# ALEIDOS COPE EXPLORING THE EXPERIENCE OF DISABILITY THROUGH LITERATURE AND THE FINE ARTS

Number 77 Summer/Fall Online 2018



THE JOURNEY CONTINUES

"Sketch" by Sam Provenzano

"Chord Changes" by Paige Cerulli

"Privileged, Old, White, and Rich?" by Elizabeth A. Sachs



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

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



Kaleidoscope (ISSN 2329-5775) is published online semiannually. Copyright © 2018 Kaleidoscope Press United Disability Services, 701 S. Main St., Akron, OH 44311-1019 (330) 762-9755 Phone (330) 762-0912 Fax email: kaleidoscope@udsakron.org http://www.kaleidoscopeonline.org

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We request credit for publication as follows:

Previously published by

Kaleidoscope: Exploring the Experience of Disability through Literature and the Fine Arts, 701 South Main St., Akron, OH 44311-1019

Indexed in Humanities International Complete and the MLA International Bibliography non-Master List. Listed in International Directory of Little Magazines and Small Presses, Magazines for Libraries, The Standard Periodical Directory.

#### **Submissions:**

Email or online submissions preferred.

If submitting hard copy, send copies of originals with SASE if you want your work returned. The editors do not assume responsibility for returning submissions without ample return postage. Address all correspondence to the editor-in-chief.

# **DOORS OPEN AND DOORS CLOSE**

## GAIL WILLMOTT

ecoming a magazine editor was not the path I originally sought for myself. I had a bachelor's degree in secondary English education and a master's degree in elementary education with a specialty in remedial reading. After graduation I spent a year tutoring children and adults with reading problems. Then in the fall of 1974, I moved to Detroit to become a reading teacher in an inner city parochial high school—a job that, for many reasons, lasted only a year. I returned home and took four introductory courses in library science from The University of Akron, hoping to combine my education degrees and background in library science into a useful combination that would lead to a job in an elementary school library where I might also help children with reading problems. However, that was not to be. (I'm sure that many of you have heard the saying, "If you want to make God laugh, tell him your plans.") I resumed working as a private tutor in English and reading.

Then came the phone call that brought me to a career that turned out to be absolutely perfect for me. Thanks to a referral from a social worker whom I met while volunteering at United Disability Services during my summers in college, I was offered a job on the staff of *Kaleidoscope* in May 1982, just

after the publication of issue 5—the first to reach beyond the confines of United Disability Services and the adult clients of the agency. I did not know anything about Kaleidoscope prior to receiving an offer to become part of the staff. I remember looking at issue 5 with poetry by Larry Eigner and art by Clayton Turner, and thinking just how are we going to top this? However, we did just that and today we receive submissions from writers and artists worldwide. That was thirty-six years ago, and though I never planned for this career, what a meaningful journey has unfolded.

I must admit I have always been the kind of person who begins any new endeavor with a large share of insecurity and fear-with questions like "Am I good enough?" "Do I have the necessary knowledge?" "Can I really do this?" running around in my head. But, one step, one task at a time, I learned. I learned much from the editors who came before me and I had the opportunity to read personal essays and creative nonfiction, poetry, and fiction. Then, as the senior editor, I was asked to assist in making selections of pieces that would eventually appear in the pages of Kaleidoscope. (How much better could work be for someone who loves literature and art?)

I have had the pleasure of working with and getting to know some incredible writers and extremely gifted artists. I always feel a great sense of joy and excitement when I read an essay, a poem, or a story which touches me in such a way that I know immediately this work *must* appear in the magazine. The same feelings have applied to the work of our visual artists.

During the time I was responsible for writing artists' profiles, our most incredible discovery was Michael Naranjo, a Native American sculptor who works in bronze and stone. I remember feeling absolutely awestruck when I first saw his work, and I knew immediately that we had to feature his work and tell his story. When I called him for a telephone interview my usual insecurities again came to the surface. I was really nervous and afraid my questions would seem silly or inappropriate. I asked, "May I please speak to Mr. Naranjo?" A gentle voice answered, "This is Michael." In that instant he put me completely at ease. I thought, this is a good man. We went on to have a delightful conversation. He was a joy to talk with and the interview turned out very well. His sculptures embody a sense of fluid motion, making them appear at once graceful and powerful. In such moments of elation I am reminded why I love this work and why I have remained with it for so long. We

featured the work of Michael Naranjo twice and all these years later, talking with him remains one of the highlights of my career.

Another memorable occasion occurred in 1985, just prior to the publication of issue 11. Editor Carson Heiner, another staff member, and I had the opportunity to meet and talk with Itzhak Perlman. He was touring and came to Akron to perform a concert. Carson made arrangements ahead of time for us to sit backstage during the concert and interview him after his performance. Just prior to the concert, Perlman was walking with his crutches backstage near where we were sitting, muttering to himself, "Where is my fiddle? What did I do with my fiddle?" I remember thinking I hope you find it or lots of people will be disappointed! When the concert was over and the opportunity came to speak with him, initially, I was speechless. I admit to a case of hero worship. After all, here was this amazing violinist who did not let his disability stop him from realizing his dream of sharing his wondorous gift.

There has always been a sense of pride among the staff that Kaleidoscope was the first literary and visual arts journal to explore the experience of disability, weaving it into the whole of life from the viewpoint of those directly affected. Over the years we have published creative nonfiction, memoirs, fiction, and poetry by established writers such as Andre Dubus, Anne Finger, Lucy Grealy, Nancy Mairs, Reynolds Price, Irving Kenneth Zola, and poets Larry Eigner, Vassar Miller, and Barbara Crooker. We have featured the work of famous artists such as Marv Cassat, Matisse, Monet, Frida Kahlo, Paul Klee, and photographer Dorothea Lange.

However, the bulk of *Kaleidoscope* has always contained the work of emerging writers and artists whose pieces have the power to deeply affect readers and viewers. In "Outroll, Outmaneuver, Outlast," Peg Daniels wrote about the aftermath of her husband's car accident which left him paraplegic. In "Forward Momentum," Susan Kennedy, who has a visual impairment, related the story of a twenty-five mile tandem bike ride in the San Francisco area that she and her husband took together. What came through in this piece was the joy, the freedom, the sense of shared accomplishment.

We have also shared many meaningful works of fiction in the pages of Kaleidoscope. Two stories by James Bellarosa were "Why Do You Ask?" and "A Problem of Plumbing." They are humorous portrayals about real life challenges regarding accessibility and the incongruent reactions of the public during everyday encounters. "Mother's New Leg" by Jeff Boyer told the story of an older woman who must adjust to the amputation of her leg and learn to walk with a prosthesis, something she accomplished with strong determination and good humor. "Pogo's Bridge" by P. J. Devlin told of the close relationship between Willie who was born with dwarfism, and his older brother Pogo who was Willie's protector and defender until a tragic accident on train tracks took Pogo's life.

In the fifteen years I have been editor of *Kaleidoscope*, we have published many strong poems. A few of my favorite poets are Shirley Adelman, Linda Cronin, Tony Gloeggler, Lola Neff Merritt, Sheryl Nelms, and as I mentioned ear-

lier, Barbara Crooker, Larry Eigner, and Vassar Miller.

We have also featured the work of some incredible visual artists. John Bramblitt, who is blind, creates colorful paintings using his sense of touch. Canadian artists Gary Curry and Alistair Green create magnificent stone sculptures. Tommy Hollenstein, uses the tires of his wheelchair as his paintbrush to create intriguing abstracts. Keith Jansz is a mouth painter working in oils, preferring to paint outdoors (en plein air) focusing on scenic landscapes, including images of snow and water. Doug Landis, a mouth painter, has created amazing animal portraits in pencil (his Vanishing Breeds series) and now works mostly with acrylics and watercolors. Becki Melchione manipulates digital photos to form beautiful mandalas and other images. Mariam Paré is a mouth painter who works in oils, acrylics, and mixed media portraying diverse subject matter including her vivid portraiture.

Seventy-two issues and thirty-six years later, it is with mixed emotions that I retire as editor of *Kaleidoscope*. I am proud of what we've done to publish thought-provoking literary work and visual arts that explore the experience of disability. It has been a privilege to be a part of the evolution of *Kaleidoscope* from the seed planted by Carson Heiner in his desire to provide the adults in his enrichment classes with a vehicle for self-expression, through the tenacious leadership of Dr. Darshan Perusek with her strong desire to reach higher and farther in her quest for powerful essays, fiction, and poetry that tell the story of living with a disability realistically and without sentimentality. Kaleidoscope has continued to feature the work of

extremely talented visual artists whose stories have been vividly told by our art coordinator. For me, encountering so many excellent writers and visual artists, and their work, has added to the person I am and enriched my life immeasurably.

There is one more seminal event in the life of *Kaleidoscope* that I feel deserves mention.

In April 2008, a collaboration between the Akron Art Museum and United Disability Services culminated in a two-month-long exhibition, curated by the museum staff, of the work of nine artists featured in past issues of Kaleidoscope. The exhibition was titled Creativity Transcends. That phrase has always seemed to encapsulate the core mission of Kaleidoscope—to demonstrate that the gift of creativity, whether with the written word or visual art, does transcend disability. That museum exhibition also validated the high caliber of work produced by those amazing artists.

While I believe it is time for me to move on, it will be difficult to let go of *Kaleidoscope* and this work that has fulfilled me for so many years. I sincerely wish success to the next editor in moving the magazine forward. An important factor in that success will be the ongoing support of readers and contributors. It is time to begin a new chapter of this thought-provoking and aesthetically-pleasing publication which will continue leading readers to think about disability in new and more positive ways.



**Gail Willmott** 

#### TONY GLOEGGLER

# SOCIAL STORY

Now that I am sick with this kidney condition I can't spell or pronounce my ex-girlfriend is worried, a little about me, but mainly about her son Jesse. She wants me to write a short social story explaining what death and dying means. Something somewhat concrete and not too frightening that he and his autistic brain has a chance to grasp. Something about not being there anymore physically, but still with him. A part of him, like blood and bones, all the time and forever. Something to prepare him if and when I need to stop visiting suddenly. Good luck I think and begin typing that some things are hard to understand and scary to think about; but learning about them can sometimes make things clearer, easier when they do happen.

One of those things is death and everybody eventually dies. Even friends we feel close to and love, die. Some people get sick and never get better and some people grow old and die. I write down no one knows what happens when people die. But when we can't hang out and see our friends anymore, we feel sad and bad and sometimes we cry. The good thing is we can always, any time we want to, think about them and how happy and lucky it made us feel to know we had someone we loved who loved us back as much as anything in the world. I sign it love, Tony, in big multicolored block letters. find an envelope, press on a superhero stamp, walk to the corner mailbox . . .

# THE WHITE CANE

The white cane is a sense organ, limited, not an eye, for its possessor is not Cyclops, so greatly gifted Tap, tap, sweep, tap, no color is realized no horizon, no sky not even the light

The white cane is a sense organ, limited,
Tap, tap, sweep, tap, it tells a continuing tale of curbs and corners, cans and trees, the white cane gives a street and then a wall

The white cane is a sense organ, limited,
Tap, tap, sweep, tap
The white cane gives the world to blind people and blind people to the world

The white cane is a magic wand but magic most limited, though its value is infinite. Tap, tap, sweep, tap it is the magic of blind people, its synonym: necessity

> A previous version was published January 1994 in the The Arizona Unconservative. Reprinted with permission of the author.

### LOLA NEFF MERRITT

# LAST PERFORMANCE

Showering the world with music, the overture is sung by hundreds of blackbirds. Then with a flurry of sound they sweep in great arcs over the meadows, uplifted wings glittering in the sunlight. This, their last breathtaking performance before fall's exit.

### Lola Neff Merritt

# ROADSIDE SERENADE

A lavender blue mist shimmers where chicory lifts small faces to a warming sun.

Morning glories play hide-and-seek through tall cornstalks, as a white butterfly lazily weaves in and out among them.

Hidden in his corner puddle, one lone frog loudly croaks his morning serenade.

# PANE

### MARK OSTEEN

y headphones were blasting hard bop when my wife Leslie pounded down the stairs: our son Cameron had put his hand through the picture window.

"He's bleeding all over the place!" she shouted as I jumped off the stationary bike. Upstairs, I dodged spatters of blood on the hallway floor.

"He broke the glass! The bleeding won't stop! Should I call 911?!"

I felt oddly composed as I walked my nineteen-year-old son into the bathroom and held his right hand, wrapped in an orange towel, over the sink.

"Did you cut yourself? Let me see."

Cam, who is autistic and almost totally nonverbal, growled and grimaced as I pulled back the towel to expose a gaping wound about two inches long just below his right thumb. Blood was flowing copiously, but not spurting. Seeing the deep, ragged gash made my own hand hurt.

After I washed off the wound, a pinkish pond lingered in the sink. Cam blew on the slowly draining pool to make it go away.

Ancient Boy Scout first aid training surged into my mind: "Apply direct pressure to bleeding wounds." Although my glasses were fogged by drying sweat, I didn't dare stop to clean them as I pressed on the cut.

Les called 911 and gave the operator the details. "No, it's not spurting, just flowing strongly. . . . Yes, he's conscious."

I placed Cam on the toilet seat and sat on the bathtub rim, keeping the pressure firm as we waited for the ambulance. A long time seemed to pass

Cam's greatest joy as a child was to bounce on a circular trampoline in front of the picture window. As wide as the living room, it provides a panoramic view of the street. Through the dogwood branches he could survey the neighborhood and scan the people strolling by. He hated to wear clothes, so passersby were often treated to the spectacle of a bouncing (naked) non-baby boy.

Even at nineteen Cameron had little sense of modesty—one symptom of his diagnosed "moderate to severe" cognitive disability—and his tactile sensitivity makes him averse to clothing. He also displayed then (and still displays) what clinicians call "maladaptive be-

haviors"—aggression, rocking, handclapping, chest-slapping, as well as (meaningful) hoots, squeals and hollers. We don't agree with the professionals; we think his behaviors are *adaptive* ways for a guy with very little spoken language to express himself, get others' attention, and contribute to (or at least interrupt) conversations.

Cam's signature behavior is shredding white shoelaces. Pulling out the fibers one by one, he transforms each strand into a floating gossamer tuft and then blows it to a far corner of the room. He often performs his operations right in front of the picture window, and given his unpredictable mood swings, it was probably a miracle that something like this hadn't happened sooner.

The cut continued to bleed into the towel.

"I really wish you hadn't felt the need to exercise this morning," Leslie said, "with Cam so agitated." He'd been pretty charged up from the moment he awoke, clapping and hooting, scurrying from room to room.

I made a sour face. "I don't see how that matters. What happened, anyway? Was he *trying* to break the window?"

"No, he was just being defiant. I told him not to pound on the window, so he had to keep doing it."

I gazed at my son's straight brown hair and long face, and glanced into his brown eyes (he doesn't like to make eye contact). He didn't let on whether he had understood us, though he most likely did. For the thousandth time, I wondered what Cam was thinking. A lot of blood is coming out of my arm. What does this mean? My parents are scared, so it must be bad. I felt his pulse; it was racing, but his face showed nothing.

It would prove to be a long day, one that would expose again the contours of my son's disability, but also open a window into his unusual mind.

\* \* \*

The ambulance brought Les and Cam to the hospital; I packed up belongings and joined them a little later. Before arriving at Cam's cubicle I passed through an emergency room bustling with white coats and patients. I heard an old man gasping for breath, saw a middle-aged woman with bruises all over her face, and an elderly woman who looked deranged. A swift look into another cubicle revealed a wan girl of about ten folded into herself, whimpering. I didn't want to know what had happened to her.

I found our son on a cubicle bed, rocking. Seeing me, he smiled briefly and bounced.

"Buddy! Dad's here!"

I'd brought his mini-DVD player, but he refused the offer to watch Raffi, his (formerly?) favorite artist.

Above him was a beeping green screen; a tangle of cords led from it to the outlet behind the aluminum sink. Voices murmured unintelligible words from the cubicle next door. The squeak of rubber soles poked through the commotion as Cam's jiggling feet made thumping sounds on the bed's metal supports.

It would prove to be a long day, one that would expose again the contours of my son's disability, but also open a window into his unusual mind.

After a while a nurse came and took his blood pressure; it was high: 145/103. But he remained cheerful, even as the wait stretched to an hour, then an hour and a half. Sitting in the room's backbreaking chair I remembered previous hospital visits.

At age twelve, Cam had jammed several objects up his nose and had to be sedated so they could be removed. You'd think that after such an experience he'd be cured of nose stuffing. You'd be wrong: he did the same thing a year later. Then there were the seizures, which started when he was sixteen. One occurred while he was in

the bathtub, which scared Leslie half to death. I wasn't home at the time, so my petite wife had to lift our 130-pound son out of the tub and hold him up until the seizure ended. Another one hit two years later, during dinner. Jerking and shaking, his lips turning blue, he tipped over backward, banged his head, and bit his tongue. That one scared *me* half to death, and led to a new medication packed with nasty side effects: dizziness, double vision and vomiting. In fact, he still vomited almost daily. A trip to the ER had followed each seizure.

Just as autism is a spectrum disorder, so Cam's doctors, we learned, were on a spectrum of their own. At one end were his female pediatrician, Polish, white-haired, warm, and his dentist, a chipper aging hippie who called my son "Chief." At the other end were the incomprehensible (a gnomish neurologist), the chilly (a lanky gastroenterologist who peered at us from over his glasses) and the condescending (a female neurologist who treated my wife and me as if we were cognitively impaired). Most were competent and professional, but a couple of them talked about Cam as though he weren't present; another wrinkled his nose as if he smelled soiled diapers.

What sort of doctor would we get this time?

At last a very short South Asian woman entered the cubicle. "Hello, I'm Doctor Shakhti. What happened?"

"Cam put his hand through a window," I said.

Les explained, "He's autistic and got excited. But he got a big gash on his wrist."

The doctor peeled back the dressing. Viewing the wound, Leslie blanched. Still seeping blood, the gash exposed the tissue deep inside his wrist. We now realized there were two wounds: the big cut and a smaller cut just below it.

"You're lucky," the doctor said. "This doesn't look too bad. A half inch to the left and we'd have a big problem."

I had a frightening vision of Cam's arm spurting blood until he collapsed and died, while we watched, frozen in horror.

"Will he hold still for x-ray?"

"Probably not."

"All right, then. We'll give him a shot to calm him down, and then take an x-ray. If there's nothing broken we'll stitch it up."

We resumed waiting. Brief, garbled announcements crackled sporadically through the loudspeakers; during each one Cam covered his ears with his hands and stared hard at the floor. Between those moments he fiddled furiously with a string, seldom looking up when we spoke to him.

Though uninterested in videos or a snack, he responded when I prompted him to play our Famous Hands Game (with left hands this time): regular handshake, "soul" handshake, fingertip link, and thumb wrestle. Regular, soul, fingertips, thumbs. Regular, soul, fingers, thumbs. RSFT. RSFT. Again. And again. And again. We learned long ago that these "stims," or repeated behaviors, help to keep him anchored. In truth, the game calmed me down too, but after several minutes of it-interspersed with a lot of rocking and clapping from Cam—I freed my hand and opened the New Yorker I'd brought.

Les reminded Cam that he wasn't seriously hurt, and we both cautioned him not to pull the bandage off the wound.

Still we waited.

After another half hour a nurse appeared with a hypodermic. She'd already given Cam a tetanus shot (a good idea), but did he really need a sedative?

"What's in the shot?" I asked.

"Dilaudid. It'll keep him calm."

# Back in the cubicle Cam, now feeling the Dilaudid, stopped bouncing and barely played with his string.

"What are the side effects? Will it make him drowsy? How long will it last?"

The nurse, a soft-spoken older woman, tolerated my pushy questions. "It could be an hour, but some people are out of it for several hours. The only side effects would be sleepiness or nausea and vomiting."

*Oh, great,* I thought, *more vomiting*. But we let her inject him.

More time passed. Cam bounced rambunctiously on the bed. Bouquets of white fluff adorned the floor, the remains of two shoestrings. His artwork. And his signature: Cameron was here.

By this point I was seething: did anybody care about us? Why was this taking so damn long? Yet our son, the patient, was, well, patient. Why was he handling this better than I was? During our second bathroom visit, he sat unmoving on the toilet for ten minutes before Les spoke through the door.

"Buddy, there's a cute girl out here who wants you to go get an x-ray."

Cam popped up, pulled on his pants, and followed the young female technician down the hall, his eyes downcast but sporadically darting up to the walls.

In the x-ray room the tech said, "Hi, Cameron. Put your hand down right here."

Cam put his head down on the table. I patted his hair. He was trying so hard! He got it right the second time.

Back in the cubicle Cam, now feeling the Dilaudid, stopped bouncing and barely played with his string. We'd arrived at 9:45, and it was now past twelve, so I called Max and Ricky, the aides who were scheduled to come to our house at noon, and filled them in.

Cam listened. "I did it. Did it!" he shouted. "Eeeee!" He whacked his chest several times with his open left hand. His howls and splats echoed through the ER. A couple of nurses turned to look. One smiled at us.

Cam slapped his head with his left hand several times.

"Be careful with the head," said Leslie. "It's in charge of everything."

\* \* \*

We checked out at 12:45, awash in relief. In the car Les and I exchanged looks. We knew it could have been *much* worse. Our son had endured it all bravely, though his hair was a mess and he had blood all over his shorts.

It turned out that Dr. Shakhti also had an autistic son. As she'd stitched up Cam's wrist, she'd told us about him. He had recently graduated from high school.

"The school was great," she told us in her heavily accented English. "He wanted to play football, but couldn't, so they made him the manager. But college, I don't know. He wants to be everybody's friend, but the English is so hard for him!"

A pang of envy passed through me as I recalled it. Her son's biggest problem was making it through college. Our son—the same age as hers, his condition bearing the same name—put his hand through a window because he couldn't control his impulses or didn't foresee that glass breaks when you pound on it. Or so I thought.

