

ARTHUR W. FRANK

*The  
Wounded Storyteller*



Body,  
Illness, and  
Ethics

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THE UNIVERSITY  
OF CHICAGO PRESS  
CHICAGO AND LONDON

## Preface

The figure of the wounded storyteller is ancient: Tiresias, the seer who reveals to Oedipus the true story of whose son he is, has been blinded by the gods. His wound gives him his narrative power. The wound that the biblical patriarch Jacob suffers to his hip while wrestling with the angel is part of the story he tells of that event, and it is the price of his story. As Jacob tells his story to those he returns to—and who else could have told it?—his wound is evidence of his story's truth.

This book presents ill people as wounded storytellers. I hope to shift the dominant cultural conception of illness away from passivity—the ill person as “victim of” disease and then recipient of care—toward activity. The ill person who turns illness into story transforms fate into experience; the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability.

The emphasis of contemporary writing is less on the wounded storyteller than on the complementary figure of the wounded healer. For example, Henri Nouwen's *The Wounded Healer* bases the spiritual vocation on the minister's acceptance and sharing of her own woundedness.<sup>1</sup> Physicians from Arthur Kleinman to Larry Dossey and journalists like Bill Moyers present the wounded healer as an ideal for medical workers.<sup>2</sup> Rita Charon writes of the physician's need “to allow

our own injuries to increase the potency of our care of patients, to allow our personal experiences to strengthen the empathic bond with others who suffer.”<sup>3</sup>

Charon can be read equally well as describing the ill person’s need. As wounded, people may be cared for, but as storytellers, they care for others. The ill, and all those who suffer, can also be healers. Their injuries become the source of the potency of their stories. Through their stories, the ill create empathic bonds between themselves and their listeners. These bonds expand as the stories are retold. Those who listened then tell others, and the circle of shared experience widens. Because stories can heal, the wounded healer and wounded storyteller are not separate, but are different aspects of the same figure.

But telling does not come easy, and neither does listening. Seriously ill people are wounded not just in body but in voice. They need to become storytellers in order to recover the voices that illness and its treatment often take away. The voice speaks the mind and expresses the spirit, but it is also a physical organ of the body. The mystery of illness stories is their expression of the body: in the silences between words, the tissues speak. This book is about hearing the body in the ill person’s speech.

The chapters below begin with how illness requires stories, the body as the ground of these stories, and illness stories as what are called self-stories. The middle chapters describe three narrative types of illness stories, understanding these narratives as ways of using the body. These middle chapters suggest what illness stories tell; the final chapters move to the force of that telling. They locate the ethical imperative of illness stories in issues of testimony and witness.

In wounded storytelling the physical act becomes the ethical act. Kierkegaard wrote of the ethical person as editor of his life: to tell one’s life is to assume responsibility for that life.<sup>4</sup> This responsibility expands. In stories, the teller not only re-

covers her voice; she becomes a witness to the conditions that rob others of their voices. When any person recovers his voice, many people begin to speak through that story.

Stories of people trying to sort out who they are figure prominently on the landscape of postmodern times. Those who have been objects of others’ reports are now telling their own stories. As they do so, they define the ethic of our times: an ethic of voice, affording each a right to speak her own truth, in her own words.

This book is a work of theory, but it is equally a collection of stories and a kind of memoir. For almost a decade I have been a wounded storyteller, and I have cultivated the stories of others who are wounded, each in different ways. The “theory” in this book elaborates my story and theirs.

Charles Lemert introduces his social theory textbook by calling theory “a basic survival skill.”<sup>5</sup> *The Wounded Storyteller* is a survival kit, put together out of my need to make sense of my own survival, as I watch others seeking to make sense of theirs. The wounded storyteller, like Lemert’s theorist, is trying to survive and help others survive in a world that does not immediately make sense.

Sooner or later, everyone is a wounded storyteller. In postmodern times that identity is our promise and responsibility, our calamity and dignity. The “theory” I propose here is one tool kit to help fulfill that promise and exercise that responsibility. Twenty years ago when I was a graduate student, theories were proposed with the tag line that they awaited “further research.” I now prefer the idea that this theory awaits further living and the stories of those lives. The theory has been shaped by the stories I have been privileged to live and to hear, and I encourage readers to reshape it in the same spirit.



## Four

### *The Restitution Narrative*

#### ILLNESS IN THE IMAGINARY

The restitution narrative is the first of three types of narrative that I will propose. A narrative type is the most general storyline that can be recognized underlying the plot and tensions of particular stories. People tell their own unique stories, but they compose these stories by adapting and combining narrative types that cultures make available.

By a narrative type, I mean what a teller of folktales means when referring, for example, to a naming story. In the naming story, the protagonist has to guess the *true* name of the antagonist. The guessing counts because the antagonist threatens the protagonist; the antagonist's power can only be undone by speaking his true name. The protagonist may do the guessing himself if he is a trickster. Other protagonists need a helper, such as the mouse in the best-known naming story, the Grimm Brothers' "Rumpelstiltskin." Learning the value of the helper, whom the protagonist may initially reject, is a frequent subplot. Around the basic plot of the naming story all sorts of variations occur, just as naming can occur as a subplot in another story, but the narrative type remains identifiably within these variations.

My description of the naming story is not a random example of a narrative type. Although few would say it in these words, the teller of an illness story seeks to learn the true name of the

disease, and perhaps her own true name as well. Nietzsche understood this, choosing to name his pain "dog."<sup>1</sup>

Why propose "types" of illness narratives and suggest that individual stories somehow "fit" one type or another? The risk is creating yet another "general unifying view" that subsumes the particularity of individual experience. The advantage is to encourage closer attention to the stories ill persons tell; ultimately, to aid listening to the ill. Listening is difficult because illness stories mix and weave different narrative threads. The rationale for proposing some general types of narratives is to sort out those threads.

