

leaving the rest to unspecified others. Second, the professor asserts certain boundaries of the social body: those who are and are not worthy of medical expertise. Finally, the professor echoes the school boy who told Primo Levi how he could have escaped. The professor cannot accept that the chaos Hilfiker describes does not leave any way out.

The truth of the chaotic body is to reveal the hubris of other stories. Chaos stories show how quickly the props that other stories depend on can be kicked away. The limitation is that chaos is no way to live. Frederick Franck writes with his usual wisdom, "Poverty may be quite compatible with a religious attitude toward existence; destitution, hunger, utter humiliation negate it."<sup>20</sup> Among recent medical authors, none are able to look as long and as steadily at the dehumanizing effects of poverty as David Hilfiker. In the lives of those living in extreme poverty, illness cannot be other than chaos.

The unquestionable achievement of modernity was its emphasis on fixing: modernity requires faith to be accountable to what was being accomplished here on earth, in the conditions of people's everyday lives. The cost of modernity is to leave no place for people like Nancy, whose troubles are too complex, in both medical and social terms, for fixing. Sacks's orthopedic surgeon simply cannot hear his complaint that he feels his leg is not part of his body.

For those who share Hilfiker's and Franck's religious attitudes, the mystery of the chaos narrative is its opening to faith: "Blessed are the poor in spirit, for theirs is the kingdom of heaven" (Matthew 5:3). The greatest chaos stories are the first despairing verses of many of the Psalms; the Psalms' message seems to be that the redemption of faith can begin only in chaos. Tragically, those who are most destitute are often beyond such solace. For the poor in spirit to recognize their blessedness, some reflective space is required, and that reflection is what poverty, like unremitting pain, denies.

## Six

### *The Quest Narrative* ILLNESS AND THE COMMUNICATIVE BODY

Restitution stories attempt to outdistance mortality by rendering illness transitory. Chaos stories are sucked into the undertow of illness and the disasters that attend it. Quest stories meet suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest. What is grieved for may never be wholly clear, but the quest is defined by the ill person's belief that something is to be gained through the experience.

The quest narrative affords the ill person a voice as teller of her own story, because only in quest stories does the *teller* have a story to tell. In the restitution narrative the active player is the remedy: either the drug itself—as in the old advertisements where the drugs appeared as cartoon characters, charging around in the body—or the physician. Restitution stories are about the triumph of medicine; they are self-stories only by default. Chaos stories remain the sufferer's own story, but the suffering is too great for a self to be told. The voice of the teller has been lost as a result of the chaos, and this loss then perpetuates that chaos. Though both restitution and chaos remain background voices when the quest is foreground, the quest narrative speaks from the ill person's perspective and holds chaos at bay.

The quest narrative affords the ill their most distinctive voice, and most published illness stories are quest stories. Pub-

lication requires sustaining one's voice for a longer duration than oral stories require, some oral stories being as brief as a single remark. Yet only a few quest stories are published. Although this chapter concentrates on published quest stories, these represent a small fraction of what can be called the *enacted stories* of people's lives: involvement in patient advocacy is one enactment of a quest story; making significant vocational and personal changes in one's life following illness is another. By learning to hear the quest in published stories, appreciation of these enacted stories can be enhanced.

#### ILLNESS AS JOURNEY

The quest narrative certainly goes back to John Donne, who recast his critical illness, probably typhus, into a spiritual journey.<sup>1</sup> My nominee for parenthood for the contemporary quest story, however, is Friedrich Nietzsche. Nietzsche suffered from undiagnosed chronic ailments, including debilitating headaches. He wrote, "I have given a name to my pain, and call it 'dog.'" Nietzsche describes his pain as having the dog-like attributes of being faithful, obtrusive, shameless, entertaining, and clever: "I can scold it and vent my bad mood on it, as others do with their dogs, servants, and wives."<sup>2</sup>

I read this passage remembering that a threshold event in Nietzsche's final madness was his attempt to rescue a horse that was being beaten by its owner. The ironic truth of his illness description—if bad moods are to be vented, best to vent them on one's pain—conceals a moral commitment. Nietzsche anticipates what David Morris calls a "postmodern vision [that] would undermine a sense that we are slaves to pain (or even occasionally masters) by encouraging alternative ways of thinking."<sup>3</sup> Nietzsche calls his pain "dog" to jar the reader into a new relationship to illness. It seems a short step from Nietzsche to Anatole Broyard a century later, writing that "nobody

wants an anonymous illness," and recommending that patients feel they have "earned" their illnesses.<sup>4</sup>

Quest stories tell of searching for alternative ways of being ill. As the ill person gradually realizes a sense of purpose, the idea that illness has been a journey emerges. The meaning of the journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking.

