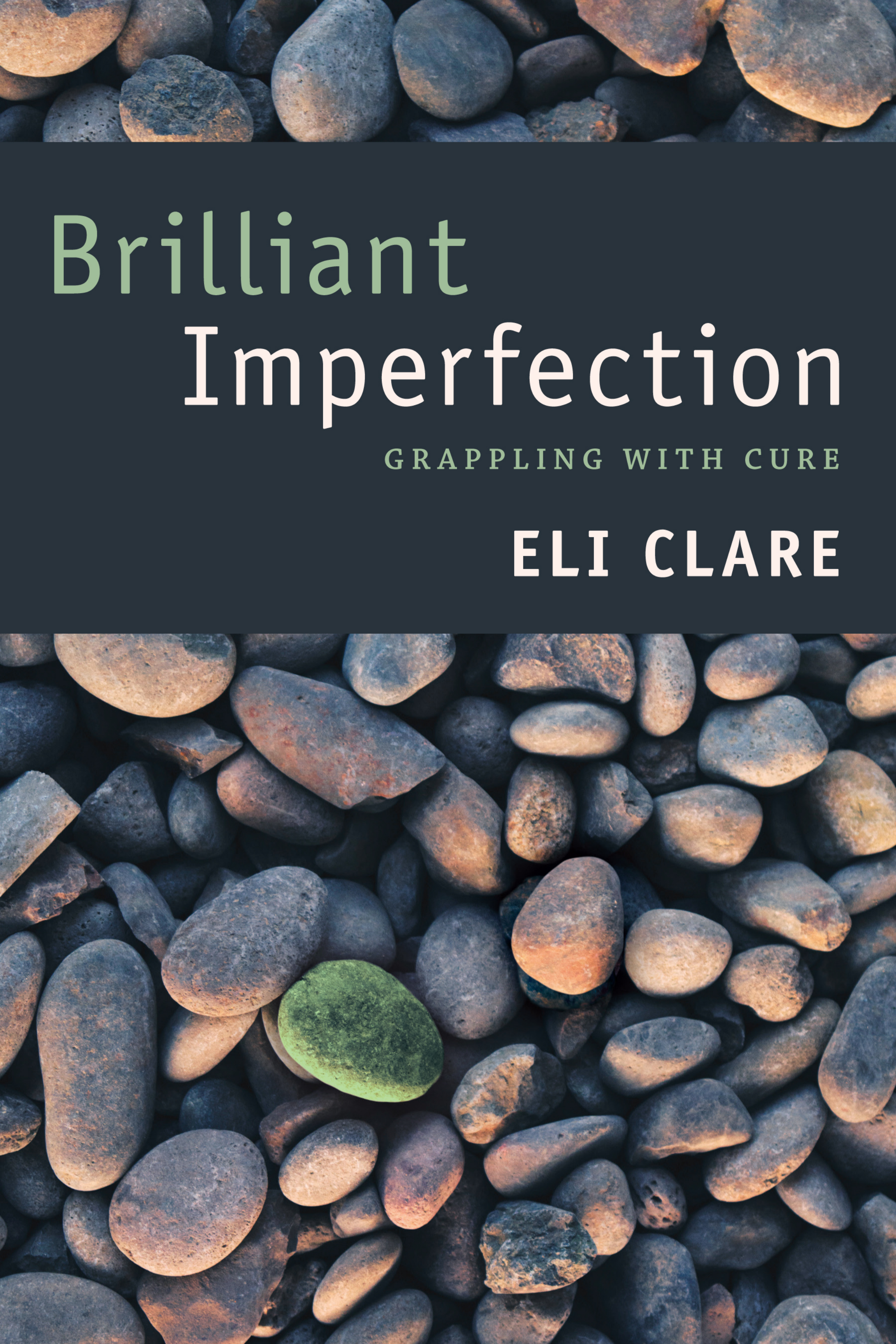
Brilliant Imperfection

GRAPPLING WITH CURE

ELI CLARE



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To the tallgrass prairie

and the crip communities

that have sustained me.

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1

IDEOLOGY OF CURE

Birth

I am alive today because of medical technology. Otherwise my mother and I would have been dead long before my first breath, dead as the ovarian cyst that grew beside me. It was as big as a grapefruit before the doctors told her it had to be removed. Her grief, guilt, bitterness twined through that crisis called my birth. She was the first who wanted a cure for the havoc wreaked when the doctors pulled that cyst away. Did I experience it as twin, competitor, invader? Did we wrestle, embrace, vie for space?

They stole her ovary, and a week later I was born. If my father could have held me, I would have fit in one palm, nestled between fingertip and wrist, no bigger than a grapefruit myself, brain cells already dead and misfiring.

Anesthetic, IV, scalpels, sutures saved my mother and me, as did the surgeon who carefully lifted her right ovary out of her abdomen, leaving enough room for me to be born. And in turn, antibiotics, heat lamps, and an incubator kept me alive. I tell this story not as a tragedy, but a truth, a shrug of the shoulders, water over rock. Tell it neither grateful for that crisis nor bitter about the doctors who didn't inform my mother about the cyst growing inside her. They knew about it for years before my conception. Maybe I have them to thank for my birth, the luck of one sperm, one egg. My parents weren't salmon, thrashing a nest into gravel, laying eggs, flooding the water with spawn. But nonetheless, one egg, one sperm—conception is that fragile, that random.

At first all that mattered was her life and mine, but soon she started wishing for a cure, maybe even before she held me, skin to skin.

Prayers, Crystals, Vitamins

Strangers offer me Christian prayers or crystals and vitamins, always with the same intent—to touch me, fix me, mend my cerebral palsy, if only I will comply. They cry over me, wrap their arms around my shoulders, kiss my cheek. After five decades of these kinds of interactions, I still don't know how to rebuff their pity, how to tell them the simple truth that I'm not broken. Even if there were a cure for brain cells that died at birth, I'd refuse. I have no idea who I'd be without my tremoring and tense muscles, slurring tongue. They assume me unnatural, want to make me normal, take for granted the need and desire for cure.

Strangers ask me, "What's your defect?" To them, my body-mind just doesn't work right, defect being a variation of broken, supposedly neutral. But think of the things called defective—the MP3 player that won't turn on, the car that never ran reliably. They end up in the bottom drawer, dumpster, scrapyard. Defects are disposable and abnormal, body-minds or objects to eradicate.

Strangers pat me on the head. They whisper platitudes in my ear, clichés about courage and inspiration. They enthuse about how remarkable I am. They declare me special. Not long ago, a white woman, wearing dream-catcher earrings and a fringed leather tunic with a medicine wheel painted on its back, grabbed me in a bear hug. She told me that I, like all people who tremor, was a natural shaman. Yes, a shaman! In that split second, racism and ableism tumbled into each other yet again, the entitlement that leads white people to co-opt Indigenous spiritualities tangling into the ableist stereotypes that bestow disabled people with spiritual qualities. She whispered in my ear that if I were trained, I could become a great healer, directing me never to forget my specialness. Oh, how *special* disabled people are: we have *special* education, *special* needs, *special* spiritual abilities. That word drips condescension. It's no better than being defective.

Strangers, neighbors, and bullies have long called me *retard*. It doesn't happen so often now. Still, there's a guy down the road who, when he's drunk, taunts me as I walk by with my dog. But when I was a child, *retard* was a daily occurrence. Once, on a camping trip with my family, I joined a whole crowd of kids playing tag in and around the picnic shelter. A slow, clumsy nine-year-old, I quickly became "it." I chased and chased but caught no one. The game turned. Kids came close, ducked away, yelling *retard*. Frustrated, I yelled back for a while. *Retard* became *monkey*. My playmates circled me. Their words became a torrent. "You're a monkey. Monkey. Monkey." I gulped. I choked. I sobbed. Frustration, shame, humiliation swallowed me. My body-mind crumpled. It lasted two minutes or two hours—I don't know. When my father appeared, the circle scattered. Even as the word *monkey* connected me to the nonhuman natural world, I became supremely unnatural.

All these kids, adults, strangers join a legacy of naming disabled people not quite human. They approach me with prayers and vitamins, taunts and endless questions, convinced that I'm broken, special, an inspiration, a tragedy in need of cure, disposable—the momentum of centuries behind them. They have left me with sorrow, shame, and self-loathing.

Beliefs about Disability

Most nondisabled people believe that I need to be repaired. But in another time and place, they might have believed something different. Over the centuries in white Western culture, people now known as disabled have been monsters, gods, goddesses, and oracles. We have been proof of events that happened during our mothers' pregnancies, demonstrations of sin, and markers of evil. We have been evolutionary missing links, charity's favorite objects, the proving ground for Christian miracles. We have been the wild and exotic grist of freak shows, test subjects for the Nazis as they built and refined their gas chambers. We are burdens on society, useless eaters. We are tragedy and heroism. We are out-of-control, excessive, incapable. We are courage, metaphor, cautionary tale, downfall. We are better off dead. Some of these beliefs are long gone; others, still current. They migrate through the centuries, contradicting and bolstering each other.

Some days this history weighs my body-mind down. Depending on the time and place, priests, scientists, freak show managers, philosophers, charity workers, and doctors have all claimed to be the reigning experts on disability. Priests used to cast both disabled people and cure as the will of God. Scientists, naturalists, and anthropologists, responding to the theory of evolution, used to believe that disabled white people and people of color, both disabled and nondisabled, were the missing links between humans and primates. Freak show owners and managers used to make big profits by displaying those same groups of people as wondrous, savage, curious.

