THE TIES THAT BIND

"Voice" by Paul Hostovsky

"Sister Secrets" by Claire McMurray

"The Shape-Shifter’s Mother" by Wendy Nikel
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Kaleidoscope, beginning in 1979, pioneered the exploration of the experience of disability through the lens of literature and fine arts. Fiction, personal essays, poetry, articles, book reviews, and various artistic media including two-dimensional art, three-dimensional art, drama, theater, and dance are featured in the pages of various issues. This award-winning publication expresses the experience of disability from a variety of perspectives including: individuals, families, friends, caregivers, healthcare professionals, and educators, among others. The material chosen for Kaleidoscope challenges stereotypical, patronizing, and sentimental attitudes about disabilities.

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Kelly Simpson, Friend in ASL, 2015, oil paint, 12" x 16"
IN REMEMBRANCE...

Phyllis Boerner, past publication director for Kaleidoscope, passed away on June 19, 2023. A graduate of The Ohio State University, she was a consummate writer and editor, who brought a high degree of passion and professionalism to the magazine. Under her direction, Kaleidoscope grew to become an award-winning international publication that continues to change the perception of disability even today. She was a lifelong advocate for individuals with disabilities and continued to be a friend and supporter of Kaleidoscope after she retired from United Disability Services in 2013. Phyllis’s wit and unique outlook on life will be greatly missed by all who had the privilege of knowing her.
Listen, my daughter is Deaf. Capital D. But she’s hard of hearing. So she hears a lot, for a Deaf person. Which, to the uninitiated, sounds kind of paradoxical, I know. What if I told you that in American Sign Language (ASL) the phrase “very hard of hearing” means the opposite of the English phrase “very hard of hearing.” In ASL, it means a person hears a lot. In English, it means a person hears very little. How can that be? It can be and it is because, as Walt Whitman said, “What will be will be well, for what is is well.” Whitman, the eternal optimist. In other words, my Deaf daughter is whole. She is perfect the way she is. In the Deaf world, Deaf is good. It’s a good thing. It’s no cakewalk, mind you, especially among hearing people who don’t see Deaf as a good thing—quite the opposite, actually—but it is, nevertheless, a good and beautiful and blessed thing. And in the Deaf world, Deaf has very little to do with how much a person hears. It has everything to do with language and culture. And ASL, the language of Deaf Americans, has very little to do with English. Though it does coexist with English: the biggest bully on the world’s linguistic playground. English is always trying to push ASL around, but ASL won’t have it. My daughter would probably say, at this point, “Dad, shut up, you’re just confusing people.” And she would be right. But the thing is, it is confusing. It’s complicated. It’s complex, as are most things when you take the time to look at them closely. But confused is good, if it leads to intrigued, fascinated, interested.

So listen, if you’re interested, my daughter is culturally Deaf and audiologically hard of hearing. What that means is her primary language is ASL and she can hear a little. A lot, actually, for a Deaf person. Not enough to understand spoken English the way a hearing person can understand spoken English, but enough to enjoy listening to music; enough to sing along while listening to Britney Spears or Adele or Black Eyed Peas with her hard of hearing Deaf friends. Also, her mother happens to be Deaf. Her best friends are Deaf. Her identity and allegiance are with ASL. Oh, and her father, yours truly, is an ASL interpreter, who learned ASL years before she was a twinkle in his eye. She was born with “a moderate hearing loss” in one ear and “a severe hearing loss” in the other. So said the audiologist. So said the audiogram. And what does that mean? That’s the question I and her Deaf mother put to the audiologist. And being an audiologist, she said it meant that with amplification, hearing aids, possibly a cochlear implant, and rigorous and persistent speech therapy, our daughter could “probably function quite normally in the hearing world.” Her Deaf mother and I didn’t like the sound of that.

We didn’t like the sound of “function quite normally in the hearing world” because we both knew that Deaf people are already perfectly “normal” and quite capable of “functioning in the hearing world.” And there was no way on earth we would ever allow a surgeon to drill a hole in our daughter’s skull and implant a metal device in her cochlea in order to “help her be more normal.” So we didn’t. We enrolled her in the local school for the Deaf. And she wore a hearing aid for a few years, but then she said she didn’t want to wear it anymore. And we said fine. And she had speech therapy for a number of years, but then she said she’d really rather spend that time on more interesting and important things, such as
math class, science class, history class, English class—which were all taught in ASL—or basketball practice or soccer practice or track practice. There just wasn’t the time—or the need—for speech therapy, she said. And we said fine.

My Deaf friend Hartmut Teuber, who grew up in Germany, told me there is a word in German that describes the choices we made concerning our hard of hearing Deaf daughter. I think he said the word was *ertauben*. Or maybe it was *vertauben*. My German is not what it used to be. In any case, it basically means “to make Deaf.” He was implying that the choices her mother and I made concerning our daughter’s speech and language and education—sending her to a school for the Deaf where the language of instruction was ASL, not insisting she wear hearing aids, not insisting she work on her speech, consistently signing to her in ASL even though she had a lot of residual hearing and could probably have learned to “function quite normally in the hearing world”—had effectively made her Deaf. Capital D. We had Deafened her.

And I suppose Hartmut was right. Because listen: if she were born to two hearing parents who had never met a Deaf person and who wanted more than anything for their child to be able to “function normally in the hearing world,” she would have had a very different upbringing. She would not have attended a school for the Deaf. She probably would have had a cochlear implant, or at least worn hearing aids all day every day of her life, spending countless hours in speech therapy, attending public schools with hearing children—the only “hearing-impaired” child in the classroom—and would probably not have learned ASL, nor met other Deaf children or Deaf adults, nor identified with them or their language. She would have seen them as “them,” as “other,” as “deaf-mutes,” which is the way much of the world—most of the world—sees my daughter as she is today, because she signs and does not speak with her voice.

So, yes, it was a conscious choice we made, her mother and I, to sign to her in ASL, which was already the language of our home, and to enroll her in the school for the Deaf, where at age three—in the Parent Infant Program—she could already understand everything everyone was saying, and say whatever she wanted to say, and be understood by all. That was what we wanted for her more than anything else: to be able to understand and to make herself understood. Speech does not equal language. Speech does not equal intelligence. In fact, speech has historically been taught to Deaf children *at the expense of language, at the expense of education*. Her mother and I knew plenty of Deaf adults who experienced this. In fact, it was the experience of *most* Deaf adults. We were adamant that it would not be our daughter’s experience.

*     *     *

It may sound oxymoronic, but there is music in sign language. Even if you don’t understand a word of it, you probably enjoy looking at it. Most people do. They say it’s beautiful and expressive, that it kind of looks like dancing. And if you’re like most hearing people, you probably also enjoy listening to music. In fact, you might say you can’t imagine a life without music. Well, ASL has its own music, and when you watch Deaf people signing—and especially when you understand every word of it—you can see the music.

Sign language, in the hands of Deaf people, isn’t linear the way spoken languages are linear—one discrete word following on the heels of the next. Rather, ASL is symphonic. It creates meaning simultaneously with the hands, face, eyebrows, eye-gaze, lips, tongue, head-tilt, shoulder-turn—all the various sections of the body’s orchestra creating meaning *at the same time*. A visual-gestural symphony rising up at once, like a controlled explosion.

ASL has its own rhythms, assonances, crescendos and decrescendos, riffs and repetitions, most of which have grammatical functions. For example, one beat versus two can indicate the difference between a verb and a noun; a single movement versus a repeated movement can be the difference between simple present and present continuous, or between modified and unmodified verbs. Additionally, much of the grammar of ASL occurs on the face, such as negation, imperatives, interrogatives, adjectives, adverbs, and something called “sound imagery,” a way of visually representing certain environmental sounds with the lips, teeth, tongue, and eyes. Hearing people often comment that Deaf people are very animated. And while it’s true that facial expression in ASL also expresses emotion, it’s usually more about grammar than emotion, more about sense than sensibility. More semantic than romantic.

And the thing is, it feels good to sign. The physical pleasure one derives from signing and watching other people signing is not unlike the physical pleasure one derives from making
music and listening to music being made. Interestingly, sign and sing, but for two inverted letters, are the same word. A happy accident? Perhaps. And yet, signing and singing are just two different (or maybe not so different) ways that the body expresses energy, shaping meaning and emotion out of thin air, putting it out there for the world to take in. And the manual dexterity required to play a musical instrument is not unlike the manual dexterity required to articulate the handshapes and movements of ASL. In fact, ASL teachers report that hearing people who have learned to play a musical instrument at some point in their lives seem to have an easier time learning ASL than those who never played a musical instrument. Go figure.

But silence, to Deaf people, who are intensely visual people, isn’t lack of sound; it’s lack of movement. Sound IS movement, in fact. It’s energy moving in waves. Which is what music is, after all. And when Deaf people look into the faces of hearing people, what they usually see is silence. They see silence because hearing people, for the most part, do not use their faces to express meaning or emotion. Compared to Deaf people, they have very little facial expression when they talk. Hearing people are pretty poker-faced, if you ask Deaf people. And that’s because their intonation is all in the voice, which is invisible to Deaf people.

But when Deaf people look into the faces of other Deaf people, what do you think they see? They see music! Movement, beauty, energy, meaning. They see intonation. They see gymnastic eyebrows, eloquent eyes, adverbial tongues, and all the risible muscles being put to good, resounding use. They see their language, a visually stunning and musical language, full of inflection, anima, soul.

Hearing people who don’t know ASL can, of course, see the hands and faces and bodies of Deaf people signing, but they can’t really appreciate the music of it, not if they don’t understand what they’re seeing. But when you understand what you’re seeing, you’re wowed by the creativity, the echoes, the assonances, the embodiments and shifts, the flights of playfulness and artfulness, the cinematic effects, and you almost want to stand up and applaud. Because Deaf signers are virtuosos.

*     *     *

So listen: what would my daughter be like today if she had had two hearing parents who had never met a Deaf person, who followed the advice of the “experts” and opted for a cochlear implant or bilateral hearing aids, parents who used only spoken language with her, sending her to public schools where she was the only “hearing-impaired” child in the class? Would she be the same person she is today or a different person? That question intrigues me. And it scares me a little. It’s a little like asking what she would be like if she grew up in Italy speaking Italian, or in Iran speaking Farsi. Wow, she would definitely be a different person. Culturally. Linguistically. And yet she would be the same person. She would look basically the same. The same height. Same complexion. Same shoe size. But psychologically, temperamentally, mentally, and emotionally, she would very likely be a very different person.

When poets and writers speak of voice, they’re not talking about the vocal mechanism; they’re talking about literary devices, they’re talking about language.

Listen, I like her the way she is. I love her the way she is. And I know she likes and loves herself. Which is just as important, actually more important. But it wasn’t always this way. It wasn’t all smooth sailing. I remember when she was little (she’s thirty now), and wearing hearing aids, and going to speech therapy—several times a week, mostly signing but occasionally using her voice with me, with her hearing brother, with her hearing grandmother. And one day when she was shooting hoops with her brother and the neighborhood children, she called out with her voice “I’m open” or “pass me the ball,” and one of the kids laughed at her, pointed at her jeeringly and laughed at the sound of her voice. And it hit her hard. Harder than if someone had thrown the ball in her face. And it hit her that her voice was not like the voices of the other children, that somehow it was different, noticeably, laughably, different. And suddenly she felt terribly vulnerable. And it wasn’t long after that incident that she basically chose to stop using her voice, if she could help it. And in spite of my reassurances that her voice was fine, that her speech was good—that if she worked on it, it would get even better—she chose to give up on speech. And I haven’t heard her speak with her voice in many years.

Does that make me sad? No. What makes me sad is that she was hurt, traumatized, by someone laughing at her in a cruel way. What makes me sad is that she internalized that hurt, and allowed it to silence her. But I am not sad that she chose ASL over spoken English. After all, her mother and I made the same choice when she was three years old. And her voice is alive and well, and I hear it when she laughs or sighs or sneezes or yawns or hums, or uses it any number of other ways. But she is not her voice. She is her personality, her character, her way. And anyway, voice is overrated. It’s the ultimate instrument, they say; the breath of God, the soul. Give me, please, a break. The souls of Deaf folk are fine and well, and perfectly happy the way they are; their personalities are as rich and varied as all the notes on all the
musical scales, and then some. And as for God, well, let’s leave God out of it. After all, religionists and oralists have been infantilizing Deaf people for centuries in the name of God. Read the history. It’s all there. When poets and writers speak of voice, they’re not talking about the vocal mechanism; they’re talking about literary devices, they’re talking about language. Deaf poets are just as well-versed in the use of voice and tone in their ASL poems and stories as hearing poets are. And finally, “having a voice,” which basically means having a say in things, having power, having agency, has nothing to do with voice and everything to do with language, the power of language, the power of community and self-advocacy. And Deaf Power is all about language and community.

So listen, yeah, maybe we “Deafened” our daughter. But it’s all for the good. Because the medical establishment and the so-called experts have been perpetrating a cultural genocide against Deaf people for generations, going all the way back to the Milan conference of 1880 and the proscription of sign language in deaf education worldwide, and then the eugenics movement in this country and abroad advocating the forced sterilizations of Deaf people, and also A. G. Bell's lifelong attempts to pass a law banning marriages between Deaf people. And now, the greatest weapon of all in the erasure of Deaf people and Deaf culture: the pervasive practice of performing cochlear implant surgery on 90% of deaf infants and children in an attempt to “cure” them of being deaf, trying to make them “normal,” which amounts to denying them their natural language, signed language, and their natural culture, Deaf culture. And denying a people their language and their culture is, by definition, genocide, according to the Convention on the Prevention and Punishment of the Crime of Genocide (CPPCG). And why isn’t anyone speaking up about that?*

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**Caitlin C. Baker**

**Plastic Butterfly**

I had never known a butterfly to drink blood, with blue plastic wings spread against young moon skin and its proboscis dipped into my veins.

Mosquitoes must have told the secret of their *aqua vitae* spiced with experimental pills and saturated with a misunderstood ailment.

A palate that favored my syrup to milkweed proved that we aren’t the only species who can fall in love with strange nectar.

It untucked its silver tongue from my body, and, in its wake, a rare flower unfolded new petals in the crook of my elbow.

---

**Gloria G. Murray**

**His Suicide**

_for Donna_

how will she sleep
and if she sleeps
how will she not dream
and if she dreams
how will she not dream of him—her son
his blond hair, chiseled face
crushed under the wheels
of the rushing train
and if she dreams of him
how will she not ask over and over
*Why? Why?*
and if she asks
how will she ever find an answer
and if there is no answer
how will she ever find consolation
and if there is no consolation
how will she not weep
and if she weeps
how will she ever stop?
“Don’t forget the house rules.”

Mom’s eyebrows knit with concern, and her freckled face is pale. She looks like she’s one second away from wringing her hands—something she does when she worries about Pearl. “No sweets, no inappropriate television, no staying up late, no getting too excited before bedtime.”

“Lily knows the rules, sweetheart.” Dad lays a hand on Mom’s shoulder, then gently steers her away from me and toward the front hallway. “We’ve been over them a million times. Now let’s put on our coats. We don’t want to be late.”

I understand why Mom is nervous, even if it bothers me. This is the first night in two years she’s going out alone with Dad. It’s also the first time I’m babysitting my little sister all on my own. My grandmother used to watch the two of us, but then Pearl got too big. Nana couldn’t do what needed to be done. Now, finally, I’m old enough to help on my own—even if Mom doesn’t quite believe it.

My parents step into the front hallway. I sneak a little closer, hoping to hear what they’re saying, but I only catch little snatches of conversation.

“...a child like Pearl...”

“...has been... for years...”

“The most responsible fifteen-year-old I know...”

The voices lapse into silence, and there’s a long series of rustling noises as Mom and Dad put on their coats. I tiptoe back to the living room and try to look as though I weren’t just eavesdropping.

Next to me Pearl is strapped into her wheelchair, the Tobii clamped onto the side of the chair’s tray. I look down at her to check if she heard anything Mom and Dad said, but given her current position, it’s hard to tell. My sister’s head is bowed over the tray, arms hanging limply by her side, chest rising and falling with long rhythmic breaths. I’m sure the pose is going to fool Mom, but it doesn’t fool me. I know what Pearl is up to.

Mom walks across the hardwood floor—it’s easier to roll around on than carpet—and plants a kiss on the top of my head. Then she glances down at Pearl and whispers. “Her pajamas are on, her teeth are brushed, and I already took her to the bathroom. She’s had everything except the trazodone. Give that to her right before bed in her applesauce.”

“I know, Mom.” I try to keep the irritation out of my voice. I’ve been fetching Pearl’s medicines since I was six and helping Mom mix them since I was ten. “I’ve got it covered.”

“I know you do, honey.” Mom gives my shoulder a gentle squeeze. “You’re my rock star.” I get a strong whiff of lavender as she leans over to place a featherlight kiss on the top of Pearl’s head. “Tell her I said goodbye, will you? I don’t want to disturb her while she’s sleeping.”
“Sure thing.”

I try not to giggle. If only Mom knew.

After my parents shut the front door, I poke my sister in the shoulder. “You can get up now, goof nut. They’re gone.”

Thirty seconds go by in silence before Pearl’s head pops up. Her blond hair is in disarray, but when her bright blue eyes settle on me, they’re alert and focused. Then she gives me a naughty smile. Sometimes my sister pretends to be asleep to escape a doctor’s appointment or a teacher she doesn’t like. Sometimes, though, I think she just does it for the heck of it. I never tell on her. If people can’t tell what’s going on, that’s their problem. My sister is the smartest ten-year-old I know.

Pearl squeaks with what sounds like triumph, and I shake my head at her. “Yeah, yeah. I know you’re proud of yourself.”

I disengage her brakes and roll her over next to the couch. Then I crouch down in front of her. Talking to her with yes/no is so much faster than waiting for her to type out things on her Tobii. “Do you want to watch TV now?”

After a moment, my sister looks at me dead on and holds my gaze.

Yes.

“Do you want me to help you come sit on the couch next to me?”

Pearl turns her head away.

No.

Pearl groans, but I ignore it.

Fair is fair. She chose last time.

I grab the remote from the coffee table and turn on the TV. I make sure Pearl is positioned where she can see the screen before I start scrolling through the shows. This could take a while. Sometimes my sister and I can’t agree on anything.

My little sister gives an excited screech, and I turn to see if she’s serious.

“Really? You want to watch this?”

Pearl stares at me.

Yes.

“Are you sure? Because Mom is going to kill me if she finds out.”

Pearl screeches again.

“All right. I guess I’ll just tell her I watched it after you went to bed. What she doesn’t know, won’t hurt her.”

Pearl beams.

I pull up an episode and scooch down to the end of the couch, right next to Pearl’s chair. We watch the opening credits and the first few minutes of the show in silence before the bachelor appears on screen with a bare chest and a pair of low-slung board shorts.

I like to tease Pearl, so I sigh dramatically. “He’s so cute, isn’t he?”

Pearl’s hands are too shaky to be reliable, so she looks around on her Tobii, searching for the right word with her eyes. I know what she’s going to say even before the machine types it and says it aloud. Pearl always makes the same stupid joke when she insults me.

bell

“I am not a ding-dong,” I tell her.

I knew it. She’s so predictable.

We watch for another ten minutes or so until the sound of the Tobii startles me out of my TV trance.

ice cream

I look over to find my sister staring at me with pleading eyes.

“I am not a ding-dong,” I tell her.

I knew it. She’s so predictable.

We watch for another ten minutes or so until the sound of the Tobii startles me out of my TV trance.

ice cream

I look over to find my sister staring at me with pleading eyes.

“Are you kidding me? Mom would have a hissy. She already brushed your teeth.”

Pearl doesn’t look away. I don’t know how she does it, but it feels like her eyes are boring straight into my brain.

“We really shouldn’t.”

Pearl turns to the Tobii.

you always

She’s right. I do always sneak ice cream. Pearl has seen me do it dozens
of times. She is always watching someone do something. Sometimes I wonder how many secrets she could tell if she wanted.

“Okay, okay, fine.” My sister knows how to play me like a fiddle. Also, she doesn’t get to do all the sneaky little things most kids take for granted, so sometimes I do them for her. “But no whipped cream and I’m brushing your teeth after, all right?”

Pearl lets out a low, throaty laugh. She always rubs it in when she wins.

