

“On Being a Cripple,” by Nancy Mairs

“To escape is nothing. Not to escape is nothing.” --Louise Bogan

The other day I was thinking of writing an essay on being a cripple. I was thinking hard in one of the stalls of the women's room in my office building, as I was shoving my shirt into my jeans and tugging up my zipper. Preoccupied, I flushed, picked up my book bag, took my cane down from the hook, and unlatched the door. So many movements unbalanced me, and as I pulled the door open I fell over backward, landing fully clothed on the toilet seat with my legs splayed in front of me: the old beetle-on-its-back routine. Saturday afternoon, the building deserted, I was free to laugh aloud as I wriggled back to my feet, my voice bouncing off the yellowish tiles from all directions. Had anyone been there with me, I'd have been still and faint and hot with chagrin. I decided that it was high time to write the essay

First, the matter of semantics. I am a cripple. I choose this word to name me. I choose from among several possibilities, the most common of which are "handicapped" and "disabled." I made the choice a number of years ago, without thinking, unaware of my motives for doing so. Even now, I'm not sure what those motives are, but I recognize that they are complex and not entirely flattering. People--crippled or not--wince at the word "cripple," as they do not at "handicapped" or "disabled." Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates /gods /viruses have not been kind, but who can face the brutal truth of her existence squarely. As a cripple, I swagger.

But, to be fair to myself, a certain amount of honesty underlies my choice. "Cripple" seems to me a clean word, straightforward and precise. It has an honorable history, having made its first appearance in the Lindisfarne Gospel in the tenth century. As a lover of words, I like the accuracy with which it describes my condition: I have lost the full use of my limbs. "Disabled," by contrast, suggests any incapacity, physical or mental. And I certainly don't like "handicapped," which implies that I have deliberately been put at a disadvantage, by whom I can't imagine (my God is not a Handicapper General), in order to equalize chances in the great race of life. These words seem to me to be moving away from my condition, to be widening the gap between word and reality. Most remote is the recently coined euphemism "differently abled," which partakes of the same semantic hopefulness that transformed countries from "undeveloped" to "underdeveloped," then to "less developed," and finally to "developing" nations. People have continued to starve in those countries during the shift. Some realities do not obey the dictates of language.

Mine is one of them. Whatever you call me, I remain crippled. But I don't care what you call me, so long as it isn't "differently abled," which strikes me as pure verbal garbage designed, by its ability to describe anyone, to describe no one. I subscribe to George Orwell's thesis that "the slovenliness of our language makes it easier for us to have foolish thoughts." And I refuse to participate in the degeneration of the language to the extent that I deny that I have lost anything in the course of this calamitous disease; I refuse to pretend that the only differences between you and me are the various ordinary ones that distinguish any one person from another. But call me "disabled" or "handicapped" if you like. I have long since grown accustomed to them; and if they are vague, at least they hint at the truth. Moreover, I use them myself. Society is no readier to accept crippledness than to accept death, war, sex, sweat, or wrinkles. I would never refer to another person as a cripple. It is the word I use to name only myself.

I haven't always been crippled, a fact for which I am soundly grateful. To be whole of limb is, I know from experience, infinitely more pleasant and useful than to be crippled; and if that knowledge leaves me open to bitterness at MY loss, the physical soundness I once enjoyed (though I did not enjoy it half enough) is well worth the occasional stab of regret. Though never any good at sports, I was a normally active child and young adult. I climbed trees, played hopscotch, jumped rope, skated, swam, rode my bicycle, sailed. I despised team sports, spending some of the wretchedest afternoons of my life, sweaty and humiliated, behind a field-hockey stick and under a basketball hoop. I tramped alone for miles along the bridle paths that webbed the woods behind the house I grew up in. I swayed through countless dim hours in the arms of one man or another under the scattered shot of light from mirrored balls, and gyrated through countless more as Tab Hunter and Johnny Mathis gave way to the Rolling Stones, Creedence Clearwater Revival, Cream. I walked down the aisle. I pushed baby carriages, changed tires in the rain, marched for peace.

