Inviting me to speak at her small liberal arts college during Women’s Week, a young woman set me a task: "We would be pleased," she wrote, "if you could talk on how you cope with your MS disability, and also how you discovered your voice as a writer." Oh, Lord, I thought in dismay, how am I going to pull this one off? How can I yoke two such disparate subjects into a coherent presentation, without doing violence to one, or the other, or both, or myself? This is going to take some fancy footwork, and my feet scarcely carry out the basic steps, let alone anything elaborate.

To make matters worse, the assumption underlying each of her questions struck me as suspect. To ask how I cope with multiple sclerosis suggests that I do cope. Now, "to cope," Webster’s Third tells me, is "to face or encounter and to find necessary expedients to overcome problems and difficulties." In these terms, I have to confess, I don't feel like much of a copier. I'm likely to deal with my problems and difficulties by squawking and flapping around like that hysterical chicken that was convinced the sky was falling. Never mind that in my case the sky really is falling. In response to a clonk on
the head, regardless of its origin, one might comport oneself with a grace and courtesy I generally lack.

As for “finding” my voice, the implication is that it was at one time lost or missing. But I don’t think it ever was. Ask my mother, who will tell you a little wearily that I was speaking full sentences by the time I was a year old and could never be silenced again. As for its being a writer’s voice, it seems to have become one early on. Ask Mother again. At the age of eight I rewrote the Trojan War, she will say, and what Nestor was about to do to Helen at the end doesn’t bear discussion in polite company.

Faced with these uncertainties, I took my own teacherly advice, something, I must confess, I don’t always do. “If an idea is giving you trouble,” I tell my writing students, “put it on the back burner and let it simmer while you do something else. Go to the movies. Reread a stack of old love letters. Sit in your history class and take detailed notes on the Teapot Dome scandal. If you’ve got your idea in mind, it will go on cooking at some level no matter what else you’re doing.” “I’ve had an idea for my documented essay on the back burner,” one of my students once scribbled in her journal, “and I think it’s just boiled over!”

I can’t claim to have reached such a flash point. But in the weeks I’ve had the themes “disability” and “voice” sitting around in my head, they seem to have converged on their own, without my having to wrench them together and bind them with hoops of tough rhetoric. They are related, indeed interdependent, with an intimacy that has for some reason remained, until now, submerged below the surface of my attention. Forced to juxtapose them, I yank them out of the depths, a little startled to discover how they were inter-

twined down there out of sight. This kind of discovery can unnerve you at first. You feel like a giant hand that, pulling two swimmers out of the water, two separate heads bobbling on the iridescent swells, finds the two bodies below, legs coiled around each other, in an ecstasy of copulation. You don’t quite know where to turn your eyes.

Perhaps the place to start illuminating this erotic connection between who I am and how I speak lies in history. I have known that I have multiple sclerosis for about seventeen years now, though the disease probably started long before. The hypothesis is that the disease process, in which the protective covering of the nerves in the brain and spinal cord is eaten away and replaced by scar tissue, “hard patches,” is caused by an autoimmune reaction to a slow-acting virus. Research suggests that I was infected by this virus, which no one has ever seen and which therefore, technically, doesn’t even “exist,” between the ages of four and fifteen. In effect, living with this mysterious mechanism feels like having your present self, and the past selves it embodies, haunted by a capricious and mean-spirited ghost, unseen except for its footprints, which trips you even when you’re watching where you’re going, knocks glassware out of your hand, squeezes the urine out of your bladder before you reach the bathroom, and weighs your whole body with a weariness no amount of rest can relieve. An alien invader must be at work. But of course it’s not. It’s your own body. That is, it’s you.

This, for me, has been the most difficult aspect of adjusting to a chronic incurable degenerative disease: the fact that it has rammed my “self” straight back into the body I had been trained to believe it could, through high-minded acts
and aspirations, rise above. The Western tradition of distinguishing the body from the mind and/or the soul is so ancient as to have become part of our collective unconscious, if one is inclined to believe in such a notion, or at least to have become an unquestioned element in the social instruction we impose upon infants from birth, in much the same way we inculcate, without reflection, the gender distinctions “female” and “male.” I have a body, you are likely to say if you talk about embodiment at all; you don’t say, I am a body. A body is a separate entity possessable by the “I”; the “I” and the body aren’t, as the copula would make them, grammatically indistinguishable.

