

A Body, Undone:
Living On after Great Pain

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NEW YORK UNIVERSITY PRESS

New York and London

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NEW YORK UNIVERSITY PRESS
New York and London
www.nyupress.org

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1

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.¹

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 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 a 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 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 her²

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 enacted around me 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 being.

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.

* * *

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 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 – . . .

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

2

The Event as It Was Told Me

I will never know what happened. The last I remember is climbing a hill, and the next is an exceedingly blurry scene in the ICU, where Janet was with me, and a nurse was . . . somewhere. The light was very bright. I had lost two days of my life and was about to lose many more.

In the time bracketed by those memories, I had caught a branch in the spokes of my front bicycle wheel, just as I crested a small hill about three miles into my usual seventeen-mile ride. I considered myself a serious cyclist, in that I hoped to ride at least four days out of seven, and challenged myself, sometimes by choosing a route that included steep climbs, and almost always by paying attention to my speed. I did my best to maintain a steady, fast cadence, and to keep a good position on the bicycle—let the legs do the work and keep the torso steady, low, and forward, with your hands over the brake hoods. Pedal through the circle, as though you're scraping mud off your foot when you get to the bottom, rather than simply pushing down with one and then the other leg. Get up out of the saddle with your body weight forward when charging up a hill.

I rode alone most of the time. Coming home tired from my office, I knew that changing clothes and getting on the bicycle would be hard to do, so as an incentive I'd promise myself to take it easy and not keep looking at the speedometer. But then, after the first three miles or so, I'd be warmed up and riding hard, easy be damned. On October 1, 2003, my bicycle was in the shop, getting new shifters and brakes. That Wednesday I was worried about a dinner the next day with the trustees and some colleagues, which I had to host as the Chair of the Faculty. I took that position seriously, perhaps too seriously, because I thought that there was a possibility of

creating some kind of pushback to certain of the Wesleyan administration's policies that undermined faculty governance and were demoralizing many of my colleagues. I knew that, starting Thursday evening, October 2, I'd be in meetings and meals for the next three days, so when the bike shop unexpectedly called and said, "It's ready to go," I was delighted. I wasn't going to be moving my body much for the immediate future. The days were getting shorter and the evenings colder.

"Hey, Jake," I said into the phone, "they just called from Pedal Power to tell me that the bike's fixed, so I get to ride today—thank God—because the trustees are in town tomorrow through Saturday dinner. At least I'll get out today, which is great, since they told me it wouldn't be ready before Friday." So when I got home, I tossed my work clothes on the bed, got into cycling gear—including a reflective vest and a helmet—and went out. I imagine I started shifting up as I got to the top of the hill, moving into a higher gear ratio to keep my cadence regular as the climb leveled out. The shifters were new to me that day and shaped differently from my old ones. I was worried about the trustees and my responsibility to my colleagues, as I understood it. Whatever was going on in my head and the rest of my body, I didn't see a branch lying in my way.

The physics of the event are beyond me, but apparently I came to a dead stop when the branch got wedged in the spokes of my front wheel, which pitched the bicycle instantly over to the right. The force of my full body weight, coupled with the force of violently arrested forward movement, slammed my chin into the pavement. Despite my fast reflexes, my hands were untouched, because it happened too quickly for me to throw them out to break my fall, nor were my shoulders hurt, because I didn't have time to twist my body. The impact of my chin hyperextended my neck so violently that I fractured the fifth and sixth cervical vertebra, which

scraped the spinal cord those bones are made to protect. Serious neurological damage started instantly—blood engorged the affected site, and the tissue around the lesion began to swell, causing more and more damage as the cord pressed against the broken vertebrae.

I also smashed my chin into tiny pieces, tore open my lips, slashed open my nose, breaking the cartilage, and multiply fractured the maxilla bone underneath my right eye. Since I hit my chin just slightly to the right of center—I must've been reflexively trying to turn my head—the damage runs from that side, through my lips, and across my nose in a diagonal cut. The wire-rim glasses I was wearing were deeply enough embedded in the bridge of my nose to leave a dark half-moon scar that I see in the mirror arching between my eyebrows. Everything bled fiercely, as facial wounds always do, and loss of blood was the most immediate danger. My front teeth were left dangling and one in the lower front was half broken. I didn't lose consciousness—how is that possible?—and was able to tell my name when asked, but nothing else. No, I didn't know what year it was. No, I didn't know who the president was. No, I didn't know where I lived or whom to call. And I had with me no identifying papers of any sort. "I don't feel well. I . . . Don't feel . . . Well," I said, a statement of fact that yielded no useful information.

On one count I was very fortunate. A car was behind, preparing to pass me, when my bicycle pitched sideways so fast that even though the driver had his eye on me, he said he couldn't see what had happened—I just disappeared. The branch caught in a mass of broken spokes told the story. Thankfully, he stopped to help and dialed 911 on his cell phone. When the EMTs arrived, they immediately called the rapid-response helicopter from Hartford Hospital. It landed on the grounds of a graveyard directly across the road from where I lay shattered, bleeding, and unmoving. I imagine a dramatic scene, just at dusk, with lots of flashing lights and

whirring helicopter blades. I had left the house wearing my reflective vest just after 6:00, so darkness was coming on fast.

The state trooper who arrived at the scene, Officer Milardo, was left with the task of trying to figure out where I lived. He knew my name, got my address in Middletown, Connecticut, and drove over to the house to see if anyone was there who should know that I was gravely injured and in the emergency room of Hartford Hospital. Friends happen to live directly across the street—when I was in my study I could look over to Anthony’s, and he could do likewise see mine. He had watched me headed off for a ride some time before, so when the cruiser pulled up, he went out to check if something was wrong.

“They’re *partners*,” Anthony said, gesturing emphatically. “*Partners*.” He was trying to tell the officer whom to call. “She’s in New York City, and they’re partners,” he said, striking the back of his open right hand in the palm of his left for emphasis. So Officer Milardo called Janet in New York City, and reached her in her office at Barnard College. When he identified himself as a state trooper and said, “Are you a friend of Christina Crosby . . .,” she instantly broke in, “How bad? How bad? How bad?” The officer told her that I was in no danger of dying, although I was very seriously hurt. “How are you going to get to Hartford?” “Rent a car,” Janet said distractedly, to which he replied, “Take the train. This is no time to drive.”

She got onto Metro-North, having called Lori, who lived in New Haven pretty close to the train station. They drove in haste up I-91 to Hartford. Janet had my power of attorney in hand, because she was prepared to do anything to get into the intensive care unit, where only family members are allowed. Imagining me lying there alone . . . she could think only of being by my side. Doug and Midge Bennett, the president of Wesleyan and his wife, were in the waiting room, keeping vigil.

“We’ve been able to see her. They asked, ‘Are you her parents?’ and I just lied,” Midge said, and Janet was suddenly overcome. Sobbing the first of so many tears, she cried, “I was so afraid, so afraid, no one was here, she was alone.” “No, no, we’ve been by her bed—but you know she’s not conscious because she’s heavily sedated . . .” At the last, Janet had no need to flourish the power of attorney to come to where I lay motionless, clean, intubated to protect against further swelling that could obstruct my breathing, and quite unconscious.

I was unable to recognize or speak to her until the end of the following day.

3

Bewilderment

How can I give an account of myself after “catastrophic injury”? That’s a technical term used by physicians and insurance companies for a severe, radically life-changing event like a spinal cord injury. A chasm—impassable, unbridgeable—opened the instant my chin hit the pavement, injuring my central nervous system and stranding me in a violent and unceasing neurological storm. I have no memory of the minutes leading up to the accident, and the accident itself is utterly obliterated. I lost days of my life in the ICU—it’s only a blur of fluorescent light. The month that I underwent major surgeries is lost forever, and the long months in the rehab hospital only gradually came into focus. Janet reported to friends that I was severely injured but had suffered no loss of my “personhood.” I can’t say how happy that makes me—my face acted as a crumple zone and protected my brain from injury—but *I* feel alienated, sometimes profoundly alienated, from “myself.” My skepticism about my “self” is not only that of the intellectual taught to be suspicious of such a clearly bounded rationality, but also an inability to recognize who I have become.

Because of my condition, I’ve been pondering the reality that everybody has/is a body. Your body emerges through the perception of others as different from yourself, at a touchable distance, and selfhood is not self-contained. What you want, who you are, how you feel are all brought into being over time and in relation to others, and those thoughts and feelings are repeatedly inscribed, creating powerful circuits that organize a sense of embodied self. Such is human interdependency that my self-regard depends on your regard for me. I need and want a more fully livable life, which turns importantly, if not exclusively, on this play of recognition.¹

Spinal cord injury has cast me into a surreal neurological wasteland that I traverse day and night. This account is an effort to describe the terrain. I want you to know, and I, myself, want better to understand, a daily venture of living that requires considerable fortitude on my part and a great dependency on others, without whose help my life would be quite literally unlivable.

