

Epilogue

The Value of Body Stories

We have banalized the body, demystified it, displayed it to the point that there may be no more to learn about it—at least, about its exterior. We have listened to its talk, in an effort to penetrate its most reticent messages. But we still don't know the body. Its otherness from ourselves, as well as its intimacy, make it the inevitable object of an ever-renewed writing project.

—Peter Brooks, *Body Work*, 1993, p. 286.

Although the personal literature of illness and disability is no longer neglected, it remains vulnerable to dismissal from different sides. Aesthetes may see it as entirely too concerned with the body, too mundane and utilitarian to be “literary.” Political activists may see it as too sentimental to be effective counterdiscourse. (They might argue that its singling out of subjects, its investment in individual fate, limits its emancipatory potential.) I hope to counter such objections here without making extravagant claims for the books in question.

To the activist, narratives of illness and disability may be suspect because they are only words, not action. Thus gay activists might argue that personal narratives are an utterly inadequate response to the urgent threat posed by the AIDS epidemic and, moreover, that for critics to treat illness as in any way a discursive construction is to trivialize human suffering. In the face of this argument one must concede that other responses to AIDS—medical and political—are more urgent than narrative treatments of it.

But in the absence of a magic bullet people continue to live and die with AIDS, and part of their suffering is caused by ignorance and by prejudicial discourse. As Verlyn Klinkenborg has noted,

When you contract a disease, you contract the world of that disease, and that world is what threatens self-definition. In this, as in so much else, AIDS has re-

minded us of things that were on the verge of being forgotten. It has distanced us from the medical optimism of the nineteen-fifties and sixties and reasserted the fact that no sickness—and certainly no epidemic—comes without its myths, which can be every bit as damaging as the sickness itself. (78).

It is this gratuitous collateral damage done by disease that counterdiscourse in the form of illness narratives can address and perhaps alleviate. (Andrew Holleran has suggested that the only thing he really wants to read about AIDS is a headline announcing CURE FOUND [Murphy 315]. At the same time, Holleran's awareness of the limitations of discursive responses to the AIDS epidemic has not prevented him from writing some of the best essays about its effect on the gay community, in *Ground Zero* [1988].) In arguing for a narrative-based approach to medicine, Howard Brody has noted that “suffering results when an illness experience is perceived as meaningless or as threatening the integrity of the patient's life and relationships, and healing occurs when a more comforting meaning is assigned to the illness and the patient sees himself reconnected to his social network” (90). If this assertion is valid on the collective as well as the individual scale, published illness narratives may be in some significant sense healing. Although they may be unable to relieve the symptoms of the body, they may help to relieve the suffering of the self.

At their best narratives of illness and disability acknowledge that our bodies are not ultimately in our control. At the same time, however, they remind us that we do have considerable influence over the way our bodies, healthy or not, are viewed. A degree of stigmatization is associated with all four conditions discussed in this book; indeed, stigma is one powerful stimulant of the narratives—individually and collectively. Although a wide range of conditions has been described in illness narratives, it is no accident that the largest bodies of works have to do with conditions that raise questions of special concern in the cultural politics of fin-de-siècle America. With each of these conditions, then, the narratives tend to address larger agendas. This is most obvious in the cases of breast cancer and AIDS, in which narratives tend to be conscripted into ongoing struggles over the bodies of women and gay men. In assigning meaning to bodily dysfunction, such narratives often contest dominant cultural constructions. The narratives, “mere” words, carry out important cultural work.

Of course, the sort of cultural work that many narratives attempt may not always be consistent with literary aspiration. In a provocative 1995 piece in the *New Yorker* dance critic Arlene Croce took choreographer Bill T. Jones to task for a work entitled “Still/Here,” which included taped testimony by people with terminal illnesses. Without having seen the work, Croce condemned it as manipulative “victim art . . . intolerably

voyeuristic." Using Jones as a whipping boy, Croce launched a broad attack on the way in which late twentieth-century art generally represents "disease and death." According to Croce, rather than transcending or sublimating painful experiences like proper nineteenth-century geniuses, today's artists tend to use raw testimony and all-too-graphic images to extort sympathy from their audiences and to disenfranchise critics: "By working dying people into his act, Jones is putting himself beyond the reach of criticism. I think of him as literally undiscussable—the most extreme case among the distressingly many now representing themselves to the public not as artists but as victims and martyrs" (54). One thing that troubles me about Croce's piece is that its logic, applied to writing, would seem to rule out nonfictional, and especially autobiographical, narratives of illness or disability; at least, by categorizing them as "victim testimony," it would put them beneath critical notice (even as it accuses them of evading critical scrutiny). There is much to be said for transmuting experience in art, as there is much to be said for rising above adversity. But not all adversity ends in triumph, and that which does not should not arbitrarily be ruled inexpressible. (The responsibility of the critic would seem to be to judge works on their merits rather than to dismiss them categorically.)