The narrative structure of this journey is best described by Joseph Campbell in his classic work, *The Hero With a Thousand Faces*.<sup>5</sup> I cite Campbell because of his preeminent influence on the popular culture of self-help and self-reflection.<sup>6</sup> Campbell is a popular moral philosopher who, regardless of his own influences, scholarship, or private personality, has profoundly affected the narrative presuppositions that inform illness stories. I mean "profoundly" in terms of both the extent of influence and the quality of influence. If the idea of "journey" has become a New Age spice sprinkled indiscriminately to sea-son almost any experience, pop psychology could have done worse. The journey may be a fad, but it nevertheless represents a form of reflexive monitoring.

Campbell's description of the hero's journey can be reduced to three stages. The first is *departure*, beginning with a call. In illness stories the call is the symptom: the lump, dizziness, cough, or other sign that the body is not as it should be. The call is often refused, because the hero, who has not yet become a hero,<sup>7</sup> knows how much suffering will be involved. In illness stories the refusal may be the ill person's denial of the symptom. A woman who had lymphoma told of waking up, seeing a large lump on her neck, deciding it must be a dream, and going back to bed.

Eventually the call can no longer be refused—symptoms are unmistakable, diagnoses are made—and what Campbell calls "the first threshold" is crossed. For the ill person this first threshold may be hospitalization and surgery that determines

the extent of the illness. Crossing the threshold begins the second stage, *initiation*. Tellers of quest stories use the metaphor of initiation implicitly and explicitly. Among the latter, Sue Nathanson's story of recovery from an abortion and tubal ligation ends with her friends staging a feminist goddess ceremony for her. The book closes with one of the women saying "The ritual begins *now*"<sup>8</sup>

Nathanson's story demonstrates the reflexive quality of journeys: she is being formally initiated into the experience that has already initiated her. As in T. S. Eliot's famous lines in "Four Quartets," she has returned to her beginning and is now prepared to know the place. In illness initiations, unlike tribal ones, only at the end of the initiation does the teller conceptualize what has been going on *as* an initiation, thus organizing the experience as coherent and meaningful.

Campbell calls initiation "the road of trials," easily identified in any illness story as the various sufferings that illness involves, not only physical but also emotional and social. This road leads through other stages, such as temptation and atonement, until the ending or "apotheosis." The quest narrative tells self-consciously of being transformed; undergoing transformation is a significant dimension of the storyteller's responsibility. The end of the journey brings what Campbell calls a "boon." Quest stories of illness imply that the teller has been given something by the experience, usually some insight that must be passed on to others.

The final stage is the *return*. The teller returns as one who is no longer ill but remains marked by illness, as Schweitzer wrote of those who "bear the mark of the brotherhood of pain." This marked person lives in a world she has traveled beyond, a status well described by Campbell's phrase "master of the two worlds." Gail, a woman who suffers chronic pain, expresses this mastery when she asserts, "We have access to different experiences, different knowledges."<sup>9</sup>

Campbell's schematic of departure, initiation, and return for the hero's journey works well to describe the narrative structure of quest stories.<sup>10</sup> The sticking point is the notion of *hero*: what sort of "heroes" do ill people take themselves to be? Illness stories include some number of "I conquered . . ." stories.<sup>11</sup> This "conquering" heroism is on the modernist side of the postmodern divide. Campbell's postmodern appeal follows what Morris says about Nietzsche: his hero discovers alternative ways to experience suffering.

For me as a member of the remission society, Campbell deserves his influence because of his moral insight that mythic heroism is evidenced not by force of arms but by *perseverance*. The paradigmatic hero is not some Hercules wrestling and slugging his way through opponents, but the Bodhisatva, the compassionate being who vows to return to earth to share her enlightenment with others.<sup>12</sup> What the myths are about is agony.<sup>13</sup> The hero's moral status derives from being initiated through agony to atonement: the realization of oneness of himself with the world, and oneness of the world with its principle of creation. Suffering is integral to this principle, and learning the integrity of suffering is central to the boon.

The problem of return is to convince others that this atonement is a boon. As Campbell notes with regret, "The significant form of the human agony is lost to view."<sup>14</sup> The return thus sets in place the ill person's responsibility, and problem, of being a witness.

### THREE FACETS OF QUEST

The range of quest stories is broad enough to make further specification useful. Quest stories have at least three facets: memoir, manifesto, and automythology.