Philosophers and pundits have long blamed mothers for their disabled children. Two and three hundred years ago, according to conventional wisdom, a pregnant woman who saw an elephant might give birth to a child who had lumpy skin and enlarged limbs. Today when HIV-positive women, drug users, poor women surviving on welfare become pregnant, their choices are scrutinized and called immoral, particularly if their babies are born disabled. Sometimes these women are arrested, prosecuted, thrown in jail. Disabled or deaf parents-to-be who might pass on their congenital disabilities commonly face a barrage of criticism. When the deaf lesbian couple Sharon Duchesneau and Candace McCullough sought out a deaf man as a sperm donor so that their child would have a better chance of being deaf, the judgments flew. They were accused of being selfish and unfair to their unborn child. Over the centuries, deaf and disabled people have so often been considered immoral or the markers of immorality.

Charity has long organized itself around the twin notions that disability is tragic and disabled people pitiful. We've become money-makers for Goodwill, the Salvation Army, the Muscular Dystrophy Association, Easter Seals, the Multiple Sclerosis Foundation, Autism Speaks, and on and on. In return they offer us sheltered employment for subminimum wages—sometimes as low as twenty-five cents an hour—and the promise of cure coming our way soon.

My joints ache in this cacophony of belief. For now, doctors inside the medical-industrial complex are the reigning experts, framing disability as a medical problem lodged in individual body-minds, which need to be treated or cured.

Overcoming Disability

Overcoming bombards disabled people. It's everywhere. I think of Whoopi Goldberg. In airports and along freeways, I see her plastered on a billboard sponsored by the Foundation for a Better Life (FBL).[1] Head in hands, dreadlocks threaded through fingers, she furrows her forehead in frustration. Or is it bemusement? She casts her eyes up, looking directly at her viewers. The tagline reads, "Overcaem dyslexia," coyly misspelling *overcame*. Underneath those two words brimming with stereotypes sits a red box containing the phrase "HARD WORK," and below that, the command "Pass It On."

The billboard makes me incredulous. The FBL tries to sell a pair of ideas: that Whoopi Goldberg—famous actor, hilarious comedian, Black woman—overcame learning disability through hard work, which, in turn, is a value we need to pass along. That disabled people can only succeed by overcoming disability is an ableist cliché, but let me turn it inside out. Maybe Goldberg became an actor exactly *because* of her dyslexia. Maybe she developed her kickass humor as a survival strategy to navigate the world as a Black, poor, disabled girl. Maybe she wouldn't have made it big without having a learning disability.

To portray dyslexia as a reversal of *m* and *e* in the word *overcame* is dismissive and stereotypical. To pose individual hard work, rather than broad-based disability access, as the key to success for people with dyslexia is absurd and ableist. To pair a Black woman with the value of hard work in a country that both names Black women as welfare queens and has, for centuries, exploited their back-breaking labor as maids and nannies, factory workers and field hands is demeaning and racist. Actually, the billboard enrages me.

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Overcoming is a peculiar and puzzling concept. It means transcending, disavowing, rising above, conquering. Joy or grief *overcomes* us. An army *overcomes* its enemy. Whoopi Goldberg *overcomes* dyslexia.

I believe in success and failure, resistance and resilience. I've felt the weight of ableism, transphobia, and homophobia and witnessed the force of poverty and racism. I know about the refusal to give up and the trap of low expectations. I have a stake in access, interdependence, community, and fierceness mixed with luck and the hardest of work. I understand that survival sometimes depends on staying silent and hidden; other times, on claiming identity and pride. But overcoming mystifies me.

That concept requires dominating, subsuming, defeating something. Pairing disabled people with overcoming imagines disability as that thing. But how could I dominate my shaky hands, defeat my slurring tongue, even if I wanted to? How could Whoopi Goldberg subsume her dyslexia even as words waver and reverse on the page?

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The chorus of a protest song echoes through my head: "Oh, deep in my heart / I do believe / We shall overcome / someday." This version of overcoming sung at Black civil rights protests and adopted by activists in a variety of social change movements since the 1960s means something different: collective action, transcending and dismantling white supremacy and poverty, believing in and working toward a future of liberation. But what this song doesn't mean is equally telling. It doesn't urge people into a future without, beyond, or in spite of Blackness. Without making an analogy between racism and ableism, the civil rights movement and disability politics, I want to note the striking contrast between "We Shall Overcome" and the FBL's "Overcaem dyslexia." The first grapples with systems of oppression; the second, with individualized body-mind conditions.

Sometimes disabled people overcome specific moments of ableism—we exceed low expectations, problem-solve lack of access, avoid nursing homes or long-term psych facilities, narrowly escape police brutality and prison. However, I'm not sure that overcoming *disability* itself is an actual possibility for most of us. Yet in a world that places extraordinary value in cure, the belief that we can defeat or transcend body-mind conditions through individual hard work is convenient. Overcoming is cure's backup plan.

Hope in Motion

Cure is inextricably linked to hope. I'm remembering a documentary called *Christopher Reeve: Hope in Motion* about the late, famed actor who became a quadriplegic in a horse-riding accident.[2] As a self-appointed spokesman for cure, Reeve repeatedly expressed this link, never failing to make me angry. In the film, he brashly dismisses disabled people who question the notion of cure, saying, "There are some people who just really don't dare to hope."

I'll be blunt: *Christopher Reeve: Hope in Motion* strikes me as propaganda. The narrator uses the words *overcome*, *fight*, *determination*, *inspirational*, *unwavering will*, *working tirelessly*, *amazing results* more times than I care to count. As these words pile one on top of another accompanied by rising violin music, the film reveals itself as another over-the-top story about a tragically disabled man who beats the odds, overcomes his paralysis, and through his courageous struggle gives us hope and inspiration. There is nothing unusual here, just the same old stereotypes.

The camera follows Reeve as he works out, grinding through his daily physical therapy routines, swimming in rehab pools, elated by his occasional water-assisted step. He grimaces, laboring, flashing quick smiles of triumph, always surrounded by a team of therapists, nurses, and aides.

The camera follows him as he chooses experimental surgery to implant a pacemaker in his abdomen with the hope that he might be able to breathe without a ventilator. His surgeon, Raymond Onders, says, “Our goal is to allow a patient to breathe the way he was born to breathe, to breathe more normally through the use of his own diaphragm.” His words epitomize cure rhetoric, medical intervention returning bodyminds deemed abnormal to their natural states of being, judging one piece of technology more normal than another. Relentlessly Reeve prepares for cure.

For a moment, I let go of my anger. *Christopher, what did you miss the most? Gripping a horse between your knees, feeling her supple muscles move against your legs, following and directing her rhythm with that wordless language of shifting weight and pressure? Walking on a set, a particular turn of hip and shoulder cuing the next line? Cavorting with your children and wife away from the camera?* I imagine his loss as deep as his drive for a cure.

The camera follows him around the globe as he advocates, lobbies, and fund-raises for stem cell research and a cure for spinal cord injuries. Repeatedly he enlists the rhetoric of hope and conquering diseases, leveraging pity and tragedy to make his case. *Christopher, how often did strangers pat your head? Did their pity ever exhaust you?*

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His story is as much about wealth, whiteness, and male privilege, about great and infuriating entitlement, as it is about disability. He claims that “the most disabling thing about being disabled is a feeling of hopelessness.” He means despair about his ongoing paralysis, not the ableist violence, isolation, poverty, and lack of education and employment faced by many disabled people. He says on the eighth anniversary of his accident: “I was forty-two when I was injured, and now I’m fifty. How long is it really going to be until human trials? Will they happen here, or will I have to go overseas? I don’t want to be a senior citizen when I’m cured. To get up, only to crawl around in my old age.” Only a wealthy white man with a beautiful white woman at his side could possess this much entitlement. Yet, not far beneath his words, I hear the fear of body-mind change, aging, and death.

Halfway through the documentary, Reeve surprises me. He sits in a rehab room surrounded by medical machinery, focusing hard as he learns to breathe with his new pacemaker, working to time his inhale to the pulse of this little electrical box. The narrator tells us that for eight vent-using years Reeve had no sense of smell, her tone meant to evoke pity and sympathy, to confirm his obvious pursuit of hope through cure. Breathing without his vent, he asks for a smell challenge. After he closes his eyes, a woman tips an open can of Folgers ground coffee under his nose. As violin music rises in the background, he identifies coffee, a smile emerging on his face. Then an orange, skin broken open, and finally chocolate mint. Of course, the film is telling that oh-so-familiar story, a story told thousands of times—the disabled person miraculously recovering, learning to walk, talk, see, hear, or, in this case, smell again. It reaffirms the tragedy of disability, the need for cure. At the same time, something compels me to pay closer attention as Reeve relishes those familiar scents. He says, "I don't think at the beginning of my injury that I would have ever realized how much one thing would matter, the ability to smell, the ability to eat. . . . I was looking at the big picture—what's the quickest research that's going to get me up and back on a horse. . . . But the little changes . . . to be able to smell, I'm surprised by how satisfying those little discoveries are." In this moment he isn't renouncing cure and its link to hope, but he is grappling with the nuances of body-mind loss.

Christopher, you were a privileged, wealthy, lucky disabled person. That is until your luck ran out, and you died of an out-of-control infection. In the end, I wish you could have found hope through your disabled body-mind, through community, through a desire for social justice. Instead ableism intertwined with your great sense of entitlement and made cure irresistible.

Rebelling against Cure

Over the years, I have ranted repeatedly about cure and the medicalization of disabled people. For decades, disability activists have been saying, "Leave our body-minds alone. Stop justifying and explaining your oppressive crap by measuring, comparing, judging, and creating theories about us." Declaring disability a matter of social justice is an important act of resistance—disability residing not in paralysis but in stairs without an accompanying ramp, not in blindness but in the lack of braille and audio books, not in dyslexia but in teaching methods unwilling to flex. In this declaration, disability politics joins other social change movements in the ongoing work of locating the problems of injustice not in individual body-minds but in the world.