“Ugh. You’re the worst.”

I get why Mom is worried, but I can handle this. I know I can.

In the kitchen I pull the mint chocolate chip out of the freezer and scoop it into a bowl. Then I roll Pearl to the kitchen table and tie a bib around her neck. No way am I leaving any incriminating evidence behind on her pajamas. After a few minutes of feeding her, a trickle of ice cream dribbles down Pearl’s chin. I wipe it away with a napkin. While I’m wiping, I accidentally brush the cloth along the side of her neck, and she lets out a loud giggle. I don’t know what it is about my sister that makes her more ticklish than other people. I skim the towel along the other side of her neck, and she breaks into peals of laughter.

I tickle her for a while like this, making sure the ice cream bowl stays safely out of the way. Pearl laughs until her shoulders shake and tears glisten in the corners of her eyes. I love it when she is like this. I think I could listen to her giggle all day.

In the middle of the tickling, my phone beeps with an incoming message. Even though I know who it’s going to be, I swipe open the screen to check.

Mom: How are you girls doing? Everything under control?

I type out a quick response. I know if I take too long, Mom will freak out and call me.

Lily: no worries things are fine

I add a thumbs up emoji for good measure, then press send.

I wish Mom would trust me tonight like she usually does. Then again, maybe she has reason to be suspicious. I look at the ice cream bowl on the kitchen table, and guilt gnaws at me. “I think that’s enough,” I tell Pearl.

I put the bowl in the dishwasher, and the carton back into the freezer. “All right. It’s time.”

“Unnggghhh.” Pearl protests vigorously. She uses the Tobii to call me a ding-dong again, but I don’t care. If she thinks she’s getting out of another toothbrushing, she’s sorely mistaken.

“Come on. It’s the price you pay,” I say as I wheel her to the bathroom.

Then I pause for a moment. I’m not really sure how I’m going to do this. Usually, Mom and Dad do it together. Turns out, it’s surprisingly difficult to brush a wriggly ten-year-old’s teeth. In the end, I’m grateful that Pearl decides to hold still for me. While I move the toothbrush around her mouth, I can’t help but think about Mom, worrying about her girls instead of enjoying her night out with Dad. As I wipe away the drips of foam, Pearl stares at me intently. She’s a master at sensing what other people are feeling. Sometimes I wonder if she can actually read minds.

“What? I’m just tired. It’s been a long week.”

And I don’t think Mom trusts me to take care of you by myself.

I don’t say this last part out loud because sometimes the truth can be painful. It’s true that taking care of Pearl is a little bit riskier than babysitting other kids. With help, she can maneuver herself on and off the couch and in and out of bed, but it’s not easy. If she falls down, it takes a lot of time and effort to get her back up again. But it’s happened before, and we’ve dealt with it. I get why Mom is worried, but I can handle this. I know I can.

I wheel Pearl back into the living room, sit down on the couch, and flick the TV off with the remote. “What do you want to do now, goober?”

Music

“Okay. You pick what you want.”

Pearl spends a minute looking around on the Tobii, then the opening notes of “Bohemian Rhapsody” float out of the device. The song is a family classic—something the four of us can always agree on. I know all the words, and I’m pretty sure Pearl does too. She starts to rock back in forth in her chair, but not with her usual random, uncoordinated movements. Instead, she moves in time to the beat. It’s her way of dancing.

My sister looks at me with imploring eyes, but I shake my head. “Sorry. I don’t really feel like it.” Pearl continues to rock but keeps her gaze trained on me. She’s so stubborn I know she won’t look away until I give in.

“Oh, fine. If you insist.”

I stand up and move in front of my sister’s wheelchair. Pearl gives me an encouraging grin. As I mouth the words to the song, her smile grows wider. A minute later I’m singing into an invisible microphone before strumming on an air guitar.

Pearl is loving it. One arm flies out to her side, then she smashes her fist down on the tray in front of her. Mom will never forgive me if something happens to the Tobii, so I’m glad it’s clamped on tight. I’ve never seen my sister this revved up before.
Is it the sugar?

Pearl bounces up and down in her chair and lets out a screech so loud my ears almost ring.

It’s definitely the sugar.

“Bohemian Rhapsody” continues building toward its final crescendo. Then, suddenly, I’m on my knees on the floor, head tilted up to the ceiling, belting out the lyrics into my pretend microphone. After the song ends, I stand up and bow to my audience of one. Pearl screeches her approval.

“Thank you. Thank you very much.”

My sister finds “Barbie Girl” and puts it on. It’s not my favorite, but I let her have it. Then we do some Zeppelin, a few random pop songs, and The Beatles. In the middle of “Yellow Submarine,” the doorbell rings.

I wave at the Tobii. “Hey, turn that down, would you?”

Pearl pauses the music while I walk to the front door. It’s already dark outside and almost Pearl’s bedtime, so I have no idea who it could be.

I turn on the porch light, peek through the little window built into our front door, and stifle a groan. Mrs. Haggerty, our next-door neighbor, waves at me, her gray curls warped and distorted by the wavy panes of glass. I pull open the door but don’t invite her in.

If it were anyone else, I’d think Mom sent her to check up on us, but none of us much like Mrs. Haggerty. She’s so weird about Pearl—always saying things that aren’t quite right but that you can’t really object to without seeming impolite. Pearl and I think of her as the neighborhood witch. My sister uses a picture of a broomstick to refer to her on the Tobii when Mom and Dad aren’t around.

I try to smile politely. “Hello, Mrs. Haggerty.”

“They seem to have mixed up our mail again.” Our neighbor waves a white envelope at me before taking a step forward. One of her feet nearly crosses the threshold, and she makes a show of looking behind me in the hallway. Pearl is out of sight but just around the corner in the living room. I feel a stab of jealousy that she doesn’t have to take part in this encounter.

There’s a look I don’t care for on her face—curiosity mixed with something that feels slimy and unpleasant.

“Where are your parents, dear?” Mrs. Haggerty looks at me, concern in her eyes, but I’m not buying it. She’s got to know they’re not here. She watches all the comings and goings in the neighborhood. She must have seen our car pull out of the driveway earlier.

“They’re gone. Dad’s getting a big award for work, so they both went to the banquet.”

Mrs. Haggerty’s pencil sharp brows rise up to her hairline. “So you and your sister are all on your own tonight?”

“Yes.” I pluck the envelope out of her hands. “Thanks for bringing this by. I’ll be sure to give it to them.”

Mrs. Haggerty glances down at the envelope, then back up at me. There’s a look I don’t care for on her face—curiosity mixed with something that feels slimy and unpleasant. “Is it another medical bill? You seem to get a lot of those.” Her eyes roam around the hallway again, no doubt still searching out Pearl. “Though one doesn’t wonder why, considering the circumstances.”

I shrug uncomfortably. “I guess so.”

It is true that our family gets a lot of bills, usually with Pearl’s name peeking out from behind the shiny plastic windows. But they’re all for important things, like pieces of equipment that help her move and bathe and talk to us.

I keep my hand on the doorframe, hoping Mrs. Haggerty will get the hint, but she doesn’t. Instead, she shoots a curious glance at the corridor that leads into our living room. It’s all quiet in that part of the house. The Tobii must still be paused.

Mrs. Haggerty is slightly hard of hearing, so she doesn’t whisper so much as shout at me a little less loudly. “It must be so difficult for you, caring for your sister all by yourself. Do you need any help tonight, honey?”

My hand tightens on the envelope. “Not really, thanks.”

“Well, let me know if there’s anything I can do.” Mrs. Haggerty smiles, but it doesn’t reach her eyes. “I hate to think of you here, so young, and with so much on your shoulders. All of the feeding and lifting and wheeling around. That’s just so much work, isn’t it?”

I grip the envelope so hard it folds like an accordion, plastic window making a little crinkling noise in my hand. That is not work. That is my sister—a person with a name and a voice and a wicked sense of humor.

“Pearl is right around the corner. She can hear you, you know,” I say.

“Yes, dear, but how much can she really understand?”

I take a deep breath, ready to tell Mrs. Haggerty exactly where to stick it, when the sound of the Tobii drifts in from the living room.

everything

Mrs. Haggerty doesn’t react to the noise. The volume must be too low for her to hear. She continues to study me with narrowed eyes, and I try to keep a
straight face. God knows what the Tobii is going to say next. Sometimes Pearl can be pretty lippy.

Again, Mrs. Haggerty lowers her voice to what she thinks passes for a whisper. “I pray for her every night, you know. It’s just such a sad thing, seeing a child like that. The day I can’t walk or talk or take care of myself is the day the good Lord can take me away. Just so terrible, that loss of dignity. You have to wonder if it’s a life really worth living.”

My hands go cold, and my heart stutters in my chest. Pearl dances, eats ice cream, listens to music, keeps secrets, and laughs with me about boys. Sure, some of her days are good and some are bad. But isn’t it that way for everyone?

As I stand frozen with shock, the Tobii shouts down the hallway at full volume.

broomstick
broomstick
broomstick

I slam the door so hard it shakes in its frame. Then I stand for a moment, back against the wall, trying to catch my breath. Mrs. Haggerty’s words have sucked all the air out of the room. When people talk like that about Pearl, I always feel as though I’ve swallowed a thousand tiny blades. They linger deep in the pit of my stomach, pointed and sharp, slicing me open from the inside. Sometimes I wonder if that’s what it feels like for Pearl too.

After a few shaky inhales, I return to the living room to find my sister’s face blank, the words she shouted at our neighbor still typed out on the Tobii’s screen.

I go down on my knees in front of her. “You know none of that was true, right?”

It’s a long time before Pearl will make eye contact with me. Finally, she answers.

Yes.

“Are you okay?”

There’s an even longer pause.

Yes.

There’s a downward droop to her mouth that wasn’t there before, so I’m not sure I believe her. “Is there anything I can do to make you feel better?” I ask.

“You want me to get the cross-country team to TP her house?”

Pearl looks away. I think she’s saying no until I realize she has turned toward her Tobii.

definitely

“That’s the spirit.”

tonight

I can’t help laughing. “We can’t do it tonight. She’d know it was us. Besides, it’ll give us something to look forward to. Maybe we can shoot for Halloween.”

I reach out and squeeze Pearl’s hand, trying not to focus on all the things it can’t do. That kind of thinking never helps, and it glosses over so many good things. People like Mrs. Haggerty never notice all the things Pearl can do—with her eyes, her smile, and the pitch and tone of her wordless sounds.

Pearl dances, eats ice cream, listens to music, keeps secrets, and laughs with me about boys.

“Hey, do you think she understood the broomstick thing?” I ask.

hope

“I hope so too.”

Without warning, Pearl lets out a giant yawn, making me realize it must be past her bedtime. A current of guilt zips down my spine. I haven’t even done her medicine yet. In the kitchen I pull a small bowl from the cupboard and fill it with a few spoonfuls of applesauce. Pearl can’t swallow tablets or pills, so we have to put them in her food. I break open a capsule, sprinkle it into the bowl, and take the bowl back into the living room. “Time for your nighttime medicine, goober.”

My sister is a terrible, restless sleeper. There are just so many things that can go wrong for her at night. Her body can move into strange positions she can’t fix, or the covers can twist around her in ways she can’t untangle. Some evenings Pearl lies awake for hours making strange noises that echo through the house. Mom thinks it’s my sister waking from a dream and trying to tell us about it. Sometimes I wonder what Pearl dreams about.
My sister looks at me and widens her eyes.

I have no idea what she wants. “Tell me with the Tobii,” I prompt.

Pearl turns to the device.

“You can’t be serious. It’s cold outside and getting really late.”

But Pearl is insistent.

I look out the front living room window. The streetlight casts a bright halo onto the sidewalk.

There’s something magnetic about the darkness filling in the edges around the light. I wonder if Pearl senses it too.

I check the time on my phone. There’s still a good hour before Mom and Dad were planning to be home. We could do it. “Okay,” I say. “We can go outside if you really want. But then you have to take your medicine and go straight to bed.”

Pearl gives me a megawatt smile. Like all of her victories tonight, that was an easy one.

I’m not about to take my sister on the front lawn where Mrs. Haggerty could see us and snitch to my parents so, instead, I wheel Pearl to the glass doors leading out to our back patio. I fetch our coats and scarves from the front hall and bundle us both up before I wheel my sister outside.

The sky hangs velvety smooth and pitch-black above us, its vastness scattered with tiny pinpricks of white. The moon, round and luminous, casts a glow low in the sky.

I pull up a chair beside my sister and sink into it. Pearl—illuminated by the light that streams in from the interior of the house—is silent, head tilted up, gaze hazy and unfocused. There’s a small smile playing at the corner of her lips, and her body rocks a little, as though too tired to hold still any longer. Little wisps of hair, bright as spun gold, curl around her ears.

As I look at her, my mind rewinds back over the evening—the adult television, the ice cream, the frenetic dancing, and now our late-night stargazing.

“Hey.” My voice cuts through the silence, making Pearl start. “Do you realize we broke every single rule Mom gave us?”

Pearl chuckles quietly but doesn’t take her eyes off the sky.

“Seriously, though. If she finds out what we’ve done, I won’t be allowed to babysit you again. You won’t tattle, will you?”

Silence stretches out between us, then weaves itself into the quiet darkness of the night. Pearl’s eyelids droop, and her head lists to the side, neck muscles too tired from the long day to hold her up properly anymore. In times like these, the Tobii is out of the question.

But it doesn’t matter. I don’t need an answer typed out on a screen. I don’t need words at all. I know exactly what my little sister would say if she could.

Pearl never tells.

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BEAUTY

a slate-blue dipper
in the logan river
dipping
on thin legs
in the wetlands
silver strands
of spider silk draped
across the road
all at once and
spontaneously
spinning out silk
floating
endlessly
two colts
one all black
a white star
on its forehead
one chestnut brown
with all white feet
followed me along
the fence
nudging
its velvet nose
three sandhill
cranes
sailing
across
a dusk-blue sky

a monarch butterfly
on the path
motionless
dark orange
black outlines
that look like
they were drawn
by a felt tip pen
ink bleeding
delicate
antennae
legs
white spots on the body
and wings
we thought it was dead
but in the car
it started to move
unfolding its wings
when we got home
I laid it in the milkweed
breathing
ACCIDENT

The moment my poem tripped over its feet and hit the concrete
I knew it wasn’t a dying fall
but serious
that my poem
wailing
would leave me
driven away by ambulance
and return unrecognizable
breaks and caesuras
I hadn’t written
bound together with artificial hinges
bulky awkward forced
to enter a workshop
for recovery
taken out of my hands
my poem now gripped (not grasped)
by specialists
slowly stretching its metaphors
bending its stiffened meanings.
I feel its agony and reproach.
My poem I fear
will never forgive my carelessness
in letting it stumble.
But I can’t forget
The Miracle:
the instant before
it crashed and smashed
when I watched it weightlessly airborne
soaring

PHYSICAL THERAPY

Clinic walls of white
are all illusions
delusions fading as
we struggle
for behind them lies
the darkness of a grove
and
in this forest we are blighted
gnarled and knobby
splintered splinted
jutting out at angles in our agony
groaning as what cannot bend
is bent
limbs hang there
deadened sapless
trunks that will not turn
are made to twist
and creak.
We do not lift our leafy arms to pray
except for stillness
(and anyway, our leaves fell on the ground
when we were felled).
Tagged with labels
none of us can read:
for some, slow sprouting
tentatively swaying
into spring
for others
just the bite of
blades and grinding
dissolution into sawdust
holes left by roots torn up
to mark
our empty places
"All systems go, general?" my wife asked.

I checked the meter on the oxygen cannister to make sure it was full and turned the dial until I could feel the oxygen blowing against my hand before turning it off. Then I lifted the cannister out of the trunk of the car, which was full of other oxygen cannisters, and placed it in the cart. The cannisters were heavy and awkward to carry but the little two-wheeled cart made it easier.

"Do we have liftoff, Houston?" She was still sitting in the passenger seat wearing a nasal cannula connected to a small oxygen tank on the floor. That tank used liquid oxygen so was very cold to the touch but the liquid oxygen was 100% pure and helped her to breathe more easily.

"Undergoing final system checks, captain," I said.

"Check. Awaiting further instructions."

I unwrapped a new cannula, connected it to the regulator of the tank in the cart, and checked the air flow. I could feel the oxygen coming out of the two little nose prongs of the cannula so I knew it worked. The tank held 680 liters of oxygen and she needed 10 liters per minute so we had sixty-eight minutes per tank. I turned off the air, repeated the procedure with a second tank, and placed it next to the first tank in the cart.

Somewhere I’d read about the early Apollo space program and how they had dual backup systems for every critical system. My wife couldn’t survive for very long without the oxygen so I followed the same philosophy.

"Hold tight, corporal," I said.

"Hey, I thought I was a captain."

"Whatever. I’ll bust you down to private if you cause any trouble."

She snorted. “Listen to you. Make him a general and it goes right to his head. Absolute power has corrupted you absolutely.”

“And that surprises you?”

“Nah, you know me. Cynical view of human nature and all that. Didn’t you once call me a disillusioned idealist? Besides, you’re not really a general. You’re barely a colonel.”

“Damn. I was just getting used to running my authoritarian regime.”

“You’re lucky. It’s the generals they always execute. Are we ready to go yet? I’m getting antsy here.”
I searched in the trunk for extra cannulas and a spare regulator. The tanks wouldn’t work without the regulators so I always had a spare. I slipped everything into my backpack along with a small third oxygen tank that I’d tested just before leaving the house. I hoisted the pack onto my back and turned to her with a thumbs-up.

“Houston,” I said, “we have lift off.”

“Excellent.”

She climbed out of the car, removed the cannula from her nose, and quickly replaced it with the one connected to the tank in the cart. I slid a pulse oximeter onto her middle finger and we waited a moment for the reading.

“Hey, I’m at ninety-six,” she said. “When I hit one hundred—sell. Sorry, just flashing back to my early days as a stockbroker.”

“You mean a stock clerk.”

“I was never a stock clerk. I started as an assistant bookstore manager before my meteoric rise to manager.”

“Yeah, because nobody else was crazy enough to work so many hours.”

“Except for you.”

I smiled. “I had hidden motivations.”

She smiled back. “Me, too. Remember all those romantic nights we spent carrying the garbage out to the dumpster together?”

“How about we head up the square?”

“Are you sure?”

“Sure as I’ll ever be.”

“Okay. Just tell me if you need to rest.”

“Will do.”

The parking lot where we were standing emptied right onto the main street. The ground was level so it was a good place to walk.

My wife’s stay at a rehab facility had strengthened her body and improved her confidence after her second lung collapse in six months but it was still scary for her to be out and about and in motion. Today she seemed more eager than in the past and I followed her with the oxygen tanks as she strode forward and peered into the windows of all the storefronts. We went into the kitchen supply store and she bought a new pair of salt and pepper shakers while the woman behind the counter smiled and pretended not to notice all the oxygen apparatuses.

“Don’t we have like three or four sets of salt and pepper shakers already?” I asked.

“You’re not the only one around here who likes backups.”

“Well played. Where to next?”

We had already walked back and forth a few times on both sides of the street. It was hot but the street was in the shade so the heat was bearable.

“How about we head up the square?”

“Are you sure?”

“Sure as I’ll ever be.”

“Okay. Just tell me if you need to rest.”

“Will do.”

The square is built on an incline that’s moderate at first and then grows steeper. It’s lined with shops that my wife had visited many times in the past and there’s a small park in the center where we once stood watching them light the big Christmas tree while a choir sang carols. We had felt happy and safe then, but it was a long time ago.

The square was not in the shade and I quickly began to feel the heat of the afternoon sun and the effort of pushing the oxygen tanks up the hill. My wife was moving at a faster pace than I thought she could and didn’t seem to be
struggling but I insisted on stopping and checking her oxygen level with the pulse oximeter, anyway.

“See?” she said. “Ninety-five. I’m doing fine.”

“Yes, you are. Better than me.”

“Poor guy. Those tanks are heavy, aren’t they? Plus you’ve got a spare one in your backpack, too, don’t you?”

“Didn’t think you knew about that one.”

“Of course I did. I know you. Let’s sit on a bench for a moment. Maybe some ice cream?”

The shop was right across the street. “Sounds good.”

I got us matching cones and we sat on the bench eating them.