"Weren't we lucky to get someone who understands?" Les said. "It's a lucky unlucky day," she reminded Cam as we pulled into our driveway.

Cameron walked around the yard, string in hand, as Ricky and Max watched. No doubt our son was rattled by the morning's hurly-burly. The gushing blood. The hospital. His parents' distress. This weird thing on his arm. But here was a familiar place: no strange people, no injections, no beeping noises or loudspeakers, just the insistent calls of cardinals in the hedge—"keeper, keeper, keeper"—and the whoosh of breeze through the trees.

After wolfing down our belated breakfasts, Leslie and I cleaned up the blood and glass near the window. A big splatter stained the floor nearby, and drops led from the living room to the bathroom. I pulled out a few shards, making a bigger mess, before realizing that we needed to call glass experts and put plastic over the window. Les and Max applied the plastic while I finished wiping up blood.

Dr. Shakhti's mending had been much more competent than mine. After pouring a brown antiseptic over Cam's wound and numbing it, she'd sewn two neat black stitches into the smaller cut and four larger ones into the gash. Cam had watched intently, holding very still. Blue gauzy material stuck the whole package together. It looked quite tidy.

"Come back in a week," she'd said, "and if everything looks good, we'll take them out." She had smiled as we thanked her profusely.

Our son—the same age as hers, his condition bearing the same name—put his hand through a window because he couldn't control his impulses or didn't foresee that glass breaks when you pound on it.

Back at home, Cam retreated to his room. He'd been there for no more than a minute when I found him kneeling in his usual position on the bed. I looked at his arm. The bandage was gone. Blood seeped from the newly opened wound, and fresh blood sprinkled the walls; more blood mottled the floor and marked his blanket.

He had pulled out the stitches.

I yelled for Les and ran to grab a towel. She wrapped up Cam's hand and tried to apply pressure, but he wouldn't allow it, so I yanked away the towel and placed it on the wound.

Cam roared. "Hold still," I told him. "I have to press this on your arm so you won't bleed. Jesus Christ, why did you pull out the stitches?" Now I was yelling.

Emitting ear-splitting screeches, Cam tried to jerk his arm away.

"Damn it, we just spent all morning getting these put in!" I shouted.

"Have fun! Have fun!" Cam protested.

"You can't have fun now. We have to go back to the hospital."

He'd been wronged, and to make it worse, I was berating him. He grunted, head-butted my shoulder and slapped me. I suppose I deserved it.

But we had never before heard him say anything like "have fun." His spoken language consists almost entirely of memorized scripts ("in the car!" or "take a bath"); this was an original sentence. Evidently, he was trying to explain. But what did he mean? Maybe it was, "I've had a rough morning and now I need to have fun." Or perhaps: "It's vacation, the guys are here and I can't have fun with this thing on." Or "It was fun pulling those strings out of my arm."

Cam has always hated having anything attached to his skin. Once, when he was small, Les bought him a wristband with his name on it. As soon as she put it on, he started slapping her and continued until she ripped the thing off. He won't even wear a Band-Aid: many times we've covered up a cut only to have him tear the wrapping off within seconds. Stuff like that *simply doesn't belong* on his body! Add to that his tactile sensitivity, and a bandage must feel like a hot iron.

For some reason it hadn't occurred to us that he might remove the stitches. But of course they are strings—probably his most powerful fascination—and with his arm still numb, he'd felt no pain when pulling them out.

What to do now? Leave it alone? Go back to the ER? Les phoned the hospital: the staff person said we should return.

As I went to get a fresh towel I heard Cam shout, "Ee could die!"

Words were flowing out of him like blood.

\* \* \*

Driving to the ER, I pondered his last sentence. I knew that when he says "ee" he means "I" (nobody has ever called him "I," so he assumes, with autistic logic, that he's "he"). But what was he saying? "All that blood made me afraid I'd die!" "You should stop yelling at me because I could die from this!"

For Cam's entire life we've struggled to interpret his actions, his meager words. I thought with longing about the autistic people who speak fluently, those who can type or successfully use assistive communication devices. Cam had none of those methods at his disposal (not that we hadn't tried every one of them at one time or another). He conveys his own moods very well, and we've learned to interpret his body language, his repertoire of hand movements and hoots, but we're seldom certain that we know what he thinks from moment to moment. Today a window had opened into his mind, yet the pane seemed as cloudy as ever.

At the hospital the nurse—the same one who had helped us earlier—wrapped up Cam's wound. The staff looked at us quizzically: hadn't these people been discharged?

Within a half hour a physician entered—a different doctor, a pink-faced, white-haired man with a soft, squeaky voice. His first name seemed to be Johannes (I couldn't read his surname). We explained that Cam's hand had been sewn up but that he'd pulled out the stitches. We told him about Cam's autism, and how he hated having anything stuck on his skin.

The doctor's brow furrowed. "I could sew it up again, but it sounds like he'd just tear the stitches out." We nodded resignedly.

He looked down at the wound again. "I could cast him up. We have fiberglass casts and we'd wrap it around his thumb so he couldn't remove it." That was the solution we'd discussed during the wait. "But that would be quite a weapon: he could really smash things with it." On cue, Cam slapped his own chest and head. "And he might hurt himself."

The doctor gazed at Cam for a few seconds, then continued. "Plus, you know, those casts can itch. And if it did become infected—they sometimes do—we'd have a real problem."

# For Cam's entire life we've struggled to interpret his actions, his meager words.

I pictured Cam smashing our large living room mirror, walloping Les with his cast. I envisioned his fingers turning black from infection.

"What if we don't stitch it up? What will happen?"

"The wound will heal on its own from the inside out. It'll take a lot longer four or five weeks instead of two." He stopped and shook his head. "This goes against my whole training, which says 'dress the wound and put in stitches.' But I'm trying to be creative. The best thing might be to just leave it alone."

"But how will we keep it clean? Won't it get infected or bruised?"

"It might, but if you put antibacterial ointment on it a few times a day and wash it thoroughly, it should be okay."

The discharge papers read: "Your diagnosis for this visit: laceration, not sutured. Since Cameron cannot tolerate anything on his skin, i.e., sutures or dressings, please let the wound heal by secondary intention with topical antibiotics like Bacitracin or Neosporin as tolerated. The wound will probably take four to six weeks to heal with constant manipulation."

Perhaps Cam was happy about the decision, but Les and I felt blue. Our son was so averse to having anything touch his skin, so unable to harness his impulses or manage his sensitivities, that he'd rather walk around with a laceration than suffer a bandage for even five minutes. He'd pulled the stitches out with his teeth! In seconds! For the thousandth time I wondered: How can we protect him from himself?

At 4:00 p.m. we walked out the hospital again with our son still displaying an open gash on his arm.

\* \* \*

A little later, Cam begged for a ride ("In the car? In the car! In. The. Car!"), so we drove around for a while. The purposeful pedestrians, the shoppers entering stores, all seemed to exist on the other side of a wall. Here was, I thought, the dominant fact of our life with autism: isolation. Cut off from the world of typical people, we were also barred from the inner life of our son, a world we suspected was teeming with thoughts but which we could not enter—or even be sure existed.

"I can't think straight," I said.

"Me, neither."

I tried to joke. "Well, at least Cam got his way: we're having fun now." Nobody laughed. "Coke!" Cam interjected, kicking the console. We hustled to a 7-Eleven; he calmed down considerably as he nursed his soft drink. About ten minutes from home, I stole a glance into the back and watched my son bend his head down and vomit all over the seat. The Dilaudid. A perfect capper to the day. At least the puke was mostly Coke.

This second development—Cam's removing the stitches—seemed far worse than the original injury. Sure, we'd been terrified upon first seeing the cut, but once we knew it was relatively minor, the day had become mostly a battle against boredom. We'd actually felt a bit triumphant: Cam had been brave, had managed to avoid serious injury, and we'd found a sympathetic doctor. Best of all, his wrist would be good as new.

All that seemed moot now. The reality of his autism—its derailment of his reasoning, its garbling of his senses and self-awareness—sliced through me like a shard. I believed I had accepted him and his disability. Why, then, did I feel a hole in my heart?

For the rest of the evening Les and I, dazed and despondent, watched TV in separate rooms. Cam wouldn't come out of his bedroom. If the day had been hard on us, I could only guess how rough it had been for him. Not only was he frightened; he was furious. By pulling out the stitches, he'd only been trying to fix what the doctors had fouled up. So why had his parents yelled at him?

All evening I found myself wondering: what did he mean by "have fun?" Was it possible he'd removed the stitches so he could return to the ER and get more attention—that is, have more fun? Surely not. Or wait—maybe he was explaining why he'd broken the window: "I didn't mean to smash it. I was just having fun!"

There was no clear answer.

We'd never imagined that he understood the concept of death. From what hidden corner of his consciousness, then, did "ee could die" emerge? Perhaps he was saying "those stitches made me want to die." Was he trying to make us feel sorry for him? No, not possible. That would require a much better grasp of others' thoughts than he was capable of.

Wouldn't it?

As is so often the case, I viewed my son's mind—his intentions, his explanations, his justifications, his apologies—through a glass darkly. And this glass was more mirror than window, for my guesses probably revealed more about my own expectations and hopes than about his thoughts.

Suddenly I realized that the shattered pane had brought about a transformation: our son had exerted his will, had demanded respect. He had spoken and we had obeyed his wishes. It was as if the gash in his arm had briefly torn a hole in a dam, and a torrent of words had gushed out. Yet his most forceful

expression had come not with words, but with actions. He was even willing to hurt himself to make his point.

\* \* \*

The next morning Cameron was upbeat, and the gash was healing with miraculous speed. It was a bit spooky: you could practically watch the skin filling in from the bottom up. And he had mostly left it alone. He listened to three CDs—John Mellencamp, The Beatles and a new favorite, Green Day—singing and clapping along, then (a first) watched the whole *Top 20 Countdown* on VH1.

Our son scrutinized the technician who pulled the broken shards from the window, installed a new pane, and replaced the molding. I don't know if the repair satisfied him, but it certainly made me feel better.

Watching him watch, I thought about windows. I reflected on how Cam had, in effect, lived his whole life behind a window, viewing the world as if through fracted glass, observing people who act strangely, do not understand him and seldom ask for his opinions, people who interpret his behaviors as problems instead of as efforts to communicate. The day before, however, he had broken through: his smashing of the window had awakened us again to the reality that he knows and thinks much more than he can say.

At that moment, another thought slammed me like one of Cam's patented head slaps: maybe he had broken the glass to tell us just that.◆

### PHILIP C. KOLIN

# THE PTSD STUDENT

He stares at the exit sign in the dorm most of the night never knowing if a flare or IED might go off. He wants to get away this time,

not like his first tour. In Afghanistan where a piece of sand-coated shrapnel lodged two inches from his heart. He got approval to go on another tour

but chose to sign on at the local college instead and get his A.S., a better set of initials than the PTSD written in red on his file.

His counselor told him to take each day one at a time. And so when he is not studying the exits he pays guarded attention

to the fire alarm boxes; he is convinced they could go off when he is asleep and be unprepared to combat whoever runs

down the dorm aisles. He has made friends who praise him for his duty to his country but some nights he wonders why

they sleep with their eyes closed. It makes getting away much harder. Another flare has just gone off.

## JUNE CAPOSSELA KEMPF

# WHERE'S THE BUNNY?

The school shrink has spoken "Your child must be crazy!
So stupid, so dumb and
Incredibly lazy."

The teacher took notice.
She's starting to nag.
You're always zigging—
When you know you should zag!

The Rorschach has proven You're programmed to fail. 'Cause you don't know the difference 'Tween bucket and pail!

And probing some more, they
Thought this was "funny."
You drew up a sketch—
And left out the bunny!

A simple brown rabbit Playing in the grass— You didn't complete it Like the rest of the class!

Sadly it lay on the old kitchen table,
A field spilling over with nothing but HAY!
With a bold red X maiming its face—
But looking quite pretty in its own kind of way.

You seemed so confused so Unable to speak Then whispered, "He's there! Playing hide-and-go-seek!"

# JOURNEYING THROUGH DEPRESSION

## TOM STAPLETON

ou're suffering from major depression."

My family doctor spoke the words softly, with sympathy in his voice. They didn't come as a surprise. I felt I'd been a bit of a depressive for a very long time, maybe years, but the condition had intensified over the past several months. Now the doctor told me my symptoms were classic: listlessness, sadness, weight loss (a worrisome eighteen pounds), anxiety, interrupted sleep and bowel-movement patterns, occasional suicidal ideations. The comedian Steven Wright once noted that depression is anger without the enthusiasm. That was exactly how I felt: no interest in anything, including sex. And I just didn't care that I wasn't interested.

Maybe most telling was that I'd stopped being my usual conscientious self when it came to work. I hadn't been paying attention, was letting things slide, cutting corners. In short, I wasn't getting the job done. I knew I wasn't, but it didn't bother me all that much, either. I knew full well I wasn't my old self, and that *did* bother me.

The worst thing wasn't so much that I felt bad; it was that I wondered whether I'd ever feel good again.

I spent some time on the Internet reading about depression, its causes and cures. It was always defined as a disease, with a lot of stock put in medications, hailed as "miracle drugs" for successfully treating symptoms of depression. My doctor had given me some samples of Pristiq and told me I should start seeing a psychologist. I called a few from the list of names he gave me and left voicemails. Only one returned my call and I made an appointment with him.

I'd begun dreading getting out of bed in the morning, having to drag myself into the bathroom to shower and get ready for the day. When I could, I'd nap in the afternoon, something I'd developed a habit of doing many years earlier. But those naps had been brief, often no more than twenty or thirty minutes, and occasional. These recent naps lasted forty-five or sixty minutes and were pretty much something I indulged in daily. In fact, I desperately looked for-

ward to them. They reminded me of the classic college-student defense mechanism of relying on sleep to put reality on hold for a while. One afternoon I collapsed on the bed at noon and awoke three hours later.

My life was becoming a shambles. I knew this, but my intellectual reaction was, "So what?" And when the hell was the Pristiq going to kick in? *That* was something I cared about. The doctor had told me it could be weeks or even longer before I began feeling some relief. I'd have to be patient, not one of my stellar traits.

I had gotten to the point where I didn't like anything about my life or my self. I didn't like the fact that I was aging, that my hair looked bad, my face was showing deep lines, the bags under my eyes had gotten baggier. I felt hopeless. I very much began looking forward to bedtime, when I could crawl under the covers and escape for a few hours. And it was only a few. I began waking at two or three a.m. and would toss and turn for hours. Sometimes I'd drift back off to sleep for a while, but I was

always wide awake by five or six a.m. and usually feeling highly anxious. The hour or so just before dawn became the worst part of the day for me, the time when my thoughts were their darkest and most pessimistic. I'd always been a worrywart, but my mind began imagining worst-case scenarios about everything; no matter what, disaster lay just around the corner, a mindset that was the residue of my Irish-Catholic upbringing. I tried telling myself that I was blowing things all out of proportion, that my mind was playing tricks on me. Things aren't as bad as they seem, I'd try to convince myself, skeptical about what I was listening to because it was coming from a guy who was depressed.

It wasn't long before I wasn't all that interested in reading anymore. I'd always been a heavyweight reader, prided myself on it, but I really slacked off. Before going to bed I would usually read from a bedside novel for a half hour to an hour. But I was barely bothering to read anything for more than ten minutes. Couldn't concentrate. It was too much effort. I just wanted to sleep.

I met an old friend at his daughter's band concert, took him aside, and told him I was depressed. He reacted with surprise and, true to character, cracked a joke. I told him I didn't have much of a sense of humor these days. I don't think he knew how to respond to that. We'd always joked with each other, about everything. I couldn't joke about this, though.

I'd begun looking forward to when the clock would strike 7:30 p.m. each night. That was when I'd pour a big glass of red wine for my wife and myself and sit with her watching TV. I was deliberately trying to get a good buzz on, confident it would help me sleep, as I'd been able to rely on it to previously. It still did. The wine, combined with the 50 mg of Pristiq I was taking, tended to put me out when my head hit the pillow.

I'd always been time-oriented, maybe even timebound, but now I measured the passing of time in small chunks, a few minutes here and there. My frame of reference morphed into an abnormal time consideration as I latched onto incremental minutes ticking by. The minutes became precious.

The wine, combined with the 50 mg of Pristiq I was taking, tended to put me out when my head hit the pillow.

My wife was glad—maybe "relieved" is the better word—when I began seeing the psychologist. She'd been telling me for some time that maybe I should "see someone." I'd never thought I needed to. A shibboleth I'd heard as a child came to mind: "Catholics don't need psychiatrists; we've got Confession." During my first session with the psychologist I began confessing things, blurting out all my shortcomings and weaknesses without even being asked. I'd never been to counseling before and didn't know how to behave or what was expected of me.

I told him I was worried about finances, going on about how deeply business was off. "You do have a predicament," he said. Good way to describe it. At the end of the first session, the psychologist gave me a self-survey to fill out to measure my condition. I answered the questions as honestly as I could and handed the sheet back to him for scoring. He looked up at me after a few minutes and said, "Yeah, you're pretty depressed."

Great. Now what?

After a few more sessions, the psychologist zeroed in on my vocabulary, how I referred to myself and my life, telling me he noticed I used the phrase "I've got to" much of the time, rather than "I want to." He told me I seemed to feel a deep sense of obligation to get things done and he told me I'd be difficult to work for. Was he implying I was a control freak . . . which I was and still am? The guy was six years older than I, so we'd had slightly different cultural experiences, but he told me he was more aligned with my generation—baby boomers-than his own. He was good at putting his finger right on things I'd been thinking or experiencing, including the tendency to negotiate with myself about doing even menial tasks, like washing the dishes. I didn't feel like doing anything, whether it was menial or important. In fact, it had taken a lot just to get myself to keep my appointments with him.

He suggested I see a psychiatrist to get my dosage of Pristiq upped to 100 mg, telling me he felt the 50 mg dosage was below therapeutic level. The admonition of Sigmund Freud came to mind as I looked up the shrink's number: "The Irish are one race of people for whom psychoanalysis is of no use whatsoever." I had an appointment to see the psychiatrist a couple of weeks later, but didn't spill my guts to him as I had with the psychologist. He told me I was a classic case and that, because I was, my depression was highly treatable. It felt good to hear that. He wrote me a new prescription, amping up the Pristig to the 100 mg level. Before I left his office I asked about sleeping pills, hoping he'd write me a prescription for them. Instead, he gave me a handful of Lunesta samples, for which I was grateful.

I kept on going, dreading the fact that there were twenty-four hours to get through each day, and sixty minutes in each of those hours. I was plodding along, not happy, joyless, thinking about Hamlet's line, "To be, or not to be, that is the question." Camus says we answer it each day when we either decide to go on living, or commit suicide. And why not commit suicide? If there are fates worse than death, surely major depression could be one of them.

I kept on going, dreading the fact that there were twenty-four hours to get through each day, and sixty minutes in each of those hours.

I had read years before in *Psychology Today* magazine about a depressed patient who went to his doctor and told him he was thinking of shooting himself. The doctor told him to wait for two months and then come back to see him. He said if the patient wasn't feeling better after eight weeks he'd load the gun himself. I know, intellectually at least, that things usually aren't as bad as they seem, that anticipation is greater than realization, and that things can change after a couple of months. Certainly, they changed for me: they got worse.

I called an old friend who'd been diagnosed with bipolar disorder and had found successful treatment. He told me he'd gotten so severely depressed that he tried three times to commit suicide; on the third try he almost took himself out. He ended up hospitalized and, after a time, was able to turn things around with the help of medication and counseling. "Depression is an insidious disease," he told me. "But you've got to take things one day at a time, be patient, and eventually you'll get better. I know you will."

His words were reassuring. It sounded like he'd been worse off than I was but that he'd gotten back on track and really did feel he was in a good place these days. I envied him.

My weekly sessions with the psychologist continued as I waited for the Pristiq to kick in. It had been nearly a month and a half and, so far, nothing. If I thought I'd been feeling desperate before, it became abject. I'd taken to sleeping in another bedroom so as not to be a nuisance to my wife. I wanted to see if I could make it through the night after a glass of wine and a Lunesta pill.

I knew I had to take it easy with the alcohol and medication mix, but both the psychologist and the psychiatrist reassured me that an occasional glass of wine shouldn't be a problem. I didn't give a damn that it might be. I think I reached my nadir one night when, after hours of tossing and turning with negative thoughts filling my head, I seriously contemplated dashing out on the roof and making my way to the highest point of the house where I could simply lean forward and fall headfirst to the brick patio below, ending my life and my troubles. But I brought myself up short as I questioned the plan. What if I don't kill myself and only suffer paralysis from the neck down? What if I lie there for hours in pain, not dead but unable to move? What if I don't die?

I didn't have a gun in the house but I did have several sleeping pills, both prescription and non-prescription. Would they be enough to do away with me? At that moment in the dead of night, I truly wanted to die. But I guess not badly enough to pop the pills. I lay there worrying, my heart pounding, unable to get back to sleep, my full bladder annoying me, my mind a nightmare. I had no escape. Somehow I endured and made it to morning, having to face a day I wished hadn't dawned.

A few days later, the black cloud lifted a bit. The Pristiq started taking hold. I felt a little better and related this to my psychologist, who was happy for me. I thought this might mean he'd suggest winding down our sessions, but he wanted to continue. I felt the sessions with him were beneficial, but that the Pristiq was even more so. I'd learned during our sessions that the medication would regulate levels of serotonin and norepinephrine in my brain, changing my gray matter chemistry in such a way that my anxiety would dissipate, my worry would abate, and my outlook would improve. "And you won't think it feels artificial or imposed," he told me. He was right. My improved mood felt completely natural.

During our sessions he talked quite a bit about chemical reactions in the brain and physiology in general. Most of it was over my head. I felt the meatier discussions were about what in my experience had gotten me to this point. I pretty much thought it was my exaggerated worry over finances. And that was a good part of it. But we also got into what it was like for me growing up, being the child of an alcoholic, going through what I'd gone through. For the first few sessions he did more talking than I did and I wasn't quite sure what his therapeutic strategy was. William Styron, in his classic treatise on his experience with depression, Darkness Visible, writes about his relationship with his therapist not being as positive as he'd hoped it would be.

