



Your Puny,  
Vulnerable Self

On October 1, 2003, I caught a branch in the spokes of the front wheel of my bicycle, and hurtled toward the pavement. My chin took the full force of the blow, which smashed my face and broke the fifth and sixth cervical vertebrae in my neck. The broken bone scraped my spinal cord, and in an instant I was paralyzed. There's no knowing right away exactly what impairments will result from a spinal cord injury, but as the days passed, it became clear that I had lost the use not only of my leg muscles, but also the muscles of my torso, arms, and hands, and that the loss of muscle compromised my body's circulatory systems. I also lost control of my bladder and bowels. (The cord was not severed, so over many months I regained limited, but functional, strength in my arms and, to a significantly lesser degree, my hands.) Lying in the intensive care unit of Hartford hospital, I knew very little about the present and nothing about the future. I only knew that I had been grievously injured, and was lost in space. Not until I reached the rehab hospital a month after the accident could I begin to put into words a body that seemed beyond the reach of language.

The accident occurred twenty-nine days after my fiftieth birthday. Quadriplegia suddenly encountered at fifty years of age has made vividly clear to me both the vulnerability of the human body, and the

myriad ways my well-being depends on both the regard and the labors of others. I hope that your life is much easier in this respect than mine. Nonetheless, because humans are born wholly vulnerable and incomplete, you have already received what is known as “total care,” which you may again need at the end of your life, should you live long enough to grow feeble in mind or body. I know for sure that we are much more profoundly interdependent creatures than we often care to think, and I know imperatively that we need a calculus that can value caring labor far differently than we do today. Life is precarious, a fact that has been borne in on me by my injury, recovery, and continuing dependence on others for survival and well-being.<sup>1</sup>

The weight of sudden spinal cord injury is crushing, and can at first be sustained only if spread out, as a suspension bridge spans great distances by hanging the roadway from cables that multiply as it reaches further across the void. Simply to save my life required the work of so many—from the EMTs who first tended my broken body, to all who in some way touched me over the next three and a half weeks of surgeries in Hartford Hospital. After five months of rehabilitation at the Hospital for Special Care, I was discharged to the “care of one.” That’s a standard used by the insurance companies to determine when you can be sent home. From that point on—in principle—I needed only one person to transfer me from bed to wheelchair and back again, to watch for pressure sores, to dress and undress me, to bathe me and brush my teeth, to feed me and help me drink, to help me relieve myself, and to purchase and administer my pharmacopeia of drugs. To keep me alive. The burden of my care was now to be transferred to private life, where one untrained person was charged with taking over. In most cases this would be a mother or wife. In my case the burden of my care came to my lover, Janet.

Janet and I had successfully spent a night together, alone, in an apartment set up in the Hospital for Special Care to test whether

patients and their caretakers are able to manage on their own. Over forty-two weeks of rehabilitation, she had learned the routine of care, and had helped the overworked certified nurse's assistants (CNAs) do their jobs. Our relationship scandalized no one, I think, because Janet's help made everyone's life easier. Lesbians were a-okay, or at least we were. That night she successfully cared for me in the apartment—transferred me to the bed, undressed me, and did all the other necessary tasks. So on March 8, 2004, I was sent home with my lover. Thank God that Donna, a CNA who had cared for me at the hospital, accepted our offer of a second job working for us every weekday morning. She suggested that we hire her sister Shannon, also a CNA, to cover the weekends. I needed so much help. Janet needed so much help helping me. Who's to know what might have become of us had not Donna, Shannon, and a network of caring friends, colleagues, acquaintances, and others assisted us at every turn, and remained steadfast for the two years that I worked my way through outpatient physical and occupational therapies. So here I am, alive.

What does it take to make a life *livable*? That's a slightly different matter, because it addresses the whole person, body and mind—bodymind—together. In 2005, I returned to work half-time, reassuming some of my duties as a professor of English literature and feminist, gender, and sexuality studies at Wesleyan University. My workplace has responded positively to my requests for "reasonable accommodation," the terms of which are established by the Americans with Disabilities Act (ADA), comprehensive legislation that mandates the removal of barriers to participation in public life by those whose bodies are impaired or minds are nonnormative—the political victory won in 1992 by activists for disability rights. The university supported my recovery and continues to make good faith efforts to increase physical accessibility. I am remarkably fortunate that I can continue to do the work I did before I was injured, though I'm able

to work only half as many hours a week. Working is hard, but not working is harder. Engaging in the classroom, in my office talking with students and colleagues, reading and writing all take me out of myself, and distract me from chronic pain and incapacity. It's a hard truth that I hurt myself just when entering the peak earning years of my profession, which makes me angry every time I think of it. Nonetheless, with Janet's income added to my reduced paycheck, I still have enough money to be insulated from the indignities of an unjust world in which so many disabled people suffer because their welfare depends on poorly paid personal aides sent out from agencies, public transportation that is often unreliable, and housing that is only barely or not at all accessible.