Whenever you offer an account of yourself to others, you labor to present yourself as coherent and worthy of recognition and attention, as I am doing right now. Yet because my sense of a coherent self has been so deeply affronted, I've also been thinking about stories that are devoted more to affect than to reason, and because the accident and its aftermath were so horrific, horror stories suddenly make sense to me in a way they didn't before. Such stories gather affective intensity as their narratives develop, and often create eerie, uncanny effects by presenting doubles—two where only one should be. Hitchcock uses this device in some of his most famous films. In *Vertigo*, for instance, the story revolves around the emotions of a detective who sees a woman he desires fall to her death while he is paralyzed by vertigo and unable to save her. Then some months later he catches sight of her again, or someone so alike that the resemblance to the dead woman is uncanny. The one he loved seems returned to him, and they begin to date. The uncanny doubling of one woman into two urges doubts that gather into a malevolent uncertainty that haunts their interactions. If she *is* the woman he loved, she's one of the undead dead and must be threatening. If she's *not* the woman he loved, she's playing an elaborate confidence game with him and must be dangerous. But she is so beautiful, and resembles his beloved so strongly, that he finds himself drawn on in spite of his doubts. A sense of dread increasingly suffuses their interactions.

The childhood in which I was so close to my brother, when we were fiercely competitive and evenly matched, ended in seventh grade, in the junior high where femininity engulfed me.

We grew up and grew apart, lovingly enough. He married and went to law school, while I discovered the passions of lesbian feminist practice and politics and went to graduate school. Just as he graduated and was beginning to clerk for a judge, he was diagnosed with MS, and by his late forties was quadriplegic. The contrast in our lives could hardly have been more complete—he was seriously disabled and I was not. In an instant, at the symbolic age of fifty, that contrast collapsed and my childhood fantasy of being his twin seemed malevolently realized, for there we were, each with seriously incapacitating damage to the central nervous system, each in a wheelchair, each requiring intensive assistance just to make it through each day. My brother/myself. Is quadriplegia doubled a fantastic coincidence or foreboding sign? If I am myself, what the hell/who the hell is this body!/? My life feels split in two. The horror, the horror.

Spinal cord injury has undone my body, bewildering me and thwarting my understanding. Yet I am certain about one thing—whatever chance I have at a good life, in all senses of that phrase, depends on my openness to the undoing wrought by spinal cord injury, because there is no return to an earlier life. I know that the life I live now depends on my day-by-day relations with others, as it did before, but to an incalculably greater extent. Now I need you to know from the inside, as it were, how it feels to be so radically changed. If I can show you, perhaps I'll be able to see, too. The intricacies of bodymind interactions defy certainties and confound representation, but I see no other way to go on—how else will I understand? How will you?

4

Falling into Hell

Because I was so powerfully and thankfully drugged, the three weeks that I spent in Hartford Hospital are a jumble of disconnected impressions. The neurosurgeons and the plastic surgeons debated who should go first. My face would remain workable only so long before starting to set, yet my neck was unstable, and needed to be shored up with bone taken from my hip and installed on either side of the fractured vertebrae, or I stood the risk of further damage to the spinal cord. I was in no way conscious of these discussions. Janet was, although the conversation was really among the physicians. The plastic surgeons operated first, and then sent me back to the intensive care unit from which I'd come.

Coming to consciousness, I felt an obstruction in my throat, the tube that prevented me from choking on my tongue. Although its purpose is to allow you to breathe, it felt as though I couldn't, and I remember struggling against it in my mind. When the neurosurgeons put me under, I was once again intubated, only this time when I returned to consciousness my mouth and throat were filled with mucus. I drew each breath through that thick fluid, which seemed to be drowning me. Janet watched over me, using a kind of vacuum tube to suction out some of the goop gurgling in my throat.

These were experiences of powerful discomfort and fear more than of pain, since I was so out of it. Because I had to recover after each surgery, I was in Hartford Hospital for a bit more than three weeks, able to talk, more or less, when I was awake, only a few hours a day. I have a jumbled recollection of being told I had broken my neck and might be paralyzed, or perhaps not—the MRI showed the damage to the spinal cord clearly enough, but there was no knowing

what kind of damage it actually had sustained until the swelling began to abate, and that takes a long time. Because Janet was by my side every day, I had the security of her love, which mitigated my fears for the future. I didn't really understand much of what I was being told.

I recall as a kind of dream seeing the stunningly white brightness of an operating room one time as I was being wheeled in. I know that dear friends came to visit me. I know that one day my bowels let loose and I fouled the sheets with liquid waste. I know that I went from the ICU, to the operating room, to the ICU, and then to a "step down" unit, only to return to the operating room and repeat the sequence. My mouth was full of metal, arch bars that ran from side to side to keep the roof of my mouth from caving in-- somehow the bits of bone that had been my chin were pinned together, as were other bones in my face--and I wore a very high, tight, and rigid cervical collar around my neck. I could not turn my body or sit up. I could not move my legs or feet. I could not lift my arms or use my hands, which were uselessly curled up into loose fists by atrophying muscles and tightening ligaments.

Right before I was to be discharged to the rehab hospital, orderlies appeared to wheel me away through the corridors, and I watched the labyrinthine greenish ceilings and walls pass by. I was headed for the first of two procedures ("minor surgeries"). The first put a Greenfield filter just at my crotch, in the big vein coming up from my leg, there to catch blood clots that develop when circulation is compromised. For the second, a surgeon ran a gastrointestinal tube through my abdominal wall and into my stomach so as to pump food into me—I had been on IVs for a month, but when I got to the rehab hospital that would change. When at last I was released from Hartford Hospital, I was delivered by ambulance to the Hospital for Special Care about thirty minutes away. October was nearly over, and I was to stay at HSC until early March. It was there that I knew I was in pain.

* * *

I had been living on an IV drip, ingesting all the while a remarkable quantity of narcotic drugs that slow down the body's systems, and now I was being fed through the GI tube. Every night I was hooked up to a machine that forced pureed food into my stomach, so I imperatively had to begin moving my bowels. Thus the horror of gastrointestinal gas began, which left my skin savagely tight over my distended abdomen. Although I was being given NuLytely, a mightily powerful drug used to empty bowels—you may have used it when cleaning yourself out before a colonoscopy—I could not relieve myself. You're quickly in big trouble if you're not moving waste from your body. As I learned, "bowels lead," a simple truth with profound ramifications. Constipation, uncomfortable for anyone, is a real threat when emerging from surgery, because the body recovers from general anesthesia slowly. I had been under twice, and each time for a long time.

The doctors needed to know whether there was a bowel obstruction, which raised the specter of another surgery. I was therefore transferred out of my bed onto a stretcher and wheeled through this new hospital, into a big stainless steel box of an elevator, and down to the radiology unit. In a dark and cold room, a technician prepared to do a sonogram of my poor abdomen. When she began spreading the gel on me, I begged her to stop—It burns! It burns! It burned because the gel was cool, and I was so neurologically scrambled that cool felt hot on my belly. How was I to describe this pain, lost in a body so foreign to me I could translate it into speech only in the most primitive way? The gas I understood, because my gastrointestinal tract has always gone awry when I'm under stress. I suffered terrible car sickness when I was a kid, and later on in college lived with acid indigestion I treated with Roloids from a great big jar I kept on my desk. As an adult, I'd experienced gas pains that at times left me doubled over. Nothing, however, prepared me for the experience of intestinal gas so high and so impossible to

pass. I literally could not fart. All below my rib cage was more or less paralyzed, increasingly so as you moved down my body and that included, of course, my bowels, my rectum, my anus. So I was turned on my side, and Winnie, my kind, thoughtful, and skillful nurse, inserted into me a tube with a plastic bag on the end that would inflate if gas passed out of me. Maggie, who day after day sat with me, reports that one time when suffering this way I said, “Winnie, the pain in my intestine is coming from my unconscious.” Doubtless I was at least partly right. No surprise, your unconscious awaits as you begin to recover from catastrophic injury.

I was plagued with thirst. The arch bars in my mouth and the pins in my face were causing the muscles in my face and throat to atrophy. The bones in my face were still unstable, the many tiny parts not yet fused with the pins. I couldn't swallow water, although I could manage a thicker liquid like yogurt. Nor could I keep my mouth closed. My lower lip had been split open, and even now does not completely close to make a seal with my upper—I hold my lips together with my hand when I rinse with mouthwash. At the time, I understood nothing of this. All I knew is that night after night after night I would awake with a raging thirst. That phrase, raging thirst, is a cliché only because when you are really thirsty, your need for water feels so exigent that the thirst holds you hostage, loudly raging for water, water, water. Water. Water. Please, water. My mouth was so terribly dry. The whole of my being felt desperate with thirst. When a CNA would appear in response to my call, she would fill a small paper cup with ice water and immerse a little green sponge on the end of a wooden stick, then put the wet sponge in my mouth. I would suck at it. The cold water felt so good, but I got just a tiny amount, and would ask for more. More, please, more. Are you done, the aide would ask. No. Another, please. Please. But she was pressed for time, and would move away, and I would close my eyes and try despairingly to breathe through my nose, feeling my lips begin to part all the while.

Late at night, as the earth turned toward the small hours, when I was wrenched from sleep by my thirst, I would awake on a wholly different floor, somewhere upstairs in the hospital—so I thought in my confusion. There I was cared for by a beneficent Polish woman in her later middle age who helped me when I called, on fire. She would fill the cup and give me the icy, wet sponge, again, yet again, yes, please, yes. Finally, smiling kindly, she would turn the small paper cup upside down. “All gone, you drank it all!” She would fill it again and stay with me until I said, “Enough, thank you.” I am uncertain of her name (Elizabeth?), but will be forever grateful for her compassion.