Christopher Reeve has frequented my rants. As a rich, white man with a whole lot of access to the media and lawmakers, we needed him to advocate for social justice. He could have talked about education, unemployment, and disability access, about Medicaid funding for community-based living and the problem of warehousing disabled people in nursing homes, about stereotypes and lies, about violence, police brutality, isolation, and poverty. But he didn't.

At the same time, my ranting neither begins nor ends with Reeve. In his quest for cure, he followed the lead of many disability charity organizations that use a fraction of their money to build ramps, buy wheelchairs, revamp schools. They're not funding an end to ableism. Rather they're raising money for research and cure. They shamelessly use pity, tragedy, and the belief that we would all be better off without disability.

To escape this quagmire—pity curling into violence, charity laced with the impulse to do away with disability—many of us have chosen rebellion. I for one have honed the blunt art of ranting.

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One day in my work as an activist-writer, I'm at a podium, debunking lies about disability and cure, ranting yet again about Reeve. I pause, look at the audience, and see my friend P. standing at the back of the room. Her story of surviving cancer—surgery, chemo, radiation, her brush with death—flashes through me. All at once, my words feel like empty rhetoric. I have no idea what cure means to her.

Later I go to dinner with her and a half dozen other people to continue the conversation. I don't know what to expect. I feel nervous, not quite ready. Over food, our talk turns to story. My friend P. tells us how she's been encouraged in dozens of ways to think about her life with cancer as a battle. She says, "I'm not at war with my body, but at the same time, I won't passively let my cancerous cells have their way with me." We talk about healing and recovery, surviving and dying. No one invokes hope or overcoming. I sit here listening. For now, my impulse to rant has vanished.

The Restoration of Health

As an ideology seeped into every corner of white Western thought and culture, cure rides on the back of *normal* and *natural*. Insidious and pervasive, it impacts most of us. In response, we need neither a wholehearted acceptance nor an outright rejection of cure, but rather a broad-based grappling.

The American Heritage Dictionary defines cure as the "restoration of health." Those three words seem simple enough, but actually *health* is a mire. Today inside white Western medicine, health ranges from individual and communal body-mind comfort to profound social control. Between these two poles, a multitude of practices exist. Health promotes both the well-being sustained by good food and the products sold by the multimillion-dollar diet industry. Health endorses both effective pain management for folks who live with chronic pain and the policed refusal to prescribe narcotic-based pain relief to people perceived as drug-seeking. Health both saves lives and aggressively markets synthetic growth hormones to children whose only body-mind "problem" is being short.

Amidst these contradictions, I could try to determine who's healthy and who's not, acting as if there might be a single objective standard. I could struggle to clarify the relationship between health and disability. I could work, as many activists and healers do, to redefine health, moving toward theories and practices that contribute to the well-being of entire communities. But in using the *American Heritage Dictionary* definition as a springboard, I actually want to move away from this mire altogether and follow the word *restoration*.

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To restore a house that's falling down or a tallgrass prairie ecosystem that's been devastated is to return it to an earlier, and often better, condition. In this return, we try to undo the damage, wishing the damage had never happened. Talk to anyone who does restoration work—carpenters who rebuild 150-year-old neglected houses or conservation biologists who turn agribusiness cornfields back to tallgrass prairie—and they'll say it's a complex undertaking. A fluid, responsive process, restoration requires digging into the past, stretching toward the future, working hard in the present. And the end results rarely, if ever, match the original state.[3]

Restoring a tallgrass prairie means rebuilding a dynamic system that has been destroyed by the near extinction of bison, the presence of cattle, and generations of agribusiness farming and fire suppression. The goal isn't to re-create a static landscape somehow frozen in time, but rather to foster dynamic interdependencies, ranging from clods of dirt to towering thunderheads, tiny microbes to herds of bison. This work builds on knowledge about and experience with an eight-thousand-year-old ecosystem, of which only remnants remain—isolated pockets of leadplants, milkweed, burr oaks, and switchgrass growing in cemeteries and on remote bluffs, somehow miraculously surviving. The intention is to mirror this historical ecosystem as closely as possible, even though some element is bound to be missing or different, the return close but not complete.

The process of restoration is simpler with a static object—an antique chair or old house. Still, if the carpenters aren't using axe-hewn timbers of assorted and quirky sizes, mixing the plaster with horse hair, building at least a few walls with chicken wire, using newspaper, rags, or nothing at all for insulation, then the return will be incomplete. It will be possibly sturdier and definitely more energy efficient, but different from the original house.

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I circle back to the ideology of cure. Framing it as a kind of restoration reveals the most obvious and essential tenets. First, cure requires damage, locating the harm entirely within individual human body-minds, operating as if each person were their own ecosystem. Second, it grounds itself in an original state of being, relying on a belief that what existed before is superior to what exists currently. And finally, it seeks to return what is damaged to that former state of being.

But for some of us, even if we accept disability as damage to individual body-minds, these tenets quickly become tangled, because an original nondisabled state of being doesn't exist. How would I, or the medical-industrial complex, go about restoring my body-mind? The vision of me without tremoring hands and slurred speech, with more balance and coordination, doesn't originate from my visceral history. Rather it arises from an imagination of what I should be like, from some definition of *normal* and *natural*.

Walking in the Prairie

My friend J. and I walk in the summer rain through a thirty-acre pocket of tallgrass prairie that was not so long ago one big agribusiness cornfield. We follow the path mowed as a firebreak. He carries a big, flowered umbrella. Water droplets hang on the grasses. Spider webs glint. The bee balm hasn't blossomed yet. He points out the numerous patches of birch, goldenrod, and thistle. The first two belong here but need to be thinned out. The thistle, on the other hand, should be entirely uprooted. The Canada wild rye waves, the big bluestem almost open. Clusters of sunflowers brighten the rainy day. We pause to admire the cornflowers and asters. The songbirds and butterflies have taken shelter. For the moment, all is quiet. Soon my jeans are sopping wet from the knees down. This little piece of prairie is utterly different from a cornfield.

A whole group of people, including J., worked for over a decade to restore this land. With financial and material help from Wisconsin's Department of Natural Resources, they mowed and burned the cornfield. They broadcast the seed—sack upon sack of the right mix that might replicate the tallgrass prairie that was once here. They rooted out thistle and prickly ash. They saved money for more seed, working to undo the two centuries of environmental destruction wreaked by plows, pesticides, acres upon acres of soybeans and corn.

The Department of Natural Resources partners with this work precisely because the damage is so great. Without the massive web of prairie roots to anchor the earth, the land now known as Wisconsin is literally draining away. Rain catches the topsoil, washing it from field to creek to river to ocean. Prairie restoration reverses this process, both stabilizing and creating soil. J. and his friends worked hard, remembering all the while that neither they nor the dairy farmer down the road owned this land. It was stolen a century and a half ago from the eastern Dakota people. The histories of grass, dirt, bison massacre, genocide live here, floating in the air, tunneled into the earth.

During my visits to see J., I have taken this walk a dozen times over the last fifteen years—at noon with the sun blazing, at dusk with fireflies lacing the grasses, at dawn with finches and warblers greeting the day. My feet still feel the old cornfield furrows.

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As we return to the farmhouse, I think about *natural* and *unnatural*, trying to grasp their meanings. Is an agribusiness cornfield unnatural, a restored prairie natural? How about the abundance of thistle, absence of bison, those old corn furrows? What was once normal here; what can we consider normal now?

Or are these the wrong questions? Maybe the earth just holds layer upon layer of history.

4

NUANCES OF CURE

Wishing You Less Pain

You and I know each other through a loose national network of queer disability activists, made possible by the Internet. Online one evening, I receive a message from you containing the cyber equivalent to a long, anguished moan of physical pain. You explain that you're having a bad pain day, and it helps to acknowledge the need to howl. Before I log off, I type a good night to you, wish you a little less pain for the morning. Later you thank me for not wishing you a pain-free day. You say, "The question isn't whether I'm in pain but rather how much." As I get to know you in person, you tell me, "I read medical journals hoping for a breakthrough in pain treatment that might make a difference." You work to locate a doctor who might believe your reports of pain. Work to create the appropriate script—the exact words and stories that will open the door, lead doctors to treat you as a patient rather than a drug-seeking criminal. Work to obtain the necessary scripts—the actual prescriptions. Work to find the right balance of narcotics. You work and work and work some more.

Many a disability activist has declared that there's nothing wrong with our disabled body-minds, even as we differ from what's considered normal. I have used this line myself more than once, to which you respond, "It's true; we need to resist the assumptions that our bodies are wrong and broken. But at the same time, the chronic fatiguing hell pain I live with is not a healthy variation, not a natural bodily difference."

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I grasp at the meanings of *natural* and *unnatural* again. The moments and locations where disability and chronic pain occur—can we consider them natural, as our fragile, resilient human body-minds interact with the world? Is it natural when a spine snaps after being flung from a car or a horse, when a brain processes information in fragmented ways after being exposed to lead, mercury, pesticides? Can a body-mind be deemed both natural and abnormal? I ask because I don't understand.

And when are those moments and locations of disability and chronic pain unnatural—as unnatural as war, toxic landfills, childhood abuse, and poverty?

Wanting Cure

You and I sit in a roomful of disabled people, inching our way toward enough trust to start telling bone-deep truths. You say, “If I could wake up tomorrow and not have diabetes, I’d choose that day in a heartbeat.” I can almost hear your stream of thoughts: the daily insulin, the tracking of blood sugar levels, the shame, the endless doctors, the seizures, the long-term unknowns. You don’t hate your body-mind, nor do you equate diabetes with misery. You’re not waiting desperately, half-panicked. I know that all the time and money spent on research rather than universal health care, a genuine social safety net, an end to poverty and hunger pisses you off.

