A Body, Undone

Living On
after Great Pain

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After great pain, a formal feeling comes—
The Nerves sit ceremonious, like Tombs—
The stiff Heart questions 'was it He, that bore,'
And 'Yesterday, or Centuries before?'

The Feet, mechanical, go round—
A Wooden way
Of Ground, or Air, or Ought—
Regardless grown,
A Quartz contentment, like a stone—

This is the Hour of Lead—
Remembered, if outlived,
As Freezing persons, recollect the Snow—
First—Chill—then Stupor—then the letting go—

Emily Dickinson
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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 of rehabilitation at the Hospital for Special Care, I was discharged to the “care of one.” That’s a standard used by the insurance companies to determine when you can be sent home. From that point on—in principle—I needed only one person to transfer me from bed to wheelchair and back again, to watch for pressure sores, to dress and undress me, to bathe me and brush my teeth, to feed me and help me drink, to help me relieve myself; and to purchase and administer my pharmacopeia of drugs. To keep me alive. The burden of my care was now to be transferred to private life, where one untrained person was charged with taking over. In most cases this would be a mother or wife. In my case the burden of my care came to my lover, Janet.

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

What does it take to make a life livable? That’s a slightly different matter, because it addresses the whole person, body and mind—bodymind—together. In 2005, I returned to work half-time, resuming some of my duties as a professor of English literature and feminist, gender, and sexuality studies at Wesleyan University. My workplace has responded positively to my requests for “reasonable accommodation,” the terms of which are established by the Americans with Disabilities Act (ADA), comprehensive legislation that mandates the removal of barriers to participation in public life by those whose bodies are impaired or minds are nonnormative—the political victory won in 1992 by activists for disability rights. The university supported my recovery and continues to make good faith efforts to increase physical accessibility. I am remarkably fortunate that I can continue to do the work I did before I was injured, though I’m able
to work only half as many hours a week. Working is hard, but not working is harder. Engaging in the classroom, in my office talking with students and colleagues, reading and writing all take me out of myself, and distract me from chronic pain and incapacity. It’s a hard truth that I hurt myself just when entering the peak earning years of my profession, which makes me angry every time I think of it. Nonetheless, with Janet’s income added to my reduced paycheck, I still have enough money to be insulated from the indignities of an unjust world in which so many disabled people suffer because their welfare depends on poorly paid personal aides sent out from agencies, public transportation that is often unreliable, and housing that is only barely or not at all accessible.

I now understand better what all disabled people owe to the early activists who demanded full access to and participation in the public sphere. Like all other civil rights law, the ADA was passed only after years of activism—people in wheelchairs picketing for curb cuts, the Deaf President Now student movement at Gallaudet, lawyers suing school boards for the supports needed for disabled kids to learn alongside their peers, and so on—and the activism that yielded the ADA was only a start. The struggle for recognition of discrimination against “the handicapped” now extends not only to the streets and courtrooms, but also to the classrooms of higher education. Scholars have convincingly argued that disability is not a personal attribute of crippled bodies or minds, but a social phenomenon that bars the full participation in public life of persons so impaired. Impassable barriers and narrowly conceived measurements of ability make it hard to acknowledge and address nonnormative bodyminds. We are conveniently invisible because we are all too often immured in private spaces. Disability is created by building codes and education policy, subway elevators that don’t work and school buses that don’t arrive, and all the marginalization, exploitation, demeaning acts, and active exclusions that deny full access and equality to “the disabled.” To focus on intractable pain, then, or grief at the loss of able-bodiedness, as I do here, may be thought to play into a pathologizing narrative that would return disability to “misshapen” bodies and “abnormal” minds. When I presented some of this work to a study group, one guy in a wheelchair more or less told me to “man up” and get on with my life—after all, that’s what he had done decades ago, before the ADA, even.

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

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

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

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

**Morning En Route to the Hospital**

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

in a trance of glitter

Live with your puny, vulnerable self
Live with 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 around me enacted a family life that undid me in ways that will take a lifetime to understand. So I kept my counsel and my distance—and felt my difference.

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

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

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

* * *

Grieving undoes you and casts you off, far from the workaday world uninfected by loss. That’s why you’re told to move through grief, to transform it into a quieter and more tractable sorrow, and get on with life. Loosen your attachments to whatever is gone. Recognize that the influence of what you’ve lost is still with you, and will remain incorporated into your life. Reengage in the present, and orient yourself to the future. These dictates make sense, but trouble me because my grief is multifaceted and its objects incommensurate. The loss of my mother, whom I loved very much, was profound, even though she was ninety-two and had lived a life full of love and backlit with joy. The loss of Jeff was shocking, despite his long decline, because he was himself so oriented to life, so vital and enthusiastic. The loss of the life I was leading with Janet before I broke my neck is of another kind. Its most important element is wholly intact, for we continue
to love each other as richly as we did before October 1, 2003. Our sex life is fun and profound, sometimes both at once. All the same, sex is very different, because my body has lost its ability to register its exquisite pleasures. Life no longer feels radiant. The more mundane enjoyments of everyday life—making a peach pie in August, feeling sexy in leather pants and silver jewelry—are also gone, because they depended on a body radically different from mine now. I can no longer feel the satisfaction of cycling forty miles, or hiking up a desert canyon, or kayaking in the ocean, or riding my gorgeous Triumph motorcycle. I don’t want to forget how those pleasures felt in my body, and I fear the erosion of embodied memory.

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

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

... This is the Hour of Lead—

I begin in that leaden place where pain seems on the other side of language, and work toward living on.
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 other bodies different from yourself, at a touchable distance, and self-

hood 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. 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 despite 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?
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 has 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 Victoriantist 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 sur-

rounding 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.” 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 nameless 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 and 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 whirrs 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 balsful 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.

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 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 push-
ing 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.
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 by 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—

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. 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 it 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 built 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 becom-
ing, always becoming. I have chosen, and for the immediately fore-
seeable 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, paraly-
sis had so weakened my hands that I couldn't turn a page of the Pen-
guin 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.
NOTES

CHAPTER 1. YOUR PUNY, VULNERABLE SELF

CHAPTER 3. BEWILDERMENT

CHAPTER 4. FALLING INTO HELL

CHAPTER 5. CARING AT THE CASH NEXUS


**CHAPTER 16. PRETTY, WITTY, AND GAY**


**CHAPTER 17. THE HORROR: THE HORROR!**


**CHAPTER 18. LIVING ON**


**About the Author**

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