More dreadful than the gas or the gel, even more terrible than the terrible thirst, were the painful currents running through my body. I’d never felt anything remotely like it. My drugged sleep yielded up a vivid nightmare—my skeleton was burning, every bone outlined in red. Pain felt like electricity somehow let loose on me, a statement that is both figurative and not, because the signal that passes biochemically from one neuron to another, lighting up neural networks, is, in fact, electricity—the passage of ions down the axon of a neuron and across the synapse to another neuron, continually, instantly accomplished trillions of times in complex networks all through your body. Trillions. My central nervous system was sending out solar flares. Perhaps the most terrible night came weeks into my stay at the Hospital for Special Care, when I finally grasped the extent of my paralysis. I awoke at night on fire, my skin crisping from the soles of my feet, up my legs and back, tight around my abdomen right up to just under my rib cage, and down my arms onto my hands. I was burning the way you burn when shocked with static electricity, but the shock was infinitely multiplied and running thickly, continuously under my skin. This ferocious buzzing was let loose on me by scrambled nerves that will never ever fully recover, neurological pain that could outline my body by thickly fizzing my skin, as it did that

night, or more deeply penetrate my extremities, as was sometimes the case. What a horror, to finally and viscerally understand how profoundly I was hurt! I “knew,” of course, from bedside conversations with my physicians and with Janet all that was known about the injury I had sustained. My mind was intact, but how could I understand a body so fundamentally transformed? I had no real idea until then of the *scope* of my injury, how far up on my body it came. And what a horror that the drugs I was being given didn’t make it stop!

It called to mind another hospital. I was seven years old and having a tonsillectomy. On my back in the operating room, I looked up at the gowned and gloved adults who were looking down at me. “Count backwards from one hundred,” I was instructed, as a mask hissing ether was put over my nose and mouth. Then in the seconds it took for me to lose consciousness I felt myself falling free, nauseated and gassed, through black space dotted all over with points of colored light. I clearly saw myself, outlined as if by a gingerbread cookie cutter, plummeting down, down. I was, for those seconds, sure I was going to hell.

Now I was there.

* * *

Years after my discharge from the Hospital for Special Care, there’s no discernible pattern that I can see to account for the good nights and bad nights. Most often I lie on my side, having positioned my legs so that the top one is drawn up, bent at the knee with my foot resting on a pillow so that the bony protrusion of my bunion, where thin skin stretches tightly over bone, does not touch the sheet and begin to throb. (Bunions, I’ve learned, are big toes that have been drawn in toward the smaller ones so that the joint on the side of the foot sticks out, making it wider at that point. These malformations developed as the ligaments and tendons of my foot contracted, which has also given me hammer toes.) After arranging my foot, I lie down and put one hand under the pillow, palm up and fingers spread, so that the weight of my head will stretch it open.

So positioned, now and then I realize to my surprise that the electricity has been turned off and I'm not in pain. Unless I consciously try to move my legs, they're just there. I can feel the weight of the duvet, and feel that one leg is bent, the other straight—though just where each leg rests on the sheet can get confusing. I lie there quietly.

More often than not I feel myself buzzing. Eleven years after the accident, on good days, pain recedes into the background of life, and when I'm outwardly engaged I don't think about the fact that I almost always feel a current running through my body. Yet sometimes I can't ignore the pain, when my skin feels thick, electrified, and vibrating. You can imagine a wet suit, the kind you'd use when windsurfing. I had one—it was made of neoprene that hugged my body tightly, and when wet held next to my skin a thin layer of water warmed by my body heat. My skin feels like that neoprene, thick and pliable, with an electric current carried through the underside wetness of blood and lymph. At this very moment of writing, I feel that current making a bold outline of my body. My feet and ankles (which swell, sometimes prodigiously, over the course of the day) buzz all the way through, while my thighs and sit bones press uncomfortably against the seat. My fingers are cold, thick, and buzzing, and stay cold unless the temperature's above 80°. This phenomenon plagues me because the injury to my spinal cord is right at the level where the spinal nerves connecting my hands to my brain branch out between the vertebrae, and those neural networks are implacably compromised. There was a pharmacologist on the staff of the rehab hospital who had a round, white button pinned on the lapel of his lab coat—PAIN was spelled out in red letters, with the international “forbidden” line in black drawn diagonally through the word from upper right to lower left. My chronic neurological pain gave the lie to that button by insistently breaching that line when I was in the hospital, and continues—though moderated—to break through whatever drug is on offer.

Sometimes the buzzing is more like burning, so that my skin feels like crinkly hot Saran wrap. That's what happened last night. It reminded me of just how horrible I felt in the hospital, and how long I felt horrible, when I wondered in rehab whether I would ever be free of that pain. Most of the time, pain only seeps through the narcotic and other chemical barriers set against it, yet it still can feel terrifying, not necessarily in the moment, but as a fated repetition. Sometimes at night I wake to it, and sometimes I fall asleep, drugged, in it. Sometimes the burning is accompanied by spasticity, as my left leg—or my right one—begins to stiffen and shake for a few seconds, and then relax, but relax for less than a minute, only to go into another spasm. The spasticity itself comes in waves: cramping, quivering, jumping, jerking my leg so that there is no sleep for me—or for Janet—without further pharmacological intervention. So I take a Valium, and lie there in bed, thinking about embodied life until I'm knocked out.

Coldness has pursued me from the first, in the hospital where Janet would find me in my overheated room, lying in bed, freezing. She would warm up flannel sheets in the clothes dryer down the hall, three at a time, and wrap me up in them. The warmth was wonderfully soothing, but so wretchedly transient, because the coldness emerges from deep within my body. I have long since left the hospital, but my circulation will always be impaired, my nerves damaged, and my hands cold.

If only pain could be vanquished. It is inescapable, unless you resort to illegal drugs, and even then pain waits on the other side. The cocktail of drugs against pain that I was given in the Hospital for Special Care included OxyContin, the artificial opiate that's like heroin, only made in a lab rather than derived from opium poppies grown in Afghanistan. Now on the streets it's often preferred to heroin—it's uniform in effect and less likely to kill you. One time, and one time only, OxyContin was put into my body pulverized along with all my other drugs, which

were given to me nightly through the gastrointestinal tube. As always during that time, I was in pain, cold, and desperate for some relief. Lying there, I felt a soothing warmth coursing through my body, warm honey in my veins, which spread and spread, engulfing me. So sweet. How unspeakably *lovely* are these drugs!—a thought I held onto for maybe fifteen minutes, floating along before sleep took me. If only I could take my OxyContin that way always! My mind was relieved from the fear that I would always be in pain, and when I'm buzzing, cold, or burning, I sometimes remember the sensation of being warmed through and suspended in no-pain, weightless. Then I long to be taken out of myself and the pain that plagues me, as I was that one time. If I were to crush and swallow my OxyContin tablets, pain would give way to a surplus of pleasure, sweetly running all through my body toward oblivion. I would drift away. Nodding off on OxyContin would, of course, in the end make my pain fatally unbearable. OxyContin is an extended-release formulation of the narcotic. If I crushed the tablets I would get a concentrated hour of bliss. But I would have used in an hour a dose meant for twelve, so I've never crushed a tablet, and they all remain whole in the pill organizer. As a result, I am almost never completely pain free.

Pain brings with it a dour companion, loneliness. I feel an unassuageable loneliness, because I will never be able to adequately describe the pain I suffer, nor can anyone accompany me into the realm of pain. I've learned that the recourse to analogy is not mine alone, since pain is so singular that it evades direct description, so isolating because in your body alone. Crying, and screaming, and raging against pain are the sign of language undone.¹ "As if" is pain's rhetorical signature, which requires the displacement of metaphor to signify—its properties can be articulated only by way of something else, and the tropes of pain display the awkwardness of catachresis. My electrified neoprene skin holds me in its tight, suffusing embrace. The current

races close to the surface, yet somehow also deeply penetrates the tissue. My fingers fumble. My toes curl upward.

If you went to the doctor's office complaining of pain, you would be asked first to rank it, on a scale of 1 to 10. There is a chart, exactly the same everywhere, showing faces as emoticons—a smiling face, with an upward curving line for the mouth, dots for eyes, with happy eyebrows drawn above—that's 1, feeling no pain. Ten, by contrast, has a sharply downturned mouth, pinched eyebrows, and dot eyes leaking tears. When I complained of pain in the hospital, the nurse invariably asked me to rate it on that 1–10 scale, an exercise I found quite confusing—the night of fiery, engirdling pain was the worst I'd suffered, so for a while any other pain felt relatively trivial. I would be buzzing and intolerably cold, but would only say, "5 or maybe 6." That ranking yielded but one short-acting dose of oxycodone (different from OxyContin's extended-release formulation). Even though giving my pain a higher number could get me two, I was afraid of ranking it too high, for fear of not being able to go high enough when it got excruciating.