My relation to the personal literature of illness and disability is clearly different from Croce's relation to dance. The works I address do not typically present themselves as art. I do not expect their intentions and ambitions to be simply or purely aesthetic, nor am I primarily interested in evaluating them in aesthetic terms, sorting out the literary from the subliterate. In focusing on only four conditions—breast cancer, AIDS, paralysis, and deafness—I have tried to sample a full range of testimony on each, with little initial concern for quality. Indeed, some of what I regard as the best recent writing about illness goes undiscussed in this book—because it did not have to do with the conditions selected for discussion.

Nevertheless, part of my response (and responsibility) is inevitably to evaluate; clearly, much of the work discussed here puts a critic in an awkward position. It is discomfiting to find fault with the sincere testimony of someone with a life-threatening condition or that of a grieving caregiver or relative. Nevertheless, the publication of a book invites, even demands, evaluation. The critic's responsibility is to apply standards—whether aesthetic, moral, or political—openly, consistently, and fairly; I hope I have done so. The alternative—not to judge the works—is far more patronizing. And to refuse even to consider them as potential art seems a form of denial, an arbitrary ruling out of an important, if threatening, aspect of human experience.

Croce's diatribe was revealing in its assumption that dance involving

anyone of less than ideal body shape and condition could not be art worthy of critical attention: "As a dance critic, I've learned to avoid dancers with obvious problems—overweight dancers . . . old dancers, dancers with sickled feet, or dancers with physical deformities who appear nightly in roles requiring beauty of line" (55). But perhaps what was most objectionable about her piece was its dismissal of any representation of marginalization—at least in relatively unmediated forms, particularly self-representation—as "victim art": "In quite another category of undiscussability are those dancers I'm *forced* to feel sorry for because of the way they present themselves: as dissed blacks, abused women, or disfranchised homosexuals—as performers, in short, who make out of victimhood victim art" (55). Croce is here attacking not only particular kinds of art but more generally "identity politics"—the tendency to identify individuals with the racial, ethnic, or gender groups of which they are members.

In the cases of the conditions dealt with in this book, to be sure, identity politics often plays a role. In our era one constructive response of those marginalized by bodily difference has been to assert solidarity, textually or extratextually, with others who share that difference. And although identity politics risks overemphasizing certain kinds of differences and reifying those distinctions in counterproductive ways, it seems to me that the current emphasis on bodily distinctions is justified if it contributes to the reduction of stigma and marginalization. It does so, I think, by helping us to see through the body in two senses: to think *about* and *with* our bodies, to reexamine the implications, cultural and political, physical and metaphysical, of our embodiment.

One of Croce's problematic assumptions is that the work she attacks exists only to seek sympathy or pity. It doesn't seem to have occurred to Croce that it might be precisely the goal of such work to challenge the idea that marginalized people are necessarily pathetic victims. In the case of illness and disability often the foremost motive of life writing is to recover variously dysfunctional bodies from domination by others' authority and discourse, to convert the passive object into an active subject. In my experience narratives of illness and disability rarely, if ever, assert victimhood as a basis for sympathy. They are much more likely to try to *devictimize* their subjects and others like them. Indeed, one of the most powerful motives in contemporary narratives of illness and disability is the impulse to invalidate the dominant cultural tropes of "invalidity"—to demystify and destigmatize various conditions. Croce seems to want to preserve not only the stigma but the invisibility of certain conditions. This book and many of the books it analyzes seek to challenge the assumptions behind such erasure.

To claim that illness narratives are worthy of critical attention is not to claim that they are literature. Generally speaking, I would concur with Anne Hunsaker Hawkins, who concluded *Reconstructing Illness* (1993) by saying that "pathography is a genre that awaits its masterpieces" (159). Of the writing I have surveyed here, little of it may prove to have lasting value as literature in the traditional sense—books that require and reward rereading and close analysis. But these works are so new that it would be premature to attempt definitive judgments. I trust that my personal preferences are evident in the body of the book, but the purpose of my evaluative comments has not been to predict canonization for, or to convey it on, any of the works but rather to analyze the role each plays in the development of the discourse of illness and disability.

