I said, you were lucky. By the time we met, I had graduated to wary silence.

A knock at the door caused my heart to freeze inside my chest. It must have skipped five beats before the knob rattled and you ambled in. You didn't strut and preen like an oversized peacock, you had the meditative gait of a horse that could break into a trot or cantor at any second. I was mesmerized. Each long stride brought you closer, which normally would have knocked my fear-addled brain into high alert, but I was too busy studying your steps to care.

"You must be Serena." Your voice was deep and even more calming than the way you moved. "I'm Dr. Jones. How are you?"



Your fingers were thin and long on the hand you offered to me. They were soft in my palm, almost delicate. Nothing like my father's rough, callous-covered digits. My father had the hands of a working man, of comfort, of home. Yours were strange, disconcerting, and they pulled me back into reality as you shook my thin arm gently up and down. This was a hospital, and you were a doctor, like all the rest.

My eyes traveled over your face, taking in each wrinkle, each twitch visible beneath your cool façade. A bushy mustache, already salt-and-peppered despite your relatively young age, danced above your lip to the rhythm of your speech. I did not answer your question. I did not ask the questions formulating in my mind. *Where did you learn to walk like that? Would you make it so that I could one day mimic those steps?* Instead, I pulled my hand away and glanced across the room to my parents.

"Sorry, our Serena doesn't really talk to doctors. It's a long story. I'm Susan, her mom."

Mother's voice was pleasant, but strained. She was worried. You simply smiled.

"It's quite all right. I run into a lot of people who would rather not talk to me. You must be Dad."

"Gerald," my father grunted.

Did they register the difference between their fingers and yours as you took first my mother's then my father's hand in your firm grasp? If they did, they didn't show it. Smiles and laughter radiated from the three of you. It was sweet and sinister and caused a chill to ripple up my curved spine (which you would later straighten). None of you noticed.

Hooking your heel around the leg of a nearby stool, you yanked it toward you. Squeaky wheels protested the movement. You proceeded to poke and prod at my hip joints while asking my parents routine questions. How active was I? (Very.) How often did I complain about pain? (Once in a blue moon.) On a scale of one to ten, how severe was the pain? (Probably a five or six.) I let out a shriek when you rotated my joint outward: a normal motion for others, but awkward for me. You jumped at the sound, your hands removing themselves from my leg.

"I'm so sorry about that," you said, a strange mixture of sadness and guilt mingling in your tone. Doctors didn't sound like that. "Can you tell me what it felt like? Just nod or shake your head. Did you feel something grinding, or rubbing together, in your hip?"

My eyes narrowed through the pouring tears, but I didn't answer you. I wasn't going to be lulled into complacency by that voice or that stride. You were just like the rest. Only, you were a better actor than most doctors. "Answer him, Serena," my father said with his usual command.

Instead, my lip curled and I crossed my arms. A black speck in the corner of the otherwise white wall drew my attention away from everyone. I knew I would get in trouble when we got home, but I didn't care. After a moment, out of the side of my eye, I noticed you move away. I wondered if it was some kind of trick, something to make me feel at ease before you started pulling and twisting at me again. I wasn't going to fall for it.

For the next half hour, you went over the options for relocating my hips. The right, you were going to notch and pop back into place, whatever that meant. But the left would need to be completely rebuilt. How could you rebuild bone? I swallowed the question before it could escape. Occasionally, you would gesture at a set of X-rays hanging above my head. The blue-white glow of the bones, my bones, was creepy and beautiful. My joints didn't line up at all. I was okay with that. After all, they had been that way for as long as I could remember. I was used to the clicking of bone against bone, used to the pain. But everyone said I needed to be fixed, that I was broken.

You turned to me with a grin that wrinkled the corners of your eyes. All I did in return was blink, wishing for you to disappear.

"When you come out of these surgeries, you'll be wearing a pair of hard pants. The hip we operate on will be covered all the way to the ankle, but you'll only be covered to your knee on the other leg. There will be a bar connecting your legs, so you won't be able to move too much. It's called a spica cast."

I had enough trouble moving on my own as it was, and you wanted to make it even more difficult. You wanted to put me in some kind of pants-shaped prison. My lip quivered. Tears flowed down my cheeks anew. You patted my head as if that would make it all better, but it only made me angrier. My mother wrapped her arms around me and my father held my hand. It wasn't enough to stop the flood of saline and snot. The look on your face was a measured mixture of sympathy and detachment, that said, you had dealt with this type of reaction more than you cared to admit. That look usually meant the doctor was about to leave the room, but you didn't. You stayed, sitting silently in the corner, until I calmed down, then you rolled your stool right up next to me and leaned close.

"You know what?" you whispered, your breath ruffling the loose hairs around my ear. "I'm going to make you a deal. If I make your cast pretty, you'll give me a smile the next time we meet. Does that sound good?"

My eyebrow twitched despite my effort to keep a straight face. Pretty how? The question danced on the tip of my tongue, but I managed to swallow it at the last second.

"How about a bow? Do you like bows?"

A laugh bubbled from my mother's throat. She held out the end of my braided ponytail, where a purple bow was tied neatly at the bottom to keep it from unraveling. I nodded.

\* \* \*

The following week, I was admitted and prepped for surgery. I don't remember much except for bright lights and being surrounded by alien beings in scrubs and masks of

varying colors. And I remember you. I was afraid, but your soothing voice told me to count backwards from ten as someone put a mask over my nose and mouth, so I did.

Ten, nine, eight . . .

\* \* \*

When I woke up, I was in my hospital room. I couldn't move much. My body and mind were numb. Through the haze of the post-op medication, I could see my parents sitting next to me, talking among themselves. Somehow, I managed to work the blanket off before either of them noticed. There, on my waist, was a big plaster bow. It was nothing fancy. It simply looked like oversized bunny-eared shoelaces. But you were right, it made my cast pretty. When the anesthesia finally wore off, I had my mother color it like a rainbow to make it even better.

A little while later, you walked into the room with that slow, mesmerizing gait to check on me.

"Hey, Doc. What's up?" I asked and gave you the agreed upon smile.

My mother and father stared, their mouths hanging open. Your eyes went wide, just for a moment, then you laughed. It was a warm, silky sound that wrapped around me like a hug.

That was when I first understood what I know now: you aren't anything like the rest. ♦

ANN-CHADWELL HUMPHRIES

---

## MY BLIND OBSESSION

Blindness has finally settled comfortably into my life.  
It hasn't always been so. We have drawn blood.  
I ignored it, chased it from my yard, but it would not leave.  
So blindness and I shook hands, became friends.

Like the fine china for special occasions,  
poetry had a place at our family table;  
but blindness dragged poetry out of storage for everyday use,  
made it accessible, aired it out.

Coleridge wrote of the tyranny of the visual.  
Poetry and blindness hold me accountable.  
They demand I abandon habits no longer relevant,  
smirking at ideas I have long held. I'm better for it.

Now, I sense the signature of a stride,  
voices as distinct as thumbprints.  
I can smell something funny going on. My memory  
muscle is as toned as an elite athlete.

Poetry has claimed me. I'm restless without writing.  
I want to swing from the r in word and paragraph,  
bounce on to the s in sentence and phrase.  
More than a want, I need to steep in good poetry.

Neither blindness nor poetry can be  
neglected, nor tolerate clutter. They stalk  
my sleep. I need writing to mix-up, up-end,  
shake-up my assumptions.

Like all good writing, poetry is portable, accessible  
to anyone. Poetry welcomes those who love or never have,  
who are loved or never have been, were lost,  
but now are found. Were blind—but now they see.

PAULA ANNE YUP

---

## ANXIETY

in the age of pandemic  
police brutality in Minnesota  
and birdwatching while Black  
in Central Park

my editor in New Jersey  
accepts "This Birthday"  
which he'll publish  
unless the virus  
takes him at 71

CINDY DECKER

---

## PERCEPTION

We, mentally ill—  
our perception is often obscured,  
dimmed by the stigma we inherit.



# THE NAMING OF A THING

JEN JACKSON QUINTANO

*The forceps of our minds are clumsy forceps, and crush the truth a little in taking hold of it.*

—H.G. Wells—

She lay in her bed, shrouded in flannel nightgown and mussed linens. Cocooned. A thing waiting to emerge. Her father hovered, hoping for a glimpse of ineffable, transformative forces at work.

She closed her eyes and sought *that* space. Her brows knit in concentration, a forced focus. Where was *that* space? The truth was, she'd never visited without prior invitation. Her sojourns were never of her own volition.

This attempt, technically, was not her choice either; but, it was often hard to discern between her father's will and her own. His ambitions were elemental, erosional, all-encompassing. He was the wind, she mere dandelion fluff.

"Tell me when you're there, Millie," her father said as he moved his sensory equipment across the delicate, bony walls cradling—and concealing—her mind and heart. "Tell me when you feel it."

With his intense scrutiny bathing her body in a sense of need—the need to know, the need to see, the need to understand and name—she was unable to leave the physical realm. His presence pinned her down, an insect impaled

upon the Styrofoam, appendages outstretched and waiting to dry in proper display.

"Daddy, I can't," she said.

"Just try a little harder for me, Millie."

She squeezed her eyes shut and wrenched her consciousness inward. She contracted around her beautiful, broken brain. She feared failing him. And then that fear was gone. Everything was gone.

There was no holiness in the moment of the seizure's onset, no visions or light. This was simply a time of the corporeal: guttural noises and spasms. A mechanism gone haywire.

Her father did not react. He did not retract. He continued to measure, to quantify, to seek the hidden and hold it in his gaze. It was her mother who swept into the room, who turned her on her side, who rubbed her arching back and waited. It was her mother who shot the accusatory glare toward her father and sent him skulking from the room. It was her mother who swept the sensors away and let the unseen remain unseen.

Here, veiled in tangled amber strands and sweat, was a bone box holding one brain's chameleon-like wonders. An organ morphing to meet the gaze of others. Science seeks and sees

electromagnetics. Sympathy seeks and sees fragility. She sees daughter. She sees Millie.

The seeker sees the sought. The seeker defines the world.

\* \* \*

Millie couldn't remember a time without seizures; they were part and parcel of her being. For years, they had been a debilitating discomfort, a manacle keeping her tethered to the home, experiencing only the tiniest sphere of greater existence.

Or, perhaps, the epilepsy wasn't the manacle; perhaps the tether was instead her mother's fear.

Recently, however, her seizures came as harbingers of visions. Recently, her world had expanded to infinite proportions.

The visions all carried the same flavor of divinity and peace. Glow and acceptance. Warmth and knowing. The content varied, but the baseline feeling of profundity remained unchanged. It was as if a radio station were constantly playing in the background of the universe, broadcasting murmuring messages of Source; only when seizing was her brain tuned to the appropriate frequency.

She kept these experiences secret for months. She sought to hold them as hers alone. She feared that in trying to put words to the visions, their façade would crumble, and she would be left with nothing but randomly sparking lobes in the nighttime's loneliest hours.

However, over breakfast one morning, she let words slip, recollections unintentionally sliding out as milk might dribble down her chin from the cereal spoon. Her father, his head swiveling like an owl's, quickly pinned her to the chair with his gaze.

"Tell me more, Millie," he said as he flipped to a new page in one of his ever-present notebooks.

Since then, she had become his experiment. He sought the source of her seeming connection to Source. He sought the electrical impulse that conjured the divine.

\* \* \*

In the hours after her seizure, she lay in bed, resting and recovering her orientation in the world. She overheard strained voices from down the hall.

"Damn it, she's not an experiment; she's a child. A sick child."

"But Caroline, if we learn the basis of this, we learn so much about the derivation of spiritual experience. Think about it! This is profound. Revolutionary, even! To measure the mystical—"

"Dean, no."

"To name the divine as a manifestation of the brain—do you know what that would do for science? Caroline—"

"Dean, NO. She's a child who needs medication, not experimentation." There was a pause. "As do you."

Another pause.

"Caroline, you know how I feel about psychiatric intervention. It's bullshit."

"You need help, Dean. If you can't do it for you, do it for your family."

"I can't believe we're having this conversation again."

"Three months. That's all I ask. Just stay on the meds for three months. Then you can decide."

"What they call 'mania,' Caroline? That's me. They want to medicate me away." Pause. "And so, apparently, do you."

"Dean—"

And then footsteps down the hall, the squeaky front door opening, closing. Silence.

\* \* \*

Millie grew up in a kind of haphazard museum. Or mausoleum. Perhaps that's simply what museums are: tombs and testaments to the departed. Death here was on display. On shelves and walls, counters and stairs, there were specimens. Pinned insects tidily labeled; jars of soft-tissued creatures and creaturely parts preserved; avian invaders in the freezer among the peas and beef; and amateur attempts at taxidermy held midstride, midflight, or midstare. Diagrams of bodily systems covered the walls—skeletal, nervous, circulatory, respiratory, digestive. The bookshelves were bursting at the seams, and volumes lay about the house open to random charts and marked paragraphs. Photographs of various dissections were taped to the windows.

Millie's home also, at times, seemed a madhouse. Random bonfires begun in the yard at 3:00 a.m.; the metronome of creaky floorboards, product of a pacing and muttering man; screaming into the receiver at all hours, the targets being scholars and researchers who had long since stopped answering calls; a scrawling hand on the wall when the whiteboard's filled to overflowing; the time the badger got loose in the house; the time a swarm of bald-faced hornets were loosed in the house; the times when all the food in the house disappeared, all the clothes in the house disappeared, or all the appliances disappeared because they were doing some kind of unseen harm to the family.

Seizures were perhaps one of the most predictable aspects of Millie's life. Though she could not control them, they were a constant. And they were hers alone.

The latter point, however, was somewhat debatable, her father perhaps having a hand in that, too. Hers was a home birth. Millie's father delivered her with forceps. The unasked, unknowable question was whether her epilepsy was trauma-induced or innate.

Millie was not interested in the answer. She was not interested in answers at all. Perhaps as a response to her father's maniacal need to know, her preference was for mystery. And magic. She believed naming pinned a thing down to one state of being, removing the infinite possibilities afforded the unwatched.

Classification was a smothering thing.

Fixing her epilepsy to her father's use of forceps necessitated resentment. Affording room for the unknown meant there was room, too, to love and be loved in that complicated household.

Millie was relieved that her experience of divinity yet remained unstudied. The thought of distilling the infinite to a single data point left her feeling distraught and lonely. She needed that gauzy magic, that barely perceptible sense of something greater than herself. A something that could be greater, even, than her father.

\* \* \*

"You don't think I'm sick, do you Millie?"

"No, Daddy."

"Because I'm not. They want me—and you—to believe I am, but they just don't understand. Genius scares them. It's easier to drug me than to accept all that I have learned. It's easier to label me than to understand me."

"Yes, Daddy."

"Even your mother."

A pause.

"Is scared, I mean."

Another pause.

"But you're not scared, right?"

Pause.

"No, Daddy."

\* \* \*

The thing Millie couldn't understand was why it was necessary to destroy in order to know. Why did so many dead creatures surround her, and how did that help her father to name them?

Wasn't the Polyphemus moth even more itself when allowed to flutter through the forest? Wasn't it less itself when desiccated and crucified?

It was as if annihilation allowed for resurrection in new, knowable skin. It was as if, in being, the creatures were too complex, too chaotic to be read. Yet, in death, there was order, a silent space in which to understand.

Millie conceded that the Polyphemus moth, until captured, could be any number of things—a similar-looking Io moth, a Polyphemus with never before seen variations, or a moth entirely new to the field of lepidopterology—none of which could be knowable until capture. But she found the world to be so much bigger with the allowance of infinite possibilities. Existence felt small and musty with everything stacked in labeled boxes, seen and accounted for.

This is why she so treasured her visions of Source: While classification orders a chaotic world, the numinous experience embraces chaos as divine order itself.

What if she believed herself not diseased, just as her father believed it of himself? What if brain trauma and mental illness simply did not exist as categories? How then might they then be named? How then might they then be disparaged, revered, or simply understood?

She thought about all this as she considered the brittle Polyphemus moth before her. She studied the label affixed beneath it, *Antheraea polyphemus* printed in a tidy hand.

Millie found a pen, scratched out the Latin name, and wrote *unknown* in its place.

There was freedom in that act, though for her or for the moth, she wasn't sure. ♦

DARREN WHITE

---

## COLOR IS GOOD

*brown is the best*  
he says  
*you won't burn in the sun*

*I am a white milk bottle*  
he complains  
*my hair is like straw*

*straw is good*  
you laugh  
*a dragon will turn it to gold*  
*it already has the right color*

*but I want your curls*  
he sighs

you are coffee, he is cream  
you are mocha, he is white chocolate  
he has legs, you have wheels

he pushes your chair, his nose in your hair  
*you smell like sun and desert*  
he smiles  
*it's called shampoo*  
you reply

# THE CRAYONS AND THE BONE

SARAH ELIZABETH

I watched her playing on her pallet of precisely folded Minnie Mouse blankets on the dark blue floor. There was so much innocence contained within the boundaries of those pink blankets and the clear-cut lines they provided for Savannah during floortime. Clear pink lines defined Savannah's space from the blue expanse around her. Savannah's space was where she organized her toys, processed information, and discovered the world around her. Even though she was almost eighteen, floortime was just as important to her development as it had been when she was two.

Finn knew there was something special about Savannah. Instinctively, he knew the first time he met her, as he watched her hesitant gait carry her to him. He knew from the way she pressed her arms against the sides of her head, hiding most of her face, stifling unfamiliar sounds. He knew by the heavy weight of her fingers pushing on him when she tried to pet him, despite my constant reminders of "gentle touches" and hand-over-hand demonstrations.

"Stroke his fur."

Finn knew Savannah was special from the way she never spoke. She laughed and giggled, a contagious laughter with squeals and bounces that bubbled through the air, infecting everyone around. Except for the occasional, "Mom," and,

"no," Savannah didn't talk. Only those who loved her best could decipher her few words. Finn was one of those who loved her best. Even when she pets him too hard, or days like that day when she wouldn't share her crayons.

Savannah lined her crayons in perfect rows. Red, blue, orange. Green, purple, yellow. Arranging them by color then rearranging them again. Ensuring the lines were straight. Trying to get the colors just right. Concentrating with the utmost perfection with occasional glances at the cartoon on TV. Mickey Mouse and friends were still her favorite.

Blue, green, red.

Finn walked slowly over to her, in his coyote way of slinking, and sniffed the waxy sticks. Savannah's brow furrowed. She placed her hand on the white patch of his chest and pushed him back until only one large paw remained on her pallet. His brow matched her creasing wrinkle, but his was pleading. He took another step back, standing apart in the dark blue expanse. He was so curious about her crayons. She lowered her head to make sure her eyes were matching his, her hand firm on his chest. Their eyes stayed locked.

No words were exchanged. No words were needed.

When she was sure Finn understood, her hand left his furry chest, and her eyes left his. Both returning to the work of her crayons. Orange, yellow, purple. Finn stood for a moment in hesitation before leaving the room. He knew what had to be done. But where had he put it? He found it in the back bedroom. The biggest and best bone he had. He lifted it in his massive jaws. His sharp teeth penetrating the tough hide. It banged into the doorway, as he finagled it into the hallway. It wobbled and clanked into the hall walls, but finally Finn made it into the living room, where he brought it to the pink Minnie Mouse pallet and laid it next to the crayons. He looked up at Savannah.

*Share*, his eyes pleaded.

She looked up at him. Her sweet blue eyes were quite stern. It was not the right color. He nudged the bone closer. Her brow furrowed once more. He sniffed his bone, to show her what a fine bone he had brought her, but she returned her attention to her crayons. Purple, green, blue. She was still not interested in sharing. Her lines were perfectly straight. Finn began to paw his bone, pulling it away from the crayons, turning it until he could lay down next to his girl on her bright pink pallet. Then he began to chew on his mighty fine bone, with only the occasional glance toward the coveted crayons.

And Savannah let him.

I wondered at Finn's secret. Sixteen years of multiple therapies, and he had successfully touched on them all. Communication, socialization, sensory, and more all in a matter of minutes. I marveled at how this wild-looking dog had entered her world so naturally. Was it his patience or flexibility or determination? Was it his acceptance of Savannah? All of her differences and disability that kept her trapped within the lines of her flesh were normal to him. Finn had no expectations of Savannah. Finn just wanted to be with her. There was so much to learn from the big dog we had found lying behind the cold shelter bars.

All Finn wanted, and all he gave, was love.

They stayed on that Minnie Mouse blanket, Savannah playing with her crayons, and Finn chewing on his bone, side by side watching Mickey and Pluto on TV. Savannah didn't share her crayons that day, which is probably a good thing, but she did share her space. As I sat there with my coffee watching them, and they sat there watching Mickey scratch Pluto's ears, I heard Mickey say, "Who's my pal? Who's my pal?" and Savannah's lips curled into a smile. ♦

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# REJOICE THE ARCHANGEL RAPHAEL!

MARILYN SLOMINSKI SHAPIRO

The gray, stooped figure stood across the road staring emptily at the paint-caked wall, the rain drizzling down her gaunt face, flattening her bedraggled hair into a misty shroud. Standing in a timeless trance every day since it happened, until realizing her lifeless body had lost all feeling, she gave an imperceptible tug on the slack leash and they turned away, the dusk shadowing their tears.

Years ago, on a balmy, New Orleans summer night he couldn't help but notice her standing there cloaked in the soft moonlight, a glow veiling her face, a sliver of heavenly light to brighten the darkness of mortal earth. Off in the distance, away from the other wedding guests, she steadied herself against the rail of a wooden footbridge, standing guard beneath the drooping branches of a weeping willow.

The lanky groom, son of a long-term senator in the Louisiana legislature, approached Scott from the white, granite steps of the plantation-styled mansion that had been in his family for genera-

tions, as long as the summer home of Scott's family on Cape Cod had stood. Todd tipped his cut crystal flute of champagne toward Emma. "She's quite a beauty, isn't she?"

The two friends had met in law school five years earlier, the charming, congenial Todd joining the established family practice in his hometown with the pragmatic, calculating Scott holding out for a more prestigious position with a firm in New York. It was in Scott's nature to seek out the more impressive things in life. As he got older, it became an obsession, a way to compensate for his self-perceived shortness in stature and unimpressively plain looks.

Emma, lost in the clouds of her own dreamy thoughts, didn't notice Scott drawing closer. Drawing closer to her, he could see how exquisite she was with her waist-length, straight black hair contrasting against the whiteness of her skin, her tall frame gracefully arching over the railing, mimicking the gently swaying boughs of the willow above. When she looked up, her green eyes glowed like fireflies, echoing the sparkle of the evening stars.

She had been a sorority sister to the bride, and like Scott, was out of place in this genteel, Southern pretense from the past. From the Northeast, the daughter of a somewhat famous artist mother and novelist father popular decades ago, she had inherited their creativity.

After studying art history and literature, she started out as a junior publisher at a highbrow magazine in New York. Out of his league monetarily and out of hers culturally and attractively, they began a passionate affair, each seeking in the other the parts to make themselves whole.

Emma had a premonition, a sixth sense something was wrong. But when the child was born and she saw how perfect he was, his skin an otherworldly pearly translucence, his delicate blue-veined infant body, each one of his ten fingers and toes so flawlessly formed in miniature, the foreboding diminished; a discarded thought enveloped into the womb of her mind.

The birth, like the whole messy process, from the years of angry, desperate, futile attempts to the last final unnatural act of in vitro, sickened her husband. When his near hysterical wife, semi-delirious from the exhaustion of the long, difficult labor pleaded with him to reconsider, how could he refuse? Like his father, it was expected the boy would inherit Scott's name, but now, once she had seen this living miracle, insisted he be called Raphael, after the archangel.

The new mother whispered her silent invocation into the tiny pink ears of this seraph of hers, who like the archangel, she prayed, would have the power to heal her marriage. As time went on, and she began to hope that those first few insignificant signs something about her tiny baby Raphael wasn't quite right, were simply flukes, that his odd developmental progress as a toddler was just her imagination, she asked the archangel himself to intercede.