Before too long, however, my rankings crept upward, and I would ask for as much narcotic help as I could get, with inevitable side effects. I would fall asleep in the middle of speaking a sentence. It was January, and Lori had just returned from her motorcycle tour of New Zealand, by lesbians, for lesbians—we had talked excitedly together about this adventure in the summer of 2003, when I had the Triumph and she was riding a Kawasaki. She had taken ravishing photographs of the landscape, plus some great pictures of the bikes. I wanted to know about it all, but I struggled, frustrated and helpless, against a kind of narcotic narcolepsy. Yet I wanted those drugs. My bowels, already a great trouble to me since they're slowed by paralysis, had an even harder time moving—but that didn't matter. When electricity stormed through my

body, I just wanted relief. The hardest part was waiting in pain after I pushed the button on my call bell. A CNA would eventually show up to ask what I needed, and then she had to find a nurse with access to the locked-down drugs. The nurse inevitably would be working with someone else, and there was nothing to do but wait. When I suffered at the time of a shift change, I knew that I'd have to be patient. Moreover, HSC was routinely understaffed, as are all hospitals now. I learned to rank my pain quite high and to request all the meds that I could get, side effects be damned.

In the years just before I broke my neck, I was deeply happy. I was joyfully engaged with my lover, delighting in her body and my own. One afternoon together, we discovered an anatomy book in a downtown Tucson store with a miscellaneous stock—toys for kids, funky sunglasses, witty postcards, and suchlike. Among the stuff was an illustrated book anatomizing the human body, with lovely simplified drawings of the viscera, the skin, the spinal cord, the fiber of nerves coated with myelin, ball and socket joints, the skeleton, blue veins and red arteries, the heart with its four chambers, sexual organs with the hydraulic apparatuses clearly detailed. Lying in bed, we would look at this book and consider the myriad pleasures of the flesh. Embodied life was then an affirmation of fully realized pleasures integrated with a rich intellectual life. One evening, when we lay side by side, reading, I repeatedly interrupted her to exclaim about some sentence in my book, *The Volatile Body*, by the philosopher Elizabeth Grosz.² I'll always remember the warm, dry desert air, the lamplight, our proximity, and the book, because then the question of how to represent embodiment was a question of pleasure, first and foremost, and of the mysterious way language could amplify that pleasure. Now, representing bodily sensations is no longer a matter of finding words for the ever renewable resource of shared sexual pleasures, but of finding words for the beyond, the nowhere of pain

that I suffer alone.

Janet takes exception to that last sentence, observing that, while she can't feel in her body what I feel in mine, my pain does affect her. She is pained by my suffering—she so wishes it were different, and her desire to make it so is baffled. She's right. Pain does radiate out into the social world, because it changes the person who feels the bodily pain, which in turn cannot but affect those to whom she relates. I have no exact account of how pain changes my interactions with my students and my colleagues, but I know there are times when I don't feel fully present. It's not that the pain is so bad that it commands all my attention, but rather that it's so chronic as to act like a kind of screen. I don't talk much about the pain to anybody other than my therapist, who is not my lover, or my friend, or a member of my family, or my colleague. To her I will complain bitterly, but not to others. I won't complain about the pain because such complaints become corrosive, and would eat at the ties that bind me to others. It's not that I'm bravely suffering in silence, but rather that I know there's nothing to be done.

5

Caring at the Cash Nexus

“Ah Goddamn it—Jesus Christ, Jesus Christ . . .” I moaned and cursed the pain electrifying my body as I lay in my bed at the Hospital for Special Care. A CNA was by my side, and when I glanced up, I saw a small gold cross on a delicate chain around her neck. Miserable as I was, I thought that I must have offended her sensibilities, and apologized. Her voice was quiet and gentle. “You couldn’t have called on a better name.”

This simple affirmation of her faith relieved me of embarrassment, for Donna transfigured my oath into praise for her Lord. I decided then and there it would be better for me to stop swearing in company, reserving oaths and obscenities for my private relief. I now say “gosh,” “heck,” “darn,” “goodness,” the acceptable refuges of offensive language, and those words no longer feel foreign in my mouth. The only time that I really let loose as I used to do is when I’m alone and have dropped something for the fifth time, or have spilled something, or am troubled with a spasm, or the dog has made a mess—then my language is as foul as it ever was. Moxie Doxie, our alert little dog, doesn’t know I’m taking the Lord’s name in vain.

When Janet and I were trying to prepare ourselves for my return to our home, we were simply overwhelmed. I’d been hospitalized and under the care of aides, nurses, therapists, and physicians for more than five months, and the thought of managing my care alone was terrifying. Friends were an invaluable help, but I honestly don’t know how we could’ve managed that first week or the ones that followed without the help of a CNA. We needed someone to put on the compression boots and elevate my legs, bring me breakfast and feed it to me, and help me with the wretchedly painful work of stretching out ligaments, tendons, and muscles that had atrophied.

We needed help getting me to a tub, because our only bathroom was on the second floor. Janet had gotten installed a chair that ran on a rail up the side of the stairs so that I could get up there, but my arrival felt like an epic achievement, every time. To get me to the tub and shower me, Donna had to transfer me (1) from the bed onto my wheelchair, (2) from the wheelchair onto the stair-lift chair that would take me upstairs, (3) off it and onto a folding wheelchair that was stored in a closet outside the bathroom, (4) from that wheelchair onto the shower bench straddling the toilet and the tub, and (5) finally onto the shower chair (like a commode, but without the bowl) in the tub itself. She and Janet together held me upright, played the water over me, washed my hair and my body, and then reversed all those steps to take me back to bed—without Donna to do those ten transfers, helped by Janet, I would have had sponge baths for months and months. Donna had been a steady, sure, skilled help to me, working the second shift every weekend of my long months at the Hospital for Special Care. I knew that I felt comfortable with her. Her mother had died right around the time that I broke my neck, so as I was crying over my broken body and upended life, she was in the first flood of deep, deep grief for her mother. We were both in mourning. Sometimes we talked, more often we were silent, and both were okay. So I asked, will you come to Middletown and work for me 8:00–12:30, Monday through Friday? To my enormous relief, she said yes.

* * *

Donna still cares for me, and will continue to far into the future, if I continue fortunate. I love her, and she loves me, for a decade of intimate care has created an intimate bond. We've talked about a world of things. She knows that I'm not a church-going Christian, though I come from a Christian family, and I've told her directly that I respect her religious faith and religious practices. I've told her lots of stories about my family life, and have gone on at some length about the evils of capitalism as we know it. She understands that Janet has become the chief

executive officer of our home, and goes to her when medical supplies need to be replenished—indeed, when any household matter needs to be addressed. She knows me, what I can—and, as importantly, can't—do. She knows a lot about my relationship with Janet and the terms in which we understand ourselves.

For my part, I know that Donna is a Pentecostal Protestant and has had the life-transforming experience of being saved. She actively studies the Bible and regularly attends the church to which her mother took her five children every Sunday. I know that her loving mother moved those children to Hartford from Brooklyn after her husband was robbed and shot dead in his cab. Donna was six years old. I know how hard Donna has worked to rear well her daughter and son, and now Kyla has graduated from college and Tyler has graduated from high school. I know that she looks to God every day—every hour—for help, and the gospels that she hums as she works suggest that her mind is often on her Savior. I know in a way that I never could have learned otherwise than through such an intimate relationship how bitterly, sometimes desperately, hard it is to be working poor. To have only the change from a twenty that you broke when you got gas, and you have yet to get groceries. To be indentured to the used car dealer who will sell to you even when you have lousy credit, only to trap you in a debt with compounding interest that will continue to demand repayment long after the car has been towed away.

Donna works harder than anyone else I've ever known, and still has constant, nagging, impossible-to-forget worries about upcoming bills. She picks up extra shifts at the hospital all the time, even as she is working a second job for me. She works “doubles,” sixteen hours straight through. Yet the bills keep coming. We've talked about how easy it is to get a “payday loan”—just google the phrase and you can see for yourself. Online or in person, the application takes but a moment, and will screw you for years. Check out CashAdvance.com. Here's what you'll learn

about interest rates if you scroll down, down the page past the many smiling faces to the small print:

The APR on a short term loan can range *from 200% to 2,290%* depending on how the APR is calculated (nominal vs. effective), the duration of the loan, loan fees incurred, late payment fees, non-payment fees, loan renewal actions, and other factors. Keep in mind that the APR range is not your finance charge and your *finance charge will be disclosed later on.* (my emphasis throughout)

CNA work is hard and low wage, which means that in Connecticut and New York City many of the workers are African Americans or Caribbean immigrants, though here in central Connecticut, the working class also includes many immigrant Poles and Latin@s. Most patients in a rehab hospital are unable to stand without assistance, let alone walk. Many are simply dead weight. Aides must transfer them from bed to wheelchair and wheelchair to bed several times a day, and help people on and off the toilet, all day long. They have to lift and turn patients in bed, a task which will simply kill your back if you don't do it right. CNA's everywhere now work short staffed as a matter of course—it's called "enhanced productivity." While profits as bright and light as digital numbers flow upward, bodies remain intransigently heavy. Donna's in her early forties. She has a bulging disc in her neck, which radiates pain, and a knee badly in need of replacement. Frequent headaches are just a fact of life. Not a day passes without pain, though some days are worse than others. I'll see her put a hand to her back or rub her neck, involuntary gestures that announce she's hurting, and now and then she walks with a pronounced limp. Her doctor advises her to wait for surgery until she absolutely can't stand the knee pain, because a mechanical joint lasts only fifteen to twenty years. Artificial joints wear out like the body parts they replace, and eventually the replacement has to be replaced, so best to push back the first

operation as long as possible. Working in the hospital is also highly stressful. Short staffing requires that the CNAs on the job always have patients *waiting* for care, with their call lights reproachfully blinking. Aides and nurses are always behind. Donna keeps her responsibilities alive in her head, which is great for me—she remembers my schedule even when I don't, and anticipates what I need. In the hospital, however, that organizational capacity of hers is wearing, because while she's helping one person, she'll have in mind the woman who needs to get from her bed to the toilet, the other woman who asked for pain medication, and the paralyzed man with a bedsore who has to be turned right on schedule, right *now*. That's high-stress work, and a very hard way to make a living.