When I was twenty-eight I started to trip and drop things. What at first seemed my natural clumsiness soon became too pronounced to shrug off. I consulted a neurologist, who told me that I had a brain tumor. A battery of tests, increasingly disagreeable, revealed no tumor. About a year and a half later I developed a blurred spot in one eye. I had, at last, the episodes "disseminated in space and time" requisite for a diagnosis: multiple sclerosis. I have never been sorry for the doctor's initial misdiagnosis, however. For almost a week, until the negative results of the tests were in, I thought that I was going to die right away. Every day for the past nearly ten years, then, has been a kind of gift. I accept all gifts.

Multiple sclerosis is a chronic degenerative disease of the central nervous system, in which the myelin that sheathes the nerves is somehow eaten away and scar tissue forms in its place, interrupting the nerves' signals. During its course, which is unpredictable and uncontrollable, one may lose vision, hearing, speech, the ability to walk, control of bladder and/or bowels, strength in any or all extremities, sensitivity to touch, vibration, and/or pain, potency, coordination of movements-- the list of possibilities is lengthy and, yes, horrifying. One may also lose one's sense of humor. That's the easiest to lose and the hardest to survive without.

In the past ten years, I have sustained some of these losses. Characteristic of MS are sudden attacks, called exacerbations, followed by remissions, and these I have not had. Instead, my disease has been slowly progressive. My left leg is now so weak that I walk with the aid of a brace and a cane; and for distances I use an Amigo, a variation on the electric wheelchair that looks rather like an electrified kiddie car. I no longer have much use of my left hand. Now my right side is weakening as well. I still have the blurred spot in my right eye. Overall, though, I've been lucky so far. My world has, of necessity, been circumscribed by my losses, but the terrain left me has been ample enough for me to continue many of the activities that absorb me: writing, teaching, raising children and cats and plants and snakes, reading, speaking publicly about MS and depression, even playing bridge with people patient and honorable enough to let me scatter cards every which way without sneaking a peek.

Lest I begin to sound like Pollyanna, however, let me say that I don't like having MS. I hate it. My life holds realities--harsh ones, some of them--that no right-minded human being ought to accept without grumbling. One of them is fatigue. I know of no one with MS who does not complain of bone-weariness; in a disease that presents an astonishing variety of symptoms, fatigue seems to be a common factor. I wake up in the morning feeling the way most people do at the end of a bad day, and I take it from there. As a result, I spend a lot of time in extremis and, impatient with limitation, I tend to ignore my fatigue until my body breaks down in some way and forces rest. Then I miss picnics, dinner parties, poetry readings, the brief visits of old friends from out of town. The offspring of a puritanical tradition of exceptional venerability, I cannot view these lapses without shame. My life often seems a series of small failures to do as I ought.

I lead, on the whole, an ordinary life, probably rather like the one I would have led had I not had MS. I am lucky that my predilections were already solitary, sedentary, and bookish--unlike the world-famous French cellist I have read about, or the young woman I talked with one long afternoon who wanted only to be a jockey. I had just begun graduate school when I found out something was wrong with me, and I have remained, interminably, a graduate student. Perhaps I would not have if I'd thought I had the stamina to return to a full-time job as a technical editor; but I've enjoyed my studies.

In addition to studying, I teach writing courses. I also teach medical students how to give neurological examinations. I pick up freelance editing jobs here and there. I have raised a foster son and sent him into the world, where he has made me two grandbabies, and I am still escorting my daughter and son through adolescence. I go to Mass every Saturday. I am a superb, if messy, cook. I am also an enthusiastic laundress, capable of sorting a hamper full of clothes into five subtly differentiated piles, but a terrible housekeeper. I can do italic writing and, in an emergency, bathe an oil-soaked cat. I play a fiendish game of Scrabble. When I have the time and the money, I like to sit on my front steps with my husband, drinking Amaretto and smoking a cigar, as we imagine our counterparts in Leningrad and make sure that the sun gets down once more behind the sharp childish scrawl of the Tucson Mountains.