Even after the opinion of yet a third doctor confirmed and gave the prognosis, it took time for Scott to acknowledge that this son of his, this gift he had never really wanted, was, because he still couldn't manage to even say the word to himself, "different."

And so, when the toddler began to incessantly bang his bruised, fragile, little head and repetitively perform the same series of monotonous motions over and over and over again, they knew. With that terrifying sense of dreaded finality, with shaking hands covering tightly-shut eyes, their panic-stricken hearts knew that this beautiful child who looked perfect from the outside, wasn't.

By the time the sandy-haired, cherub-cheeked Raphael was five years old he still couldn't speak. With training, he was teachable, communicating with his relentlessly fatigued and worn-down mother almost telepathically. Contact with his distant father, who buried himself in his law practice to escape from a situation he was neither equipped with, nor inclined to handle, was rare. More often than not, Scott stayed overnight in the city, which was just far enough away to justify his increasing absences. He preferred the couch and the solitude of his office to the claustrophobic pall that blanketed their home in the small seaside community in the Connecticut suburbs.

It could have been mere coincidence, blind luck or simply happenstance, but as time passed, Emma grew to believe it was a miracle of divine intervention. The neglected cottage next door had finally sold and their new neighbors, Nick, a trumpet player in a jazz quartet and his eclectic wife, Marguerite, who managed the local pizza shop they had inherited, took the frazzled mother and her now seven-year-old son under their wing.

Every afternoon, as if harkening the start of his day, the trumpeter played his gilded instrument, rehearsing for that night's gig at one of the city's up-and-coming jazz clubs. Returning faithfully to his wife just before the first light of dawn, the too-thin, scraggly-bearded musician woke mid-afternoon, and like clockwork, blew the sweet soulful notes out the windows of their screened-in back porch sharing his gift with the universe.

Raphael, mesmerized by the sound, would sit, head cocked slightly upward, like a dog hearing the distant call of a mournful wolf until one day, and every day after, he answered back. This self-cloistered child who couldn't speak, lifted his head skyward and emitted an ancient, primeval, heart-stopping howl up to the heavens. The utterance was the most exquisitely beautiful noise his mother had ever heard.

Marguerite smiled as the young teen hopped on his shiny red bike and took off, hair flapping wildly in the wind, with the pure joy and exhilaration of a free bird suddenly sprouting wings to take flight. She'd watched him blossom over the past five years, discovering possibilities and innate talents that none of them, even the boy's skeptical doctors, could have foretold. And now this guardian angel neighbor had given him another chance to once again prove them wrong.

She needed somebody to deliver flyers door-to-door who would not get bored with the monotony of stopping at every house and meticulously positioning the advertisements onto each front porch. She wanted someone who would take the time to tack her advertisements onto neighborhood telephone poles, making sure hers stood out among the layers of other rainbow-colored flyers hanging there. The first few times his mother went along to guide him, but soon the beaming teen wearing the fire engine red cap and T-shirt bearing the "Pizza with Wings" logo became a welcome and familiar sight, a harbinger of hope that somehow peeks out from behind the too common dark cloud of man's selfish, carnal nature.

That dreary day as he rode home on the wet streets, slick from a sudden spring downpour, just past the concrete block wall caked with dozens of coats of paint, he heard a pained whimpering. From behind a patch of emerald green bushes sprouting their tiny saffron blossoms, an injured dog lay shivering under the rain-soaked leaves, matted with black mud and smeared with streaks of bright red blood. Raphael carefully lifted the animal into the oversized bike basket, now empty of flyers, and peddled home as quickly as his twelve-year-old legs could carry them.

Raphael, afraid to reveal his secret, hid in the garage beside the dog, fashioning a second cave and burrowing beneath the protective shield of a stained, faded terrycloth robe his mother had worn when she was pregnant with her unborn child. When Emma finally found them, paws and arms entwined in a sweet embrace, panic melting into grateful tears of relief, her mind branded the angelic image of those two innocent creatures into her forever memory.

After slowly pulling the coat away, Emma inspected the bloody, matted fur of the young, yellow lab. Gently calming the dog, and rolling her onto one side to check its muddy underbelly, she finally discerned the blood was coming from severe scrapes on the inside of her swollen hind left leg and paw. Searching for her collar, Emma read out loud "Rainbow." And then turned to Raphael, "Her name is Rainbow." And that is when the second miracle occurred. Because her silent little boy who had never spoken even one, solitary word before, pointed at the dog and in a faltering voice said "Bo."

That night Raphael's father came home, an unusual midweek occurrence ever since he had purchased the studio apartment a few long blocks from his Midtown Manhattan law firm. Prone to exaggerating the child's achievements, he

didn't quite believe his spouse's claim that his son had spoken, something her husband had given up on years ago. And Scott wanted to nip in the bud any thought his son or wife had of keeping that stray, flea-infested mutt.

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**Because her silent  
little boy who had  
never spoken even one,  
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pointed at the dog  
and in a faltering voice  
said "Bo."**

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When Scott, through clenched teeth, heatedly blurted out "For God's sake, we have enough to contend with without adding an inane complication like this animal to our problems."

Emma responded venomously with "Then you take it away from him because I can't."

Raphael then took his father's hand and led him to the bandaged dog cowering beneath the dining room table. He knelt beside Rainbow and placed Scott's palm on the top of the shaking pup's head. Staring down at man's best friend, Raphael once again spoke "Bo." Looking up into the teary eyes of his father he stated once again, but with more surety, "Bo."

In the beginning, Scott, completely infatuated with the loveliness and demeanor of his future wife, pursued her with romantic weekend getaways, expensive candlelit dinners and a weekly bouquet of exotic flowers matched only by her rare beauty. But the ethereal Emma, who sought inner beauty, emotional connections, and a purity of love, was slow to warm to her beau's ostentatious gestures.

As time went by, the shape of their relationship, like two halves of a heart, grounded together at the bottom, blossoming outward in their own directions, but then dramatically arching back toward the other to meld in the middle, created their whole. Scott grew to love his demonstrative girlfriend and knew deep in his being that she was his savior. And Emma realized her fiancé would protect her from her vulnerable self, even if at times it would make her question her own truth and morality.

The couple was married in a small, private ceremony at an exclusive hotel on Martha's Vineyard. Career-wise, Scott was of the opinion it was practical to be married no younger than thirty, but not too much longer than thirty-five. The frequent hints from his associates that in order to make partner, it was better for him to portray the stability of a married, family man, along with the nascent tick of Emma's biological clock, finally convinced him to commit.

Scott's marriage boosted his career and enhanced a social life he previously hadn't recognized as lacking. Emma's radiant presence, like a halo, softened the serrated edges of his blunt personality creating a conduit into a circle of avant-garde, artsy friends and acquaintances he had never imagined himself being part of, much less accepted by.

In kind, with the newly-found financial security Emma's marriage now afforded her, she felt the liberty, for the first time in her life, to joyfully pursue her passions. Within a few years, her own artistic endeavors began to take precedence over her job at the magazine. Finally, she was able to persuade her skeptical husband that leaving her position and following her true path would increase her creativity and eventually allow her the flexibility to raise a family.

The popularity of her works began to soar. She started to create paintings appearing to emit light, the primary colors

she chose radiating an incandescent glow, as if backlit from the stained-glass windows of an ancient cathedral steeped in the white haze of burnt incense.

Akin to his wife's success, Scott made partner, partly a consequence of the perception of stability his marriage made to his firm, but more so because of the rapid succession of cases he won for the corporate clients he represented. Sought after for his specialization in environmental law, he had a reputation for saving companies millions of dollars in settlements to the detriment of those sickened by their greed and negligence.

In the beginning, they were in no hurry to have children, both engaged only with the other and absorbed solely within the passion of their jobs. But by the time Emma had reached thirty-five, her desire to create another living being became an unrelenting obsession.

As each barren month passed, the light in her art morphed into darker and more sinister images. The blackened stained glass burnt as if in a terrible fire, mirrored her mood, drained of life and color; every piece more depressingly morose than the last.

As if in some deranged synchronicity, the gross injustice to the innocent victims in the cases Scott was winning became worse with each settlement. By the time the couple began the first in vitro procedure, Scott's heart had hardened so much so that it was impenetrable to feelings of guilt, regret, or remorse.

When Emma finally, miraculously, knew she had conceived, Scott did not share her joy, and instead delved more intensely into the sins of his profession, intent only on winning—never mind the consequences. He didn't care about Emma or his marriage, nor was he concerned about his baby or family. It was as if his proverbial soul had been sold to the devil.

Once it became undeniable that his child, this baby he hadn't wanted was faulty, he slipped further into an abyss of selfishness and immorality. His wife, too consumed with the care of their son with autism, didn't have time to pay heed to her fallen by the wayside husband. Until one day, simply by chance, she saw him with another woman and realized the state of devastation to which her marriage descended.

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**But then Raphael spoke. Like a heavenly bolt of lightning, the magnitude of hearing the word "Bo" struck through the black-hearted shield of Scott's soul.**

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The other woman, like Scott, was a fallen soul. She knew of Emma from the beginning reveling in the game of leading him astray from his wife and child. Plotting each of her moves like a sinister game of chess, she watched as each piece of their marriage fell, until finally only one remaining move was left for her to claim checkmate.

But then Raphael spoke. Like a heavenly bolt of lightning, the magnitude of hearing the word "Bo" struck through the black-hearted shield of Scott's soul. Allowing one tiny pinprick of white light into his being, it became a candle shepherding him out from his self-induced plunge into inner darkness.

Rainbow, innately sensing the seismic shift in the father's demeanor upon hearing his son's first word, ever so delicately offered her paw upward to

her new master. Scott, broken, dropped to his knees, arms protectively cradling his child and dog, sobbing the grateful tears of a sinner to whom salvation had at long last, mercifully shined its face.

That night and for the next seven days, Scott stayed home standing watch over the doe-eyed dog as she healed, marveling at the bond forming between his son and this heaven-sent animal. Somehow, she had been able to deliver a message to his unreachable child, waking him from a long-muted sleep.

A changed man, when Scott returned to his windowed office overlooking the New York skyline, he placed the pictures of Emma and Raphael, hidden for many years in the bottom of his desk drawer, in plain view, heralding the restart of his marriage and family life, and marking the end of his affair.

Each night, the prodigal father returned home to his welcoming family, relishing in their newfound togetherness. Arm-in-arm, the three two-legged creatures walked the four-legged friend into the lush, green wood surrounding their secluded property, Raphael holding tightly onto the leash of his best friend.

At work, Scott began to empathize with the victims of the cases he represented. When he decided to represent the parents of one of the children who had contracted leukemia linked to overhead power lines on a pro bono basis, the firm saw it as a goodwill gesture for the organization.

But by the time the suddenly environmentally-conscious lawyer began to actively search for similar cases to represent, the firm could no longer look the other way. With pressure from the partners, and encouraged by the breakthrough with his son, Scott took a leap of faith. In an attempt at redemption, he started a home-based practice to help the kind of victims he would have robbed of their rights in the past.

Raphael, overjoyed by the attention bestowed upon him by his previously absentee father, would sit contentedly watching his dad for hours, Rainbow faithfully at his side. When his child sweetly attempted the word “da” the first time Scott, clutching his boy, tearfully interpreted it as a sign from above that he had finally chosen the right path.

Each afternoon, like a ritual now, mother and father would grasp each other’s hand and listen, mesmerized by the haunting sound of Raphael’s voice as he answered the trumpeter next door. Joined in harmony by his furry companion, they lifted their heads craning necks skyward, offering their chant-like howl in prayer to the heavens.

Emma, encouraged by her husband’s welcome change of heart, began to share her art through street painting as a way of expressing her gratitude while giving back to the community. Her latest work, a display of graffiti on a local neighborhood wall, spelled out in bold red letters on a gold background the word: Rejoice!

On that overcast day in late September, Emma was taking the dog on a brisk afternoon walk. As she passed the vibrant wall, Raphael’s mom noticed her son gleefully racing his bicycle down the street toward them, back from his job delivering flyers. It was then that Rainbow, pulling the leash out from her owner’s grasp, bolted toward the boy, oblivious to the speeding car approaching far too fast. Acting on maternal instinct, Emma lunged to save the dog, but tragically, not in time for the driver to screech to a stop, instantaneously cutting short both their lives.

Every day since, father and son visited the site, staring at the high concrete wall caked with dozens of layers of paint with the bold red letters. Today, next to the shrine of burnt-out candles and bouquets of withering flowers, Raphael places another teddy bear next to the others, soggy from the wet rain that seems to mourn alongside the two joining in their grief.

Across the street stand two spirits, the stooped gray woman and her ghostly dog, watching as her husband lovingly enfolds their child in his arms as they turn toward home. The Archangel Raphael, standing stoically beside them, bends down and whispers into Emma’s ear “It is time!” before leading them up the ladder into the blinding white light of the world beyond. ♦

# SEIZURE

EILEEN OBSER

**D**ecember 19-20, 2001

10:30 p.m.: Emily, Suzanne's coworker, calls this Tuesday night, and she is crying. I know immediately what has happened. My daughter is dead. Suzanne is dead. Thirty-five years old, not to turn thirty-six on her birthday, this coming Friday, the twenty-second. I don't know if I can bear it.

But no, Suzanne's alive. She's had a seizure. She's at her company's Christmas party at the Polish Hall in Southampton. "Take her to the hospital," I say. Ms. Calm. But the ambulance squad is already there; of course they'll take her to Southampton Hospital. The coworker wails and I ask to speak to a technician. A woman comes on the phone—a nurse or paramedic—who tells me "Suzanne is comfortable" and "she's in good hands." I should go to the hospital as soon as possible.

11:00 p.m.: Yes, drive there, and quickly. I've been avoiding James, my on-and-off boyfriend, but now I have to tell him to please take care of the house and dog and cat and to "stay out of trouble," which means "DON'T DRINK." I dress in slacks and boots, grab my handbag and leave for the hospital. All evening I have been angry, at James and at myself, for taking him back into my life. I went to an Al-Anon meeting earlier and have been wrapping Christmas presents, none too happily, since I returned home.

The annual holiday party at my house in East Hampton two nights ago, on Sunday, for my writing students, colleagues, and friends, was a huge success. Suzanne was here, blond, petite and pretty, dressed in a red velour top and black dressy slacks. Her friend, Charlene, and she took over the kitchen, as they do each year, handling all the food and beverages. In her usual standoffish, bossy way, Suzanne dismissed me from the kitchen. This kind of behavior always irritates me. I irritate her too, of course. We've never sat down to discuss our differences and try to work out a more amicable mother-daughter relationship.

Now, we may never be able to do it. Now, my world is falling apart. I can't manage things within my own household—within my own *life*, no less. James is evidence of this, his very presence here again. I have been hiding him from people, and especially from my two grown kids.

I must be in control, no matter what, for Suzanne's sake, but I'm so terribly frightened. Again? This has to happen to her *again*? I call my son Jeffrey and find him at his apartment in Brooklyn; I call my ex-husband Fred in Arizona, where he spends the winters. Then I drive to Southampton Hospital, twelve miles away.

11:30 p.m.: I drive much too fast and soon arrive at the emergency ward. My thoughts are with Suzanne's previous episode, six-and-a-half years ago, in August. I was asleep that night, with the phone turned off. I did not yet own a cell



phone. *Damn*, I thought then. *Why didn't someone ask the local police to come wake me up?* Fred and his wife were called and went immediately to be with Suzanne. The next morning, after I learned what had happened, I packed and left for the city, and Columbia-Presbyterian Hospital, for a week-long stay at a borrowed apartment.

Suzanne's boss, Andrew, plus Emily and another coworker, Raquel, are huddled outside the emergency room, relieved to see me. "I'm sorry she ruined your party," I find myself saying. Then I go to see my daughter, who is in a lot of head pain. Suzanne tells me she thinks she is going to die. She's so frightened. They give her morphine and try to calm her down. Suzanne has never been a person who takes drugs recreationally, like so many of her peers. She missed that scenario of American life in the 1970s because she was diagnosed with a heart condition at the age of twelve. When she was forced to take medications, strong stuff like Prednisone and Digitalis, she couldn't wait to be weaned from them. But now, in pain and in fear, she'll try anything.

Someone hands me her jewelry and I stash the necklace and bracelet in my handbag. On her hands, perfectly manicured and polished in bright red, are two antique rings that I believe she recently purchased. I should take them off, for safekeeping, but I don't want to upset her. Actually, I don't know what I'm doing. So I don't make that move. I walk down the hall to the radiology department, to the CAT scan room. The brain scan shows bleeding. I report to Suzanne's anxious coworkers a few times. Just to keep busy.

It's a long hour, watching the doctors and nurses silently go to and from Suzanne's bedside—not talking to me, but letting me stay there—and not giving any opinions, or hope. I try not to ask too many questions so they don't chase me away.

#### December 20

12:30 a.m.: The doctor on duty makes the decision to have Suzanne taken to Stony Brook University Hospital, fifty miles east of here. I want her to be taken to Columbia Presbyterian in New York City, where her specialists are, but the doctor is concerned she's too traumatized to make the trip. He's young and arrogant; an all-purpose doctor, not a specialist. And there's no neurologist to be called in. On that night six-and-a-half years ago, the doctors at Brookhaven Hospital in western Suffolk, where she wound up, let her be transported quickly to Columbia, after doing a spinal tap to relieve the debilitating pain in her head. But Brookhaven was closer to New York City. I have to accept that she will go to Stony Brook, but tell myself, and Suzanne, that we will transfer her to New York City as soon as possible.

I call my son Jeffrey again; Suzanne wants him to drive out from Brooklyn to Southampton and take care of her house and pets. He agrees. Fred calls and he's able to talk with Suzanne briefly. We don't discuss his flying to New York; everything is too uncertain and minute by minute, as far as our daughter is concerned.

1:00 a.m.: I leave Suzanne, who's on morphine and dozing, and go talk with Andrew, Emily, and Raquel. I tell them she's being transferred. They offer to drive to Suzanne's house to get the schedule. Oh, right. It's Tuesday. She's probably dying, but her company needs the goddamn employee schedule, for which Suzanne is responsible! I go back to her side and try to confer with her in her drowsiness. We mutually decide to keep everyone out of her house. I will gather all the paperwork and place it in her mailbox. One of the coworkers will pick it up in the morning.

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### **I walk down the hall to the radiology department, to the CAT scan room. The brain scan shows bleeding.**

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"Thank you so much for being here," I say, and I promise to stay in touch. Then I drive to Suzanne's house, where I walk the dogs and leave a few notes for Jeffrey. By this time there have been many calls back and forth with Jeffrey and Fred and James. James tells me he is fine; my pets are fine; I shouldn't worry. "I'm praying for you and for your daughter." I am teetering between control and utter panic.

Suzanne's house is filled with clutter—colorful clutter, such as plants and magazines, food and pet supplies, gifts not yet wrapped for Christmas. There are photographs everywhere, and Christmas cards. She left the lights on for the animals, because she expected to be back here by now, working on the schedule. All the papers are scattered across the kitchen table. As she instructed me, I gather them; put them in a folder, then in plastic, to keep the packet dry after I stuff them in the mailbox across from her driveway.

As I walk through the rooms, I think to myself: *it's really not her time. She won't die. All this stuff! And the pets, her two dogs and four cats, waiting for her.* I'm not totally convinced as I think this, but at least I don't have morbid thoughts about what to do with all the clutter if she actually does die. I walk the dogs, and leave food and water for all the pets.

Right before I leave, I try to call the hospital to see if she's still at Southampton. But when I pick up the phone, there's no dial tone; someone is on the line. Of all the people who don't know what's happened and who might call, and at that hour, it turns out to be Steve. Steve, her friend and colleague, and the guy who was with her as a Jitney bus driver, the last time this happened, six-and-a-half years ago. He doesn't act stunned. Why not? Has he been partying? Steve tells me Suzanne and he have a lunch date two days from now, on Thursday, in Sayville, while her new car is being serviced at the nearby dealership.

"Consider the lunch date cancelled," I tell Steve, and I make a mental note to cancel the servicing. He'll call Stony Brook tomorrow, we agree, to find out how Suzanne is doing.

I leave the lights on, the way they were when I arrived. Jeffrey is on his way east. We'll probably pass on the road, although on different sides of one of the wide highways, so we won't recognize each other. Also, it's very late, and we're so tired. We'll be lucky to keep our eyes on the road, without searching for each other's cars.

Later, Jeffrey will tell me that while driving on the Manorville Road, at Exit 70 of the Long Island Expressway, toward Route 27, he was the lone driver on his side of the road. Coming in the other direction, the only vehicle he passed was an ambulance, lights flashing in the night. He knew it was carrying his sister.

1:30 a.m.: I lock the front door, hide the key for Jeffrey, and make my way down Suzanne's dark, bumpy street where I steer the car west toward Stony Brook. I want tea; I need something to drink and maybe to eat. From the moment the news came at 10:30 p.m. I lost my appetite. I didn't even want to sip water. But I'm afraid I'll doze off. In my semi-panic state, I could also become so distracted that I could lose control of the wheel and go off the road. At Manorville, I stop for tea—regular, not decaf—at 7-Eleven, and buy a pastry as well. I will need energy during the next many hours.

I'm alone on the road most of the way. I speed, not caring if I get stopped by the police. In fact, I'd rather like an escort to the hospital. I don't feel safe at all, in my body or in my mind. People in my condition should not be behind the wheels of cars. I play music for awhile; it keeps me alert. I'm trying not to project: my reaction when they tell me Suzanne didn't make it; my grief and despair; my interactions with all the people who will have to be told; the funeral. God, *the funeral!* I have no idea what she wants in the way of a funeral; we've never discussed it. Most Holy Trinity Cemetery in East Hampton?

I think of *Paula*, Isabel Allende's book about her own daughter's illness—porphyria, a rare blood disease; Paula's year in a coma, then her death. When I read the book in 1999, I was afraid that it might depress me. It did not. But it stayed with me. Will I lose my daughter? Will I go through the motions of trying to write a *Paula* myself?

Stop! I bring myself back to the present, in the middle lane of the expressway, heading toward Exit 62. It's the same exit for the Selden campus of Suffolk County Community College, where I teach a weekly writing course, so I know it well. At Southampton Hospital, I was told to drive farther north on Nichols Road "about a mile past Route 347. You can't miss it." I see the large "H" sign, then edge closer and closer to Stony Brook Hospital that, sure enough, looms high and wide, with a very tall, round building at the center of the complex. It is well lit, even in the middle of the night. I turn right and make it to the traffic light where I must then turn left and drive into the emergency area parking lot. There's no one around, so I decide to go through the light. A glance to my right, however, brings a confrontation with a police officer in a patrol car. He gestures: are you all right?

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**Coming in the other direction,  
the only vehicle he passed was  
an ambulance, lights flashing in  
the night. He knew it was  
carrying his sister.**

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I nod and give a weak smile. Without a word, we understand each other. He takes off. I'm alone again at the light that will-not-turn. I do it. I turn illegally. I'm anxious. I don't know if she's here yet—or how long she's been here, but I've got to be there, too. I ask at the entrance where I should park, and I'm told to turn around and park with the other vehicles across the way, about a city block walking distance. It's freezing cold; it's wet underfoot; I do what I'm told.

2:30 a.m.: I'm inside the emergency area now, and a receptionist points me to a door—Trauma Center. Suzanne is awake and looks a little better, not yellow like she appeared back in Southampton. She's on painkillers—I'm not sure what—but still has head pain. She is hooked up to machines that, I'm told, are controlling fluids to enter her body and lower her blood pressure. Doctors, or what appear to be

doctors, are in and out, and I answer many questions about her medical history. I have most of the answers, including her other doctors' phone numbers. I remembered to pack my telephone book, the one I keep by the phone at home. Right now, it could be a lifesaver.