I now understand better what all disabled people owe to the early activists who demanded full access to and participation in the public sphere. Like all other civil rights law, the ADA was passed only after years of activism—people in wheelchairs picketing for curb cuts, the Deaf President Now student movement at Gallaudet, lawyers suing school boards for the supports needed for disabled kids to learn alongside their peers, and so on—and the activism that yielded the ADA was only a start. The struggle for recognition of discrimination against “the handicapped” now extends not only to the streets and courtrooms, but also to the classrooms of higher education. Scholars have convincingly argued that disability is not a personal attribute of crippled bodies or minds, but a social phenomenon that bars the full participation in public life of persons so impaired. Impassable barriers and narrowly conceived measurements of ability make it hard to acknowledge and address nonnormative bodyminds. We are conveniently invisible because we are all too often immured in private spaces. Disability is created by building codes and education policy, subway elevators that don't work and school buses that don't arrive, and all the marginalization, exploitation, demeaning acts, and active

exclusions that deny full access and equality to “the disabled.” To focus on intractable pain, then, or grief at the loss of able-bodiedness, as I do here, may be thought to play into a pathologizing narrative that would return disability to “misshapen” bodies and “abnormal” minds. When I presented some of this work to a study group, one guy in a wheelchair more or less told me to “man up” and get on with my life—after all, that’s what he had done decades ago, before the ADA, even.

Chronic pain and grief over loss nonetheless remain as unavoidable facts of lives shaped by catastrophic accident, chronic and progressive illness, or genetic predisposition. Despite their strategic elision in disability studies or transcendence in happy stories in the popular press about trauma overcome, bodily pain and grief persist, to be accounted for as best one can. This book is my contribution to that record. I find that Emily Dickinson is right—in the wake of great pain, the pulse of life slows, and the interval between life-sustaining beats interminably extends. Life is suspended. In that interval, the difference between the one you once were and the one you have become must be addressed, the pain acknowledged and the grief admitted. It can be a treacherous process, given all that might be lost.

In the months after the accident, as I lay in my hospital bed unmoving and in a firestorm of neurological pain, I sometimes—many times—wished I had died at the instant my chin struck the pavement. Had it not been for Janet, my dear lover, this wish would, I believe, have gathered darkness around it to become an active desire for death. This is not to say that I live *for* her. What a weaseling evasion that would be, and a truly impossible burden to foist on one I love so dearly. Janet, whose life was intertwined with mine before the accident, made it clear from the beginning that she desires me and desires my touch. “I’m your physical lover,” she said to me in the hospital, and she meant it. She is infinitely precious to me. Yet I

know that I need more if my life is to be truly livable. Those first two years after the accident, as I recovered and reoriented myself, I was especially in need of the love of my friends, and I'm deeply grateful that so many gave so freely of their time and attention.

When I was in the Hospital for Special Care, Maggie, who had been an undergraduate student of mine ten years earlier, drove up to New Britain from New York City many Saturdays so that Janet could have a break. Waking in a haze of pain and confusion, I would find her quietly beside the bed, watching over me, waiting, sometimes writing in a spiral-bound notebook. I was not surprised—language had always been, for her, the most likely medium for addressing the imponderable. Later on she told me she had written poems about the hospital and about my body. Was it okay to publish? She would gracefully honor whatever decision I made. I trust Maggie implicitly, and with no further investigation of the question, I said publish. In 2007 I held in my hands her fourth book of poetry, *Something Bright, Then Holes*.

In the middle of the book you'll find a section of those poems. This is the short, first one.

#### MORNING EN ROUTE TO THE HOSPITAL

Snow wafts off the little lake  
along Route 66, momentarily encasing the car

in a trance of glitter

Live with your puny, vulnerable self  
Live with her<sup>2</sup>

Anything can happen, at any moment—a trance of glitter, a rush of injury—and we must live with one another and our unhoused selves.

Simply live with. You can't always be intent on protecting yourself or fixing someone else, always looking for some way to "make it better." My friend offered her open, loving proximity, the gift of her presence. I fell asleep, and awoke, and she was still with me. Maggie's poems were a second gift to me, for they represent to me my life as another saw it in those first months after my injury. The poems recall a time that left a deep, confused, and overwhelmingly painful impress on me, and suspend my life in the richness of poetic language.

I wish I could have similarly helped and sheltered my brother, who was diagnosed with multiple sclerosis in his late twenties. Voice-recognition technology, exactly what I'm using to write at this moment, allowed him to keep working as a lawyer even as his body became ever less functional. He had the support of his law practice. All the people there helped him work far, far longer than he would've been able to without their help. MS finally forced his retirement when he was forty-nine years old. Over the decades, my mind veered away from imagining his home life with his wife, Beth, and their children, Kirsten and Colin, as the disease undermined his capacities. It's complicated, as family stories always are. As he came into adulthood, his life flowed into familiar religious and familial channels. Mine did not. I was never alienated from my family—we all loved one another dearly—but from my college days on, I needed to love at a distance. I suppose I feared being conscripted through my affections into obligations I'd quietly resent, while everyone around me enacted a family life that undid me in ways that will take a lifetime to understand. So I kept my counsel and my distance—and felt my difference.