The *memoir* combines telling the illness story with telling other events in the writer's life. The illness memoir could also

be described as an interrupted autobiography. Most of the authors are persons whose public status would make them candidates for formal autobiography writing, but illness has required what would have been written later to be done earlier: Stewart Alsop's and Gilda Radner's memoirs are motivated by imminent death, and William Styron is rumored to have written about his depression in order to squelch other rumors about what happened to him.<sup>15</sup> Still other illness memoirs are fragments of an autobiography that the author prefers, for whatever postmodern reasons, to write in such fragments. John Updike's story of how psoriasis affected his life is an example.<sup>16</sup>

Events are not told chronologically in these memoirs, nor is a life rehearsed in detail. Rather, present circumstances become occasions for the recollection of certain past events. The illness constantly interrupts the telling of the past life, although alternatively, memories of the past life interrupt the present illness.

The memoir is the gentlest style of quest story. Trials are not minimized, but they are told stoically, without flourish. No special insight is claimed at the end; the insight is rather the incorporation—a good pun in this case—of illness into the writer's life. In the many illness memoirs by "famous" people, the memoir returns a life that has been publicly known through words and images back to the body with its tumors and tremors. The public person's split between media image and experienced reality is always a subtext of these stories and sometimes an explicit topic. Gilda Radner describes her need to find a balance between "being funny, being Gilda Radner, and being someone going through cancer."<sup>17</sup>

The least gentle quest stories are *manifestos*. In these stories the truth that has been learned is prophetic, often carrying demands for social action. Writers of manifestos underscore the responsibility that attends even provisional return from ill-

ness. Society is suppressing a truth about suffering, and that truth must be told. These writers do not want to go back to a former state of health, which is often viewed as a naive illusion. They want to use suffering to move others forward with them.

The clearest prophetic voice is that of Audre Lorde. Lorde's anger at social secrecy and hypocrisy finds its focus in demands that she begin wearing a breast prosthesis after her mastectomy. When she visits her surgeon's office ten days after surgery, the nurse points out she is not wearing a prosthesis. The observation turns into an order: "Usually supportive and understanding, the nurse now looked at me urgently and disapprovingly." The nurse's bottom line is, "We really like you to wear something, at least when you come in. Otherwise it's bad for the morale of the office." Lorde describes this incident as "only the first such assault on my right to define and to claim my own body."<sup>18</sup>

The issue expands from claiming her own body to claiming visual recognition of other women who bear her mark of pain. She does not want to conceal her difference but to affirm it, "because I have lived it, and survived it, and wish to share that strength with other women" (61). Women's enemy is silence; if silence is to turn into action, "then the first step is that women with mastectomies must become visible to each other." The alternative is isolation, not just as a woman with one breast, but as a human being facing mortality. Only by displaying our common mortality can humans accept this mortality as common and cease to fear it. "Yet once I face death as a life process," Lorde writes, "what is there possibly left for me to fear? Who can ever really have power over me again?" (61).

Disability stories frequently combine the facets of memoir and manifesto. Irving Zola, who had polio as a child, writes a memoir of visiting a village in the Netherlands, Het Dorp, that was built entirely for the needs of the disabled.<sup>19</sup> At the time of the visit Zola was already a successful sociologist, and the visit

was arranged through professional channels while he was on sabbatical nearby. Arriving at the village, Zola decides to live as one of the disabled members. In myths the hero is often stripped of worldly possessions and powers as she enters the underworld where the adventure begins. In Zola's case he leaves behind the braces he walks with—symbolic of his professional status—and puts himself in a wheel chair, becoming one of the Het Dorp residents. His journal of the days that follow is a progressive self-discovery of all that he has denied about the effect of disability on his identity.

Het Dorp is a model of technological convenience for the disabled, yet it continues to remind Zola of "emotional needs that seemed to have been taken away, or never granted." His recognition of these needs leads him to a conclusion that is a manifesto. He realizes, uncomfortably, that the last twenty years of his life represent "a continuing effort to reclaim what I had lost—the right to act sexy, get angry, be vulnerable, and have possibilities" (214). After detailing how these rights are denied to the disabled, what rationalizations are used to justify these denials, and what resistance might restore these rights, Zola concludes in a prophetic voice: "If we lived in a less healthiest, capitalist, and hierarchical society, which spent less time finding ways to exclude and disenfranchise people and more time finding ways to include and enhance the potentialities of everyone, then there wouldn't have been so much for me to overcome" (235). The manifesto asserts that illness is a social issue, not simply a personal affliction. It witnesses how society has added to the physical problems that disease entails, and it calls for change, based on solidarity of the afflicted.<sup>20</sup>

A third facet can be called the *automythology*.<sup>21</sup> The predominant metaphor of the automythology is the Phoenix, reinventing itself from the ashes of the fire of its own body. William May uses the Phoenix metaphor to describe the totality of self-reinvention following massive trauma or catastrophic illness.