Someone hands me a plastic bag. Her clothing. What she was wearing at the party when she had the seizure. I glance inside, then at the large black lettering on the plastic bag. "Patient's Belongings." Cute. I am so tired that I long to lie down somewhere, anywhere, just for a short while and doze. I ask, but this is an efficient, brisk, almost unfriendly crew here on night duty. No one seems to care. If I fall over and go into spasms, preferably cough up blood and have my eyes roll up into my head, perhaps they'll find a cot. Nothing less than a full Monty will do here, however.

3:00 a.m.: Suzanne is in and out of sleep. When awake, she winces from the pain in her head. I drag a chair over and sit down next to her. When I hold her hands, which are cold but still beautiful, I notice that her red manicured nails stand out against the pale, soft white skin. I look closely at her fingernails, as I did earlier at Southampton Hospital, to make sure they aren't rounded, curled, the way they were at age twelve when she went into cardiac failure in San Francisco. That was what you looked for, I was told. Her nails and hands were as lovely as a model's even then, as a twelve year old.

"How long have you known that she has congenital heart disease?" an emergency room doctor asked me then. I never knew. I never would have imagined. And no, to his question, there was no one else in the family with this condition, to my knowledge.

Her nails are flat now, normally rounded. Thank God. Carefully, I remove the rings. There will be lots of tests. She'll be poked and prodded by all kinds of people, possibly even crooks. The rings are safer with me. Into the handbag they go, along with the other jewelry which, in my haste and anxiety, I did not leave at her house earlier.

As I look at her sleeping face, so young-looking and vulnerable, a teenager again or even younger, bound to me not by her choice but by this horrible circumstance, I feel tears come to my eyes. I love her so much, and I may never be able to tell her that. Never. It has hurt me for years that we haven't had a warmer relationship. I've tried to rationalize it by saying, oh well, I didn't get along with my mother either, and my mother didn't along with hers, so why should this relationship be any different?

3:30 a.m.: A doctor appears who, I will soon find out, is a well-regarded neurosurgeon, Dr. Ralph Davison. He is

on call for this night, so he is in charge of the case. That's how the system works. "You the mother?" I believe he asks me. I answer his questions, which are few, and he and his colleagues intermittently write down my answers. Then, brusquely, he tells me that Suzanne probably won't survive, that she might not live until morning.

"Why?" It comes from me in the form of a cry, very deep and not really audible. I look around the brightly lit emergency room—all fluorescent overhead lights that are really too much for the middle of the night. Then I run to her bedside to make sure she's still alive. She is barely moving, but I push at her hand and she grabs it, frowning but not opening her eyes. Alive! I run down the ward after him, after Dr. Davison. "Please explain," I say to him. "Please be more specific."

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**If I fall over and go into spasms,  
preferably cough up blood and  
have my eyes roll up into my  
head, perhaps they'll find a cot.  
Nothing less than a full Monty will  
do here, however.**

---

So he goes into specifics, about trauma and her seizure and its unknown cause. He barely looks at me but directs his words more to his colleagues. I feel an immediate aversion to the man. He has no bedside manner whatsoever. Did we disturb his evening? Was he a nicer, less overbearing doctor in the daytime, after a full night's sleep?

Because of Suzanne, I was used to being around hotshot doctors, mainly at Columbia-Presbyterian, and some of them could be very haughty and aloof. Dr. Jerry Jacobs, Suzanne's late rheumatologist, took quite a bit of time to warm up to, back when she was twelve and thirteen years old. We had to learn, over time, that his manner also included great caring and empathy for his patients, and that he had a special, loving spot for Suzanne, his first patient ever with Takayasu's syndrome or "The Pulse-less Disease of Young Females." Dr. Jacobs would eventually write a chapter on Suzanne's case in his textbook on rheumatology.

4:00 a.m.: It occurs to me as I sit near Suzanne's bedside: I've never seen a copy of this chapter. I think I asked Dr. Jacobs once if I could read it. Did he brush me off, saying I wouldn't understand it? Or did this conversation never take place except in my imagination? Have I ever really *wanted*

to read the chapter or would it frighten me, more than I've already been frightened by her Takayasu's? Right this minute, here at Stony Brook, the Takayasu's is probably at the root of her seizure and brain hemorrhage. The arteries, stupid. It's got to be those arteries.

A rheumatologist appears, concerned about her arteritis. In my crazed, sleepless state I think he means arthritis. But, no, he means what he says. He's on the phone with someone from Columbia.

Suzanne will not be admitted there until December 26—and we will not learn that she has had a stroke until her neurologist at Columbia, Dr. Stephan Mayer, director of the Neurological Intensive Care Unit, looks at the first X-rays taken Tuesday night, December 19, at Southampton Hospital. No one at Southampton or at Stony Brook ever picked up on it. I'm relieved that she's finally in good hands, with her own doctors. She'll stay here for another week. Fred will fly in from Arizona when I call for help—and she will recover.

\* \* \*

In February 2010, Suzanne was hospitalized again, this time due to a kidney malfunction. I was with her then and it was I who brought her to the hospital. It meant another ten-day hospitalization for Suzanne, and her father and brother flew in from Arizona and California, respectively. Not as dramatic as the "seizure" of 2001 perhaps, but it kept us all on edge.

On May 8, 2017, mid-morning, Suzanne called me. Would I please come over and take her to the emergency room? She didn't want an ambulance. We had spoken the night before about her concerns about breathing, but both of us felt she could see her doctor the next day.

I dressed and was at her house, a thirty-minute drive, in forty-five minutes. She was in bed, her beloved cats and dogs surrounding her, too weak to get up, too weak to feed them or walk them. I did all that for her, for them, and then helped her get dressed so we could leave. "I can't . . . I can't . . ." she told me, as I tried to get her into her jeans and shirt. Not since she was a very small child did I have to help my daughter get dressed; it seemed surreal.

Then she was dressed and ready to go but, no, she couldn't walk. She was small in stature, but I wasn't strong enough to carry her. I waited for her to say it: "Call for an ambulance." *Thank God*, I thought, and quickly dialed 911. This was just another medical event, I was sure. Another scary time for her, for all of us, another long hospital stay. First Southampton, then maybe Stony Brook; and perhaps Columbia-Presbyterian, too. Whatever it took. We'd get through it. Suzanne would get through it.

But she didn't get through it, not this time. On May 11, at Stony Brook, after a succession of breathing problems, the damaged heart, the lungs, the kidney failure, all came together, and she was plugged with tubes down her throat, in her arms, and God knows where else. The team of doctors and nurses worked over her, as her father was pushed out of the room, to watch, from a distance, as her body jerked up and down until it didn't. She was dead. I arrived half an hour later, and her brother, Jeffrey, arrived half an hour after that. We missed the final act of Suzanne's struggle, and could only sit with her in the silent ICU room, now that the staff was gone, talking to each other, talking to her. May she rest in peace. ♦

# How Do You Say GOODBYE?

WAYNE RAPP

The match seemed implausible from the start.  
She was too short for this tall guy.  
Anne, a full-blooded Italian from New York.  
Wayne, a jumble from a border town in Arizona.  
She had never eaten tacos and enchiladas.  
He had never heard of gnocchi and braciolo.  
And yet, here they were spending time together.  
This short gal and this tall guy.

Thinking about the attraction, he couldn't miss her nice figure, and those dimples made her that much cuter. She was an extrovert with a great smile and laugh, natural and easy around people. She had left home to accept a teaching job in Southern California, he to work in the motion picture department of an aerospace company. And here they were spending time together.

They started attending Sunday Mass with his father's relatives, who were quickly charmed by her. When Anne made lasagna for all fourteen of them, they were won over. One aunt pulled Wayne aside, and said, "You better grab that little gal," and so that's what he did, this tall guy.

From California to Ohio they moved.  
Four beautiful children,  
Intelligent and talented.  
The couple was leading the good life.

They filled their lives with children's activities but tried to remember each other's needs and let their own love continue to grow. Anne was a teacher, an excellent one who had been honored as Outstanding New Teacher in the California school district where she first taught. She continued teaching, but as a substitute, allowing her to devote more time to raising her family. Between teaching assignments, she volunteered at Children's Hospital and her church. Always a lover of words and their proper spelling and use, she also worked as a freelance editor. A giver of time and talent to others who needed help, Anne and three friends started Respite, a program for low-income single mothers so that they could get a break and be pampered. This was a busy woman  
**until an autoimmune disease began taking control of her life.**

Inclusion  
Body  
Myositis  
(IBM)

Robbing her of strength  
In her lower extremities

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**Inclusion body myositis (IBM)** is a progressive muscle disorder characterized by inflammation, weakness, and atrophy (wasting).



**Symptoms:**

- muscle weakness progresses
- over months or years
- weakness in the thighs, wrists and fingers
- difficulty in swallowing (dysphagia)
- may have a history of frequent falls

Most people with IBM progress to disability over a period of years.  
There is currently no cure.

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A new life for the couple.  
Canes, walkers, wheelchairs  
and the stair lift. God bless  
the women who donated it.

Anne was going downhill. There were good days always followed by a bad day or a bad week. Then she had to be helped out of bed and to the stair lift, from there transported by wheelchair. Out of the blue, with the help of medication, she had a surprisingly good week and felt stronger. Things can change in an instant. They did for this couple in late September, 2017. One minute they were talking about her getting out of the house for the first time in ages. The next, she fell. Fear in his heart, Wayne sat on the floor cradling Anne gently until the rescue squad arrived.

Following a speeding ambulance to the hospital.  
Long Term Parking for the Emergency Room.  
Then the wait, the long fearful wait for details.  
“We got most of the clot, restored blood flow  
to that part of the brain.” First news was good.  
It was the hope the family needed to hang onto.  
But as long days wore on in ICU, hope faded.  
Her condition worsened, and agony set in instead.

The impact of Anne’s autoimmune disease was overshadowing the stroke. Her dysphagia, the swallowing difficulty that was a characteristic of some IBM patients, was dominating her condition. She could not rid herself of the saliva she was generating. It was choking her, making it difficult to breathe. She had to be suctioned constantly. At first, Anne had the strength to do it herself. But she was rapidly losing strength and dexterity. Her family and the nurses took over. The Palliative Care Team and her family were faced with the horrible reality of what lay ahead.

Anne was restless and slipping in and out of consciousness. When awake, she kept scooting from the center of the bed to the side, and her daughter asked her why. “I want to be next to Wayne,” she said. “Because he’s my guy.”

He hadn’t heard the remark, but when his daughter relayed it to him, he was overcome with emotion. The thought that in her last hours she was thinking about him was overwhelming. How do you say goodbye to this kind of deep love? At the end, Wayne knew he could not say goodbye to this good woman God had sent to greet him at the mailbox in Downey, California, so many years ago. He would say goodbye to her pain; he would say goodbye to her suffering. Wayne knows Anne’s spirit is still with him, and her smile and laugh would always reside in that special place in his heart until this short gal greets this tall guy again when he comes to join her. ♦



MARI-CARMEN MARIN

How to Tame Wild Thoughts

My mind knows no breaks. It works  
when I read, when I write, when I teach,  
when I drive, when I walk, when I fly,  
when I cook, when I clean, when I shower,  
when I watch TV, when I talk. Even when I  
sleep, it jerks me up and makes me scream  
and cry and kick and punch the air.

My mind never pauses. I’ve always been told, “Stop  
thinking,” or “you think too much,” as if I could turn  
off my thoughts with a remote that controls my mind.  
I’m learning how to tame them, though, these wild  
creatures. They like roaming over my body to find extra  
space and avoid trampling on each other. Sometimes they  
sit at the base of my skull till my head becomes too  
heavy. Other times, they dwell in the pit of my stomach  
and don’t leave room for food. If they go to my lungs, they  
take part of my air; if they move to my back, my spine  
creaks and bends. They always make sure I know where they are.

So I draw and do puzzles  
to quiet my mind,  
dance  
to shake off the weight of my thoughts on my body, and  
turn my spinner around and around  
till its whirring sound  
lulls them to sleep and sends  
them away like balloons  
thrown against a ceiling fan.

## INTRUDERS

8 a.m.

I'm driving on I-45 North to work—four lanes packed with sleep-deprived commuters. A man over fifty drinks a Starbucks Blonde Espresso while checking the Houston traffic in his GPS. A young brunette adds mascara to her already thick lashes between stops. I turn up the radio and listen to Roula and Ryan Show. The Weeknd is on when an image flashes through my brain—

*my brother      lying unconscious      inside his car, upside down  
like a tortoise      flipped onto its back.      His leather seat  
soaked with blood.*

*Are you okay?* I type in WhatsApp, my eyes moving fast from road to phone back to road, till his words on the screen, *Yes, why?* let go of the hand crushing my chest.

1 p.m.

I open the door to my office. My classes went well. Students talked, laughed, and left without questions. I check my phone. I have one missed call—my son's school nurse. The message cuts off after the first three words—*Hello, my name (blank)*. Silence follows and my head fills up with voices in panic:

*something's wrong    jackson is sick    but he wasn't this morning  
maybe he fell    another kid hit him    what if he's hurt? he needs you  
why didn't you check your phone before?*

I call the number, my heart in my ears. I can hardly hear the nurse's request to bring an updated record of my son's shots for the current year.

7 p.m.

It's time to cook supper—*cherigan mixto* with melted cheese and tuna using my mom's aioli recipe, the one I wrote on a Post-it note that I can't find now. It's 2 a.m. in Spain. Mom is asleep. Too late for a call. Then, it happens, the kitchen vanishing and I am in my head, the voices coming like party crashers—

*What will you do when your mom is gone?      Will you be able to tell her goodbye?  
Will she leave knowing her life was worthy?      Who will tell you yours is, too?  
Will home in Spain be still home?      How will you fill the hole of her absence?*

Pain pours out my eyes, a torrent I can't swim against.

I can't stop them—the voices, the panic, forcing themselves in until I am forced out.

# GUIDE AND GUARD

NICOLE A. SCHROEDER

“What else do you think we should know about you?”

I had been sitting in a tucked-away conference room in the corner of campus, interviewing for a summer internship via Skype. It was a question I was prepared for—after all, I’d been asked plenty of times before. On applications for financial aid, when first arriving at university, during icebreaker exercises at the start of each semester. That day, I answered the question the same way I always did. But thinking back on that moment the other night, I realized that my answer—then or any other time—was never really about myself.

*What do you think we should know about you?* Most people answer with some obscure achievement that wouldn’t fit on their resume or a hobby they enjoy in their free time. But my response was usually about my younger brother, Matthew.

It was one of those self-discoveries people can only ever make at night, when their bedrooms just aren’t dark enough and the fan’s whirring and their thoughts echo too loudly to make sleep possible. I’ve had a lot of those nights recently as I face graduation and life after school. The end of something I’ve known for so long somehow brings a new perspective on both the past and the future. But of course, that perspective has led to another realization: Thanks to

Matthew, my future will never look the same as it does for my friends.

\* \* \*

I’ve always loved stories about those families who, even when they’re a slightly dysfunctional group, look out for one another. I think it’s part of the reason I find myself drawn time and again to books like *Little Women* or to those superhero team-up films where the biggest lesson they have to learn is how to work together. The idea of putting those you love above all else in your life isn’t only heartening, to me, it’s reflective.

I know I didn’t grow up with a “typical” family (if there even is such a thing). Matthew has Down syndrome and a host of other related diagnoses, and he shapes my life in more ways than I even know. We’ve never treated Matthew any differently; I don’t even remember when I truly learned he had a disability. My two other siblings and I grew up knowing how to care for him: how to give insulin shots for his Type 1 diabetes, help him with homework, convince him to shower, and lecture him with a straight face on why we don’t shove the bath towel into the toilet when we’re upset . . . Okay, if I’m being honest, I’ve still not figured out how to do the last one. Unintentionally, Matthew has shaped all of our lives. We are his siblings, his friends, and his caregivers.

Maybe that's why I find it so odd to hear friends and classmates talk about their families in such negative terms. I've listened as a friend complained to me about having to be in the same room as his brother during the holidays when the two of them have been fighting for years over something neither of them can even remember. I've talked to classmates who can't sit through a dinner conversation with their parents, and I've known people whose only motivation to still go home is visiting their pets. Deep down, I know I can't be the only one my age who feels a stronger connection to my family than to my friends, who feels as protective of someone as I do of Matthew. But it's hard to look past it, when no one you know seems to truly empathize with or even understand your situation.

\* \* \*

Under Missouri state law, a guardian's duties are described as follows: "A guardian must always act in the best interest of the ward. The guardian of a minor is charged with responsibility for the minor's custody and control, and must act and make decisions relative to the minor's education, support, and maintenance."

For families of those with disabilities in Missouri, the guardianship process is arduous. It takes thousands of dollars, multiple meetings with a family lawyer, a year and a half of preparation and piles of paperwork to prove that once someone has turned eighteen, you are still able to take care of them and will "act in the best interest of the ward." To keep the state from stepping in and moving Matthew to a care facility after he turned eighteen, my parents and I went through police background checks and were interviewed by a judge. My mother filled out a survey that determined just how disabled my brother really is, answering questions like, "Would he know how to check that he received correct change?" or "Does he regularly practice good hygiene?" in order to determine his "level of incompetence."

My parents have already had to decide what happens to my brother when they die. Who becomes his contingent caregiver—his "back-up" guardian? Who will be there to take care of him for the rest of his life?

Of course, when we got to that point in the process, my siblings and I felt we already knew the answer.

\* \* \*

On another one of those sleepless nights a while back, as I was tapping through Instagram stories, I saw a photo posted by an old roommate and was reminded of a conversation we'd had one night a few months ago. The five of us who were living together at the time had been chatting while we ate dinner, talking about everything and nothing all at once. Someone had posed a question about how many kids each of us wanted to have when we were older, and when we got to her, she scoffed and smiled. "I'm not having any," she said. "I'm barely responsible enough to take care of myself. I don't need to be responsible for someone else, too. It'd be way too much pressure." The others laughed and agreed; I don't think they noticed when I didn't. I think it was the first time I realized that, all my life, I've grown up knowing that I could decide never to have children, but when it comes to being responsible for another human being, I've never had a choice.

When my mom first asked us who she should make Matthew's contingent caregiver, we were sitting in the parking lot after picking my sister up from high school. I spoke up first, but my sister and brother were both in agreement. It would be one of the three of us, though as the oldest and the only legal adult at the time, I was the first in line. She kept reminding each of us of the responsibility it would entail. What about our careers? Our own families? But I'd made up my mind before the words even left my mouth, and so had the others. "If my husband has a problem with it," I remember telling her, "then he wouldn't be my husband."

Not everyone sees the responsibility the same way. Last year, as I was scrolling through Twitter, I read a post written by another sibling to someone with Down syndrome. She talked about a Facebook group she'd found called "SibNet," which brought together siblings of those with disabilities from all around the world. I immediately joined, expecting to finally find people who understood what life with my brother was like.

They understood, but many of them didn't relate.

Scrolling through the posts, I was met with stories of sibs who hated the burden their parents had placed on them, who felt miserable and forgotten in their childhoods and who struggled with the things they'd had to give up in their lives to accommodate their sibling's differences. I tried to see where they were coming from. I know not everyone is born into a situation like ours—my brother is only moderately affected by his intellectual disability, and my parents were always sure to make time for each of us siblings to have a life of our own outside of serving as caregivers. But I've always leapt at the chance to talk with Matthew's teachers in school or bring him along with me to social events when my parents were busy. I've supported Matthew, just as I have always supported my other siblings, because I love him, and I can't imagine feeling resentful toward him or anyone else in the family because of his needs.

Maybe I sound defensive or judgmental. I truly don't mean to. But I've been advocating for Matthew for as long as I can remember, and sometimes I just can't relax from the fighting stance I feel I've had to adopt over the years. Perhaps my protectiveness stems from being the oldest sibling. But among those same bitter-sounding SibNet posts, there are others sprinkled throughout the page that celebrate a brother's accomplishment or show off a sister's artwork made during her day program. Maybe I simply can't see myself reflected in the page because so many other sibs, like me, have worked to keep the spotlight off themselves for so long.

As I researched for a class earlier this year, I remember sifting through legal precedents and historical accounts of the disability rights movement for a final paper, wondering whether family members like me were there when everything was taking place. Some of them were, and eventually, I found them, mentioned only in the footnotes or in one-sentence snippets from family testimonies. For so many of us, caring for our siblings is not something we want celebrated. We are not inspirational for taking care of someone we love. It's Matthew who deserves the recognition.

And for him, I'm okay only being in the footnotes.

\* \* \*

In the end, after multiple family discussions at the dinner table and a few teary-eyed hugs (after all, you can only plan for life after your parents' death for so long without getting emotional), we all decided I would be Matthew's contingent caregiver. As his siblings, the three of us knew Matthew best, and as the oldest, it only made sense that I would be first in line to take care of him. While my parents sat on one side of the courtroom that day to explain to the judge Matthew's needs, I sat beside my brother, returning his

smiles and explaining things to him under my breath when he asked questions. Of course, I learned later that the guardianship process is fickle; when the time comes, I'll still have to apply to become his guardian again with the same convoluted and expensive process as before. But somewhere among the court documents and legal paperwork my parents filled out, my name is printed there. And in truth, I love having the official legal title.

In a way, those words are proof to the world of everything I've done for my brother over the years—something that tells people what being a sibling to someone with a disability truly entails. The long hours, the added responsibility, the odd routines and schedules others might not even think about. Especially as we've gotten older, and after Matthew's diabetes diagnosis, it seems there are always insulin shots to give or finger sticks to manage or carbs to count at lunch. And there are the days when I just need to be there to watch him. Countless times, I've stayed home with him while my mom picked up my sister from school or taken him with me as I run errands around town. On those days, we'll talk about his favorite types of music or quote movies to each other in the car, challenging my memory of the cartoons that he never seems to have trouble recalling. He'll poke fun at me the way most siblings would, but when I help zip his jacket or make his sandwich, he'll tell me, "You'll make a good mother one day," and I'll smile just a little wider.

Of course we've had to sacrifice certain things as a family to accommodate his disabilities—that foodie vacation to New Orleans I've always wanted to take would need to be scheduled around his diabetes, and a camping trip in the mountains would need to look very different from what most would envision in order for Matthew to enjoy it. But I also know how many opportunities he's been excluded from: cooking in his home economics class in middle school, working a typical job out of high school, being invited to a birthday party—any birthday party—by his classmates. With all he has given up, I don't mind adjusting a few things in my life so he can participate.

\* \* \*

I'm not sure there's truly any way to make my peers understand what it's like to grow up with a sibling with a disability. It's challenging; I won't lie and say it's not. When Matthew decides to be difficult, it can take all my strength and patience not to react to his eye rolls and mumbled retorts. He's bigger than me and can't always express himself well, and when his blood sugar spikes, his excitement and frustration seem to amplify without him even realizing it. It's a lot of responsibility; I won't lie about that, either. When I stop and think about it, I measure out and deliver medication almost every day that, if I were to mess up, could kill my brother. I have fed him, bathed him, helped

him complete his homework and sat in on his medical appointments. But being Matthew's sibling has also been the most rewarding role I've been given in my life. Writing this now, I can't help but think about the tears that traced my cheeks when I saw my brothers walk across the stage at their graduation last year—Daniel first, then Matthew, taking his brother's hand at the foot of the steps, so the two of them could walk side by side to the end of a journey that Matthew had worked for fourteen long years to complete. Then and now, as his older sister, I'm proud of the small part I've played along the way.

\* \* \*

*What else do you think we should know about you?*

Among my three siblings, I have one younger brother with Down syndrome named Matthew. He is witty and funny and sweet, and one day, I will likely be fully responsible for taking care of him. I know my future will never look the same as it does for my peers. And I know that it will come with challenges and responsibilities—some that I'm prepared for and others I'm not. But for now, I am ready to embrace with open arms the day I will gain another title in life: sister, friend, advocate, caregiver, guardian. ♦

CATHERINE COUNDJERIS

## A DREAM CATCHER

A dream catcher lets dreams pass through  
like sunlight through a screen door.  
When I was nine, I joined a ballet group.  
I danced every week then  
dreamed of becoming a ballerina.