I've read that certain populations in our country are given over to "slow death," among them workers in the bottom-level jobs of the one reliably expanding industry in the United States, healthcare.¹ The business section of the New York Times reports that "personal care aides will make up the fastest-growing occupation this decade[,and an] Economic Policy Institute study found that some 57 percent of them live in poverty."² That phrase, "slow death," captures the endless process of wearing down, the hush enervating demand of small yet consequential decisions (can I bring take-out home for the kids tonight? How much can I pay on the electric bill so they don't shut it off?), and the quiet despair that can suffuse everyday life. Wellness programs, like the one directed at CNAs at the Hospital for Special Care, are just another reason to feel bad about yourself—why aren't you going to the gym, with weight machines and elliptical machines and a heated pool, just waiting for you? Regular exercisemoreover, is just the beginning of what's required for a healthy body. With Michelle Obama's bright encouragement, you know you have only yourself to blame for making poor "choices" that undermine your family's health, starting with decisions about food. Such decisions, however, can

be imagined to be those of an autonomous and freely willing subject only if you abstract the embodied realities of grinding poverty into weightless ideas—it’s called “grinding” precisely because it wears you down and wears you out.

I smoked cigarettes in college, but gave it up years ago. No one I know at Wesleyan still smokes, though when I came in 1982 I could always bum a cigarette at a party. Now the people who smoke are the ones working low-wage, high-stress, physically demanding jobs. People smoke in order to take a break and hang out in the parking lot with their friends, and they smoke to schedule in the sharp pleasure of doing what their bodies desire in an otherwise dreary and repetitive day.³ Coke delivers caffeine and a much-needed sugar kick that feels good in the moment. Fried food tastes right and at McDonald’s reliably will taste right every time. You can pick it up at the drive-through and eat it in your car driving to your second job. If you look at the advertisements on daytime TV, you’ll see (1) personal injury lawyers asking if you’ve been injured at work, and (2) diets organized around prepackaged food that costs a lot just because it’s prepackaged, and (3) smoking-cessation programs. You may be on your couch watching daytime TV because you were hurt on the job, but you could, nonetheless, lose weight and quit smoking. You could make healthy choices—if you don’t, it’s your own damn fault.

* * *

I know a lot about Donna, yet her life remains, in many regards, unknown to me and unknowable. She works *for* me, in *my* home, and has to learn *my* ways and the ways of *my* household. It’s just a fact that black people know “the ways of white folk,” in Langston Hughes’s turn of phrase.⁴ Black people in this country have been taking care of white people in their homes as domestic workers for centuries, necessarily amassing many generations of knowledge about the oddities of how white people live. I listen to arias from Baroque operas that were written for castrati who sang in the soprano range, music now performed by countertenors, who

are men singing in falsetto. How bizarre is that? Neither I nor the white women who are my colleagues will be taking jobs in the homes of black women, and getting to know their lives as only a caretaker can—intimately, every day, over time. *Of course* Donna knows more about me than I know about her. I know that we depend on each other. Our mutual dependence does not, however, bring me into her household, and there's plenty I don't know about her life, despite our personal closeness.

To rebuild our lives after my terrible accident, Janet and I turned to our families and friends. Their financial support made so much possible that otherwise would have simply been out of reach that first terrible year, and I continue to be actively thankful for their open-handed generosity. We've told Donna that if there's ever a crisis she can come to us, and forgo the payday loan. Borrowing from us, she would be spared onerous interest rates. We can get our hands on money. She can't. Our good intentions, however, can't transcend the structural racism that has advantaged us so grandly, and disadvantaged her so wrongly. I am seriously worried about patronage, for which there are all too many precedents. The black artists of the Harlem Renaissance, including Langston Hughes, were patronized by well-off "white folks" who supported "their" authors, facilitated the production of "their" artists' books, and then took the privilege money afforded them to suggest how "their" artists should go about their lives. What if Janet or I somehow patronize Donna? The prospect makes me ill. My delicate feelings, however, are no guarantee against patronage—our intimacy is very real, but it's we who have the money.

There's a constitutional amendment forbidding slavery, and indentured servitude has long since been a thing of the past, but as of the early twenty-first century, white people with money too often still do not honor the workers who labor in their homes or compensate them fairly. Were wages calculated on a different scale, according to how dearly loved are those in need of

care, domestic labor would no longer come so cheap! Righteous anger may be some relief, but there's no ethically safe solution for me, or for any employer of caring labor. Political action is the only effective response to systematic injustice. My contribution as an educator has been teaching *Valuing Domestic Work*, the fifth in the Barnard Center for Research on Women's series *New Feminist Solutions*.⁵ It's a report "based on a three-year collaboration with Domestic Workers United (DWU) and the National Domestic Workers Alliance (NDWA)," which lays out the political groundwork required for transformative action. I don't confuse putting this report on my syllabus with the work of organizing. Teaching the report is instead a way to name social reproduction as an object of knowledge consequential to feminist thought, and to link my dependency to a broader vision of caring labor and reproductive work. It is to see the political in the personal and the personal in the political.

I must simply admit, however, that my personal relationship to Donna is an irresolvable contradiction. We meet at the cash nexus, the labor market. Donna brings to that market her bodily capacity for work and her imperative need for money, while I bring money and my imperative need for help with my bodily incapacities. Donna can't live without money, and I am glad to pay her what I owe. Yet money cannot begin to measure the value of her work. Money cannot calculate what Donna's presence does for me or how she goes about the profoundly intimate work of helping me manage my body. *I value her for who she is*, the beautiful, gentle, skillful, kind, sad, singular person that I love.

17

The Horror! The Horror!

Years before my accident, I was sitting in my study preparing to teach George Eliot's novel *The Mill on the Floss* to the thirty-two students in my course titled Reading the Victorians. Tears were running down my cheeks, and I knew that I wanted the students to understand how words on a page could elicit such strong emotion. So I worked that afternoon to teach the class how the conventions of realism project a space-time populated with "round" characters whose imagined lives we follow, often with real interest. We discussed how the happenings of this fictional world can move readers even when—or perhaps especially when—melodramatic conventions intrude. *The Mill on the Floss* is the second of Eliot's eight novels, written before she had fully mastered the genre, so the opening scenes prefigure somewhat too heavily the tragedy that will overtake the novel's passionate heroine, Maggie, who conforms only with difficulty and great inward effort to the narrow dictates that tell her how to be a good girl. The conclusion is flawed, too, veering close to melodrama as the heroine's virtues—manifestly evident to us throughout, but unrecognized by those she loves—are at last witnessed by her upright and judgmental brother, Tom, just moments before they are together overwhelmed by the waters of a great flood she had braved to rescue him. "In their death they were not divided." It's a story about a brother and sister, so of course I was moved. Melodramatic tactics work, and I was crying not only over the death of the heroine, but over missed chances to overcome the painful distance from her brother, the impossibility of turning back the flow of time so that Maggie's life could be different, the impossible regret of "if only" so central to melodrama.

What one scholar has called the "realist consensus" upholds the widely shared belief in

the morally complex characters realist conventions create, characters whose depths are accommodated by the expansive, three-dimensional space in which they appear.¹ We take “depth of character” for granted, as characters repeatedly display the attributes that we recognize as belonging to them, seen first from this angle and then that, which is one of the reasons that Victorian novels are a pleasure to read. A masterful writer like Eliot can create and populate a whole town and its environs. Her narrators encourage readers to pass moral judgments, though with a writer as accomplished as Eliot, we’re not readily tempted to become moralistic and imagine ourselves above it all. So even when a novel governed by the realist consensus takes a melodramatic turn and ends tragically, as happens in *The Mill on the Floss*, the narrative has created an ordered imaginative world where my mind can rest, and characters whose contradictions I can understand.

Realism progresses through chronologically sequential time toward a knowable future, and creates an imagined world you find continuous with your own. Most importantly, the realist consensus urges certain beliefs, perhaps most importantly the idea that “we” are all complexly motivated, but knowable human beings, fundamentally alike. I have grave reservations about such beliefs, which presuppose history as progressive and unified in space and time -- imagined from a European point of view, of course, since Europe is clearly where humanity is furthest advanced. These premises are contradicted by the world we live in. I know that the “realist consensus” does not produce novels that “reflect real life.” Rather, a comprehensible world is conjured by the imagination of an artist, illuminated by the austere, searching light of the Anglo-European Enlightenment, and laid out on the premises that history progresses organically and that we all belong to the family of man. Knowing how these books call upon readers to participate in the realist consensus and legitimate its claims does not, however, diminish my

pleasure in entering into an imaginary world ordered according to its unspoken rules. To the contrary—it's a familiar and reassuring domain that offers the substantial comfort of knowing where I am, especially since I needn't believe what I read.