This lively plenty has its bleak complement, of course, in all the things I can no longer do. I will never run again, except in dreams, and one day I may have to write that I will never walk again. I like to go camping, but I can't follow George and the children along the trails that wander out of a campsite through the desert or into the mountains. In fact, even on the level I've learned never to check the weather or try to hold a coherent conversation: I need all my attention for my wayward feet. Of late, I have begun to catch myself wondering how people can propel themselves without canes. With only one usable hand, I have to select my clothing with care not so much for style as for ease of ingress and egress, and even so, dressing can be laborious. I can no longer do fine stitchery, pick up babies, play the piano, braid my hair. I am immobilized by acute attacks of depression, which may or may not be physiologically related to MS but are certainly its logical concomitant.

These two elements, the plenty and the privation, are never pure, nor are the delight and wretchedness that accompany them. Almost every pickle that I get into as a result of my weakness and clumsiness--and I get into plenty--is funny as well as maddening and sometimes painful. I recall one May afternoon when a friend and I were going out for a drink after finishing up at school. As we were climbing into opposite sides of my car, chatting, I tripped and fell, flat and hard, onto the asphalt parking lot, my abrupt departure interrupting him in mid-sentence. "Where'd you go?" he called as he came around the back of the car to find me hauling myself up by the door frame. "Are you all right?" Yes, I told him, I was fine, just a bit rattly, and we drove off to find a shady patio and some beer. When I got home an hour or so later, my daughter greeted me with "What have you done to yourself?" I looked down. One elbow of my white turtleneck with the green froggies, one knee of my white trousers, one white kneesock were blood-soaked. We peeled off the clothes and inspected the damage, which was nasty enough but not alarming. That part wasn't funny: The abrasions took a long time to heal, and one got a little infected. Even so, when I think of my friend

talking earnestly, suddenly, to the hot thin air while I dropped from his view as though through a trap door, I find the image as silly as something from a Marx Brothers movie.

I may find it easier than other cripples to amuse myself because I live propped by the acceptance and the assistance and, sometimes, the amusement of those around me. Grocery clerks tear my checks out of my checkbook for me, and sales clerks find chairs to put into dressing rooms when I want to try on clothes. The people I work with make sure I teach at times when I am least likely to be fatigued, in places I can get to, with the materials I need. My students, with one anonymous exception (in an end-of-the-semester evaluation), have been unperturbed by my disability. Some even like it. One was immensely cheered by the information that I paint my own fingernails; she decided, she told me, that if I could go to such trouble over fine details, she could keep on writing essays. I suppose I became some sort of bright-fingered muse. She wrote good essays, too.

The most important struts in the framework of my existence, of course, are my husband and children. Dismayingly few marriages survive the MS test, and why should they? Most twenty-two- and nine-teen-year-olds, like George and me, can vow in clear conscience, after a childhood of chicken pox and summer colds, to keep one another in sickness and in health so long as they both shall live. Not many are equipped for catastrophe: the dismay, the depression, the extra work, the boredom that a degenerative disease can insinuate into a relationship. And our society, with its emphasis on fun and its association of fun with physical performance, offers little encouragement for a whole spouse to stay with a crippled partner. Children experience similar stresses when faced with a crippled parent, and they are more helpless, since parents and children can't usually get divorced. They hate, of course, to be different from their peers, and the child whose mother is tacking down the aisle of a school auditorium packed with proud parents like a Cape Cod dinghy in a stiff breeze jolly well stands out in a crowd. Deprived of legal divorce, the child can at least deny the mother's disability, even her existence, forgetting to tell her about recitals and PTA meetings, refusing to accompany her to stores or church or the movies, never inviting friends to the house. Many do.

But I've been limping along for ten years now, and so far George and the children are still at my left elbow, holding tight. Anne and Matthew vacuum floors and dust furniture and haul trash and rake up dog droppings and button my cuffs and bake lasagna and Toll House cookies with just enough grumbling so I know that they don't have brain fever. And far from hiding me, they're forever dragging me by racks of fancy clothes or through teeming school corridors, or welcoming gaggles of friends while I'm wandering through the house in Anne's filmy pink babydoll pajamas. George generally calls before he brings someone home, but he does just as many dumb thankless chores as the children. And they all yell at me, laugh at some of my jokes, write me funny letters when we're apart-in short, treat me as an ordinary human being for whom they have some use. I think they like me. Unless they're faking....