A dream catcher lets dreams pass through  
like music through walls and windows.  
At sixteen, I studied genetics in biology class,  
figuring out everyone's heritage.  
I dreamed of becoming a scientist.

A dream catcher lets dreams pass through  
like sand through an hour glass.  
In grade school, I wrote a poem,  
reading it to everyone who would listen.  
I wrote more poems and  
dreamed of becoming a poet.

A dream catcher lets dreams pass through  
like blood through white and red cells.  
My dreams hit a wall in my late twenties  
like the red-headed woodpecker  
hit the patio door on Mother's Day.  
It lived that day after a long and troubling rest  
then flew away surviving.

A dream catcher lets dreams pass through  
like tears from eye ducts.  
I hit my own wall when  
I was diagnosed with arthritis  
and my joints didn't work anymore  
and my frozen neck sat on a crooked spine.

A dream catcher lets dreams pass through  
to the other side of things.  
Now facing fifty with bamboo spine,  
my soul dances on a quiet walk down our lane.  
I study the egg sac of a praying mantis  
I study a mother fox by her den.

And I have time to write poetry  
as the ice hangs on the branches and  
the sun's golden waterfall glints off the mountain.  
A dream catcher lets dreams pass through  
like starlight through leafy tree branches.



# CREATIVITY UNLEASHED

SANDY PALMER



Rana Awadallah, *Quarantine Mood*, digital, 2048 pixels x 2048 pixels

With people sequestered in their homes during this worldwide pandemic, it isn't surprising to see creativity bursting at the seams all over the globe. COVID-19, a contentious presidential election, racism, devastating hurricanes, flooding, and wild fires all seem out of control. We yearn for normalcy. But lacking that, many creatives reflect on the situation and throw their anxieties, sadness, exhaustion, anger, and frustration onto canvases or pour them into words that flow onto paper—anything that will help channel those restless emotions into something tangible,

something we can control. Perhaps even something that brings us peace.

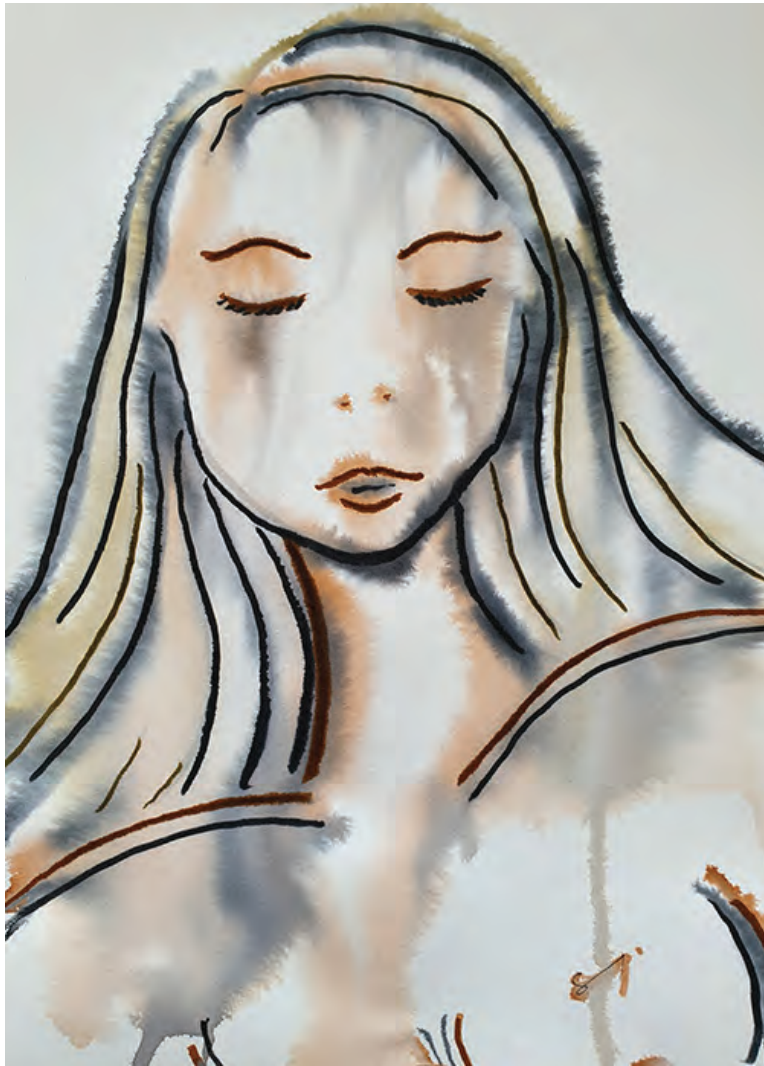
Since these are not typical times, we have decided to forego featuring just one artist in this issue. Instead, we are sharing the work of multiple artists from different parts of the world who have expressed themselves during these unusual circumstances. The pandemic may have put a halt to many things but creativity cannot be silenced. Though we have to be apart, we believe these images have the power to bring us together as we simultaneously experience current events as they unfold.



## Rana Awadallah of New York

"My inspiration for this piece was how I was feeling during the start of the COVID-19 pandemic. I just wanted to be wrapped up in a blanket and feel safe. As a person with chronic illness, I was isolated long before the pandemic started. So I was used to it, but also afraid." Born and raised in New York, Awadallah is "a black, disabled artist" who creates most of her work on an iPad with themes of chronic illness, mental health and self-love. Her childhood was less than idyllic, riddled with poverty, abuse, and trauma, which led to diagnoses of major depression and extreme anxiety. Last year, at the age of twenty-four, she was diagnosed with osteoarthritis, fibromyalgia, and polycystic ovary syndrome. After years of working in the food service industry, on her way to becoming a chef, she had to leave it all behind due to physical limitations of chronic illness. Since then, art has become a huge part of her life and she says, "Art and a beautiful community of people dealing with chronic illness are what have kept me going ever since I was diagnosed with chronic illness last year. Sending everyone lots of love."

Instagram:  
@Rana2.0 / @Rana2.0\_shop



Suzanne Berry, *Quiet Desperation*, watercolor brush pens, 11.7" x 16.5"



### **Suzanne Berry of Queensland, Australia**

"This angelic face is my vision of prayers being said in quiet desperation as the world now living in self-isolation and lockdowns waits and prays for a vaccine and an end to the COVID-19 pandemic. It embraces the heartache, suffering, fears, sadness, and faith we are experiencing globally. There is still hope, though. With this piece, I have tried to show the strength of the world as we rally and fight. Our humanity tested, we shine and fight knowing with strength and faith we will triumph." Berry was a professional artist before a seizure caused her to fall from a third-story balcony which resulted in a spinal cord injury, shattered vertebrae, brain injury, broken ribs, hip, and leg, as well as a punctured lung and liver. She feels blessed to be alive. With a T-10 injury, she has paraplegia, uses a wheelchair, and no longer has the range of motion necessary to complete large format pieces like she once did. Ten years post-injury, she has adapted and found new ways of creating art. Her current medium of choice is watercolor brush pens. She also enjoys writing poetry and plans to release an illustrated autobiographical book of her poetry and art in 2021. By the time the book is released she will also have a website revealing her new work.

Instagram: @suzanneberry0



Blur, *Mandatory vs. Optional*, digital illustration, 12" x 12"



### Blur of Pennsylvania (cover artist)

"The anti-mask movement that started after the initial lockdown quarantine in March was very confusing to me. It seemed like common sense and common decency to me, so I wanted to create an image that would give the

viewer perspective on the matter in a humorous way." Blur is an anonymous street artist and poet who strives to create unifying artwork that addresses our basic human need to be seen and heard. Starting as a sticker artist in 2015 in Philadelphia, she quickly became known for her iconic "mouth" designs and empowering prose as her work moved toward larger public installations in East Coast cities. Themes of her work focus on social/political commentary, empowering reassurance, her own experiences with dis-

ability, and healing from trauma. Her career began when her health severely declined and she suffered neurological issues that affected her speech. For a month she couldn't speak, her words became a sea of vowels, and it was during that time she pushed herself to express what she'd left unsaid. Since then she's been empowering others through her work, one mouth at a time.

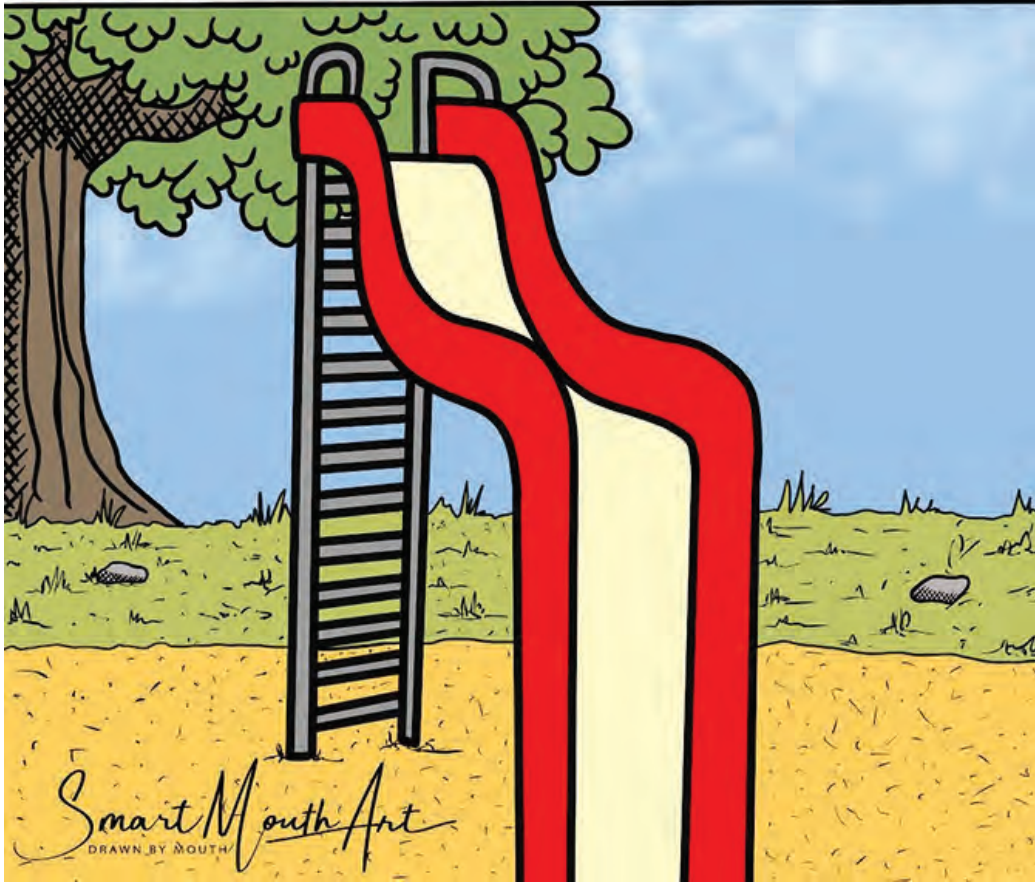
Website: [www.blurstreetart.com](http://www.blurstreetart.com)

Instagram: [@blurstreetart](https://www.instagram.com/blurstreetart)

Twitter: [@blurstreetart](https://twitter.com/blurstreetart)



# IF 2020 WAS A SLIDE



Andrew Evans, *If 2020 was a Slide*, digital (iPad/Apple pencil/Procreate)

## Andrew Evans of Queensland, Australia

Inspired by a meme he saw online, Andrew Evans created this cartoon. After losing his job in April due to COVID-19, he began drawing full time and opened an online shop on Etsy to sell his work. “It has been a steep learning curve and it’s slow going but...it’s a great feeling knowing that people around the world like my art, and I appreciate it so much.” The image shown here is printed on a mug and just one of the products available for purchase. A sporting accident resulted in a C4-C5 spinal cord injury and quadriplegia. With no functional use of his hands, he is a mouth artist. He is currently working on tutorials for his YouTube channel as a way to help other artists sell their work online, like he does. “It can be a great way for people, such as myself, with a high-level of disability to earn a living and there’s no limit to how big you can scale it.”



YouTube: Smart Mouth Art  
Instagram: @smartmouthart  
Pinterest: Smart Mouth Art  
Etsy: [www.etsy.com/au/shop/SmartMouthArtShop](http://www.etsy.com/au/shop/SmartMouthArtShop)



Gary Floden, *Yearning to Breathe Free*, digital



### **Gary Floden of Texas**

“The title, *Yearning to Breathe Free*, is an excerpt from ‘The New Colossus,’ a poem by Emma Lazarus that is mounted in bronze on the pedestal of the Statue of Liberty. I wanted to emphasize that the coronavirus is a life-changing event that continues to impact the health, well-being, and liberty of the American people.” Floden has struggled with chronic pain for thirty years and although it may prevent him from doing many things, art is not one of them. He says, “Art is my therapy.”

Instagram: @silkflour





Nicole Wheat, *Wishful Thinking*, digital, 11" x 14"

### Nicole Wheat of Delaware

"I dedicate this illustration to the lives that are put on pause due to the pandemic. The world is at a standstill and it feels like a dystopian fever dream." Wheat was born with severe bilateral hearing loss and her eyesight is deteriorating. Working digitally has allowed her to continue to create because she can use a brightly-lit screened device, enlarge the image while working to capture every detail, and select specific hues from the color wheel which provides assurance that she is working with the correct shade. "I extend the internal struggle of my disabilities by visually expressing human emotion by taking my memories, fears, and delusions, and lying them before you, encouraging your own individual association."

Website: [www.nicolewheat.com](http://www.nicolewheat.com)

Instagram: @meekonoss







### **Kim Gerry Tucker of Connecticut (back cover artist)**

“This piece was inspired by Michelle Obama’s speech about going higher. The collage contains various hidden inspirational words with images of disaster: cyclone, fire, Republican versus Democratic party symbols, COVID-19, plague mask, tidal wave, murder hornet, and more. There are figures climbing out of the chaos toward peace. That sums up 2020 to me.” Tucker was diagnosed as an adult with Asperger’s syndrome, selective mutism, dysthymia, alexithymia, and social anxiety. In her memoir *Under the Banana Moon: Living, Loving, Loss and Asperger’s*, she shares some of the struggles she has faced, as well as the laughter and love she’s experienced on her journey. Her art was featured in issue 81 of *Kaleidoscope*.

Blog/Artwork: [www.ravenambition.wordpress.com](http://www.ravenambition.wordpress.com)

### **Robaba Mohammadi and Ali Rahimi of Afghanistan (back cover artist)**

Mohammadi is from Afghanistan and at birth, her limbs were visibly different than those of other infants. She watched her brothers and sisters go to school but, as a child with a disability, she was unable to join them. With the help of her younger sister, she learned the alphabet and with a pen in her mouth, began to write. At the age of fifteen, she taught herself to paint with a brush in her mouth. Most of her time was spent alone, but she discovered “friends and followers in a virtual world” and her work has now been exhibited in multiple venues. Unable to use her hands, arms, or legs, she didn’t let that stop her and, in 2019, she founded The Robaba Cultural and Art Center where she teaches and provides assistance to people with disabilities. She collaborated with Rahimi, an instructor at the school, to create *Our Earth*, in response to the worldwide pandemic.

Facebook: Robaba Mohammadi Artist

Website: [www.robaba.org](http://www.robaba.org) ♦



# DONNY

JOHN ATKINS

Julie Anderson had a roommate. Her doctor called it major depressive disorder, but Julie wasn't convinced. It sat at the breakfast table every morning to watch as she struggled to take meds and keep down a slice of toast. It forced her to watch sappy movies and stared as she cried herself to sleep. Most nights, it whispered suggestions in her ear. "Go ahead. Kill yourself. Nobody cares. Worthless. You are worthless."

After months of struggle, Julie gave it a name: Donny Black, and he was an asshole.

Sometimes, during the early weeks of new antidepressants and over-the-counter supplements, Donny would stay several feet away, like a stalker under a new restraining order. However, she always knew he was waiting. He would be back. He always came back.

Today, Donny was pissed. Julie's psychologist prescribed a new medication she claimed could enhance the efficacy of her current drug. The downside is that it might make her suicidal. She and Julie decided it was worth the risk, since they met twice a week.

The new drug didn't work, and Donny waited six weeks before making a move. As Julie's alarm clock screeched its early morning song, Donny sat on her chest, oozing hopelessness and forcing his hot breath, smelling of rotting flesh, into her lungs.

"Thought you could win, didn't you? Thought you'd kick me out of your life, didn't you?" Donny whispered as he covered her face with a hand the size of her bed pillow. "I never lose, bitch."

Julie knew there was no reasoning with Donny when he was angry. Her best hope was to struggle just enough to let him think he won. Next, she let her body go limp. Her head filled with dark thoughts of suicide, embracing a never-ending dirt bath, accepting it as the only hope for eternal peace. Her body embraced Donny's weight until he stopped and slithered to the edge of the bed.

"Boring little loser," he said. "Boring, boring, boring. I don't know why I even bother. I'll sit here while you talk yourself into getting up one more time. While you force yourself to get dressed and see Little Doctor Headshrinker with the crappy meds and hopeful attitude. What a quack."

Donny was right. Julie would be late to her counseling session if she didn't get out of bed. It took every ounce of energy to move a body filled with lead. It seemed to weigh dozens of times more than the hundred and ten pounds her bathroom scale registered. Scales lie, as Donny was always quick to remind her. No breakfast today. What's the point? No makeup. Why bother?

A sun-drenched spring day forced Julie to squint and sounds that reminded her of birthday cake and chocolate sprinkles made her brain itch. Too nice out for Donny. Deciding the observation wasn't worth telling her doctor, Julie climbed behind the wheel of the old Impala sedan made before seat belts and headed out for her weekly appointment.

A twenty-minute drive along the narrow, winding roads gave Julie time to think. *It's all his fault. It's all his . . . my fault.* She watched passing traffic, people singing, smiling, a few talking on phones. She was tempted to push the gas to the floor and swerve into oncoming traffic. "Come and get me, Donny. I'll be gone, and you'll be dead, you heartless bastard."

Julie pointed her two-ton death missile at a late model Buick until at the last second, she saw a young boy staring from the back seat and a four-legged fluff ball riding shotgun. She yanked the steering wheel hard to the right and screeched to a halt in a shallow ditch. And there he was, sitting beside her. Donny's soul-piercing laughter filled her mind for what Julie thought was a lifetime before fading into the background. Long after he went silent and disappeared, she climbed out of her car and vowed never to drive again.

\* \* \*

Sitting with Donny at her side, Julie looked at her shoes and mumbled about the accident. "I didn't mean it. The car just skidded."

Dr. McKensie took notes on a yellow pad, nodding from time to time. "Julie, I think it's time for a more immediate treatment."

"What do you mean?" Julie wasn't sure who asked the question. Her or Donny.

"Have you ever heard of electroconvulsive therapy?"

"What? Shock treatment? You want to zap my brain?"

She heard Donny whispering in her head. "Don't do it. You'll be sorry. I won't let you get away with this. Don't you dare."

"Honestly, Julie," Dr. McKensie spoke about safety and positive long-term results. "I think it's our best option."

"Don't do it," said Donny. "You'll be sorry."

Julie closed her eyes, pretending to be lost in thought. In fact, she was fighting Donny, who had filled her mind with images of old movies about shock treatment. People with uncontrollable seizures, scorched temples, cowering

in fear. He cackled and sang, "It will be you. You'll be like them, too. It will be you, stupid girl."

Clenching her fists, Julie thought about the kid in the Buick. The dog riding shotgun. How close she had come to taking the lives of innocents. "Enough!" she shouted, her eyes hardened, cold. "Okay. Let's do this."

\* \* \*

The next morning, Julie arrived at Alachua General with the doctor's orders in hand. An orderly brought a wheelchair and whisked her past X-ray, Outpatient Services, and several other black and white signs to an isolated wing with locked doors. A chirpy young nurse greeted her and wheeled the new patient to a private room. *At least I don't have to hang out with the crazy people*, she thought.

They scheduled her first treatment for the following morning. While the rest of the ward slept, she was awakened, transferred to a gurney, and taken to a small room next to the janitor's closet.

A face with thick glasses and a smile that exposed yellowing teeth looked down at her. "I'm Dr. McCurdy. ECT is safe. You'll be fine. We will give you a little something to help you sleep. Best news? You won't remember a thing."

The doctor's assistant placed a mouth guard between her teeth as the doctor explained what was about to happen. "I'll attach an electrode to each of your temples. When you're asleep, the doctor will send a tiny electric current through your brain. Nothing to worry about, dear."

A voice behind a mask told Julie to count back from one hundred. Her body relaxed and felt warm. Just before falling asleep, she noticed a small potted plant and wondered if it was thirsty. She heard a muffled scream, just perceivable through the dense fog that enveloped her. It tried to smother her, but Julie gave herself to it just as she had

done with Donny so many times before, turned to vapor, and disappeared.

\* \* \*

Julie sat under a tree, the likes of which she had never seen. A fifty-plus foot Christmas tree, each branch adorned with a single, oblong-shaped silver fruit that pulsed with light. The tree itself had no leaves or needles, just long thin branches on a pencil-thin trunk that reached high into an ice-blue sky.

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**Julie closed her eyes, pretending to be lost in thought. In fact, she was fighting Donny, who had filled her mind with images of old movies about shock treatment.**

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As Julie stood on unsteady feet, she noticed her tree was one of dozens planted in neat rows, all well maintained, weed free. The trees, or maybe it was the fruit, filled the air with a sound that was both disturbing and peaceful. A humming, like an orchestra before the start of a concert. This place made little sense, but it wasn't a dream. She was certain that wherever this was, it was real.

"Who the hell are you and what are you doing here?" The voice, a whisper, startled Julie. She spun around to see an old black man, carrying a hoe, and wearing dusty overalls and a baseball cap.

"I'm . . . I don't know," she answered. "I can't remember."

The old man pulled a small leather-bound book from his back pocket and riffled through its worn pages. Several moments later he stopped on one of its pages and stared at its contents. "Oh," he said, looking up at the tree. "It's you."

"Who am I? And who are you?  
And . . ."

"You're not supposed to be here," he interrupted. "It's not time. I'm not ready."

Pressing her back against the tall tree, Julie said, "I asked you a question. Who are you?"

"Not ready. Go away." The man returned the book to his pocket, turned, and walked away. "Go away. Not ready."

Julie tried to follow, but her feet wouldn't move. She tried to call out but couldn't speak. The sound that moved through the air changed from humming to pulsing and piercing, and Julie tried to move lead-filled hands to her ears. Instead, her body fell in a heap and filled with a familiar warmth.

\* \* \*

"Julie? Can you hear me? Squeeze my fingers, dear."

Head spinning like the time she tried to drink herself to death, Julie gripped fingers that touched her palm. Someone said, "Good. She's coming around." She heard Donny somewhere nearby. He was whimpering.

Opening eyes that didn't want to focus, Julie asked, "Are we there yet?"

"There?" A woman dressed like a nurse smiled. "We're done, dear. Wake up a little more and I'll help you back to your room."

Images flashed in Julie's mind. People she didn't know, places she had never been. But Donny was in the room, she

saw him lying in the room's corner, hidden behind various pieces of medical equipment that seemed familiar. "Donny. I see you."

"Leave me alone," he said. "I don't want to play with you."

For the first time she could remember, Julie smiled. "Okay."

The rest of the day passed with no major incidents. There was little to do, and Julie faded in and out. Blocks of time passed without her knowledge. More images passed through her jumbled mind. An old black man made a few appearances in the forefront of her memory but seemed to melt away just as he began to speak. *I know him*, she thought. *I want to know him*.

Unless he visited when she slept, Donny did not show himself the rest of the day. Even with all the other memories that tried to force themselves through the fog that surrounded her, Julie kept thinking of Donny. *Nice to be free of him, but where is he? He'll be mad*.