“This stuff is good but wildly overpriced,” she said.

“One of us says that every time we’re here.”

“Yes, I know. It’s been a while, though.”

“Yeah, it has.”

She handed me a napkin. “You’ve got ice cream on your face.”

I wiped it. “Thanks.”

“They had ice cream at the rehab place but it sucked. Ice crystals.”

“Don’t you hate that?”

“Yes. But the food at the hospital was good.”

“I don’t think I would choose it for our next hot vacation spot, though.”

“Agreed. Let’s walk the rest of the way up to the top of the square.”

“Are you sure?”

“Yes.”

“What about the blebs.”

She stood up. “Fuck the blebs.”

I remembered the doctor in the emergency room explaining that blebs were little lung cysts that could burst at any moment and cause a lung to collapse. My wife had dozens of them on each of her lungs along with scar tissue caused by an underlying illness called sarcoidosis that limited the elasticity and effectiveness of her lungs.

“Are you sure?”

“Sure as shit. Come on.”

I knew there was no way to talk her out of it. The doctor had said to me privately that she really shouldn’t be alive but the good news was that she was now at the top of the transplant list. All she needed to do was be in strong enough condition to qualify for the procedure. So we walked toward the top of the hill and her steps grew steadily surer as we passed all the shops and benches and people, and I struggled to keep pace with her in the hot sun with the weight of gravity slowing but not stopping either of us.♡
It is my first night in New York City. Eight million residents shuffle from one block to the next, together but alone, as polluted breath begrimes every surface of this bustling metropolis. Today I joined eight million souls, sinking into the mire of urban opportunity. I only knew I’d be living here a few months ago, when I accepted my admission to Columbia University, yet everything in my life seems as if it were leading up to this point.

I was stymied by a serious mental disorder from a young age. At twelve, I was diagnosed with obsessive-compulsive disorder (OCD), a generally misunderstood illness. My parents felt that a public school would be more equipped to accommodate my disability and academic needs, so I transferred out of private school, acquired an individualized educational plan, and began seeing a therapist. In my sophomore year of high school, the sudden and tragic loss of a family member caused my mental health to further deteriorate. The measures my parents took no longer pacified OCD’s bubbling rage.

OCD is a fear-based mental illness in which a patient succumbs to “compulsions” in order to appease their “obsessions.” The fears that fed my obsessions and the rituals I performed, however, were irrational. Everything had a number: forty-five brush strokes when combing my hair, fifteen for each section of my head, the surface area of my hair split into three. What if my comb missed a hair? Then what? Perhaps a knot would develop over time? And then what? Beyond the nonsensical nature of my rituals, my symptoms were debilitating. I would spend forty-five minutes brushing my teeth, only relenting at the sight of my bleeding gums. I began this ritual to prevent my teeth from falling out, and while brushing one’s teeth does prevent tooth decay, gum damage can actually lead to root canals and other issues. This ambivalent logic was immaterial to my disease. I was plagued by a dream—a nightmare, in fact—I would smile, revealing gory nubs where my teeth should have been. Onlookers shrieked in horror. Then I would wake up and brush my teeth even harder.

This malicious, twisted disease is an affliction of self-imposed subjugation; it stirs in the mind, lying in wait. If I diverted my attention from my rituals for even a second, my OCD would overtake my brain, berating me with thoughts: You must have missed something. Do it all over again. As I continued to fear the irrational and conciliate the demands of these fears, I gradually lost trust in my own abilities. I started to believe I was perpetually negligent; that I was worthless. I could no longer distinguish myself from the image of repulsion that I despised. The culmination of my various rituals resulted in a six-hour process just to leave the house, and by the time I was ready to go, I had exhausted all my mental energy. By adhering to my rituals, I became completely dysfunctional. I became submerged in the rigid routine of impossible maintenance, and I wondered if I loathed my illness or myself more.

I have learned that living with the burden of OCD is more than meticulousness, it is more than...
excruciating. It is an explosive plight of anxiety and disablement; it is an active war zone in your mind. It is a cesspit of inflexibility, effervescent and molten, magmatic, until it can no longer be contained within you alone. It erupts, and burns the people you hold dearly as well. When my mother touched me, I felt an unpleasant, almost revolting sensory vibration along my skin. I began wiping off any part of my body that she touched. I prohibited hugs, kisses, or even taps on my shoulder. I was under the control of my illness, and eventually, school became secondary to surviving. I continued to sink into a deep depression; I contemplated giving up.

My therapy and medications were failing me. In search of an effective solution, my parents sent me to a residential treatment program for children and teens with severe anxiety disorders. During my junior and senior years of high school, I lived at the Rogers Memorial Hospital in rural Wisconsin. At Rogers, I was assigned a specialized team, including a behavioral specialist, a psychologist, and a psychiatrist. The hospital facilitated my treatment primarily with cognitive behavioral therapy, exposure-response prevention, and group and individual psychodynamic talk therapy. I embarked on tackling my “hierarchy” of fears. In the end, I held sixteen ounces of live worms in my bare hands, ate raw fish for the first time, went camping without any access to running water, showered for only five seconds, and brushed my teeth for only one second. The goal in this program was to “overcorrect” my symptoms so that when I returned home, my behaviors would slip back into a range of normalcy. These measures may seem trivial, unsanitary, or just odd, but to me, they are some of my proudest achievements. I credit this program with saving my life.

Mental health professionals who treat patients with OCD are usually familiar with the term “ick factor.” This describes a sensation in which the aggravating stimuli may not be explicitly dirty, or there may be no dirt at all, but for one reason or another the patient with OCD feels “icky.” Now, at twenty-three years old, I have moved to New York City, the dirtiest, ickiest city in the country, arguably the dirtiest, ickiest city in the world. It has been six years since my two periods of hospitalization. Recently, I have been taking the perfect combination of psychotropic medications. I have a support system in place, including my aunt, uncle, and older brother, all of whom live in Manhattan. I have a reliable disability counselor at my new university. The bubbling rage I knew for so long has stilled and cooled, and formed igneous self-assurance in its place. I now live in the national hub of ick and I am not afraid. I am confident in myself and my abilities, and in the event that my symptoms worsen, I anticipate my tenacity. I will persevere against my illness, just as I have done my entire life.

I said goodbye to my mother and father today. We stood on aged cement, solid and wise, the squares discolored from years of directing city dwellers to their ambitions. My father kissed my forehead and told me he is always a phone call away, day or night. My mother pressed her weight into me as she held me tightly. I felt her gentle tears on the sleeve of my right shoulder. This time, I did not wipe off her touch.
Fog lifting at dawn over Frenchman Bay, the misty silence fractured by the familiar chorus of loons laughing at me—back again, digging clams with one hand.

Brandishing my clam rake high above my head, I muttered “Zol er krenken un gedenken,” the curse I’d heard my mother scream in her sleep at the refugee camp that means let him suffer and remember.

The memory of it haunted me as a child and for many years echoed in my dreams, a recurrent nightmare, until I myself began to repeat it, but softly and reverently, transforming the curse into a blessing for the tormented, a prayer for the dead and those still living whose screams in the middle of the night go unheard. Invoked over and over, it became my mantra reminding me to live only in the moment, like the loons.

If only it were that simple. If only I were a loon.

I watched them dive into the dark sea and disappear, then slogged through the muck of the tidal pool. At the water’s edge, Joe sat in the stern of his leaky, lapstrake dinghy, a Bud in one hand, a Camel dangling out the corner of his mouth. He took a long drag then flicked the butt overboard. As I stepped into the boat he passed me the six-pack at his feet.

“How can you drink this shit at the crack of dawn?”

Joe grinned, tapping my stump with his rake. “How can you make a livin’ clammin’ with only one hand?”

I could’ve told him that the first time I dug clams I fell in love and knew I’d finally come home. The glorious muddy mess where it all began.

But I never told Joe any of that. We talked about the weather, the tide chart, the crappy wholesale price of clams, and the 1967 World Series last October—his beloved Red Sox losing again.

Two beers later, we trudged across the mud flat to the tidal island called Loon Rock, his favorite clamming spot. Mine
too, where Lori and I first made love, racing against the spring tide rushing in, sinking deep in the mud in our thigh-high rubber boots. I wrote a poem about it—“Love in the Mud”—and sent it to her, worrying the words in its refrain were all wrong, much too strong, a raging hurricane.

* * *

Under a flower moon she leapt into my molten heart and hers melted too
Both ablaze in the mud in the blinding light of love
Two hearts now one?

Would she prefer the lilting whispers of a gentle rain? Did she want to be the muse of a poet stuck in the muck of his own mind?

“Bet today’s your lucky day,” Joe said. “Look at all them wicked good breathin’ holes!”

I stomped on one. Water squirted out. “I could use some luck for a change.”

Joe coughed, spitting into the mud. “Sure can. A bushel a tide at ten bucks a bushel won’t cut it.”

“Don’t know how you dig so fast, three bushels a tide.”

“Been doin’ it since I was a kid, just like Lori. And we both got two hands.”

Picturing Lori’s strong hands on my hips, pulling me close, I plunged the short-handled rake into the breathing hole, turned the mud over, unearthed a clam. Dropping the rake, I picked up the clam.

“Figures,” I muttered, seeing it was too small to sell. I tossed it and turned to Joe. “Is she coming home for Thanksgiving?”

Joe lit another Camel, started digging. “Hope so,” he said, then paused, shrugging his shoulders. “But hard tellin’ not knowin’. She’s right straight out, I suppose. Don’t write me no more.”

Lori didn’t write me anymore, either. Ever since I mailed her that poem, the memory of my skin tingling, our lips locking and tongues probing, leaping off the page, then her silence stinging.

And she was beautiful. The sea goddess Amphitrite in a faded yellow slicker.

Lori ran her long slender fingers slowly through her wet auburn hair. “Sometimes I just want to disappear in the sea like they do.”

“And do what?”

“Hide.”

“It’s cold and lonely down there.”

“No colder and lonelier than on terra firma. My home anyway.”

“Your dad seems nice enough.”

“He is, I suppose. Means well, but doesn’t understand me at all. No one does around here. My mom wanted to, tried hard. Maybe she would’ve by now if—” Lori looked away.

“If what?”

She sighed. “I can’t wait to get out of here come September.”

“College?”

“First in my family . . . to even graduate high school.”

“Where?”

“Radcliffe, on a scholarship.”

“That’s impressive!”

“You mean, for poor white trash?”

“No, for anyone.”

Lori kicked the wooden clam hod at her side. “I’m sick of clammin’ if you really want to know. Only do it to please my dad and help put food on the table.”

“I did the same for my mother. Went to college to please her but never had my heart in it.”

In the distance thunder boomed. I jumped back, dropping my rake in the mud.

“Relax,” Lori said. “It’s just a passing thunderstorm, a sun shower.” She turned to the east. “Look!”

A double rainbow arched over the bay. “Magnificent,” I said. “I’ve never seen a double one before.”
“I’ve read they symbolize good luck. Hope, I suppose. For hopeless dreamers anyway.”

“To Buddhists they symbolize the last step before enlightenment.”

“. . . The destruction of nature and the divinity in us and all living things. Civilization is the bane of human existence.”

“Does that mean one of us is getting close?”

“Maybe you, but not me.”

“Let’s set our hods and rakes over there,” she said, indicating Loon Rock. “Go for a walk.”

We walked along its craggy shore. At the south end we stopped for a moment to watch a hedge of blue herons wading in the shallow water. We crossed to the north side, sat on a gray granite slab and gazed out at the sea. Another loud crack pierced the silence. I flinched, sensing this was a gunshot, not thunder, and now hearing a different but familiar gunshot and seeing the contorted face of the man I knew I’d never be.

I glanced at Lori who’d turned her head. I followed her eyes up to a boulder where two teenage boys sat, rifles in their hands. Their laughter wafted down and it seemed to calm me, the echoes of that other gunshot and the image of the face fading away.

“What are they shooting at?” I said.

“Seabirds. Probably those herons we saw. The boys around here love to shoot their heads off. Target practice.”

“They’re laughing.”

“Right. Their idea of fun. At our Sunday family dinners my cousin Billy brags about how many he’s killed.”

“That’s sad . . . no, sick. But at least your family talks. My mother hardly said a word at dinner, except to kvetch about the goyim and what they did to us.”

“Who are they and what’d they do to you?”

I swatted a mosquito on my forehead. “A long story. I’d rather talk about your home. You’re lucky to live here so close to nature. To wake up each day to the beauty and peaceful—”

“You’re dreaming. Flatlanders think this is paradise. But life here’s primitive. Brutal.”

“I don’t see it that way.”

“You don’t see what really goes on behind the doors. Cousin Billy’s nothing compared to the drunken illiterate savages I have to live with every day. Now do you understand why I want to get the hell away from here as fast as I can?”

“You may be disappointed.”

“Why?”

“It’s no better in the city, or anywhere else today.”

“You’re exaggerating.”

“Trust me, only the weapons and their targets are different.”

“What are you talking about?”

“Napalm, the Klu Klux Clan, our police. Harmless farmers bombed in the rice paddies. Negroes lynched in the dead of night. Protesters shot in broad daylight. The sordid history of mankind. War, greed, hate, and now the silent spring. The destruction of nature and the divinity in us and all living things. Civilization is the bane of human existence.”

Lori stood and threw her arms up. “Whoa! I didn’t see that coming from you, despite your long hair. You remind me of that crazy yippie guy I saw on TV, Abbie something or other.”

“Hoffman.”

“Except for your walrus mustache you even look a bit like him. The same black curly hair and olive skin.”

“That’s as far as it goes. He’s old, real old, in his thirties. And I’m not as crazy.”

Lori sat, her right knee touching my left. I moved mine slightly away, but she pressed hers against it. “I hope not,” she said. “And anyway you’re more . . . cunnin’.”

“I doubt it, if you mean shrewd.”

Lori’s thin lips pulled back slightly. “No, here it means cute. I also think you’re gentler, more philosopher than fighter.”

“What makes you think that?”

“I hear a touch of Thoreau or Emerson in you. An idealist, a dreamer.” She sighed. “Easy to dream and think profound
thoughts when your belly’s full and have the time and energy to do it.”

“Can’t argue about that.”

“I’m just rich with lots of ancient baggage of a different sort.”

“It wouldn’t surprise me if every single one of those transcendentalists has a trust fund. Like the hippies, from away, living in the commune on Mount Desert Island. Going back-to-the-land, they call it. Going back to the bank every week for their allowance is more like it.”

I stroked my mustache. “Can you blame them for wanting out of this sinking world of hollow men?”

“Hollow men? Sounds familiar. And you’re dreaming again. I know what I see when I go clammin’ there. Lazy phonies. Stoned, dancing naked on the shore, they make me sick. So do the filthy rich summer people I sometimes work for, cleaning their damn mansions—cottages those snobs call them—that their greedy ancestors built. The robber barons and slave traders you probably also hate.”

“I get the feeling that’s not the only thing we’ve in common.”

“Perhaps there’s more, Mr. Hoffman,” she said, then smiled for the first time, revealing a couple of crooked front teeth that made me think I might have a chance with her.

I nudged her knee with mine. “Can you blame them for wanting out of this sinking world of hollow men?”

“I get the feeling that’s not the only thing we’ve in common.”

“Perhaps there’s more, Mr. Hoffman,” she said, then smiled for the first time, revealing a couple of crooked front teeth that made me think I might have a chance with her.

I nudged her knee with mine. “Maybe the two of us should start a clam diggers’ union. Better yet, organize all the workers here and bring the revolution to Hancock Point.”

Lori kicked my foot. “Liar. You are as crazy as him.”

“Let’s burn down those summer cottages. Take back the land. Workers of the world unite!”

“You’re joking of course, Mr. Marx.”

“I am. It’s just that I’ve never been any good at it.”

“You need practice, that’s all. As do the workers here if you expect them to revolt. They’d much rather watch football on TV and drink beer, then beat their wives. More of those hollow men of yours and T. S. Eliot’s. Only these are real.”

“History tells us they would if they had the right leader to follow.”

“Who do you have in mind?”

I smiled. “Someone charismatic . . . who sometimes wishes she were a loon.”

Lori picked up a rock and faked tossing it at me. “You’re joshing again.”

“Now I’m not, I swear.”

“Cha . . . ris . . . ma . . . tic. I like how it sounds. No one’s ever called me that, and it sure beats some of the things I have been called behind my back. Strange and a freak, to name a couple.”

“I know where you’re coming from.”

“Except you don’t know what it also means to be a girl . . . a woman. No one’s ever gonna listen to and follow us, charismatic or not.” Lori dropped the rock. “Anyway, I’ve other plans.”

“Yes, you’re leaving soon.” Much too soon.

Lori sat up straight and looked me straight in the eye. “Do you have a trust fund?”

“I’m just rich with lots of ancient baggage of a different sort.”

“Different is right! I’ve never met anyone like you . . . unfortunately.”

I winced, feeling a familiar stinging jab.

“You’re gritting your teeth. In pain?”

I nodded, rubbing my stump.

“What happened?”

“Nothing, the pain comes out of nowhere. Phantom limb pain, the doctors call it. But it’s as real as my baggage. Luckily, unlike that, this pain disappears quickly . . . and it’s gone now.”

“I’m glad. Let’s walk some more. I’ll show you my favorite spot here.”

We strolled slowly and silently along the narrow neck of Loon Rock that jutted out into the bay. Lori stopped to pick up a little brown and white banded shell.

“The striped periwinkle, my favorite shell,” she said, holding it up. “Perfect, isn’t it?”

“It is. Lovely. Being one with nature is what we’ve lost, our so-called progress an illusion.”
“Not these shells. When I was a kid I’d collect them. I believed in God then—that other illusion—and went to church every Sunday. Thought only a God could create such beautiful things. Hadn’t heard yet about the Holocaust. Why don’t you take the shell home, a souvenir.”

“Of what?”

“Your time in Maine.”

I looked past Lori at a broken lobster trap wedged between two boulders. Entangled in its tattered net was a lobster claw, a Coke bottle, and a G.I. Joe toy. “What are you saying?”

“That this is only a temporary stop on your journey, probably not the first and certainly not the last.”

I stroked my mustache.

Lori passed me the shell, her knuckles brushing against my stump. She pulled her hand back. “You’re bleeding Ben!”

“Must’ve scratched the scar earlier with my rake. Do that a lot. It doesn’t have much feeling.”

“When you get home you should put Mercurochrome on it.”

“My mother would rub honey and garlic on it. A remedy Sylvia brought with her from the old country. The sweet and the bitter, like life itself, she’d say.”

“She sure got that right. Which country?”

I glanced down at my boots covered with seaweed. “It doesn’t exist anymore. And sweetness didn’t exist in her life either. Only misery. Tsuris.”

“I love the sound of that word, all your words. Want to hear more. But the tide’s coming in quick now . . . .”

“I’ll probably study something more practical. Maybe marine biology.”

“You’re much smarter than me, bound to do something actually useful. What my mother wanted me to do, to be.”

“Which was?”

“Anything but, God forbid, a philosopher. Only a schlemiel, she’d remind me constantly, thinks he’ll make a living as a philosopher. Her dream was for me to be a doctor. A surgeon, like . . . like—”

“What’s wrong? You look like you just saw a ghost.”

“That gunshot we heard. I’ve always hated guns, they make me nervous.”

Lori put her hand on my knee and squeezed it. “You’re the first man I’ve ever heard say that around here.”

“A man doesn’t need a gun to prove he’s one.”

Lori removed her hand. “What does he need?”

“Just to be a mensch.”

“What’s that?”

“A good person. Someone who does good for others. Though my mother would say he just needs a good job, and a wife who makes good matzo ball soup.”

“I love your accent, Ben. It’s sexy.”

I kicked the pebbles at my feet. “Sexy? Hardly.”

“Well, exotic then. Brooklyn?”

“What are you going to study?”

“Don’t know yet, can’t decide. I was thinking of majoring in literature, love to read.”

“Me too. If you’d been at Radcliffe a few years ago we might’ve been in the same classes. At Harvard I majored in philosophy but took a lot of lit classes . . . before I dropped out.”

“Cadillac Mountain on Mount Desert Island. Can’t see it clearly now—with the clouds—but after gathering shells I’d come here just to gaze at it, dreaming about what was beyond the horizon. Even then I knew I wanted more, a different life.”