I desperately hoped my condition wasn't horribly affecting my wife. I'd become the personification of lethargy, not feeling much like going out or, for that matter, seeing anyone. Not even family or friends. I was hermitting yet didn't care. My wife had noticed (how could she not?) that I wasn't my old self, particularly in that I was getting even more forgetful than usual. I checked to see whether this could be a side effect of the antidepressant. It wasn't, but dizziness was. Maybe it affected blood pressure, but I'd often feel a strong vertigo when rising from lying down.

One night I arose to let the dog out before calling it a night and began walking unsteadily toward our bedroom door. I remember taking a couple of steps and then passing out, dropping like a sack before the TV at the end of our bed. I was lucky I didn't crash into it. I was also fortunate that I didn't make it to the stairway before passing out. Falling down twelve steps could have been disastrous. My wife screamed out my name and she tells me I came to after a minute or so. It seemed more like seconds to me. That was the first time in my life I passed out. It scared the hell out of me.

The psychologist would ask me at the beginning of our sessions how I was feeling. My answer was always "So-so," even though I did feel a little better. A little. Our visits were spacing out a bit farther, from once a week to once every two weeks or even longer. He asked me if I'd ever read Viktor Frankl's book about surviving a Nazi concentration camp. I told him I had, though I couldn't remember the title. He couldn't either. He'd had Frankl

as a teacher once. "Fascinating guy," he said. "Fascinating story." It was interesting to hear that he'd interacted with Frankl, but what did that have to do with my condition? I later found out his book's title was Man's Search For Meaning. The way I was feeling, if I'd written a similar book, I'd have titled it Man's Search for Meaning in a Meaningless Universe.

On top everything else, I now worried that I was becoming a nihilist, stumbling through life wondering what was the point of it all like some stoned college freshman asking "Why are we here?" fascinated by the realization that "dog" spelled backwards is "God."

I haven't been keeping my condition from anyone. I'm not ashamed or embarrassed by it, no more than I would be if I were getting treatment for something like, say, diabetes. I don't feel there's a stigma attached to depression, though it falls under the general category of "mental illness." That's what it is; no big deal, though I know if I'd ever told my father I was suffering from a mental illness he'd respond,"What are you, crazy?"

At our latest session my psychologist mentioned something about forgiving myself. I'm not quite sure what he meant and I didn't ask, thinking it was something I was supposed to puzzle out on my own. I've certainly screwed up enough in life to have a lot to forgive, but I guess I've always thought that forgiveness is supposed to come from without rather than within. So I'm still working on the forgiveness thing. I want to make sure I deserve it first.

Today, I'm trying to concentrate on living in the moment, really taking things one day at a time. My anxiety levels are down, I don't feel as pessimistic as I had been feeling, and my doctor tells me my testosterone levels are higher than they've been in ages. I just wish I knew what that means. So I keep pushing myself forward, putting one foot in front of the other on my journey to . . . to where? Mental health? Maybe there is no end point. Maybe the journey is the destination. Maybe that's the insight I've been seeking.

Maybe I'm starting to give a damn again.♦

# Call for submissions KALEIDOSCOPE



Kaleidoscope magazine has a creative focus that examines the experience of disability through literature and the fine arts. A pioneer in the field of disability studies, this award-winning publication expresses the diversity of the disability experience from a variety of perspectives including: 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 accepted at kaleidoscope@udsakron.org or online at kaleidoscopeonline.org.

# HOPSCOTCH ON THE PROM

## CHRIS WILSON

want to play hopscotch, Teddy, is it time for us to go outside and play?"

That is how it began that day, as it began every day after breakfast if it wasn't raining. As Edward gently helped Judy step through the hopscotch squares on the promenade he wondered, not for the first time, as to where their future together might lie.

"Hopscotch one to ten, turn around and back again!"

She was well into her game now. Today was good, she could remember the order of the squares, but this wasn't always so. Sometimes she was confused, other times angry and frustrated, and sometimes she simply stood still and gazed out over the empty bay. Edward loved Judy. As he stood at the altar on his marriage day so many years ago, he meant every word he said before God and the congregation, but the woman he married had long since gone. Then, they were both medical students, and she had been a passionate orator and debater within the student union. Then, they were both happy with no thought for the future beyond the enjoyment and pursuance of their dreams.

Not now though, not now, as Judy had returned to the realms of her childhood, and the real world had been left far behind. Edward had a problem though; he hadn't been around during her childhood, and it was a world that he could never enter or ever understand.

Where was the help the doctor and Social Services had promised him? What would happen as she slipped further into senility, and where was the land into which she had so completely disappeared? How could he pay for all their food, their utility and medical bills, as they had no income beyond their pensions and savings. Where could he find the time and the energy to open and answer all of the well meaning yet hopelessly ineffective mail that constantly streamed through the ever-flapping letterbox of his now battered and bruised front door?

One such letter had arrived that morning, and it was still unopened in his pocket. It was from Social Services, but what could they do, apart from say sorry. They were sorry that they couldn't be of more service to Edward and Judy. They were sorry that they couldn't offer more professional care services, but understanding and sympathy was all that lay within their hands. He couldn't blame them, as they didn't have the money or the staff to help him and Judy, and they certainly didn't have enough time.

When she was sleeping, he would read the letter, but not here, and not now. For as he stood beside her a young boy called Tommy, who had been watching her from a distance, was coming over to speak to her, and, as ever, Edward felt slightly alarmed.

Judy couldn't always cope with strangers and changing or new situations. A good day could so easily turn into a bad day for Judy, and on such days she got confused and aggressive. She didn't mean to do so, of course, it was her illness that fuelled such problems, but at the same time he had to monitor her mood changes constantly. Tommy was young, he was a good lad, and mentally mature for his age, but this was Alzheimer's. Tommy could be vulnerable, and Edward didn't want him to feel any pain. Then he began to relax a little. Tommy lived with his parents in the house opposite Edward and Judy, and he was a quiet and very gentle boy. They had often talked in Edward's front garden as Judy lay upstairs sleeping and, somehow, he always seemed to understand Judy. Edward would have to watch them both carefully, but maybe, for a moment, he might be able to stand to one side.

\* \* \*

Judy stepped through the hopscotch squares carefully, and as she slowly counted up the squares her mind drifted swiftly back to when she had been a child. She was confused, however, as, for her, childhood was all about safety, security, summer fairs, ice cream, candy floss, Punch and Judy shows, and hopscotch. It also meant slim, sleek, elegant ferries, sooty smoke stacked pug-nosed colliers, and streams of visiting tourists as they rushed off the boats toward the fair. To her, as she played hopscotch, it was still summer, but now life was far more unsettling. There were no crowds as there were no visiting ferries, the fair had vanished, and there was no Punch and Judy show, let alone candy floss and ice cream.

She still could play hopscotch though, but she sometimes forgot the order of the squares and what her name was, and then, of course, there was always Teddy.

She knew he always washed, dressed, and fed her. She knew he was a good man; and in her own befuddled way she knew she loved him, but why did he sometimes get angry and shout at her, and why could he never leave her alone?

Why did he always call her my love, or by her first name of Judy; and why did he lie in bed and sometimes snore beside her. Why was he always there at breakfast time; and why did he sometimes stroke a gold ring that mysteriously encircled one of the fingers of her hand?

Too many whys, Judy thought, and too few answers. There was nobody she could talk to about how she was feeling. Nobody in her wide awake world to help her, let alone to help her understand.

Worst of all was trying to make sense of her dreams that sometimes haunted and bemused her.

They were funny things as hidden in a strange fog, she could neither feel nor find her way through. Sometimes the fog cleared slightly, and, in the far distance she could see a man and a woman, walking, talking, holding each other, and laughing. They were standing on mountain peaks, at other times inside or in the gardens of a big building which

very occasionally seemed familiar to her. But all too soon the happy couple was hidden from her and, once more she found herself isolated and alone.

# Judy stepped through the hopscotch squares carefully, and as she slowly counted up the squares her mind drifted swiftly back to when she had been a child.

She wanted to pull the fog to one side as if it were a curtain. To tie it back, to meet the couple, and walk and talk with them, as she could hear their laughter, and they seemed so very happy, but it was of no use. They never saw her, they never spoke or waved to her, and she didn't know to go over and say hello.

Judy didn't like such dreams, as the fog, and her inability to reach the couple, made her feel both scared and lonely. Part of her, a strange and mysterious part of her, still wanted to go there and in a confused way, wanted so much more.

In a big red building Teddy called a hospital, a man wearing a white coat had told her that such dreams weren't dreams, but periods of what he called lucidity, whatever that meant. Then he said that her ever-present companion was called Edward and that she and Edward were married, but as she was a child she couldn't be married. Marriage was for grown-up people, her mother had once told her, and not for children. Also, this man was called Teddy, not Edward, so the man in the white coat had to be wrong. She looked at the gold ring on her finger. Teddy always seemed happy when he stroked the ring so perhaps she should stroke it. It might be a magic ring, and if she stroked it hard enough all her dreams and memories might come back to her; and if they came back to her they might even become real. She could almost taste the ice cream and candy floss, and she could almost climb on the merry-go-round horses. Maybe all she had to do was to close her eyes; to sing; to rub that ring, and then to quietly dream.

"Hopscotch, one to ten, turn around and back again."

She closed her eyes, sang to herself softly, and then, very tenderly, she rubbed her shiny gold ring.

She opened her eyes, but there was no merry-go-round, no ice cream, and no candy floss. There was a little boy stand-

ing before her though. He was smiling, and he was holding out an apple. Judy liked apples, and little boys with friendly smiling faces, and, if she was lucky, he might want to give her a bite of the apple, and even want to join in her game.

"Hello, my name's Tommy, I live opposite you! Would you like an apple, and can I join your game!?"

Judy just looked at him for a moment, and then grinned. It was a big red apple, it was shiny, and a new playmate had come to join her. Perhaps it was summertime after all.

\* \* \*

Tommy rested his back on the promenade's railing behind him, and he watched silently and intently as Judy slowly, and hesitantly, picked out the hopscotch squares on the prom. His mother had told him about the couple some while ago and said that one day he would understand what something called Alzheimer's was, and how people thought when this strange thing occurred. She had also said he was very grown up for his age, and very observant, but he was only seven years old and, as he watched Judy closely, he was confused. She wasn't playing the game correctly, and that was strange.

The game was hopscotch in name, and it meant hopping by nature, yet she moved through the squares very slowly and unevenly. She didn't quite seem to know where her feet should go, or how to play the game. Also Edward, her husband, whom he had often talked to while Judy was sleeping, was standing close by her, and helping her. Tommy had never heard of anyone being helped at hopscotch. It was a quick, easy game that you played alone, or with other friends around you, but, once upon the hopscotch grid, it was a game that you played alone!

Edward looked tired and worried and, as he was standing close to Judy, it seemed to Tommy that the couple was in a world of their own. That was odd to Tommy as he thought there was only one world where people lived. Perhaps if he went over and asked to join them playing hopscotch, he might be able to help them play the game more quickly. If he was lucky, he might be able to join them in their world that, as yet, he couldn't fully understand.

"Be nice to people and they will be nice to you." His mother had once told him, so he peeled himself off the promenade railings and fished out a bright red apple that his mother had given him. Everybody liked apples, especially bright red shiny apples. What if he went over to the lady and offered her his apple? What would happen if he told her what his name was, and then asked her if he could join her game?

"Hello, my name's Tommy, I live opposite you! Would you like an apple, and can I join your game!?"

Judy looked at him for a moment, took the apple that was held out before her, and then began to grin.

# Nobody asked him about how he was feeling though; he seemed to be invisible, and no one seemed to care.

\* \* \*

Edward thought it was lovely just sitting on the promenade bench watching Judy and Tommy playing together, as just for a moment his time was almost his own. He rarely had time to himself now, for these days life was all about Judy. People solicitously inquired: "How is Judy?" "How is she coping?" "Is she having a nice day in the sunshine?" Nobody asked him about how he was feeling though; he seemed to be invisible, and no one seemed to care.

Nobody asked him about how he coped bathing and feeding her, how he dealt with her senility, anger, frustration, and her constant need for reassurance and repetition. There seemed to be no cure for her increasing incontinence, and there was no guidance as to what he should do when she reacted as if he was a total stranger. Or when she ignored him as if he simply wasn't there.

He was happy to be her long-term caregiver; he still loved her and wanted to help her, but he was getting older. There was no relief; no haven and no one there to help them, and he was scared in regards to their future.

He had a moment to himself. Although he felt slightly guilty and selfish, as he always felt when he took time away from her, it still felt wonderful as he watched them play.

Play! That is what he and Judy had done when they were younger, and before the onset of Alzheimer's. Edward hated the wretched disease as it had no voice, mind or body, but did have an innate power to nullify all that was good and wonderful within their marriage, it had nearly destroyed a wonderful relationship. It was this cruel and pointless waste and destruction that he could never accept or easily endure.

Watching friends and relations growing old and dying had never been a problem for Edward and Judy since they met when they were medical students. They had developed a passion for psychology and philosophy, but this vile degenerative disease was different. It had robbed them a wonderful marriage and friendship and substituted such joys with an unending tide of loneliness, despair, anger, frustration, and pain. Once they had kissed, passionately kissed, and danced and shouted for joy as, hand in hand they had giddily cavorted across the immaculately groomed lawns of the university's quadrangle. That had earned them a ticking off from the college principal, but it was worth it. They had made themselves dizzy by delving into the minds of the great philosophers and made love on many a mountain top while proclaiming their passion into the fresh, clean, vibrant mountain air.

Then they got married.

It was a good marriage, although for medical reasons, sadly childless. Maturing together like a bottle of vintage port, snuggling up to a top grade round of Stilton, their future as a couple, a wonderful secure and happy future, seemed to open up before them.

Then she began to forget things, and that is when Judy, a friend, a wife, and lover, had relentlessly begun to drift away.

What was left of such dreams and happy days now? Just an empty, battered husk of a partner. Just whispers in the wind, faded billet-doux, course notes, essays, and unread silent, dusty books from whence great minds had once proclaimed. Sad-voiced ghosts from the past calling to him, tediously repetitive days, and an irrevocably broken marriage. Plus, for both of them, the strain of living with a stranger who, by the vows that both of them had taken, they were fully meant to know.

Even their faith had been shattered by Judy's illness. Jesus loves both of you, you are His children, and He will always be there to support you, the parish priest constantly reminded them. So what had the pair of them done so wrong as to be treated so severely? If He was their Father, then why didn't He do something to help them, and to support them in such a time of obvious need? The last time Edward had been in church, he had sworn at the priest, furious at such pointless, if well meant, platitudes.

Then he had shaken his fist at the crucifix above the altar, denounced God and all His minions, and upon storming out of the church he had slammed the once comforting, stout wooden doors behind him. He had later apologized to the priest in person, but not in the church, and not to God, who seemed so cruel and callous. If God was so all-powerful, was He also so utterly to blame? Edward knew that he

shouldn't be bitter about the cards life had dealt them. Through sharing his life with Judy he had experienced a depth of life and love he always thought would bypass him, but he alone had to deal with Judy. He was exhausted, and, though he still held his joyful love for a woman who once walked proudly beside him, such joy, and his associated memories also brought him so much pain.

# What was left of such dreams and happy days now? Just an empty, battered husk of a partner.

Time was passing though, and a screaming seagull, standing close to him, seemed to chide him for his time away from Judy. Stop daydreaming, the seagull seemed to say to him, or Feed me, as Edward thought more likely. But do something practical and keep an eye on the game! Edward cheerfully stuck out his tongue at the seagull. Fancy that, he thought to himself ironically. Fancy listening to a talking seagull!; but inside he was grateful for such an intervention, as now, his attention was brought back to Judy and Tommy, and to how they were playing their game.

At first Tommy had danced quickly through the squares, but now the pair moved slowly across the hopscotch grid, with Tommy guiding her every step of the way. Very quietly, he sang her little song with her. Very carefully, with a degree of patience far beyond his natural years, he turned her around slowly at the grid's apex before she began her long, and at times, tortuous trail home.

No other words were spoken or sung, for an older language coursed between the pair of them, and it had no need for poetry or prose. It was like watching a young wild animal guiding an old matriarch though a thick and entangled forest. Half-blinded by years of suffering and hardship she had forgotten the way through the forest. Her feet were constantly getting caught up in the undergrowth, but she had the help of a younger pack member now, and she was carefully shown the way to go.

It was true that Tommy didn't really know about Judy's condition, but through that apple, that open smile of friendship, and a simple game of hopscotch it was clear that something very wonderful was beginning to unfold. Was this the start of something special, Edward wondered, and might this be the start of a new and infinitely better day?

He sighed to himself, however, and pulled out the letter that he had jammed into his pocket earlier that day. There were few tides for turning in his experience, and few days delivered much beyond high winds, foggy confusion, and rain. The letter still glared at him, and it still bellowed that it was urgent. Maybe he had better open it and see what the letter had to say.

\* \* \*

Dear Sir:

We know of your wife's condition and your ongoing care difficulties and commitments through Social Services. Please see our enclosed range of services. If we can help you in any way, please let us know.

Helping Hands, a private care company. Home care, it said, within an enclosed leaflet, hourly care, respite, and still so much more. He lowered the letter and looked over toward Tommy and Judy. It would take time, it would take money, and, if both Tommy and Judy wanted to do so, many more games of hopscotch, but perhaps there was a God after all. Wryly smiling to himself, he wondered, for one glorious second whether God would accept credit cards or hire purchase agreements, but then his smile faltered and eventually faded away. He had no credit card, or access to a hire purchase agreement, as apart from his small state pension he simply had no money to spare.

"There's time enough to worry about such things," his bank manager had once cheerfully told him, but the manager couldn't have anticipated Judy's Alzheimer's or Edward's premature retirement. Now there was too little time to get any real financial package organized, and though Edward tried to hide it from Judy, deep down he was both worried and scared. It was nice of Social Services to contact him though, but it would have been even better if they could also pay the £700 per week average home care bill!

That, if it ever came to fruition, was in the future though. Judy needed to rest now; otherwise she would soon get tired. If she tired, she got agitated, so he tucked the letter away carefully then took out a book from a bag that lay by his side. It was Judy's day book, and he hated it with every cell in his body. It was a cruel and constant reminder of her illness, and the wasted years that had so painfully destroyed their lives. It was a vital book, however, for both of them. With brightly-colored pictures and color-coded prompts and instructions, it was often the only way that he and Judy could communicate, and he carried it with him every minute of their waking day. He raised himself from the bench slowly and crossed over to stand beside her. He smiled, took her hand, and the held the book and his wristwatch before her.

"Look, Judy, the big hand and the little hand on the clock are saying it's three o'clock now. Look at the book Judy. At three o'clock we have a rest and a cup of tea and a biscuit. Come on my love, it's time for us to go!"

\* \* \*

Judy looked at the book and the shiny watch that Teddy held in front of her. The watch and its funny little hands seemed to be silent. On certain days, they meant nothing to her, but she knew that book. The book was important, and it had to be obeyed. It was Judy's book, and her name was Judy. It had a bright orange cover with a big smiley face on it, pretty pink flowers and yellow butterflies around the sides of each page. This page said three o'clock in bright red letters, and there were three words of, rest, tea, and biscuits, all clearly written in blue. Red meant it was time for her to do something, and blue told her what she had to do, but she wanted to carry on playing hopscotch. She wanted to eat her apple, and she wanted to eat it with Tommy standing by her side.

Hopscotch was written in blue letters, so she had to play hopscotch, and if she was lucky, Tommy might even come and play with her and stand by her side.

She had to do what the book said though. She had been told that many times by the white-coated man and Teddy, so very slowly, and very reluctantly, she allowed her herself to be guided away.

She still looked over her shoulder; she still smiled at Tommy, and Tommy still stood waving at her from within the squares.

If the sun was shining, she might play hopscotch tomorrow. Hopscotch was written in blue letters, so she had to play hopscotch, and if she was lucky, Tommy might even come and play with her and stand by her side. She bit a large chunk out of the apple that Tommy had given her. It was sweet and succulent, and she felt the juice dribbling between her fingers, as well as an apple pip that slowly

slipped over her chin. It was summer again, the sun was shining, and she had just had a lovely game of hopscotch. If she closed her eyes and listened very carefully, she might even hear the sound of the fair.

\* \* \*

"Hopscotch, one to ten, turn around and back again."

Tommy walked back slowly along the now deserted prom. As he walked, he gaily sang the song that Judy had just taught him, and he thought about Judy and Edward and the game that they'd played. His grandma, according to his mum, had also got a little bit of this thing called Alzheimer's and, like Judy, she was also getting a little forgetful. She wasn't quite as childlike as Judy, but maybe she might like to come along one day and play hopscotch with them. It seemed to Tommy that everybody should play hopscotch, especially when it was sunny, and it was hopscotch on the prom. •

Previously published in the author's book Pause for Thought Short Story Collection Volume 1, November 2016 (self-published). Reprinted with permission of the author.

### Ingi House

# SIMPLE SILENCE

I lied to you the other day when I said I turned the fan on because my neighbors left and I needed white noise.

The truth is I was simply hot, the sound of the fan the price to pay for cool air wicking away night sweats from my skin.

The truth is: It's never quiet enough.

The sound of my beating heart keeps me up at night and I think of ways to make it stop so I can finally sleep in simple silence.

## DAUGHTER OF DISTRACTION

The books say it's not a matter of discipline. It's simply a difference of chemicals flowing toward neurons, invisible except in the consequences: your inability to stay on the lapping shores of the routine; your constant need to float away from time.

My friends say I should try sticker charts and token jars as though this isn't obvious, as though I've not already tried.

But these are better tacks for minds like mine, or my friends', or their children's, which yours is not, which is, of course, the point.