At the same time, you’re weary of the analogies: the hope that one day AIDS will become as treatable and manageable as diabetes, the equating of transsexual hormone replacement therapy with insulin. You want to stamp your feet and demand, “Pay attention to this specific experience of type 1 diabetes—my daily dependence on a synthesized hormone, my life balanced on this chemical, the maintenance that marks every meal.” You’d take a cure tomorrow, and yet you relish sitting in this room.

Birthmark

You and I talk, as we so often do, over food—this time pasta, bread, and olive oil. It would be a cliché to begin with a description of your face across from mine. Certainly I observe the vivid curve of your birthmark, its color and texture, but it doesn’t become your entire being. I know from your stories that your face precedes you into the world, that one visible distinction overtaking everything else about you.

You say, “I’m wondering why at fifteen I stopped wearing thick waxy makeup. Why did I—after a childhood of medical scraping, burning, tattooing—still pursue laser surgery, seduced by the doctor’s promises? But the excruciating pain of the first treatment made me sick, and I never went back. I don’t know when I stopped cupping face in hand, shielding the color of my skin from other humans.” I listen as you track your body-mind’s turn away from eradication toward a complicated almost-pride. You research beauty, scrutinizing the industry of birthmark removal.

You page through medical textbooks, see faces like yours, and swallow hard against shame. You've started meeting other people with facial distinctions, talking about survival and desire, denial and matter-of-factness. Tonight you wear a bright shirt, earrings to match. You insist on your whole body-mind with all its color.

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I don't understand: what becomes natural and normal? It genuinely mystifies me. Who decides that your purple textured skin is unnatural, my tremoring hands abnormal? How do those life-changing decisions get made?

Cautionary Tale

You and I meet at a disability community event. We end up in a long conversation about shame and love. You tell me the military dumped trichloroethylene near your childhood home, that chemical leaching into the groundwater and shaping your body-mind as you floated in utero. When you talk to people about this pollution and its impact, they mostly respond with pity, turning you and your wheelchair into a tragedy.

Your story reminds me of a series of advertisements in the Sierra Club's campaign Beyond Coal. In one, the tagline reads, "Asthma. Birth defects. Cancer. Enough," superimposed over a looming smoke-belching power plant.[1] In another, we see the big belly of a pregnant woman dressed in pink, one hand cupping her stomach. Her skin is light brown. Her face isn't visible. Her belly is captioned, "This little bundle of joy is now a reservoir of mercury." The fine print tells us: "Mercury pollution from our nation's coal-burning power plants is harming pregnant women and their unborn children. Mercury is a powerful neurotoxin that can damage the brain and nervous system—causing developmental problems and learning disabilities."[2]

To persuade viewers that these plants need to be shut down, both ads use disability to make an argument about the consequences of environmental destruction. There is so much to pull apart here about gender and race. The second ad relies on stereotypes about femininity and the supposed vulnerability of women and children. It objectifies a woman of color, reducing her to a body part, which is then further reduced to a reservoir. But at the center of this argument lies disability.

Seemingly the ads ask us to act in alliance with the people most impacted by the burning of coal.[3] But digging down a bit, the Sierra Club twists away from solidarity, focusing instead on particular kinds of body-mind conditions—asthma, birth defects, cancer, learning disabilities—transforming them into symbols for environmental damage. This strategy works because it taps into ableism. It assumes that viewers will automatically understand disability and chronic illness as tragedies in need of prevention and eradication, and in turn that these tragedies will persuade us to join the struggle.

Certainly ending environmental destruction will prevent some body-mind conditions. But by bluntly leveraging ableism, the ads conflate justice with the eradication of disability. The price disabled and chronically ill people pay for this argument is high. It reduces our experiences of breathing, of living with conditions deemed birth defects, of having cancer, of learning in many different ways to proofs of injustice. This reduction frames disability yet again as damage located entirely within individual body-minds while disregarding the damage caused by ableism. It ignores the brilliant imperfection of our lives. It declares us as unnatural as coal-burning power plants. The price of this argument would be one thing if it occurred in isolation, but the Sierra Club's rhetoric is only a single example in a long line of public health campaigns—against drunk driving, drug use, lead paint, asbestos, unsafe sex, and on and on—to use disability and chronic illness as cautionary tales.[4]

Amidst this cacophony, you want to know how to express your hatred of military pollution without feeding the assumption that your body-mind is tragic, wrong, and unnatural. No easy answers exist. You and I talk intensely; both the emotions and the ideas are dense. We arrive at a slogan for you: "I hate the military and love my body."

Undoubtedly we could have come up with a catchier or more complex slogan. Nonetheless, it lays bare an essential question: how do we witness, name, and resist the injustices that reshape and damage all kinds of body-minds—plant and animal, organic and inorganic, nonhuman and human—while not equating disability with injustice?

Body-Mind Yearning

The desire for cure, for the restoration of health, is connected to loss and yearning. What we remember about our body-minds in the past seduces us. We wish. We mourn. We make deals. We desire to return to the days before immobilizing exhaustion or impending death, to the nights thirty years ago when we spun across the dance floor. We dream about the body-minds we once had before depression descended; before we gained twenty, fifty, a hundred pounds; before our hair turned gray. We ache for the evenings curled up in bed with a book before the ability to read vanished in an instant as a bomb or landmine exploded. We long for the time before pain and multigenerational trauma grabbed our body-minds.

We reach toward the past and dream about the future, feeling grief, envy, shame. We compare our body-minds to friends and lovers, models in *Glamour* and *Men's Health*. Photoshopped versions of humans hold sway. We find ourselves lacking. The gym, diet plan, miracle cure grip us. *Normal* and *natural* won't leave us alone. We remain tethered to our body-minds of the past, wanting to transport them into the future, imagining in essence a kind of time travel.

Even without a nondisabled past tugging at me, I too find myself yearning. Occasionally I wish I could step into the powerful grace of a gymnast or rock climber, but that wish is distant, fading away almost as soon as I recognize it. Sometimes in the face of a task I can't do, frustration overwhelms me, and I long for steady, nimble hands. But in those moments, I've learned to turn away from yearning and simply ask for help. At the same time, the longing I feel most persistently centers on body-mind change. As my wrists, elbows, and shoulders have grown stiff and sore, I've had to stop kayaking. It's a small loss in the scheme of things, but I do miss gliding on the rippling surface of a lake, the rhythm of my paddle dipping in and out of the water.

Cure is such a compelling response to body-mind loss precisely because it promises us our imagined time travel. But this promise can also devalue our present-day selves. It can lead us to dismiss the lessons we've learned, knowledge gained, scars acquired. It can bind us to the past and glorify the future. It can fuel hope grounded in nothing but the shadows of *natural* and *normal*. And when this time travel doesn't work or simply isn't possible, we need a thousand ways to process the grief prompted by body-mind loss.

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Certainly our losses are real, but so is our adaptability. People living with body-mind conditions that grow more significant over time talk about drawing lines in the sand beyond which life would be intolerable. But as their body-minds change, they find their lines also shift. Reflecting on having multiple sclerosis, essayist Nancy Mairs writes:

> Everybody, well or ill, disabled or not, imagines a boundary of suffering beyond which, she or he is certain, life will no longer be worth living. I know that I do. I also know that my line, far from being scored in stone, has inched across the sands of my life: at various times, I could not possibly do without long walks on the beach . . . ; use a cane, a brace, a wheelchair; stop teaching; give up driving; let someone else put on and take off my underwear. One at a time . . . I have taken each of these (highly figurative) steps. . . . I go on being, now more than ever, the woman I once thought I could never bear to be.[5]

What begins as loss or pure suffering frequently becomes ordinary and familiar over time. This transformation is another response to body-mind loss.

Yearning for the Peeper Pond

i.

The connections between loss, yearning, and restoration aren't only about human body-minds. Many of us mourn the vacant lots, woods, and swamps we played in as children, now transformed into landfills, strip malls, and parking lots. We fear the far-reaching impacts of climate change as hurricanes grow more frequent, glaciers melt, and deserts expand. We long for the days when bison roamed the Great Plains and Chinook salmon swam upstream in the millions. We desire a return.

And so environmentalists, partly motivated by this longing, have started to learn the art and science of ecological restoration. They broadcast tallgrass prairie seeds, raise and release wolves, bison, whooping cranes. They tear up drainage tiles and reroute water back into what used to be wetlands. They pick up trash, blow up dams, plant trees, hoping beyond hope that they can restore ecosystems to some semblance of their former selves before the white, colonialist, capitalist, industrial damage was done.

When it works, restoration can be a powerful force, contributing to the earth's well-being, as well as providing an antidote to loss. But the damage may be irreversible; some ecosystems, irreplaceable. Restoration may take centuries or may be a Band-Aid stuck onto a gaping wound. We may not be able to fix what has been broken.

ii.

Below my house on the edge of the cow pastures, there used to be a little swampy pond surrounded by cattails, where in the early spring, just after the ice melted, hundreds of peepers would breed. These small, light-brown frogs would sing through the night. Sometimes I'd walk to the pond and stand for ten or fifteen minutes, surrounded by their chorus, eardrums and chest reverberating, shoes growing soggy. Two summers ago, neighbors built a house down there. I watched the structure go up but didn't register what it might mean for the peepers. Last spring I headed down the hill as usual, tromping through the upper field, then the hedgerow, coming out at the western edge of the cow pastures. But there was no pond, no chorus of peepers abruptly stopping as I approached. I wandered around for a while, feeling disoriented, before I realized that my neighbors' backyard was exactly where the peeper pond used to be.