“You’ll have it soon.” And I might never see you again.
I nodded. “Walt Whitman’s hometown.”

“And Ginsburg’s.”

“You’ve read him . . . too?”

“There’s something very unusual about you. What I see in . . . behind . . . your dark eyes . . . .”

“I saw the best minds of my generation destroyed by madness, starving hysterical—”

“Howl.”

“I say it’s overrated.”

“I do too.”

“I’d take Dickinson’s ‘I heard a Fly buzz—when I died’ any day over it.”

“Not bad, if too dark for me. I’d take Whitman’s ‘When Lilacs Last in the Dooryard Bloom’d.’”

“Too sentimental for me. I read ‘Howl’ mainly because I was curious why it’d once been banned. Just as I’m curious about you . . . your accent. Never heard it before actually spoken, only imagined how it sounds from other books I’ve read, like Last Exit to Brooklyn.”

“You seem to like banned books. That one’s too violent.”

Lori picked up a pine cone at her side, studied it for a moment then dropped it in her lap. “Maybe, but realistic I think, that’s why I like it. And I think you’re Jewish.”

I smiled. “How can you tell? My horns?”

Lori laughed. “There’s something very unusual about you. What I see in . . . behind . . . your dark eyes. Always thinking intensely. Or is it dreaming?”

“You’re on to me.”

“Not that I’ve ever known, even met, a Jew before, except from books they’ve written. Marx, Freud, Kafka, Roth, and Betty Friedan. All troublemakers. Are you one too? I think so. Portnoy’s one of my favorite characters.” Lori wiggled her eyebrows. “But I hope you’re not like him in one respect.”

“I wouldn’t worry. I’ve always hated liver. Though I had the same kind of mother, a real piece of work. Intent on making me suffer like her, and to enjoy it.”

Lori punched my leg playfully. “Do you? I sense you do. And that you’re a writer, a poet’s my guess.”

“Good guess.”

“And a romantic. A dangerous combination. If you’re not careful you’ll die young like Dylan Thomas. Broke. Drunk. Alone in some seedy hotel room.”

“At least he didn’t live a life of quiet desperation.”

“Thoreau. Can’t say I’m surprised you’re quoting him. And I wouldn’t be surprised if his mother cooked and did his laundry for him. Who’s your favorite poet? A doomed romantic?”

“Try this, a clue. ‘The force that through the green fuse drives the flower—’”

“‘Drives my green age.’ Try this. ‘Do you rage, rage against the dying of the light’ while writing A Child’s Hanukkah in Brooklyn?”

“Clever.” I scratched my stump. “But I stopped writing.”

“Writer’s block?”

Out in the bay, gulls mewed, circling above a lobsterman hauling a trap onto his boat. “Decided to just live now, and to the full.”

“Like Rimbaud, and be a gunrunner instead? No, I forgot you hate them. Salinger, then. Become a hermit and do yoga?”

I laughed. “Getting close. Go on, I’m enjoying this.”

Lori picked up the pine cone in her lap and tossed it at me. “So am I, more than you can imagine. You could of course copy Kerouac and do both at the same time. Write, if poorly, while chasing experience. Or Hemingway, a much better storyteller. And, if you were to believe him, a real man who lived life to the full. Dressed like a girl as a kid, dumped four wives as an adult, and in the end put a shotgun to his head. A life to emulate?”

“There’s something very unusual about you. What I see in . . . behind . . . your dark eyes . . . .”
“What is . . . life?”

“That I’d given up on this place. Excited to finally leave.” Lori put her hand on to top of mine. “And now you show up.”

“But that should make you happy.”

Lori breathed in deeply and lifted her hand off mine. “The wind’s shifting, now blowing in from the sea. Don’t you just love that scent?”

“I do.”

“Another thing I’ll miss. And the purple lupine swaying in the breeze in the meadow behind my house.”

“I want to listen to you, Lori, be the one you want . . . to talk to. To love. There’s nothing ironic about that. Maybe it’s fate that brought us together. That rainbow speaking.”

Lori stretched out her long legs and leaned her shoulder into mine. “You are a romantic, just as I thought.”

“And you are amazing. Not just brilliant and wise beyond your years, but so perceptive. You have a gift.”

Lori pulled her knees to her chest and hugged herself. “At times it seems more like a curse, seeing and feeling too much. More than what’s good for me. For anyone. Maybe I got that from my mom. Maybe that’s what made her drink too much . . . and kill herself.”

I turned and looked at Lori, wanting to put my arm around her. “Sorry about that,” I said, patting her knee instead.

“Don’t be, it happened when I was six. I’m long over it now.”

“Still, that had to be traumatic. My father also died when I was young. But too young for me to know him at all.”

“You must know something. Your mother must’ve told you about him.”

I tugged on the end of my mustache. “Sylvia told me very little other than his name, Sam . . . Samuel . . . and that he was a surgeon. A famous one in Munich.”

“How’d he die?”

I picked up a rock and threw it into the surf. “Murdered . . . at Dachau. Where I was born.”

Lori’s mouth opened wide. “Born there? Incredible! Now, that’s something you should write about. Talk about traumatic.”

“I have no memory of any of it. I’m lucky compared to you, or my mother who knew . . . the horror.”

“You’re clenching your fist. Your eyes look sad. There’s more, I sense, something you’re not saying.”

“At times it seems more like a curse, seeing and feeling too much. More than what’s good for me . . . .”

I closed my eyes. “There is one . . . one memory I can’t seem to shake. The horrific stench.” Tell her. “And . . . and—”

“And what? Tell me.”

“What still haunts me . . . hurts the most, returns whenever I hear a gunshot . . . or think, talk about the death camp. Like now.”

“Okay, I’ll shut up.”

“I . . . I saw my father shot to death. Saw the terrified look on his face. See it now.”

Lori scooted closer and gently stroked my face. “I can tell that hurts. Hurts real bad. But can I say just one more thing? Then no more, I promise.”

I nodded, her touch seemingly making the image and pain disappear.

She stroked my hair, her mouth so close to mine that when she spoke I could taste her warm sweet breath. “I just know that one day you’ll be able to face your fear, and that’ll free you.”

The murky sea approached, the surf now just a few feet away crashing on the rocks below. “I suppose I’m no different than Sylvia who could never talk of the death camp. Both of us afraid to—”

“You don’t have to talk about it anymore.”

“Afraid to face the truth, and feel the terror again.”

“Understandable.”

“But I have known that other feeling you mentioned, wanting to hide, luckily not much anymore. With me it’s feeling embarrassed. Ashamed.”

Lori reached out to touch my stump, but stopped. “I don’t have such a good excuse. Just being poor.”
I took her hand in mine. “That’s not your fault.”

She squeezed my hand. “You’re sweet, Ben, I really like you. It seems a shame to give up writing when you’ve hardly begun.”

“I’ll write again when I’ve truly lived, have something worthwhile to say. Finally know who I am.”

“But what do you do if you never find that out? Never write again? That’d be a great loss. We’d never know what you’d experienced along the way.”

I looked past Lori at Mount Desert Island, sunbeams breaking through the clouds, lighting up the face of Cadillac Mountain. “A loss? I suppose so . . . but only if I had talent.”

“Just hearing you speak, knowing what you’ve already been through, sensing what’s in your heart, tells me you do.” She touched my stump. “What happened?”

I leaned in to Lori, my stump pressed against her side. “A dumb thing I did when I was a kid. So childish, such a cliché, I’m embarrassed to talk about it.”

She stroked my stump. “I want to know.”

“Tony Razzeri, a hood from school, had it in for me ever since he’d caught me kissing his ex-girlfriend Connie Favioli. I should’ve seen it coming. Because the truth is I encouraged him all along. A couple of months later he challenged me to a fight. Not exactly a fair one. He pulled a hatchet from under his jacket and hacked off my arm at the elbow.”

Lori’s head jerked back. “Shit . . . that’s awful! Gruesome.”

“It was my fault anyway, I could’ve just walked away. But I was looking for a fight. Trying to prove something, be someone I wasn’t.”

“Which is exactly what you’re doing now, isn’t it? Trying to be a clam digger when you must know you’re not—never will be—one. What are you trying to prove?”

I dropped my head, muttering “Zol er krenken un gedenken.”

“What’s that?”

“Something I say to myself. Sometimes when I’m confused . . . and need help.”

Lori put her arm around me and pulled me close, the tip of my nose grazing her damp cheek, the scent of her, the sea and mud making me dizzy.

She whispered in my ear. “Why dig clams with one hand when you can write beautiful poetry with it. Flowing straight from your heart, with all your heart. Like digging clams with no hands.”

LIP-READING

It’s like putting together a jigsaw puzzle
With no reference picture and, sometimes,
With no edge pieces.

I stare hard at moving lips, always a phoneme
(or two, or three, or four) behind the conversation,
While my brain plays the matching game
With puzzle pieces that constantly change
Colors and shapes that get lost among
The pieces from other puzzle boxes.

I have a warped piece that won’t fit without a bit of force—
But while I work on that,
Turning it round, and round, and round to try all its sides,
Other pieces are slipping off the edge of the table
Into the silence where I cannot touch them.

Quiet consonants and inaudible vowels are
All meaningless as I try to keep up, to catch up,
To combobulate from the discombobulation
That is one of the too many puzzles
Spread out on my overflowing table;
I try to figure it out, put the pieces together fast enough
To respond, to participate,
Try to ignore the fact that everyone else has completed
Their puzzles while mine looks like the aftermath
Of a monopoly game gone inevitably bad,
(And no one has ever been able to find the shoe piece since
And no one can afford to buy Park Place)—do not pass GO,
Do not collect $200 because these hearing aids
Cost a total of $6,000 even though they don’t help
Put together the puzzle; they only make the colors brighter.

Then hovering hands over moving lips mute the colors, conceal
What little of the puzzle I was able to piece together,
Blocking my progress and pushing more pieces
Over the edge of my overflowing table.

Still,

I pour all of myself into solving the daily,
Ever-changing multitudes of puzzles
Even as I’m wearing down, wearing down;
Even as more pieces tumble into the quiet,
As I’m wearing down, wearing down;
Even as the puzzle in front of me becomes unsolvable,
As I’m wearing down, wearing down;
Even as the batteries in my hearing aids and laptop are
Wearing down, wearing down;
Until there’s nothing left of me to wear down

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DEAF ENOUGH

every time i am forced
to go to the audiologist
so they can confirm
that i have not been
the recipient of a miracle
or lying about my deafness
since birth
they tell me that i am
a great candidate for
cochlear implants

in other words
i am
defa enough
to become
hearing enough
that ignorant people
will refuse to believe that
i am deaf
Product Review # 9,235: 
Vacuums All-Day Long

Shelly Jones

Vacuums All-Day Long
Reviewed in the United States on January 12, 2017
Verified Purchase

My wife bought me this vacuum for Christmas. It took us a while to get it out of the box and read the instruction booklet. Val and I were impressed as the vacuum wandered around the house, mapping out the table, radiator, and bookshelves. Eventually it seemed to sniff us out in our usual spots on the couch, slowing down as it made its way closer, so as to not run over Val’s toes. We let it run as long as it can before needing to return to its nest to recharge. DO dodododo DO! The robot sounds triumphantly, proud it has found its way to the docking station in the dining room. When it’s ready again, it will resume its path throughout the house, learning our trouble spots, avoiding them in the future.

Update: January 30, 2017
What a marvel this robot is! Especially as we’ve grown older, stiffer with our aches, unable to clean up as much as before. Val is particularly relieved and takes the opportunity to nap while the robot cleans around her. Occasionally she’ll reach out from the couch and pet it as it comes near. The cat hisses in jealousy and sulks in another room until the robot is done.

Update: May 27, 2017
Sometimes I sit with the robot on my lap and clean its bristles while we watch Jeopardy! The cat’s hair or a stray piece of Val’s yarn tangles up the roller and I have to cut it gently with her sewing scissors. We wait for the hospital to call with an update, but the phone never rings. I plunk the robot on its dock and fall asleep in my recliner—the robot’s blue battery indicator lights flashing, filling the darkness.

Update: December 18, 2017
The robot picks up everything: dust, crumbs, cat hair, the browning lily petals that have fallen from the arrangements covering the dining room table. Occasionally it will accidentally eat some of the blanket ends that dangle from the couch, and then it growls until I come untangle the wool from its teeth. It’s even swept away some pieces of mail, hiding them under the sofa or behind the bookcase as if saving me from having to read another sympathy card. I watch it weave along the floor and wish it were casting a spell, an incantation, that could magically bring Val back.

Update: December 26, 2017
I wake up to a crash in the middle of the night. The microwave flashes an impossible time of 00:00; a snowstorm must have knocked out the power. The cat is growling at the vacuum wandering around in the dark, bumping into furniture. It can’t seem to sleep either now that Val’s gone. I tuck it back in its cradle, fix the time on the microwave, and stumble back to bed.

Update: February 10, 2018
Sometimes I sit on the floor next to its docking station and see my house from a totally new perspective. There are cobwebs in between the chair rails in the dining room, a few inches of bare drywall where we never finished the molding, a cat toy stuck beneath the refrigerator that the vacuum can’t reach. I tap my fingers lightly on its casing, and think of Val.
How often did she ask if we could do something new, take a different route home from the store, or explore those streets we’ve never once been down even though we’ve lived here all our lives? What would she say if she saw me here now on the floor? The robot sighs, its battery fully charged, and I stand up once more, unsure what to do next.

Update: April 27, 2018
In my efforts to downsize, I’ve been cleaning out the attic. I found an old home video of Val from when we were first married. Val laughs on the television, head thrown back, eyes shimmering. She hands me a dust rag as I hold the video camera, telling me to start cleaning before guests visit. At the sound of her command, the robot chimes and comes scurrying into the living room, expecting to see Val there. It slows, searching beneath the coffee table and chair. Eventually, it whines and spins in the room, empty of Val, disappointed.

Update: June 12, 2019
Doo doo do DOOOO, the robot cries, spinning in the middle of the living room, unsure where it is. Sometimes, I stand behind it, trying to give it a sense of place, my body reminding it of where it is, what it was doing, what path through the house it had intended on traveling. It purrs in recognition, charging forward, its bristles sweeping cat hair and dust under it. But a few minutes later it is whining again, lost. We return to the couch and watch Jeopardy! together, but somehow the questions seem harder, more obscure. I shout out to Val for help, but she doesn’t seem to hear me, probably busy sewing something, my voice drowned out by the thrum of her machine. I pluck the dust from the robot’s bristles as we continue to watch. I’ll ask Val tomorrow about the questions.

Update: October 24, 2019
The vacuum died in the night. This morning it won’t budge. I place it on the docking station, but it just falls into place with a sickening thud. No melody plays. No lights greet me. We sit on the couch once more and wait for Val to come home. She will know what to do, I promise the robot. She always does.

307 People Found This Helpful

Marya Summers

A HARD CLimb

Tehachapi, I am told, means a hard climb in the language of the Nuwa, the indigenous people of this hardscrabble land.

The rugged terrain mounts on desert feet, and at dawn, the sun creeps over the eastern peak, wild with scrub oak and piñon pine.

The transit, like mine, from East to West Coast, trails memories, dreams, despair – dust among particles of light. Oh, how it feels like progress that journey, that narrative arc. Tehachapi: up and up And, maybe – maybe someday – maybe Over!

For five years, my body has scrambled for a foothold in well-being while disease and its consort, disability, are loose stones shifting beneath me, daily tripping me up, rolling me down the unforgiving, graveled face of this occupied territory while the sun sinks into the snaking western ridge.

Each day, hope’s rays reach for me, rouse me to rise into courage, to return to my body and to carry its burdens beyond

Tehachapi.
It was not really a hospital room with a door. I would learn about regular hospital rooms later. This was the white place I was left in after that night in which my legs could no longer do what I wanted or needed them to do on their own.

I was alone in this small, curtain-enclosed space. My bed was white. My gown was white. The sheets, the blanket, the pillow, the cold, metal basin on the stand to the right of my bed were white. I could see no walls, only white curtains, which surrounded my bed. The ceiling was white. Even the nurses who occasionally came into the room were dressed in white; their hats and their shoes were white. There were white metal bars behind my head, below my feet, and along the sides. My bed was a cage I did not need; I could not have escaped even if I’d tried.

All I had, other than the white I saw, was what I heard: the doctors’ or nurses’ shoes as they struck the floor: each making their own unique sound as they walked outside my space. The quick clop of the shoes of this one, the slower clunk of that one. When the sound stopped, I knew by that loss of sound that my curtain would open, and I would see someone. But not my mother or my father—I was told they were not allowed. No one who was not dressed in white, who was not a doctor or a nurse, was allowed.

Years later, I would learn of the term “quarantine.” I cannot remember how long I was quarantined; I was only two and a half and I did not yet have a picture of a clock in my head, or a calendar like I do now. It just felt like I was trapped in a white “forever.”

I know now, from what my mother told me years later, that the quarantine began when I tried to get up in the middle of the night and cried out to her that I needed to go to the bathroom. She called back that I should “get up and go.” My response was: “I can’t walk.” My spinal tap was positive, hers was negative. From then on, the words “polio” and “infantile paralysis” became a different “forever” and permanent parts of my vocabulary.

I decide I shall help that small child escape the room of white. I tell her there is a window that breaks through the space and she can hear new sounds and see new things, from a street outside. The sounds are made by many things that move and display different colors. I will let her pretend she can hear the green and cream-colored trolley cars as they rattle down gray streets and for once she won’t mind the boredom of gray because it is a relief from white. On the sidewalks that line the street, she will see shops with colored signs, houses of brown, or red, perhaps even orange. She’ll see women in bright clothes, in high-heeled shoes like her mother’s that click on the pavement. Men like her father, dressed in navy blue suits, who tip their dark hats when approaching women like her mother. Women, who then blush, smile and continue walking down the street.

*     *     *

I cannot remember how long I was quarantined; I was only two and
A million trillion times as bright as the sun, cosmic gamma-ray bursts are the most energetic and short-lived in the universe. Your brain vessels shattered at birth into a million stars, just like that, a trillion ideas of you lost in cosmic minutes. Hope flashes like comets, or bonfires, or candlelight. Maybe moonlight on sugared snow. Let’s pretend it is poetic, sublime. Pretend in darkness we see a glint. Pretend yours a universe we’re not meant to know.

ELLIOTT ELLIOTT

BURST

In your dreams you float, buoyed and secure following the finless dolphin to the water cavern limbs loose and tremorless. You spin forward and down, an undulating merman. Water the color of peacock courses cold into your ears to soothe the fiery brain, release contracted muscles. Ligaments lengthen, sinews thaw, supple and joyous. As you swim to the surface: a flood of words. They jump and arc like fish onto the boat, filling the bow.

LEE ANNE WILSON

A PERFECT DAY

The day was azure blue, green, and yellow bright with sun. A perfect day. A perfect wind. So I flew and soared aloft, alive, alight with joy to see from my great height the countryside below me spread; a carpet, blue-green and yellow bright with sunflowers softly swaying in the light of an Indian summer’s day. So I flew and soared aloft, alive, so light I sailed above the tiny houses shut tight against the windy panoply of azure blue, green, and yellow so bright it filled the day and spilled into the night. With big and little bear pointing the way I flew and soared aloft, alive, so light a mote of dust, the evening wind might swat me like some annoying fly, but the day was blue-green and yellow bright as I flew and soared aloft, alive, so light.
In a home that’s nestled among rolling hills and plateaus, artist Kelly Simpson is surrounded by her horses—haflinger, Arabian, dapple Percheron. These majestic creatures don’t roam the land around her though, they grace the walls of her home. The equine images she paints comfort and inspire her. She brings them to life on canvas and with them around her, she is content. An unbridled love for horses and art was sparked as a young child when she began drawing as a means of communication. Born in Nova Scotia, Canada, one of seven children, she was the only deaf child. Shy and quiet as a young girl, she began drawing horses at four years old. One Christmas morning her parents led her to the basement where they had hidden a surprise. She could hardly believe it when she walked down the stairs to discover a pony! She was overjoyed to have her own horse and named him Bullet. He was boarded at a nearby stable so she would hop on her bike as often as possible to see him and take him out for a ride. At six years of age, Simpson transferred to a Deaf school that was about six hours away from home. Missing her pony, she would constantly draw horses everywhere—on the chalkboard, paper, whatever she could find. An employee at the school learned she had a pony at home and devised a secret plan with her parents and students in the woodshop class. Simpson was in the cafeteria when she looked out the window to see a truck pulling a trailer. Puzzled when she saw her parents get out of the truck, she asked for permission to go outside to see them. “The trailer door opened and Bullet came out! I was so surprised when they told me they brought my pony to the school so I could ride him every day. I was thrilled to be close to my horse again.” The woodshop students had gained some real life experience by secretly building a barn for Bullet before he arrived. At eleven, her parents decided to move her back home and enrolled her in a mainstream school. Bullet was older by then so he stayed put and
she returned occasionally to visit him and some of her friends at the school. At fifteen, she exhibited advanced art skills so her mom purchased a case of painting supplies and enrolled her in an oil painting class. Initially she was hesitant, a teenager among adults, with no experience painting with oils, but she thrived in the class and discovered a passion for painting. The first subject she painted—a horse. She continued to develop her skills with oils until she left for college.