"One cannot talk simply of a new accessory here, a change of venue there," May writes. "If the patient revives after such events, he must reconstruct afresh, tap new power, and appropriate patterns that help define a new existence."<sup>22</sup> Automythology fashions the author as one who not only has survived but has been reborn. Like the manifesto, the automythology reaches out, but its language is more personal than political. Individual change, not social reform, is emphasized, with the author as an exemplar of this change. The automythologist may be an unwilling hero, but he is never an unwitting one.

Oliver Sacks's *A Leg to Stand On* is an automythology with a narrative structure that follows Campbell's quest almost moment by moment. Sacks is injured while hiking, when he encounters a bull on a mountain side, runs away, and trips. The bull appears suddenly, focuses all manner of fears in Sacks, and then just as suddenly disappears. The bull's disappearance renders Sacks's initiation curiously self-induced: the proximate cause of his injury is both objective and intrapsychic.

Sacks then descends through several levels of hospitalization, descends to deeper psychic depths after surgery when his leg seems no longer his, and returns across several thresholds of rehabilitation. Each of these levels poses not only a physical but a moral challenge. At each threshold Sacks must always find new resources. Each of these, like the music that helps him to walk again, is invariably something that was at hand but not attended to: the music was not a piece he particularly cared for or admired. Part of the lesson is learning to see the ordinary as already containing all the resources one needs.

At the end of this process, Sacks claims a new identity, and here is the purest voice of automythology: "My adventure was ending. But I knew that something momentous had happened, which would leave its mark, and alter me, decisively, from now on. A whole life, a whole universe, had been com-

pressed into these weeks: a destiny of experience neither given to, nor desired by, most men; but one which, having happened, would refashion and direct me."<sup>23</sup> Sacks has become Campbell's master of two worlds: he has traversed the experiential universe, suffered what few others have or would want to, and now makes his return. The language of automythology is heavy with words like *momentous*, *decisively*, *universe*, and *destiny*.

Other languages can serve the same end. Broyard creates his automythology from his tap dancing lessons and dancing language. Broyard treats his ordeals with an off-handedness that places him above his fate. His myth is his lightness, but this lightness remains his alone. A more inclusive automythology than Broyard or Sacks, and perhaps the best known of all illness stories, is Norman Cousins.

Cousins's first best-seller was *Anatomy of an Illness*.<sup>24</sup> In 1964 he returns from a diplomatic mission to the Soviet Union with symptoms that develop into an acute inflammatory disease of the connective tissue. The diagnosis is obscure and debated, but the debilitating effects are clear. Cousins finds it difficult to move, he develops nodules, suffers from "gravel-like substances under the skin" (30), and finally his jaw is almost locked. He is told his disease is "progressive and incurable" (45). Cousins's descent is complete as he contemplates paralysis.

The story of his return, further mythologized as a made-for-television movie with Ed Asner as Cousins, describes Cousins's "own total involvement" in his recovery. Cousins checks himself out of the hospital and into a nearby hotel suite, rented for one-third the cost. He takes massive intravenous doses of ascorbic acid, which he has read affects collagen breakdown and helps rheumatoid arthritis patients. He does all this as part of a therapeutic alliance with his friend and physician, who believes that "his biggest job was to encourage to the fullest the patient's will to live and to mobilize all the natural resources of

the body and mind to combat disease" (44). The mission that Cousins thus attributes to his physician is his own philosophy in a nutshell.

The final part of his self-treatment is humor. Cousins encourages his will to live and helps his body mobilize its natural resources by watching slapstick movies and reading joke books. The reliance on humor is the basis of the myth of Cousins as the man who laughs himself well. His own account is more complex, reflecting Cousins's sophistication as a lay reader of the medical literature, but automythology prevails over possible placebo effects. Cousins takes laughter's therapeutic effects seriously, these effects both supporting and supported by his refusal to "accept the verdict" offered by the specialists.

The end of his book's first chapter shows Cousins's project: he rewrites the philosophy he developed as a political journalist into individualist medical terms, creating the automythology of his own recovery. Cousins ends the chapter with William James's idea that "human beings tend to live too far within self-imposed limits." Cousins holds up his recovery as showing how anyone can step beyond these limits. At issue is not merely medical cure but enhancing "the natural drive of the human mind and body toward perfectibility and regeneration. Protecting and cherishing that natural drive may well represent the finest exercise of human freedom" (48).