As sunlight faded through the small window in her room, Julie's head had cleared enough that she wanted to get a glimpse of the world beyond her closed door. Still unsteady on her feet, Julie took small, deliberate steps as she reached for the doorknob. As her fingers touched cold metal, a familiar black man appeared just inside her eyelids and spoke more clearly than ever. "We need to talk."

Surprised, Julie slipped and fell, hitting her head hard on a cold gray linoleum floor. Just before losing consciousness, she heard Donny giggle.

\* \* \*

A familiar hum that filled the air overcame the throbbing in her head. Her eyes still closed, a pair of hands grabbed Julie's arms and pulled her to her feet. "Time to get up." She knew that voice.

"It's you," she said as if the old black man wouldn't know. "I remember this place. This tree."

"Yeah." The man's dark eyes seemed kind.

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## Even with all the other memories that tried to force themselves through the fog that surrounded her, Julie kept thinking of Donny.

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"Who are you?"

"William."

"What is this place?"

"It's us."

Julie did not understand what he meant, but somehow it made sense. "Us?"

"Yeah." Breathing slowly, William said, "It's time for us to integrate."

"What?"

"Come on, Julie. Look at me. You know me. You know who I am." He held out the leather book.

"Take it. It's our story."

As she opened the book and read the first few pages, memories flooded through her. The more she read, the more she knew. The more she knew, the more she saw. And the things she saw made her cry.

"Goddamnit." Julie knew everything. "Why did you show me this?"

"Like I said, we have to integrate. I've been the main protector, but it's time to grow. I need your pain, your experiences and you need mine. We gotta move on."

Stepping away from William and the tree, Julie listened. The humming changed to a pulsing chant, calling to her for help. She turned and looked at the tree. The silver fruit seemed to shine more brightly in time with the chant. All but a single dark red star that topped the tree. "That." She pointed to the treetop. "That's where it started, isn't it?"

"Yeah. That's our origin. We're all here because of him."

"Him? Donny?"

"No. His name is Samuel. Abused by the father from the time we could first walk until we saw Mother shoot the bastard."

Staring at the star, Julie's voice squeaked. "Dr. McKensie. She's seen Donny, hasn't she?"

"Yeah, but no one else. Not even me." Taking Julie's hand, William guided her along a well-worn path to a small tree with a single piece of fruit. "Here's where Donny lives."

Tears formed but wouldn't fall. Still and silent for a long time, Julie reached for the fruit and felt it quiver against her touch. "Why?"

"He's a persecutor. He protects you."

"Bullshit!" Julie shouted, pulling her hand away. "He tries to kill me. The asshole wants me dead."

"He does what he does to strengthen you. You front our system most."

Pressing her eyes into slits, Julie felt bile rise in her throat. "Sometimes I don't remember doing things. I figured

it was Donny not letting me wake up. But it was you, wasn't it?"

"Julie, you host this body most of the time. Sometimes it's me. A few others come out and do things neither of us know how to, like taxes, but mostly it's you."

Faces floated through Julie's mind. Increasingly familiar voices whispered to her. "Our system. You keep saying something about our system. How many?"

William looked around. "Not sure. Many of them don't talk to me. We're . . . complicated."

Walking back to the first tree, Julie turned her attention to the leather-bound book. She skimmed through pages of names, ages, colors, shapes, sizes. "How old are we?"

"I'm seventy-four. How about you?"

"Twenty-nine." Closing the book, she added, "And holding."

They both laughed. "Good for you, girl."

"William, how old is Samuel? Why can't I see him?"

"Seventeen. Same as Donny. He stays up on top, kept safe from the outside by the rest of us."

"What if I don't want to integrate? It's scary, maybe more scary than just being who I already am. Depressed all the time and barely functional."

His eyes glistening, William looked away. "Yeah. Me too. This orchard is my home. I'm safe here. But you and me, we keep Samuel safe in our own ways."

"Not me. I've tried to kill us more times than I can remember."

"But you never did. You didn't want to die, just to feel better." William cocked his head to one side and put an arm around Julie's shoulders. "You took on the sadness so Samuel didn't have to."

The tree hummed and Julie took it as a sign of gratitude.

"And Donny?"

"It's in the book."

Julie sat under the tree and read. Through its pages, the book told the story of Samuel, his early childhood trauma, his inner circle of protectors who stood guard at all times, and many other alters who were part of the system. The only family Julie had.

"Okay, William. I'm ready. Let's do this."

"I'm ready when you are. What's our name gonna be?"

"Can it wait? I'd like to know more about who we will be, not what we'll be called."

"Yeah. It can wait awhile, but not too long. We have work to do." William's voice softened. "Time for us to go."

The tree where they met began to sing, its fruit twinkling multiple colors. The two protectors' bodies melted into one another, first forming a taffy-colored lump that blurred and gurgled. The tree-song became silent and the fruit color faded to a dull gray. The lump formed into a new humanoid shape, barely five feet tall and ninety-five pounds. Lavender skin, emerald green eyes, and spiked platinum hair completed the look. "Cool. We're badass."

\* \* \*

Dr. McKensie looked at the small, dark, sobbing figure huddled in an oversized armchair pushed in a corner of her office. "Hello, Donny. What shall we talk about today?"♦



TONY GLOEGGLER

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## LARRY

Because we've taken such good care of him,  
 Larry's lived long enough to start showing signs  
 of dementia. Sometimes, it can be difficult to tell  
 the difference between possible signs and his quirky,  
 comical mannerisms. Yes, he had already stopped  
 pirouetting like a clumsy teddy bear every ten steps  
 or so, stopped reaching down to pull up his socks.  
 In fact, he hasn't worn socks in fifteen years.  
 Even yesterday, with wind blown snow  
 steadily swirling, I couldn't change his mind  
 before we walked to the corner bodega  
 and his buddy behind the counter gave him  
 his usual: coffee, black, two sugars. These days  
 he eats with his fingers more than his fork  
 and the other night when I slid the cover  
 off his straw, handed it to him, he tried  
 to suck up a rippled potato chip. He dropped  
 the straw, spread his arms wide in a *what*  
*the fuck* gesture until I rubbed his neck,  
 pushed his cup closer. Sometimes, on the way  
 to his bedroom, he turns left instead, walks  
 downstairs, spends a half hour shooting  
 on our basement hoop. Recently, he's hit  
 himself, a quick jab to the jaw a few times,  
 but he's done stuff like that before. Years ago  
 he smashed his arm through the front window.  
 A flood of blood poured out and his bicep  
 looked like chopped meat. We spent the night  
 in the ER while he drank three Diet Cokes,  
 made faces, sounds and hand signals that cracked  
 the orderlies up. We've held weekly meetings  
 with our nurse, social worker, psychologist;  
 constructed baseline charts, set up medical  
 appointments, talked about what to expect,  
 how bad things might get, possible alternate  
 placement options. But he still recognizes  
 everyone, asks for Kevin to work every night,  
 slides his hand over his smooth dome indicating  
 he wants a shave, greets me with a sideways  
 lingering hug, still moves into me when I palm  
 his head like a Nerf basketball and every evening  
 when my shift ends, he walks me to the door,  
 opens it and says *comin' tomorrow* at least twice.  
 Last night, he kept walking: through the doorway,  
 down the stoop, past the gate in his slow, side to side  
 Charlie Chaplin shuffle, all the way out to the curb.  
 I shadowed him, hugged him from behind, pressed  
 my face to his cheek, whispered something soft,  
 something silly, and helped him grab the handrail,  
 walk inside while I told him he wasn't going anywhere.

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# THESE HANDS

SARAH BUTCHIN

**I**t started with the proper amount of shame. I snuck squirts of hand sanitizer after touching student papers and practiced social distancing before it became standard. But I quickly learned that I couldn't harness the monster with a few squirts of sanitizer—I had to burn off the skin. If my hands weren't beet red and bleeding, I wasn't safe.

I'm unsure how many times I washed my hands during those days, but I know that I protected them from everything but me. I didn't allow them to touch doorknobs—the bottom of a shirt or dress did that job. They couldn't touch carts at Costco or my friends' backs when they embraced me for a hug. So they stopped hugging me. I didn't want anyone to touch me. I couldn't take the risk.

There was a time I never thought of my hands. They did what they were supposed to do, and I didn't give them a moment's attention. They weren't the center of my universe. They were utilitarian and unremarkable. I didn't concern myself with nail polish or rings, too focused on other things to care about adornment. I didn't love my hands, and I didn't hate them, because I didn't know them the way I know them now.

Throughout my teens, my hands didn't understand hard work. They weren't calloused or war-beaten. The most I put

them through was one too many passes on the oboe when my mother made me practice and late nights of writing fanfiction with my friends in notebooks we had decoupled with the faces of our favorite *Teen Beat* stars.

I played soccer. Hands weren't necessary in soccer. I was a forward and never the person to toss the ball into play. My legs carried me up and down the soccer field, just as they'd lifted me through arabesques and leaps in ballet. When I wore the skirts my mother warned me not to wear, my legs garnered glances from boys, and I liked that. I loved my legs because I understood them—what they did, what they represented, how they served me.

My hands served me too, but not as much as they would eventually scare me. They went from being commonplace to becoming my greatest enemy, my most vulnerable portal to places I didn't want to go. I never thought of my hands until I thought of nothing but them.

I was thirty when my hands took hold of my life. My husband and I were dealing with infertility. His, not mine, but ours. It was ours, but mostly mine because I needed to get the shots; I needed to grow an absurd amount of eggs in my supercharged body so a doctor could harvest them and marry them with the sperm of the man I'd married three years before.

Our reproductive endocrinologist, Dr. Patel, was amazing. We chose him because he didn't mince words. He deemed our chances of getting pregnant without medical intervention as likely "as hitting a golf ball to the moon," and I told him to take our life savings and to help me get pregnant.

Every day we injected hundreds of dollars' worth of drugs into my butt muscles before I headed to work. I was a middle school teacher, and it was October—flu season with a bunch of kids who weren't aware of how to cover their coughs. Dr. Patel had warned me that a fever, even a low-grade temp, would fry my eggs. That would be thousands of dollars down the drain, all because I was irresponsible and didn't protect myself from getting sick. He was a truth-teller, that's why I wanted to go with him in the first place, but he didn't know that his truth would reveal mine. And there was a lot to expose.

My mother had me in therapy from the time I was nine. My father's psychiatrist told her it benefited children of depressed parents to speak to someone from an early age. After our first meeting, Dr. Chefski informed my mother that I had generalized anxiety disorder, and my mother reminded him that we're Jewish, and we all do. My Jewish stomach had a hard time tolerating dairy or any small wave of anxiety. She resisted the doctor's recommendation to put me on medication until I was seventeen. All it took was one fateful night of vomiting my way through my father's birthday—and according to my disappointed father—"ruined his night." Obsessive thoughts and a crippling fear of getting sick the way I had that night were enough for my mother to allow me to go on anti-anxiety medication. My anxiety planted the seeds for a more formidable illness.

Nearly ten years after taking my first pill, my otherwise under control obsessive compulsive disorder gained force as I weaned off my Zoloft in anticipation of getting pregnant. While the medication is considered safe for pregnant women, I halted my intake just to be exceptionally safe—because of anxiety. Facing in vitro fertilization was challenging enough, but dealing with it while unmedicated was a brand-new beast.

I held tight to my husband, because his was the only hand I would hold—but only after he undertook a strict routine of

cleanliness. He said nothing about the way my anxiety had manifested itself. He recognized my sacrifice to build our family, the black and blue marks all over my lower back, how painful it became to sit. He would not complain about how I cosseted my hands, not when they were watching out for our investment.

I saw the way he looked at me, how everyone did. I wore gloves to school, wool gloves because I was "cold." There was no hiding it anymore. They all knew I'd snapped, that my hands were tugging me down a spiral. I could tell by their sad stares. I wouldn't touch the microwave in the teacher's lounge without a paper towel wrapped around my finger. Everything I did was a process, and every process began with two minutes of handwashing with steaming hot water. I wasn't secretive about IVF or my germaphobia, but I never shared the lengths I took to ensure my cleanliness. They thought they saw a lot when I stood at the sink for half of my lunch break—a wash before the microwave, one after, another once I had eaten my food, and a last trip for good measure—but they didn't know the half of it.

At home, I sprayed the cracks and wounds with bleach, relishing the excruciating sting. The sound of the faucet running was an aphrodisiac, the only release I found that poked at the problem. I loved the scent of the soaps I collected from Bath & Body Works; there wasn't a more soothing smell than Eucalyptus Mint from their aromatherapy line. The bottle touted stress relief. Stress relief—was that a thing?

I would stand over the stark white ceramic basin, wondering why it wasn't black. My hands were filthy. I felt the germs crawling on my skin, but I never saw them fall away from me. I needed to know they were gone, that they couldn't squander our investment, wouldn't make me sick through birthday dinners, wouldn't cause me to let people down, to be a problem.

I saw a therapist who specialized in infertility. She understood the emotions that surrounded a person's desperation to have a child, but she wasn't ready for me. She told me to visualize myself somewhere else to escape the germs, so I placed myself in Paris. I sat at Ladurée eating macarons with a fork and knife. I ate nothing with my hands, but I

wasn't surprised the French found my behavior offensive. They were sophisticated, and I was sick. While visualizing, I enjoyed the raspberry vanilla macarons, and when I stopped imagining myself somewhere else, I was at my sink rubbing raspberry soap all over my skin. The flecks of glitter in the soap weren't supposed to be irritating, but Bath & Body Works didn't assume people would have hands like mine.

I despised my hands, so I did my best to hurt them. From hydrogen peroxide on the soft spots to rubbing alcohol on the open wounds, I wanted the pain. They were the biggest hurdle to my wellness, yet I needed them. No matter how much I tried to ignore them, they were there, being important. Contaminated. And I was at their mercy because they'd always been there, essential to my daily life.

I should have understood it sooner, but I had been shielded, medically corrected. How much horror had I allowed by being away from my post? Maybe none. Perhaps only a few colds, but that didn't matter. Everything could've changed with one rogue touch. I had to be careful. If I wasn't, who

would've been? I didn't have control over many things, but I had control over the hands I hated. So I took it, and somehow they carried me.

I made it through two rounds of IVF without so much as a sniffle—eighteen months without a virus, fever, or bug. I was weak, but my resolve was strong, and ultimately these hands held two babies simultaneously. Once my twins were born, I had to be better for them, for me. I didn't want them to fear their hands the way I did, to feel danger with every touch. I went back on my medication when they were six months old. It took five days to get my life back. After a week, I saw glimpses and glimmers of an obsession-free future, a come to rest for my compulsions. That hope that it could be done was enough to carry me through to day ten, when I stopped thinking of my hands again and used them instead. ♦

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## Call for submissions

# K<sup>A</sup>LEIDOSCOPE

*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](mailto:kaleidoscope@udsakron.org) or online at [kaleidoscopeonline.org](http://kaleidoscopeonline.org).

# Coming Around: A Drabble

JEFF HUNT

*Editor's note: A drabble is a short work of fiction of precisely one hundred words in length.*

Playgroup goes to the carousel.

Sean and Meg hold hands—it's the first of a million times. In high school the carousel's a favorite date, and college breaks aren't complete without riding the lacquer and brass. Though later, the horses become a well of anxiety: everyone expects Sean to propose, and the carousel seems the perfect place. But it's too much pressure.

They think he can't commit. But Meg understands. So she asks Sean to ride by himself. This will be the last time anyone waits for him "to come around."

And as Sean does, Meg opens the ring box.♦

# MY MAN GEORGE

JUDI FLEISCHMAN

**I**t was hard times, so it became necessary to send my husband, George, off to do the grocery shopping. When I made a list of items we needed, I thought it would be best to go over each one, since he was a rookie grocery shopper. There were only five items on the list, one small container of ricotta cheese, sourdough bread, four center-cut pork chops, one box of boil-in-bag white rice, and one head of iceberg lettuce. George took the list, and as he was leaving, I heard him mumbling something, but I could not make out what he was saying.

When George returned, he confessed to having trouble, but he said one of the employees jumped in and helped find the ricotta cheese. As George began removing the items from the bags, I saw a container of ricotta cheese that would have lasted any Italian restaurant six months. George said he wanted to make sure we had enough. Then, I noticed George pulling out one loaf of bread after another. When I asked how much he bought, George said he found a better deal on rye bread, buy one get one free, so he bought four loaves. The

nine pork chops George chose were paper-thin, when I held one up to the light, I was sure I could see the beam in the ceiling through the chop. The rice he bought was not the rice I had envisioned, but a box of rice that required many steps to get it eatable. The iceberg lettuce turned out to be a bag of collards. George said that they were out of lettuce.

It was necessary to use a little psychology to get George to go back to the store and exchange a couple of items without damaging his ego. I came up with a plan to blame myself for not being clear enough on the list and to praise him for his efforts to seek out good deals. When George got to the store, he called me, and while we were on the phone, I heard voices. George said he had two employees helping him find the boil-in-bag rice. Once they found the rice, they all headed to produce to return the collards and get the lettuce, then to the Bread and Roll section to return four loaves of rye bread. At that point, I suggested he should come home. When George returned, he had a headache and needed to rest for a while.

Two weeks after my surgery, I had an appointment with the doctor. George insisted he drive and explained that I needed to recover completely before I got out on the road alone. It was eighty-nine degrees, so George started up the car and turned on the air for a few minutes. By the time we got to the car it was comfortable.

After my exam, we headed to the car, this time it was scorching inside. Shortly after we left the parking lot, the air stopped working. When George said, "There it goes again," I asked him, "What do you mean there it goes again?" George explained that the air conditioner had been acting up for some time, but since the heat did not bother him and he did not want to spend the money, he decided to wait. George had always been a little tight with his money, so I informed him unless he got the air fixed, I would no longer be a passenger in his car. The temperature climbed to ninety-four degrees, that is when George suggested putting the windows down. When the windows went down, the hot air came in full force. My hair went straight up, I could not hear, and George lost his potato chips to the wind.

Seven months went by, and George had not fixed the air conditioner. He was still refusing to spend the money. Of course, when the air goes, the heater goes, so when winter rolled around, and the temperature dropped in the thirties, I was sure George would rush his car to the service department and get the heater fixed, but I was wrong.

The following day, I heard George call out that he was going to the hardware store to pick up some large nails. Out of concern for George, I offered him my car, but George said the cold did not bother him, and he let me know that he had a hat and coat. I looked out of the window as George was diving away with his heavy jacket, extra-large

gloves and a hat with a fuzzy ball on the top, and I asked myself, *How could anyone be that stubborn?*

When he returned, I saw a dent on the lower left side of his car and another dent on the upper left side. George said when he was driving on Route 4, he hit a parked car and could not stop because of the traffic behind him so he went around the block to see how much damage he had done and hit the car again. George blamed the accident on the heavy moisture that had built up on the windshield. There was no way I was going to imply that he should have had the heater fixed, and it was the right decision because George moped around the house for three days before taking his car in for repair.

It drives me crazy when I see George pulling his suspenders up so high that his pants end up around his chest, leaving a part of his shirt hanging out on one side or the other, snoozing in church, and refusing to buy shoes with Velcro instead of shoestrings, even though, he complains about his back when he bends over to tie his shoestrings. There is no way I would ever trade George for anyone despite some of his quirks. George is my hero. He is smart, kind, loving, and not a day goes by that George does not feed every animal in our neighborhood, no matter what species. At times, I cannot tell what he is feeding. I love you, George. ♦



# BEFORE US

SHIRLEY EAVES

I drive to the hospital and forget where they've moved him. Oh, yes. He's in the permanent care facility now. Not the hospital. The doctors are assessing his reaction to the drugs they've prescribed and after that, well, it's up to his body, I guess. I was confused about the disease at first. The doctor was kind and tried to explain, but he used scientific words. What regular person uses words like "lateral sclerosis"? I understood "atrophy" and "prognosis," though. When I got home I looked up Drew's condition online just to make sure I understood it perfectly. Then I sat by the window facing the woods and just stared out.

I arrive at 9:00 a.m. and sit next to Drew's bed. He's awake and blinks a greeting. I bring up pleasant things, how the leaves in our backyard have changed to gold and the burning bushes are an exhilarating red; the mums next to the garage gleam purples and oranges in full bloom.

"Would you like a drink?" I say, and pick up his plastic cup. "Too bad it's not beer like those we pounded down at Vanzos, huh?" I give a false laugh that bounces off the wall and dies in a corner. Drew doesn't answer. He merely stares at the TV. It's the *Good Morning Show*, a barely altered version of the show we saw yesterday morning and the morning before that. I see the slightest bobble of his head which I take for a "yes." I tilt the cup up to his mouth and insert the straw.

I try not to notice the way his hand shakes when he wraps it around the cup or the drip of saliva sliding down his chin, try not to think about the day when even this simple task will be too much for him, how at fifty years young, my age, his nerve cells are simply shutting down. While holding the cup I escape into memory. I think of pleasant things, like the night we first met.

It was Halloween at Vanzo's bar and he was dressed up as Fred Flintstone. I was "Eggs over Easy," with an egg carton on top of my head and dressed like a hooker in animal print with cleavage down to there. He smiled at me with bleary green eyes and told me that he wanted to "Yabba dabba Drew" me. I was on my fifth beer and thought he was funny, with an original line. There was something else too, that intrigued me. A depth or sadness maybe. We were lovers at first blurry-eyed sight. I smile at the memory.

He stops drinking and burps. Belched back to the present, I pull the straw away.

I chatter. He listens. I place a hand on his arm and tell him about my latest shift at work. The blue-haired lady who left me a quarter tip, the young couple who wouldn't stop arguing as I stood at their table to take their order, the howling two-year-old boy who upset the entire restaurant and his parents wouldn't take him outside.

Drew doesn't speak. The effort of talking is too much for him, the forced words hard to decipher. It's the nature of the disease which has no cure. This is our reality now.

Six weeks and two days ago, on a Saturday, he collapsed in the Stop-N-Shop grocery and was taken to the emergency room. When I arrived, a nurse asked me if I was next-of-kin. I paused to calm myself, saw his body lying on the table like a gasping guppy, an IV in one arm, a blood pressure cuff on the other, saw the bag of groceries on its side in a corner, spaghetti noodles sticking out the top and tomatoes spilled out, and all I could say was, "He likes to cook spaghetti. He's a good cook."

"Are you his wife, then?" the nurse said. She was young with pale blond hair.

"No. We live together. But Drew has no one but me."

"I understand," the nurse said.

Once they had gathered his medical records together the picture became clearer.

"Drew's father had ALS, I see," said the doctor, a bespectacled man in his forties.

I nodded, staring at my feet. Wait. "What?" I tried to remember just what ALS meant. I'd heard of it. Some famous person had it. Lou Gehrig. That was it. I don't know why I remembered that. Didn't he die from it?

"The disease is hereditary in about ten percent of cases. Did they tell you that when Drew's father passed away?"

"Drew and I weren't together then. I'm sorry, this is hard for me to take in." I looked up and stared into piercing gray eyes. I pressed my lips together to keep from saying something stupid.

"Yes," he said. "Unfortunately, Drew has ALS, too."

This is where he started using the big words. I grabbed a pen and paper and wrote some of them down, but I wasn't listening. Not really. Part of me had flown far away.

Drew and I drank merlot at a winery by the river our first summer together. Sailboats skated by, the sun smiled down on our wine-saturated heads, a band played the music of Crosby, Stills and Nash. Later, we sat by a bonfire and watched the flames dance. I leaned my head on his shoulder and sighed, then breathed in deeply as the smells of the river and his salty smell comingled in my brain like a savory soup.

"I'm thankful for this moment and for the way our world has changed color since we met," I said.

The flames threw shadows on his face. "What color is our world now?"

"It's a vibrant mix of reds and golds," I said, and kissed him lightly on the cheek.