Genres are not justified only or even mainly by their production of classics. Moreover, it is well to remember that most nonfiction books that come to be considered timeless classics had rather immediate, pragmatic aims when they were composed. (Consider, for example, Frederick Douglass's *Narrative*.) Like related life-writing subgenres devoted to particular kinds of experience—captivity narratives, conversion narratives, and slave narratives, for example—narratives of illness often have specific, limited, utilitarian agendas. Partly because of the pressure under which much of it is composed, autopathography in particular may be highly conventional and even formulaic. Indeed, writing about illness may have inherent limitations that makes the production of masterpieces unlikely.

To those who dismiss illness narratives as inherently non- or subliterary, however, I respond that we should think of illness narratives as serving concentric circles of readers in different ways. In the center are those most immediately involved with the condition in question: those who are ill, those who are at risk, those who are caregivers, those who are bereaved. Written illness narratives may help these readers by providing specific sorts of information, resources, and reassurance; more generally, written accounts may help them achieve some therapeutic perspective on their predicament, to assign it redemptive meaning. For such readers one major function of illness narratives is simply to give formal public expression to their experience, to suggest that it matters.

For those less immediately involved—families and friends of those with the conditions in question—the narratives serve to communicate what those in the center are living through. Thus, for example, friends and acquaintances of people with cancer are often uncertain how to interact with them. Written narratives may help to provide a sense of what the person with cancer is going through and how to respond appropriately. One quite practical purpose of such narratives, then, whether one

considers it a matter of manners, ethics, or morals, is to teach those who are well how to respond to those who are ill.

One of the most fundamental functions of illness narrative, then, is to validate the experience of illness—to put it on record, to exemplify living with bodily dysfunction, to offer lasting testimony.¹ (The same could be said of talk shows and other media attention.) Readers in these inner circles may not be fussy about what they read; indeed, they may find themselves reading voraciously in a single narrow subgenre to help them live through a crisis. Paradoxically, some of the most intimate bodily experiences may be easier to read and write about than to discuss in person; such discourse, however, ought not to be dismissed as voyeuristic. At base, narratives of illness are efforts to give meaning to, or find meaning in, bodily dysfunction and thereby to relieve suffering. People who narrate their illness or disability may be said to share their bodies with others in a kind of secular healing ritual.

For the broader public the purposes of such narratives and the effects of reading them are less well defined. With less personal interest in the condition in question and less pressing need for validation of it this circle of readers may be more oriented to aesthetic qualities—more interested in the poetics than the politics of illness narrative. They may seek out narratives that are particularly self-conscious, writerly works. Or not. Though the sample of works surveyed here is perhaps not entirely representative, personal narratives of illness and disability are in general less transgressive and formally innovative than one might expect. Though their foregrounding of bodily dysfunction may resist or oppose the Western repression of the body, they may also revert in different ways and degrees to formulas or conventions that privilege the soul (such as the conversion narrative). On the whole, though, they generally remain rooted in a familiar solid world and tell more or less straightforward stories. In some ways, then, they tend to perpetuate premodernist narrative conventions. Indeed, part of their appeal to general readers may be that they may satisfy certain appetites that much contemporary literature does not. As the novel has moved toward minimalism, on the one hand, and self-reflexive postmodernist metafiction, on the other, readers may long for old-fashioned plot, vivid characters, life-and-death crises, definitive closure—all of which many illness narratives supply. For these reasons many of these narratives are surprisingly good reads, gripping narratives with compelling topics.

In addition, illness and disability—once they have been validated as subjects for life writing—serve as pretexts for the writing of lives that would otherwise be unstoried and evanescent. As we have seen, the flourishing of illness narrative has been the occasion for the writing of the lives of individuals who until recently might have been excluded

from even the democratic provinces of autobiography and memoir. The tendency of illness narrative to graft another story onto the basic plot of bodily dysfunction means that the repertoire of life writing is enriched by such narratives. Because of their initiative in such dysfunction, such narratives may serve to bring into the light topics traditionally taboo. For example, I think of Mark Doty's memorable description of his partner's body immediately following his death, as its vital warmth dissipated (29–30). To write this without voyeurism, morbidity, or embarrassment requires consummate control of language; the passage is among other things a tour de force. But its value is not so much aesthetic as more broadly cultural; it demystifies a taboo scene, casting light into a dark corner from which most of us avert our eyes. (Though not formally innovative, such writing is significantly transgressive.)