Cousins's language may be quieter than Sacks's, but his automythology claims more. Cousins cures himself, and this cure becomes metonymic for concepts of *perfectibility*, *regeneration*, and ultimately *the finest exercise of human freedom*. Cousins presents his automythology as potentially inclusive—anyone can laugh, thus anyone can mobilize his body's natural resources—but the story could only be his. Few patients move their treatment into hotel suites, research their own diseases, forge alliances with physicians who support eccentric treat-

ment plans, and, through all this, keep laughing. Not least of Cousins's appeal is that his genuine humility affords others their own vicarious enjoyment of his privileges.

Automythology turns the specific illness into a paradigm of universal conflicts and concerns. The body of the storyteller becomes a pivot point between microcosm and macrocosm, and human potential—"freedom" for Cousins and "destiny" for Sacks—depends on whether the lessons that the storyteller has learned can be accepted and practiced by others.

#### THE COMMUNICATIVE BODY

The communicative body is told in quest stories, but more importantly, quest stories are one ethical *practice* of this body.

The quest hero accepts *contingency* because the paradox learned on the quest is that surrendering the superficial control of health yields control of a higher order. Lorde expresses this paradox when she writes that only by facing death can she become someone over whom no one has power.<sup>25</sup>

The quest teaches that contingency is the only real certainty. If Lorde expresses this lesson in political terms, Madeleine L'Engle, writing of the time just after her husband died, expresses it as a spiritual truth. She describes her situation by quoting a bishop saying of his wife's death, "I have been all the way to the bottom. And it is solid."<sup>26</sup> The point of suffering, from a spiritual perspective, is that *only* the bottom is solid. L'Engle writes of her husband's illness, "We have had to be open to crisis" (181). Being open to crisis as a source of change and growth and valuing contingency even with its suffering are the bases of the communicative body.

The desire of this contingent body is *productive*, but the direction of this desire—unlike the desire of the mirroring body—is conditioned by its *dyadic* relation to others. In the Buddhist metaphor of the Bodhisattva, the communicative

body desires to save all beings. Posthumous illness stories have a particularly Bodhisattva-like quality. Why does someone like Alsop or Radner or Broyard spend his or her last months of consciousness and energy writing about illness? These people had every other option of entertainment or companionship open to them, but they chose to write. Why does Lorde, immediately after her mastectomy, expend her energy writing? The tautological answer is that reaching out to others is what the dyadic body does; its desire is to touch others and perhaps to make a difference in the unfolding of their stories.

Writing is not, as it could be, a means of dissociation from one's own body. Quest storytellers write of their own bodies, including pains and disfigurements, in sensuous detail. Their *association* with their bodies allows them to feel Schweitzer's "mark of pain" upon their flesh and to see the pain in the other's flesh. Body association is the ground of dyadic relatedness, just as dyadic relatedness and desire are inseparable.

Seeking to be *for* the other, reaching out as a way of being, does not mean rescuing this other from his own contingency. What will happen to the other person, what he will end up suffering, remains as contingent as what happens to the self. Communicative bodies seek instead to affect how the other understands her embodied contingency. To use Campbell's terms, the communicative body seeks to share the boon that it has gained upon its own return. Others need this boon for the journeys they necessarily will undertake.

This boon, describable only in another tautology, is the body's ability to grasp itself reflectively as a communicative body: to be associated with itself, open to contingency, dyadic toward others, and desiring for itself in relation to others. The nature of this boon is that it must be shared, which means sharing the self. The story is one medium through which the communicative body recollects itself as having become what it is, and through the story the body offers itself to others. Recol-

lection of self and self-offering are inseparable, each being possible only as the complement of the other.

#### QUEST AS SELF-STORY

In quest stories the interruption is reframed as a challenge. The self-story hinges on William May's question, "How did I rise to the occasion?" The genesis of the quest is some occasion requiring the person to be more than she has been, and the purpose is becoming one who has risen to that occasion. This occasion at first appears as an interruption but later comes to be understood as an opening.

A woman whom Deborah Kahane calls Terri expresses what is said in almost every quest story: "I would never have *chosen* to be taught this way but I like the changes in me. I guess I had to go to the edge to get there."<sup>27</sup> What started the illness is secondary to the effect of going "to the edge." Terri's purpose is coming back from that edge to become the person she is, someone who is changed. Illness was an interruption she would not have chosen, but she now accepts it as the cost of changes she likes. Losses continue to be mourned, but the emphasis is on gains.