Faking. There's the rub. Tugging at the fringes of my consciousness always is the terror that people are kind to me only because I'm a cripple. My mother almost shattered me once, with that instinct mothers have--blind, I think, in this case, but unerring nonetheless--for striking blows along the fault-lines of their children's hearts, by telling me, in an attack on my selfishness, "We all have to make allowances for you, of course, because of the way you are." From the distance of a couple of years, I have to admit that I haven't any idea just what she meant, and I'm not sure that she knew either. She was awfully angry. But at the time, as the words thudded home, I felt my worst fear, suddenly realized. I could bear being called selfish: I am. But I couldn't bear the corroboration that those around me were doing in fact what I'd always suspected them of doing, professing fondness while silently putting up with me because of the way I am. A cripple. I've been a little cracked ever since.

Along with this fear that people are secretly accepting shoddy goods comes a relentless pressure to please--to prove myself worth the burdens I impose, I guess, or to build a substantial account of goodwill against which I may write drafts in times of need. Part of the pressure arises from social expectations. In our society, anyone who deviates from the norm had better find some way to compensate. Like fat people, who are expected to be jolly, cripples must bear their lot meekly and cheerfully. A grumpy cripple isn't playing by the rules. And much of the pressure is self-generated. Early on I vowed that, if I had to have MS, by God I was going to do it well. This is a class act, ladies and gentlemen. No tears, no recriminations, no faint-heartedness.

One way and another, then, I wind up feeling like Tiny Tim, peering over the edge of the table at the Christmas goose, waving my crutch, piping down God's blessing on us all. Only sometimes I don't want to play Tiny Tim. I'd rather be Caliban, a most scurvy monster. Fortunately, at home no one much cares whether I'm a good cripple or a bad cripple as long as I make vichyssoise with fair regularity. One evening several years ago, Anne was reading at the dining-room table while I cooked dinner. As I opened a can of tomatoes, the can slipped in my left hand and juice splattered me and the counter with bloody spots. Fatigued and infuriated, I bellowed, "I'm so sick of being crippled!" Anne glanced at me over the top of her book. "There now," she said, "do you feel better?" "Yes," I said, "yes, I do." She went back to her reading. I felt better. That's about all the attention my scurviness ever gets.

Because I hate being crippled, I sometimes hate myself for being a cripple. Over the years I have come to expect--even accept--attacks of violent self-loathing. Luckily, in general our society no longer connects deformity and disease directly with evil (though a charismatic once told me that I have MS because a devil is in me) and so I'm allowed to move largely at will, even among small children. But I'm not sure that this revision of attitude has been particularly helpful. Physical imperfection, even freed of moral disapprobation, still defies and violates the ideal, especially for women, whose confinement in their bodies as objects of desire is far from over. Each age, of course, has its ideal, and I doubt that ours is any better or worse than any other. Today's ideal woman, who lives on the glossy pages of dozens of magazines, seems to be between the ages of eighteen and twenty-five; her hair has body, her teeth flash white, her breath smells minty, her underarms are dry; she has a career but is still a fabulous cook, especially of meals that take less than twenty minutes to prepare; she does not ordinarily appear to have a husband or children; she is trim and deeply tanned; she jogs, swims, plays tennis, rides a bicycle, sails, but does not bowl; she travels widely, even to out-of-the-way places like Finland and Samoa, always in the company of the ideal man, who possesses a nearly identical set of characteristics. There are a few exceptions. Though usually white and often blonde, she may be black, Hispanic, Asian, or Native American, so long as she is unusually sleek. She may be old, provided she is selling a laxative or is Lauren Bacall. If she is selling a detergent, she may be married and have a flock of strikingly messy children. But she is never a cripple.