It's a tiny loss in the scheme of things. This patch of land, occupied Abenaki Territory, has endured so much ecological change in the almost four centuries since white people stole it. We've clearcut it three times. Fenced it with stones walls, hedgerows, barbed wire. Planted grass. Put sheep and cows out to graze. Built houses and barns in wetlands. Created manure piles. Drilled wells for water. Leaked gas. Made garbage heaps of wire, tires, railroad ties. Bulldozed roads. More than enough damage has been done, and yet many native plants and animals are somehow doing well, including the peepers. Still, I miss this particular peeper pond, yearn to stand again at its edge, listening.

There is no return to the time before my neighbors' house, before the sheep and cows, before white people arrived. Instead I carry these losses with me. I'm slowly learning the importance of bearing witness—a quiet daily recognition, so different from the desire to repair. I let these losses sit uncomfortably in my heart. At the same time, I walk in the woods. I recycle. I take to the streets to shut down the natural gas pipeline that the Vermont Gas Company wants to build not far from here. I grow kale and beets in our backyard. I join the solar electric co-op down the road. I remember that the Abenaki Nation has not vanished, four bands making home on the land currently known as Vermont. They've relearned old traditions and are creating new ones. They've gained recognition from the state government. They've acquired, in recent years, several pieces of land, one of them an old burial site and another a sacred spot they've frequented for thousands of years. They join Indigenous peoples from all over the world in finding many ways to survive, to cultivate well-being, to defend their sovereignty.[6]

And still, there is no return to the past.

iii.

I remember my conversation with the woman whose body-mind has been shaped by military pollution, remember her slogan, "I hate the military and love my body." I sit with the question: how do we witness, name, and resist the injustices that reshape and damage all kinds of body-minds—plant and animal, organic and inorganic, nonhuman and human—while not equating disability with injustice? I feel my grief and rage over environmental losses as small as the disappearance of a single peeper pond and as big as the widespread poisoning of the planet's groundwater. I think about how we might bear witness to body-mind loss while also loving ourselves just as we are right now. I begin to understand restoration—both of ecosystems and of health—as one particular relationship between the past, present, and future.[7]

Jostling My Anti-Cure Politics

I have long brandished a vehement anti-cure politics to defend myself against the unending assertions that disability equals damage, lack of health, defect. In one diatribe, I write: "Rather than a medical cure, we want civil rights, equal access, gainful employment, the opportunity to live independently, good and respectful health care, unsegregated education. . . . Needless to say, a cure is not high on our list of goals."[8] In direct response, white, queer, disabled and chronically ill writer Peggy

Munson states, "This [politics] does not . . . apply to those of us who see treatment or cure as the only viable accommodations that would allow us back into society. . . . I have spent too many days in a place beyond living, watching hours of reality TV because reality has become like an interesting form of fiction to me. I am too sick to have employment, attend any school, or live independently without treatment or cure."[9] I could quibble about treatment versus cure, protest by saying that I've never been anti-treatment. But in actuality, my anti-cure politics has all too often shut out chronically ill people. I need to sit with Peggy Munson's words.

I listen again to the cancer survivor: "I'm not at war with my body, but at the same time, I won't passively let my cancerous cells have their way with me." To the woman for whom a pain-free day doesn't exist: "The chronic fatiguing hell pain I live with is not a healthy variation." To the power-chair-using friend who told me recently: "My wheelchair is a part of me that I wouldn't give up. But my lungs that threaten to kill me every time I get a cold—I would trade them in for a better pair without a second thought." I let their voices jostle my anti-cure politics.

As I listen, I feel the lived experiences of illness, disorder, debilitating pain and exhaustion—the moments when disability is in truth linked to being unhealthy—mount up. They ask me to pay attention. Disabled, feminist thinker Susan Wendell writes, "Some unhealthy disabled people . . . experience physical or psychological burdens that no amount of social justice can eliminate. Therefore, some very much want to have their bodies cured, not as a substitute for curing ableism, but in addition to it."[10] She insists on all our looping realities, refusing a disability politics that denies illness. All too often, even in disability communities, chronically ill people hear: "You don't seem sick," "You can't be sick again," "It's all in your head." I let Wendell's words jostle me too.

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Amidst these voices, I think again about the Sierra Club ads, which, while leveraging ableism, make important connections between environmental destruction and illness. They tell us unequivocally, "Pay attention: burning coal causes cancer and asthma." Frustratingly, in its current form this environmentalist message also transforms illness into a symbol. However, I can imagine a slightly different series of billboards and commercials, integrating a broad-based, multi-issue politics of chronic illness and disability. They would locate injustice in many places all at once: in coal burning; in extracting fossil fuels from the ground; in poisoning the planet and the many beings that make home here, including humans; in the racism and classism that force poor people and people of color to live and work near environmental destruction. Cancer and asthma would become not symbols but lived realities amidst injustice.

Using this broad-based, multi-issue politics as a guide, the restoration of health doesn't only involve the use of medical technology to repair a boy's lungs and return his breathing to normal or to stop the ravages of cancer in a woman's body and create permanent remission. Cure also requires dismantling racism, poverty, and environmental injustice. I let health and cure take on multiple meanings.

At the same time, in a world saturated with ableism, it's difficult to acknowledge the connections between disability, chronic illness, and injustice while also holding on to the inherent value of disabled and chronically ill people. I yearn for a future when everyone has health care that promotes well-being and self-determination; enough nourishing food to eat; access to clean, plentiful water and warm, dry, safe places to live. I long for a time after we've stopped spewing tens of thousands of human-made toxins; cleaned up the garbage dumps, radiation leaks, and oil spills; put an end to body-mind-breaking work conditions. I'm desperate for a world where war, imperialism, and genocide no longer exist, and colonial-settler nations are making ongoing reparations. In this imagined future, the body-mind differences we now call disability and chronic illness will be diminished, some of them eradicated. Yet humans are too fragile and the world too unpredictable for disabled and sick people to disappear. And if we did, what a loss that would be.

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I let this multitude of relationships we have to disability, illness, suffering, injustice, and cure jostle me, knowing that I need this exact tangle of conflicting and overlapping conversations. Holding it all—sickness and human vulnerability, health and disability, the need for and the rejection of cure—is much harder work than writing anti-cure diatribes. And much more necessary.

Your Suicide Haunts Me

Bear, it's been over a decade since you killed yourself, and still I want to howl.[11] I feel anguish and rage rattling down at the bottom of my lungs, pressing against my rib cage. If ever my howling erupts, I will take it to schoolyards and churches, classrooms and prisons, homes where physical and sexual violence lurk as common as mealtime. I know many of us need to wail. Together we could shatter windows, bring bullies and perpetrators to their knees, stop shame in its tracks.

Once a week, maybe once a month, I learn of another suicide. They're friends of friends, writers and dancers who have bolstered me, activists I've sat in meetings with, kids from the high school down the road, coworkers and acquaintances, news stories and Facebook posts. They're queer, trans,[12] disabled, chronically ill, youth, people of color, poor, survivors of abuse and violence, homeless. They're too many to count.

Bear, will you call their names with me? It's become a queer ritual, this calling of the names—all those dead of AIDS and breast cancer, car accidents and suicide, hate violence and shame, overdoses and hearts that just stop beating. The names always begin wave upon wave, names filling conference halls, church basements, city parks. Voices call one after another, overlapping, clustering, then coming apart, a great flock of songbirds, gathering to fly south, wheeling and diving—this cloud of remembrance. Then quiet. I think we're done, only to have another voice call, then two, then twenty. We fill the air for thirty minutes, an hour, a great flock of names. Tonight, will you sit with me? Because, Bear, I can't sleep.

I remember your smile, your kindness, your compassionate and fierce politics. I remember our long e-mail conversations about being disabled and trans. I remember a brilliant speech you gave at True Spirit, a trans gathering in Washington, DC. I remember you telling me about how you'd disappear for months at a time when your life became grim, how you'd do anything not to go to a psych hospital again. I remember your handsome Black queer trans disabled working-class self. And then, you were gone.

The details of your death haunt me. You had checked yourself in. You were on suicide watch. I imagine your desperation and suffering. I know racism, transphobia, classism colluded. The nurses and aides didn't follow their own protocols, not bothering to check on you every fifteen minutes. You were alive and sleeping at 5:00 a.m. and dead at 7:00 a.m.; at least that's what their records say. Did despair clog your throat, panic coil in your intestines? In those last moments, what lingered on your tongue? I know about your death as fleetingly as your life.

Bear, I'd do almost anything to have you alive here and now, anything to stave off your death. But what did you need then? Drugs that worked? A shrink who listened and was willing to negotiate the terms of your confinement with you? A stronger support system? An end to shame and secrecy? As suffering and injustice twisted together through your body-mind, what did you need?

I could almost embrace cure without ambivalence if it would have sustained your life. But what do I know? Maybe your demons, the roller coaster of your emotional and spiritual self, were so much part of you that cure would have made no sense. You wrote not long before your death, "In a world that separates gender, I have found the ability to balance the blending of supposed opposites. In a world that demonizes non-conformity, I have found the purest spiritual expression in celebrating my otherness."[13]

Yes, Bear. I know that truth. Your otherness was a beautiful braid—your hard-earned trans manhood looping into your Black self, wrapped in working-class smarts and resilience, woven into disability, threaded with queerness. I saw you last in an elevator at True Spirit. You told me that you were spending the weekend hanging out with trans men of color. I can still see your gleeful smile, sparkling eyes.