The "changes" that ground Terri's statement are changes of character: *who* she is. Character merges both *persona*, the character in the story, and quality, having a good character. The self-story must go beyond simply claiming changes in character and demonstrate these changes. Much of the success of the story—its impact both on others and on the self—depends on how convincing this display of changed character is. Readers pick up published illness stories for all sorts of reasons, but the moral purpose of reading is *to witness a change of character through suffering*. In this witness the reader both affirms that change, which is one sort of moral duty, and gains a model for his own change, another moral duty.

The most extreme change is the automythological claim to have become someone else. Sacks claims to be altered, "decisively, from now on."<sup>28</sup> The essence of his alteration is that he is now prepared to discover what he calls, in his own emphasis, "*a neurology of the soul*." He now sees his way beyond his intellectual mentors and claims to have found "a new field . . . a new and true way of thinking" (222).

This latter statement constitutes a promissory note. In the redemption of this promise, *A Leg to Stand On* does not stand alone, and possibly could not stand alone. Most readers of *A Leg to Stand On* will read the book informed by who Sacks became: best-selling author, portrayed by Robin Williams in the movie version of Sacks's book, *Awakenings*. The promissory note at the end of *A Leg to Stand On* is thus read as substantially redeemed. Sacks's hyperbole about his new self and new neurology, which could fall flat if he were otherwise unknown, is forceful. Sacks really *has* produced a new "neurology of the soul." But the automythology of his illness story requires his other stories to make fully credible the change of character he claims.

Most stories tell of less dramatic changes. What tellers discover is not someone wholly new, but rather "who I always have been."<sup>29</sup> This self is not so newly discovered as newly *connected* to its own memory. The past is reinterpreted in terms of the present and takes on an enhanced meaning. This present is no longer a contingent graft on a past that was supposed to lead elsewhere.

Audre Lorde establishes this newly connected self when she asks the rhetorical question, "How did the Amazons of Dahomey feel?"—referring to Amazon warriors whose initiation involved having one breast cut off, the better to shoot a bow.<sup>30</sup> Lorde thus fashions a potent metaphor for her new identity, the one-breasted woman warrior, complete with third-world location and lesbian connotations. This metaphor



joins her post-mastectomy body to her earlier black, lesbian, feminist self. The power of the metaphor is to give the mastectomy a kind of retrospective necessity: she had to lose a breast to become the full version of what she was before, but then only incompletely. Her metaphor becomes what Schaffer (chapter 3, above) calls the storyline of her self-story.

Lorde's rhetorical question about the Amazons of Dahomey convinces readers of her self-change because this change is *not* new but represents a recollection. Lorde has become what she always has been, but empowered by the full knowledge and the now embodied scars of that identity. The metaphor of the Dahomey Amazon is the epiphany of Lorde's becoming; it expresses her character because coming up with the metaphor—telling it—is the expression of her character.

Self-change seems remarkably unrelated to gender, and a story similar to Lorde's is told by Robert Murphy, whose demographic profile is as unlike Lorde's as could be found. Murphy was a prominent academic anthropologist, chair of his department at Columbia, when he noticed symptoms that were eventually diagnosed as a benign tumor in his spine. The growth of this tumor eventually renders him quadriplegic. His illness story juxtaposes his body's deterioration and restriction with his mind's expansion. Murphy compares illness to an anthropological field trip and finds the medical worlds he enters "no less strange" than the jungles he traveled in to do research.<sup>31</sup>

From his research Murphy finds the metaphor that joins who he has become with who he always has been. As he writes his book he is almost totally paralyzed, strapped in a chair, moving only his fingers over the keyboard of his computer. He writes, "My narration bears an eerie resemblance to the myth-telling of the shamans of the . . . Peruvian Amazon, who . . . relate their myths while holding their bodies absolutely motionless" (222). Not just the credibility but the morality of Mur-

phy's change lies in this metaphorical joining of his past to his present. No promissory note is offered here: the metaphor itself delivers what it promises.

Murphy, on his own description, would not fit the ideal type of the communicative body. He describes himself dealing with his physical degeneration by "radical dissociation" from his body. This dissociation is made easier because he "never did take much pride in my body. . . . I cultivated my wits instead" (101). I can hardly disagree with Murphy's self-description, but I can argue that in his telling he is associated with his body. In the shaman metaphor, Murphy's body is not only the subject of his telling but, in its rigidity, the medium of his telling. Just as the shamans' telling somehow depends on how they hold their bodies, so Murphy's telling does also. Earlier in his life Murphy may not have taken much pride in his body, but as he writes he places enormous metaphorical, and even mythic, weight upon it.