The doctors say
I can give you this
or that or the other medication
to help you stay on course,
but I should watch your growth,
your sleep, your appetite,
your heart.
Nothing is a cure.
Some drugs may help cut through
the fog.

And you, dear drifting daughter: You say nothing, ask for nothing. You are happy. You float calmly on your raft of books and dreams. So why do I worry? You have all your limbs, your health, your warm eyes and bright smile.

But I'm afraid that daily life may drown you when you become adult, when the world expects more of you, and is less willing to forgive.

For now, I can draw you back to the solid ground of schoolwork, chores. But when I do not, you stray from your peers, cannot attend to massing clouds, coming tides.

Your father says that when rough seas do come, then they will come regardless of my worry.
But worry steers my course to you.
If your task is to learn to safely swim away from me, then mine is still to teach you how to stay afloat.

# **CHORD CHANGES**

### PAIGE CERULLI

The doctor looks up from the blood test results and places both hands on the bony protrusions behind my ears. He presses gently into my neck, then into my shoulders, then just above my elbows, each time eliciting an electric-shock response. Until now, I haven't known that these areas were painful, but it's as if my nerves come alive at his light touch.

"Well, I have some good news, and I have some bad news," he begins. I steel myself, knowing that my career hangs in the balance.

"You don't have rheumatoid arthritis," he starts, and I exhale slightly—this is good, yes? "But you do have fibromyalgia." I'm numb, not out of pain, but more out of confusion. I've heard the term fibromyalgia before, but always in the context of older women. At the time, I don't know the weight that I will come to associate with the word.

And from that moment, my life changed forever.

\* \* \*

To be fair, the actual diagnosis was the last step in a long string of events that had sent me down this turbulent road. The pain actually started when I was a teenager, but was written off by a number of doctors as various strains and injuries.

When I decided to attend college and to major in music performance on the flute, I never thought that the pain I'd been having would actually threaten my career, let alone alter my life. The pain had largely subsided when I began college, but became debilitating during my junior and senior years. I had my sights set on becoming a performer; I spent countless hours in the practice room perfecting every note, and successfully auditioned into the performance concentration (I was one of four students in the department to do so).

As a musician, you train to make the physically impossible possible. You learn that if you work hard enough, you can attain near-perfection, or at least what others would see as being perfect. You control everything; you control your own world by how much you practice and how hard you work and how much you believe. And that's magic.

So, I set about training my body to accomplish the physically impossible. I taught myself how to master difficult fast passages, how to make three-octave leaps seem seamless, and how to attain complete control over the muscles of my mouth, my tongue, and my throat. In short, I became a master of my body.

But as much as I mastered the physical, I was discovering that there was another factor that I couldn't master: Pain. The pain in my hands became a real issue during my junior year, and it started to threaten performance, and then my career itself. I began to lose control over my fingers, had numbness that spread from my wrists to my hands, and had pain that radiated up from my wrists into my shoulders.

There's something to be said about determination, though. I had seen numerous doctors about the issues and they all felt the problems could be resolved with surgery. So, I pushed on, determined to graduate, have the surgery, and then attend graduate school. I took high doses of pain meds, ac-

cumulated a vast collection of muscle rubs, wore braces and ACE bandages, and frequently wrapped ice packs around my wrists for long rehearsals or practice sessions.

And in the end, I made it. I cried through many late-night practice sessions leading up to my senior recital. I completed performances based on adrenaline and muscle memory alone, often not being able to feel my fingertips. But I knew it would be worth it; once I'd had the surgery to repair my hands, I would be headed for graduate school and from there, I'd be headed into a career in performance.

\* \* \*

After receiving my fibromyalgia diagnosis, I went and sat in a McDonald's with my laptop to research the condition. I learned more than I wanted to know—that it can be debilitating, that there's no cure, that even managing it well can be a challenge. I learned it was responsible for a slew of symptoms I'd had that, until that moment, doctors had just written off as being unexplainable. Extreme fatigue, headaches, balance issues, all-over body pain, and more.

I also learned that fibromyalgia often set in or flared up after a traumatic incident, such as an accident. I'd been in a car accident just before my junior year when a drunk driver crossed four lanes of traffic and hit my truck head-on. Suddenly, so much made sense, even though this wasn't the answer I wanted to hear.

I had rehearsal that night; I had continued to play in my university's wind symphony after graduating. When I walked into the building, everything felt different. Suddenly the practice rooms were no longer mine, and I felt like a fake when I took my seat for rehearsal. I knew it was all coming to an end.

\* \* \*

It's hard to explain what music means to me, especially if I'm talking to someone who isn't a musician themselves. In short, it becomes the most important thing in your life. It affects how you see the world—I hear lines and countermelodies and harmonies and note values when I'm listening to a song on the radio. I count stairs in octaves. I guess the pitches sent out by the fan, the fridge, the radiator.

And as for the stage? It's the best place in the world. Has there ever been a place where you knew you were meant to be? For me, that was the stage. It was both terrifying and elating at the same time. Each time I stepped out onto the hardwood floor, I knew that magic could happen.

Imagine that, all your life, you've trained to do something. You've sacrificed your nights, your weekends, your entire social life during college. You've bled for this thing, knowing that you were forming your future with every muscle spasm and exhausting hour.

# I learned more than I wanted to know—that it can be debilitating, that there's no cure, that even managing it well can be a challenge.

In doing this, you've carved out an identity for yourself. You knew where you belonged, you knew what your future would consist of, and you knew you had the talent and drive to take you there. You've experienced some of the highest highs in your life thanks to this passion. It makes you feel good about yourself, about the fact that you're talented and you can embrace the world in this special way.

Then imagine that it's all taken away. The dreams that you have been counting on, all of the work and sacrifices that you have made, it all means nothing. And there's nothing you can do to change it.

\* \* \*

Here's what they don't tell you about fibromyalgia. It's one of those conditions where everybody's heard the word at some point, but no one quite understands it in its entirety. And when you have to explain it, it almost sounds like you're making it up. You see, fibromyalgia is a conglomeration of symptoms, and it doesn't act the same way in every person. Nerve pain is pretty consistent across the board, as is fatigue, but after that the symptoms vary.

The kicker of my whole diagnosis? I'd been sent to a rheumatologist when my primary care physician thought I might have rheumatoid arthritis. I'd been terrified that I'd actually have RA, fearing that it would end a performance career. My rheumatologist explained that, if I'd had RA, he would have recommended that I continue on with my music career. But fibromyalgia is much more difficult to manage, and my body would just not be able to sustain the lifestyle that my dream career demanded.

The human body is blessed with more than ninety-five billion neurons which protect us; they scream "Ouch!" when we brush the blade of a knife, or "Too hot!" when we get too close to fire. They keep us from getting too hurt; they keep us from killing ourselves. Only now my nerves have rebelled; they scream at me "STOP" and "It hurts!" when I'm doing nothing to hurt them. They're wrong, and I can't trust them anymore. But that doesn't mean I can silence them.

Before, when something bothered me, I used to practice through it. It's incredible what driving deep into scalar runs can do for your emotions. When I felt loose, floating along in the world, I would ground myself with Bach and with Mozart and Chopin. I was improving myself, and I had a purpose. I was working toward something, and as long as I was working, and improving, then I couldn't be as aimless as I felt.

\* \* \*

Things got dark for a while after that diagnosis. That night, I didn't cry until I was driving home from rehearsal and the Eli Young Band's version of "Even If It Breaks Your Heart" came on the radio. Then I lost it.

When I got home I went for a walk down the street, despite the fact that it was nearly midnight. It felt like my chest was caving in on itself, and I began to curse every twinge of pain that traveled through my wrist. I became furious at the doctors who had written my ailments off as minor afflictions. Then I started to hate my body for not being strong enough to do something so simple—to play an instrument, to live a life normally.

Now everything is divided into the before and after. When I brushed my teeth that night I knew I was doing so for the first time as a non-musician. Now every act is an elegy. A remembrance. A part of the letting go.

A few months after my diagnosis, my friend introduced me to her colleague as someone who "used to be a musician." What hurt so badly was, at that instant, I realized it was true. Now, three years later, I find myself saying the very same thing during introductions. I used to be a musician. I'm not any longer.

I envy others' hands. The cashier at the grocery store has beautiful hands, strong, agile, elegant, and they work effort-lessly as they lift milk containers and cans, objects which would send pain shooting up my own wrists. I wish her hands were mine.

# Now everything is divided into the before and after. . . . Now every act is an elegy. A remembrance. A part of the letting go.

I go through periods of time when I bleed envy for other musicians. For the first year or so that I knew I had fibromyalgia, I avoided going to concerts, since I would sit in the audience and the envy would take over my enjoyment of the music. I still feel twinges of envy when my friends advance in their music-related careers. Facebook statuses bring painful reminders of where I should be in my own career right now.

What I hadn't anticipated was how out of place I would feel when I reconnected with my music major friends at a college friend's wedding. We were all seated at the same table, and the conversation naturally revolved around music, careers, and recent performances. While I could understand the music talk, I had nothing to contribute myself. No exciting performances, no technical piece that I was tackling.

I took almost two years off from playing. My talent had decreased as the pain worsened, and years after graduating my playing skills nowhere resembled the talent I had exhibited while in college. I've since begun to play again a bit, but only for myself. No more ensembles, no more performances.

\* \* :

Fibromyalgia has altered my life in other ways, too. At the time of the diagnosis I didn't realize how all-encompassing the condition is. I find that it affects my work, my relationships, my outlook on life. Try to explain to a new boyfriend that, while you'd love to see him, you're too physically tired to safely drive your car. And then remember that it's 8:30 p.m. on a Friday night. See what his reaction is.

Then think about kids. Is it practical to have them? Is there some chance of their inheriting the condition? Fibromyalgia is largely not understood; while no hereditary factors have been identified, do I really want to take that chance? And then there's just the very act of having kids and caring for

them. When I can barely care for myself, how in the world would I be able to keep up with kids and their never-ending energy?

I find myself wondering if this is a diagnosis that I should hide from my employers. I grow paranoid when writing about it publicly, wondering if it might affect my chances at landing a job in the future. I begin to build my freelance writing business, anticipating that I may not always be physically able to perform an office job.

One of the largest changes I make is to save money and buy a house of my own. An avid equestrian, I now know that my body will not always allow me to perform the physical tasks that go hand in hand with caring for horses. And so, two months before I turn thirty, I buy a small home with a small barn and bring my horse home.

I spend time on fibromyalgia-focused forums, and it's an eye-opening experience. Many of the members are on disability, and they talk about how greatly their lives have been altered. Some members are better regulated than I am, while others suffer from far more debilitating symptoms. It makes me at once grateful for my health and terrified for what may come in the future.

I'm lucky in that my writing mentor has also been diagnosed with an autoimmune condition, and we discuss the stress of trying to maintain health, how to preserve energy throughout the day without becoming total recluses, and the emotional toil that being chronically ill takes.

I learn about the spoon theory—the idea that when you have fibromyalgia, you only have so much energy—so many spoons—per day. Every task, like doing the laundry or going for a walk, costs you a spoon. Run out of spoons and you're done for the day. So, choose your activities carefully. Learn to count, to plan, to budget your energy stores. It's a far cry from my eight-hour practice sessions and livelife-fast college approach.

Perhaps the most challenging aspect of living with fibromyalgia is that it is, largely, an invisible illness. Many days, I look just fine. I may limp a little or seem like I didn't get a good night's sleep, but if you were to pass me on the street, you wouldn't know what I'm actually going through. Sometimes I want to scream it from the rooftops, when I'm tired of hurting and aching and I'm stuck in a long line at the grocery store while I only want so desperately to be home.

\* \* \*

I think what I loved the most about music was that I could connect with listeners in a magical way. I could breathe life into that flute and make it convey the deepest emotion without using words. I could make people cry. I could move my-

self to tears. And I could open myself up, show people what I was feeling, show them pain and elation and love, and let them share in it. I could heal both myself and the audience.

Now, my way of connecting with others is only through words. I have focused heavily on my writing as music has been pushed out of my life, but the connection is not the same. I can't feel the silence and the anticipation of the audience when they read a piece I've written. I can't draw on their energy to make my writing even better. It's a very different kind of connection.

I never thought my life would change in the way that it has. I had everything all planned out—I'm a planner, and a dream chaser, and a firm believer in the fact that if you work hard enough, you can accomplish grand goals. As a musician, I made the physically impossible, possible. Sheer determination and will power can get you far. But as I've learned, they can't carry you all the way.

So I continue to try to make my peace with it. I have a rheumatologist who is supportive and understanding, and who has done a great job of finding a treatment plan which gives me a quality life. I play my flute every few days, sinking down into its sound and remembering how great I had it. I remind myself that I was very talented, and that I poured myself into every performance, and that, for a while, I lived that dream I had carved out for myself.

\* \* \*

It is nearing midnight and the quiet of the building wraps itself around me. The practice room smells a little musty, though I've opened the window to bring in the cool March air. I've already played for eight hours today, but will continue practicing for the next two hours until I feel like I've made enough progress to stop for the night. My senior recital is two weeks away.

Reinecke's "Undine" Sonata floats out through the room, and I press hard against the high notes, putting urgency into the phrase as Undine learns she must kill her husband due to a curse. She's water and life and at the end of the piece, she will vanish, swept back to the seas where she belongs.

My wrists are wrapped in ice packs and I carry the scent of Icy Hot with me always, but this last movement of the sonata is my favorite and for the last five minutes of rapid-fire sixteenth notes, I don't feel the pain. I am Undine, screaming her frustration out over the ocean, letting herself break apart over the loss of what could have been. I will play this piece at my recital, but it will never be as powerful as it is tonight. Through tears I reach the final measures, hold the last note, stay on pitch. This is how I'll learn to say goodbye. •

# **Hues of Blue**

## SANDY PALMER



Rora Blue, The Unsent Project, 2015 - Present, collage

"Above all else, I am an artist." ~Rora Blue

That color is love? Inquisitive and creative nineteen-year-old Rora Blue wondered what the answer might be and initiated a simple concept in 2015 that exploded online. What color do you associate with the person who was your first true love? What would you say to that person today if you could send a text message? More than 34,000 people have pondered those questions and reacted to Blue's prompt to participate in an interactive art project that struck a chord with people around the world. The response was beyond what she ever could have imagined with press coverage from Teen Vogue,

The Huffington Post UK, Women's Health, and ABC News, to name a few. One year after launching The Unsent Project she tweeted: "An artist who was a huge inspiration to me when I was starting the #unsentproject submitted a message to the project today . . . life is crazy."

Yes, life is definitely crazy at times, filled with amazing highs, devastating lows, and a mix of all that is between. Unknown to many, while *The Unsent Project* went viral, the artist was experiencing fatigue, pain, migraines, blurred vision and brain fog, among other things, but for several years no diagnosis or treatment helped. She was finally correctly diagnosed with Lyme disease in 2016. Treated early with antibiotics, a full recovery is likely. By the time she was di-



Rora Blue, Chronic Illness Reimagined as Something Glamorous, 2017

agnosed, treatment had been delayed so long she now lives with the chronic form of the disease that has no cure. Lyme disease is caused by bacteria transmitted by black-legged ticks. Since Blue's mom, brother, and sister also have been diagnosed with the disease, they suspect they all were exposed during a camping trip eight years ago.

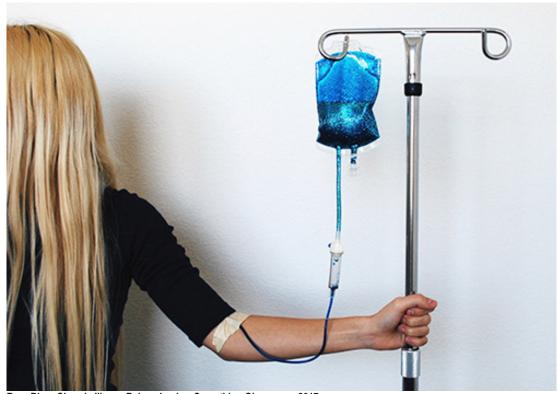
"Lyme disease has impacted every aspect of my life. It has definitely placed limitations on me and how much I am able to do. For a long time my diagnosis was something I rarely opened up about. Now, I am using my art as a way to process my experiences and connect with other people who have chronic illnesses." Her series Chronic Illness Reimagined as Something Glamorous was created in response to her condition. The images depict elements she has encountered during treatment—medication, IVs, hospital gowns. "This juxtaposition comments on how life can appear glamorous for those living with invisible illnesses despite suffering from many symptoms. With this series I hope to show that just because an illness cannot be seen, that does not mean it is not there." Creating art is a cathartic process for Blue who says, "I am healing in new ways by talking to others about my experience."

As a young child she spent hours painting at a little easel in the kitchen, "I would tell my mom I had to get my 'thinks' out. I have always expressed my creativity in one way or another." In high school, that expression took the form of everything from dance to choir. In art classes she was taught traditional mediums that were unfulfilling because she didn't feel she was able to fully communicate her ideas through drawing or painting.



Rora Blue, Chronic Illness Reimagined as Something Glamorous, 2017

After spending most of her life in Texas, she graduated from high school and moved back to her birthplace in California with a desire to interact with people and listen to their stories. The internet connected her with people online and that's when she invited people on Tumblr to share a text message they never sent to their first love, along with the color they associate with that person, so she could explore the relationship between love and color. The response was immediate and impactful. Messages were diverse: lighthearted, snarky, empowering, heartbreaking. She quickly realized that reminiscing about a first love evokes a wide range of emotions and conjures up every color of the rainbow. Struck by what clearly resonated with a lot of people, the artist says, "I knew I had



Rora Blue, Chronic Illness Reimagined as Something Glamorous, 2017



Rora Blue, Phantom Pain, 2017



Rora Blue, Phantom Pain, 2017



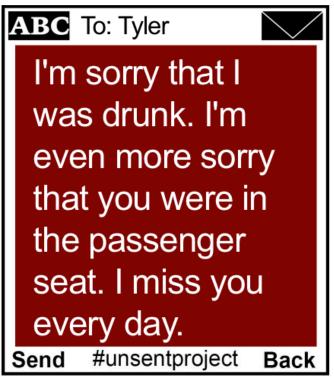
Rora Blue, Chronic Illness Reimagined as Something Glamorous, 2017



Rora Blue, Phantom Pain, 2017



Rora Blue, Phantom Pain, 2017



Rora Blue, The Unsent Project, 2015 - Present, digital submission

We were just two people that became too different of people.

Send #unsentproject Back

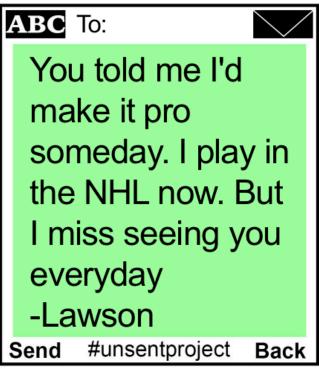
Rora Blue, The Unsent Project, 2015 - Present, digital submission

to find a way to display them in a meaningful way. I began creating large, colorful collages which evolved into what is now *The Unsent Project*. It allowed me to see there were more ways to create art outside of drawing and painting." The project received international attention, opened up a lot of doors for the budding artist, and she has continued to create ever since. "I like to think I was born in Sacramento twice. First in 1996 and then again in 2015 when I began creating art."

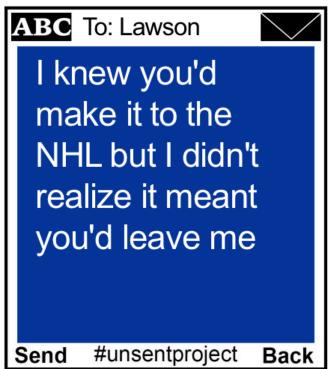
Blue is currently pursuing a bachelor of fine art degree in new media art, a comprehensive term that includes art forms produced with digital/emerging technology and an emphasis on the connection between the artist, the work, and the viewer. Interaction is essential in her work, along with bold colors and text, as she merges art with social media. Sexist comments about women are explored in her series *Handle with Care* and *(Don't)* considers phrases that force gender roles on men. The messages conveyed in both have led people to describe her as a feminist and an activist. She certainly isn't afraid to inquire, explore, and produce work that challenges perceptions and, hopefully, causes people to stop, contemplate, and see things from a different perspective.

Vibrant hues, line, shape, and text are signature elements of Blue's work but Phantom Pain is a somber departure from that style. It is gray. Haunting. Cold. And in the end... empty. The tingling, icy pain is still palpable, yet no longer visible. Open to interpretation, as much of her work is, one may relate these images to the process of losing someone. Maybe a death. Or someone who chose to depart, leaving us empty-handed. With poor circulation from chronic Lyme disease, the artist experiences numbness and tingling similar to sensations felt while holding a piece of ice for a while. An onlooker may see her as a healthy, beautiful young woman without a care in the world because her symptoms are invisible, just like the melted ice, but the pain and other ailments are very real. Things aren't always as they seem.

Her latest project, *The Walk*, examines the objects that women carry when walking alone at night. She hopes to start a conversation about the measures women take in order to complete the simple act of safely walking to their cars. While speaking at an International Women's Day conference she invited the women in attendance to participate in the project by writing on pink sticky notes the various objects they carry for protection and she incorporated what they wrote in this work. She has merged her love of art and interaction with people to shine a light on issues that are important to her. She encourages others to find their passion



Rora Blue, The Unsent Project, 2015 - Present, digital submission



Rora Blue, The Unsent Project, 2015 - Present, digital submission

and says, "Make space to do what you love, whatever that may be. Be mindful of your body and your limitations, but don't be afraid to push yourself to try new things."