Friend, what would have made your life possible with all its aches and sorrows? I ask as someone who has gripped the sheer cliff face of suicide more than once. Calling the names exhausts me. Your death exhausts me. The threat, reality, fact of suicide exhausts me. Its arrival on the back of shame and isolation exhausts me. Bear, will you come sit beside me tonight? I'm too exhausted to sleep.

brilliant imperfection

SHELLS

Camped on a barrier island off the Gulf Coast of Florida in occupied Calusa Territory, I hunker over shells, riveted by their shapes, sizes, textures. I marvel at the spirals broken open—sunset oranges, reds, pinks. I slip a spindle of shell into my pocket and down the beach find the same shell alive, muscle of animal protruding, then retracting in response to my touch. The shells taper to fragile points thinner than my little finger. They bulge into hollow chambers bigger than my fist, the biggest bleached white and covered with barnacles.

I've brought a field guide with me, because I know virtually nothing about this subtropical coastal ecosystem. I flip through it, finding whelk, conch, cockle, in addition to the shells I know well—sea urchin, sand dollar, scallop. I whisper their names to myself.

I sit near a mound of shells, sift them through my fingers, all the spirals broken except the tiniest, the hinged shells separated at the joint between their wings. Paper thin, milky white, ridged—mostly this mound is made of fragments. Corkscrew of moon snail, cap of whelk, ring of urchin: I hang on to these names. But in truth, the shards are largely unnameable as the ocean grinds them back into sand. Through my fingers fall wriggling crabs. Down the beach, lanky white shore birds poke their long bills into the sand, feasting.

10

PROMISE OF CURE

Normal and *Natural*

The medical-industrial complex pushes normal weight, normal walking, normal ways of thinking, feeling, and communicating as if *normal* were a goal to achieve and maintain. Sometimes *normal* is attached to *natural*; multinational corporations marketing natural beauty, natural strength, natural skin every day, as if *natural* were a product to sell.

At the same time, white Western beliefs separate human animals from nonhuman nature and devalue the natural world. Coupled with capitalism, these beliefs drive an out-of-control greed for and consumption of coal and trees, fish and crude oil, water and land. Drive the destruction of what is natural. Drive the declaration of cornfields as more productive and necessary than prairie. In short, the white Western world both desires to be *natural* and destroys what is *natural*, depending on the context. It makes no sense.

The standards called *normal*—sometimes in tandem with *natural*—are promoted as averages. They are posed as the most common and best states of being for body-minds. They are advertised as descriptions of who "we" collectively are—a *we* who predictably is white, male, middle- and upper-class, nondisabled, Christian, heterosexual, gender-conforming, slender, cisgender. And at the very same time, these standards, which supposedly reflect some sort of collective humanity, are sold back to us as goals and products. It makes no sense.

This nonsense couldn't exist without the threat of *unnatural* and *abnormal*. Whether focused on repairing disabled body-minds or straightening kinky hair, lightening brown skin or making gay, lesbian, and bi people heterosexual, cure aims to make us as *normal* and *natural* as possible. The pressure is intense, created and sustained by the consequences and dangers of being considered abnormal and unnatural. Inside this pressure cooker, the promise of cure is continually at work.

Finding Wholeness

In the years leading up to my chest reconstruction surgery, doubt gripped me. I didn't hate my breasts but still wished them gone. I sat with questions and misgivings. Only a decade and a half before, I had wanted to amputate my shaky right arm, to be done with the tremors I couldn't hide, the tension locked into shoulder and forearm. I asked myself flat out: What's the difference between these two desires—the one to amputate my breasts and the other to cut off my right arm?

I could say I never wanted breasts, drawing a straight line between the nine-year-old protesting my mother's command to put a T-shirt on and the thirty-five-year-old saving money for surgery. I could, but I would be simplifying a looping and contradictory history. No single story holds the entire truth.

I knew what body-mind hatred felt like—its desperate numbness tearing at me, willing away my lopsided flesh, clumsy gait, ugly tremors. I had worked hard to disentangle myself from the bleakest of that hatred and in the process abandoned my fantasy of cutting off an arm. But as my longing for a flat chest emerged, I returned to that work, tunneling some more through the thicket called shame. I came to trust that my gendered and sexed desire shared almost nothing in common with my disability hatred. That desire arose, quiet and insistent, not from self-loathing but rather self-love, flesh whispering, "*This*, this body-mind, is what I want." Shame and love fluttered like shadow and light.

I used this insight to explain my body-mind, first to myself, then to family, friends, and acquaintances. I leveraged shame as wrong and imposed from the outside and self-love as unassailable and entirely internal. The contrast between shame and self-acceptance became the way I justified my desire, as if what my body-mind wanted couldn't quite be trusted.

I am the genderqueer who binds my breasts tight against my chest wall, flattening them as much as possible. It is uncomfortable and necessary, another way to both ignore and love my body-mind. I start buying crisp Oxford shirts and thin retro ties, dress clothes no longer a misery.

I felt buffeted by the endless prurient questions: “How do you know you’re transgender?” “Isn’t surgery mutilation?” “Are you a boy or a girl?” I used my insight to shield myself. But in doing so, I was defending, rather than claiming, the yearning that streamed through me.

I am the lover who finds a way to unbind my breasts. My nipples come alive to fingers, tongue, teeth, stone melting away.

……

I could end this story right here; let my insight about shame and self-love be the resolution, the answer to my presurgery ambivalence. But I actually want something less neat, less resolved, because even today as I run my hand over my pecs, adore how my shirts fit, and feel immense comfort inside my skin, I hear echoes of my earlier self-doubt. How can I reconcile my lifelong struggle to love my disabled self exactly as it is with my use of medical technology to reshape my gendered and sexed body-mind? I’m searching for a messier story.

I return to transabled people, those folks who actively choose disability for themselves and in the process encounter so much revulsion, anger, disbelief. I have to say that I don’t fully grasp their desire, but I do know that it is real and unrelenting. I could be one of those people who ask endless questions, allowing prurient curiosity to take the place of courtesy, respect, connection. Or I could quiet myself and sit with what I don’t understand.[1]

In the documentary *Whole*, which profiles five white, transabled men, George recounts, “I carried out . . . a lifelong obsession that my leg should be amputated. I very methodically planned an injury with the shotgun. . . . And [after it happened], I felt absolutely . . . transformed. . . . I have become whole.”[2] I sit with his words, recognizing his desperation and contentment but still not understanding transabled desire. His story makes me uneasy. Kevin, another of the men profiled in the film, says of his longing that led him to find a surgeon willing to amputate one of his legs: “I think it’s weird. What is it that visits this on people? . . . It’s obviously peculiar. But knowing it’s peculiar . . . doesn’t do away with [it].” I think about our body-mind desires and which ones we choose to follow, to trust even when they are contradictory, mystifying, inexplicable. I listen to Kevin’s puzzlement, George’s certainty; both feel familiar to me. Toward the end of the documentary, George reflects, “What I did that day [I shot my leg] was imperative. The alternative was suicide.” I’ve heard the exact same sentiment in trans communities about gender transition. George’s and Kevin’s words, coupled with the ways I both recognize and feel unsettled by them, stir up the messiness I need.

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I am the female-to-male transgender person who lets a scalpel touch my chest. The surgeon slices half-moons around my aureoles, cuts tissue away, and preserves as many nerves as possible. I lie in this operating room, anesthetized and in relationship with medical technology yet again.

Nothing I tried satisfied my desire for a flat chest—not denying it, not talking about it, not working to love myself more, not binding. So I went looking for a surgeon and started saving $8,000, slowly, paycheck by paycheck.

Three days later, I remove the bandages for the first time and stand in front of the mirror. I haven’t seen this flat, smooth chest in a long time. Still later, after the surgeon removes my bulb drains, I button up my flannel shirt, and it fits exactly right.

I could have turned my desire into a diagnosis, named it gender identity disorder, declaring myself a man who needed a man’s body-mind, and surgery a cure. But my yearning was more paradoxical than that, as is the body-mind rightness I feel now, never missing for one instant the weight, size, shape, or sensation of my breasts.

It’s midsummer, and I am the white guy walking a dirt road between cornfields in occupied Dakota Territory right after sunset. I take off my T-shirt, tucking it into the waistband of my shorts. The fields are lushly green, quivering in the humidity. The cornstalks stand tall and sturdy, tassels silky and the color of honey, kernels of corn plump and hidden. Dusk licks my ribs, sternum, collarbone. I think about how good these ears of sweet corn taste, fresh from the field, husked, boiled, and buttered.

I struggle with the concept of body-mind rightness. I don’t quite believe in it, even as I’ve felt it spread across my chest. As an idea, it suggests that we can disentangle our body-minds from all the forces the world exerts on us and feel some kind of pure, individual rightness humming under our skin. I don't believe we can separate ourselves that definitively from oppression and privilege, stereotypes and shame. And yet in my technologically reshaped flesh, I feel an abiding contentment, which I can only describe as rightness. I so need that messier story that allows our body-minds and desires to be inexplicable.

> *But as I walk farther down this dirt road, I remember how easy it is to mistake beauty. The monoculture of agribusiness corn has brought nothing but soil depletion and erosion, a glut of non-nutritious, corn-based processed food, and wholesale destruction of prairies. I think of the ecosystem my friends are restoring. I think yet again about* natural *and* unnatural, normal *and* abnormal. *But mostly I feel dusk licking my bare skin—a soft, airy caress. It would be all too easy to mistake this individual body-mind pleasure and comfort for collective liberation.*

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This welter of feelings and beliefs brings me back to transabled people. I still don't understand their unequivocal choice of disability. But then, I am also the person who doesn't fully understand my own visceral desires. I need that messier story because there is no real way to reconcile my lifelong struggle to love my disabled self exactly as it is with my use of medical technology to reshape my gendered and sexed body-mind. I can either try to fix the contradictions or embrace them.