To widen the rift between the self and the body, we treat our bodies as subordinates, inferior in moral status. Open association with them shames us. In fact, we treat our bodies with very much the same distance and ambivalence women have traditionally received from men in our culture. Sometimes this treatment is benevolent, even respectful, but all too often it is tainted by outright sadism. I think of the bodybuilding regimens that have become popular in the last decade or so, with the complicated vacillations they reflect between self-worship and self-degradation: joggers and aerobic dancers and weightlifters all beating their bodies into shape. “No pain, no gain,” the saying goes. “Feel the burn.” Bodies get treated like wayward women who have to be shown who’s boss, even if it means slapping them around a little. I’m not for a moment opposing rugged exercise here. I’m simply questioning the spirit in which it is often undertaken.

Since, as Helene Cixous points out in her essay on women and writing, “Sorties,”* thought has always worked “through dual, hierarchical oppositions” (p. 64), the mind/body split cannot possibly be innocent. The utterance of an “I” immediately calls into being its opposite, the “not-I,” Western discourse being unequipped to conceive “that which is neither ‘I’ nor ‘not-I,’” “that which is both ‘I’ and ‘not-I,’” or some other permutation that language doesn’t permit me to speak. The “not-I” is, by definition, other. And we’ve never been too fond of the other. We prefer the same. We tend to ascribe to the other those qualities we prefer not to associate with ourselves: It is the hidden, the dark, the secret, the shameful. Thus, when the “I” takes possession of the body, it makes the body into an other, direct object of a transitive verb, with all the other’s repudiated and potentially dangerous qualities.

At the least, then, the body had best be viewed with suspicion. And a woman’s body is particularly suspect, since so much of it is in fact hidden, dark, secret, carried about on the inside where, even with the aid of a speculum, one can never perceive all of it in the plain light of day, a graspsable whole. I, for one, have never understood why anyone would want to carry all that delicate stuff around on the outside. It would make you awfully anxious, I should think, put you constantly on the defensive, create a kind of siege mentality that viewed all other beings, even your own kind, as threats to be warded off with spears and guns and atomic missiles. And you’d never get to experience that inward dreaming that comes when your flesh surrounds all your treasures,

* In The Newly Born Woman, translated by Betsy Wing (Minneapolis: University of Minnesota Press, 1986).
holding them close, like a sturdy shuttered house. Be my personal skepticism as it may, however, as a cultural woman I bear just as much shame as any woman for my dark, enfolded secrets. Let the word for my external genitals tell the tale: my pudendum, from the Latin infinitive meaning “to be ashamed.”

It's bad enough to carry your genitals like a sealed envelope bearing the cipher that, once unlocked, might loose the chaotic flood of female pleasure—jouissance, the French call it—upon the world-of-the-same. But I have an additional reason to feel shame for my body, less explicitly connected with its sexuality: It is a crippled body. Thus it is doubly other, not merely by the homosexual standards of patriarchal culture but by the standards of physical desirability erected for every body in our world. Men, who are by definition exonerated from shame in sexual terms (this doesn't mean that an individual man might not experience sexual shame, of course; remember that I'm talking in general about discourse, not folks), may—more likely must—experience bodily shame if they are crippled. I won't presume to speak about the details of their experience, however. I don't know enough. I'll just go on telling what it's like to be a crippled woman, trusting that, since we're fellow creatures who've been living together for some thousands of years now, much of my experience will resonate with theirs.

I was never a beautiful woman, and for that reason I've spent most of my life (together with probably at least 95 percent of the female population of the United States) suffering from the shame of falling short of an unattainable standard. The ideal woman of my generation was . . .

perky, I think you'd say, rather than gorgeous. Blond hair pulled into a bouncing ponytail. Wide blue eyes, a turned-up nose with maybe a scattering of golden freckles across it, a small mouth with full lips over straight white teeth. Her breasts were large but well harnessed high on her chest; her tiny waist flared to hips just wide enough to give the crinoline under her circle skirt a starting outward push. In terms of personality, she was outgoing, even bubbly, not pensive or mysterious. Her milieu was the front fender of a white Corvette convertible, surrounded by teasing crewcuts, dressed in black flats, a sissy blouse, and the letter sweater of the Corvette owner. Needless to say, she never missed a prom.

Ten years or so later, when I first noticed the symptoms that would be diagnosed as MS, I was probably looking my best. Not beautiful still, but the ideal had shifted enough so that my flat chest and narrow hips gave me an elegantly attenuated shape, set off by a thick mass of long, straight, shining hair. I had terrific legs, long and shapely, revealed nearly to the pudendum by the fashionable miniskirts and hot pants I adopted with more enthusiasm than delicacy of taste. Not surprisingly, I suppose, during this time I involved myself in several pretty torrid love affairs.