“Of course you have to begin with the preface!” I said decisively from the hospital bed where I was lying for a third day awash in the bright lights and encompassing whiteness of the intensive care unit. “You can't skip!” I was instructing Janet, who was sitting in a chair by my bedside, holding *Middlemarch* on her lap. Apparently I had asked for this book the previous day when I'd emerged from my induced unconsciousness, which suggests the hold that this novel has on my imagination. “You know it's a parable that situates the ‘ardent’ and ‘theoretic’ character of Dorothea—besides, there's the voice of that comprehensively instructive narrator!” (Several years before, Janet and I had gone to a conference on narrative form, where she met some of my Victorianist friends, and came away amused and impressed by my colleagues' belief that you must attend to every detail, down to the very syntax of Eliot's sentences.) So she began at the beginning. *Middlemarch* is Eliot's penultimate novel, and demonstrates her truly masterful control of realist conventions. No heavy-handed forecasting or “if only” regrets, just the slow accretion of detail that populates an imagined provincial manufacturing town and its surrounding countryside with a multitude of fully rounded characters and their intricate web of interactions over time.

I was so bewildered by my injuries and sedated by drugs that I have no memory of Janet reading aloud to me. I do know that when I got to the Hospital for Special Care, she borrowed from the public library in Middletown a twenty-three-cassette edition read by an accomplished speaker of British English. That way I could enter the imagined provincial world of *Middlemarch* when Janet was not there and I was not doing therapy, during the long, empty

hours in the unimaginable world I had entered and the incomprehensible body I'd become. I was far better off in the Vincys' hospitable house, or the oppressively evangelical Mr. Bulstrode's office at the bank, or with young, vibrant Dorothea in the Lowick house of the Rev. Mr. Casaubon, where she is slowly coming to understand that her husband is far from the great divine she had imagined him to be. Day after day, I had only to patiently wait for the CNA to answer my call bell when I needed to have one cassette taken out and another put into the small boombox sitting on the table next to me.

* * *

The realist consensus is an achievement of Renaissance humanism and Anglo-European Enlightenment, and the world it represents is expansive, comprehensible, and rationally ordered. Not so the neurological storm of spinal cord injury. I was lost in its vastness and shades of unilluminated darkness, and in desperate need of familiar things. Of course I asked for *Middlemarch*! Given this fact, I can hardly fault memoirists who answer to the dictates of the realist consensus when writing about disability. Many accounts of living with a disabling incapacity begin at the beginning—the discovery at birth of a supposed “defect,” the account of a genetic anomaly, diagnostic test, or catastrophic accident. The narrative develops chronologically after the advent of incapacity, all the while implicitly articulating events into a consequential order. Moving through time is simultaneously moving through space, of course, and that space is three-dimensional, oriented by a single vanishing point in the distance toward which the narrative moves as it develops. You conjure this space in your imagination as you read, and discover the common horizon that organizes the trajectories of all the characters, including yourself as you become absorbed in the story. You enter into the scenes and follow the incapacitated person as she seeks to regain lost abilities or discover new ones, and sympathize when she must persevere through setbacks and disappointments. Authors and audience alike rely

on common sense, and the story moves sequentially from beginning to end.

From the very first pages, you are reading with the “anticipation of retrospection.”² Readers attend to the details of the emerging narrative with the expectation that the author has organized his story to end with a satisfying sense of conclusion. Frank discussions of setbacks tend toward workable solutions and the discovery by the protagonist that he is, in fact, living his life—a difficult life, yes, and certainly different from what he had expected, but a life with its satisfactions and pleasures. The quadriplegic poet Paul Guest has written a memoir I admire, *One More Theory About Happiness*, in which he describes the blankness that followed from his terrible bicycle accident when he was thirteen, just on the verge of puberty. He does not shy from representing the dark moods and thwarted desires that inform his writing and shadow his growth into manhood and his development as a poet. The poem “My Index of Slightly Horrifying Knowledge” is a catalog of indignities large and small that I read with a wry, nearly bitter, laugh of recognition. Yet the narrative of his memoir, which begins in childhood and ends when he is engaged to be married, is motivated by his longing for a fully adult life, imagined as the familiar story of reciprocated heterosexual fulfillment. This happy narrative arc is at odds with the dark comedy of the horrifying knowledge he represents with an enviable poetic precision. A longing for heterosexual normalcy drives Guest’s narrative, which in consequence I can’t reckon as one *more* theory about happiness. Narratives of disability may be grim at some points, but they almost always move toward a satisfying conclusion of lessons learned and life recalibrated to accommodate, even celebrate, a new way of being in the world.

Nothing of the sort is happening here, because I can’t resolve the intractable difficulties of disabling incapacity, any more than I can suggest that everything will be (more or less) okay. Even the most accomplished cripple you can imagine is undone, and living some part of her life

in another dimension, under a different dispensation than that of realist representation. In my case, spinal cord injury casts a very long shadow, the penumbra of which will only grow darker as the years pass and the deficits of age begin to diminish me still further. I'm living a life beyond reason, even if I have invoked some of the stabilizing conventions of realism in this narrative. Those conventions are the ones I know best, but profound neurological damage actually feels to me more like a horror story, a literary genre governed not by rational exposition but rather by affective intensification and bewilderment.

* * *

In horror stories “the boundary between the real and the fictive, the interpretations of experience by the audience and the characters, is continually drawn and effaced,” Susan Stewart writes in an essay on the epistemology of the genre. “Both the story and its context of telling dissolve into a uniformity of effect. Hence, the ‘didn’t really happen’ of the fiction is transformed into a ‘really happened,’ a fear which is ‘real,’ yet which has no actual referent.”³ In other words, such a story depends on the feeling of fear that it evokes in its characters, and the simultaneous unease it engenders in you. Edgar Allan Poe’s story “The Fall of the House of Usher” works this way. From the opening paragraph’s “dull, dark, and soundless days of the year, when the clouds hung oppressively low in the heavens” to the “full, setting, and blood-red moon” of the end, Poe’s first-person narrator inhabits a terrible world, and as you read, you discover that there’s never a relief from the sense that something very bad is upon you.⁴ Every element of the narrative is overcharged with significance, every detail mysteriously endowed with a blank surplus that oppresses rather than enlightens. Horror stories insist on this referential surplus to overwhelm our efforts to figure out what’s going on. Such stories defy the cerebral undertaking they seem to encourage, because their meaning is affective, not referential. The fear they induce is the fear of fear itself.

In Poe's story, the unnamed narrator, who in his anonymity could be any one of us, begins the story as he is approaching the House of Usher, where he comes in response to the urgent call of an old friend who is terrified. Of what? He doesn't know, but the setting is desolately foreboding and the narrator increasingly uneasy. He attempts to soothe his friend, to no avail. His friend has a twin sister, but she is ill, and he glimpses her but once. "[T]he lady Madeline . . . passed slowly through a remote portion of the apartment and . . . disappeared. I regarded her with an utter astonishment not unmixed with dread—and yet I found it impossible to account for such feelings." After several gloomy days, her brother "informs him abruptly that the lady Madeline is no more." She has died—of what? We never know. His host fears her medical men, implying they would dig up the corpse for dissection, though the story affords meager evidence of this particular threat. It must be, he declares, interred in a crypt below the mansion. The men together do the work. The atmosphere of foreboding grows only stronger in the days following, and at last the narrator finds himself giving way to "unaccountable horror." As a wild storm whirls outside, he discovers his friend in a kind of trance, muttering that he's heard his sister alive in her coffin, when a great gust blows open the heavy door that communicates with the crypt. There she stands in her shroud with arms outstretched, his terrifying doppelgänger, only to pitch forward in her final agony into her brother's embrace. Her death calls for his, and both fall lifeless at the feet of the narrator. In great haste he leaves the mansion, and just in time, for as he looks back, a jagged fissure divides the House of Usher down the middle. "My brain reeled as I saw the mighty walls rushing asunder," he tells us, and "there was a long tumultuous shouting sound like the voice of a thousand waters—and the deep and dank tarn at my feet closed sullenly and silently over the fragments of the 'House of Usher.'" In this horror story, the brother and sister twins in their mimetic relationship terrify as René Girard

says they must always do.

The tumultuous end leaves unanswered all causal questions, which actually never had purchase in the story, anyway. In a horror story, *how* the characters and events of the story are ordered and discussed collapses into the *what* of those events that gathers affective force. The result is generalized fear, a feeling that doesn't *refer* to anything real, but *is itself real*. From the title of "The Fall of the House of Usher" forward, we've been waiting for a collapse, an end that's reached as the narrator flees. The house first splits in two, a violent rending apart of what had been perversely conjoined, and is then entirely obliterated. Readers have been aligned throughout with the narrator by virtue of the first-person address to an implicit "you," and with him readers experience the fear of fear that amplifies into horror. This horror detaches the audience from the realm of the ordinary and precipitates us elsewhere.