In the end, I, like transabled people lucky enough to find surgeons willing to operate on them or desperate enough to carry out disabling events, had healthy flesh cut away and in the process found wholeness. Shame and love still flutters like shadow and light.

Gender Transition

My slow turn from butch dyke to genderqueer living as a white man in the world was never about curing disorder or fixing brokenness, but rather about desire and comfort—transition a door, a window, a cobalt sky.

That said, trans people who want to transition using surgeries, hormone replacement therapy, or both have many different relationships to cure. Some folks name their transness a birth defect, a disability in need of repair. The word *defect* always takes my breath away. It's a punch in my stomach. These folks reason, "I should have easy access to competent, respectful health care just as other disabled people do. I simply need a cure." Their logic makes me incredulous, even as I work to respect people who name their transness this way. Do they really believe disability ensures decent—much less good—health care? I could tell a thousand stories, cite pages of statistics, confirming the opposite, and rant for hours about ableism in the medical-industrial complex. I hate their unquestioned acceptance of cure.

But I need to pause my rant for a moment. Until the early 1990s, when trans communities began finding strong, collective voices, medical providers' explicit goal for gender transition was to create normal heterosexual men and women who never again identified as trans, gender-nonconforming, gay, lesbian, or bi. In other words, the framing of transness as defect, an abnormality to be corrected, didn't start with trans people but with the medical-industrial complex.

And then there are the real forces of gender dissonance and body-mind dysphoria. Scholar Alexandre Baril reflects, "The problem with framing transness as a defect resides, I believe, not in the concept of transness as disability, but in such individualist, ableist, pathologising views of disabilities."[3] He continues, describing his experience as a transsexual disabled man: "My transness has been and continues to be a debilitating and disabling component of my life. My dysphoria, although much less intense than before my transition, is a constant presence that manifests itself through a variety of concerns that, taken separately, might seem insignificant but that, taken together, reveal a persistent discomfort about my body. This dysphoria is as psychologically disabling as my other mental disabilities."[4] Rather than resorting to some naive and stereotyped notion of defect, Baril is grappling with a complex tangle. His words ask me to sit with the reality of body-mind dysphoria as a sometimes overwhelming or disabling force.

Still other trans people turn the idea of gender dissonance inside out, refusing to name transness a disease and gender nonconformity a pathology. Their refusal locates dysphoria not in individual trans people but rather in a world that often denies, mocks, and criminalizes our genders.

Transition as an open door, transness as defect to fix, gender dysphoria as disability, transgender identities as nonpathologized body-mind difference—all these various realities exist at the same time, each with its own relationship to cure and the medical-industrial complex.

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Even as my transition was not about fixing disorder, the promise of cure still called out to me, burrowing into my body-mind and channeling what I wanted. The medical-industrial complex taps into our desires, promising us so much. Through cure, it assures us that we can control and reshape our body-minds; restore them to some longed-for, imagined, or former state of being. Assures us that the unhappiness we feel resides within our individual selves. Assures us that on an individual level we can be whole and that on a collective level disability, illness, and body-mind difference can be eradicated. This assurance—that medical technology can align our body-minds with what we desire (whether it be an end to pain or depression, the ability to walk again, the loss of weight, or the reshaping of our sexed and gendered selves)—is so seductive.

When I started taking testosterone, I was impatient for facial hair and a deeper voice, slimmer hips and a squarer jaw. But underneath those defined body-mind changes, I hungered for a settledness that *girl* and *woman* had never given me. I caught myself thinking of that pale yellow synthetic hormone as honey and light, the smell of sugar pine, infusing me. Through metaphor, I was trying to wrench my transformation away from the medical-industrial complex.

But in truth, the people who control transition technology—surgeons, therapists, endocrinologists, family doctors—are all embedded in the white Western system of medicine, trained to identify and repair body-mind trouble. Diagnosis in the form of gender dysphoria and the recently discarded gender identity disorder plays a significant role in who receives treatment in the form of hormones and surgery and who doesn't. Multinational pharmaceutical companies develop, produce, distribute, and profit from hormones. In short, the medical-industrial complex shapes gender transition in dozens of ways. I wasn't injecting honey and light into me but rather a chemical compound, contributing to the profits of Sun Pharmaceutical Industries. I was stepping through the door held open by the promise of cure.

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Trans people aren't alone in our encounters with the promise of cure. Any time we—trans and cisgender, disabled and nondisabled—access medical technology to change our body-minds in little ways or big ways, we are engaging with that seductive assurance. We go to a fertility clinic wanting to become pregnant, to our primary care doctor wanting meds to stop daily full-blown panic attacks, to the emergency room wanting to mend a broken leg. We enter the medical-industrial complex with many different needs and desires, interacting with cure's promise in many different ways.

But cure doesn't only follow the lead of our body-mind yearnings; it also pushes us toward normality. Transition certainly didn't make me a normal guy. Yet I'm no longer "ma'am" on one street corner and "sir" on the next—my body-mind no longer a pry bar, leveraging space between man and woman. For the first time in my life, I'm read consistently as a single gender. Even as I've remained twisted, bent, rebellious, unrepentantly queer, my relationship to *normal* has definitely changed.

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The promise of cure held the door open, and I stepped through. I listened to desire. I found body-mind comfort. I live more easily inside the gender binary. I still feel akin to my nine-year-old self who flew her kite in the hayfields and knew she was neither girl nor boy. I cured nothing because there was nothing to cure. All these forces jostle through me.

Bullied

Annette, you and I met thirty years ago walking across the United States on the Great Peace March for Global Nuclear Disarmament.[5] We shared a tent for those eight and a half months and still call each other tentmates. Such an intimate relationship—neither sisters nor lovers—we slept together in a rose-colored dome tent night after night across the desert, mountains, Great Plains, through cornfields, cities, and industrial sprawl. A decade and a half later, we fell apart over body-mind change.

The same year I had chest reconstruction surgery, you had gastric bypass surgery. Neither of us liked the choice the other was making. You wanted me to stay a woman, and I wanted you to remain fat. As someone who loves your breasts, you had no understanding of why I wanted mine gone. And I, with a long history of appreciating fat women, had no understanding of how fatness itself, not only fatphobia and shame about being fat, was trouble in your life. Your feminist politics made gender transition hard to accept, and my fat politics made weight loss surgery equally unpalatable. We ended up explaining and justifying our body-minds to each other.

Annette, I remember an evening camped on Powerline Road, middle of the Mojave Desert. The whole ungainly lot of us—feminists and anarchists, middle-of-the-road Democrats and socialist revolutionaries, longtime peace activists and Vietnam vets—erupted in anger as we tried to work through some contentious community issue. That evening, you slipped me a love note on a scrap of paper. Last year I reread my journal from those months and found your note tucked inside.

I don't want to repeat the hurtful things we said to each other as we fought about surgery. In all my years of doing ally work in fat activist communities, I had never been close to anyone who decided to undergo gastric bypass. And in your time in queer communities, you had never seen anyone through gender transition. I wanted you to work against fatphobia and love your fat body-mind, just as you wanted me to fight sexism, homophobia, the gender binary and love my butch woman's body-mind. I didn't trust doctors to reshape your gastrointestinal tract and wondered if you were under the thrall of a highly profitable, well-advertised bariatric surgery industry and a media-driven panic about the "obesity epidemic."[6] Likewise, you suspected I had caved to masculinity and misogyny. We both responded with a singular, determined "change the world, not our body-minds" politics, distrusting each other's desires. In short, we were a hot mess.

Annette, I remember an afternoon at the Rocky Flats nuclear weapons plant as hundreds of us sat in front of the main gate, mountains to our backs, protesting weapons, war, radiation leaks. You and I sat close, leaning against each other.

We came back together through love, patience, time, and listening, you a smaller, but still fat, white dyke and me a genderqueer who lives as a white guy in the world. We both talked about how audacious our decisions felt, allowing scalpels and synthetic hormones to rearrange fundamental body-mind functions. We witnessed each other's changes. You shed pounds as my voice deepened; your eating shifted as I grew stubble on my face.

Listening and patience helped us through this deep struggle, but we both needed to do other work as well. You had to grow beyond your sense of transition as abandonment and betrayal into a wider understanding of gender that the binary denies. I had to embrace contradiction, letting your choices and my politics jostle against each other rather than insisting on some simple resolution. For me, compassion had to become as important as struggle. In the end, we were both transformed and utterly the same.

Annette, I remember a night camped at a racetrack on Lake Erie, our tent flapping wildly in the wind. We fell asleep giddy and laughing.

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On the phone you tell me, "I was desperate not to be fat." We talk for a long time about desperation. You wonder out loud if your surgery was a cop-out. I ask about fatphobia—the daily jokes, laughter, whispers behind your back, outright street harassment. I remember your stories: doctors calling you "morbidly obese" and strangers heckling you on airplanes. I feel your exhaustion in my bones. I think about the gender binary and the unending trouble I've encountered in public restrooms; the daily routine of "ma'am, oh, sorry, sir, I mean ma'am" at coffee shops, gas stations, grocery stores; the frat boys who shout at me from their cars—how it all has worn me down.

Together we name fatphobia, transphobia, and the gender binary bullies, our body-mind politics still fierce but more flexible. Both of us spent our childhoods tormented, you called *fatso* and *Mama Mammoth*, me *retard* and *monkey*. I want to go back in time to sit with the twelve-year-old you who turned all that taunting inward, hating yourself more every day. Sit with you twenty-five years later as you decided to have surgery, desperate and full of desire. Sit with you now.