The beginning of MS wasn't too bad. The first symptom, besides the pernicious fatigue that had begun to devour me, was "foot drop," the inability to raise my left foot at the ankle. As a consequence, I'd started to limp, but I could still wear high heels, and a bit of a limp might seem more intriguing than repulsive. After a few months, when the doctor suggested a cane, a crippled friend gave me quite an elegant wood-and-silver one, which I carried with a fair
amount of panache. The real blow to my self-image came when I had to get a brace. As braces go, it's not bad: lightweight plastic molded to my foot and leg, fitting down into an ordinary shoe and secured around my calf by a Velcro strap. It reduces my limp and, more important, the danger of tripping and falling. But it means the end of high heels. And it's ugly. Not as ugly as I think it is, I gather, but still pretty ugly. It signified for me, and perhaps still does, the permanence and irreversibility of my condition. The brace makes my MS concrete and forces me to wear it on the outside. As soon as I strapped the brace on, I climbed into trousers and stayed there (though not in the same trousers, of course). The idea of going around with my bare brace hanging out seemed almost as indecent as exposing my breasts. Not until 1984, soon after I won the Western States Book Award for poetry, did I put on a skirt short enough to reveal my plasticized leg. The connection between winning a writing award and baring my brace is not merely fortuitous; being affirmed as a writer really did embolden me. Since then I've grown so accustomed to wearing skirts that I don't think about my brace any more than I think about my cane. I've incorporated them, I suppose: made them, in their necessity, inescapable but fundamental parts of my body.

Meanwhile, I had to adjust to the most outward and visible sign of all, a three-wheeled electric scooter called an Amigo. This lessens my fatigue and increases my range terrifically, but it also shouts out to the world “Here is a woman who can't stand on her own two feet.” At the same time, paradoxically, it renders me invisible, reducing me to the height of a seven-year-old, with a child's attendant low status. “Would she like smoking or nonsmoking?” the gate agent assigning me a seat asks the friend traveling with me. In crowds I see nothing but buttocks. I can tell you the name of every type of designer jeans ever sold. The wearers, eyes front, trip over me and fall across my handlebars into my lap. “Hey!” I want to shout to the lofty world. “Down here! There's a person down here!” But I'm not, by their standards, quite a person any more.

My self-esteem diminishes further as age and illness strip from me the features that made me, for a brief while anyway, a good-looking, even sexy, young woman. No more long, bounding strides: I shuffle along with the timid gait I remember observing, with pity and impatience, in the little old ladies at Boston's Symphony Hall on Friday afternoons. No more lithe, girlish figure: My belly sags from the loss of muscle tone, which also creates all kinds of intestinal disruptions, hopelessly humiliating in a society in which excretory functions remain strictly unspeakable. No more sex either, if society had its way. The sexuality of the disabled so repulses most people that you can hardly get a doctor, let alone a member of the general population, to consider the issues it raises. Cripples simply aren't supposed to Want it, much less Do It. Fortunately, I've got a husband with a strong libido and a weak sense of social propriety, or else I'd find myself perforce practicing a vow of chastity I never cared to take.

Afflicted by the general shame of having a body at all, and the specific shame of having one weakened and misshapen by disease, I ought not to be able to hold my head up in public. And yet I've gotten into the habit of holding my head up in public, sometimes under excruciating circum-
stances. Recently, for instance, I had to give a reading at the University of Arizona. Having smashed three of my front teeth in a fall onto the concrete floor of my screened porch, I was in the process of getting them crowned, and the temporary crowns flew out during dinner right before the reading. What to do? I wanted, of course, to rush home and hide till the dental office opened the next morning. But I couldn’t very well break my word at this last moment. So, looking like Hansel and Gretel’s witch, and lisping worse than the Wife of Bath, I got up on stage and read. Somehow, over the years, I’ve learned how to set shame aside and do what I have to do.