Simpson attended Gallaudet University and painting quickly faded into the background. She graduated with a degree in museum studies and art history, and shortly after, embarked on a career in Washington, D.C., as a museum technician with curatorial duties for the National Park Service. After nineteen years on the job, she found herself off work for several weeks following foot surgery. Not one to sit idle, she’s too restless for that, she wondered what she could do while keeping her foot elevated. She remembered that case of painting supplies she’d tucked away, untouched for more than two decades. When she opened it, she was surprised to find the tubes of paint and brushes were all still in good condition. She placed a canvas on an easel, propped up her leg and began to paint. All of the training and experience came back to her as soon as she picked up the bush, as if she’d never stopped. And what do you think she painted? A horse, of course. Friends who came to visit were impressed. The artist began receiving commissions.

Once she returned to work, she continued to paint on the weekends. “On Friday night I would set up my paint supplies, easel, and canvas. Saturday morning I would wake up early and begin to paint and then suddenly it was Monday. Monday already?!” The same thing happened every weekend. Simpson loved painting so much, the time just flew by. More commissions came in. She worked and painted. There was no time for anything else.

Simpson met her husband, Dennis, when they were both attending Gallaudet and he could see a remarkable change in her when she started painting again. He encouraged her to leave her job just shy of twenty years, and paint full time, vowing he would support her. “When I left my career in 2009, we didn’t have space in our home for a studio so we moved to Frederick, Maryland, which has a large Deaf community. Now I’m here in my fourth-floor loft studio with a beautiful view from my rooftop terrace. I love it so much! It was time for a change. I am so much happier,” she says, with a beaming smile that lights up a room. She loves the slower paced, simpler
life, after decades of living in a big
city. With large windows that bathe her
studio in natural light, she paints every
day, as long as there is sunlight. When
the sun goes down, the painting ends
because she doesn’t use artificial light.

She was hesitant to start promoting
her own business until she took a class
about Deafhood (a term coined by
Paddy Ladd in his book Understanding
Deaf Culture: In Search of Deafhood).
Reflecting on the class she says, “I
learned about myself as a Deaf person.
Who am I? What’s my identity? I was
shy and thought I couldn’t do what
hearing people could do because I’d
been colonized by hearing people for
so many years. Deafhood opened my
eyes. Mind blown. I decided I would
stand strong in who I am. I am Deaf
and I am proud. That class was in 2015.
Since then, I’ve really seen my business
grow.”

In the early years, she also provided
photography services and painting
parties, but she decided to end those
services and now her sole focus is
on oil painting, specializing in pet
portraits. “Social media and email make
communication so much easier—there
really are no barriers. People are often
surprised when they meet me and find
out I am Deaf.” When commissioned
for a pet portrait, Simpson asks for
several high-quality photos of the
animal. She incorporates elements
from multiple photos into a couple of
preliminary pencil sketches for the
customer to choose from. Maintaining a
good relationship with clients is crucial
so she sends photos of commissioned
portraits as they progress—from
preliminary sketches to underpainting
and layers of color until the final details
are added and the image is complete.
Then, it hangs to dry for a month in
her studio where she has a chance
to enjoy it before delivering it to the
owner. She loves bringing animals to
life on the canvas and receives great
joy from seeing the way people respond
to her work. She and her husband
like to travel so, whenever possible,
they deliver paintings to customers
in person, within the US and Canada.

Kelly Simpson, *Sweet Rambo*, 2020, oil paint, 10” x 10”
Kelly Simpson, *Tin*, 2021, oil paint, 8” x 8”
Kelly Simpson, *Val and Sheltie in the Snow*, 2018, oil paint, 12” x 16”
Most of her business is within the US but she has had two international commissions.

“I work at my own pace. No time limits. I go with the flow, depending on my motivation and my mood.” Usually there are two to four paintings in progress in her studio at any given time. One advantage to working with oil paints is the slow drying process. She can work on one, move to the next, and the next, and return to the first one again to blend, make changes, and add details. Last year Simpson took a month off from commission work to paint *Zee*, a beautiful Arabian. “The detail in each strand of hair in the mane takes patience. Patience is the key. And relaxation. There are times when I go on vacation or have other commitments and I’m unable to paint. When I return to my studio, it is a great feeling. I love it. I walk in and my response is: Yes! I’m back. Let’s go!”

Whether it is a ground-level view of a chestnut mare grazing, the saddle view atop a palomino with a gentle breeze blowing through its mane as it overlooks the ocean, or a bold view from behind two haflingers swishing their tails, muscular hindquarters exposed, it is obvious from her personal work that she prefers nontraditional poses. Prim and proper, perfect-looking animals are not her style. She likes to depict the character of the animal in its natural state. Of course, business is business, and if the customer wants a perfect, proper pose of their pet, she is happy to oblige. In her quest to capture the essence of the subject and personalize paintings, some include a reflection of the owner in the animal’s eyes (example on back cover).

Several years ago she completed a series of seven paintings depicting American Sign Language (ASL) commands for an exhibition held at Gallaudet University. *Sit in ASL* is one painting from the series that shows a beagle looking up at its owner, obeying the signed command to sit. When the exhibit was over, the University purchased that painting and it now hangs in President Roberta Cordano’s office.

In American Sign Language, a name sign is a unique sign, specific to the individual—a way to identify them without spelling their name each time. Simpson’s name sign is a “K” pressed into the cheek because she has dimples and her first name begins with a K. Her creative flair is evident in the stylish and artsy eyeglasses she wears—spectacles that are as colorful and vibrant as her bubbly personality.

Last year, on Deaf Awareness Day, she was invited by the Maryland School for the Deaf to serve as an example of a successful Deaf artist and teach students how to draw a puppy portrait. As she demonstrated step by step, the students followed along and were shocked and excited by their results. She had so much fun spending the day with them, helping them realize what they can accomplish by simply taking things one step at a time. Anything is possible.
After years of collecting dust, that case full of painting supplies was opened. It unleashed the creativity of an artist that had been dormant for decades. PAH! Finally! In ASL, “PAH” is an emphasized version of the sign for success, finally, at long last! The mouth movement is used with the celebratory sign. Her life is a good example of this—PAH—creativity is flowing and she is living her best life as the artist she was always meant to be. Learn more about her, or commission her to paint your pet, by following her on Instagram @kelly_simpson_artist or on Facebook where her page is Kelly Simpson Photography And Oil Paintings. Prints of her personal work are available through www.deafmainstreet.shop/collections/kelly-simpson-artist.

Kelly Simpson, Wendy, 2023, oil paint, 16” x 20”

Artist Kelly Simpson at home with some of her horses.

Kelly Simpson, Any treats?, 2022, oil paint, 20” x 20”
On Monday, Jeremy Sanders woke as a turtle.

He hadn't always been a turtle. His mother certainly hadn't given birth to a turtle that rainy night five years ago, but there was no denying that's what he was now, from his exquisite, beak-like mouth all the way down his coarse shell to the scaly tip of his tail. Unable to leap from his bed as he normally would, he tumbled to the floor with a thud that sent his mother's heart racing and her feet flying to his room from across the hall.

If the olive hue of his face or his newly leathered skin surprised her, she didn't show it. She gently helped him off his back and carried him downstairs, in much the same way as she did every morning, though this time taking care to avoid his claws. Today, breakfast consisted of greens and carrots, which Jeremy ate much more readily than when he'd been a human boy.

That afternoon, his mother took him to the pond. Choosing a shaded bench beside the banks, she peered out from between her wide-brimmed hat and the top edge of her novel to watch him scuttle down to the water. She wondered what she'd ever done to have a turtle as a son and how long he meant to remain one. It hardly seemed fair that the other boys should be allowed to run and jump and play ball when her son—only hers—should have such stubby, short legs and slow gait.

Jeremy, however, seemed entirely unbothered by these things. He bathed in the pond's shimmering shallows and basked in the golden sun until the other children rushed down from the schoolyard to throw rocks and catch frogs, at which point his mother stood, brushed off her skirt, and called him inside.

That night, as he tucked his head into his shell and she laid out the blankets around him, she whispered in his ear, the words which—even as a turtle—she knew he'd understand.

*  *  *

On Tuesday, Jeremy woke as a bird—a magnificent, rubicund bird with a large plume of feathers atop his head.

He swooped from the rafters and sang at the top of his voice, shrieking in delight at his newfound abilities. Why, he could see everything from his perch atop his mother's bookshelf, and he could fly faster than he'd ever been able to ride on his bike. What boy wouldn't be delighted to be a bird?

His mother opened a bag of sunflower seeds and set them upon his plate, trying to mask her concern with a wan smile. She'd have to call her hairdresser to cancel the afternoon's appointment and let the babysitter know that she wouldn't need her services today. There was simply no way old Mrs. Bartles would be able to keep up with him this afternoon, not with her bum knee and his sweeping about. She tried not to let him see the crease in her brow as he tested out his wings.
out-of-doors, flying ever higher and higher until he was but a speck in the ocean-blue sky.

Without her monthly hair appointment, the silvery gray roots were more apparent than ever as mother and son made their way to the village arboretum. Jeremy swooped and dove through the sun-speckled treetops, while his mother watched, breathless and squinting. Each time he flew near, she'd clasp her hands and eagerly praise the graceful form of his dives.

Evening fell and she built a nest for him of scraps of linen and washcloths atop his mattress. She kissed him goodnight and whispered gentle words that, even in birdsong, were clear.

* * *

On Wednesday, Jeremy woke as a fish—a shimmering, silver fish with scales like the stars and eyes like milky marbles.

He gasped and flopped about on his bed until his mother heard his struggle and carefully carried him to the kitchen. She'd always hated the slimy, wet texture of fish scales, but that didn't matter now. She filled a glass bowl that she'd gotten for her birthday and plopped him inside, where he swam about dizzily to show his appreciation.

All day, she sat by the bowl and read to him tales of the sea. She read of waves and squalls, of whales and minnows, of pirates finding their fortune on stormy seas. Her heart ached, and she wished he could tell her why he'd become a fish, but fish—as you know—cannot speak. Nighttime came and she carried the bowl to his bed, tucked a blanket about it, and her words rippled over the waters.

* * *

On Thursday, Jeremy woke as a tiger.

Claws tore his bedclothes to shreds. Teeth gnawed at the windowsill. He howled in frustration when his mitten-like paws fumbled at the knob on the door, and the entire house shook when he beat his head against the wall.

His mother sat in the hallway, her back pressed against his door, singing his favorite songs until he soothed. At midday, she dragged the tallest ladder from the gardening shed and propped it up beside his window where she could toss roast beef and a whole chicken in through the tattered curtains.

Throughout the afternoon, he paced the floor and raged and prowled until finally the sun set through the curtains. By the time he wearied and stretched out to sleep, his mother's voice was hoarse from singing and her eyes were red from her frustration.

When the steady, sleeping breath came from within the room, she crept quietly inside. She removed the tattered curtains, swept up splintered chicken bones, and spread a soft sheet over her son's feline form. She whispered into his velvety ear, and even in his sleep, the boy within the beast flicked his tail contentedly at her words.

* * *

On Friday, Jeremy's mother tiptoed up to his room before dawn. She hesitated at the door, wondering how she might find him today. Her throat was still raw from the evening of singing the raging tiger to sleep. What if today he was something else, something she wasn't prepared for? What if he was a wolf? Or a shark? Or a terrible, venomous spider?

She approached his bed with tentative steps, but before drawing back the covers, she leaned in and softly whispered their secret words.

* * *

On Friday, Jeremy woke as a boy—a small, somewhat skinny, brown-eyed boy with freckles on his cheeks and knobby little knees that were perpetually covered in grass stains and scrapes.

His mother made him waffles for breakfast, and he spilled syrup down the front of his shirt. He laughed as his mother tickled his chin with her washcloth, and after breakfast, they took a walk to the park.

At bedtime, she brushed his hair back from his face and planted a kiss upon his forehead. As his eyes drooped closed, the carefree joys of the day gave way to worry. What would tomorrow bring? She never knew.

Banishing a wayward tear, she leaned in and whispered their secret words, words which in any language always meant the same thing: “No matter what, I love you forever.”

“Find middle C,” I tell Lydia. She does, and without any hesitation forms her fingers into the perfect arches that I can’t even remember telling her to make. This is only our second lesson, but clearly she has been watching me as I play. I smile; I am always amazed at how quickly Lydia can grasp new things.

It’s easy to be surprised at how Lydia always seems to know more than she is told, but really no one can be blamed for that. Lydia is mute. Always has been. It sounds terrible when you say it like that, but it’s the truth, and we’ve all long since gotten past skirting around the fact and begun treating her like a “normal” human being, just one who speaks to you through her eyes and gestures rather than through her mouth. The reason for her muteness is obvious, though I don’t know the story behind it. Right beneath her chin there’s a scar that extends directly down the center of what I assume is her trachea, and it’s so perfectly straight that it must be from some sort of surgery. I’ve heard that it was done due to some sort of complication at birth, but that’s only hearsay. It all comes to the same thing in the end, and once you get to know her you barely even notice the scar under her pretty twenty-something-year-old face.

She’s a petite young lady who lives with her retired grandparents and takes care of her grandfather, a lifelong smoker who’s surrendered his ability to breathe without the help of a machine. But really, Lydia’s a blessing to the whole neighborhood. Each week she makes it to every house on the street to help out with the cleaning, and in turn we pay her enough to keep her going. But, I like to notice, she tends to linger at my place the longest. Perhaps it’s because of the smell of the lilacs in my front yard or perhaps it’s the melodies I play on the piano, which, I’ve noticed recently, she loves. Thus, the piano lessons. “Play a C scale,” I say, and she does, perfectly. I beam at her. Lydia smiles back at me as if to say, “Come on, can’t you give me something a little more difficult?”

I leaf through the mess of papers on the music rack, searching for the beginner’s book I’d bought for such an occasion as this, and Lydia waits patiently with her hands folded on a plain pink T-shirt that creases neatly over faded jeans. She often dresses simply in this way, but even when she’s cleaning she somehow keeps herself looking well-kept, a feat I, in my floral-print blouse that seems to look a little more grandmotherly each day, only wish I could achieve. I pull a book out from the jumble, but it’s the wrong one, and just as I’m about to put it back, we hear the faint notes of another piano begin to drift through the open window.

“No who could that be?” I ask. She shrugs. No one else on our street plays.

We listen. I recognize the piece; it’s Chopin’s “Raindrops,” a strong, moving ballad. Fitting, since it’s been alternating between sprinkles and an outright downpour for the past two days. Earlier, I’d opened the window as the rain had lightened in the hope that it would send the skies a message to clear out and let the sun shine, but no such luck. I reach to pull the top panel shut.

Suddenly, there comes a loud, dissonant ruckus from behind me.
Lydia is pressing two keys directly next to each other and shaking her head expressively. Leave it open, she motions with her hands, or at least I assume that’s what she means. I let the window go, and she smiles and nods. Together we listen as the melody floats mysteriously through the air until it begins to rain harder and its loud pattering drowns out the music.

* * *

It isn’t long before I discover from where the music had come.

“Did you know,” Susan practically sings through the phone at me, “that someone’s moved into the Bayer house?”

Susan is my neighbor across the street, which means each of us is directly adjacent to the Bayer house. Ask anyone in our neighborhood which house I’m talking about and without hesitation they’ll point you down the road to where it ends in a dilapidated fence, a clump of weeds, and an old, one-story brick cottage that in no way lives up to the standards of the rest of the much newer homes on our street. No one knows who the Bayers are nor what became of them, only that they printed their name on the brick posts that border the walk leading up to the front door. Each of us has wondered, however, whether someone would ever move into the place, though with its crumbling fence and unkempt yard it seemed unlikely.

“What?” I ask.

“A man, I think. It was hard to tell; there were a couple of moving guys walking around in the rain, but this one man just stood by the door and watched them bring things in. Do you know, they were only there for twenty minutes though! I watched, and the only things they brought in besides boxes were a couch, a table, a lamp, and a single chair. Not even a bed!”

“Nothing else?”

“Oh, and that gigantic piano of course. You know, I’d always wondered how they get those things through the front door.”

“A grand?”

“Well, I don’t know. What’s the difference?”

I chuckle. Susan’s got a “good eye”—a nice way of putting it, if you know what I mean—but I wouldn’t expect her to know a thing such as the differences between pianos.

“Well,” she says, “I’m thinking us ladies should make him some sort of welcome basket, you know? Some cookies and bars and things. Make him feel at home.”

“Shouldn’t our husbands also say hello?”

“Oh, well, sure, eventually. But you know how men are. Ask them to do something sociable like welcome a new neighbor and they’ll just say, ‘oh sure,’ and the next thing you know it’ll be September and the poor man will have been living there for months without having met a single person.”

“You’re probably right.”

“Well of course I am!” she says.

* * *

The next day four of us women, each carrying a small basket of treats, gather at the short brick pillar with “Bayer” stenciled into its shaft. The yard beyond looks as hapless as ever, and we all hesitate, gazing disdainfully at the foot-high grass leaning across the sidewalk that leads to the door. The rain has let up some, but we each carry an umbrella lest it starts to pour again and ruins our baking.

“At least we know he’s home,” I say, for again we can hear a piano being played, faintly, and once again I know the piece; it’s “Vocalise” by Rachmaninov, and I give myself an inward pat on the back for recognizing two compositions in a row. Gloria and Denise, two women from further down the block, giggle in response, but none of us makes a move.

“Well, ladies, it’s now or never!” Susan decides as if she hadn’t just been standing there with the rest of us and marches up the path, swinging her cloth-covered basket the whole way. We fall meekly into line behind her, quite the entourage, and I wonder whether someone whose yard looks like this is going to be thrilled with a flock of visitors.

Susan gives the door three hard raps and we all step back. Our new neighbor is a long time coming. I gaze absently at the house as we wait; the brick is fading throughout, but it still seems sturdy. A little cleaning up and a new roof, and the place wouldn’t look bad at all. A little homely, perhaps, but not bad.

“What did he look like?” I ask, just as Susan begins to become impatient and gives the door three more raps, this time harder.

“Tall.” She responds, curtly. “Black hair, really thin, seemed young. Youngish, that is. I couldn’t really tell through the rain.”

I nod, a comical picture of a large-nosed, skinny, and mustachioed virtuoso hunched over his piano forming in my mind. A few more minutes pass and we continue to wait.

“Perhaps he’s using the restroom.” Denise says.

“Or taking a shower.”

“Does the water even run in this place?”

“I’ve already knocked twice!” Susan complains, and does so once more.
“Whatever he’s doing had better be important!”

But what he’s doing quickly becomes obvious. As we stand in silence, ears pointed toward the door and expecting to hear footsteps approaching to open it at any second, our ears instead catch the rising and falling melody of the piano. In fact, it is still that same song, as if he had never stopped playing for a moment. The four of us look at one another, dumbfounded.

Then Susan explodes. “Well! Come on girls, let’s go. We don’t need to waste our time on someone who can’t appreciate his friendly neighbors!”

Baskets in hand, we follow her lead down the weed-covered sidewalk, music trailing behind us as we go.

* * *

There’s a knock on the door, and I breathe a sigh of relief; guests will be visiting tonight and every time I clean the house it seems to get a little bigger. Some people might say that guests can handle a little dust above the mantle—they probably won’t see it anyway—but I certainly can’t, so I’d finally decided to enlist a bit of help for the job.