Just like the diversity and depth of the work she creates, there are many shades to artist Rora Blue. She loves to travel, spend time by the sea, and visit as many different art museums as she can find. She was included in Cosmopolitan article, "Seven Young Women Doing Amazing Things to Empower Others," in August 2016. Her work has been on display right in her hometown of Sacramento and as far away as Dresden, Germany. She's an artist, speaker, motivator, and student. She's accomplished so much already and she's only twenty-two! Of all the submissions received for The Unsent Project, blue is chosen significantly more than any other color. "I hope to explore the psychology behind the color blue and find out why so many people associate it with love." If you're first love came to mind as you read through some of the examples from the project and you want to post an anonymous text to that person, you can still do so on her website www.rorablue.com. While you're there, check out some of her other work, and follow her on Instagram or Twitter for up-to-date information on new work. Maybe you can be a part of her next project that goes viral!♦



Rora Blue

# PRIVILEGED, OLD, WHITE, AND RICH?

ELIZABETH A. SACHS

hat's what they say of me. I agree with the old and white part. But I'm not rich, at least not according to my bank statements, charge cards, and accountant. I barely cover my monthly bills, especially since I'm living the remainder of my days on a librarian's pension in a wheelchair. With no relatives, nearby, I've never thought of myself as privileged.

Because I'm a paraplegic, I need help around the clock. Long term life insurance, it turns out, is not so long term. Mine kicked-in six years ago, when I had several spinal surgeries to support my already weakened spine. The insurance, will probably last another two or three years and after that who knows? For now, I spend my days and nights with aides. Somewhere between nurses and companions, the women I employ validate their competency in dealing with the elderly, disabled, and ill through certified training.

The ones I've known are young women, immigrants who've come to this country to escape poverty, political upheaval, to better their lives, and the lives of their families. They've come from Ghana, Jamaica, Puerto Rico, Brazil, Sierra Leon, Ukraine and Russia, Haiti, the Dominican Republic.

They bring the world with them, but it's not the TV news version that reaches the United States in sound bites. They tell me about their mothers and fathers, their children left behind or dead. They tell me about fishing on the beach for

breakfast. They love their polygamous fathers and accept the jealousy of sisters who share the same father but different mothers.

Experiences of being raped by military gangs are recounted along with descriptions of how beautiful their country is. Their stories of mass murders are relayed in a casual way. Just life, their tones suggest. The stories so much the same, they are a chorus singing a song the world will not listen to.

The food they bring for their workday hints at other lands: a breakfast of home-roasted peanuts and banana, a dinner of eggplant cooked until it is gravy, thrown over spiced beef. When they warm their meals in my microwave, I smell spices that make me think of dusty market places. I picture tents, dark-skinned women carrying large baskets on their heads.

When they talk on their cell phones, it's a rapid language and I cannot distinguish a word. There is no way to understand any of what's being said unless it's my own name. One woman speaks twelve African tribal dialects, another an impenetrable Jamaican patois.

Beneath their work smocks are bright colorful mixtures no fashion designer has thought to put together. Beneath their bright, intricately woven head scarves, their hair is dark and coarse-looking, but soft to the touch. They complain that the water here ruins their hair. "Chemicals," they say. "Our water doesn't have chemicals back home."

Their skin is all shades of browns and tans. No wrinkles on the face or at the neck. I've learned to appreciate the beauty of facial scarring, delicate lines, crescents just where the skin folds back at the smile. The scars might denote tribal heritage or feminine adulthood.

In Ghana, Margaret's father is a tribal chief who climbs tall coconut trees using a belt around his waist and the tree, to help him shimmy to the top. To come to her day job with me, Susan has to leave six children, the youngest severely autistic, in the care of her oldest girl who is almost twenty-one and struggling to pay for college. Another of my aides, a single mother, has to lock her ten-year-old daughter at home alone in an apartment at night and on the weekends. She can't afford a babysitter. And the girl, newly arrived, is not yet able to speak or read English. She is physically mature and likes to sneak out. She's already been accused of shoplifting.

There have been parental deaths and no money to fly home, boyfriends who've come and gone. There have been tales of love lost, cheating husbands, and spouses' girlfriends who taunt them on social media.

I've assured more than one woman that fliers stapled on telephone poles about getting rich are scams. Don't bother to respond to banks and department stores' friendly ads for credit cards. There's no such thing as free money in America. I've explained the difference between credit cards, credit card debt, and credit scores. These women come believing that the United States truly is the land of milk and honey only to wind up saddled with huge debt.

I say it's important to master the convoluted way things work, that on top of everything the winters are colder than where they've come from so they need heavy coats for themselves and the children, that they need to learn to read train schedules and sometimes the trains don't run on time. Even if they struggle with exhausting work schedules, juggling two or three low paying jobs and childrearing over the phone, they remain true to the belief that their children will be better off someday. In the end, I want to believe they will succeed.

"Please, Martha," I say, "You need real shoes, not the dollar slippers, you buy from the street vendors. They are pretty but won't last a week on the concrete." She's not the only one I'm trying to protect. Because they are all so strapped for money, they show up sick and coughing, and hardly able to keep their eyes open. I've sent many away to avoid picking up something myself.

I've learned to accept the indignity of needing Iris or Martha or Susan to clean my butt when I've had an accident or change my adult diapers because I am incontinent since the surgery. We converse in spite of the situation, telling family stories or just joking as a way not to focus on the indelicacy of the moment. But it's taught me that this is not an indignity—far from it—it's a moment of profound intimacy.

I sit in my wheelchair maintaining a roof over my head. They tell me I'm rich. For years, I insisted it wasn't so, but they've shown me how the world works, why the women who come to this country are grateful. And from them I've learned just how privileged and rich I am.

## SKETCH

#### SAM PROVENZANO

s I entered the front door to the tiny corner bar, my dog, Harry, by my side, a hand took my elbow.

"Hey Sketch, good to see you," a woman's voice said.

"That you Katelin?" She squeezed my elbow in response.

"You want to sit in front?" she asked as she led me past the

"Sure," I said, estimating from the sound of the voices that there were about forty people in the bar.

"Johnny Walker Black, straight up?" she asked as Harry and I sat down.

"And a bowl of water for Harry," I said.

Moments later I heard blues chord progressions being played on a piano. The ice in the glasses around me stopped clinking and everyone in the bar stopped talking at the sound of that first note. A woman's voice started singing the blues, and I swear, it sounded as if everyone there stopped breathing.

When the song ended and the applause began, Katelin brought my drink and Harry's bowl of water. She put my drink in my hand then she placed Harry's bowl in front of him. As I reached for my wallet, she put her face close to

mine.

"Mick says your money's no good here," she almost hollered over the applause.

I always carry a sketchpad; that's why many of the folks who've seen me around the neighborhood call me Sketch. I can't comment on my work, for obvious reasons.

I finished my drink and raised my arm for another. Katelin came to my table.

"Ready for another?"

"Bring one for the singer too," I said.

Within ten minutes this girl was standing next to me. As soon as she was within three feet of me, before she said a word. I knew it was her.

"Hey, Sketch."

"You know me?" I asked.

"Seen you around the neighborhood, but I just learned your name from a guy at the bar. Thanks for the drink."

I nodded.

"Mind if I sit here?"

"Please," I said coolly, but my heart was in overdrive.

She sat down next to me and I could feel her eyes on me.

"How'd you get your name?"

"Guess it's what I do," I said. There was a pause then, and I didn't want her to leave.

"Can I touch your face?" I asked. She pulled her chair very close to mine, took my hands in hers and placed them on her face. It was just as I had envisioned: the length of the forehead, the depression between the eyes, her nose, her lips, her chin, her cheekbones, her hair.

"Did you see me now?" she asked.

"Yeah, but everything is like I already knew." I said.

"What's that mean?"

"Beautiful."

"So you gonna sketch me?" she asked.

"Yeah, but I'll wait till you're up there singing," I said. We had another drink together and then she went back to the stand. Everyone stood up and applauded as she sat at the piano.

Four bars into "Stormy Monday," I took my sketchpad from my pack and began to sketch. I can't go back and fix things; when my pen goes to paper, that's it. I sketched during the whole second set and, by the end of it, I could tell there were at least three people looking over my shoulder. I closed my pad as she ended the last tune of the set and people stood and applauded while she stepped down and walked to my table.

"Did you sketch me?" she asked as she sat down. I didn't answer, I just opened the sketch pad. "You're even better than I heard," she said.

"You heard I was good?"

"I heard you were somebody who would become famous after you died," she said.

"Hmmm," I said. And then, to fill the silence, I added "Isn't the bar scene a step into hell for you?"

"Hell?"

"Yeah, I mean you're a church singer aren't you?" She laughed then and covered my free hand with hers.

"This ain't hell man, hell is four blocks west of here, right where Potomac crosses Main."

"Well," I said, "you're a slice of heaven." She laughed again.

"No, heaven is on Capital Avenue, up past Madison, where everybody's rich and white."

"So, we're somewhere in the middle?" I said.

"Yeah, it's where real people live," she said.

"Amen," I said.

After her last set, the three of us left the bar together and walked down East Avenue along the river. We stopped at a hot dog cart and she handed me a hot dog; I gave half to Harry.

"You like me 'cause I'm black?" she said.

"Yeah," I said. "You like me 'cause I'm white?"

"I'm serious, my color turn you on?"

"I can't see your color, and who says you turn me on?"

"Do I?" she asked. I thought for a moment.

"I guess it's your voice," I said.

"That enough?" she asked.

I didn't know. "What do you think?" I said.

"I think we must both be crazy for having this conversation." "Why?" I asked.

"Because you're some blind white guy who bought a drink for a girl in a bar and you can't even look into her eyes," she said.

"Sure I can," I said, "I just can't see them, that's all." She didn't say anything for a while, and I felt uncomfortable. "You prejudiced against blind guys?" I asked.

"Naw, I ain't about to prejudge anything or anybody," she said. "Anyway, that gives you a good excuse to be with a black woman, doesn't it?"

"What?" I said, "You think I need an excuse to be with somebody?"

"Well, you don't have to look at people's faces judging you; people cut you slack because they figure you might not even know I'm black."

I felt my face burn and my eyes sting. "Damn, that's cold," I said. "What's that say about how you see yourself? There ain't nothin' low about my standards."

"Sketch, I ain't out to hurt nobody, but I calls 'em like I sees 'em."

"And you're blinder than I am," I said. "I can't see you, but I heard you, I felt your face; you saw my sketch. You think other people, people who ain't blind and people who ain't black have a better understanding of each other than you and I?"

"I don't know what I think . . . maybe I'm a little scared," she said.

"Scared of what?" I asked. "Where's a seat? I want to sit down." She took my arm and led me to a bench where we both sat. Harry laid down by my feet with his body against my leg.

"You're the first white guy I ever liked this way and I'm having a rough time relaxing with it." I felt my shoulders relax when she said that.

"Okay," I said, "but that's what you got to tell me, not that BS about us being a couple of sorry-ass misfits and that's why we're becoming friends."

"I never said that," she said. "Look, I just got off a long bumpy ride with a guy from Newark and I need a rest."

I leaned back against the warm hard backrest and concentrated on the air on my face. "Yeah girl," I said getting up, "you have yourself a rest. Home Harry." And Harry pulled me toward home.

A week went by before I allowed myself to think about her again. Her face appeared before me suddenly like bread in the toaster you forget until it pops. Once she appeared, she wouldn't go away. I couldn't understand the longing I began to feel for her company. Maybe she was right, I thought, maybe I'm a desperately lonely blind guy.

It was Saturday morning, I leashed Harry and we went out for a walk. As we passed the corner bar, I heard her voice. Harry and I stood outside until the song ended and then we continued down the block. I heard someone running behind us and getting closer.

"Sketch?" her voice said. "Is that you?"

"Hello," I said, "I don't even know your name."

"It's Veronica," she said. "I've missed you."

"Then I guess you're all rested," I said. I felt her lock her arm in mine.

"Yeah, rested" she said. "Now where were we?"

## HOTEL IN THE DESERT

J. D. CHANEY

The night seemed interminably long to the balding, bespectacled night clerk. Nothing appeared to be moving, no sounds to be heard. And that held particularly true for the tired, old hotel in which he worked. The Mulege hotel was made of faded brick with a second floor wooden balcony in dire need of repair. Supporting it were concrete Ionic-shaped columns along the four corners, painted white. Around the back was a set of stairs extending to the second floor.

He fingered the register, looking for at least the third time at the number of occupants they'd gotten that day. Two names appeared: Mr. and Mrs. Jaime Gonzales from Mexico City. Other than that, the remaining nine rooms were unoccupied. The two appeared young, possibly newlyweds. But for the life of him he couldn't understand why they'd want to spend the night here. Ramon, closed the book, shaking his head and glanced around the once ornate lobby. The hotel was built in the early 1920s, by an American dreamer named Ronald Tillman who swore, at the time, that this part of Baja would be teaming with foreigners. He called it the Mexican Palm Springs; a warm desert oasis festooned with cactus, orange and mango trees, beautiful scenery, and friendly faces just waiting to take in Yankee dollars.

Mulege, founded by Spanish missionaries in 1658, is a remote village 618 miles south of the United States border. It is situated at the mouth of the Rio de Santa Rosalia overlooking the river valley on one side and the tranquil Sea of Cortez on the other. Tillman, looking to recover from nagging wounds suffered in World War I, drifted south

from his hometown of San Diego. What he found left him spellbound. The warm Baja sun and salubrious dry climate seemed to magically draw away the pains in his back and neck and the bracing waters of the sea cleared his head of self-pity and depression. Rounding up enough money to complete the small but ornate hotel Tillman sat back and waited for the throngs of Americans to show up and make him a rich man. And, for a while, they did come, filling his hotel and forcing him to take on additional employees.

Ramon Guzman, then only seventeen, became his first and eventually only worker. Fiercely loyal to Tillman, Ramon acted as hotel clerk, bellboy, and custodian, working two shifts a day even when business began to wane. Sadly, the end of the '20s brought with it a worldwide economic downturn that left millions unemployed and hundreds dead from suicide due to financial ruin. Eventually, patrons stopped coming and the American was forced to lay off all his employees save Ramon.

The two had grown close in the six years they'd been working together with Tillman acting as a surrogate father to the boy whose own father had abandoned him, his brother, sister, and mother when Ramon was an infant. The Mexican had come to acquaint himself with the physical nuances of his boss. He watched as Tillman's lack of energy began to expose itself, his normally quick pace morphed into a shuffle. Now, hunched over and carrying a three-day-old beard, the ex-soldier called the diminutive Ramon into his office.

Ramon watched as his boss tumbled into his desk chair. He looked up at the young man with eyes reddened from lack of sleep. "Ramon, my friend, I think we need to face some facts." He rubbed his eyes vigorously in an attempt to clear them. "The hotel has had it . . . . I've had it, especially after nearly thirty-five years, other than the fact that it's paid for, I am completely broke. I don't even have enough to pay you this month."

"Oh, Señor Tillman, that's ok. I'm sure . . ."

Tillman interrupted. "It's not okay and I intend to do something about it. He reached into his drawer and removed a long sheet of paper. "This is my deed to the hotel. I'm turning it over to you."

Utterly shocked, Ramon moved to speak but remained mute. "I'm returning to the states. I've got a sister in San Diego whose husband just died and she'd like me to come live with her. I'll be sixty-six this year and don't have much to show for it. His head drooped momentarily and he shook it in capitulation.

"I don't know what I was thinking building this heap of bricks. I mean it's in the middle of nowhere and hard as hell to get to.

"Anyway, it's yours to do with what you want, although I doubt if anyone would offer you a peso for it." Before the Mexican could gather his wits and say anything, the owner spun on his heels, heading toward his room and began to pack. Within an hour he exited, hugged his employee, and without any further words, walked to his car and drove away, bounding north along the rutted dirt road that led out of town.

"We're ready to check out," came a woman's voice directly behind him. Startled, he spun around, completely forgetting about the couple that had checked in two night's back. Guzman settled their bill and took their bags out to their car. Once they were gone he returned to the hotel lobby making a note that the large overhead fan in the lobby had stopped working once again. A looming feeling of loneliness crept over him, compelling Ramon to charge back out into the light where the warm Baja sun soothed his uneasiness.

For the next two weeks he served alone at the Baja Hotel, checking in a total of four guests. Two were American geologists headed for a conference in Cabo San Lucas. They'd rented a van at the border and drove, stopping along the way to pick up the odd assortments of stones they found while traveling through the desert. Another was a young man who'd come up from San Jose del Cabo to attend his uncle's funeral and the fourth was a haggard looking husband from town whose wife had thrown him out of the house for having an affair. He stayed at the hotel for three

days until his wife finally forgave him and welcomed him back into their home.

At day's end, the new owner returned to the room that was adjacent to Tillman's. No one would be looking for a room after sunset so he felt confident he could close up for the day. As he was removing his shoes he heard a loud knock on the hotel door. Curious about who it could be, he scrambled to slide on his sandals and hurried to the entrance.

Ramon recognized him instantly. "Letter for you, Señor Guzman. Special delivery."

"The hotel has had it . . . . I've had it, especially after nearly thirty-five years, other than the fact that it's paid for, I am completely broke . . ."

"Señor Valencia, haven't seen you in a few days."

The mailman nodded. "I took a little holiday with my wife. Sadly, in a town this size we had no one to deliver the mail." He pointed to a large canvas bag in his truck. "It looks like I'll be delivering all night." He offered a quick smile then turned, walking rapidly to his vehicle.

Looking at the envelope Ramon spotted the San Diego address. "Señor Tillman," he said excitedly. He furiously tore open the envelope and unsheathed the letter.

It read, "Dear Mr. Guzman. My name is Natalie and I'm writing to let you know of my brother Ronnie's passing. A week ago he suffered a fatal heart attack in the backyard. The doctor feels he didn't suffer so at least that's a blessing. I wanted to tell you that he talked of you often. You were like a baby brother to him. He would often say that the best years of his life were working with you in that run-down hotel and that he hoped you could somehow eke out a better living than he had. I'm sorry I had to be the bearer of bad news. Sincerely, Natalie Tillman-St. James."

Shuffling over to the lobby couch, Ramon dropped heavily into a corner, impervious to the exposed springs that gapped through the foam rubber and faux leather. He reread the letter a couple more times before realizing that the paper's lettering began smearing with tears. The Mexican drew a hand over his eyes wiping them as best he could, then refolded the letter, placing it back in the envelope. For several

minutes he sat in silence while the evening sun disappeared, leaving him cloaked in darkness.

The following day a rare deluge greeted the townsfolk of Mulege, allowing Ramon enough time to drive into town to pick up laundry detergent and bottled water. *No hurry getting back anyway*, he thought. While picking up his supplies he looked out the window watching as men and women scrambled to and from their destinations, fumbling for car keys, or frantically ducking their heads deep into their collars in a futile attempt to stay dry.

Strangely, a wave of loneliness swept over him. Most of the people he'd seen were couples; some with kids, some without. The innkeeper had never married, reminding himself that his mistress was the hotel. Now fifty-two, Ramon was acutely aware that a village this size was in short supply of single, middle-aged women who didn't look like sumo wrestlers. For years he would fantasize that one day, in would walk a beautiful, dark-haired beauty looking for a room, only to fall in love with him and share in his affection for the hotel. But as the years rolled by, the dream began to fade. Ramon didn't even have any family to speak of. His parents were dead and his older brother left home as soon as he'd turned eighteen to work the oil fields in Venezuela. It had been over twenty years since he'd heard from him.

Ramon also had a sister, Sarita, three years younger than he who was born with Down syndrome and placed in an institution in Mexico City. He visited her once six years ago but was saddened by the fact that she failed to recognize him. As he approached his sister, she recoiled, eyes failing to meet his as she clutched tightly to a ragged doll the entire time he was there.

To keep his mind off of his current woes, Ramon decided that the hotel needed a bit of a face lift. The mosaic tiles, which led from the entranceway through the lobby and partially down the two opposite sides of the first floor, were caked with grime and had lost their luster years ago. A thorough cleansing was in order and he was eager to complete the task. Ramon reflected back to when he was a young teen entering the hotel for the first time. Opening the double doors wide, the sun rose behind him, casting its golden hue on the tiles, illuminating them like rows of multi-colored diamonds which left him blinded in wondrous delight.

He entered the basement, finding sponges and cleansers on the top of two long shelves which ran the length of one wall. An oversized plastic pail lay in the corner, heaped full of rags. As he began his assent, the bell which was affixed to the top of the door leading into the lobby jingled signaling company.

Skipping every other step, the innkeeper emerged from the basement, only to find a tall, trimly built man with a pencil-

thin mustache leaning against the front desk. The man turned, staring at Ramon whose hands were weighted down with his cleaning utensils. "Oh, I'm sorry señor, I was just about to do some cleaning."

The man nodded ever so slightly, a blank expression appearing on his face. "I was wondering if you had a room available?"

Ramon, placed his pail and cleanser on the floor behind the counter. "Yes, señor, we do. Will it be just you?"

For years he would fantasize that one day, in would walk a beautiful, dark-haired beauty looking for a room, only to fall in love with him and share in his affection for the hotel.

Again, a slight bobbing of his head.

"And how long will you be staying with us?"

For the first time, the man looked up staring directly at Ramon who seemed struck by the weariness of the man's face. Handsome to be sure, but exhausted and in desperate need of rest. The outer rims of his deep-set eyes were coated in red, his cheeks shallow and lined. His salt and pepper hair rested on his forehead, matted stiffly with perspiration. A nasty rust-colored scar ran from the right ear lobe to his Adam's apple before disappearing into the folds of his shirt. It contrasted with his pale skin which appeared to foil the efforts of the hot Baja summer sun.

"I am not sure, maybe two days." Ramon watched him sign the register before he grabbed a key from off the wall. With considerable effort, the man reached for his bag then stepped away from the desk in order to allow Ramon to escort him to one of the rooms on the second floor.

"Here you are, Señor...?"

"Tavarez . . . Eduardo Tavarez," came the reply.

Guzman blushed, embarrassed by the fact he'd already forgotten the name he'd seen scribbled on the register. "Oh yes, of course. And I am Ramon Guzman, at your service.

Uh...well, this is your room. You'll find it has a nice view of the river along with the afternoon sun, so you won't have to worry about being awakened too early." The innkeeper handed the key to his guest. "Is there anything else I can do for you, Señor Tavarez?"