Like many women I know, I have always had an uneasy relationship with my body. I was not a popular child, largely, I think now, because I was peculiar: intelligent, intense, moody, shy, given to unexpected actions and inexplicable notions and emotions. But as I entered adolescence, I believed myself unpopular because I was homely: my breasts too flat, my mouth too wide, my hips too narrow, my clothing never quite right in fit or style. I was not, in fact, particularly ugly, old photographs inform me, though I was well off the ideal; but I carried this sense of self-alienation with me into adulthood, where it regenerated in response to the depredations of MS. Even with my brace I walk with a limp so pronounced that, seeing myself on the videotape of a television program on the disabled, I couldn't believe that anything but an inchworm could make progress humping along like that. My shoulders droop and my pelvis thrusts forward as I try to balance myself upright, throwing my frame into a bony S. As a result of contractures, one shoulder is higher than the other and I carry one arm bent in front of me, the fingers curled into a claw. My left arm and leg have wasted into pipe-stems, and I try always to keep them covered. When I think about how my body must look to others, especially to men, to whom I have been trained to display myself, I feel ludicrous, even loathsome.

At my age, however, I don't spend much time thinking about my appearance. The burning egocentricity of adolescence, which assures one that all the world is looking all the time, has passed, thank God, and I'm generally too caught up in what I'm doing to step back, as I used to, and watch myself as though upon a stage. I'm also too old to believe in the accuracy of self-image. I know that I'm not a hideous crone, that in fact, when I'm rested, well dressed, and well made up, I look fine. The self-loathing I feel is neither physically nor intellectually substantial. What I hate is not me but a disease.

I am not a disease.

And a disease is not--at least not single-handedly--going to determine who I am, though at first it seemed to be going to. Adjusting to a chronic incurable illness, I have moved through a process similar to that outlined by Elizabeth Kubler-Ross in *On Death and Dying*. The major difference--and it is far more significant than most people recognize--is that I can't be sure of the outcome, as the terminally ill cancer patient can. Research studies indicate that, with proper medical care, I may achieve a "normal" life span. And in our society, with its vision of death as the ultimate evil, worse even than decrepitude, the response to such news is, "Oh well, at least you're not going to die." Are there worse things than dying? I think that there may be.

I think of two women I know, both with MS, both enough older than I to have served me as models. One took to her bed several years ago and has been there ever since. Although she can sit in a high-backed wheelchair, because she is incontinent she refuses to go out at all, even though incontinence pants, which are readily available at any pharmacy, could protect her from embarrassment. Instead, she stays at home and insists that her husband, a small quiet man, a retired civil servant, stay there with her except for a quick weekly foray to the supermarket. The other woman, whose illness was diagnosed when she was eighteen, a nursing student engaged to a young doctor, finished her training, married her doctor, accompanied him to Germany when he was in the service, bore three sons and a daughter, now grown and gone. When she can, she travels with her husband; she plays bridge, embroiders, swims regularly; she works, like me, as a symptomatic-patient instructor of medical students in neurology. Guess which woman I hope to be.

At the beginning, I thought about having MS almost incessantly. And because of the unpredictable course of the disease, my thoughts were always terrified. Each night I'd get into bed wondering whether I'd get out again the next morning, whether I'd be able to see, to speak, to hold a pen between my fingers. Knowing that the day might come when I'd be physically incapable of killing myself, I thought perhaps I ought to do so right away, while I still had the strength. Gradually I came to understand that the Nancy who might one day lie inert under a bedsheet, arms and legs paralyzed, unable to feed or bathe herself, unable to

reach out for a gun, a bottle of pills, was not the Nancy I was at present, and that I could not presume to make decisions for that future Nancy, who might well not want in the least to die. Now the only provision I've made for the future Nancy is that when the time comes--and it is likely to come in the form of pneumonia, friend to the weak and the old--I am not to be treated with machines and medications. If she is unable to communicate by then, I hope she will be satisfied with these terms.

Thinking all the time about having MS grew tiresome and intrusive, especially in the large and tragic mode in which I was accustomed to considering my plight. Months and even years went by without catastrophe (at least without one related to MS), and really I was awfully busy, what with George and children and snakes and students and poems, and I hadn't the time, let alone the inclination, to devote myself to being a disease. Too, the richer my life became, the funnier it seemed, as though there were some connection between largesse and laughter, and so my tragic stance began to waver until, even with the aid of a brace and a cane, I couldn't hold it for very long at a time.