“Hello!” I sing as Lydia steps into the house holding a pair of cleaning gloves and wearing an oversized shirt and sweats which, along with her hair in a neat ponytail, somehow still make her look as nice as ever. “Thanks for coming over on such short notice.”

She shrugs and smiles—the universal gesture for No problem!—and heads straight for the bathroom. Lydia has long since adopted my house as if it were her own and knows better than I where to find anything she needs, and I assume she’s just going to get a bottle of spray or something. But when I turn around, Lydia is down on all fours with her gloves pulled to her elbows and is at work scrubbing the area around the toilet.

“Oh! No, please.” I tell her. “You don’t have to do that. Here, grab the vacuum; the living room still needs to be done.”

She turns, smiling, and points to her ear. For a moment I am confused, but then I realize: she means she is listening, and it quickly becomes clear as to what.

But she just smiles and keeps scrubbing no matter how much I plead. Eventually, I give up and let her do what she insists, but secretly I’m glad; I don’t know if my back can take that much time bent over on the floor.

Together we make quick work of the cleaning. Soon, I am finishing up and putting the last dishes on the now-sparkling tabletop when I see Lydia sitting by the open window in a chair she had pulled over from the dining room table. I watch her for a moment to see if she will notice me there, but she just rests her arms on the sill and keeps gazing at whatever is outside. I slide up behind her, but there’s nothing out of the ordinary that I can see. “What are you looking at?” I ask.

She turns, smiling, and points to her ear. For a moment I am confused, but then I realize: she means she is listening, and it quickly becomes clear as to what. Our neighbor is at his piano again; I had completely forgotten about him after the other day.

“You really like the music, don’t you?”

She nods and we both return to listening. This time the piece is something by Liszt—one of the Hungarian Rhapsodies, I think—and for the first time, I realize how genuinely good our neighbor plays. Although I do not consider myself an accomplished pianist, I can find my way around some advanced pieces of music, but the way this mysterious person eases through the sort of compositions most piano players only dream of playing with such exactitude sets him on an entirely different plane. It’s like listening to the radio, and I can’t blame Lydia for taking a moment at the window, probably the only time I’ve ever seen her slacking on the job.

The guests arrive early, of course, but I am prepared, and soon Susan and Gloria, along with their husbands, are sitting at the dining table beside me and my own. The conversation waxes and wanes throughout the evening and at some point, I try to mention what I’d heard with Lydia earlier in the day.

“You know,” I say, “I heard our new neighbor playing his piano again today. He’s really . . .”

“Speaking of!” Susan interrupts and then takes a moment to dab the corners of her mouth with her napkin as my lost sentence dwindles into nothingness, “Mike, tell her what happened yesterday.”

Mike, Susan’s husband, a somewhat beefy man with a deep, booming voice, shrugs. “Well, I was walking by his lawn, pulling up the weeds near the fence and said, ‘Hey, neighbor!’”

That lawn still doesn’t look any better though,” Susan laughs. “Go on, Mike, tell them what he did.”

“Well, that’s just it.” Mike drawls. “Guy didn’t do anything. Didn’t wave, didn’t come and chat, didn’t even stop what he was doing for a second, just kept on pulling weeds like I wasn’t nothing but a ring in the fence.”
“Just like when we went over, isn’t it?” Susan shrieks. “What an ass!”

“Did he see you?”

“I assume he did. I mean, I was standing right there. Said hello. Everyone knows I’m not a quiet sort of guy.”

“Maybe he’s shy.”

“Well,” Mike says, “shy or not, a man ought to learn that you can’t get by without communicating with people. And what sort of person can’t even say a simple hello?”

* * *

The mystery surrounding our new neighbor affects us all in different ways. Susan, of course, can hardly contain her annoyance at the man, his yard, his reclusiveness, and “That stupid piano that I can hear all the way from my kitchen! What does he do, pound on the keys with a hammer?”

Her husband is a bit less hostile, yet still seems to think lowly of the man. “Maybe,” he responds to one of Susan’s scornful remarks, “the fella didn’t have any real friends growing up and so he never learned how to interact with people. Doesn’t explain the yard, though.”

When I tell my own husband about how I am beginning to feel sorry for our neighbor, as if he can hear the things that are being said about him, my husband just shakes his head. “What’s to feel sorry about? Maybe he doesn’t mind being left alone. Not everybody cares about what Susan’s got to say.”

The next afternoon, I am surprised to hear shouting coming from the direction of the Bayer house. I can tell that the voice is Susan’s, and my first instinct is to muse, “Oh well, the poor man’s finally met his first neighbor! Pity it had to be her.” But when I look out of my second-story window I see, not our neighbor, but Lydia in the neighbor’s yard, hunched over an overgrown hedge with a gigantic pair of garden shears in her hands.

“What are you doing?” Susan is shouting, and it sounds as if there is fear rather than anger in her voice, like she is scolding a thrill-seeking child. “That isn’t your yard! You don’t even know that man! Who knows what he might do if he caught you out here chopping his hedge.” I can see Lydia trying to explain the best she can with her motions, but they are lost on Susan who hustles Lydia away from the house, leaving a push mower and a sidewalk broom behind.

As I watch them leave, I realize that our new neighbor has affected Lydia as well, but in a different way than the rest of us. Rather than feeling snubbed or sorry, she simply sees somebody new to take care of, just as she takes care of her grandparents and, I realize, the rest of us. Looking at the Bayer house, I notice that it suddenly looks much different; the grass is cut short, the sidewalk is cleared of weeds, and the hedges are cut neatly up until the point at which Lydia was forced to stop. We all have our different ways of saying “hello,” and as I again hear the music of a piano drifting through the air and notice a little basket covered in a checkered napkin resting at the door, it almost seems as if the Bayer house fits perfectly in its place at the end of our street.

* * *

Almost a month goes by before I finally catch my first glimpse of our new neighbor. Although I’m ashamed to say it, I’m surprised that he is neither sickly pale, nor does he hunch over as he walks, nor does he have any other physical impairment that I subconsciously assumed he must have, being a recluse. In fact, he is a decently handsome young man who I would guess to be about thirty, with a thin, angular body, short, dark hair, and a completely normal face. He walks briskly from his house to his car, a small, blue hatchback of some sort, and disappears down the street.

The mystery surrounding our new neighbor affects us all in different ways.

Just as I’m about to close my blinds, I catch a glimpse of another face somewhere in my peripheral vision, and there’s Susan, perched at her own window which is a mirror to my own, and for a moment we meet eyes. She sadly shakes her head, as if some tragedy has taken place before her, and I shake my head back without realizing what I am doing, a silent affirmation that Susan is right: the man is strange, he is rude, he is an “ass.” Once my blinds are closed and I am feeling ashamed for giving in and letting myself join in Susan’s disdain for our neighbor, I cannot help but wonder: what is it about people that seems to want to tear apart anything they don’t fully understand? If something doesn’t react to them the way they think it ought to react, is there always something wrong with it? What has this man done, besides perhaps hurting people’s pride by not acknowledging them in the way they want to be acknowledged?

But then I wonder: what have I done any differently? Sure, I don’t verbally abuse my neighbor, but when I leave my home I always glance toward the house at the end of the street as if I am frightened he will suddenly walk out and shout, “Hey, you! What were you and your friends doing at my door the other day?” Haven’t I also expressed pity, as if I knew anything about what my neighbor should be pitied for? Then there’s my husband, with his “live and let live” attitude. Is that the attitude I should take? These thoughts and more are blistering through my head as I grab my keys and prepare to run a few errands downtown.
I never was able to find the beginner’s book for Lydia’s piano lessons, so after a stop at the pharmacy and the grocery store, I swing by Erv’s Music Shop, a place known more for its pianos and orchestra instruments than its ear-shredding electric guitars, a fact for which I am grateful. The shop is full of books, but of course the one I’m looking for is out of stock, so I ask at the front desk if there are any extras in the back.

“Could be,” says Erv, “I’ll ask Thomas to check.”

He disappears for a moment and then reappears with a tall, young man who is holding a few beginner’s piano books. I glance at the man and then do a double take. It’s my neighbor.

“We don’t have the one you’re looking for,” Erv is saying, though I barely hear a word, “but Thomas says that any of these would work well for someone just beginning.” I take the books from Thomas while looking into his eyes, as if this will somehow make him realize who I am even though he has probably never seen me before. He gives me a quick, businesslike smile and disappears back into the other room.

“I would trust him,” Erv winks at me. “Thomas is the best piano player I’ve heard, well, probably ever. He used to play with the symphony.”

“Oh . . .”

Erv raises his eyebrow. “Everything all right?”

“That man,” I say, “Thomas? He’s my neighbor.”

“Is he? Well, I knew he just moved into town. I just hired him a couple of weeks ago. He’s a friend of my nephew.”

“He’s deaf, if that’s what you’re wondering.”

I blanch. “Deaf? No. Well, that’s impossible!”

“Amazing is more like it,” Erv says. “Though I know he hasn’t been deaf his whole life. Like I said, he used to play with the symphony until whatever happened that made him lose his hearing. Can you imagine, music being everything to you, your entire livelihood, and then losing the ability to hear it?”

“Like Beethoven,” I say in wonder.

“Only more so; Thomas is only thirty-two.”

“Can he communicate?”

“Oh sure. He knows sign language, though I don’t, but he’s pretty good at reading my lips as long as I talk slowly and use hand motions along with what I’m saying. And he speaks fine, just a little off-pitch if you know what I mean. But I’ll tell you, the best communication in the world is when he sits down at one of those pianos and just starts playing. Usually all of the customers stop whatever they’re doing and just listen. It’s like going to the symphony for free.”

I chuckle a little, mostly for reasons that Erv wouldn’t understand. I imagine a group of ladies pounding at a door and listening to music that infuriates them while Thomas sits and plays happily without a clue in the world.

“Who would’ve known,” I say. “A deaf man working at a music shop.”

“It sounded strange to me too when my nephew suggested it. But now I don’t know what I’d do if he left.”

We chat for a while longer, I in the hope that Thomas will reappear from the back of the store, but no such luck. I am in for one more surprise that day, however. Arriving home in the evening after having dropped the groceries off at my mother-in-law’s place, I notice, illuminated by the orange light of the setting sun, two figures standing in the doorway of Thomas’s house. One is Thomas himself, wearing a white T-shirt and a pair of faded jeans, and the other . . .

“Is that Lydia?” I say to myself.

And sure enough, it is. Both are rapidly moving their hands in some sort of animated conversation and I remember that, of course, Lydia knows sign language too. And for a moment I feel left out, being able to see a conversation but not being able to take part in it. But then I laugh at myself and turn, still chuckling, into the driveway. Imagine how Lydia and Thomas feel all the time!

*.     *     *

I can’t tell who is more excited about our piano lesson the next week, Lydia or me. I couldn’t decide whether or not to leave the plastic cover over the new piano book, so after picking it up and setting it back down dozens of times, the plastic now loosely covers about half of it and is torn on the back, probably the worst possible compromise now that I think of it. But when I respond to a knock on the door, Lydia, in a new, sunny yellow top that replaces the regular T-shirt, gives me a round-the-neck hug and heads straight for the piano, stopping only for a moment to take off her shoes.

I start to give an instruction, but Lydia quickly puts up a hand and smiles as if to say, Wait a second. She takes a deep breath, positions each finger over a white key, taps them one by one up and
down the scale, and then, much to my surprise, she proceeds to play “Ode to Joy,” complete with chords in the left hand. I am impressed.

“Well!” I exclaim when she finishes and gives a little seated curtsey. “Somebody’s been teaching you some things!”

Lydia smiles, and I can see a red tinge in her cheeks. Her eyes keep darting back and forth to the window near the piano, and so I lean over to look out of it. Standing in his perfectly manicured yard and leaning against one of the “Bayer” posts stands Thomas. He smiles and waves, and I wave back.

“Did he tell you to play that for me?”

Lydia nods.

“He’s a nice man.”

She nods her head sheepishly and I want to ask her so many questions, about her, about Thomas, and most of all about them together. I want to ask whether Thomas knew it was her who had helped him with his yard, whether he had told her that he used to play with the symphony, and that he had helped me pick out her book at the music shop. I want to ask how she had gotten his attention in the first place. But I don’t, because there is no way I would understand Lydia’s answers to them all, and for a moment, that makes me discouraged.

But when I look at her with all those questions in my mind and she smiles right back at me, I can see all the answers in her face and I realize that she doesn’t have to say a single word. ♦
My Apartment

My apartment might be messy when you come over
But it probably won’t be
Probably
I won’t invite you if I can’t clean it that day.

When I am well
My apartment is spotless
It is rarely spotless
Usually the spots
Are a guerrilla army
Unnoticed until you realize that you are surrounded.

It is dusty
But I would invite you if it were just dusty
We all have some dust on our inner shelves
You probably wouldn’t notice mine.

Right now
There are books on the floor and dishes in the sink
But I could make a book tower in the closet
Hide the dishes in the dishwasher
Or the oven
Dust frantically using a still damp face cloth
And invite you over.

You would assume that my books are always shelved
Alphabetically or by color.

You would think that I wash my dishes
Immediately
And put them away in perfect lines
In a dustless cupboard
And you would wonder
If I would notice if you moved each one by a millimeter.

The collection of pieces from my day
Would not be sitting in the corner
They would be in their places
And you would think that my days
Do not collect things.

You would never know about the broken hinge in a box
That my cat played with for a week
And is still on the floor
And has not been made into art.

You wouldn’t miss my favorite wine glass
Which belonged to my Grandmother
And is discontinued
Or remember
The crystal shards that mocked me from the table
For days.

Since I have not invited you over
The only reason to clean today
Is that if you showed up
Unexpectedly
I would have to speak to you on the stairs in the dingy hallway
With the door closed.

You would think that it is my landlords who are messy
And wonder how I could live
In a building like this.

My apartment might be messy when you come over
The books may have spread like raindrops over every surface
My cat might be playing with the remains of healthy days
There may be ninja spots and soul dust
And no clean cups to offer you a glass of water from.

If my apartment is messy
I am no longer pretending
I am comfortable
In front of you.

If my apartment is messy
And the door is open
Know that it is the same thing
As wrapping my arms around you
Whispering Love.

If my apartment is messy
And I invite you in.
My father gave me sound advice when I was a child. “Never put in writing anything you don’t want published.” I wonder if he gave the same advice to my mother.

In the far corner of the closet, behind my mother-of-the-bride dress still in its protective bag, sits a cardboard box marked “Childhood Memories.” I carry it to my bed and pry open the four flaps, uncertain of what awaits me inside.

I discover Mother’s Day cards with poems copied from the chalkboard. A picture of a chubby fifth grader with a flipped-up hairdo. A wrinkled green Girl Scout sash with five gold stars and troop number 2124. Official certificates with glowing ratings from piano competitions I entered starting at age nine despite my fear of being the center of attention.

A brown paper folder contains my report cards from first grade through high school. I pull out the “Pupil Progress Report” from 1961-1962, my first-grade year. It unfolds into three pages. Under each section, Mrs. Warren checked every box “Satisfactory.” I become absorbed in the amount of detail and the volume of feedback she has provided in her comments.

“Lori is outgrowing some of her earlier reticence and is doing nicely in oral work.” I read on. “Encourage her to retell to you the library books she is reading and the day’s story or poem. Do not talk down to her but rather use words new to her. This sort of thing as well as ‘Show-and-Tell’ give her practice in organizing her ideas and using her growing vocabulary . . . . Lori is reading in the second group and is doing very well and should move steadily ahead . . . . When Lori is fresh and does her writing early in the day, her papers are among the best in the room.”

Reading my teacher’s comments makes me giddy. Folding the report back up, I see my mother’s familiar handwriting on the last page.

Under the “Parent’s Comments” for the first reporting period, my mother has written, “When is ‘Show-and-Tell’ day? She is usually halfway out of the house when she remembers she needs something—hence no time to talk or plan things. We will encourage her to talk more—but she usually chatters constantly about nothing, and we try to silence her.”

There are additional comments, but I can’t see anything beyond we try to silence her.

On the first day in Mrs. Warren’s class, I had to go to the bathroom, but I couldn’t bring myself to raise my hand and ask. As I stood reciting the Pledge of Allegiance, I knew I should ask the teacher for permission to use the restroom, but I didn’t want to draw attention to myself in the middle of the pledge. I stood with my hand on my heart, mouthing the words as I wet myself, the hot liquid trickling down my leg, praying no one noticed. When the pledge ended, I looked to the floor and saw a puddle at my feet. My classmates sat down, and I walked up to the teacher and whispered in her
ear. She took my hand and walked me to the school nurse, who called my mother to take me home.

After my mother cleaned me up and changed my clothes, she folded a pair of clean underwear and stuck them in a thin, black, faux leather briefcase. She brought me back to school, whispered something to my teacher, and handed me the stiff-handled briefcase, so out of place in my small hand. I placed the briefcase on the floor, leaning against the legs of my desk, and sat down. For the rest of the school year, every time I glanced at the briefcase, with its business-like appearance, my cheeks flushed with embarrassment. No other classmate had a conspicuous black briefcase sitting at their desk. I felt I was being punished too long. Thankfully, I never needed to use the contents of the briefcase.

I blink, breaking the spell of the memory, and look down at the report card again. I wonder what Mrs. Warren thought when she read my mother’s comment. “When is ‘Show-and-Tell’ day?” School had been in session for two and a half months when my mother wrote that. Did my teacher assume my mother was an overwhelmed first-time mother, unable even to keep track of Show-and-Tell day, instead of the veteran mother of three she actually was?

“She usually chatters constantly about nothing, and we try to silence her.” I read that sentence over and over. Something big percolates in my mind. My heartbeat quickens. Memories surface.

My mother’s face is inches from mine, nostrils flaring, pupils the size of pinheads. She’s yelling.

“Be quiet!”

“Children are meant to be seen and not heard!”

“Shut up, or we’ll send you to an orphanage!”

I shelve the memories aside. I notice still more written on that report card. A reply to my mother’s comments from Mrs. Warren: “This chattering is normal after the new experience of all-day confinement and being held down to a routine.”

I close the report card. My initial exhilaration at uncovering a long-lost memento is gone. I imagine Mrs. Warren had high hopes when she typed my report card. She probably meant well, but she had no way of knowing her words fell on deaf ears. She didn’t know my family.

My parents’ focus was never on me but always on my two older siblings who lived with juvenile diabetes, now referred to as type 1 diabetes. Before medical advances made diabetes management easier, every day was a struggle to keep them healthy and alive.

Our kitchen and bathrooms looked like a chemistry lab. My parents sanitized glass syringes in a pot of boiling water and sharpened needles on a flat stone. Every morning, they tested sugar levels by dropping a reagent tablet into a small test tube containing a few drops of urine mixed with water. The contents fizzled like a scientific experiment, and the resulting colors—from dark blue to orange—indicated the amount of sugar in the urine. My parents compared the color to a chart and gave my siblings insulin injections based on the test results. If my siblings’ blood sugars spiked dangerously high or low, my parents rushed them to the hospital, often in the wee hours of the night. I held my breath until they returned home.

I suspect my parents secretly wished they’d called it quits at two children. They had nothing left to give for their third. My mother had been a homemaker, staying home with her first two children. But when I reached school age, she returned to work full time, opting to pay my neighbor, Mrs. Sitka, five dollars a week to watch me each day after school. I found solace in their home and, in time, I grew to love their fun-loving house with three happy children my age. I dreaded the moment when my parents got home from work and came to get me. I returned to a somber house clouded by illness and an older brother who loved nothing more than bullying me.

Mrs. Warren didn’t know this was the home into which I was born.

My parents felt weighed down. They worked full time and drove my siblings to doctor’s appointments, the emergency room, and picked up prescriptions. My mother hovered over my brother and my father hovered over my sister. No one hovered over me. My basic needs—food, clothing, shelter—were met, but anything beyond that became superfluous.
Preparing for Show-and-Tell day was simply not a matter of life or death.