"Yes, you can make sure I'm not disturbed for the rest of the day." As he was about to close the door, Tavarez suddenly turned, facing Ramon. "Actually there is something you can do for me." Reaching into his pocket he pulled out several bills, handing them to Ramon. "Can you get me a bottle of tequila as soon as possible?"

The innkeeper was hesitant for a moment. "Well, I'll have to go into town. We have no one here to man the front desk. I'm afraid it will take me close to an hour." The weary-looking stranger managed a faint smile. "That will be fine. Thank you, Señor Guzman."

Ramon descended the second-floor stairs, stuffing the money in his pocket. He quick-stepped through the lobby, placed a sign on the hotel door stating he'd be gone for an hour and walked out into the setting sun, a ratted out baseball cap tossed carelessly onto his balding head. As he biked into town, his brow furrowed, deep in thought. His new guest looked faintly familiar to him, but from where?

So deep in thought was Ramon that he failed to see an old Ford pickup backing out of a used tire shop as he entered the village. The dual exhausts roared loudly, offering a last second warning to the bicyclist, who frantically turned his wheels at an impossible angle before losing control. Over the handlebars, he tumbled landing roughly on the dusty main road.

The driver of the pickup, apparently unaware of what happened, set his automobile in gear and rumbled down the road, leaving the innkeeper dazed but unhurt. An elderly woman, shuffling up the street, aided by a cane reached him as he woozily stood up, dusting himself off.

"Are you alright, Ramon?"

His eyes, not yet focused, recognized the voice. "Señora Valencia?"

"I asked if you were alright."

By then he'd recovered sufficiently to remember that he was talking to his old elementary school teacher. "If you hadn't made that suicidal turn of yours at the last moment, you could have been seriously injured or maybe even killed! You always were a quick little boy with the reactions of a matador." A hacking laugh accompanied her comments.

Ramon managed a painful smile, rubbing his left hip with the heel of his hand. "Some matador I'd be. Why I'd . . ."

He broke off his words mid-sentence, then mouthed silently, "matador... matador." His body suddenly stiffened with eyes widening in acknowledgment. "Tavarez, I know who he is!"

The old teacher cupped a hand behind one ear. "What did you say?"

"...You always were a quick little boy with the reactions of a matador." A hacking laugh accompanied her comments.

"Uh . . . nothing important. Just talking to myself." He reached down, picked up his baseball cap and swiped it against his leg a couple times. "I really have to be going, señora. But it was very nice seeing you." His overturned bike rested a few yards away and when he righted it, found that the front fender and wheel had been bent. This meant it would take an extra twenty minutes buying the tequila before getting back to the hotel on foot.

Walking alongside the wobbly bike, Ramon guided it awkwardly to the tire shop garage where Ricardo Munoz could be seen sprawled under the front end of a '57 Chevy pickup. "Señor Munoz," he called out.

Immediately a blackened, oil-stained face peered out from beneath the automobile. "Ah, Ramon, how are you?" His attention was immediately drawn to the bent bicycle. "What happened to your bike?"

Ramon looked at his watch. "It's not important. I just fell and bent it up a bit. Do you think you can fix it?"

"Just lean it up against the garage. I'll have a look at it when I'm done with this." His head disappeared back under the Chevy where the heavy clanking of a wrench against metal could be heard.

By the time the innkeeper returned, his new guest was nowhere to be found. Guzman knocked repeatedly on the door, then taking the pass key, opened it. "Señor Tavarez?" He hesitantly walked into the room where he noticed a suitcase spilt open onto the bed. Clothes had tumbled to the floor, along with a number of prescription bottles. He turned to inspect the bathroom, the door was open but it was unoccupied. Upon seeing this, the innkeeper backtracked, exiting the room and locking the door.

"Looking for me?" came a voice from behind. Ramon jumped, turning to face Tavarez. "I went out the back entrance for a moment to look at the sunset."

Still shaken from having been caught exiting the room, Ramon held up the bottle of tequila. "I . . . I just wanted to give you this."

His guest took it. "What do I owe you?"

"Oh, nothing señor. Tequila is very cheap around here." He hesitated a moment, fiddling with his glasses before continuing. "Besides, it isn't every day we have so famous a guest as you."

The dark-haired man froze, his eyes suddenly sharp. "You . . . you know who I am?"

"Oh yes, señor, I think the whole of Mexico knows of you. Are you not Eduardo Gutierrez, known as El Gato, the most famous matador in all the land?" Ramon's pulse quickened, feeling very much like a schoolboy meeting a famous athlete. "I saw you fight in Mexico City about fifteen years ago," he gushed. "You were magnificent."

The guest winced, clearly uncomfortable with Guzman's praising words. His eyes seemed to sink even deeper into their sockets, exposing a layer of pain and discomfort so disabling that Ramon was forced to turn away.

The innkeeper shifted his weight, clearly angry with himself for his "outing" of the famed matador. The man only wanted to be left alone and it was obvious he was hurting. Summoning up his courage, Guzman spoke, his words barely audible, lest anyone else could be listening in his empty hotel.

"Señor Gutierrez, I'm sorry if I have said things that you didn't want to hear. I promise you I will never divulge your identity to anyone. As far as I'm concerned, you are as you said—Eduardo Tavarez."

The man's lips pursed and he straightened, rising to his full height. For a moment he seemed to be appraising the little innkeeper before thrusting out his hand, adding, "I would be very grateful to you, Señor Guzman."

Ramon accepted his hand heartily before turning and heading back down the stairs. His mind, however seemed overtly occupied and as he got to the front desk, he was nowhere near reaching a point of clarity. What was it about the matador that left him in such a tattered state? The man was a god, a knight in a suit of lights whose throngs adored his every move.

Still, something was not quite right. Ramon recalled that when he'd last seen El Gato perform, the great matador was already in his late thirties and contemplating retirement. Guzman, deep in thought, ambled to the rear of the hotel, a bag of trash in his hand. As he stepped outside, he tossed the trash into a large green can, then stood back, staring down at his village.

## What was it about the matador that left him in such a tattered state?

Just over the rise to his left was a small farm comprised of a single cow. Mostly brown in color, it seemed agitated, dropping its head and moving it from side to side, its bovine cry weak and labored. Ramon could see that its udders were full and in need of milking. A small boy named Pablo, dressed in a soiled T-shirt and baggy jeans was chasing after it, twirling a red shirt above his head which he snapped across his body in a fierce action. But the cow seemed unimpressed and continued its elusive trot along the pasture.

His interest waning, the innkeeper returned his gaze back down the hill, seemingly never tiring of looking at his picturesque village.

Mulege was a living canvas of time lost. News traveled slowly and most townspeople liked it that way. The external energies of the outside world had little meaning here. And that held true for Ramon Guzman. He rarely read a newspaper and didn't have a TV like two-thirds of the population.

Inexplicably, Ramon felt a compulsion to return his gaze toward the cow, watching intently its every move. At once his heart beat faster. The hazy words of something that his old boss said in passing began to materialize.

Guzman began picturing his old boss, propped up on that painful couch, his feet extended over a small teak coffee table. He was poring over a week-old newspaper which had been left there by one of the guests who'd come down from Yuma on a hunting trip.

"Monsoons are hitting Phoenix pretty hard," he said aloud. Ramon, dust cloth in hand, was busily wiping off the front desk counter, seemingly deaf to what his boss was saying. He was focusing on a small, yellow scorpion which had steadfastly blocked the clerk's efforts at reaching into the corners of the wood panels. Grabbing a whisk broom, he flicked it onto the floor before clumsily attempting to step on the arachnid.

"Hey, this one's a little closer to home." Tillman chuckled before paraphrasing the article aloud. "Seems some bull-fighter suddenly turned chicken while in the ring. Threw down his sword and hightailed it out of there. Even the American press is hot on this story. They say he was a legend, even had a name for him . . . hmmm . . . hey, isn't the word for cat, *gato*?"

"When my little boy was about five or six, my wife told him whenever he felt threatened to look up into the heavens at night and search for a blinking star. . . ."

But the little clerk did not respond. His eyes remained on the eight-legged animal and with each step he struck, the scorpion scurried just far enough to stay out of range.

A singular high-pitched mooing of the disgruntled cow instantly brought Ramon back to the present. His head, now clear reaffirmed the answer he was looking for. "Thank you, Señor Tillman," Ramon whispered to himself. He recalled his boss asking him about the word, *gato*, as the legendary Eduardo Gutierrez was better known. It also came to him that El Gato had suffered the loss of a child which the press pounced on immediately. However, out of respect for the revered matador they put little effort into ascertaining exactly the cause of death. Only a cadre of high ranking police officials knew the specifics.

Guzman returned to the hotel and as he began to take a seat behind the front desk, heard the shricking voice above him. Instantly, he knew it was coming from Gutierrez's room. Ramon jumped from his seat and began running toward the steps. Reaching the second floor, he was about to knock on the door when suddenly it flew open. There stood Gutierrez, shirtless and bathed in sweat. He was panting heavily.

"Señor Gutierrez, is everything alright?" the little innkeeper asked. "I heard a scream and—"

The matador brushed him aside, rushing for the rear exit. "I can't breathe... I can't breathe."

The innkeeper followed him as the door was thrown open. Down the wooden steps they went, Ramon right on his heels. When both cleared the stairs, Gutierrez leaned forward at the waist, sucking in as much oxygen as he could.

Ramon faded back a few paces, waiting for the matador to regain his composure. After a few moments, his guest began to relax. "Señor, may I get you a glass of water?"

Gutierrez seemed not to have heard him and when Ramon was about to repeat his question, the guest turned to him, shaking his head. "No, I'm alright. Just had a nightmare . . . these sleeping pills I'm taking often do that to me . . . I'm sorry."

"There is no need to apologize, Señor Gutierrez. I under . . ." The innkeeper caught himself, thinking it best not to continue with what he was about to say. "Ah . . . are you sure I can't get you anything?"

He again declined the offer, training his eyes upward at the star-filled sky. "When my little boy was about five or six, my wife told him whenever he felt threatened to look up into the heavens at night and search for a blinking star. That star would be his protector and watch over him whenever things looked bad." He lowered his head, directing his attention toward Ramon. "Tonight I see no such star." And after a moment's silence he added, "How fitting."

Ramon, clearly feeling ill at ease over the disquieted pall that hung in the air, blurted out, "I always wanted a child... or for that matter, a wife. But I never seemed to have found the time. My mistress is what we see right behind us." He pumped a pointed thumb over his right shoulder in the direction of the hotel. "And now if you'll excuse me, I think I see a guest pulling up."

Greatly relieved to have escaped an uncomfortable situation, the little man ran to the hotel entrance just in time to see a family of four exiting from their car. Ramon escorted them inside where he checked them in for the night. They'd come from Disneyland in Los Angeles where they'd vacationed and were headed home to La Paz. Ramon, sensitive to Gutierrez's plight and need for privacy, offered them a room on the first floor.

The following morning, just after dawn, a yawning Ramon sat behind the registration desk sipping a cup of strong coffee. He'd slept restlessly the past night as he kept reflecting on yesterday's encounter with Gutierrez. The man was clearly a shell of his former self. The matador he remembered all those years back was a proud almost arrogant man, prancing dangerously close to a thousand-pound beast, daring it to charge him. With his back turned to the bull, he kicked up first his left slipper, slamming it upon the dusty ground before duplicating the same movement with his right. Ramon, mesmerized by El Gato's seemingly suicidal dance with death could only stare wide-eyed with mouth agape.

When it seemed the infuriated bull could stand it no further, it erupted in an explosive charge, its spear-pointed horns zeroing in on its victim. But when it looked as though the bull was just about to gore the matador, Gutierrez side-stepped in one fluid motion, leaving the bull gouging at nothing but wisps of dust. This action seemed utterly surprising to anyone who'd never seen the bullfighter in action, but to those familiar with his signature move, it was to be expected. More than one voice in the stadium could be heard exclaiming. "Well, what did you expect? After all, he is El Gato."

An hour before noon the family that had checked in the day before had gone, allowing Ramon access to their room. As he was removing their sheets, he heard a loud thump overhead. "Señor Gutierrez!" he said under his breath. Reigning in his inclination to rush upstairs, he stood silently, listening for some signs of activity. At long last, he heard heavy footsteps moving about, assuring him that his famous guest was okay. Moments later, the muffled sounds of what seemed like shouting and crying could be heard.

Unable to contain himself any longer, the innkeeper left his cleaning duties and hustled up the stairs to Gutierrez's room. Placing his ear to the door, he strained to hear further sounds but the room was silent. A minute later, Ramon knocked lightly on the door. "Señor Gutierrez, is everything alright?"

No answer. He repeated his knock, this time a bit harder. "Señor, are you okay?"

Again, total silence. Reaching into his pocket, he pulled out his master key and slipped it into the lock. Opening the door only a few inches, he poked an eye into the room. There, on the bed, motionless and on his stomach, lay the matador.

Ramon rushed in, turning the man over. Two empty bottles of pills rolled to the floor. Returning his gaze to Gutierrez, he noticed to his chagrin that the man did not appear to be breathing. His chest lay flat, unmoving. A frothy spittle formed on the corners of his mouth. Ramon instinctively pounced on the bed, straddling the body. Using both hands,

one atop the other, he pushed down hard on Gutierrez's chest, halting momentarily before repeating the process. "Please Señor Gutierrez, don't die."

For the better part of a minute, Ramon continued in his attempt to revive Gutierrez. The room, already warm from a sweltering day, made the diminutive man's efforts even more difficult. At long last he sensed a quickened puff of breath followed by a second. "Señor Gutierrez?"

Hopping off the bed, he leaned in, his ear positioned an inch from the man's mouth. A faint, soured exhale of breath greeted him, followed by a series of coughs. Ramon stood, smiling. "Señor Gutierrez, you gave me quite . . ."

## There, on the bed, motionless and on his stomach, lay the matador.

At that moment, the matador bolted upright, quickly swiveled his head towards the floor and vomited. "Gracias Dios," exclaimed a delighted Ramon, crossing himself in exaggerated reverence.

Gutierrez sat at the side of the bed, his head buried in his hands. Ramon removed one of his hands, placing a glass of water in it. "You must drink. It's important to dilute the last of the medicine inside you. Please, señor."

Complying, the matador drank, swallowing half the glass in three large gulps. He looked up at the innkeeper, his bloodshot eyes studying Ramon. "You should have let me die."

Ramon said nothing but shook his head vigorously. Cautiously, he spoke. "Nothing is worth taking your life. You are too brave a person to die this way. Have you forgotten you are El Gato?"

A mocking grunt met with Ramon's comment. "El Gato? I haven't been called that in years. Did you not hear about me? Señor Guzman, they say I am a coward. I threw down my sword and ran from the corrida." He drew back his head and finished the glass of water.

The innkeeper knelt beside him. "Then there must have been a reason. Why would a man who has fought dozens of times in the ring suddenly run away? It makes no sense." Gutierrez exhaled deeply before going silent. It seemed an eternity before he spoke again. "If you had been in the ring with me and seen what I saw, it would have made sense."

"Then please, if it's not asking too much, will you tell me?"

The matador pursed his lips, obviously deep in thought. "Alright, I have nothing to lose. I will tell you. But first . . ." he gestured toward the night stand where the bottle of tequila lay on its side. "Don't worry, I only want to rinse my mouth out. Those pills were burning my throat."

Handing him the bottle, Ramon watched as Gutierrez unscrewed the cap, took a large swig, then swished it around his mouth before spitting it in the glass. "Ah, much better."

He handed the bottle back to Ramon, then sat back in the bed. "You know, I've never told anyone what I'm about to tell you." Gutierrez offered a faint smile. "And why I'm telling you I really don't know."

Ramon said nothing, but his wide-eyed expression indicated to his guest that he was waiting to hear the explanation.

"Two years before my . . . cowardly act, I had gone with my eight-year-old son to a ranch outside Mexico City to look at some young bulls which the owner was grooming for the ring. These bulls were about two years old and weighed about 450-500 pounds. They had shed their baby fat and were gaining muscle quickly, especially in the neck and shoulders. They were not aggressive at this stage so I let my son accompany the owner and me into the corral. As we were talking, my son Antonio wandered close to where the bulls were closely clustered. The next thing I knew there was a scuffle between two bulls which forced the others to scatter. One shot by Antonio knocking him to the ground. A second bull followed." Gutierrez, stopped, taking in a deep breath before letting it out. "The second bull . . . ran directly over my son, kicking him in the head. I ran to Antonio just as he was slowly getting up. He appeared slightly dazed, even managed a smile. As he took two steps toward me he fell . . . dying there on the spot.

"The owner had his men surround the bull and were about to destroy it on his orders. But I shouted, 'No,' it wasn't the bull's fault." I lifted my son and began to carry him out of the corral, passing the cornered bull who seemed—for those few seconds anyway—to stare at me as if . . . as if he understood." Gutierrez traced his thumb and forefinger over his long mustache, as if in doing so, could more clearly recall the incident. "He was a magnificent creature, black as night, except for a tiny, white crescent just above his nose."

Ramon's guest rose from the bed, staring out the window as he continued talking. "I never forgot that image and it haunted me for nearly a year. Oh, I continued to fight but in doing so, I lost my wife. Toward the end she could no longer stand to even look at me and I really can't blame her. Antonio was our only child and of course, she blamed me."

He turned from the window, his eyes avoiding Ramon's. "With each passing day, I became angrier, more aggressive. I began taking chances in the corrida . . . stupid chances which I hoped would end my career. A well-placed horn by a thousand-pound beast while my back was turned could certainly do that. But, nothing happened to me. The press began calling me invincible. But little did they realize that vulnerability was about to greet me and it wouldn't be from a bull.

## "... What stood in front of me was this beautiful jet-black animal —with a white crescent image above its nose!"

"It was in the late afternoon and I'd already killed two bulls that day. The crowd seemed drunk with delight when the new bull entered. Oh, Ramon, he was a big bull. Probably the biggest I had ever faced. I watched as the picadors on horseback drove their lances into the shoulder of the bull, weakening it just enough for me to challenge it on my terms. As they left the corrida, I moved in closer, placing the sword behind my red cape, listening to its snorting. I could see the blood that dripped from its flanks and as I faced its massive head, I froze. It was as though all the air had been drained from my lungs. I couldn't breathe. What stood in front of me was this beautiful jet-black animal—with a white crescent image above its nose!"

Ramon's throat tightened. He drew back, his brain scrambling for the right words to ask, yet afraid to speak. "Thaaat bull . . . he was the one that . . . that . . ."

"He was the one that killed my son. You don't forget a bull with those distinct markings." His eyes began to moisten. "Looking into the eyes of the bull, I could swear he recognized me from that . . . that day. These were not the eyes of a defiant animal. But if anything, they seemed confused, unsure of what he was to do next."

Rising unsteadily from the bed, the matador stood, placed both hands on Ramon's shoulder and stared down at him.

"Oh, I know it sounds foolish, but I swear to all that's holy, that is what I saw. I knew then I couldn't kill it—in fact I'd had enough of killing. Without thinking I threw down my cape and sword and ran for the exit."

"And the crowd, señor, what did they think?"

Gutierrez let his hands drop to his sides and his expression seemed to intensify. "To hell with the crowds. I didn't care what they thought and I never felt the need to explain myself to anyone . . . until now."

It appeared to the innkeeper that the matador's confession left him exhausted. Gutierrez returned to his bed seemingly devoid of any further movement. He lay quietly on the bed, spread eagle with eyes closed. "And now if you'll excuse me Ramon, I'd like to get some sleep."

Ramon shuffled to the door and as he reached for the knob he asked meekly, "Señor Gutierrez, you're not going to do anything . . . crazy, are you?"

Barely audible, and with a slight smile, he answered while yawning, "No Ramon, never again." After a moment, he added, "and thank you."

The matador slept soundly for the first time in years, so deeply in fact that he had no idea what day it was when he awoke almost twenty-four hours later. He opened his eyes in time to see the back of Ramon's head as he was leaving the room. "Ramon," he said in a garbled voice.

The innkeeper turned. "Ah, Señor Gutierrez, I just came by to see how you were. I was worried that you . . . that you . . . "

Gutierrez managed a smile. Wiping his eyes he asked, "Didn't I tell you I'd never do that again? As a matter of fact I feel pretty good, except for this mouthful of cotton balls in my throat." He reached for his watch which lay on the bed stand then glared out the darkened window. His eyes widened. "Dios Mios, did I sleep all the way through to early morning?"

This time it was Ramon's turn to smile. "No señor, you slept all the way to early evening!"

The matador could only shake his head in disbelief. "I guess I needed it. It's been far too long." Kicking his feet out from beneath the sheets, he rose carefully, one hand firmly placed on the headboard.

"Phew, that took some effort." He held that pose for several seconds before exclaiming that he was ravished. "How far is it to the nearest restaurant?"

"Oh, it's just down the road. There is a little family-operated restaurant in town owned by the Dominguez brothers. They make the best frijoles in town. And their chicken mole is the finest in all of Baja."

"Then the Dominguez restaurant it is. He released his hold on the headboard, knelt down and grabbed his boots. As Ramon turned again to leave, Gutierrez called out, "And you're coming with me. You've done more for me than you realize. Please. Accompany me and I will treat you to anything you wish."

His mouth agape, he observed the child's unabashed glee as the matador draped the shirt in front of his waist, pounding one boot into the earth before doing the same with the other.

The matador noticed some reticence in the innkeeper's eyes. "You must say yes. It would mean a lot to me. What do you say?"

Ramon shrugged his shoulders. "Why not. It's not like customers are going to start filling this hotel in the next couple hours. Okay, Señor Gutierrez, I accept."

Together, they left the room and walked down stairs past the hallway. The final rays of sunshine burnt brightly on the hills. Ramon glanced over to Gutierrez and was surprised to see a wide smile on his face. He seemed to be staring at the small farm and pasture just beyond the hotel. As they began their walk down to the village, the matador stopped in his tracks. He watched as Pablo was once again chasing the brown cow, his bright red shirt twirling about him.