* * *

I find myself repeatedly, daily, relentlessly, and wearily horrified by the elsewhere of spinal cord injury. All too often I feel as if I'm living in another world, a dark realm overshadowed by the life-threatening accident that didn't kill me, but obliterated the life I had been living and put me in a mimetic relationship to my brother. I'm advancing toward something that evokes horror in me, the referent of which is shrouded in a baleful mystery rendered more menacing as I proceed, my horror gathering as I realize that whatever "it" is, it has already happened, yet worse lies ahead. I'm not writing a horror story, I'm living one. In becoming Jeff's twin, my world was destroyed, and the terrifying aura of neurological destruction and paralytic incapacity encompassed me.

What is it I'm so afraid of? I've turned this over in my mind repeatedly, and think that I have some glimmer of what's at stake. I don't relive the day of the accident. The fact is, I don't remember anything about the accident itself. My memory stops about a half mile before the spot

where the branch caught my spokes, pitching my bicycle sideways in an instant—in a nanosecond—so quickly that I arrived at the hospital with my chin obliterated, and not another scratch on me. My face was smashed and I broke my neck. Yet my fear is not retrospective, incessantly returning to the accident that so wrecked my life, but prospective. Something horrible awaits—the future. Life will go on, day after day, until I die. I fear getting older and bearing the trials of aging in my deeply compromised body. I fear living with interminable pain, both neuropathic and emotional, and I fear interminable grief. It colors the world and is just too hard sometimes to bear. I fear not death, but living.

Otto Kernberg, in a psychoanalytic account of the process of mourning, makes this observation:

Daily reality militates against the full appreciation of a loving relationship, and only retrospectively emerges the possibility of a perspective that fully illuminates the potential implications of every moment lived together. The paradox of the capacity to only appreciate fully what one had after having lost it, a profoundly human paradox, cannot be resolved by communicating this experience to others. It is an internal learning process fostered by the painful, yet creative aspect of mourning.⁵

No. Damn it, no! I appreciated every moment of the life that Janet and I made together and I fully appreciated her. I knew what I had. I could not integrate my intellectual and sexual passions until I was forty-six, so all the more reason to be alert to the joys of daily life. Take the motorcycle, for example.

I had always wanted a bike, and bought a used Honda Nighthawk 750 in the first year of my life with Janet. It was a great bike. The world of motorcycles now breaks down into sport

bikes with engines whining at really high RPMs and seats that pitch the rider aggressively forward into a racing position, versus low-slung cruisers with engines that rumble, the louder, the better. Cruisers put the rider in a cool laid-back position—think *Easy Rider*. The 1984 Nighthawk is what's called a hybrid, more of a sport bike, but with a bench seat that can accommodate a passenger. I happily rode it the fifty-mile round-trip to New Haven when I was in psychoanalysis—the only happy part of my analysis, I might add—but it wasn't really comfortable for Janet. To celebrate my fiftieth birthday, we decided to buy a bike that would be great for both rider and passenger. Looking around, I found a black Honda Shadow, a cruiser with great lines, the kind of bike I thought I wanted. But when I took it out for a ride, I didn't like how cumbersome it felt, with its wide handlebars and foot pegs set out in front. Leafing through the classifieds on a Sunday morning in spring 2003, we found the right bike—a black-and-silver Triumph with a lovely 900cc “speed triple” engine and the shorter turning radius and maneuverability of a sport bike, plus the lower carriage of a road bike. It had a seat contoured to carry a passenger, was highly polished, beautifully cared for, and looked brand-new. It even came with black leather saddle bags. When we went over to Poughkeepsie to get the motorcycle, I came back on Interstate 84 among the tractor-trailers, which reminded me of riding my bicycle in the scrum of taxis in New York City. I was proud of myself and loved the bike. I printed a photo from the Triumph website that showed it to perfection, and Janet had it hanging on the door to her office.

On September 2, my birthday, I had meetings in the morning, and went off to work carrying anxieties about my job that year as the chair of the faculty, a highly visible position that burdened me with responsibility even as I was glad my colleagues thought well enough of me to vote me into it. When I returned home for lunch, my worries about work vanished. There was

Janet, all proud and happy, dressed in a sexy, sleeveless black velvet top, a silver velvet skirt, and silver sandals. The garage door was open, showcasing the black-and-silver bike with black-and-silver wrapped gifts piled on it. A red ribbon accent picked up the thin red sporting stripe on the gas tank. The presents themselves were little things—on this occasion, the real gift was the presenter and presentation. I vividly remember how happy I was.

Photographs confirm that memory. We used to take pictures all the time, and recalled our pleasures as we put them into photo albums, where we have six years of happiness on page after page. One day a couple of years ago, wondering whether my memory had somehow burnished past happiness, I dared to search for the birthday photographs. Was I inflating in my memory the daily pleasures of my life with Janet and the moments of sheer joy that illuminated those days and years? I found the pictures seemingly untouched in their Mystic Photo Labs envelope. Flipping through them, I realized that I had not exaggerated my happiness, and that the photos fairly hum with merriment and desire.

I don't know if Janet's ever looked them over. I've never talked about it with her. We've certainly never gone through those photos together, as we used to do with each new envelope of negatives and prints, and I've looked at them only that once. They are still out in the living room. That envelope is somewhere. At this moment, eleven years after my accident, they still feel like green kryptonite to me. Dangerous, dangerous. Love, passion, giddiness, joy, pleasure, desire fairly burn through those photos and the ones arrayed in the albums that record six years of birthdays, holidays, and everyday adventures. There's no way to rewrite what happens, my lost body is forever lost, and I am forever reliving the events of the past that take on a dangerous golden glow. It's the glow of illuminated amber in which my remembered body is transfixed. Dr. Kernberg would have it that "the painful, yet creative act of mourning" will allow me to fully

appreciate in retrospect what I've lost. This "internal learning process" is a concept so innocent of complexity that I really can't stand it. I knew what I had. I know what I've lost.

Besides, the analytic talk about grief is always focused on the relationship between the dead and the living. No one's dead in this case, although I often wished in the early months and years that the accident had killed me and sometimes still do. Janet got angry at me one evening after I'd been home a couple of months, as she was pushing the wheelchair toward the dining room that was serving as our bedroom. I had been worrying with my tongue what felt like a new tooth protruding from my gums just below my lower front teeth, and I wondered aloud what it could be. "It's probably a bone chip," Janet said, and I cried out, "I am so fucking fucked, I can't believe how fucked I am," thinking of my broken face pinned together by the surgeons and wondering what else would emerge. "What does that say about me?" Janet said, her voice rising, clearly pissed. "When you talk like that you're just erasing me and all the work I do, as if it were for nothing." Immediately scared, certainly because of my dependence on her, and perhaps contrite, I said I was sorry. But she went on, indignantly, "All my work, all my care . . . and me—it's as though I don't matter to you at all." I protested the contrary, and again apologized, saying that I'd think about her position. It's very true that I loved her dearly and was sorry to have hurt her.

"It's not just the labor—although that's part of it, for sure. There's something else, though, and it's this—You also overlooked—no, refused to see—negated—my love for you. You may not love your body, but I do—you should know by now that I want to be your physical lover. I'm working on understanding and accepting the fact that you do not love your body and, from the way you talk about it, it doesn't seem likely you ever will. But saying you're completely fucked is saying that my desire for you and my love is of no consequence." We were

drinking our morning tea in bed, and Janet was describing how she'd felt the night before. As we talked, I came to understand the logic of her complaint, and from that moment forward I vowed not to break out in imprecations against my life, a life that is sustained by her considerable and absolutely necessary labor and even more by her loving regard. Yet on a bad day of pain and discomfort that abstracts and alienates me from my life, I feel my attachment to the world attenuate, and cannot contemplate aging, with its attendant physical and mental decline, with anything but horror. At such a moment, death turns a benignant aspect to me.

* * *

What is it about my injured life that militates against mourning and keeps grief fresh? What makes it feel like a horror story? In a horror story, you begin by being afraid, and all its devices are dedicated to stoking the fear of fear, making it clear that there's worse to come, that, if you're afraid now, you'll be terrified in a moment. When? Wait. Just you wait. You'll see. You'll see . . .

I'm afraid I'll stop grieving and equally afraid that I'll never stop grieving. If I *do* stop grieving, I will necessarily have come to terms with my profoundly changed body and my profoundly changed life, for I can leave off mourning only by no longer cherishing and burnishing my memories of the past.

I may be perverse, but I'm terrified of what I'll lose in making my peace with what I've lost. I fear I'm forgetting how it felt to be comfortable in my body as time does its wearing work. I fear I'm losing how my embodied passions felt through my whole body, and I'm afraid that I'll forget the feeling of joy.

If I *don't* stop grieving, and refuse to move on, I fear that I'll be always missing the body and the life I had at the moment I broke my neck. I'll be caught in the sticky resin of amber. New pleasures will be foreclosed. I fear being impossible to live with—and I fear not wanting to live.