Not ready to pack this away, I read the note again. “Lori is outgrowing some of her earlier reticence and is doing nicely in oral work.” Another memory percolates, this from my career in financial management. I stood at a podium, looking at forty or so top-level managers, all men, waiting for me to present the budget I’d worked long hours on, including weekends. Although I knew the details practically by heart, my hands trembled. My papers shook, my body shook, it even felt like the floor shook. My mouth, dry as sandpaper, had difficulty forming words. I mopped my brow, prayed for no questions from my audience, counted the seconds until I could sit down. Even though I knew every aspect of the budget inside and out—assumptions, methodology, numbers—I still wasn’t confident. I felt at any time someone would find fault in my numbers. Questions from the audience felt like personal attacks, more barbed grilling than polite inquiry. Yet, surprisingly, despite my heightened anxiety, my answers satisfied the audience, and I received congratulations on my excellent presentation. I had survived. Back at my desk, I sank into my chair, relieved to have finished my presentation without fainting, vomiting, or my mind going blank. It wasn’t the only time I experienced speaking paralysis.

How much of it stemmed from my childhood? From my silencing?

I stare at the closed report card again. My impulse is to return it to the brown paper folder, take the cardboard box and shove it back into the closet. But if I bury this keepsake and its memories in my closet, am I burying a part of me?

In that moment, it’s as if my report card is speaking to me, like the playing cards in *Alice in Wonderland*, the ones with human heads, arms, and legs. *Lori! Examine me carefully! Don’t put me back in the box!*

This report card is proof—proof of actions my mother has taken over the years to diminish me. Proof that many of the things from my childhood I preferred not to believe, actually happened.

I’d recently begun writing about my childhood memories after taking a memoir writing class, and most of my stories focused on the difficult relationship I’ve had with my mother. For years, I shared my feelings about my mother in my journals and with my therapists, but rarely beyond that. Often, when I tell someone about a painful remark my mother made, I am offered condolences and hugs, but some faces hold a faint look of disbelief. I want people to know these stories are not exaggerations; they’re based on a lifetime of cutting words that chiseled my soul even as her painful barbs vanished into thin air. In the same way my parents struggled to contain and control my siblings’ diabetes, I struggle with my intense feelings for my mother. Conveying those emotional scars feels impossible. How many times have I wished I had something—something more concrete than my memories—to validate my stories?

And there it is. Lying on my bed. A critical piece of paper. Legible proof. And in my own mother’s handwriting. “She usually chatters constantly about nothing, and we try to silence her.”

If I put this away, I’d be doing the same thing: silencing myself. I close my eyes and pray for wisdom, stamina, courage. I can almost hear the voices of my support system. My mentor whispers, “You can do it, Lori!”

My friend, after reading one of my pieces months ago, said, “Your voice isn’t being heard.”

Members of my writing group encourage me: “Keep telling your truth!”

My son said, “Thank you for sharing your story with me.”

I was silenced as a child, and my adult voice may be shaky, but I will not stop. My fingertips tingle. Still sitting on the bed, I reach for my laptop and start typing.

My father gave me sound advice as a child. “Never put in writing anything you don’t want published.” I didn’t follow his advice as much as I should have. But, I will now.♦

Leo turns four today. After waking with the sun, he skipped around the house in his cowboy hat and tropical-colored vest.

I’m now at the dining room table, reading the LA Times, sipping coffee. He speeds past, saying “Ickle Me, Pickle Me, Tickle Me too, went for a ride in a flying shoe!” In recent weeks, he’s memorized several Shel Silverstein poems. He loves saying them as fast as he can.

My daughter, Addie, has had a harder start to her day. After getting out of bed at eight and cuddling on the couch with Angel, our cat, seizures struck and my six-year-old fell back asleep.

It’s almost ten o’clock when I hear her padding toward the kitchen.

“Wow, Addie! You look fantastic,” I say. She wears a curly red wig and her Little Mermaid Ariel dress. “Come on over here! Mom and I are making Leo’s birthday breakfast.” While true, my statement contains the sin of omission: Addie’s meal will be separate and unequal.

As I pour heaping ladles of pancake batter on the buttered griddle for Leo, Jackie gets out our newly purchased gram scale. Instead of hot and fluffy birthday pancakes drenched in maple syrup, Addie will be served some form of fat with a side of protein and a dash of carbs.

Her meal is based on the Ketogenic Diet, a non-pharmaceutical epilepsy treatment. She’s been on the Diet for six months. The recipe for this morning’s meal, “Eggs ’n’ Toast,” reads as follows:

- 32g Heavy Cream
- 23g Fat (Butter, Margarine, Oil or Mayo)
- 5g Wonder Bread Light
- 32g Egg

As a visual, that’s approximately two tablespoons of cream, one-and-a-half tablespoons of butter, half an egg and a tenth of a slice of bread—about the size of an index finger. Addie’s current meals are more laboratory experiment than dining. Each fraction of a gram matters. If it’s a tenth of a gram too heavy, we remove a portion and reweigh.

This morning’s “Eggs ’n’ Toast” brunch will provide Addie with 331.54 calories and achieve the desired four-to-one ratio of fat to carbs plus protein. Because her body will be using fat rather than carbohydrates as fuel, she will maintain a state of ketosis. In recent months, these high levels of ketones in her bloodstream have somewhat reduced her seizure activity. As is the case with many drugs as well, the exact reason for improved seizure control is unknown. With the guidance of a nurse nutritionist at Children’s Hospital Los Angeles, we continue to make monthly adjustments to her menus.

We were reluctant to take on the added stress of the Diet. But Addie’s seizures have been back for two-and-a-half years. She’s tried half a dozen anti-convulsant medications, including vigabatrin, Depakote, zonisamide, Topamax, Lamictal, and prior to the Diet, Felbatol. Because nothing has controlled her seizures, her epilepsy is now considered “refractory.”

Since we’re striking out with drugs, Jackie and I agreed to try yet another
Leo blows out his candle, takes a bite of pancake and begins marching in place. He often eats while standing. Marching seems to be a birthday addition.

“Hey birthday boy,” I say, “chocolate milk?” He nods and loads another hunk of pancake onto his fork. “And Addie, seltzer?” Addie can drink as much diet soda, water, and seltzer as she wants.

“G-rape!” she says.

I mail-ordered bottles of unsweetened flavors and often create cherry and grape sodas for her. With everything else she eats so tightly controlled, I encourage this rare, if empty, indulgence.

Leo pours more syrup onto his shrinking pancake pile. Addie’s tiny-to-begin-with pile of food remains untouched.

**At last, like a starved animal, Addie inhales her meal and licks her fingers.**

“Why isn’t Mom having birthday pancakes?” Leo whispers to me.

“Mom already ate,” I say. I don’t feel comfortable telling him the truth: Jackie’s not eating pancakes because she doesn’t want Addie to be the only one not enjoying them. So Jackie sips seltzer alongside Addie, and pokes at a small piece of bread on her plate that matches Addie’s in size and shape.

“But I’m gonna eat your pancakes if you don’t finish!” Jackie says. Leo’s eyes bulge, his mouth opens and he devours his remaining pancakes.

“Dinglehopper,” Addie says, as she combs her wig with her fork.

“Alright Ariel, finish your eggs and toast,” I say, adopting my best King Triton impersonation. At last, like a starved animal, Addie inhales her meal and licks her fingers. I’m not sure she even tasted it. I’m relieved by the thought.

* * *

It’s 1:00 p.m. A motley crew of four-year-olds and their parents will arrive any minute for pizza and swimming. I’ve heated the pool to an expensive eighty-eight degrees.

In the kitchen, Jackie prepares all of Addie’s meals and snacks for the day. At the moment, she’s placing a slab of butter onto a fingernail-sized sliver of Wonder Bread. I don’t know how long we’ll be able to restrict Addie’s food intake like this. It feels like we’re depriving her of one of life’s great joys. After confirming the precise, mandated weight of each item on our gram scale, Jackie places each “meal” in individual Tupperware containers. This way we can enjoy Leo’s party without having to excuse ourselves for portioning and weighing.

The doorbell rings. I open the door to the first wave of party guests. But instead of greeting them with me, Jackie escorts Addie into the den. I’m not sure why until I see Addie’s head jerk down and her shoulders thrust forward. A seizure. Biblical suffering right here inside my house.

“Hi Luke, hey Tristan, come on in,” I say. Their parents follow. Behind me, Jackie lays down with Addie on our big red living room couch. Addie tries to fight off the seizures. “Isn’t Leo cute?” she says. “He’s such a little guy, isn’t he Mom?”

“Hey, nice bathing suit, Miles. I like the smiling shark,” I say. Leo appears in his blue bathrobe covered in footballs, baseballs, and basketballs. The three boys run downstairs. The door slams as they talk loudly, laugh, and make their way to the pool.

On my way outside for lifeguard duty, tray of fresh-baked brownies in hand,
I peek over at Addie. Jackie’s covering her with a chenille blanket. Addie’s falling asleep, like she did six months ago at her sixth birthday party. She slept upstairs in her room while her friends and their parents enjoyed a petting zoo in our driveway. We even had a llama that Addie had specially requested. I felt sad for her then, just like now.

For the next five months, while the rest of us eat pancakes, ravioli, and chicken pot pies, Addie continues to drink special oil we get by prescription, lick tablespoons of butter, and swallow a supplemental, powdered drink called KetoCal, which we buy at the pharmacy. We feed her just enough protein to continue growing and barely enough calories to maintain her health. While Addie doesn’t complain about the meals, Jackie and I are unsure if this is a relief or another reason for major concern. Is the fact that she accepts this routine a sign of mental obliviousness?

At a checkup, our neurologist warned us that kids on the Diet often become desperate for regular food. “We haven’t seen indications of that,” I said. “At least not yet. But, if we do, how do we handle that?” I asked.

“You’ll have to padlock the fridge and cupboards,” the doctor said. Although we never resort to such techniques, Jackie and I now understand why tube-fed kids are great candidates for the Diet. They’re powerless to resist the meals.

While she doesn’t resist the “meals” we provide her, Addie’s often hungry during the Ketogenic Diet year. Jackie carries several lunch boxes at all times, full of premade meals of mayonnaise and bacon bits, Diet Coke and butter. When it’s hot, we offer her ice cubes, or sugar free Jell-O. Six-year-old Addie develops a taste for lukewarm black coffee with Sweet ‘N Low.

Birthday parties are the worst. “Yes, Ads, I see the chocolate cake,” I say. “How about another Diet Coke instead?” Jackie and I receive disapproving looks from other parents as we offer Addie diet sodas and water. I sometimes wonder if we’re creating an eating disorder to go along with the epilepsy.

Addie loses weight consuming so much fat. One afternoon at Cheerful Helpers, while Jackie and I sit inside the soundproof, parental observation room, another parent says, “Addie looks so thin and beautiful.” Addie has indeed transformed from an inflated, irritable girl during her ACTH (adrenocorticotropic hormone) injections, to a paper-thin waif. The parent continues. “You must share your secrets.”

“Oh, I can tell you all about it later,” I say. Even my own parents compliment us on Addie’s trim figure.

* * *

After a year, the 50% reduction in seizure activity is notable; Addie’s quality of life degradation is equally notable. Despite her—and our—commitment to the strict regimen, Addie has not been able to participate in family meals, enjoy birthday parties, or have a cookie. She’s more isolated than ever.

It’s after midnight, one Sunday in January. Jackie and I walk downstairs for a late-night snack. Our two cats, sources of comfort to both kids, lie asleep on the couch. An unexpected light radiates from the kitchen. We stop. In silence, we ease closer until we come upon an unexpected tableau: Addie kneeling on the kitchen floor with our two recently adopted dogs, Bernadette and Lady, on either side.

Bernadette’s a full-grown boxer, pit-bull mix. She looks like a reincarnation of Paley. Lady’s a black lab puppy. The three of them sit in a circle, in the glow of the refrigerator’s open door. On the counter, a candle flickers. It looks like a séance.
As Beethoven lost his hearing, he would bang on his piano, a pencil clenched in his teeth, the point touching the instrument so the vibrations would rattle his skull.

His right hand pounding out phantom notes, *piano to forte*, desperate, searching as I do, for sound.

His deafness started with buzzing and whining.

(Do the hearing do not realize the incredible volume of deafness.)

His ears became hot to the touch of loud voices, as mine do.

My own tinnitus drives me to the knife block;

Like Van Gogh, I, too, would drop my ear in the mailbox,

But we know that does no good.

Van Gogh and I share a diagnosis, Meniere’s disease.

I fall into his paintings and breathe in the familiar landscape,

Transformed by our vertigo, shining with unnatural loveliness.

It is the awful inner workings we cannot touch, that part of us interior as anger—

Hammer and stirrup . . . fractured labyrinth

I need a farrier to slam at the bones of my inner ear, a blacksmith willing to destroy tools that have rebelled against their master.

I know why sailors keep to the roar of the sea, old roadies put their faces on the sub woofers,

And I know why Beethoven beat the music out of his piano.

The nauseating bell choir, the relentless concert in a venue without zoning restrictions inside his head,

Inside mine.

*The Tinnitus Tarantella* at the volume of a tornado siren. *Molto fortissimo.*

Poor Ludwig, so much lovely music left to hear, to write, to breathe . . .

I hope that was the last thing he heard.

I hope it was music.

I hope it was a long, rattling chord,

Not his buzzing skull, the bees of deafness invading to sting and waste his eardrum,

Like the hypodermic pierces my tympanic membrane to quell the vertigo (even though it silences all but my own voice)—

Because bees make very poor percussionists and even worse companions.

It is lonely here for me and Beethoven, for all who are stung.

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**Beethoven’s Bees**

Rebecca Brothers

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**Beethoven’s Bees**

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TWO FATHERS

Navy sailor, Georgia farmer, factory worker, three boys’ father, lifts you in and out of wheelchairs, drives you to the neighboring county’s school with special education. Every month he takes you to the South Carolina children’s clinic.

Six months old in 1960 - doctors said cerebral palsy. Put him in an institution. He will never sit upright or walk.

Your mother
Boston-born, worn out with Georgia leaves him. Sells his homestead, takes his sons over to his sister’s verdant farm. You heave your small contorted body up from wheelchair to the towering tractor. With your brothers you milk cows, bale hay, come sunset volley cow dung balls on weathered barns.

Then his new wife, country widow with two children. Moves his family to a little bungalow in town. They swap night and day in mill swing shifts take you kids to ball games, clinics, camping, doctors.

Surgeons work to straighten twisted legs, then home rest. Teachers send you work. You skip three grades, dream you’ll be like him: a working guy.

1999: alone
By his grave, his wife says, “There was never anyone like you.”

But don’t you see him in this photo? Lounging lion on the couch our girl at three, her new kitten cradled in your arms, your office-smooth accountant’s hands upon their backs child and kitten fall asleep to the peaceful clock of a father’s heart.

S. Leigh Ann Cowan

TELEPHONE

a troop of girls in green sashes and blue jeans crisscross apple sauce duck duck goose style on the cafeteria floor small hands cupped over ears shoulders hunching protectively against the breathy whispers tickling ear canals giggling, eyes squeezed shut lean over to cup the next girl’s ear tickle her with your fricatives

i pretend that the sharp hisses and whistles and clicks the roaring ocean of hot air blasted directly into my hearing aid don’t hurt i cringe and hunch my shoulders and giggle i am just like them put a finger against the ear mold and wiggle it massage away the ringing with soothing static as i invent a sentence to whisper to the girl on my right

“That’s not what I said at all!” exclaims the first girl amazed laughing playfully accusing isn’t telephone so fun
“W”

hat are you in for?”

“Corrective surgery for my spina bifida. What about you?”

“Leukemia.”

“Bugger, that’s a bummer. Will your hair grow back?”

“Yeah, my hair will grow back; it’s just the chemo that makes it fall out.”

“Are you going to be okay? I mean, you’re not going to die, are you?”

“Jeez, I hope not, mate! Now, that would be a bummer! What about you, you going to live?”

“Yeah, I’m going to live, but in a wheelchair, my stumbling days are over.”

“Sorry, man, that’s bad.”

“Yeah.”

Asha expelled weighty air from his chest. He looked at the ceiling, counted those stupid pitted ceiling panels. Yeah, he thought, it’s bad. Too bad! That’s the end of my exploring days! Not that they had ever really started, in reality, they had actually ended before they began.

Ever since he could remember, he wanted to be an explorer. Scott, Livingston, Cook, Amundsen, Hilary, and so many more. He knew them all, and memorized their stories of bravery, discovery, and glory. His bedroom was filled chockablock with books, encyclopedias, and posters. He even had an old-fashioned globe with raised relief!

And here he was, Asha Challies age eleven, lying in ward nine, staring at a ceiling, knowing he would never walk again.

“Are you okay?” The girl in the next bed asked. She looked over and gave Asha a timid smile.

He had been asleep when she had been wheeled in, so he didn’t know how long she had been there.

“Waiting for a space to come free at the other end,” she told him when he woke. “They don’t like putting girls and boys together. How wacky is that?”

Not used to company and not feeling like talking, Asha mumbled, “I’m okay, thanks.”

He remembered looking over, noticing her bald head. He tried not to stare, but without hair, he found it difficult to gauge her age. Probably about the same age as me, he concluded after a moment. He thought she looked pretty; he tried to focus on her face, imagining her with hair. Yes, she was pretty alright, even if her eyebrows and eyelashes had also fallen out.
“I’m sorry for staring,” Asha said.

“It’s okay, you don’t see many bald girls, and I am especially bald! I worry my teeth will fall out too.”

“They won’t, will they?” Asha questioned in alarm.

“He-he, no, of course not, silly boy, my eyes will fall out first! Anyway, my name is Alex; what’s yours?”

“Asha.”

“Asha, are you okay?”

He wasn’t. Tears now pooled in the divots of his cheeks.

Alex jumped out of her bed, still hooked up to fluid in a bag. She flung her arms around him. “Don’t cry, Asha, don’t cry; not being able to walk is not the end of the world.”

“I know,” he sniffled, “but not being able to be an explorer is.”

* * *

“Asha, what do you want to do for your seventeenth?”

“I want a picnic on the beach!”

“Asha, darling, you say that every year, and every year it’s the same answer. We can’t do that. We can’t get your chair anywhere near the sand, and your father is too old to carry you now.”

“There’s no such word as can’t, Mum!”

“I know, darling, I’m sorry, but what about going to the lake instead, freshwater, seawater? What’s the difference?”

“There’s a shed load of difference; Abel Tasman didn’t discover New Zealand by puddling around in a pond!”

“Asha, I wish you would stop thinking about explorers. Anyway, there’s nothing left to discover. You, me, your father, we were born too late. Everything’s been done.”

“Bullshit Mum, I will find something. Believe me! You say you wish for me to stop; well, my wish is to start. I will have a picnic on the beach. It was my favorite place when I was a kid, remember? I could walk then, barely. Trundle into the sea by myself, feel the sand beneath my toes, the cold water, the sun and the breeze on my face. Smell the salty air. Please do not deny me my greatest pleasure. I love you, Mum, and know you love me, so can we please try and do this.”

“We’ll see what your father says.”

“No.”

* * *

Asha drove to the beach in the adapted car his parents bought him for his birthday. He kicked off his shoes and, upon exiting his car, didn’t bother transferring to his chair. Instead, he grabbed his long-forgotten crutches and lurched toward the sand. The sand felt warm and nourishing on his feet. His mood was buoyed by the burst of independence and achievement.

“Excuse me, ma’am,” he called out to a passing mother with her children in tow. “Can you please throw these crutches under my car? It’s the green Toyota.”

“Yes, of course,” the woman said sympathetically. “Are you going to be okay getting over the dunes?”

“Thank you, and yes, I’ll be fine. Enjoy your swim; I hope I’ll see you down there soon.”

The sand was hotter than Asha initially thought, and by the time he crawled to the top of the dunes, he had blisters on his knees and hands. Knackered and sweating, he took a break at the top, resting his back against a clump of pikao grass. He grinned; stretched out before him was the immense Pacific Ocean. The horizon playing hide and seek between the blue sky and the bluer sea. Made it, he thought.

He heard the girls coming before he saw them. Gossiping and giggling, that’s all girls seemed to do. They walked past. Five girls about his age, all wearing bikinis, smothered in sunscreen and cheap sweet perfume, carrying bags and towels.
“Hi,” one of the girls called as she walked past.

“Hi,” he replied.

“Asha, Asha, is that you?”

He looked up. Sun in his eyes, straining to see. “Yes, I’m Asha.”

“It’s me, Alex. Remember me?”