The matador turned and faced Ramon. "My friend, would you mind if I met you at the restaurant? There is something I need to do." With a quickened step, he strode toward the farm where he hopped over a wooden fence. A confused Ramon stood in silence watching the matador as he approached the boy. It was when Gutierrez asked for the red shirt that he finally understood. His mouth agape, he observed the child's unabashed glee as the matador draped the shirt in front of his waist, pounding one boot into the earth before doing the same with the other.

"Eduardo Gutierrez is alive and well," Ramon heard himself say. "Viva, El Gato." ♦

## **OooWee**

#### KATRINA BYRD

f course she didn't pay it any mind at first; just a letter—one of the most common forms of communication—smooth folded paper no doubt with printed words in black ink. A letter she couldn't read. She'd been blind since the accident ten years ago.

The small town of Collinsville was beautiful despite the duplicitous people and their ability to turn a blind eye to the suffering of a five-year-old girl. Wide bricked streets offset by banks of red and white petunias outlined the town square which consisted of one restaurant, one grocery store, and one clothing store. The courthouse at the center of the square loomed over the sheriff's office which sat directly in front of two brick churches. One religion-Baptist. Two churches-one for whites, the other for blacks. Separate but equal only on Sundays during church—the townspeople preferred it that way.

Everything there was to experience from the town was found on the town square or at Fast Fanny's fifteen miles south of town where a lone blind woman stood on the front porch with her hair pinned in a ball, all natural like. Wearing dark sunglasses and dressed in a simple white blouse with a lace collar and an aqua skirt, OooWee appeared dazed as she took in the warm day. Birds shrilled high in the trees. Squirrels scurried about making clicking sounds. A cat off in the distance to her right meowed lightly. A car engine hummed from somewhere near the end of the dirt road. Hummingbirds buzzed near the feeder she had placed in the front yard near the pecan tree about twenty steps from the bottom step of her front porch.

"A letter, Miss," Rick the mail carrier said minutes earlier when he handed the letter to her. He was shy about saying her name. No doubt he was shy about delivering mail to a brothel, but it was his job and he did it despite the new bill which became law in Collinsville. It allowed civil servants and business owners the right to deny service when the lifestyle of the potential customer or client violated their religious convictions.

"And one package. Just like always."
He laid the package in her outstretched

"Thank you, Rick," OooWee said quietly. Rick was one of the few people in town who would still speak to her. She felt the warm sun on her face as she heard Rick's footsteps moving away from her toward the end of the walk, then to the street. It always took him thirty even steps to reach the end of the walk, but she heard a long pause on step number twenty-six. Not an odd action. Just something that registered in her mind a bit. A long pause on step number twenty six—then the next four steps—the door slam of his truck—engine start—then silence.

The letter rested in her hand like a ton of bricks. *What gall. Some bold assed sons of bitches.* No doubt the letter bore codified hate. Nothing she hadn't heard before.

"That damned law." Her words were barely audible and if they could've been heard, there was no one around to hear them. All of her girls quit. The incident the week before was the last straw. They couldn't handle it. OooWee didn't know how long she would be able to hold out. *Gotta man up, honey*.

The leaves rustled off to the left side of the porch. A squirrel, she assumed. A light breeze washed over her lifting her skirt slightly. She ran her finger over the small package. *Can't stop now.* She had to hang on for little Melinda Stevens' sake. A little girl with a rare cancer. "Playful and loving to everyone she meets." At least that's how the reporter described Melinda on the newscast that played on OooWee's fifty-sixinch flat screen TV the day of the white preacher's first visit.

"Good evening," he said. His voice was kind. Baritone in pitch. It was a hot day. August of the previous year. One hundred two degrees in the shade. The preacher couldn't keep still. He moved from side to side. His shoes tapped lightly on the tile floor of the foyer. This was the first and only time the preacher used the front door.

"It's afternoon," OooWee said. She turned from him briefly and used the remote to switch off the TV. She heard a small sound escape the preacher's throat with the new silence that surrounded them.

"Good afternoon," He finally said. His voice vibrated lightly.

"OooWee will serve you at any time of the day, honey," OooWee said. "What do you need?"

"I . . . Uh . . . Well, that is to say . . . "

It took the preacher four minutes to find his words. He finally settled on the word "proposition."

"Fast Fanny's is the right place for that, honey," OooWee said as she led him through the kitchen to the reception area for clients.

"You're blind," he said as they moved down the hall toward the bedrooms.

"Only my eyes. I can see with everything else."

OooWee opened the door and they entered a room where the soft sound of Nina Simone's voice came from a speaker on the table next to the king sized bed. "I want some sugar in my bowl," Nina swooned.

"I hope I didn't offend you. I just didn't realize." His voice shook as he spoke.

"Honey, OooWee is just fine," OooWee said softly. The preacher seemed even more nervous than before. "Sit down, honey."

"I...I." I've never been in a...a brothel before." he said.

No shit Sherlock, OooWee wanted to say but she didn't. The preacher dropped down on the bed. The mattress squeaked lightly with the weight of him. She could hear his breath quicken.

"Tell me what you want."

She moved closer to the preacher. She stood directly in front of him. Her right foot touched his left. Her right hand rested lightly on his left shoulder. The smell of lavender surrounded them.

"I've got a wife," he said.

"Honey, what goes on at Fast Fanny's stays at Fast Fanny's."

"I...I...I—" The preacher touched her hand which rested on his shoulder. He gently removed her hand from his shoulder.

"What do you want, honey?" OooWee could hear the frustration in her voice.

"I . . . want . . . uh . . . It's complicated."

"We can do complicated," OooWee said. "What do you want?" When he didn't answer OooWee said, "Perhaps you should come back when you know exactly what you want."

"I want you," he said. He sounded desperate. He took hold of her hand again firmly.

"You've got me, honey," OooWee said. She moved in closer to him and placed her other hand on his sweaty face. She kissed him softly on the cheek then he rested his head on her bosom and he told her exactly what he wanted. And they'd been meeting once a week since.

Another rustle in the leaves brought OooWee back to the present. Back to her porch surrounded by the spring morning. She stood very still. The package, the letter still in her hand. Then the smell of perfume assailed her nostrils. She sneezed. Why did people have to bathe in their perfume? For OooWee perfume was as personal to her as her underwear. A person had to be very close to her to smell her essential oils.

"Who's there?" OooWee said. Her voice mingled with the soft sound of the wind. She waited for a reply. None came. She sneezed again. "I know you're there," she said followed by another sneeze. "I smell your perfume."

There was another rustle in the leaves followed by steps on the concrete path that led to the porch. The smell of perfume was almost suffocating. Next came the voice.

"You're blind." Female. Mid-forties. White.

"You're trespassing," OooWee said bluntly. She knew the city was trying to close Fast Fanny's and so far they had succeeded. The most recent incident—a raid by the sheriff and his deputies scared off the last of her girls. She had no girls to work for her. No clients. No money coming in. *They had won*. The city wanted her gone. The letter in her hand was just a formal "Get your black ass out of town" message. She was sure of it. Now this woman.

"I just want to share the Word of God with you," she said.

Share the Word of God? OooWee knew the sweet sounding white woman was lying. Why didn't she come to the door instead of hiding in the bushes?

The woman made her way up the steps. She took slow hesitant steps. Heels. Three inches. Just the right height for a church lady. The woman came to a complete stop on the porch directly in front of OooWee. She stank of the loud smelling perfume but OooWee managed not to sneeze. OooWee heard the woman's quick breaths. She wasn't winded from the three steps that led to the porch. The woman was nervous.

"I'm Helen," she said finally. "I didn't mean to offend you. You know . . . uh . . . about your blindness."

"I can see where it counts, honey," OooWee said flatly. "They call me OooWee."

"That's odd," Helen said. A small laugh escaped her throat. It stopped immediately possibly because the woman with the high pitch voice realized that OooWee didn't crack a smile. Helen continued on sweetly as if she were talking to a little kid. "Now why do they call you that?"

"Because if I don't make my customers holler ooowee in the first two minutes of service, I perform the same act a second time for free."

OooWee heard a small yip escape Helen's throat. She sounded like a wounded dog that had been kicked in the belly.

"Come on in, honey," OooWee said after a long uncomfortable pause.

"Huh?" Helen's voice sounded distant like she was caught up in thought. More likely the woman was trying to digest what OooWee had said. Many women were uncomfortable around her.

"You want to talk about Jesus?" OooWee said.

"No. YES! Yes. I—" The woman sounded like she had a lot on her mind.

OooWee stepped aside so that Helen could enter. Helen brushed her lightly as she stepped through the door. She was small, dainty, probably had always been a "good girl."

In the house Helen took on about the natural lights, pictures, and books. OooWee wondered what the little church lady expected from a whorehouse. OooWee always provided the unexpected; that's why she was good at her job. You can't half step when somthin's wrong with ya.

"Beautiful," Helen said as they moved deeper into the house.

Of course it was beautiful. OooWee planned it that way from the inside out. Banks of purple and white impatiens lined the front brick walk that led to the front porch. Pots of pink and white petunias adorned the front porch. The front door was painted a deep red. The front door opened into the small foyer with a tiled floor. The walls were a soft brown. Fourteen steps ended the foyer. To the left was a long wide hall that led to several bedrooms—a living area for OooWee and her girls. To the right was the kitchen, a large area with granite counter tops, a large refrigerator and a gas stove. OooWee's Braille cookbook rested on the counter near the spice rack. Beyond the kitchen was a small reception area for clients.

OooWee's favorite room was the large great room directly in front of the foyer. Beige walls. Floor to ceiling bookshelves lined the wall to the right. Straight ahead—a large glass door that looked out over a bricked patio and cutting garden. On the left wall a picture of Josephine Baker hung over the mantle. There were two plush chairs in the center of the room facing the gas

log fireplace. A small oak-stained table sat between the chairs.

"Thank you," OooWee said. She stood near one of the chairs as Helen continued to examine the room. Her heels resounded on the hardwood floor.

"So many books!" Helen said. Her voice sounded like she was impressed, like finding out that a table could walk and talk.

"Yes," OooWee said. People don't expect a whore to have an appetite for reading. OooWee's shelves were just as diverse as the rest of the house. Her shelves were filled with everything from Langston Hughes to Greek mythology. Nevada Barr, Zadie Smith, James Baldwin, and, of course, she had a copy of the Kama Sutra.

"Do you actually read these?" Helen asked. Her voice came from the direction of the bookshelf.

"I have audio and Braille copies as well," OooWee said.

"But why have the print copies if you can't read them?"

"My girls are not blind. They like to read as well," OooWee said quietly. When she set up shop in Collinsville four years ago, OooWee had no idea she would be moving so soon. But no girls equaled no work. *Every decision comes with a price*.

"Girls?"

"Employees," OooWee said. She leaned on the back of the chair intrigued by this woman in her space. Who was she? Why was she here? Any self-respecting Christian wouldn't be caught dead in a whorehouse and there she was moving about OooWee's house with ease.

"This painting," Helen exclaimed. Her voice raised an octave. The woman was in the kitchen at this point. "So full of color."

OooWee knew she was talking about a New Orleans jazz band piece that she commissioned from famed artist Michele Campbell. OooWee met her twice. Once at a gallery in New York and once on a job they both did a few years ago with Patches, the hit woman.

"That painting is from the Michele Campbell Collection," OooWee said speaking with pride as she stepped through the door of the kitchen. "Would you like some tea?"

"Yes, please," Helen said. Something had caught her eye. OooWee heard it in her voice, the brief pause before her answer. OooWee heard the woman leave the kitchen and return to the living room. Her exit from the kitchen was a brief reprieve from the funky perfume.

OooWee placed the letter and the package on the granite countertop near the sink, while she filled the tea kettle and placed it on the burner. As the water heated OooWee took the package and letter and slipped behind the silk curtain that led to the entrance where she received customers. She placed the letter and the package in the top drawer of the small oak desk in the reception area. *The preacher is comin' by today*, she thought to herself as she stood in the small space surrounded by the sweet smell of lavender.

Suddenly she caught a whiff of the stinky perfume. OooWee pretended not to notice. Then there were the light footsteps moving quickly through the kitchen toward the living room.

When OooWee returned to the kitchen, the perfume was there but no Helen. OooWee switched off the burner when the tea kettle whistled. She slipped her small piece from the drawer near the stove just in case this Helen stepped out of line. OooWee was sure this woman was here to tell her, as sweetly as pos-

sible, to get out of town. OooWee was going to leave but she would do it on her own time. She slipped the gun into her LaBrolster then quietly pushed the drawer closed.

Back in the great room OooWee placed a tray topped with fruit, cheese and crackers, two small tea cups, and a pot of ginger mint tea on the small wooden table. She was very careful, she knew Helen was watching.

"Jesus teaches us to love everyone,"
Helen said after the tea was poured.
She went on for what seemed like hours talking about sin and how it separates sinners from God.

OooWee wondered if the woman had the courage to say what she had come to say. She herself had no trouble speaking her mind. She was confident in who she was. She was no Christian, especially according to the Collinsville Christian women. OooWee recognized herself as a sinner. There was a lot she regretted. If she had spoken up twenty years ago, Felicia may not have been raped and killed; that's why she was going to stand firm for Melinda Stevens no matter what it cost her. OooWee took in a deep breath as Helen drew her sermon to a close.

"That is why we must turn from our wicked ways," Helen said.

"Define wicked ways," OooWee took a sip of her tea and waited. The woman sounded as if she was caught off guard. They often were when presented with difficult questions.

"Why sin of course," Helen said quickly.

Sounded like a tape recording of one version of Christianity; didn't know anything new. Couldn't think for herself if her life depended on it. Probably wouldn't know her own opinion if someone told it to her.

"Of course."

OooWee knew a lot about sin. According to people like Helen, she was responsible for sin. The difference between OooWee and "saved" folks like Helen was that OooWee took responsibility for her sins. She knew she was a sinner. She knew her sins. She believed in Jesus who taught love, understanding, and mercy. But OooWee didn't understand religion. She didn't understand how religious people could deny medicine to Melinda Stevens, a five-year-old child who hadn't hurt anyone. OooWee felt her fist clench. Denying her medicine just because her parents are gay. If that ain't sin then what is?

"I'm sure you have seen plenty of sin in your line of work," Helen said sweetly. She sounded like the type of woman who held a dime between her knees till she was married. *It was probably still there*.

"Yes, I have," OooWee said calmly. She took another sip of tea. These Christian women wanted OooWee out of town. They weren't bothered that she ran a brothel. Many of them were glad to have their husbands out of the house because they were steppin' out on their husbands as well. They wanted her out of town because they knew she was sneaking medicine to Melinda Stevens.

"What about yourself?" Helen said pointedly.

"What about me?"

"How do you see yourself? I . . . I mean do you think of yourself as a sinner?"

"We are all sinners," OooWee said. Again Helen made a small squeak like she'd been kicked.

"I know we're all sinners to an extent," she said, all proper like.

"Sinners are sinners," OooWee said.
"We're all sinners."

"But our sins are different," Helen said.

"I perform sex for a living and you and your so-called fellow Christians are willing to let a child die simply because she has two mothers," OooWee said. She kept her voice low and controlled.

"What?" Helen said angrily.

"Your religion is more important than a child's life," OooWee said quickly. She had never met this woman before, but it was no coincidence that she showed up at her house out of the blue.

"Marriage is between a man and a woman," Helen said. Her voice had lost its sweetness.

"You and I are both sinners," OooWee said. She placed her teacup on the table then sat back in her chair. She'd met a ton of people like Helen in her life.

"Excuse me!" OooWee could tell by Helen's tone that she wasn't happy to be considered equal to a madam. "You do most of your work on your back."

"I do most of my work with my mouth," OooWee shot back.

"Excuse me!" Helen's voice was frantic. Her tea cup hit the tray hard.

"Most of the work I do here is talking, Helen." OooWee noted the softness in her own tone. She didn't want a fight. She'd already decided that she would help Melinda Stevens until the end. She could always open another house. Her cousin Paula emailed her that there was plenty business in Delta Pride, Mississippi. OooWee continued speaking, "The men who come here are in search of conversation."

"So you're saying it's the wife's fault if her husband comes to this . . . this den of iniquity," Helen said angrily. "You don't care about the marriages you destroy." OooWee sat silently. Helen was out of control. OooWee knew how to deal with out of control people.

"Helen, we are all just people doing the best we can." OooWee said.

"You are a whore!" Helen said. The woman was on her feet. OooWee felt her gun pressing against her chest.

There was a pause. The room was as quiet as a church on a Saturday night. There was uneasiness. The tension between the two women was interrupted by the doorbell. OooWee got to her feet. "If you'll excuse me."

OooWee left the woman in the great room and walked through the kitchen to the reception area.

"Good morning" the preacher said when OooWee opened the door.

"We can't go on like this," OooWee said once he was in the reception area and she'd closed the door behind him. She heard the nervousness in her own voice.

"Just a little longer," he said touching her hand lightly. "Just a little longer."

"They're running me out of town," OooWee said.

"What? Who?"

"The city. The Collinsville Christian women" OooWee sounded paranoid even to herself. She slipped him the letter from the top drawer of the small desk. "Read it."

"This isn't good," he said refolding the letter.

"What does it say?"

"They want you gone by the end of the month or they will arrest you," he said. "They claim you are violating the morality law."

"Damn!"

There would be barely enough time to pack the house. OooWee folded her arms across her small bosom. She wasn't as worried about herself.

"What about our proposition?"

The tears came. His arms were next. They encircled her. Then the perfume was there. *This bitch had some balls*. OooWee pulled away from the preacher and turned in the direction of the funky perfume. Before she could utter a word, the preacher let out a big rush of air.

"Helen?" He said. "What are you doing here?"

"What are YOU doing here?" Helen's voice had lost all traces of the sweetness it possessed earlier.

"I . . . I . . . "

"A whorehouse, Eric?" Helen said. Her heels clicked on the tile as she moved closer to OooWee and the preacher.

"You don't understand," the preacher said. His voice trembled as he spoke.

"I understand that my husband is ..." She took in a big breath then spoke rapidly in a high-pitched voice. "You are destroying our marriage."

"Listen to what the man has to say, Helen." OooWee said.

"You, of all people, want to tell ME how to behave?" Helen was close to OooWee. Too close.

OooWee took a step back. She took in the events of the day. Helen showing up at her house was no mistake. *The woman came here on purpose!* OooWee went to the desk and took the package from the top drawer. "Melinda Stevens," OooWee said softly.

"What has that sinful girl got to do with you sleeping with my husband?" Helen asked angrily.

"WHAT?" OooWee and the preacher said in unison.

"We aren't sleeping together," OooWee said as calmly as she could. She couldn't believe the nerve of Helen sneaking around her house with the idea of catching her with her husband.

"Honey, Melinda Stevens is very ill and this new law prevents the doctors from treating her because her parents are gay," the preacher said without taking a breath. "She's too sick to travel so OooWe gets the medicine she needs and I come every Monday to pick it up."

"Then?" Helen said. OooWee imagined that she had her hands on her hips.

"Then I take the medicine to her," the preacher said. "She's getting better. She'll be able to travel soon."

"You're breaking the law," Helen said.

"But, honey, the law is *wrong*," Eric said. Disbelief in his voice.

"You could go to jail, then what about me?"

"Helen?"

"What about your reputation; your job?" Helen said angrily.

"We're talking about the life of a child here," the preacher said.

"What about our life? What happens to our life while you're out playing hero to these lesbians and their child?" Helen said.

"You mean what happens to you?" the preacher said. This was the first time OooWee had heard him raise his voice.

"The church will fire you. The whole town will talk. You could go to jail," Helen said.

OooWee felt like a horror movie was unfolding in her own home. She stood next to the preacher with the package in hand. Helen was close to her again. Her perfume stunk up the whole room. OooWee felt the package slide from her hand.

"You will thank me later," Helen said smugly and left the room. OooWee heard her heels click on the tile kitchen floor. Her fastidious footsteps came to end at the front door with the small click of the door being shut. The start of a car. Rev of the engine. Squeal of the tires.

The news of Melinda Stevens' death came three weeks later. Ten minutes before the limo was to arrive. OooWee stood in the greatroom with her hand pressed against the warm window that looked out over the cutting garden. Her other hand held her cell phone to her ear. She froze as Eric's trembling voice spoke on the other end of the phone. "It just happened," he said.

OooWee couldn't speak. She felt about as helpless now as she did when she got the news of Felicia Gale Griffin's death fifteen years ago. A young girl. Raped and killed by some dumb bastard. Her death upset the neighborhood where OooWee used to live.

Anger rose up in her like a freshly opened soft drink that had been shaken vigorously. Maybe she was just a whore, but she had respect for human life and that had to count for something.

"They want to meet you," the preacher said over the phone. His voice was clouded with phlegm.

"They?" OooWee asked as she moved from the window of the great room.

"Melinda's mothers," he said softly.

There was a brief pause as OooWee considered the preacher's words. She came to a stop in the center of the room. "Why?" she asked softly.

"To say thank you. They couldn't have done this without you," the preacher said after he cleared his throat. "I couldn't have done this without you?"

What had we done? OooWee moved closer to the foyer. We let a little girl die. That was hardly worth a "thank you." A horn sounded from the direction of the front of the house. OooWee took her purse and red feather boa from a hook near the front door.

"Maybe another time." OooWee said softly. The idea of leaving Collinsville became more welcoming by the minute. "My car is here."

"Where will you go?" he asked.

OooWee took hold of the brass knob on the front door. "Delta Pride," she said as she stepped onto the front porch and headed to the limo.

## SANITY DREAMS

#### PAMELA CARTER

ometimes in my dreams I still walk, though in my waking life I use a wheelchair and have for over two decades. My gait becomes surer as the years pass, and I feel the need to explain to others who people my dreams that I usually use a wheelchair. The phenomenon of walking dreams isn't uncommon among those of us who acquire a disability after years of unimpaired mobility. For forty-three years I walked or ran everywhere I went. I was an avid backpacker, hiker, and rock climber, so it makes sense that my subconscious mind, ruler of the realm of my dreams, would return to its more familiar means of movement.