"The best colors of my life." He put his arm around my shoulder and pulled me closer as the blue-black night crept along the riverbank, the wine coursed through our veins, the fire logs crackled, the flames did a cha-cha in the open air.

We talked of everything. Our mutual divorces. Two for me. One for him. Our lack of children. Our deceased parents.

Everything, but the ALS that killed his father.

I'm jolted back to the present by Drew's wet cough. I wipe his lips with a Kleenex and pull out a book to read to him. Caught up in the words, for a while we are the wild and reckless characters of Kerouac, cruising on a beatnik journey of drunkenness and wonder. Before I notice, an hour has passed.

"Honey, I've got to get ready for work. I'll be back in the morning."

Drew blinks goodbye. I gave up on kisses from him.

*Maybe I'm not observant*, I think, as I drive home to change clothes before going to work at the Pizzeria Palace. Maybe Drew tried to give me clues that he was ill, but I was too dumb to notice. Drew slurred his words since the day we met. I thought the slurring was just the way he talked. Sometimes he walked with an uneven gait. When I asked him about the walk, he told me he had arthritis.

As I think back over the past summer, I realize that Drew's speech was garbled on occasion. But it was summertime with its endless barbecues, ballgames, wineries, and music festivals. We drank more in the summer. My speech was affected too, depending on how much I drank. Drew had lost weight, but I thought it was because we were eating lighter. He must have known that he had the symptoms of ALS. He knew and chose to keep it from me—maybe to keep it from himself. What would I have done in a similar situation? I couldn't say.

"Follow me down the highway to hell," he liked to joke. We were having so much fun; I didn't stop to think that he might be telling me the truth.

People at work are kind and full of well wishes and prayers. "How's Drew?" they ask. "He's holding his own," I tell them. I give them optimistic answers to cheer them up.

My boss, Arturo, sends me home with raviolis and salads, pretzels, and pizzas. "You're too skinny, Beverly. Eat," he says. I haven't cooked since the day I brought the mangled grocery sack home and sat it in the garage. The tomatoes must be rotted by now.

Time crawls onward. The leaves on the trees turn a drab brown and then slide listlessly to the earth.

I bring up boxes of sweaters from the basement, but don't have the heart to unpack them. I pull one out of a box as I need it and toss the soiled ones on a chair in our bedroom. As the days pass, the pile grows and then topples to the floor.

I'm tied up in memories. They help console me that life wasn't always so unkind. There was the night Drew and I lay naked on a blanket in the backyard, high on wine, laughing and howling at the moon. The night Drew hustled a pool shark in an Alton bar and we had to leave quickly for fear of a fight. I called him "Pool Pussy" in jest for a week after that, but was secretly glad we escaped. And there was the night we smoked grass with Jimmy Williams and hurried home to have sex. The only words I remember being able to speak while rocket high in his embrace were "Wow. Wow." The words seem ineloquent and inadequate now. Just like me.

On bad days, I sit in the chair next to his bed and touch him somewhere, anywhere. I don't talk or read. I just touch. Those are the days he can barely lift his head off the pillow, days when it's an effort to focus his eyes on my face. Some days tears spill from his eyes, followed by an empty laughter that bubbles up from him like Drano. The doctors

call it "emotional incontinence," but that's not what it is. It's Drew's way of living life to the fullest, even if he can't hold a cup.

I've reduced my work hours now to spend more time with Drew. I've turned off the incessant babble of the television and brought in my iPod to play music. Coltrane and the Beatles seem to soothe him. His skin is pale, his muscles toneless. One side of his mouth slides down toward his chin. He looks like a Pillsbury dough-boy figure of his former self. Time rises and stretches as we sit together in the music. Before I know it, another day is gone. I drive home to sleep alone.

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**He must have known that he had the symptoms of ALS. He knew and chose to keep it from me—maybe to keep it from himself.**

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I try to organize my thoughts. They're muddled messes in my head, similar to a hangover, except that I haven't had the will to drink. The laundry has piled up. The milk spoiled. I threw the carton in the trash without rinsing it and now the kitchen smells like rotten milk. I can't make myself go to the grocery store. I forgot to make the last house payment. The zinnias in a pot at the back door wilted. My Jeep is overdue for an oil change. My roots need coloring and my nails are jagged.

I don't tell Drew any of these things. I keep things upbeat.

"Hi, honey," I say one morning while planting a kiss on his forehead. I plug in my iPod and turn on Bon Jovi. "I've got a hankering for pumpkin custard. How about you, would you like some custard?" Normally, he loves pumpkin pie but he has difficulty swallowing now.

He lifts his head ever so slightly from off his pillow and looks me full in the face. The muscles strain in his neck as he tries to talk. He hasn't spoken in weeks.

"Pissin," he says.

"What?" I hover over him to listen.

He squeezes his lips. He's sweating and looks like he's run a marathon and he's only said part of a word.

"Put pissin' in."

I pick up both of his hands very slowly and press them to my lips. I try to memorize his face, each line, the green of his eyes, the cleft chin and the tiny scar next to his nose. He holds my gaze as if willing me to comprehend. The words of his favorite song by Bon Jovi needle my brain: *I don't want to live forever. I just want to live while I'm alive.*

"I understand, my love," I say finally.

A turtledove moans from the oak tree outside his window. The clock on the wall ticks. A bleach smell emanates from his pores. The medicine—for all the good it does him.

He stares at me as long as he can and then falls asleep from the effort.

I collapse into the chair and stare out the window. A mother dressed in tennis shoes and yoga pants pushes a child in a stroller. The child holds a black and white panda bear similar to one I owned as a child. An old man in a blue ball cap is pushed down the sidewalk in a wheelchair by someone who appears to be his wife. Her red scarf flaps in the breeze. Life goes on.

What did I do before us, Drew? My world changed color when you walked in. Now it's faded to its former shade of gray.

Later, on the way back to the house, I make a decision. I stop by the grocery store and buy milk, vanilla, and pumpkin in a can. I make one other stop, and then go home and cook Drew two kinds of custard: vanilla and pumpkin. While the custards cool, I take out the trash. I wash three loads of laundry and hang them up. I pour a bucket of water on the zinnias, and then I polish my nails a pale pink color. I unpack all my sweaters and place them into drawers, sorting them by color, the blacks together, and the blues. I find a box of hair dye in the bathroom cabinet and color my roots. Then I soak in a tub full of suds, so hot that it turns my bottom pink. I place a wash rag on my chest, lean back and breathe in the steam. I stay up until 3:00 a.m. high on adrenaline in spite of the bath.

The next morning, I arrive in Drew's room with a sack.

"I've brought you puddings," I say as I'm taking out plastic containers.

The morning nurse comes in to check the drip on his IV. She's my favorite nurse on this shift. She's competent, but disheveled. Just like me, without the competent part. She looks tired. I feel the urge to hug her, but I don't.

"What's this?" she says.

"Pudding."

"For him?"

"Yes, I thought he would enjoy a taste." I'm talking about Drew as if he weren't in the room and it bothers me.

"Well, it's highly irregular. Our patients are required to keep to the diet recommended by their doctor," she says. "Besides, he might choke. I'm sorry."

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**The words of his favorite song by  
Bon Jovi needle my brain: *I don't  
want to live forever. I just want to  
live while I'm alive.***

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"Just a taste?" I say. "What difference could a little bite of pudding possibly make?" I continue to unpack the pudding resolutely. "Please."

She stands in front of the window and a piece of hair falls into her eyes. Her hair could use a cut. I wonder what her life outside the hospital is like. What would it be like to be a nurse, to be anyone really, instead of the twice-divorced, unaccomplished dolt I've allowed myself to become? The best part of my life was Drew. Now our life together has blurred like a watercolor left out in the rain.

I stand by the sack like a statue and she can see that I'm unmovable.

"Well, maybe just a taste. But, please don't make a habit of bringing food in," she says.

"There's enough here for you to have some, too. Would you like vanilla or pumpkin?"

She softens. "Vanilla, please. I didn't eat breakfast this morning and I'm starved."

I hand her a container of pudding. She thanks me and walks out.

I open a container and place a spoonful on Drew's tongue. "Good?" I say. He opens his mouth slightly for another bite. I'm reminded of a baby robin and I can't help but smile. "Yes, it is good, isn't it?"

I eat some too and sit the leftovers on the windowsill. I turn on music and shut the door to Drew's room.

I pick up a special container of pudding and a different spoon and climb beside him onto his bed. I unfold a satin coverlet over our legs, taken from our bed at home. It falls off to one side and fans out, white and shiny, before us. Sitting the pudding on his tray table, I lie down beside him. I nuzzle my nose into the familiar hollow next to his shoulder and wrap an arm around his chest. He feels skinny. He's not much more than bone and skin anymore.

"You had the best smell of any man I ever met. Like seaweed and the ocean," I say. "Now you smell like Clorox."

His lips curl into a makeshift smile.

"We were meant to be together forever," I say. "You know it too, don't you?"

He blinks.

I arrange the hair on his forehead and wipe the spittle from his mouth with my sleeve. I reach over and pick up the special pudding and the spoon. About half of the pudding, which contains ground up capsules of my sleeping pills and a drug to keep us from throwing up, is probably all it will take. I'll feed half to Drew, then I'll eat the other half.

"This has poison in it, honey," I say. He looks at me at first with a question and then his eyes seem to fill with quiet resignation.

I hold a spoonful of the pudding in front of his face so that I'm sure he sees it. "I'm willing to die with you today if that's what you want. Is this what you want, Drew? If it is, then blink." He doesn't blink.

"All the other puddings are normal but I made this one special. Do you want me to feed it to you and then eat my share? Is this the way you want us to go out?" He doesn't blink.

"Can you blink your eyes today?"

He blinks.

"Is today the day we die? It's your call."

No blink.

"You want us to live." I have to choke out the words. I feel for a moment that we have reversed places, that I'm the one with the debilitating disease and he's my cheerleader. Drew blinks.

I set the pudding back on his food tray and hunker down next to him. "Okay. I'll be right here."

I'm beyond tears.

The Beatles are singing "All You Need is Love."

The day passes. We hold each other and breathe. ♦

# PARENTING AND THE PANDEMIC: ADAPTATION AND FAMILY GROWTH DURING THE COVID-19 CRISIS

ELIZABETH CUMMINGS

**I**t was a Friday morning in what has become the new normal. Breakfast was on the counter for my ten-year-old who would soon wake and join his morning class meeting on Zoom. My thirteen-year-old, a child with a complex disability, was outside listening to music on his swing, trying to regulate enough to come in and start his day. I kept one eye on my oldest in the backyard through the window while trying to work at home from a makeshift office I'd assembled in the corner of the dining room. It was our second month of stay-at-home orders, and I was leading a team meeting from my kids' Lego table while caring for my son with severe autism. Like virtually every other working parent raising a child with a disability, within hours, my world had been turned upside down by the COVID-19 crisis.

The global health emergency of 2020 brought to the national forefront an issue I have long struggled with personally. I am blessed to raise a sweet and unique child named Charlie. Charlie has enriched my life in every way, and he also has complex needs. With a range of diagnoses including a genetic disorder, intellectual disability, and severe autism, raising Charlie is a big job that requires a team of specialists and therapists. I long ago understood and ac-

cepted that because of his unique processing needs, Charlie could only handle a shortened school day. He needs multiple therapies a week and medical management as well. Before COVID-19 brought the issue to the headlines, a central theme in my life had been: How do you maintain your career while also raising your children, especially if your child has complex and diverse needs? As a full-time single parent, how could I work and also be Charlie's mom?

The answer to these complex challenges for me has been years in the making. I moved back to my hometown for many reasons, but foremost among them was the need for increased family support. Despite being on our state Medicaid waitlist for nine years, my child does not receive any respite services. As the health crisis developed, I would have preferred to fully social distance from my parents, who are in the high-risk category for COVID-19 due to age. However, it soon became clear that wasn't feasible, as the intensity of Charlie's needs at times simply requires more than one person. For years I have paid for private care for my son in our home, so that I can continue to work full time. This cost outweighs my mortgage, and is a financial challenge out of reach for many families. Despite the struggle, I realize how fortunate I am to have part-time high-quality care for my son with special needs, as well as an understanding and sup-



portive work environment. As a teacher, years ago I moved from general education to special education to help develop stronger supports for families like mine. The COVID-19 crisis has only further illuminated the need for wraparound services and a comprehensive safety net for individuals with disabilities and their families.

Despite the many challenges, this period has also been a time for personal reflection and growth. Many parents raising children with disabilities develop new skill sets over the years. As we adjust to changing realities and life expectations, many of us become more flexible and resilient, skills that have been beneficial in adjusting to new norms over the last months. A great many of us have already experienced significant life challenges. We are no strangers to hard work, and understand the delicate but important balance of self-care and caregiving as we work to juggle the needs of our families and careers simultaneously. In ways, some of my personal social opportunities have actually widened through the pandemic, as the door to technology opens. I can join a Zoom book club or online networking event from home while maintaining the presence in the house my son's safety requires. It has always been a challenge for me to join activities or events that require me to leave my home. Now, many of these opportunities are more available to me through virtual platforms as we all face the same challenge together.

In my professional work with students, this time has increased my commitment to family partnership and also offered insights of hope. As we develop classes using online methods, I am seeing my students, even those with very complex challenges, learn new skills in their use of technology. With thoughtful development, this model could take them further in education and open new doors to them in

the future. In ways, we have experienced an unplanned and communal transition in disability parenting as much of the school experience has suddenly been moved to the home setting. As a special educator and parent, I find myself more committed than ever to help create meaningful post-high school partnerships and to further develop adult services in our community.

Without question, these times have been hard. Many of our children with disabilities also have special health care needs, and I find myself worrying more about my child's health vulnerabilities as well. Social-emotional regulation has become the priority in our home, and we've very much needed the expertise of our therapists and counselors now offering services through telehealth to support our family as a whole. A trampoline for the backyard, something I've always considered, was recently dubbed an essential purchase.

But despite the challenges, on this Friday morning at the Lego table, between the French toast and the team presentation for work, it occurs to me that we are making it. It is surreal and at times overwhelming, but as a family we are learning to navigate these new challenges using the tools we have utilized to face previous obstacles. Raising a child with a disability has taught me to take one day at a time, to focus with intention on the present. I remind myself to be grateful for what is in front of me, chaotic as it feels at times. New normals are hard, but I have learned on this journey, they can also be beautiful. ♦

*Previously published in Complex Child Magazine (June 2020). Reprinted with permission of the author.*

MARI-CARMEN MARIN

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## WHEN YOU STOP CARING

I don't want the morning to come. I don't want to open my eyes.  
I don't want to see the sunlight stream in through the slats  
of the blinds announcing the beginning of a new day as in nothing  
like yesterday, as in a brand-new start, while everything I'm feeling  
is so old and heavy that I can't walk or even stand. So I lie down in bed,  
a wingless moth stuck in a spider web with nothing left to do but wait  
to die. Darkness helps me forget that I am still alive and I should fight.  
The calm in sadness brings silence to my mind, a sacred silence without  
voices screaming, demanding, demeaning, a silence swaddling me for sleep.

The phone rings and rings and rings, till it stops. It rings and rings and rings  
again. It stops. I know who it is. My husband is worried. How hard it must  
be to help put someone's pieces together, to see them break apart time and again.  
How frustrating! Tears roll down my cheeks and form a patch of my own blue  
funk in the pillow, a steady drizzle in the dark woods where I find myself dwelling.

A few minutes later—maybe hours—he rushes into our bedroom, pulls back  
the curtains, opens the blinds, and grabs me in his arms. “We are going  
to the doctor's office,” he says, without expecting a reply. With my arms  
around his neck and my head on his left shoulder, he carries the dead weight  
of my body, lifting the heavy burden of someone who has stopped caring.

# RICHARD

KIM HORNER

Richard left Terrell State Hospital with nothing but the clothes on his back and his meds. There was Se-roquel, for bipolar disorder; Celexa, for depression; and trazodone, a sedative.

Richard was suicidal when the state psychiatric hospital admitted him. He was hearing voices telling him to hurt himself again. The hospital diagnosed him with “major depression with recurrent psychotic features, alcohol, and cocaine abuse.” His records said he had tried to kill himself before.

But after three weeks, it was time for Richard to go. After he was discharged, Metrocare Services, a local mental health provider, gave Richard a ride back to one of its Dallas-area clinics. Richard was supposed to meet with a caseworker there and get connected with a boarding home. But later that night, the thin, forty-eight-year-old African-American man in a jacket far too light for the near-freezing January weather, was wandering through downtown Dallas looking for a place to sleep.

Richard may have disappeared into the streets that night if it wasn’t for the city’s annual homeless count. That’s when teams of volunteers go to shelters and outdoor spots where homeless people sleep to get an estimate of the population on a given night and survey people about their needs. It’s

a rough guesstimate at best. Volunteers cannot possibly find all the people who sleep under bridges, in tents in the woods, and cardboard boxes under the freeways, especially those who do not want to be found.

\* \* \*

Our team had just parked on a dark downtown street to look around. I was tagging along as a reporter for *The Dallas Morning News*. I was writing a story about the count and looking for people to follow for a story about chronic homelessness and the revolving door that people with severe mental illnesses and/or addictions face as they bounce from shelters to psychiatric hospitals to jails. The three of us were walking in opposite directions, surveying the area. It was after ten o’clock. No one was around. Downtown was silent aside from distant car sounds.

Then I saw someone headed our way. At first I could barely see him in the dim hazy glow from a street light farther down the street. As he came closer, I couldn’t tell if Richard was homeless. He didn’t give off any obvious signals. He wore plain, dark work pants, dark sneakers, and his light-weight tan jacket. His hair was closely cropped and he had a well-groomed mustache and slight beard. There weren’t many other reasons, though, to be in that deserted part of downtown so late at night.

I crossed the street, debating what to say. There's no way to ask someone if they are homeless without it being awkward. "Excuse me sir," I said as I approached him on the dark sidewalk, trying to be as polite as possible as I was about to ask such an intrusive question. He stopped. I introduced myself and held out my hand. He shook it and said his name was Richard Antwine. I told him I was working on a story about the count for the paper.

"Can I ask you—and don't answer if you don't want to—are you homeless?"

He nodded.

"Would it be OK if I asked you a few questions?"

"OK."

Richard's voice sounded like someone had rubbed the inside of his throat with sandpaper. He spoke in quick, jagged bursts. He said he didn't feel ready to be out of the hospital and that he had nowhere to go.

"I don't like being on the streets," he said.

Richard's responses were brief, but he answered my questions as if being stopped on the street late in the evening and asked personal questions was nothing out of the ordinary. He was candid and matter-of-fact about having bipolar disorder, a criminal history, addiction, and that he'd been in and out of psychiatric hospitals more than thirty times. It was as if he had lost so much, there was nothing left to hide.

Richard fit the textbook definition of chronic homelessness, a subset of people who have been homeless repeatedly, possibly for many years, who have serious mental illnesses and/or addictions. The chronically homeless are predominately men and disproportionately African American. They are disabled, ill, and vulnerable and we leave them to fend for themselves on the streets. In a previous era, Richard might have spent most of his life in a psychiatric facility. These days, people with severe, persistent mental illnesses like him are more likely to end up in jail, a shelter, or cardboard box under the freeway. The federal government had been putting money into housing that came with treat-

ment and other services meant to help chronically homeless people rebuild their lives. I wanted to find out if it was working. I asked Richard if I could keep in touch with him for my story. He said, "OK." He didn't have a phone. I gave him my card.

"Where are you going—do you have somewhere to stay?"

Richard looked uneasy. He shook his head.

"Do you know about The Bridge?" I asked. The Bridge, a new shelter at the time, was probably full at this hour. On really cold nights, the shelter would let people sit in the rows of uncomfortable chairs in the Welcome Center. At least it would be a place to stay warm.

"Where is it?" he asked.

I pointed past City Hall, a few blocks away. I asked him to come by the newspaper soon.

"Thanks for talking to us, Richard."

A few days later, our receptionist called my extension. I had a visitor. I went downstairs to the lobby. It was Richard. We sat down in the stylish, but stiff and uncomfortable, chairs in the lobby. His hands fidgeted and his foot tapped while we talked. Richard said he had walked from Oak Lawn, a few miles away, and he spent his days walking and looking for odd jobs such as sweeping parking lots for extra cash. As we talked, I found out that Richard had grown up in the area. He attended a South Dallas barber college. He was divorced, with three grown daughters, and a sister in Garland. He was a father, brother, barber, and, at one time, a husband.

Richard's criminal record offered more clues about why he was homeless—he had spent most of his adult life in prison or jail. Richard was locked up mostly for theft-related charges and parole violations rather than violent acts, according to records from the Texas Department of Public Safety and Dallas County Jail. When he was eighteen, he was sentenced to two years of probation for unauthorized use of a motor vehicle. After that, he was in and out of jail. When he was twenty-eight, a judge sentenced him to twen-

ty-five years in prison for unauthorized use of a vehicle. Richard was in his early forties by the time he got out. Then he was arrested for cocaine possession and spent more time in and out of prison before being admitted to Terrell State Hospital.

It didn't seem like Richard could fall much further. He never "hit" bottom—he seemed to be there from the start. What were the chances that a guy like Richard could get a job, apartment, and live a so-called normal life? There was serious mental illness and addiction. Plus, he had felonies that would make it difficult to find work. And a lack of work experience since he'd lived so much of his life behind bars.

A couple weeks later, Richard called from Medical City Dallas Hospital. He said he had been robbed and stabbed after he cashed his Social Security disability check near downtown. (He received a monthly check due to his illness. It wasn't much; about \$700 a month.) He rambled in a fast and fierce paranoid garble.

"I don't know how I got to the hospital," he said. "Nobody knows who found me; nothing. I don't know if it's a cover up."

Richard talked about being kicked out of another hospital, having his clothes stolen, and not having bus fare to leave. I hoped he would stay in the hospital a while so he could heal. I wanted to know more about Richard, his family, and childhood. He had given me the number for his sister, JoAnn, who lived in Garland, so I called. JoAnn said she has watched her brother go in and out of psychiatric institutions, shelters, and jails for years. She tries to help but has her own children to take care of. She faces a common problem for people with relatives with serious mental illnesses: Richard needs more help than she can possibly provide.

"I don't know where he is from one day to the next. If I don't hear from him, I don't have no way of calling him. He don't have a phone, and I don't know if he's dead," she said. "Sometimes I am scared to watch the news."

JoAnn did not want to talk any further about her brother. She did not return my calls when I tried to follow up.

After I started asking public mental health officials about Richard's case, he was assigned to an Assertive Community Treatment (ACT) team. ACT teams provide the most intense level of service in the public mental health care system, next to hospitalization, reserved for the most vulnerable patients, or "consumers," as they were called. ACT teams are designed to watch people with severe mental illnesses more closely and help them get to places like ap-

pointments or boarding homes. Maybe Richard wouldn't have been roaming downtown late at night after being released from Terrell if someone had made sure he got to his appointment earlier that day. As one psychiatrist who worked with people with severe mental illnesses told me, it was unrealistic to expect people struggling with schizophrenia, major depression, and other illnesses, serious side effects from medications, the withdrawals, and temptations of addictions, to navigate multiple bus transfers to get to appointments with caseworkers or psychiatrists.

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## **It didn't seem like Richard could fall much further. He never "hit" bottom—he seemed to be there from the start.**

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The ACT found Richard at the ER at Parkland Hospital in early March. He had a catheter because of his recent stab wound, and it had become infected. Once Richard was able to leave the hospital, the team helped him get situated in a boarding home called Faith House. The modest three-bedroom house offered the standard deal—\$500 a month for room and board, which would eat up most of Richard's disability check. He shared a small nondescript bedroom with two beds on opposite sides of the room, two dressers and not much else. The room was neat, clean, and bare. Richard had no photos or belongings to give his living space a personal touch. I knew so little about him. I wanted the kinds of details that help readers connect with him, to root for him. Richard was not a talker. He had the serious tone of a man in survival mode. I don't remember ever seeing him smile. A couple of other residents watching TV in the sparse living room looked over and smiled as we walked outside.