After my injury, as I lay in the hospital thinking about Jeff, I felt the strangeness of being on the other side of the looking glass. Suddenly I was quadriplegic, too, just like my brother. The odds against that doubling just beggared my imagination. It seemed a terrible and uncanny repetition of an intermittent childhood fantasy of mine.

Jeff and I were born just thirteen months apart, and, when young, I could imagine myself as his twin. We played active, physical games together all the time. In the small, rural Pennsylvania town where we grew up in the 1950s, gender figured as a boring hierarchical dualism, masculine/feminine, and was treated as a law of nature. How some people lived their lives creatively affronted that order, of course, as I did with my “tomboy” ways when a child, for gender is neither binary nor natural, but a variable state wound up with power that can both enhance life and subject you to rigidly normative stylizations. My childhood of play with Jeff was an intimation of gender’s pleasurable malleability, even as I felt the pinch of its reductive strictures. When we reached junior high, that theater of puberty where gender’s normative powers are enthusiastically enforced, I suffered as only a thirteen-year-old girl unable to master femininity can suffer. Jeff and I went our separate ways thenceforth into adulthood—then came his diagnosis, and slow but implacable paralysis.

In our middle age, I joined him in quadriplegia. In this account, I represent much that takes place behind closed doors, and draw back the curtain behind which the chronic pain and dependency created by damage to the central nervous system are managed, revelations that may carry a whiff of the apocalyptic—my straightforward discussion of moving paralyzed bowels, for example, where I lay out a protocol necessary to both Jeff’s life and mine, thus representing the fundamentals of the fundament. Diving into the wreck of my body. I have no wish to embarrass you or mortify myself, but I do believe that living *in extremis* can clarify what is often obscure, in this case the fragility of our beautiful bodies and the dependencies of all human beings.

Dad died thirteen years before my accident. Mother lived on after his death for eighteen years, though she became increasingly diminished by senility and the afflictions of old age in the last ten years of



her life. Thankfully her grace and generosity remained unchanged, and her difficulty in forming new memories in the end preserved me as I had been before the accident. Eight years earlier, Mother had decided to move from our family home. Jeff was in a wheelchair. He took care of the paperwork and I did the physical labor, the Herculean task of completely emptying a two-story house that had been lived in for forty years, including attic, basement, and garage. The role of the healthy, strong one had come to me alone. About a year before I broke my neck, Jeff retired, and while I was in the hospital, Mother suddenly needed a major operation. As the shadow of mortality lengthened over her, so did death approach Jeff more nearly. Mother died in October 2008, Jeff in January 2010. By the time I was fifty-six, all my immediate family were gone, as was the body I had delighted in all my active, athletic life.

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Grieving undoes you and casts you off, far from the workaday world uninflected by loss. That's why you're told to move through grief, to transform it into a quieter and more tractable sorrow, and get on with life. Loosen your attachments to whatever is gone. Recognize that the influence of what you've lost is still with you, and will remain incorporated into your life. Reengage in the present, and orient yourself to the future. These dictates make sense, but trouble me because my grief is multifaceted and its objects incommensurate. The loss of my mother, whom I loved very much, was profound, even though she was ninety-two and had lived a life full of love and backlit with joy. The loss of Jeff was shocking, despite his long decline, because he was himself so oriented to life, so vital and enthusiastic. The loss of the life I was leading with Janet before I broke my neck is of another kind. Its most important element is wholly intact, for we continue

to love each other as richly as we did before October 1, 2003. Our sex life is fun and profound, sometimes both at once. All the same, sex is very different, because my body has lost its ability to register its exquisite pleasures. Life no longer feels radiant. The more mundane enjoyments of everyday life—making a peach pie in August, feeling sexy in leather pants and silver jewelry—are also gone, because they depended on a body radically different from mine now. I can no longer feel the satisfaction of cycling forty miles, or hiking up a desert canyon, or kayaking in the ocean, or riding my gorgeous Triumph motorcycle. I don't want to forget how those pleasures felt in my body, and I fear the erosion of embodied memory.

I started writing this book to create something from an otherwise confounded life. Only through writing have I arrived at the life I now lead, the body I now am. I've done this work in language, because my profession is the study of literature. It's what I have and what I know. I have found solace in tropes, since figurative language helps us approach what's otherwise unapproachable or incommunicable. Emily Dickinson writes,

After great pain, a formal feeling comes—  
The Nerves sit ceremonious, like Tombs—

. . .

This is the Hour of Lead—<sup>3</sup>

I begin in that leaden place where pain seems on the other side of language, and work toward living on.