He involuntarily grinned, “Oh my God, Alex, yes, I do remember you. You have hair now! Beautiful long blond hair. Oh, my goodness.”

“I have my eyes and teeth too!”

They both laughed.

“It’s so nice to see you,” they both said simultaneously.

“Do you need a hand getting down to the beach? My friends and I can support you if you wish. Please don’t be shy; I can see your hands and knees are a bit cut up. I’m happy to help.”

The girls sunbathed in the sun, swam, and shared their picnic with Asha. All the while, Alex and Asha caught up, swapping horror stories about teachers, school, and medical adventures.

“What are you going to do after school?” Alex asked.

“I’m going to study electronics at Canterbury; what about you?”

“I want to study marine biology, probably in Auckland. So, are you a bit of a gadget man then?”

“I guess so,” he replied.

“Well, take a look at this then,” she said, smiling, reaching into her bag.

At first, he couldn’t see what it was, but quickly worked out it was a drone.

“Do you wanna fly it?”

“Shit, yes, Alex, can I? Thank you so much!”

“After today, you can even keep it. I don’t ever use it; I think my father bought it for me to stop me whining about not having a car.”

“Did it work?” Asha asked.

“Hell no!”

The rest of the afternoon, they reconnected and took turns flying the drone. They swapped instas before they left, promising to keep in touch.

* * *

Three years later, Alex contacted Asha out of the blue.

“Hey Asha, remember me? Hey, you still got that drone?”

“Wow, nice to hear from you—yep, sure have. You gave me the bug; I’ve bought another one since. It’s wicked, top of the range. I’ve even installed a camera and heat sensor. Why?”

“Well, my professor wants to make a field trip to Fiordland; he’s studying the decline in dolphin numbers there. During next semester’s break, he wants to do a survey. A drone with an experienced operator will be invaluable for the census. I’ve told him about your disability, and he’s cool. We’ll stay on board a launch, and he says he can ensure it is accessible for you. What do you think?”

“Will I have some time to myself? I’m never going to explore Fiordland by foot, so will I have time to fly the drone over the land?”

“Can’t see why not, Asha . . . so that’s a yes then?”

“Yep, that’s a yes!”

The Christchurch Press
March 18, 2021
C.U. Student discovers famed lost Fiordland moose herd.

. . . When asked what he would do next, Asha Challies, said he would undertake expeditions with his girlfriend, Alex McManus, to find the South Island Kokako and the probably extinct Huia. “There is a whole world of undiscovered flora and fauna out there, and I intend to find them.”
My cerebrospinal fluid leaked, causing my brain to sag within my skull, like a boat sinking to the bottom of a bathtub. No, less serenely. Like a body settling onto a bed of nails. No, still less serenely. Like a gourd being flattened by an elephant’s foot. Yes, that sounds right.

For a year I didn’t know this was the cause of my crushing headaches. I thought it might be a trigger food, and so I ate nothing but rice and potatoes, to no avail. I took migraine medicine, which did as much good as eating Pez from a plastic doctor dispenser.

A neurologist finally diagnosed me. “You have brain sag,” she said, and so it was painfully obvious, pun intended, that I had a cerebrospinal fluid leak. There was a hole somewhere in the membranes surrounding my brain or spinal cord.

Now I knew, so finally I would be healed!

Not so fast, leaker.

The cause was unknown, and so they called it a spontaneous leak, which brought to mind spontaneous combustion, which seemed fitting, somehow.

With no known cause, the dribble was hard to find. Like searching alongside the entire Amazon River for a stray trickle of water. And so I underwent procedure after procedure, scan after scan, injection after injection. Doctors tried epidural blood patches to cure me. They removed my blood, like vampires, but unlike vampires they injected it back, alongside my spinal cord. It didn’t work.

In the meantime, nothing stopped the pain, but caffeine eased it, and so, tethered to an IV stand I joked about veins full of Starbucks. Morphine was useless. It slipped through my blood vessels, uncar ing, just sightseeing. Dilaudid, morphine’s odd cousin, tried to help. It made me more willing to endure.

Some people think you can’t leak for that long without dying. And yet, there I was, alive, half wishing I wasn’t, with brain fluid draining, seeping, debilitating, deflating. I took to my bed. No, that sounds like a choice. The vertigo and pain knocked me down like the bullies they were, pushing me back down again every time I tried to rise.

I had always wanted to be on a list. The bestsellers list, the Nobel Prize winners list, the Jeopardy! winners list. I made the disabled list. That had to do.

“We need motionless scans of your insides,” the doctors said. “We have to stop your heart. Sign here.” I did. And so I got my half-wish, to be dead, but I was only deceased for a short time, just long enough to give me my life back.

Surgery and glue stopped the leak. Glue! If I’d only known, I would have grabbed my Elmer’s and slathered my spine with it myself. But of course it was no elementary school glue, but a special fibrin glue that dammed the flow. I could not have applied it on my own.

My brain unsagged, floating upward to the correct position in my skull. Like a rubber ducky rising in bathwater. No, like a blue whale surfacing in the ocean. No, like the sun breaching the horizon after a terrible storm. Yes, that sounds right.

I was without pain for the first time in a year and a half, all because my tiny leak was found and repaired. My rising brain allowed me, in turn, to rise.
NANCY SCOTT

CROSSINGS

It used to be tricky street crossings—
veering, curb cuts, quiet cars.
Now it’s big open spaces—
dining room, activity area, loading zone.

Nothing to shoreline.
Nothing to trail.
Echoes and wheelchairs and walkers.
Jigsaw puzzles, caged parakeets, open-cupped juices.

You’re the first congenitally blind person here.
Balance attention and not understanding.
Balance ability and assistance.
Balance shelter and worldliness.

Survival is a creative act.
You have no family and friends age.
The beautiful balcony is a four-lane away.
How eager is helplessness?

You can misstep.
You can’t hear walls anymore,
let alone shorter objects
and independence exhausts.

Manage Independent Living halls and stairs.
Tap or constant contact
past the immovable fireplace
to the mat and the front door.

Staff is mostly young and able.
They move fast,
learn life lessons ’til
the better job offer comes along.

Be grateful when other residents
call you by name and
know where they are and
remember you can’t see.

Learn not to ask
if others like living here.
Learn to tip-toe on tact or evasion
when asking ages and disabilities.

Hear repeated stories and sundownings.
Sometimes choose to gently correct—
“But you don’t have a kitchen now.”
“You won’t ever need a snow shovel.”

Listen for squads and transports.
Counting table mates at every meal.
Be grateful you chose this
before it was too late.

Repeat words said from across the room
or from quiet nearby voices.
Remind what day it is
or the next meal’s menu.

Ask nearby companions about our table’s
in-the-moment napkins and crackers
or if the sun is out.
Smile and sometimes crave adult conversation.

Truths and myths cross
paths of economics and purpose.
Forgot, remember, ignore.
There is more joy than you expect.

Reach for your next landmark.
Learning to Mother with Countercultural Love

Connie Buckmaster

Review of Raising a Rare Girl: a Memoir by Heather Lanier, Penguin Press, 2020

In Heather Lanier’s debut memoir Raising a Rare Girl, readers journey through the early years of her daughter’s life. Fiona was born with Wolf-Hirschhorn syndrome, a chromosomal disorder which resulted in the deletion of the tip of Fiona’s fourth chromosome. The effects of Wolf-Hirschhorn syndrome were put starkly by doctors and online information hubs: seizures, mental retardation, developmental delays, lack of speech, no treatment or cure. From the very beginning, Fiona’s aptitude and worth were questioned. Raising a Rare Girl depicts an almost daily uphill battle with physical therapists, doctors, family members, strangers, and a culture which consistently devalues the life of a person with disabilities. “Among my fellow Wolf-Hirschhorn syndrome parents,” Lanier writes, “I’ve heard horror stories” (70). Doctor’s telling parents they “should” terminate their unborn child, that their child would be a burden to the family and society.

When the healthcare of millions of Americans is up in the air, and those living with preexisting conditions facing a perilously uncertain future, Raising a Rare Girl comes at a time when our culture needs to once again grapple with our violent history toward disabled bodies and our flawed cultural value of “normal.” There is a hierarchy in our culture based on ability, and able-bodied people sit on top as the “norm.” But this ideology has a violent past and continues to be a struggle today.

Only an hour from Lanier’s hometown was Pennhurst State School and Hospital in Pennsylvania, an institution
for people with intellectual disabilities. Lanier writes of NBC’s investigative reporting in 1968, which exposed horrific, inhumane conditions. “The network’s viewers saw close-ups of thighs narrower than knees, of wrists tied to bars, of ankles shackled to beds” (278). A slew of lawsuits in Pennsylvania and across the country had a domino effect: Congress eventually passed the Education for All Handicapped Children Act, later renamed IDEA (Individuals with Disabilities Education Act).

As laws have changed, so too has culture. In Virginia, where Fiona began going to school, the Lanier family was empowered by medical professionals and local educators to support Fiona’s growth. No goal for Fiona was too big, all that was needed was dedication and patience. This, in contrast to our nation’s history, strikes me like it struck Lanier the first day Fiona went to school, “With my phone’s camera, I captured my fedora-wearing, sauntering, twenty-one-pound kindergartener, claiming her rightful place in what would have been prohibited just decades earlier” (279).

Lanier writes, “the simple act of loving her was countercultural” (120).

In fact, much about raising and caring for Fiona was countercultural—even the name of her diagnosis itself. Lanier and her community opt for the name “four pee minus” instead of “Wolf-Hirschhorn syndrome” due to the deeply ableist views of Dr. Hirschhorn and the medical field in general. Lanier describes a conference she and her family attended for 4p-, where she, her husband Justin, and still-infant Fiona met other families with the syndrome. As they roamed the conference room, Lanier saw people with 4p- at all stages of life: giggling Arnold running around with his father in pursuit, Maggie and her mother handing a necklace to Fiona to play with, Rebecca and her father enjoying a quiet moment eating together. Conversations about Fiona, about 4p-, about struggles and day-to-day life, came with ease. Here, in a room full of others who understood, she found a sense of normalcy. “This was the gift of ‘normal.’ In this room,” Lanier writes, “my kid was perfectly unsurprising” (157).

What if our culture and the medical field responded in the same way? What if our notion of “normal” could recognize its ableist biases? What if we questioned “normal” itself? Lanier does, time and time again, and finds her own bias, her own fragment of ableism hidden in her mind. To love Fiona, to raise and nurture her, broke her right open, exposed every tiny tender bit inside, and transformed her. *Raising a Rare Girl* is this story, the story of a woman transformed into a mother, into a role where the biases of others and herself appeared before her. What she does is what many of us need to do: erase any concept of “normal” and embrace the life we’ve been given.

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Poetry by Shanan Ballam:

**THE OWLS**

in the nest we spot them:

| two baby  
great horned owls,  
fluffy and camouflaged 
to look like decaying tree matter |
| --- |
| huge eyes, flecked with gold shimmer,  
stare out at us |
| a pink crabapple petal, thin as tissue paper, clings to my walker |
| loosen your grip on helplessness and sorrow |
| the crocus petals are dusted with saffron |
| a wash of light on the ash tree |
| the gold light shining in the owls' eyes |

---

Shanan Ballam
Roly Andrews of Nelson Tasman, New Zealand, says, “I’m passionate about putting people at the center of all I do.” He has been published in *Fragmented Voices Magazine* (2023), *Rural Fiction Magazine* (2023), and others. Living with chronic illness, Andrews uses writing to divert his mind from his symptoms. “I’m a soft-spoken big guy who loves to create.”

Caitlin C. Baker is an educator and writer from Northeast Ohio. Growing up with epilepsy, it largely defined her childhood. When she isn’t being published in *Belmont Story Review* (2022), *Red Ogre Review* (2022), and *Paddler Press* (2022), Baker can be found traveling, gardening, or making up cute and fun songs about her cats: Purrlock Holmes and Professor Meowriarty.

Shanan Ballam is a senior lecturer at Utah State University. In addition to teaching poetry and composition, Ballam is the author of *The Red Riding Hood Papers* (2010), as well as two full-length manuscripts. She also has a chapbook, *first poems after the stroke*, scheduled to be released in May 2024 by Finishing Line Press. "The reason my poems float down the page is because I felt a mind-body disconnect, and I wanted my poems to reflect that."

Rebecca Brothers is a Kentucky native who taught English for twenty years before establishing a full-time career in writing. With a passion for incorporating Kentucky folklore and rich history into her writing, Brothers pens novels, short stories, and poems geared toward middle schoolers. Living with Meniere’s disease, she says, “I write because I know, very deeply, how stories teach and heal us.”

Connie Buckmaster is a queer writer, editor, submission reader, musician, and teacher based in New Jersey. Obtaining their M.A./B.A. in writing arts from Rowan University, Buckmaster works as an assistant editor. Their works have seen publication in *The New York Times* (2021) and *Jo Literary Journal* (2021).

S. Leigh Ann Cowan is from Arkansas and has an extreme passion for deaf representation in literature. Growing up as a deaf child, the written word was her access to a complete language and she “took refuge in literature.” She publishes an ongoing blog, “Ranked: Deaf Characters in Fiction,” which looks at what authors get right or wrong about the subject. Cowan is also an assistant acquisitions editor at the University of Illinois Press.

Benjamin Decter is a Los Angeles resident, devoted father, husband, and writer of both music and words. Having a child born with epilepsy, words and music have provided him with a creative outlet. Working as a composer, Decter says he, “struggles each day to remember that even though I am living the life I dreamed of, it doesn’t make it easy.”

Ellis Elliott is a Juno Beach, Florida, resident who “bows to the world.” Elliott has a fascination with “the world replicated in miniature.” A mother with a blended family of six grown sons, one of which has multiple disabilities and one with Asperger’s, Elliott is a writer, teacher, and dancer. Her work has appeared in *Signal Mountain Review* (2021), *Plainsongs Poetry Magazine* (2021), and *Spotlong Review* (2022).

Robert Douglas Friedman is a communications consultant from Skillman, New Jersey, and obtained an English degree from Montclair State University. A caregiver for his late wife, he wanted to express himself through writing. Friedman’s work has appeared in *StoryQuarterly* (2008), *Slow Trains Literary Journal* (2009), and *Every Day Fiction* (2017).

N. J. Haus is a writer and educator from Shawnee, Kansas. His work has appeared in *The First Line* (2022) and he holds a degree in international business from MidAmerica Nazarene University. Gaining experience with those who have disabilities as an educator, in his writing, Haus looks to challenge the notions of disability. A proud father of two, Haus has a passion for learning, creating, experiencing new things, and caring for the natural world.

Paul Hostovsky is a sign language interpreter living in Medfield, Massachusetts, who has spent forty years with Deaf and DeafBlind people. He has published several books, including *Late for the Gratitude Meeting* (2019), *Deaf & Blind* (2020), and *Mostly* (2021), and also won a Pushcart Prize and a FutureCycle Poetry Book Prize. Hostovsky isn’t quite sure who he is, but also acknowledges that he’s not alone in that sentiment.

Shelly Jones is a professor at a small university in upstate New York where she teaches classes in folklore, writing, and mythology. Jones’ work has appeared in *A Field Guide to Prehistoric Motherhood* (2023), *The Magazine of Fantasy and Science Fiction* (2022), and others. Living with chronic pain and fatigue, she “wanted to see more characters experiencing these kinds of everyday problems (without falling into the stereotypical portraits of people with disabilities).”

Susan Whiting Kemp lives in Seattle, Washington, and is the author of *The Climate Machine* (2022) and coauthor of the short story collection *We Grew Tales* (2019). Kemp’s writing has appeared in *Wilderness House Literary Review* (2020), *Hobart* (2018), and others. She earned a B.A. in drama from the University of Washington and encourages those with “upright headaches” to seek specialists who are knowledgeable about cerebrospinal fluid leaks, because many are misdiagnosed for years.
Lori Lindstrom is a retired financial manager from Lancaster, Pennsylvania. Lindstrom shares her stories because she wants others to know what it was like growing up with two older siblings who were chronically ill. She also was diagnosed with latent autoimmune diabetes of adulthood, or LADA. Her work has been featured in bioStories (2021) and Discretionary Love (2022), as well as other publications.

Claire McMurray is a writer and blogger from Lenexa, Kansas. She is a former academic who left the field to take care of her daughter who lives with Rett syndrome, a rare, progressive neurodevelopmental disorder. With her work appearing in several publications, McMurray dedicates herself to creating visibility for those living with Rett syndrome.

Gloria g. Murray is a self-proclaimed misanthrope from Deer Park, New York, who enjoys art, painting, and writing. Constantly perplexed by the universe and the curiosities it holds, Murray’s work has appeared in Mudfish (2020, 2023), Kaleidoscope (2007), Paterson Literary Review (2019, 2020), and more. She says, “I found writing and reading poetry helped me understand and put into perspective the disorder of my world and bring it some cohesiveness.”

Wendy Nikel is an author of speculative fiction from Utah. With a degree in elementary education, her work has appeared in Analog Science Fiction and Fact (2022), Beneath Ceaseless Skies (2022), and others. Her novella series on time travel, starting with The Continuum (2018), is available via World Weaver Press.

Rachel Papirmeister is a cognitive science student at Columbia University. She is also a research assistant at a neuroscience lab, where she studies early relational health as well as the developmental impacts of COVID-19 on dyads of mothers and children. She says, “As a disabled writer, I find community in sharing my experience with others.”

Ujjvala Bagal Rahn is a scientist, artist, and northerner living in the southern United States. A first-generation American with an Indian heritage, her husband lives with cerebral palsy. Meeting and marrying in their thirties, the two have one daughter. In poems that focus on her husband, she wants readers to “feel the fullness of our life together.”

Melanie Reitzel is a Pacifica, California, resident who has dedicated her life to helping mothers and babies connect and thrive. A retired maternity nurse lactation consultant, her physical limitations led her to a develop and depend on other skills. Reitzel has been published in ZYZZYVA (2010), Waxing & Waning (2022), Adult Children: Being One, Having One & What Goes In-Between (2021), and others. When not writing, her retirement includes cooking, spending time with family and friends, volunteering, and knitting.

Kate Robinson is a resident of Ontario, Canada, and lives in the converted attic of an elderly apartment building alongside her “giant scaredy cat.” While being capable of holding intense conversations about Shakespeare and poker, Robinson also enjoys getting lost in her favorite bookstore, which she assures readers has more books than square footage.

Seth Schindler is a writer and sculptor in Tucson, Arizona. A Ph.D. recipient from Southern Illinois University, Schindler has worked as a clam digger, pretzel peddler, museum curator, anthropologist, stockbroker, and philanthropist. He says, “By writing stories, I have found the most meaningful way for me to share with others what I have learned in my long life.”

Nancy Scott is a writer living in Easton, Pennsylvania. Her total blindness, she says, allows her to pay more attention in her life. With a focus on essays and poetry, Scott also enjoys NASA and the ideas of space flight. With more than 950 bylines to her credit, her work can be found in publications such as Wordgathering (2022), ACB Braille Forum (2022), and Disability Studies Quarterly (2022).

Margaret D. Stetz is a professor of women’s studies at the University of Delaware. After dedicating her life to academia, Stetz never forgot her working-class background. She is also a committed feminist and has a passion for social justice. Her book, Aubrey Beardsley, 150 Years Young (2022), was published by The University of Chicago Press. She is the author of more than 130 cited articles and essays.

Marya Summers is a writer and educator out of Tehachapi, California. She says, “I am a disabled poet who strives to find the ability within disability and the opportunity within catastrophe.” Summers’ work has been featured in the New Times Broward-Palm Beach (2006 – 2008), Tiferet Journal (2017), and the Freedom to Speak: National Poetry Slam (2003).

Lee Ann Wilson is an artist, writer, genealogist, independent scholar, and retired university professor in Cochiti Lake, New Mexico. Wilson’s work has appeared in The Arts of Africa, Oceania, & the Americas: Selected Readings (1993), American Indian Art Magazine (1985), and others. She is a biological descendent of Indian treaty signers, the founders of Quebec, and a woman hanged for witchcraft. In reference to the poem included in this issue, she says, “As someone who lives with the restriction of wheelchair life . . . I think it expresses the wish of everyone, disabled or not, to soar above the earth, reveling in the freedom of flight.”
Kelly Simpson, Petey in Memorium, 2019, oil paint, 6" x 6"