Here, I think, is where my “voice” comes in. Because, in spite of my demurrals at the beginning, I do in fact cope with my disability at least some of the time. And I do so, I think, by speaking about it, and about the whole experience of being a body, specifically a female body, out loud, in a clear, level tone that drowns out the frantic whispers of my mother, my grandmothers, all the other trainers of wayward childish tongues: “Sshh! Sss! Nice girls don’t talk like that. Don’t mention sweat. Don’t mention menstrual blood. Don’t ask what your grandfather does on his business trips. Don’t laugh so loud. You sound like a loon. Keep your voice down. Don’t tell. Don’t tell. Don’t tell.” Speaking out loud is an antidote to shame. I want to distinguish clearly here between “shame,” as I’m using the word, and “guilt” and “embarrassment,” which, though equally painful, are not similarly poisonous. Guilt arises from performing a forbidden act or failing to perform a required one. In either case, the guilty person can, through reparation, erase the offense and start fresh. Embarrassment, less opprobrious though not necessarily less distressing, is generally caused by acting in a socially stupid or awkward way. When I trip and sprawl in public, when I wet myself, when my front teeth fly out, I feel horribly embarrassed, but, like the pain of childbirth, the sensation blurs and dissolves in time. If it didn’t, every child would be an only child, and no one would set foot in public after the onset of puberty, when embarrassment erupts like a geyser and bathes one’s whole life in its bitter stream. Shame may attach itself to guilt or embarrassment, complicating their resolution, but it is not the same emotion. I feel guilt or embarrassment for something I’ve done; shame, for who I am. I may stop doing bad or stupid things, but I can’t stop being. How then can I help but be ashamed? Of the three conditions, this is the one that cracks and stifles my voice.

I can subvert its power, I’ve found, by acknowledging who I am, shame and all, and, in doing so, raising what was hidden, dark, secret about my life into the plain light of shared human experience. What we aren’t permitted to utter holds us, each isolated from every other, in a kind of solipsistic thrall. Without any way to check our reality against anyone else’s, we assume that our fears and shortcomings are ours alone. One of the strangest consequences of publishing a collection of personal essays called Plaintext has been the steady trickle of letters and telephone calls saying essentially, in a tone of unmistakable relief, “Oh, me too! Me too!” It’s as though the part I thought was solo has turned out to be a chorus. But none of us was singing loud enough for the others to hear.

Singing loud enough demands a particular kind of voice,
I think. And I was wrong to suggest, at the beginning, that I’ve always had my voice. I have indeed always had a voice, but it wasn’t this voice, the one with which I could call up and transform my hidden self from a naughty girl into a woman talking directly to others like herself. Recently, in the process of writing a new book, a memoir entitled Remembering the Bone House, I’ve had occasion to read some of my early writing, from college, high school, even junior high. It’s not an experience I recommend to anyone susceptible to shame. Not that the writing was all that bad. I was surprised at how competent a lot of it was. Here was a writer who already knew precisely how the language worked. But the voice... oh, the voice was all wrong: maudlin, rhapsodic, breaking here and there into little shrieks, almost, you might say, hysterical. It was a voice that had shucked off its own body, its own homely life of Cheerios for breakfast and seventy pages of Chaucer to read before the exam on Tuesday and a planter’s wart growing painfully on the ball of its foot, and reeled now waithlike through the air, seeking incarnation only as the heroine who enacts her doomed love for the tall, dark, mysterious stranger. If it didn’t get that part, it wouldn’t play at all.

Among all these overheated and vaporous imaginings, I must have retained some shred of sense, because I stopped writing prose entirely, except for scholarly papers, for nearly twenty years. I even forgot not exactly that I had written prose, but at least what kind of prose it was. So when I needed to take up the process again, I could start almost fresh, using the vocal range I’d gotten used to in years of asking the waiter in the Greek restaurant for an extra an-

chovy on my salad, congratulating the puppy on making a puddle outside rather than inside the patio door, pondering with my daughter the vagaries of female orgasm, saying good-bye to my husband, and hello, and good-bye, and hello. This new voice—thoughtful, affectionate, often amused—was essential because what I needed to write about when I returned to prose was an attempt I’d made not long before to kill myself, and suicide simply refuses to be spoken of authentically in high-flown romantic language. It’s too ugly. Too shameful. Too strictly a bodily event. And, yes, too funny as well, though people are sometimes shocked to find humor shoved up against suicide. They don’t like the incongruity. But let’s face it, life (real life, I mean, not the edited-for-television version) is a cacophonous affair from start to finish. I might have wanted to portray my suicidal self as a languishing maiden, too exquisitely sensitive to sustain life’s wounding pressures on her soul. (I didn’t want to, as a matter of fact, but I might have.) The truth remained, regardless of my desires, that when my husband lugged me into the emergency room, my hair matted, my face swollen and gray, my nightgown streaked with blood and urine, I was no frail and tender spirit. I was a body, and one in a hell of a mess.