It seemed like it could be a place where Richard could work to get back on his feet. Then again, what is a person who's spent his life in prison and psychiatric hospitals getting "back" to? I didn't hear from Richard for a couple weeks. A quick check with the Lew Sterrett Justice Center showed that he had been arrested for a parole violation. I filled out a form to request an interview with Richard. The next day, the jail spokeswoman said he accepted. At the jail, I went through the metal detectors, put my purse in a locker (I wasn't allowed to take it with me), and a correctional officer took me up the elevator to another floor. He led me

down a narrow hallway and into a tiny interview room with a stained white wall and large cloudy Plexiglas window that looked into another tiny room on the other side.

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**The only comfort was knowing  
that the day before he died,  
Richard at least got to experience  
some kindness.**

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Within a few minutes, Richard sat on the other side of the window, wearing a prison uniform with thick horizontal black and gray stripes. His voice was muffled. He said he was arrested when a police officer stopped him downtown. The officer discovered a warrant for Richard's arrest because he had missed a meeting with his parole officer. Richard had a good excuse for missing the meeting—he was at Terrell State Hospital at the time being treated for suicidal depression. So, Richard spent more than a month sitting in a jail cell where he was fed skimpy bologna sandwiches and stared at the wall since he couldn't afford to buy anything to read. All because he missed a meeting with his parole officer while being treated for a life-threatening illness.

"I don't know what's going on. I'm just sitting here doing nothing when I shouldn't be here," Richard said as he stared at the counter between us.

A hearing was scheduled in April. Richard was led into the courtroom in handcuffs. He sat at a table facing the judge. His attorney, a public defender, argued that her client tried to do everything right. Suddenly, a few minutes into the hearing Richard's arm started jerking. He slumped over and fell to the floor. Within a few minutes, medics came and took him to the infirmary. The hearing was over. Nobody could or would explain what happened.

\* \* \*

"Could it have been a reaction to antipsychotic medication?" I asked a mental health care worker later.

"Maybe," he said. "But crack can also do that to you."

Richard finally got out of jail in early May. The ACT team was expecting a call when Richard was released. The plan was to pick him up from jail and take him to a boarding home. The call never came.

After his release, Richard disappeared. He did not show up in the jail log or prison database. His sister did not answer calls. Her comments about being scared to watch the news haunted me. Metrocare discovered later that Richard went to his sister's house to pick up his disability check that day. Nobody knows exactly what happened next. But he showed up at Green Oaks Hospital, another psychiatric hospital, the night he was released from jail, suicidal. He also tested positive for cocaine. Sometime after that, another parole violation—this time related to a 1989 car theft—landed him back in prison. He was released to a halfway house but had to leave after using illegal drugs there, according to the Texas Department of Criminal Justice. I did not hear from Richard after that. I hoped he'd get back in touch. Months passed with no word and no trace.

Until November 2010. That month, a man hung himself from a downtown bridge. It made the news because evening rush hour traffic was stopped for hours. Police did not release the man's name at the time. A few days later, I received an email with the subject line: "Mr. Richard Antwine." I opened it slowly. It was from a priest who had met Richard only days earlier. He wrote to let me know that Richard had died, that it was Richard who had hung himself from the bridge. The police report said that Richard was dead when officers arrived at 6:30 p.m., when it would've been getting dark. He had a shirt wrapped around his neck. It was attached to the bridge railing with his belt. The Medical Examiner ruled the death a suicide. His body was released to the Chapel of Mercy and his family had a small funeral service.

The only comfort was knowing that the day before he died, Richard at least got to experience some kindness. One of the last people Richard met was the Rev. Jemond Taylor, of Saint Michael and All Angels Episcopal Church in Dallas, who sent me the email about his death. Taylor said that Richard had approached him outside the Jubilee Community Center near Fair Park. "He said, 'You are just the man I need to see,'" Taylor said. He said he had just been released from prison. He needed clothing. "I fed Richard and inquired about DART passes," Taylor said. The reverend drove to Rockwall to pick up a donation of clothing for Richard—five shirts, a jacket, slacks, underwear, socks, and shoes—from a ministry dedicated to helping men released from prison. He never got to deliver them. "I did not find Richard during my several trips to the boarding house. No one seemed to know him there," Taylor said. "I'm still riding around with the clothes in my car."♦

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DONNA BAUMAN

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## MOMENTS AND MEMORIES

As the morning glory  
 opens to greet the dawn,  
 the sound of ocean waves  
 are heard in the distance.  
 The old wooden pier stands silent,  
 as people begin their morning walk  
 and grandchildren,  
 impatiently wait their turn  
 for the hook to be baited.  
 Splash, one grandson caught a sunfish  
 that pulled like a salmon on the line.  
 Grandpa smiles  
 and Grandma pulls out the cookies  
 to enjoy the moment.

DAVE PARK

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## BYE POLAR

I am the Icarus man.  
 Flying upwards on waxen wings.  
 The thoughts, the ideas, fast forward and I can do ANYTHING.  
 It all becomes a ball of string with endless interconnectivity.  
 Flying ever upward, sun is burning, and my thoughts become beautiful noise.

But then as always, as always, waxen wings melt.  
 Plummet into dirt, deep down.  
 I am trapped in a sticky mass of tar and muddle,  
 flight is a distant memory, and I can barely rise.

And in between, there are the days without wings, the days without tar.  
 But the cycle continues,  
 and I am the Icarus man.

## OCTOBER

The woman in the JetBlue seat  
next to me is talking about  
her weekend getaway. Every  
year she leaves NYC behind  
for fall in New England: a cabin  
made of tree trunks, feeding  
evening fires, ordering a stack  
of pancakes soaked in fresh  
tapped maple syrup, guys  
in the next booth talking  
Red Sox, Celtics and hunting,  
two lane highways winding  
deeper into woods, the explosion  
of leaves, deep brush strokes  
of colors, that breathtaking  
blend and how no words  
can touch their beauty.

No, I don't really give a crap  
about her damn leaves  
and I wish I could say that,  
strap headphones on,  
get lost in my music.  
Instead, I explain I'm going  
to visit Jesse. He turned  
twenty-two in June, graduated  
high school. I saw photos  
posted online, his family,  
his workers, surrounding him  
at Buffalo Wild Wings and Jesse  
laughing. I haven't seen him  
since May. I told him I was sick.  
My youngest brother gave me  
a kidney and recovery was slow,  
but I am moving much better now.  
It was a perfect match  
and my nephrologist said  
I'll probably have to find  
a different way to die.

He's an ex-girlfriend's son  
and I've known Jesse  
since he was five. I decide  
not to tell this woman he's autistic  
thinking she can figure it out  
if she listens. I describe  
how good it makes me feel  
when his worker drives him  
to the airport. I ask for a hug  
and he gives me one, always  
hesitating before he wraps  
his arms around me, tightens  
his hold for a few seconds.  
We do whatever he wants:  
ride the city bus, eat sizzling  
chicken fingers, French fries,  
Ben and Jerry's brownies,  
walk to the nearby bridge,  
that park in Oakledge  
to throw rocks into the lake,  
and every minute or so  
his eyes fill with delight  
as if he has discovered  
this amazing, messed up  
world and the hidden  
magic of its people  
for the first time again.

Sometime, during my visit,  
maybe when he's taking  
a short or long break  
at his apartment or riding  
in the back seat, he'll lean  
forward, tell his worker, "*Tony,*  
*come October, two nights,*  
*October 12th.*" The worker  
always tells him to talk to me  
and Jesse repeats his question,  
his demand, only a tick slower  
as he stares into my eyes.  
I nod, give him my promise.  
Boarding my flight, I already  
miss him. I feel a chill,  
the distance between New York  
and Portland growing wider  
and I hear Jesse's request  
singing in my ears like a mantra.

# STANLEY

SHEILA M. CRONIN

Mid-afternoon found Jonquil Bloom in her office at the department store mulling over her dinner menu. Meatloaf or hamburgers? She wanted things to be perfect, right down to the side dishes. Since her husband's death years ago, she'd only had to contend with her son's appetite and he'd never been a picky eater. She was still discovering her fiancé's likes and dislikes.

Her deliberations, however, were cut short by the sound of a muffled cough. Instantly, she straightened up and peered at the door but saw no one.

"It's open," she called. Possibly a curious walk-in lurked in the reception area and her assistant had gone on break.

"M-m-ms. B-bloom?"

To her utter astonishment, the Coles kid materialized in the doorway.

"Stan—?" she blurted then caught herself, remembering how much the boy detested his name. "Why, hello there, Mr. Coles. What brings you here

today?" Translation: *Have you gone AWOL from Children's Home?*

"I'm here with m-my d-dad. He's getting f-fitted for a new suit," he stammered. By the boy's casual stance, she knew he was telling the truth. His reply also informed her that the senior Mr. Coles could be located on the floor directly above them, if need be.

Stanley and she first met four months earlier at her previous job under very different circumstances. She was completing a psychology internship at Children's Home, a residential treatment center for emotionally disturbed youth. Stanley Coles, a lanky fourteen-year-old strawberry blond with a cracking voice, was admitted for acute depression and anxiety. He'd become morbidly withdrawn and refused to go to school. His parents' nasty divorce preceded his admission by two months.

Jonquil, after administering the required battery of psychological tests, met with him for a handful of supportive, follow-up sessions. He showed

progress, but allergic reactions to the medications prolonged his hospitalization.

Then, a budget snafu put a sudden end to her position. Stanley was still a patient there when Jonquil lost her job. Raising a ten-year-old son, she needed to work. A nearby department store in Santa Monica hired her, which helped keep her research on track. The serendipitous opportunity proved to be a win-win.

For she knew by then she wasn't cut out to do psychotherapy.

And the job in the store led her to become a gift counselor.

"How nice to see you," she said recovering quickly. Perhaps he'd earned a day pass? "Can I offer you a snack? We've got these gonzo cookies, fresh from our bakery." She gestured gaily toward a tray of them on the coffee table while wondering what had prompted his visit.

"I-uh, n-nah." He shook his head from side to side causing his thick eyeglasses to slide down his nose. Reflexively, he pushed them back into place.

"So, how've you been? Come, have a seat," she coaxed, indicating one of the matching wing-backed chairs opposite her desk. He complied, but had difficulty maintaining eye contact. He was trying, though; that showed improvement.

"I-I saw you on TV. Y-you did g-good." The reference to a snippet about gift counseling that had aired on local news recently broadened her smile.

"Thanks."

His tone changed. "Wh-why'd you l-leave?"

She gave him a rueful look. "It wasn't my decision. There was a problem with the budget and I had no choice. I'm so sorry I didn't get a chance to say goodbye."

His face contorted. "Wh-what is it you do h-here?"

"I'm a gift counselor. People come to see me when they need to buy a gift, but they can't do it for one reason or another. They can afford to buy a gift, but the people I deal with have issues with giving or receiving gifts. I offer suggestions to help resolve their dilemma so they can be good gift-givers."

Birthdays and wedding anniversaries were the gift occasions that regularly filled her calendar. A common complaint would begin, "My partner's nothing but a cheapskate—how can I make

him spend the same amount of money on me that I spend on him?" She'd explain that she was not there to teach people how to manipulate their loved ones, only to help them to select good gifts. Or, "My wife is so demanding. If I don't get her flowers, a fancy gift, and take her out to an upscale restaurant on her birthday, then I'm a failure as a husband and human being." She wasn't a marriage counselor, either.

"K-kids, too?" The sound of Stanley's voice brought her back to the present. His eyes roamed her office, curiosity lighting up his face.

"Kids, too." She sat back in her chair and waited.

He swallowed hard. "I g-got outta that p-place. I'm b-back in school now. I ain't crazy!"

"That's good to hear. So, how are you, Stanley?" There, she said his name.

His body, usually in perpetual motion, went limp.

"L-lonesome, I g-guess," he muttered. His chin dropped, his fists tightened, while his knees resumed knocking against each other.

Her gaze cut to the framed photo of her son Billy resting on the desk before peering back at her visitor. The man in her life had brought to her attention how lonesome her son had seemed when they first met. That observation had surprised her. Had she been too busy with school and work to notice?

"Who do you miss?" she ventured in a gentler tone.

The youth's head shot up. "You!" He uttered the one syllable minus any trace of his stutter.

Noting his vehemence, she gauged his demeanor. He seemed to be reaching out, presumably having fought down high anxiety while discovering her location in the store. Admittedly, it felt jarring to have a former patient drop by unexpectedly, but there was nothing to prevent it from happening again. So, Jonquil paid close attention.

"I must say, you sound upset today," she stated evenly.

"D-damn right." He smirked at having gotten away with the swear.

"Because—?" A strand of hair fell across her face. Reflexively, she raised her left hand to tuck it behind her ear.

"You-you—" He broke off excitedly and his face turned red. "You're en-gaged?" On cue, his voice cracked.

She fingered her ring and said, "That's right." The moment brought into sharp focus the contrast between her two employment settings. At Children's Home, she'd received comments daily about her frizzy auburn hair and freckles, her pea-green eyes, and attire. The slightest change to her appearance provoked instant feedback that ran the gamut from sweet to derisive. Whereas in the store, her engagement had garnered predictable, happy wishes from staff and patrons alike. Folding her hands on the desk, she considered her next move.

He interrupted her thoughts. "No one cares about me."

"Do *you* care about you? It starts there."

“Puh.”

“Do you love yourself, Stanley?”

He stared at the blue dreamcatcher hanging in a window across from them as she continued speaking. “The color of your eyes, for example, or your hair? Or the way your corny jokes made the other kids at Children’s Home laugh?”

He shot her a surprised look.

“I believe you do. It’s clear by your action today. I think you came here to talk to me again because you do care about yourself.”

“I hate myself,” he retorted with a healthy dose of adolescent bravado and then began biting his cuticle.

Meanwhile, the private line on her desk phone blinked. Probably her fiancé, he usually called about this time to discuss dinner. The newness of their commitment made her pulse flutter. He didn’t care if things were perfect, nor did her son. Hamburger, meatloaf, what did it matter as long as they were together? After the long years of emptiness, thank God. The simple realization calmed her and she let the call go to voicemail.

Someone was milling about in the reception area. “Excuse me, Stanley.” Jonquil stood and, after making sure it was only her assistant, pushed the adjoining door half-closed to give them more privacy. As she reclaimed her seat, she heard him ask, “D-do you like w-working here?”

“Yes, I do, very much.”

He frowned and bobbed his head. “Better than w-working with c-crazy kids, huh?”

She let a beat pass. “What do you mean?”

“Y-you know,” he said as pushed his glasses into place again.

“Hm. I’m not sure I do.”

He squirmed in his seat.

“It’s like the k-kids at that p-place were all l-losers. And...and here, um, p-people are just people.”

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**“I hate myself,”  
he retorted with a  
healthy dose of  
adolescent bravado  
and then began biting  
his cuticle.”**

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“That’s not how I see it. We all need help sometimes. We may also need to be in a safe place to receive that help. It doesn’t make a person a loser—far from it. Getting help is the smart thing to do. Some things in life are bridges, Stanley, not necessarily the destination.”

He chewed his lower lip and appeared to be taking in her words.

Jonquil decided to be more direct. “You’ve never told me whom you’re named for. You’re Jewish, aren’t you? Please tell me, I’m interested.”

“My great uncle, Uncle S-s-s-stan,” he said with disgust.

“Tell me about him.”

“He was a bum. Worked in the movies a long time ago—p-prop man. Worked for some Italian guy, Cap-something, and some other g-geezers.”

“He doesn’t sound like a bum if he had a job in the movies.”

“Whatever.” He strummed his fingers on the arms of his chair.

“Sounds like someone loved *him* enough, and *you* enough, to give you his name,” she commented.

“Puh. M-my m-mom.”

“I see. Did I ever tell you how I got the name of Jonquil?”

“Uh-uh.”

“My dad knew my mother’s favorite flowers were jonquils. So, even though it was the middle of winter in Minneapolis, he brought her a fresh bouquet of them to the hospital on the day I was born. We never learned how he managed it.”

“Oh.”

Her shoulders drooped slightly. Had she said too much about herself? Therapy could be tricky that way. Time to redirect.

“She gave me my name to always remind her of his gift. Maybe your mom gave you your name because it was special to her. Have you ever asked her about it?”

“Huh?” He licked his lips. “I should go find my d-dad now.”

“Please stay a few minutes longer. This is important. You made me a carving out of wood at Children’s Home. Do you remember?”

He grunted and his face turned red.

“You made me a gift, Stanley, with your own hands. You’re creative. It sounds like your great Uncle Stan was, too. He worked in films. Okay, so he wasn’t Dwayne Johnson. But if

he worked for a director named Frank Capra, he was there alongside of famous stars and the crew.

"Look, Stanley, you have art talent. It's part of your identity, it may be your destiny. Own it. You've inherited the rare gift of talent. Receive it. At least try to find out more about great Uncle Stan before you decide you hate your name or anything else about yourself. Will you do that much?"

Though it got quiet again, the tension he'd entered her office with had vanished. Or maybe he had tuned her out, maybe she'd overdone it and he'd stopped listening five minutes ago.

He puffed out his cheeks and let air escape his mouth. "Guess I've n-never thought about it that w-way." Then, he met her eyes unwaveringly. "Thank you, Ms. Bloom."

She smiled back at him, relieved. "Anything else I can do for you today, Stanley?"

He shook his head no.

"Go find your dad now. Would you like me to call security and have him paged?"

"Uh-uh," he adjusted his glasses again, then slipped a cell phone from his shirt pocket. "I can find him myself."

Stanley Coles stretched to his full height, gave her an adolescent "see-ya" wave, and strode a tad more confidently out of the office.

Jonquil marveled at his retreating figure. The session or visit or whatever it was had gone well, not perfectly perhaps, but well enough. She, too, felt more energized, and ready to tackle the dinner menu. *How fragile we all are*, she thought. *How amazing.* ♦

VENETIA SJOGREN

## OLE GARDEN LADY

She sits in the jungle-like garden  
(in a small, artsy, Seattle neighborhood  
where small people know everything and everyone)  
pulling weeds and filling a corroded wheelbarrow  
with a verve and vim reminiscent of her youth  
yanking them out with a determined zeal  
the entire focus is on the guilty plants.  
Neighbors walk by, picking up the pace  
as they avert their faces.  
*(If you don't make eye contact does it mean she is invisible?)*

She is nothing to them  
an unkempt and old hippy  
with a certain decrepit, aged, Camembert de Normandie, cheese smell.  
You know the one—  
pungent  
it reeks of age, disability and experience  
informs you flagrantly, that one closer is to death  
than birth (*you fear*).  
Her caramel face  
is etched with lines and crowned with dingy-colored, gray, braided hair  
and bright, metallic beads  
no Renoir, to soften her lines and wrinkled skin  
Rubens, to plump and round out her flesh  
what master would want to immortalize her.

Finished weeding, she stands  
dusts her pants off  
peers around  
while rubbing her back catches a glimpse of me  
spying out my window.  
She smiles and slowly winks.  
I pretend not to see her  
after all  
she is just a senile, old woman  
with no friends and family to drop by  
for a plate of cookies and milk  
or companionship.



# INDIVISIBLE

JON FAIN

In a waiting room, some are alone with their thoughts. Others are with a spouse, friend, or their adult children. Nurses or medical assistants call names, best-guessing the hard ones. The TV's on. Some watch it; others read, most are on their phones.

Some people watch us. My wife uses a power chair with head and neck support, and a chin control that she can use, but not in tight spaces. When we go on appointments, I run the chair to bring her into the waiting room. Give her water. Crack jokes. She's beautiful all the time, but especially when she smiles.

When people stare at her, wondering what's wrong, or maybe glad it's not them, I watch them watch. In those moments, while others focus their whole attention on her, I'm invisible.

I wasn't with her, decades ago, on the appointment when she found out what was causing her to walk unsteadily. She received the diagnosis, and called me at work. I said we'd get through it—hoped saying it would convince my own legs to stop shaking.

Multiple sclerosis symptoms come and go, leaving deficits, increased disability. In spite of this, she forged a career in city planning. After working for various towns and cities around New England, she got a job teaching at MIT part time, and leveraged her contacts and good reputation to work as a consultant.

All this time, she dealt with the “new normals” of her condition. She went from using a cane to a scooter. She could run it with her remaining good hand, but when she had medical appointments, I came along, to transfer her to exam tables, help decide what to do next, be there when the next new thing was injected to relieve symptoms or stop the “progress” of the disease.

When she could no longer drive, I took her places. I helped with her consulting business, took her to client meetings. I took her to MIT and waited while she taught classes, went to faculty meetings, and met with students.

On medical appointments, I brought my briefcase, although I wasn't working that much anymore; it was filled with a change of clothes for her. If it was an infusion that would take a couple of hours, I'd go to the cafeteria where there was one cashier who, maybe because of the briefcase and I was there a lot, always chatted to me like I was a coworker.

Throughout the years, my wife became worn down by constant, chronic pain. Her voice became weaker; she could no longer keep a classroom of sharp graduate students engaged. She wasn't being called for any consulting work either. I wished the new students and others who met her for the first time could have seen her when she was, although growing disabled, so dynamic.

When I stopped working, it was so she could, for as long as she could. But we reached a point where I was overwhelmed. Unfortunately, I began to take it out on her. I

would yell over and over that I couldn't do it anymore—that I was leaving, we should get divorced.

We made arrangements for what would become her last semester, after close to twenty-five years.

We were almost through when blood started showing up in my urine. I didn't feel sick; it would come and go. Maybe I'd done something transferring her out of bed, to her chair, the toilet, or into the shower. I delayed calling a doctor; I didn't want to find out I couldn't help her so close to the finish line.

But even after we made it, and she taught her last class, I didn't tell her or anyone else—I let it go into that summer. Until it got much worse one day, not a few drops—more blood than piss.

I called my doctor's office; because it was a Saturday, a nurse told me to go to a walk-in center. My wife wanted to go, but her sister was staying with us that weekend and could stay with her.

The waiting room had a half-dozen chairs, a line of people to check in. A TV up in a top corner, some breaking news. Some obvious couples. I stood against the wall and watched people watching TV.

No briefcase. No one helping me pretend I was there because I worked there.

No easy tricks left to make myself invisible.

But that was all right. She wasn't with me, but I wasn't alone. I had all those times I'd been with her, when she handled whatever came at her better than anyone could have imagined.

How could I not try to do the same?

Then at some point, back together, I'd have another chance to make her smile. ♦

# THINGS NOT SEEN

GRACE UTOMO

“Tests? What tests? I thought you said it was just Ivan’s eardrum.” My hands shook as I clutched the phone.

“Don’t worry, darling. Those CAT scans are probably just protocol since he fainted. One sec . . . the doctor’s sticking his head in . . .”

“But Daddy, he’s *okay*, right?”

“He’s going to be just fine, except they said he’s definitely not fit to fly—”

*Call ended.*

The tears I’d been stifling for the past two hours finally surfaced. “I’m so, so sorry, Grace,” Mom stroked my back as I slumped at the edge of her bed. “I know y’all have been working so hard to get ready for Paris. But I promise you’ll make it eventually, even if it’s not this anniversary.”

“It’s—it’s not that at all—” I choked. “I don’t care about Paris. I just want Ivan to be okay.” My own years of ER trips

foreboded those CAT scans might not be standard protocol. Was Dad telling me everything?

\* \* \*

“It’s your anniversary tomorrow, honey?” I grimaced as the nurse redressed the feeding tube protruding from my stomach. “Which one?”

“First.”

“That makes more sense . . . you look so young I thought he was your boyfriend!”

I’d stopped tallying how often I heard that, but I still forced a smile so she wouldn’t feel awkward.

“How old are you, anyway?”

“Twenty-three.”

She clucked and shook her head. “I’d ask if you have plans, but I guess we both know the answer to that one.”