Murphy's story works because his body sustains its weight, just as Lorde's life and Sacks's writings sustain what is claimed through their bodies. As storytellers of their illnesses, each more than rises to the occasion. Character is demonstrated, reflexively, in the writing that is the measuring up of that character.

Realizing who they always have been, truly been, each becomes or prepares to become the re-created, moral version of that self. In this display of character, memory is revised, interruption assimilated, and purpose grasped. "Whatever has happened to me or will happen," the storyteller as hero implicitly claims, "the purpose remains mine to determine."

### THREE ETHICS OF SELF-STORY

Because the communicative body is dyadic, the self-story is never just a *self-story* but becomes a *self/other-story*. In telling

such a story, the three issues of voice, memory, and responsibility merge. Finding a voice becomes the problem of taking responsibility for memory. Different quest stories all express this voice-memory-responsibility intersection. The self-story thus becomes an ethical practice of the communicative body. Three ethics, as overlapping as the three styles of quest, suggest the diversity of responsibility in storytelling.

An *ethic of recollection* is practiced when one who recollects shares memories of past action. Displaying one's past to others requires taking responsibility for what was done. Past actions can be disapproved, but they cannot be disowned, no one else did them, and they cannot be changed. The story is a moral opportunity to set right what was done wrong or incompletely. When Audre Lorde was told to wear a prosthesis, she reports being "too outraged to speak then."<sup>32</sup> The key word is *then*. Human frailty is such that *then*, at the time of the outrage or impasse or whatever dilemma, voice may fail. Lorde's ethical action lies in her willingness to recollect that failure and offer it to others with an indication of what should have been done. She may have lapsed *then*, but she uses her outrage to speak more clearly and to many more people in her recollecting story. The voice she finds fulfills her responsibility to memory.

An *ethic of solidarity and commitment* is expressed when the storyteller offers his voice to others, not to speak for them, but to speak *with* them as a fellow-sufferer who, for whatever reasons of talent or opportunity, has a chance to speak while others do not. When Zola takes off the leg braces that allow him to walk upright, he expresses solidarity with Het Dorp residents confined to wheel chairs. As he finds the wheel chair suits his body better in some ways, he gains the prophetic voice to express all that sustaining appearances of "normality" cost him and other disabled persons. The manifesto expressing

such a prophetic voice becomes a kind of rallying point, which is how many women with cancer use Lorde's book.

Finally, quest stories practice an *ethic of inspiration*. Humans need exemplars who inspire. The heroic stance of the automythologist inspires because it is rooted in woundedness; the agony is not concealed. Sacks tells how despondent he was after his surgery. Cousins details the nearly complete incapacity of his body when his symptoms were most intense. Their stories show what is possible in impossible situations, and thus point toward what Cousins calls freedom.

These three ethics—recollection, solidarity, inspiration—overlap, just as memoir, prophetic voice, and automythology overlap in any story. Both the styles of quest story and their respective ethics are facets of the communicative body. They are practices this body adopts variously, as contingent situations require.

The quest self-story is about voice finding itself: when the nurse tells Audre Lorde to wear a prosthesis, Lorde is rendered speechless for a moment; from this she learns the awful potential of silence. The problem of being seriously ill becomes the problem of finding a voice. Lorde writes, "I was going to die, if not sooner than later, whether or not I had ever spoken myself. My silences had not protected me. Your silence will not protect you."<sup>33</sup>

Voice is found in the recollection of memories. The storyteller's responsibility is to witness the memory of what happened, and to set this memory right by providing a better example for others to follow. Lorde summarizes this responsibility as it only can be summarized, in the most particularistic terms, because each of us can only witness from the particularity of who we are: "Because I am woman, because I am black, because I am a lesbian, because I am myself, a black woman warrior poet doing my work, come to ask you, are you

doing yours?" (21). Taking up this challenge is the ethical practice of the self-story.

#### FROM QUEST TO TESTIMONY

The quest narrative recognizes ill people as responsible moral agents whose primary action is witness; its stories are necessary to restore the moral agency that other stories sacrifice.

Ill people need to be regarded by themselves, by their caregivers, and by our culture as heroes of their own stories. Modernism made the physician, specifically the surgeon, into the hero of illness. In this modernist construction, heroism is not perseverance but *doing*. Ill people's passive heroism, when recognized in obituaries, is equated with a stoicism that is praised for its silence. Quest stories as they are told, and chaos stories when they are honored, call for a shift from the hero as Hercules to the hero as Bodhisattva: from the hero of force to the hero of perseverance through suffering. The story is the means for perseverance to become active, reaching out to others, asserting its own ethic.