But I never have dreams in which the misfiring neurotransmitters in my brain discharge in sync. Dreams need an experience in waking life with which the subconscious can work. I have no such experience; no memory of a time when my brain disorder didn't color my awareness.

Its distortions of reality filter every thought, all memories. Even remission—periods of time free of symptoms of mood episodes—causes its own distortion of reality. I know, from years of experience and research, that I am not destined to remain in remission forever. Bipolar disorder (Type I), or manic-depressive illness, is a chronic condition for which there is no cure. Eventually something I may not recognize as a trigger will send me back to the arid, featureless plain of depression on which I may wander, lost, for months, or to the too-bright kaleidoscopic world of mania. I forget this condition is inexorable, that the next mood episode is inevitable. Instead I convince myself that if I do all the right things—take my medication, see my doctors, structure my

time as best I can—I will wear the mantle of remission forever.

I was born in 1948, half a century before Dmitri and Janice Popolos published their seminal work on early-onset bipolar disorder, *The Bipolar Child*, so I was viewed as an unusually bright but extremely difficult child rather than one with a treatable mental illness.

Nevertheless my childhood, while solitary, was full of pleasures: the vanilla aroma of a sun-warmed ponderosa pine as I sat on summer afternoons, my back against its rough bark, while Quannah, my foal, slept, his delicate head resting on my lap; the wonder and diversity of wildlife—deer, Steller's jays, Albert's squirrels, magpies, coyotes, lynx, and once, an enormous golden eagle that flew onto our property and perched on a dead limb only yards from the house. I stared at him in the dawn's diffuse light until he seemed a mythical creature. I loved swimming naked beside my horse in the pond on the Falcon Wing Ranch and letting my body dry in the sun afterward. I remember lying shirtless (free as a boy) on the warm rocks of the Holland Ranch, fashioning nooses from grass blades in hopes of catching a blue-tail skink. Best of all, though, were whole days spent in solitude, writing stories in my Big Chief Tablet.

Then one day in the fall of 1962, the year I turned fourteen, all those pleasures vanished inexplicably. The magpies, jays, and squirrels still abounded, Quannah still followed me everywhere, the pond on the Falcon Wing hadn't dried up; I just derived no pleasure from them anymore. I could think of not one thing that felt good, though I scoured my

JULIA ANNE MILLER

memory for some thought to stir the feeling of pleasure once so central to my life. I couldn't remember why I'd been happy the day before—or *if* I had; because even as this absence of joy baffled me, something about it felt timeless, as *if* I'd always felt this way and always would.

Days turned into weeks, though I wasn't aware of time's passage, at least not as I once was. Each day was like the one before, as if I was doomed to repeat the same day endlessly. I had no landmarks, despite school and my piano and ballet lessons. Even the holidays passed without notice in this featureless vacuum. Sleep provided no escape as I woke in the predawn darkness, my heart pounding with some nameless fear.

On a gray, misty day in spring, I stole one of my father's razor blades. I don't remember now if I intended to end my life; I only remember needing to do *something*, to take some action, even if I couldn't decide what to do. I rode to a secret place of mine on the Falcon Wing Ranch, a circle of tall cedars that shielded me from the road. I knelt down in the center of the circle of trees. I found a milky-blue vein on the back of my left hand. I think now if I intended suicide, I would have sought out the pulse on the inside of my wrist, but I was only fourteen and unschooled in matters of anatomy.

I pushed the corner of the razor blade deep into my hand and pulled swiftly. The resulting sting surprised me; I felt more awake than I had in months and pleasure outweighed the pain. I sliced again . . . and again. Blood welled up in the narrow furrows made by the blade; bright red, *vibrant* blood, the first color I'd seen in weeks.

My cheeks flushed with warmth. I took great gulps of air, frightened by my own daring. Slowly color returned to the trees around me as blood flowed down my hand and dripped from my fingers.

I'd found my first coping mechanism. ♦

#### UNINVITED

Grief stands at the door Tapping its foot Petulant Entitled

Grief is the guest who will not leave Who eats all the ice cream Acting like it doesn't know The cold sweetness was being saved For the end of a long day

Grief takes up space I don't have
It hogs the blankets
Leaves clothing scattered on the floor
Lets the dishes pile high
In Dr. Seuss stacks
And will never take out the garbage

Grief wakes me up on mornings off Demanding to be let outside Then wanders around sniffing And refuses to go

Grief is the nagging thought In the middle of the night When the world is asleep And nothing can be changed It steals sleep until just before dawn And the alarm goes off at 6:00 a.m.

Grief barges in and watches sports At full volume While I'm trying to write it away It sneaks up and startles And though it laughs At its own joke It is never funny

> From the author's collection entitled Off Track: life in a derailed brain. Reprinted with permission from the author.

#### KIRA COMPTON

## A Sun Salutation Prayer

Tadasana, mountain pose The room is dark I cannot see my mat Inhale, and

Urdhva hastasana
Shoulders rise up
Life expectancy is about the same—this is a quality of life disease, not quantity
Reach fingers towards the ceiling

Exhale, and

Uttanasana
Air rushes past my ears
I almost touch my toes
You'll need to avoid stress...meditation, yoga
Inhale, and

Lunge

Knee drops slowly

Oh my God, is that blood?

It wavers but stays strong

Exhale, and

Plank

Arms are shaking

We're looking at management options, here
I am no longer strong
Inhale, and

Chaturanga
My face is red
It's six in the morning
It's like knowing your cause of death forty years early
Exhale, and

Downward Facing Dog

You'll be the youngest person in all the waiting rooms

My roommate sleeps

A siren blares outside

Inhale, and

Lunge
Thighs are shaking
I don't want to alarm you, but children—
The morning light comes in
—will be difficult. Nearly impossible.
Exhale, and

Uttanasana
Head pounds
There is no known cause.
Hold breath and rise to stand
There is no known cure.
Inhale, and

Urdhva hastasana
Dark shapes in dark rooms
Reach fingers up to nothing
Patient is eighteen years old
Exhale, and

Tadasana, mountain pose Make me a mountain Lord, make me stone Lord, I must be stone

Inhale, and repeat.

Previously published in Gauge Magazine, May 2015.

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#### HUMMINGBIRD FOR BECKY BREEZE

We are coming in too fast, my seatmate says on our sweep from Seattle. We swerve and bump, shoulders conversing in the racing air. She trained as a pilot, her sense of motion and lift still guiding navigations in another sphere.

We exchange belated stories of daughters. And then, unexpected, this image when I relay the racing pulse, quintessential yoke of a child with POTS,\* whose story everyone else greets with *oh*, *is there something they can give her?* 

She says instead: *oh, like a hummingbird*. It is even how she eats, I think, parsing the day's nourishment, flitting from one clay bowl to another. We have landed, at last, the sky a memory of light and calm, gate rumbling ahead.

Humming in my ear, a stranger's words feathering hope. I will ask her to supper. As the sun slides into some other night-drenched town, I think how she could rub wings with my daughter, handle the too fast engine, teach her

the ways and means of flight, how even on this recalcitrant earth, one can turn the clouds.

\*Postural orthostatic tachycardia syndrome is a debilitating illness most often diagnosed in children 11-16, for which there is no known cause, or cure. An abnormally high pulse is one of the cardinal symptoms.

Previously published in The Healing Muse: A Journal of Literary and Visual Arts, Vol. 15 (1), 1995. Reprinted with permission of the author.

#### J. F. PRITCHARD

## URINE-STREAM OF CONSCIOUSNESS

sweat pants leg pulled thigh high (bald patch?) entranced by a clear medical tube running down my leg connected to a bag (didn't get groceries) filled to brim with urine discolored darkened by the meds for (i miss getting high)

bladder-spasms depression leg-spasms nerve-pain six others symptoms of damage done to sixth cervical vertebrae (*curvy black nurse with beautiful fake hair*) causing paralysis immediately after the motorcycle crash the old man that ran (*what's he doing these days?*)

a stop sign but luckily called the ambulance who determined my injury above their pay (can't get survivor benefits) request a life flight to pittsburgh where i gain (pirates cubs foul ball straight through my then working hands)

consciousness and realize tubes protruding from my body (garage bench press) my penis one tube of thousands like the one i study (blades of grass)

i push my pant leg down (autonomic dysreflexia) the bag needs emptied

## MISOGYNY AND THE WANDERING WOMB: THE POETRY OF A MISDIAGNOSED PARALYSIS

SANDRA J. LINDOW

Review of Cures for Hysteria, poems by MaryAnn L. Miller, Finishing Line Press, 2018

ature . . . seems to me to have strayed from that good sense by which she had created and formed all things, when she built woman." (Hippocrates, c 460-377 BC)

Medicine is an inexact and incomplete science. Prior to the twentieth century, doctors knew so little about the human body that they were as likely to do harm as they were to do good. Even today, medical care is fraught with ill-conceived prejudices and protocols based on averages with insufficient evidence about the care of exceptional cases. Consider, for example, the opioid epidemic and all the backtracking the medical establishment is doing regarding the safety and effectiveness of long term use. In Cures for Hysteria, poet MaryAnn L. Miller, describes an intimate journey through medical misdiagnosis, misogyny, and malpractice. Beginning at age three, she began experiencing periods of paralysis every day that were later misdiagnosed as exaggerated guilt conversion disorder, hysteria, suggesting that doctors, lacking the means to specifically diagnose a rare problem, simply decided to blame the victim. Much later, after her own three-year-old son began exhibiting the same symptoms, the disease was correctly diagnosed as hyperkalemic periodic paralysis with myotonia or Gamstorp disease, not psychological at all, but by that time Miller had been emotionally traumatized by combined social prejudice and medical mistreatment.

take one each day
Mutation on Chromosome 17
Sodium channel, voltage sensitive
Type IV cramps familial
...
all I need is a pill. (38)

Miller holds degrees in art education/English, school counseling, and creative writing; the forty poems in this collection demonstrate a sophisticated grasp of poetic technique as well as research into related medical misadventures throughout written history, particularly those where women's medical needs were misunderstood. The poems themselves are complex, often using metaphors from the art world to describe the internal world of a body that does not reflect the norm: "She is a screen print, / Sitting wrong causes the cells to slip . . . printer's ink on a wet page, / an unsigned proof, ad edition of one" (1). The cover is a photograph of a marble votive relief of the ancient hero-physician Amynon, a particularly evocative image because the physician embraces the massive detached leg of a giant statue, suggesting the poet's own desire for enduring stability—if only leg strength could be a matter of simple replacement parts.

With no way to predict when paralysis will occur and no one to explain why it is occurring, fear is a common denominator throughout the collection: "I watch myself writhe, / expect my heart to stop, until I learn it probably won't" (5). Her child's eye view reflects the worries of a bright child who is beginning to create a socio / political frame for events: "What if the Russians drop the bomb? How can I duck and cover?" (5). "I break: white specks in a black sky, / Sputnik in the summer night" (12).

Paralysis is a physical condition that is difficult to explain to someone who has never experienced it: "I'm welded to the bed / legs and arms flatten like a shirt in a mangle". . . "imagine someone big and fat on top of you / flesh sticking like hot plastic" (6). For a young person, being different can be deeply embarrassing, and in high school, Miller attempts to hide her disability, waiting for the halls to clear before pulling herself up the stairs. Later at lunch, "I work a finger between my teeth to chew" (15). Anonymity, however, is impossible. Her differences cannot be hidden.

Hysteria was defined as a psychological disorder with symptoms including conversion of psychological stress into physical symptoms. It is now regarded as an invalid umbrella diagnosis that covered individuals suffering traumatic aftereffects of physical and sexual abuse as well as those demonstrating delusional behavior resulting from other causes such as brain tumors and poisoning. Giovanna M. (1823-1913) was incarcerated in a madhouse for a bad headache, diagnosed with hysteria, and received the usual treatment of the time: "Bathing, tonics, tinctures, polenta poultices . . . regular purgings," (21). The ancient Greeks thought hysteria to be the result of a "wandering womb" and devised novel "cures" which continued to be practiced in the twentieth century (23). In "Cures for Hysteria" Miller relates a history that includes (30-31):

hold something foul-smelling at the patient's nose something sweet smelling at the patient's vagina the uterus will respond.

remove the erectile turbinate bone from the nose
...
effect hysterical paroxysm by stimulation of her genitals
...
an emulsion of asafetida by mouth
if the patient resists shoot it up her ass

Dealing with personal disability has given Miller insight into others who have suffered from misdiagnosis as well as compassion for their despair. Many of the poems reflect her research: Diabetics misperceived as drunks, homosexuals forced into "reparative therapy" (55, 56). The anger informing many of these poems is almost palpable: rage regarding medicine, psychology, the church, and the comfort-seeking good old establishment boys who minimize and fantasize that women's illnesses must in some way be caused by the (obviously inferior) organs that differentiate them from men's. Freud, Jung, R. D. Liang—Miller relates evolving discourses on the treatment of the entirely fabricated disease of female hysteria, what she renames as "the prison of disregard" (60). Years later, she still struggles with memories from her traumatic childhood. In "Far Out on the Comet's Tail," written after reading Swedish poet Tomas Transtromer, Miller reflects on the nature of memory, time, particle physics, and the medical miracles at Bethesda (John 5:1-18):

Near the end we stand on wobbling particles. Ahead, we see: unremembered infancies. Here there is no denial of earthly change.

On the far end we cast lures into a Bethesda pool gathering mercy and disgrace. Remember how your spine folded halfway through the journey. (44)

Apparent in the words "gathering mercy and disgrace" are the mixed messages of organized religion, the not-so-subtle suggestion that those who are truly right with God will be miraculously healed, along with the corresponding disgrace when no healing occurs.

Although most of the poems are written in free verse, the last third of the book contains some experimental forms. Most interesting of these is "Charcot's Iconography," a poem whose short segments mimics a chart of supposed hysterical gestures. Extensive notes at the end provide historical context as well as the implication that patients became actors in a play orchestrated by the doctor involved, a kind of Stockholm syndrome of complicit disease dynamics where mental illness is reinforced by the doctors involved and patients gain attention and approval by exhibiting symptoms that the doctor has identified. This fascinating collection is highly recommended for anyone who has struggled with medical mistreatment and disregard.

Carol Barrett coordinates the Creative Writing Certificate Program at Union Institute and University. Her books include *Calling in the Bones* from Ashland Poetry Press, *Drawing Lessons* from Finishing Line Press, and *Pansies*, forthcoming from Sonder Press. Her poems have appeared in *The Journal of the American Medical Association*, *Poetry International*, *Poetry Northwest*, and *The Women's Review of Books*.

**Katrina Byrd** writes fiction, nonfiction, and plays. Her play, *Water Sample*, was named best play by Vicksburg Theatre Guild. Her fiction has appeared in *(DIS)ability Anthology* and in the journal, *The Disappointed Housewife*. Byrd says, "I write because it gives me the power to be myself." She has a visual impairment.

**Pamela Carter** graduated with honors from the University of Denver's Sturm College of Law. Nine months after graduation she nearly lost her life after suffering a massive hemorrhagic stroke. She is now a full-time writer. Her work has appeared in *Midway Journal* among other publications.

Paige Cerulli is a copywriter. Diagnosed with fibromyalgia, she says, "Writing has become an outlet for channeling the struggles that fibromyalgia has caused in my life. It is a way to connect with others, to explore the way that my life has changed, and to come to terms with my post-diagnosis life."

**J. D. Chaney** is a retired teacher. His fiction has appeared in *Aquila Magazine* (2014-2017). His nonfiction appeared in *Coal People* (2015). Chaney shares, "I enjoy being creative with pen and paper. An adventurer at heart, I love to travel, meet people, and go to far away locations. . . where stories just seem to seep into my head."

**Kira Compton** earned a B.F.A. from Emerson College in theatre. Her poems have appeared in *Pif Magazine* (January 2016), *Young Scribbler's Magazine* (August 2016), and *Right Hand Pointing* (June 2018). Compton struggles with Crohn's disease and moderate depressive disorder. She says, "I write because it brings me joy. . . ."

**Jennifer L. Freed** is a teacher whose poems have appeared in *Zone 3* and *Worcester Review* (2017). Freed was a finalist in the 2013 New Women's Voices contest, and her chapbook, *These Hands Still Holding*, was published by Finishing Line Press (2014). She was the winner of the Spirit First Meditation Poetry Contest in 2017.

Tony Gloeggler has managed group homes for men with developmental disabilities for thirty-five years. His poems have appeared in *Rattle*, *The Raleigh Review*, *Chiron Review*, and *New Ohio Review*. His full-length books include *One Wish Left* (Pavement Saw Press, 2002). *The Last Lie* (NYQ Books, 2010), and *Until The Last Light Leaves* (NYQ Books, 2015). It was a finalist for the 2016 Binghamton University Milt Kessler Poetry Book Award, focusing on his work and connection to an ex-girlfriend's son with autism.

**Ingi House** is "insatiably curious" and combines her love of history and "being nosey" by working as an archivist. She deals with depression and anxiety. She writes because "I have to get the inside out." In 2017, her work was published in *The Literary Hatchet*, *Helen Literary Magazine*, *NOUS* "The Work Issue," and *A Beautiful Resistance*.

**June Capossela Kempf** is an educator whose two books were published by Keith Publications, *Yo God! Jay's Story* (2013) and *Lady of the Dollhouse* (2017). She was inducted into the Long Island Authors Circle in 2018. Kempf is inspired by the words of Maya Angelou: "One of the worst burdens is an untold story."

Philip C. Kolin taught at the University of Southern Mississippi and is a Distinguished Professor of English–Emeritus. He has written more than forty books including textbooks, theater history and eight collections of poems, two of which are *Benedict's Daughter* (Wipf and Stock, 2017) and *Emmett Till in Different States* (Third World Publishing, 2015). Kolin says, "I want to help readers see beneath surfaces."

Sandra J. Lindow is a semi-retired teacher and editor. Her publications include a poetry chapbook, *The Hedge Witch's Upgrade* (Linden Leaf Press, 2012). Her poem, "Cinderella Breast," was published in the anthology, *New Poetry from the Midwest* (New American Press, 2017). Her scholarly article on Ursula Le Guin's *Hainish Cycle* appeared in the *New York Review of Science Fiction* (April 2018). Her disabilities are posttraumatic stress disorder from childhood abuse and post breast cancer lymphedema. Lindow says, "These issues have driven my poetry as well as my scholarly criticism."

**Lola Neff Merritt** is a retired librarian. She has been a poet for many years, and has been published in numerous magazines and journals, most recently in *The Almanac for Farmers & City Folk, The Gem, Mature Living*, and *Salesian Missions Magazine*. Merritt has limited mobility due to severe lumbar stenosis, arthritis, and neuropathy.

Julia Anne Miller is a doctoral candidate focusing on neurodivergence at Union Institute & University. Her poem focusing on traumatic brain injury appeared in the Kentucky Poetry Society's *Pegasus* (Summer/Autumn 2017), and another poem is included in the book *Corners: Voices on Change* (Jack Walker Press 2018). Miller says writing, "keeps my emotions balanced and allows me to express my experiences in a way that I cannot express through my speech limitations."

**Denise Noe** is periodically employed as a writer, researcher, and proofreader. Her book, *The Complete Married with Children Book: TV's Dysfunctional Family Phenomenon*, was published by BearManor Media (2017). Her book *Suffer Little Children* was published by BuzzwordBooks.com (2016). Noe's disability is psychiatric along with chronic pain.

Mark Osteen is a professor of English. His memoir is *One of Us: A Family's Life with Autism* (University Press 2010). He also edited *Autism and Representation*, a collection of essays on literature, film, and autism (2008). He won two awards, the Dorothy Cappon Prize in Creative Nonfiction, from *New Letters* (2016), and the SAR Essay Prize: Best Essay in *South Atlantic Review* (2017). Osteen's son has severe autism. He says, "I write about autism to help educate the world about the value of people with disabilities—what they have to offer all of us—but also to address, honestly and without judgment, the challenges that autism families face."

**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.

**J. F. Pritchard** earned a B.A. in English from Kent State University in 2017. He describes himself as a "quadriplegic philosopher." His poetry has appeared in *Tule Review* (August 2016), *OX Magazine* (August 2015), *Pentimento* (November 2015), and *Wordgathering* (June 2015). He is also an artist working in paint, pencil, and charcoal. Pritchard shares, "I'm a 26-year-old quad trying to find an oasis in a desert . . . . I have to navigate the world with my mind."

**Sam Provenzano** is a semi-retired professor of English who still teaches a few classes in freshman composition. The story, "Sketch," that appears here is included in his self-published book entitled *Corazon*.

Elizabeth A. Sachs has a master's degree in library science and studied narrative medicine at Columbia University. Her novel, *Just Like Always*, was published by Atheneum (1982). She wrote book reviews for *The New York Times* and also wrote for *The News-Times* of Danbury, Connecticut. Sachs received a writing stipend from Vermont Studio Center (2017/2018). She has published numerous books for adults and children but her "mission" is writing about living with a disability (paraplegia).

Tom Stapleton teaches communication skills to clients in the corporate world and public sector. He has various publication credits including newspaper articles in the *Los Angeles Times* and *The Denver Post*. He has also written for *Training* magazine—focusing on corporate staff development (April 2018) and *Celtic Life International* (April 2016).

Gail Willmott has been a staff member with *Kaleidoscope* since 1982 and became editor-in-chief in July, 2003. She received both her bachelor's and master's degrees from the University of Illinois. "This is a career I have loved for thirty-six years—getting to know our contributors as well as working with very accomplished and supportive colleagues."

Chris Wilson is from the United Kingdom. His short story collection, *Pause For Thought, Volume 1* was self-published in November 2015. Wilson struggles with depression. He shares, "I'm an outsider in life. I have experienced and studied life in the raw, but the reward is an understanding of what others are going through."



Rora Blue, Handle with Care, 1 image of 6 in a series, 2016



Rora Blue, (Don't), 1 image of 4 in a series, 2017