18

Living On

Yet here I am. I'm sitting at my desk, outlined by and suffused with neuropathic pain, that tingling, vibrating, burning sensation that I've been describing from the very beginning. The pain is uncomfortable—today, that's all. When I'm concentrating, my bodymind turns to the task at hand and this sensation becomes background, only to reassert itself as I lose focus and return, as it were, to my resting state. How am I to represent this complex embodied fugue? My skin is an organ of sense that runs imperceptibly from inside my body to the outside, or from outside to inside, which defeats the idea that I'm living *in* my body. There are 108 single-word prepositions in the English language, and none is adequate to representing the relation of mind to body. Body and mind are simultaneously one and the same and clearly distinct. Thinking my body, I am thinking in my body, as my body, through my body, of my body, about my body, and I'm oriented around my body. I'm beside myself. Perhaps the most powerful effect of the realist consensus is what Ermarth calls the “concordance of difference,” the summing up at the end of a novel that's sometimes explicitly offered to the readers by an author, as Eliot apprises us of where and how her characters live on after the end of her story in *Middlemarch*. The more detail, the more exhilarating and exhaustive is the effort to orient it all toward a single vanishing point, and the more perspectives from which we see a character like Dorothea, the more she acts differently, but always like “herself.” Differences multiply, but in the end they add up with no remainder. The account balances. My account doesn't. I can't make sense of this body, which continues to

surprise and baffle me.

When I was first hurt, I began to feel a dense and obdurate need to put into words a body that seemed beyond the reach of language. I searched for words to describe to Doctor Seetherama phenomenological realities that made no sense to me, and tried to explain what I felt to the aides who were turning me in bed. I live on in a neurological storm—it's electric, even now sometimes violent enough to be overwhelming, and certainly endless enough to be horrifying. Yet my life is not in truth a horror story, and I have no wish to claim that it is, however powerfully that genre has helped me conceptualize my fear of the future.

I have lived on eleven years beyond the accident, through the suspension of life occasioned by terrible loss that Emily Dickinson represents with such fierce precision in her poem "After Great Pain." The experience may be so intense that it freezes rather than burns. Then death beckons.

This is the Hour of Lead –

Remembered, if outlived,

As Freezing persons, recollect the Snow –

First – Chill – then Stupor – then the letting go –^{xvi}

Sportswriter Brian Phillips describes this state, which he experienced once when stranded for several hours on an icepack in the Bering Strait. "It was the first time I ever understood why freezing to death is sometimes described as . . . *just like falling asleep*. . . . It was like certain parts of [my] body just accrued this strange hush."^{xvii} I recognize the temptation to lay down the burden of living, because I felt it when my body metabolized crushed OxyContin. I left my body and went elsewhere as my bodymind

knew the strange rushing hush of nonbeing. Nodding off, I experienced the relief from my suffering as complete . . . myself gathered into a blissful absence of pain, below zero on the pain scale. Lovely, easeful, unsustainable, unlivable life.

Janet's told me how deeply relieved she was when I greeted her with "Hi, Jake" the second day she came to visit me in the ICU, where I had emerged from deep sedation. She further reports that the second thing I said was, "How was your conference?" In so doing, I immediately recognized her and her projects. She was reassured. I had a spinal cord injury, she had no idea what that would bring, but I knew her for herself and wanted to hear about her work. In other words, I was myself, which, in turn, helped her to recover a sense of who she was that had been terribly shaken over the preceding forty-eight hours. Our lives are intertwined, and my life is not mine alone, but shared with her. My living makes her life better, and she tells me so—it's that simple and that profound. I think it's accurate to call my injuries "catastrophic," and it's a testament to the sheer durability of our feelings for each other that the love that was so vital and alive before the accident survived without a scratch. This fact, more than any other, makes my inexpressibly difficult life livable, and I know that Janet and I enjoy a reciprocity of feeling that's very precious to us both.

Writing, no matter about what subject, has its way with the writer. Writing helps to teach us what we can't know otherwise, which makes it a demanding and invaluable discipline. Writing offers, not a way out, but a way into the impossible dilemmas of not-knowing. Each sentence begun can wander off, sometimes irretrievably into confusion and mistake, sometimes to greater clarity. Tropes transport memories and transform them, as resin is transformed under pressure into amber, sometimes with a small, ancient

bit of life suspended inside. Amber can be remarkably clear, but the piece that conserves a suspended life is often more valuable. Writing works on memory, compressing and doubtless distorting the past, and offers bodies for the inspection of reader and writer alike.

Writing has turned me in ways I didn't know I was going to go—outward as well as inward. Attending to my family led toward a particular intimacy with my brother, Jeff, with whom I shared so much. Searching to represent unfathomable experience—both his and mine—has sent me repeatedly to the dictionary and to the concentrated language of lyric poetry, to ways of knowing like phenomenology and psychoanalysis that seek to understand human subjectivity, and to feminist and queer thinking about embodied and relational life. I've reached backward in memory to my childhood and young adulthood, but the process of writing has taken me forward, and continues to do so. Sentences unfold before me, always into the future, even as I return and work over what's already there.

I understand that every day I'm faced with an impossible choice—remembrance of things past or living on into a future that is troubling, even terrifying, but nonetheless underdetermined. I don't know what is going to happen, and I can't forget the past. I won't. I need it, I want and I need to remember the body that I once was. That body has suffered grievous injury, and to believe in myself as a strong, competent, and desirable woman I **build** on my memories of the many moments when I felt all that. Forgetting is impossible.

Forgetting is also imperiously necessary. In order to live on I must actively forget the person I once was, and be committed to forgetting more mindfully than you probably

are as you go about your daily life. I am no longer what I once was—yet come to think of it, neither are you. All of us who live on are not what we were, but are becoming, always becoming. I have chosen, and for the immediately foreseeable future, will choose, to live as fully and passionately as I can. Every time I make that choice, I move further from the past, and am increasingly detached from what once was. It's a taxing process.

When I was rehabilitating at the Hospital for Special Care, paralysis had so weakened my hands that I couldn't turn a page of the Penguin paperbacks that line the bookshelves in my study. As you know, I was unable even to grasp a Kleenex and move it from right to left on my tray table, when Patty instructed me to do so. I cried tears of despair and rage, bitter tears. Day after day in therapy, I very slowly strengthened my grip as I followed her instructions. Several months after she had tried the tissue, Patty returned with a pencil and a book. She opened the book flat before me, and holding the pencil with the eraser facing outward, used it to grab the edge of a page. She turned it over. Then she handed the pencil to me. I grasped it with all my strength, and as Janet and my nurse, Winnie, watched, I turned a page. "I have my life back," I said with tears overflowing. I said again, "I have my life back," and we all four cried together.

¹ See Judith Butler, *Precarious Life* (New York: Verso, 2004).

Chapter 3. Bewilderment

² Maggie Nelson, *Something Bright, Then Holes* (New York: Soft Skull Press, 2007), 42.

¹ See Judith Butler, *Giving an Account of Oneself* (New York: Fordham University Press, 2005).

Chapter 4. Falling into Hell

- 1 Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (Oxford: Oxford University Press, 1985), 4, 5.
- 2 Elizabeth Grosz, *The Volatile Body* (Bloomington: Indiana University Press, 1995).

Chapter 5. Caring at the Cash Nexus

- 1 Lauren Berlant, *Cruel Optimism* (Durham, NC: Duke University Press, 2011).
- 2 Eduardo Porter, “Unionizing the Bottom of the Pay Scale,” *New York Times*, December 5, 2012, <http://www.nytimes.com/2012/12/05/business/unionizing-at-the-low-end-of-the-pay-scale.html>, accessed March 7, 2015.
- 3 See Richard Kline, *Cigarettes Are Sublime* (Durham, NC: Duke University Press, 1995).
- 4 Langston Hughes, *The Ways of White Folk* (1934; New York: Vintage Classics, 1990).
- 5 Premilla Nadasen and Tiffany Williams, *Valuing Domestic Work*, New Feminist Solutions, vol. 5 (New York: Barnard Center for Research on Women, 2009), <http://bcrw.barnard.edu/wp-content/nfs/reports/NFS5-Valuing-Domestic-Work.pdf>, accessed March 6, 2015.

Chapter 6. Lost in Space

- 1 Elizabeth Ermarth, *Realism and Consensus in the English Novel* (Princeton, NJ: Princeton University Press, 1998).

² Peter Brooks, *Reading for the Plot: Design and Intention in Narrative* (New York: Alfred A Knopf, 1985), 23, 323.

³ Susan Stewart, “The Epistemology of the Horror Story,” *The Journal of American Folklore* 95.375 (Jan. - Mar., 1982): 35-36.

⁴ Edgar Allan Poe, “The Fall of the House of Usher” (1839), *Literature Network*, <http://www.online-literature.com/poe/31/>, accessed June 26, 2011.

⁵ Otto Kernberg, “Some Observations on the Process of Mourning,” *International Journal of Psychoanalysis* 91.3 (June 2010): 601–619.

Chapter 18. Living On

^{xvi} Emily Dickenson, “After great pain, a formal feeling comes –,” Poetry Foundation, accessed July 3, 2015.

^{xvii} Brian Phillips, “Out in the Great Alone,” *Grantland (ESPN.com)*, http://espn.go.com/espn/feature/story/_/id/9175394/out-great-alone, accessed June 8, 2015.