Four weeks earlier I’d been hit by a car that ran a red light as I was crossing the street. A severe traumatic brain injury, two strokes, two brain bleeds, and multiple internal injuries should have ended my life that night. They didn’t. When I was still breathing the next morning, doctors wondered if I would have cognitive function when I woke from the coma. I did.

That sympathetic nurse couldn’t realize just how much our anniversary was ruined. Ivan and I forwent a traditional honeymoon since we got married while he was in grad school, but we’d planned to fly to Indonesia and meet his family around our first anniversary. Until I was hit by a car. “Celebrating” anything while I was partially paralyzed, on a restricted diet, and unable to put weight on my restructured legs might have seemed absurd. But all those injuries meant I was very much alive, and my being alive meant we were very much married. And *that* was worth celebrating, even in a sterile white hospital room with my roommate blaring her crime show on the other side of the curtain.

Ivan was late to dinner that night. He'd spent the day moving from our rickety second-story apartment to a first-floor handicap unit, and I realized it must have been raining since his coat was nearly soaked when he slung it over a chair beside my bed.

But as Ivan gulped down his plate of hospital fried rice and I picked at teaspoonfuls of mashed potatoes (I'd just been upgraded from "nothing by mouth" to "soft foods"), I noticed more to worry over than a wet jacket. Ivan's eyes are large and round despite his Asian background, and I was startled by how narrow and strained they suddenly seemed.

"Hey, Ivan?" It took me a couple of tries to get his attention. My roommate certainly was enjoying the volume on her TV. "I'm not mad about all this—are you? It's hard to be mad when things could have been so much worse. I mean, think about it. They said I should have died that night." These thoughts bolstered me on days when I was tempted to give up. Had it been a mistake to assume Ivan felt the same way?

"I know." The weight behind his eyes made me wonder if he was afraid I couldn't handle what he really thought.

"But we both still think God has some sort of purpose since he kept me alive, right?" I ventured, hoping his eyes would release a little.

He nodded.

"Right." I echoed myself, still watching his eyes. "I'm sure this will all make sense at some point. And hopefully we can have a *real* anniversary next year!"

\* \* \*

*Our second anniversary was nothing like the first.* That's what I'd hoped to post on my blog in December 2017. I'd imagined resuming our lives as free-spirited newlyweds once I was discharged from the hospital at the beginning of the year. But we discovered that managing my recovery was a full-time job, and my mom moved into our three-room apartment in Riverside, California, to care for me while Ivan finished school. He graduated five months later—around the time I was classified as legally disabled—and found a job near my parents' home in San Jose so they could care for me while he worked. As for me, I started a blog and an online English degree to exercise the only portion of my brain that hadn't been permanently damaged—the verbal portion.

*Our second anniversary was nothing like the first.* That particular lede never made it on the blog because our second anniversary was almost identical to our first. I'd developed violent, medication-resistant seizures, and my neurologist had admitted me to an epilepsy monitoring unit for further diagnosis.

My eyes crawled along the gauze tail that connected my wire turban to a machine at the upper left-hand corner of my bed, a machine that was recording my brain waves twenty-four hours a day. The tail was long enough for

me to sit up in bed—and shuffle to the airplane-sized bathroom a few yards away—but how long was the tail of my accident?

"Your anniversary's in a couple of weeks," Mom interrupted my thoughts as she passed me a second coffee. Some seizure drugs were worse than sedatives.

"Um, yeah . . ." I hedged. "I'd hoped it was going to be better than last year's, but . . ." There was nothing to follow the "but." My seizures were still unexplained and I'd already decided I was making our second anniversary even worse than our first had been.

"It *is* better than last year's," she corrected, brushing some stubbornly blond curls behind her ear. "You have each other and you've made it another year in spite of some pretty awful circumstances. And you still believe in God's plan, right?" I sighed. Mom was right. Ivan probably said she was right, too, although I can't actually remember.

I also can't remember what we did for our anniversary.

Those drugs must have tampered with my memory.

\* \* \*

CARLA'S COUNTRY KITCHEN. I think the letters were scrawled in large white cursive across a royal blue awning, but I'm not sure. My eyes were closed so I wouldn't have a seizure from the bright headlights still shining at 7:30 a.m. It was December 30,

2018—our third anniversary and the first one on which I’d managed to stay out of the hospital.

By this time Ivan and I knew my seizures were permanent, so we were too nervous to stray far from my parents in case something went wrong. But we were also determined to try *something* on our own, especially after two years of doing nothing. We finally settled on two nights in Morro Bay, which was our original “mini honeymoon” and only a couple of hours from San Jose.

Morro Bay was our favorite pre-accident memory of just the two of us enjoying each other, and Carla’s seafood omelets were our richest Morro Bay experience away from the boardwalk. Ivan wanted to scrap the Carla’s breakfast in favor of microwaved oatmeal at our Airbnb so I wouldn’t have a seizure from car headlights in the early morning, but I said absolutely not. My only concession was closing my eyes until we were safely inside.

And, so, we shuffled into Carla’s stuffy dining room fifteen minutes after its sign blinked “OPEN.” This could have been the day after our last breakfast in 2015 for all that had changed. I considered joking about our own sameness—or lack thereof—but decided the pills I was swallowing with my starter coffee probably made the joke for me. Ivan, ever the philosophizer, commented that the only part of us that was the same was our belief that things happened for a reason.

\* \* \*

I was right. Dad wasn’t telling me everything about those CAT scans. Not only had Ivan punctured his right ear canal, but he had also fractured his right jawbone in three places and his cheekbone next to his sinuses. The hospital was scrambling to fit him in for jaw surgery.

I canceled our flight to Paris the next day.

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**Ivan, ever the philosophizer, commented that the only part of us that was the same was our belief that things happened for a reason.**

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Morro Bay had slaked our thirst for a “real” anniversary at the time, but it quickly became mere bait for that thwarted international honeymoon. Another year of hospital visits and worsening neurological conditions convinced us that if we waited for me to get better, we might never go. Our original plan to visit Ivan’s Indonesian relatives was out of the question since we couldn’t risk a third world country with my disabilities, but Europe offered an advanced healthcare system along with its centuries of history. My obsession with modernist literature and Ivan’s fixation on Chopin made Paris an alluring choice. What better destination for our fifth anniversary next year? But when the school where Ivan taught choir scheduled a European tour over spring break, we realized seeing Europe for the first time together meant visiting *now*, even if we had less time to prepare.

And so we bought two non-refundable tickets in September and spent the next ninety days plotting our Parisian adventure. Our itinerary was conservative yet—to us—perfect: The Musée D’Orsay, Notre Dame, a day of Christmas marketing, chamber music at Saint Chapelle (for him), and lunch at Les

Deux Magots with an excursion to the Bouquinistes (for me). While my parents visited Europe frequently—and were probably worrying over which safety hazards we’d ignored—they limited their proffered help to an oversized suitcase, a French language book, and a ride to the San Francisco airport. They understood this was *our* trip, our self-actualization as independent adults. As the days until our departure dwindled, I wondered if this anniversary might also meet another increasingly desperate need. Perhaps, surrounded by the glamour of Paris, we’d finally glimpse that elusive greater meaning behind my accident.

Ivan came down with a stomach virus four nights before we left. I wasn’t particularly worried—Didn’t those peeter out after twenty-four hours?—but I grew puzzled when I heard a thud, then silence, then scrubbing after he headed for the bathroom around two in the morning. I decided that he must not have made it to the toilet in time, but I finally investigated after the scrubbing continued for twenty minutes. I was horrified to find him seated by the bathtub, blood trickling out of his right ear.

When I asked what happened, Ivan only shook his head and pointed to a string of text messages on his iPhone. Apparently he’d fainted and thought he damaged his ear drum, then texted my parents, who were already on their way. He explained later that he hadn’t called out to me in case I panicked, flipped the wrong lights, and triggered a seizure. He’d spent twenty minutes scrubbing blood off the floor—and himself—for the same reason. Ivan wouldn’t speak to me after I *did* discover him since his mouth was still full of blood. Mom and Dad arrived a few minutes later: Dad rushed him to the ER while Mom took me to their condo to soothe me while I waited.

Two weeks later, Ivan and I sat facing each other in my parents' spare bedroom, where we'd been living since Dad brought him home from the hospital. It was December 30, 2019. Our fourth anniversary. Mom, undeterred by post-surgical restrictions, had tried her best to evoke a romantic atmosphere. Her "gourmet" menu consisted of roasted cauliflower soup with slices of toasted baguette for me, a translucent cauliflower-water adaptation for him, and sparkling apple cider for both of us. No table was the right height for Ivan to reach his "soup" from the recliner that kept his head at the proper angle, so she'd positioned the bench from the family piano beside his arm rest instead. I ate beside him on my knees. Dimmed lights, a Spotify playlist, and—voilà! A romantic, convalescent, pseudo-European anniversary dinner.

But all I could think about was our first anniversary at the hospital. Ivan's head was swathed in bandages from his surgery and his jaw was wired shut. Now *he* was the one on a restricted diet. Unlike me for our first anniversary, Ivan couldn't even talk, at least with his own voice. He'd become surprisingly flu-

ent in Google translate, although I was a still off-put every time my husband sounded like a computerized woman.

Would we ever grow up? We didn't have a "move home" date on the calendar since I couldn't take care of Ivan by myself. His recovery from this surgery alone would be at least six weeks—not to mention that second jaw procedure the surgeon kept mentioning. I'd blamed my accident for all our problems, but apparently accidents could happen to Ivan, too. Wasn't there some sort of "enough" button to push on life? As in, "Have experienced enough trials, have earned right to nice life." Or at least a "Deserve answers now, please," button. I was twenty-six. My health only got worse. We'd only had one normal year of marriage.

"Thanks for being the bestest wife ever. Smiley face."

An automated female voice punctuated my thoughts and forced me to laugh.

My favorite part about Ivan's "phone voice" was that it read emojis verbatim. "I love you too, sayang," I said, using his Indonesian nickname. Our anniversary wasn't a total failure. We were still together. We were even stronger.

But what about the bigger purpose that was supposed to make sense of our lives? I couldn't see that anywhere. *Now faith is the assurance of things hoped for, the conviction of things not seen.* The phrase from my childhood comforted me, in spite of that plane ticket cancellation sitting in my inbox and my husband sipping soup-water from a food syringe. I realized that, just like at the hospital, I could still choose what to think. Did I really need Paris to believe in a good God or a purpose for our lives?

"You know what? I think we can still say this is a good anniversary." I reached up and touched Ivan's hand, hoping he'd understand what I meant.

"Let's do year five in Paris. Smiley face," the phone voice chirped back at me. ♦



DANIEL MARK PATTERSON

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## CELEBRATORY MADNESS

*You seem fine* said the nurse practitioner.  
As if it didn't take me years of  
fear, anxiety, depression,  
to extend a trembling hand.

As if all of us who are broken,  
flash this in neon lights on our foreheads.  
As if we don't camouflage  
our vulnerability to survive.

*You're intelligent and articulate.*  
*You have a good sense of humor.*

She never saw the hours and days  
hiding in my room,  
because I didn't want to face the other people  
living in the same house.  
Never mind the outside world.

The number of times  
I've rehearsed this conversation.  
The tremor in my throat as I  
force out the words  
*I'm not coping. I haven't been for a long time.*

It takes a year of pleading,  
before I get an assessment.  
The psychologist eyes me like an exotic insect.

His diagnosis takes minutes:  
*Severe depression,*  
*severe anxiety disorder,*  
*severe social avoidant personality disorder.*  
Describes me as cold, emotionless,  
lacking empathy.  
Robotically rattles off the traits of a psychopath.

In actuality I disassociated myself,  
hid my emotions away  
as he took a meat cleaver to the sacred,  
dropped pieces of personality in neat,  
tidy boxes.

I laughed, silently, bitterly,  
as he said  
I would never be able to speak in public,  
my lack of emotions would stop me  
from ever truly being able to fall in love,  
from ever developing close friendships

with other human beings.

I never told him about the years  
of Theatre and Spoken Word.  
Kept the car crash heartbreak to myself.  
Never told him about those friends  
I loved so fiercely,  
the times that love saved my life.

Truth is even though I was a  
long way from understood,  
part of me was just happy to be finally seen.  
My dysfunction displayed like a merit badge.

How do we know you're disabled? Prove it.  
The jurors  
scrutinize me for hunched shoulders,  
lack of dignity, obvious weakness.  
Where is your stammer? Remove request.  
Replace it with a grovel.

For 3 years I fell through the  
titanic fault lines of this system,  
my less than, not less enough,  
my destitution too hopeful.

The letter finally arrived:  
"Congratulations,  
you have been found permanently disabled."  
As if it was something to celebrate.  
*You're super-calla-fragilistic-exbe-broke-a-docius,*  
*even though the sound of it*  
*is something quite atrocious,*  
*you're super-calla-fragilistic-exbe-broke-a-docius!*

*Congratulations you lucky few,*  
*you lowest of low,*  
*your failures are fully documented.*

*Dance with stooped shoulders,*  
*dance without joy,*  
*dance with surrender in your heart,*  
*slower, get that spry out of your step,*  
*that glimmer out of your eye.*

*Yes. Excellent. Excellent.*  
*Bravo. Job. Well. Done.*

**John Atkins** was abused as a child and began “building worlds and stories” within himself as a way to cope with the experience. He has grown, learned, watched, worked, retired, and is now sharing his findings with others. His work appeared in *The Esthetic Apostle* (August 2018).

**Donna Bauman** lives in West Covina, California, and has been writing articles and poetry for twenty-five years. Her work has been published in *Purpose Magazine*, *The Gem*, *Kaleidoscope*, and many others. She has cerebral palsy and says, “I write for the reader and to share with them.”

**Shawna Borman** holds an M.F.A from the University of Southern Maine’s Stonecoast program. She believes having muscular dystrophy gives her the ability to create realistic characters with disabilities in the stories she writes. The essay published in this issue was a nonfiction finalist in the 2019 Pen 2 Paper contest.

**Sarah Butchin** lives in Scottsdale, Arizona, and is the author of *In the Time of Towertown* (Black Rose Writing). Her work has been published by, or is forthcoming in, *The Smart Set*, *Across the Margin*, *Grey Sparrow Journal*, *From Whispers to Roars*, *The Big Windows Review*, and *Flora Fiction*. She is currently an M.F.A. candidate at Lindenwood University.

**Catherine Coundjeris**, a former teacher, defines herself as “a perpetual student.” She lives in Frederick, Maryland, and says, “I write because it transports me out of myself and into another dimension.” Her work has appeared in *Nine Cloud Journal* (August 2020), *Yellow Arrow Journal* (Spring 2020), and *Inkling Magazine* (2020).

**Sheila M. Cronin** is a retired psychiatric art therapist who lives in Chicago, Illinois. Her book *The Gift Counselor* (2014) won the Beverly Hills International Book Award and the sequel *Best of All Gifts* (2017) was short listed for the Wishing Shelf Book Award. She lives with scoliosis and arthritis and says, “My writing is an expression of hope. Through writing, I endeavor to make the world a better place.”

**Elizabeth Cummings** is a special education teacher from Kalispell, Montana, who is mother to two boys, one with a complex disability. She also serves on the Rural Institute Consumer Advisory Council for Inclusive Communities. Her work has appeared in *Complex Child Magazine* (June 2020) and *Montana Voices Amplified*, *University of Montana Rural Institute: A Center for Excellence in Developmental Disability* (July 2020).

**Cindy Decker** lives in St. Marys, Pennsylvania, and loves animals and art. Being diagnosed with bipolar disorder and depression has made her more sensitive to others and she says she writes because, “I feel I have something valuable to say.”

**Shirley Eaves** lives in Edwardsville, Illinois, and has creative writing certificates from UCLA and Stanford University. Publication credits include *T-Zero Quarterly* (January 2009), *Short Story America* (March 2010), among others. Her seven-month-old daughter died from spinal muscular atrophy and she says, “The element of death and loss is present in much of my work.”

**sarah elizabeth** lives in the East Tennessee mountains and is a contributing writer for the StoryTown Radio Show and Podcast on the NPR station WETS. Her work has appeared in *Chicken Soup for the Soul: The Magic of Dogs, Haints and Hollers*, and *Lucky Jefferson*. She enjoys spending time with God, her children, and their rescue dog, Finn.

**Jon Fain** is a freelance writer and editor who began publishing fiction in the ’80s. His work has appeared in *Oak Square Magazine*, *VerbSap*, and *Winning Writers*, among others. He lives in Andover, Massachusetts, with his wife who has MS, and the story published in this issue “is adapted from a memoir-in-progress, tentatively titled, *Disabled Like Us—A Love Story*.”

**Judi Fleischman** is a retired medical technologist who has been drawing and painting since childhood. With art, and with writing, she recreates life experiences. Her book *A Time to Remember or Forget* was published in 2019 and her art has been exhibited at the Arts Alive Center in West Point, Virginia.

**Tony Gloeggler** worked and managed group homes for people with developmental disabilities for forty years and says, “I want to understand and express what goes on in my life, and writing is what helps me do it best.” His books include *One Wish Left* (Pavement Saw Press, 2002), *The Last Lie* (NYQ Books, 2010), and *Until The Last Light Leaves* (NYQ Books, 2015). He won the Pearl Poetry Prize in 1988 and has received Pushcart Prize nominations.

**Kim Horner** is a communications manager and currently pursuing a master’s degree in creative writing from the University of Arkansas at Monticello. Her work has appeared in *Seventeen* and *Ten Spurs*. “I am passionate about reducing stigma and telling stories that I hope can help change misperceptions and educate people about mental illness.”

**Ann-Chadwell Humphries** has always loved poetry, but did not begin to write until she retired. She lives in Columbia, South Carolina, and has won numerous poetry contests, an emerging voice award, and a writing scholarship. Her work has been published in *Jasper Magazine*, *Emrys*, and *Fall Lines*, among others. Selected by Muddy Ford Press for its Laureate series, her first book of poems, *An Eclipse and a Butcher*, was recently published (2020).

**Jeff Hunt** lives in High Point, North Carolina, and is a teacher. His stories have appeared in *The Norwegian American*, *New Myths*, *Cleaver Magazine*, and *Eunoia Review*. He has received honorable mention twice from Writers of the Future and says, “I write because it’s how I express myself.”

**Mari-Carmen Marin** has a Ph.D. from the University of Zaragoza, in Spain, and is now a professor of English living in Spring, Texas. Her work has appeared in *Mothers Always Write* (June 2020), *The Comstock Review* (Spring/Summer 2020), and *Poetica Review*. “I write because it helps me make sense of myself and the world. Turning anxiety and depression into art has helped me understand it, accept it, and deal with it.”

**Eileen Obser** is an author and teacher living in East Hampton, New York. Her memoir *Only You* was chosen as winner of Oak Tree Press’s memoir contest and was published in 2014. Her work has also appeared in *Newsday Sunday Magazine*, *Proteus*, and *The Southampton Review*. Earning a master’s degree in her sixties led to even more writing.

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

**Dave Park** lives in Ontario, Canada, where he is an IT solutions provider by day and an author by night. His work has been published in *iBusiness Magazine* and *CannaB2B Magazine*. He says having a bipolar diagnosis has given him a different worldview. “I believe we are all artists, just some of us choose to practice.”

**Daniel Mark Patterson** is a writer, poet, and spoken word artist who lives in Ontario, Canada. His work has appeared in *Scarlet Leaf Review* (2020), *Millennial Pulp* (2020), and *Gateway Review*. In 2018 he received an Arts in Action Award and says, “Ultimately I want to create something of beauty and meaning that survives long after I am gone.”

**Jen Jackson Quintano** is the author of *Blow Sand in His Soul: Bates Wilson, the Heart of Canyonlands* (2014) and her landscape-inspired essays have appeared in numerous publications and anthologies. In addition to writing and raising a daughter, she runs an arborist business with her husband. “I am fascinated by the myriad ways of being in the world and how that being affects our understanding of the world.”

**Wayne Rapp** is a freelance writer living in Columbus, Ohio. His collection of short stories, *Burnt Sienna*, was a finalist for the Miguel Mármol Award and his story, “In the Time of Marvel and Confusion,” was nominated for a Pushcart Prize. His work has appeared in *BigCityLit* (2020), *High Plains Literary Review* (2000), and *The Americas Review* (1994).

**Nicole A. Schroeder** is a journalist, editor, and author from Columbia, Missouri who recently graduated from the University of Missouri, with a major in journalism. Her work was awarded the 2020 Kerr Award in creative nonfiction and her fiction was published in *Scribendi*. “I believe words are beautiful, powerful tools that can inspire us, connect communities, and shape how we view the world.”

**Marilyn Slominski Shapiro** lives in Rochester, Michigan, and, after a creative career in international television, she is now pursuing a passion for writing stories that are inspired by her travels and the people she has met along the way. The story published in this issue was partially influenced by a family member who has autism.

**Venetia Sjogren** is a proud Afro-Latina mother and grandmother whose work has appeared in *Rigorous* (2019), *Breath and Shadow* (2019) and *Obsidian* (2020). For her, “writing is as necessary as breathing,” and has been her refuge from abuse. She always carries a notebook with her so that she has an outlet for sudden flashes that prompt her to write.

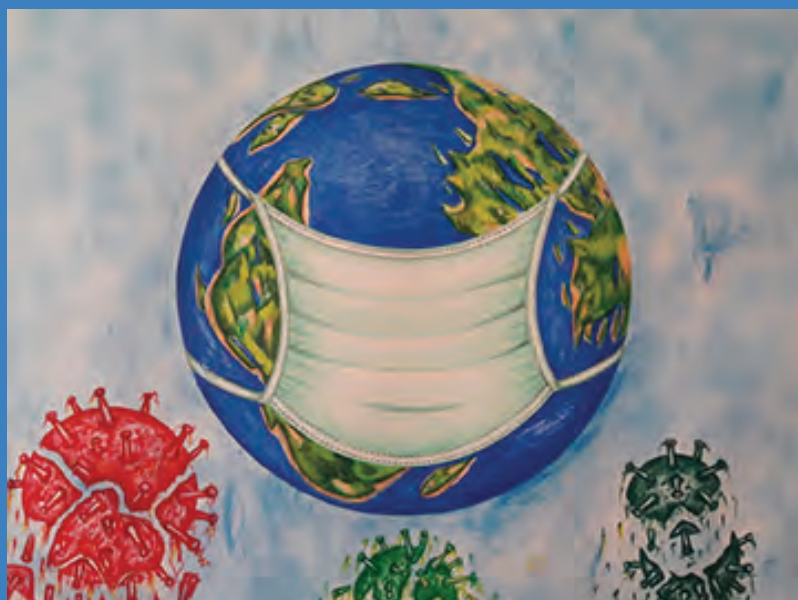
**Grace Utomo** is a student, freelance book reviewer, and contributing writer for the *International Examiner* in Seattle. “I believe resilience is a choice that’s available to everyone, no matter their background . . . I hope my work encourages readers to seek and choose hope in the midst of adversity.”

**Darren White** is a student who lives in the Netherlands. He was once a dancer but after years of abuse, a spinal cord injury, brain injury, vision and hearing loss, he says, “My world is a lot smaller now and my expression is limited to the written word.” His work has appeared in *Flashes of Brilliance* (2019) and *Love is Love: A Comic Book Anthology to Benefit the Survivors of the Orlando Pulse Shooting* (2016).

**Paula Anne Yup** is a poet living in Spokane, Washington. With a stammer, she found it hard to express herself until a teacher asked her to write a poem and she discovered it was empowering. Her work has appeared in *Making a Clean Space in the Sky* (2011), *Exit 13 Magazine* (2020), and *Chiron Review* (2020).



Kim Gerry Tucker, *Go Higher Toward Peace*, multi-media collage, 12" x 16"



Robaba Mohammadi and Ali Rahimi of Afghanistan, *Our Earth*, colored pencil, 50 x 70 cm

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