This shift in heroic style challenges fundamental presuppositions of modernity. The modernist hero is a person of action and, as Bauman observes, of abstract ideals. For such a hero, conquering illness is itself a cause, and a cause that may supersede the immediate welfare of the particular ill person.<sup>34</sup> The wounded hero of illness stories speaks only of what she has experienced. In offering a personal experience to another person, the hero of illness quests is more like Bauman's post-modern moral person, oriented to "the life or well-being or dignity of another human being."<sup>35</sup>

The problem for storytellers who would be moral persons is keeping in mind what Paul Ricoeur writes about prophetic testimony: the prophet receives his testimony from elsewhere.<sup>36</sup> The opportunity to tell one's own illness story as one wants to

tell it—in one's "own" voice—is a kind of grace. Campbell is always clear that undertaking the hero's journey requires grace; the hero who thinks he travels on his own will fail.

Falling into the hubris that one's voice can ever be entirely one's own is only one of the failures that quest stories risk. Automythologies can easily become stories to reassure the healthy that just as the author has risen above illness, they too can escape. The antidote to this pretense of invulnerability is chaos stories, reminding us that some situations cannot be risen above. Most significantly, quest stories risk romanticizing illness. Here the antidote is restitution stories, reminding us that any sane person would rather be healthy, and most of us need the help of others to sustain that health.

The risk of quest stories is like the risk of the Phoenix metaphor: they can present the burning process as too clean and the transformation as too complete, and they can implicitly deprecate those who fail to rise out of their own ashes. Many ill people invoke the Phoenix to describe their experiences, but May expresses a significant reservation about this metaphor. While the Phoenix remembers nothing of its former life, the victim of some trauma—May writes specifically of burn victims here—does remember:<sup>37</sup> May's reservation is given added force by Lawrence Langer writing on Holocaust witnesses.

Langer quotes the Auschwitz memoirs of Charlotte Delbo, who "uses the image of a serpent shedding its own skin and emerging with a 'fresh and shining' one."<sup>38</sup> The problem is that renewal is never complete: "She knows that though shedding a skin may leave the snake unchanged, similar results apply to *her* only in appearance" (4).

Ultimately, her experience is too complex for the serpent metaphor, and probably for any metaphor: "The skin covering the memory of Auschwitz is tough," Delbo writes. "Sometimes, however, it bursts, and gives back its contents." She tells

how her embodied memories of Auschwitz came back to repossess her in a dream. She feels herself "pierced with cold, filthy, gaunt, and the pain is so unbearable, so exactly the pain I suffered there, that I feel it again physically, I feel it again through my whole body" (6–7).

Delbo upsets the Phoenix metaphor, showing it to be too clean, too heroic. After reading Delbo I hear the Phoenix storyline as a restitution narrative that conceals the agony. I myself am no Phoenix. Whenever one of my own medical tests requires "further investigation," the skin that covers over the memories of my first cancer bursts. I do not suggest my experience has anything of the terror of Delbo's, but suddenly the pain of having cancer bears down on me again with all its indescribable weight. Each time I learn how close to the surface those memories remain.

Metaphors, as Lorde and Murphy show, can be powerful means to healing. But generalized metaphors, offered as storylines for others' self-stories, are dangerous. The Phoenix does not mourn what lies in its ashes; the serpent does not mourn its old skin. Human illness, even when lived as a quest, always returns to mourning. The boon is gaining the ability to mourn not for oneself only, but for others.

## Seven

### Testimony

I once spoke at a conference for persons who had cancer or were in remission. One of the organizers opened the conference by posing the question of what we—he himself was currently in treatment—should call ourselves. He proposed "survivors," dating one's survival from the time of diagnosis. I have no quarrel with the notion of survivors, but my first choice as a designation is "witness."

Survival does not include any particular responsibility other than continuing to survive. Becoming a witness assumes a responsibility for telling what happened. The witness offers testimony to a truth that is generally unrecognized or suppressed. People who tell stories of illness are witnesses, turning illness into moral responsibility.

Bringing back the "boon" at the end of the quest narrative is self-conscious testimony. The chaos narrative requires a listener who is prepared to hear it as testimony; Nancy's immersion in her frenzied telling of her multiple interruptions (chapter 5) prevents her from hearing herself as a witness. The restitution narrative is the least obvious form of testimony, but it too tells a truth: the will to live, to cure and be cured.

The postmodern affinity for testimony is one response—and often a frustrated one—to the accumulated chaos stories of modernity; testimony tells these stories.<sup>1</sup> Thus testimony, for all its commitment to truth and its ability to break through