As children, we resisted, hid, ran away, changed ourselves, taunted right back, but none of these strategies stopped the bullies or the damage they inflicted. We swallowed the hurt, caved to their demands, cried our eyes out, fell silent. Now, as adults, we live in fat community, disability community, queer and trans community. We've found lovers and friends, demonstrated in the streets, and led anti-oppression trainings. Even so, we sometimes still swallow the hurt.

So many external forces pushed and pulled at us as you chose surgery and I chose transition. Certainly exhaustion, shame, and desperation factored into our decisions. But right now, right here, as we say good night and end our call, I can feel us holding space for each other, our stories overlapping and colliding, love humming between us.

A Maze of Contradictions

i.

Grappling with cure has led me into a maze of contradictions and colliding forces. Making profit sits next to extending life. Insisting on eradication piles on top of providing comfort. Ending pain and suffering justifies the vilest of research. All of it lives publicly in an amorphous tangle called the medical-industrial complex and privately in our bedrooms, kitchens, and bathrooms. Inside this maze, I keep stumbling into dead ends, revisiting the same intersections, discovering well-worn paths that circle back onto themselves.

I, along with many of us, am alive because of medical technology and the ideology of cure, which drives the discovery and development of that technology. Yet cure also responds to the "trouble" of being fat with gastric bypass surgery, dieting, and shaming. I have found bodymind comfort and connection through the medical-industrial complex. Yet cure also responds to the "trouble" of significant facial birthmarks with laser surgery and the "trouble" of walking in ways deemed broken by breaking bones, resetting them, stretching them. Without hesitation, I use antibiotics, ibuprofen, synthetic testosterone, appreciating everything they do for me. Yet cure also responds to the "trouble" of voices and visions with mind-numbing psychotropic medication. This maze repeats itself endlessly.

I entered it hoping to find places where all the contradictions met matter-of-factly. But now I want to step out. Step out of these constrained and constraining corners, roundabouts and dead ends. Step out and let cure be the contradictory mess it is.

ii.

Once fatphobia, ableism, sexism, racism, classism, homophobia, transphobia, xenophobia, and all the rigid constraints placed on body-mind variation are dismantled, what will we desire? This question overwhelms me. It requires an impossible flight of imagination. So let me start with what I know for sure.

No to Fairview, the Colony in Lynchburg, the Asylum in Ionia, the Judge Rotenberg Educational Center. No to the La Frontera Psychiatric Health Facility where Alexander Goodrum spent his last days and the Bronx Zoo where Ota Benga lived with Dohong the orangutan. No to ethics committees that define personhood and approve growth attenuation treatments, like the one Ashley underwent. No to generations of removal and genocide. No to daily bullying, gawking, and endless prurient questions. No to the Foundation for a Better Life selling the virtue of overcoming and the Muscular Dystrophy Association using pity and tragedy to fund-raise. No to coal-burning power plants and agribusiness cornfields, undrinkable water and unbreathable air. I sit amidst a great cloud of noes.

I catch glimpses of a world where many kinds of body-mind difference will be valued and no one eradicated; where comfort, pain, well-being, birth, and death all exist. Cure promises us so much, but it will never give us justice. In this world reconfigured, cure may not exist, but if it does, it will be only one tool among many. In this world, our body-mind desires will spread through us, as vibrant and varied as a tallgrass prairie in midsummer.

Mama, What Will You Swear?

My mother is a woman with one kidney, one ovary, and lungs that often forget how to breathe, made worse by thirty years of smoking; a woman who is allergic to half of everything that grows outside; a woman of unrelenting, sleep-all-day depression. She called me *handicapped*, a word I believed for a long time that she had invented to describe me.

But she never called herself that, even as she remembered long childhood nights spent gasping for one breath after another, hour upon hour. Her mother would gather her up, and they'd sit together in the living room, shadows thrown against the walls, lungs heaving, diaphragm straining.

On Battle Rock Beach, she and I hunted for glass floats—those green-blue, hollow glass balls Japanese fishermen used to buoy their fishing nets. In lulls between winter storms, we found them, glinting in the sun, after they had broken loose and been tumbled, tossed, blown across the ocean. Some of them arrived on the beach still wrapped in fishing net.

Daughter of a car mechanic, first generation to grow up in the city and finish high school, she learned early how to breathe air thicker than water. There was never enough money for an inhaler, much less visits to the emergency room during the worst of her attacks. *Mama, what would you have given on those desperate nights for a shot of adrenaline to open the collapsed sacks of your lungs?* She grew up, a girl living on the edge of oxygen and panic, never trusting her next breath.

She became the mother who never connected her body-mind differences to mine, her desire to have me cured palpable between us. She watched her mother have one stroke, then another, blindness descending, before she died alone and confused in a nursing home. My mother counted the women in her family—sister, aunt, mother, grandmother, great-grandmother—to die of blood clotting in the brain and heart. She swore against dying like that.

> *Today Japanese fishing nets are buoyed with plastic floats—white and orange, shaped like bowling pins—that no one collects, except commercial fishermen. I have a single glass float from our walks on those storm-lulled beaches—the size of a baseball and pockmarked, an ordinary object turned rare.*

As her lungs grew worse—all those years of smoking Pall Malls in public, corncob pipes in private taking their toll—she taped a Do Not Resuscitate order (DNR) to her refrigerator and supported Oregon's physician-assisted suicide law. She swore against living with emphysema.

But the blood clot that rushed her brain heeded no one's sworn desires. It left her alive and immobile, sent language reeling into the netherworld. She spent months in rehab, learning the art of maneuvering a wheelchair with one floppy arm. Speech therapy returned some—but not enough—words to the warm cave of her mouth.

She used to make her way through the world with words, studying old Icelandic ballads, teaching Shakespeare and Milton, retelling the stories of King Arthur and Beowulf. She grew up with a single book—the King James Bible—and believed literacy and worthiness to be bound together.

Mama, what do you swear now as you gasp words, thicker than water, from your reordered brain? What do you want from your own bent body-mind with a heart that pumps blood prone to clotting, you who never wanted me as I was?

When you go to the grocery store, post office, movie theater, shuffling your wheelchair along with your feet, and encounter some coworker from a decade ago, what do you want? In that moment as he pats your head and kisses your cheek, murmurs some useless platitude and rushes away before your tongue can find even a single stumbling word, do you want to roll over his sensitive toes? Kick him in the shins? Flip him off with your stronger left hand? Or do you just want to retreat?

She used to tell me that I had to accept all the pity, charity, patronizing heaped on me, a fifteen-year-old trying to make sense of strangers who cried and prayed over me. *But now, let me tell you a secret: you can kick the bastard and then tell the story in all its infuriating and comic detail.*

> *If this float were ever to break, all I would have left is the body-mind memory of palm curving around ocean-drenched glass—those blue-green balls no longer shaped by glassblowers, broken loose from fishing nets, and found glistening in the surf on faraway beaches. And if memory were ever to be fractured, shards of glass sharp and unyielding, what then?*

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Come join us—a multitude of mad, sick, disabled, and deaf people. We won't ask you to check your shame and loss at the door. We are not Pollyannas or poster children, inspirations or tragedies. Rather we are cranky and stubborn, defining neither beauty nor ugliness, punishment nor reward. We won't ask you to desire your life, but among us, you might choose to tuck that DNR *away.*

Mama, what will you swear?

Walking in the Prairie Again

I return again in early fall to the thirty acres of restored tallgrass prairie in occupied Dakota Territory. I walk, thinking not of concepts, but of beings. The grasses swish against me. A few swallowtail butterflies still hover. A white-throated sparrow sings. I see coyote scat next to the path. I hear a rustle and imagine a white-footed mouse scurrying and a red fox pouncing. Above, vultures circle on the thermals. A red-tailed hawk cries not so far away.

In this moment, the prairie is made up of millions of beings. But just over the rise, another agribusiness cornfield turns brown and brittle.

Just over the rise is a barbed-wire fence, a two-lane dirt road, an absence of bison. Just over the rise is the illogic of *natural* and *unnatural*, *normal* and *abnormal*. Just over the rise, we wrestle with loss and desire, promise and injustice. Just over the rise are the bullies with their rocks and fists, the words *monkey*, *defect*, and *retard*. Just over the rise, we need to choose between monocultures and biodiversities, eradication and uncontainable flourishing.

This little pocket of restored prairie is not a return to the past nor a promise to the future, although it may hold glimmers of both. Rather it is simply an ecosystem in transition from cornfield to tallgrass, summer to winter. I feel the old corn furrows underfoot, the big bluestem waving above me, my own heart beating, imperfect and brilliant. I walk—a tremoring, slurring human, slightly off balance, one being among many. Could it all be this complexly woven and yet simple?

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brilliant imperfection

CYCLING

You and I are cycling buddies, you on your handcycle and me on my recumbent trike. We make a good match, both of us on three wheels, sitting ten inches off the ground. You fly downhill, way faster than me; I adore watching you lean into the first turn of a descent before you disappear. Maybe I climb faster than you, but only maybe.

We seek out hilly loops in western Massachusetts, training for a three-day hundred-mile ride in New Hampshire's White Mountains. We curse and groan our way up Mount Tom, sail back down. On flats, we gab and tease. When there's not enough room to ride side by side, I follow close behind you, charting my course on bumpy asphalt by watching your tires, admiring your shoulders flexing through every pedal stroke. On steep hills, you tuck in behind me, watch my rear wheel, and keep cranking.

When we're in the White Mountains, climbing the Kancamagus—fourteen hundred feet of elevation gain in the last four miles—you'll slide behind me, and we'll ride together, quiet except for the creak of your handcycle and the wind whipping around us. Those four miles will take us well over an hour. There'll be no pity, no tragedy, no standing ovations, no over-the-top inspirational human-interest stories in the local paper; just the two of us moving slowly and steadily, defying gravity.