I “should” have kept quiet about that experience. I know the rules of polite discourse. I should have kept my shame, and the nearly lethal sense of isolation and alienation it brought, to myself. And I might have, except for something the psychiatrist in the emergency room had told my husband. “You might as well take her home,” he said. “If she wants to kill herself, she’ll do it no matter how many precautions we take. They always do.” They always do. I was
one of “them,” whoever they were. I was, in this context anyway, not singular, not aberrant, but typical. I think it was this sense of commonality with others I didn’t even know, a sense of being returned somehow, in spite of my appalling act, to the human family, that urged me to write that first essay, not merely speaking out but calling out, perhaps. “Here’s the way I am,” it said. “How about you?” And the answer came, as I’ve said: “Me too! Me too!”

This has been the kind of work I’ve continued to do: to scrutinize the details of my own experience and to report what I see, and what I think about what I see, as lucidly and accurately as possible. But because feminine experience has been immemorially devalued and repressed, I continue to find this task terrifying. “Every woman has known the torture of beginning to speak aloud,” Cixous writes, “heart beating as if to break, occasionally falling into loss of language, ground and language slipping out from under her, because for woman speaking—even just opening her mouth—in public is something rash, a transgression” (p. 92).

The voice I summon up wants to crack, to whisper, to trail back into silence. “I’m sorry to have nothing more than this to say,” it wants to apologize. “I shouldn’t be taking up your time. I’ve never fought in a war, or even in a schoolyard free-for-all. I’ve never tried to see who could piss farthest up the barn wall. I’ve never even been to a whorehouse. All the important formative experiences have passed me by. I was raped once. I’ve borne two children. Milk trickling out of my breasts, blood trickling from between my legs. You don’t want to hear about it. Sometimes I’m too scared to leave my house. Not scared of anything, just scared: mouth dry, bowels writhing. When the fear got really bad, they locked me up for six months, but that was years ago. I’m getting old now. Misshapen too. I don’t blame you if you can’t get it up. No one could possibly desire a body like this. It’s not your fault. It’s mine. Forgive me. I didn’t mean to start crying. I’m sorry... sorry... sorry...”

An easy solace to the anxiety of speaking aloud: this slow subsidence beneath the waves of shame, back into what Cixous calls “this body that has been worse than confiscated, a body replaced with a disturbing stranger, sick or dead, who so often is a bad influence, the cause and place of inhibitions. By censuring the body,” she goes on, “breath and speech are censored at the same time” (p. 97). But I am not going back, not going under one more time. To do so would demonstrate a failure of nerve far worse than the depredations of MS have caused. Paradoxically, losing one sort of nerve has given me another. No one is going to take my breath away. No one is going to leave me speechless. To be silent is to comply with the standard of feminine grace. But my crippled body already violates all notions of feminine grace. What more have I got to lose? I’ve gone beyond shame. I’m shameless, you might say. You know, as in “shameless hussy”? A woman with her bare brace and her tongue hanging out.

I’ve “found” my voice, then, just where it ought to have been, in the body-warmed breath escaping my lungs and throat. Forced by the exigencies of physical disease to embrace my self in the flesh, I couldn’t write bodiless prose. The voice is the creature of the body that produces it. I speak as a crippled woman. At the same time, in the utter-
nancy mairs

ance I redeem both "criple" and "woman" from the shameful silences by which I have often felt surrounded, contained, set apart; I give myself permission to live openly among others, to reach out for them, stroke them with fingers and sighs. No body, no voice; no voice, no body. That's what I know in my bones.

patricia stevens

stiff upper lip

It was somewhat of a shock to discover a few years ago that men weren't looking any more. If I had been a raving beauty in my youth, it might have been more of a jolt; nevertheless, it is hard to accept that now, when I walk down the street, I am close to being invisible. This realization came to me about the same time that I started avoiding myself in the mirror. I would run a comb through my hair, put on a little mascara and blush, and get out of the bathroom. Otherwise, it was too painful. That rectangular piece of glass over the bathroom sink spoke the truth. It was unavoidable: I was really getting wrinkles. I'd given up the sun a few years earlier, after a dermatologist told me that the fingernail-size pearly patch of skin on my left shoulder was a basal cell carcinoma, but it was too late. I had to pay for all those hours of lying on my back, doing absolutely nothing but baking my face under the thinning ozone.

I've accepted some of my wrinkles. Crow's feet are okay with me; they're laugh lines. The crease between my eyebrows is a bit more troublesome as are the lines across my forehead—all are frown lines—but since we all frown, I've