In some texts, then, the details of particular illnesses or disabilities recede in importance; the significance of embodiment more generally comes to the fore. And it is here that other forms of "body writing" may come into play. I am particularly enthusiastic about writing—not necessarily "narrative"—that takes advantage of bodily dysfunction to explore embodiment as a medium of experience. When I first undertook this study, I expected to find more of this in current illness narratives. What I found, however, was that generic illness narrative is, understandably, so invested in recovery that the achievement of closure often takes precedence over consideration of what dysfunction feels like and how it alters self-perception. The essay and the pathographic sketch, which do not depend on plot, are in some ways better suited to this than the chronological narrative. Books by Oliver Sacks (*The Man Who Mistook His Wife for a Hat* [1985]), Leonard Kriegel (*Falling into Life* [1991]), Nancy Mairs (*Carnal Acts* [1990] and *Plaintext* [1986]), Samuel Wilson Fussell (*Muscle* [1991]), John Hull (*Touching the Rock* [1991]), Lucy Grealy (*Autobiography of a Face* [1994]), Tim Brookes (*Catching My Breath* [1995]), Anatole Broyard (*Intoxicated by My Illness* [1992]), Andre Dubus (*Broken Vessels* [1991]), Mark Doty (*Heaven's Coast* [1996], especially Part I), and John Updike (*Self-Consciousness* [1989]) exemplify the range of what I would call body writing. Such writing relies less heavily on chronology and plot; it combines vividness of description, apt and detailed verbal simulation or representation of somatic experience (personal or witnessed firsthand) with speculation about the cultural, political, and epistemological implications of embodiment. (Among narrators of illness, Mark Doty is notable for the degree to which he dissolves the boundaries between himself and his partner, body and spirit, heaven and earth, grief and love, absence and presence, without subordinating either element to its counterpart.) By addressing particular and sometimes rare bodily conditions such as asthma (Brookes), facial disfigure-

ment (Grealy), exercise bulimia (Fussell), stuttering and psoriasis (Updike), they help to take us out of our bodies and into others'; ultimately, though, they return us to our bodies with greater understanding of how they may shape and condition our identities: our bodies, our selves.

Our bodies are, after all, the medium of our experience, our individuation, our very existence—"the source of sensation and the spring of action," in Jonathan Miller's phrase (14). They give us being, and (from a secular perspective, at least) they take it away. On the one hand, in an era when medical technology promises to replace vital organs and extend life, narratives of illness and disability may serve, among other things, as a kind of reality check. They remind us of the vulnerabilities of embodiment. As Anne Hunsaker Hawkins has put it, "For readers who are not themselves sick, pathography serves a preparatory function, so that when they do encounter some life-threatening illness (and most of us eventually will), this experience will inevitably be informed by what they have read" (11). On the other hand, when the same biomedical technologies tend to reduce people to patients and patients to cases, personal narratives may individually and collectively help to reclaim bodies from medical colonization, to reinvest bodily dysfunction with meaning. If the threat of meaninglessness is the most profound threat posed by illness, disability, or other bodily injury, by organizing the experience of bodily dysfunction in coherent ways narratives of illness promise to restore or shore up our sense of the integrity and value of our lives. As Arthur Frank has said, "Illness can teach us all how to live a saner, healthier life. Illness is a threat to life, but it also witnesses what is worth living" (*Will* 15). Finally, then, narratives of illness and disability are a medium in which the writers probe and give expression to the complex dialectic of mind, body, and culture. At best, then, illness narratives remind us of what we share with each other—living in and as bodies, with all the pleasure and pain, joy and frustration, that that entails.

When the body takes a turn for the worse, the mind often turns toward words. Thus, if illness and disability are reminders of our mortality and frailty, narratives of those conditions are testaments to our resilience and vitality. Today especially, narratives of illness and disability are helping us recover our bodies and restore our lives. But there will always be a call for stories of illness and disability; their ultimate value is, after all, to help us understand what it means to be some body.

Notes

¹ In his *Wounded Storyteller* (1995) Arthur Frank has been especially attentive to the ethical dimension of witnessing illness.