After several years I was satisfied with my adjustment. I had suffered my grief and fury and terror, I thought, but now I was at ease with my lot. Then one summer day I set out with George and the children across the desert for a vacation in California. Part way to Yuma I became aware that my right leg felt funny. "I think I've had an exacerbation," I told George. "What shall we do?" he asked. "I think we'd better get the hell to California," I said, "because I don't know whether I'll ever make it again." So we went on to San Diego and then to Orange, up the Pacific Coast Highway to Santa Cruz, across to Yosemite, down to Sequoia and Joshua Tree, and so back over the desert to home. It was a fine two-week trip, filled with friends and fair weather, and I wouldn't have missed it for the world, though I did in fact make it back to California two years later. Nor would there have been any point in missing it, since in MS, once the symptoms have appeared, the neurological damage has been done, and there's no way to predict or prevent that damage.

The incident spoiled my self-satisfaction, however. It renewed my grief and fury and terror, and I learned that one never finishes adjusting to MS. I don't know now why I thought one would. One does not, after all, finish adjusting to life, and MS is simply a fact of my life--not my favorite fact, of course--but as ordinary as my nose and my tropical fish and my yellow Mazda station wagon. It may at any time get worse, but no amount of worry or anticipation can prepare me for a new loss. My life is a lesson in losses. I learn one at a time.

And I had best be patient in the learning, since I'll have to do it like it or not. As any rock fan knows, you can't always get what you want. Particularly when you have MS. You can't, for example, get cured. In recent years researchers and the organizations that fund research have started to pay MS some attention even though it isn't fatal; perhaps they have begun to see that life is something other than a quantitative phenomenon, that one may be very much alive for a very long time in a life that isn't worth living. The researchers have made some progress toward understanding the mechanism of the disease: It may well be an autoimmune reaction triggered by a slow-acting virus. But they are nowhere near its prevention, control, or cure. And most of us want to be cured. Some, unable to accept incurability, grasp at one treatment after another; no matter how bizarre: megavitamin therapy, gluten-free diet, injections of cobra venom, hypothermal suits, lymphocytophages, hyperbaric chambers. Many treatments are probably harmless enough, but none are curative.

The absence of a cure often makes MS patients bitter toward their doctors. Doctors are, after all, the priests of modern society, the new shamans, whose business is to heal, and many an MS patient roves from one to another, searching for the "good" doctor who will make him well. Doctors too think of themselves as healers, and for this reason many have trouble dealing with MS patients, whose disease in its intransigence defeats their aims and mocks their skills. Too few doctors, it is true, treat their patients as whole human beings, but the reverse is also true. I have always tried to be gentle with my doctors, who often have more at stake in terms of ego than I do. I may be frustrated, maddened, depressed by the incurability of my disease, but I am not diminished by it, and they are. When I push myself up from my seat in the waiting room and stumble toward them, I incarnate the limitation of their powers. The least I can do is refuse to press on their tenderest spots.

This gentleness is part of the reason that I'm not sorry to be a cripple. I didn't have it before. Perhaps I'd have developed it anyway--how could I know such a thing?--and I wish I had more of it, but I'm glad of what I have. It has opened and enriched my life enormously. This sense that my frailty and need must be mirrored in others, that in searching for and shaping a stable core in a life wrenched by change and loss, change and loss, I must recognize the same process, under individual conditions, in the lives around me. I do not deprecate such knowledge, however I've come by it.

All the same, if a cure were found, would I take it? In a minute. I may be a cripple, but I'm only occasionally a loony and never a saint. Anyway, in my brand of theology God doesn't give bonus points for a limp. I'd take a cure; I just don't need one. A friend who also has MS startled me once by asking, "Do you ever say to yourself, 'Why me, Lord?'" "No, Michael, I don't," I told him, "because whenever I try, the only response I can think of is 'Why not?'" If I could make a cosmic deal, whom would I put in my place? What in my life would I give up in exchange for sound limbs and a thrilling rush of energy? No one. Nothing. I might as well do the job myself. Now that I'm getting the hang of it.