My suggestion of three underlying narratives of illness does not deprecate the originality of the story any individual ill person tells, because no actual telling conforms exclusively to any of the three narratives. Actual tellings combine all three, each perpetually interrupting the other two. I limit myself to three basic narratives because if these types are to be used as *listening devices*, more than three seems less than helpful. Certainly, other types of narratives can and should be proposed.<sup>2</sup>

I consider each narrative type in four sections, beginning with its plot. Second, I describe the elective affinity that the narrative type has to the action problems of embodiment (control, body-relatedness, other-relatedness, and desire). Third is how the narrative works as a self-story. Finally I discuss the power of each narrative type and its imitations.

In any illness, *all* three narrative types are told, alternately and repeatedly. At one moment in an illness, one type may guide the story; as the illness progresses, the story becomes told through other narratives. The particularity of any experiential moment can thus be described by the narrative type that predominates at that moment. The three narratives are like patterns in a kaleidoscope: for a moment the different colors are given one specific form, then the tube shifts and another form emerges. The retelling of illness stories, particularly the

writing of oral stories, isolates the story of the moment from the narrative flux that marks lived storytelling. At the bedside, the kaleidoscope turns much more quickly than in print.

Each narrative reflects strong cultural and personal preferences. The strength of these preferences presents a further barrier to listening to the ill: both institutions and individual listeners steer ill people toward certain narratives, and other narratives are simply not heard. But barriers provide possibilities for insight. Reflection on one's own narrative preferences and discomforts is a moral problem, since in both listening to others and telling our own stories, we become who we are.

#### THE RESTITUTION PLOT

The restitution narrative dominates the stories of most people I talk to, particularly those who are recently ill and least often the chronically ill. Anyone who is sick wants to be healthy again. Moreover, contemporary culture treats health as the normal condition that people ought to have restored. Thus the ill person's own desire for restitution is compounded by the expectation that other people want to hear restitution stories.

The plot of the restitution has the basic storyline: "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again." This storyline is filled out with talk of tests and their interpretation, treatments and their possible outcomes, the competence of physicians, and alternative treatments. These events are real, but also they are metaphors in Schafer's sense of enacting the storyline of restoring health (see chapter 3). Metaphoric phrases like "as good as new" are the core of the restitution narrative. Such phrases are reflexive reminders of what the story is about: health.

Restitution stories can be told prospectively, retrospectively, and institutionally. I heard a prospective restitution story when



I met a man who, I had been told, was about to undergo surgery for cancer. I told him I was sorry to hear he was ill. He looked at me as if he was not sure what I was talking about and then, changing his expression to sudden recognition of what I referred to, immediately assured me it was “nothing.” When we later spoke at length about his surgery, he told a story of how he would be able to assimilate various outcomes into his life without undo change. His prospective restitution story gave him the courage to face surgery. Later, following what turned out to be a long surgery and serious diagnosis, he might have needed a different story at a time when he lacked the energy to put one together.

I heard a retrospective restitution story one evening at a cancer support group. The group begins with a ritual that many groups use some variation of. Each person says his or her name, what kind of cancer he had, and when. Sometimes a bit of personal news is added. Most people close by saying, in a rising voice, “I’m fine!” Most regular group members are in remission from cancer, but this evening a woman attended who was currently in treatment. While she was describing the cancer she had, she broke into tears. The group response was for the person sitting next to her, the next speaker, to interrupt with her own introduction. She did this very briefly, moving to a particular emphasis on “I’m fine!” No one commented on the interruption or returned to acknowledge the distress of the person in treatment. Thus the group expressed its preference for restitution stories and its discomfort at hearing illness told in other narratives.

The restitution narrative not only reflects a “natural” desire to get well and stay well. People learn this narrative from institutional stories that model how illness is to be told. A major northeastern American hospital distributed an oversize tabloid newspaper supplement describing its cancer center. The brochure is sixteen pages long, printed on better than newsprint

paper, and features obviously professional photography. Most of the content comprises the stories of three cancer patients. All three are told as restitution stories: “Within two weeks, Joan was back to work full-time,” “Harry now has a new immune system that gives him every reason to believe it’s a whole new ball game,” and “Today, Mary has resumed her active, productive life—even adding a new pastime.”

The brochure certainly fulfills a public education function, providing sidebar glossaries that clearly explain types of cancer and different treatments. But no patient is shown *in* treatment or affected by treatment. Photographs show patients pursuing their various “pastimes” of gardening, sports, and other hobbies. One radiotherapy machine is shown but not in use; the professional staff are posed sitting on it, as if having a conference. The patients’ stories tell what their treatments were, but the emphasis is on life after treatment: returning to “I’m fine!”

Prospective patients reading this brochure are being educated not just about different cancers and their treatments. The brochure provides models of the stories patients ought to tell about their own illnesses. Institutional medicine is asserting its preferred narrative. This assertion goes beyond hospitals to the strategies that more powerful interest groups use to shape the culture of illness.

The most pervasive or, depending on one’s values, the most insidious model of the restitution story is the television commercial for non-prescription drugs, frequently cold remedies. The plot unfolds in three movements. First, the ill person is shown in physical misery and, often though not always, in social default. Some activity with spouse or children is going to have to be canceled or work missed. The second movement introduces the remedy. As in the naming story, a helper may be involved in bringing the remedy, and also as in the naming story, a subplot may involve the sufferer’s initial rejection of the remedy and thus of the helper. Eventually the remedy is taken,

and the third movement shows physical comfort restored and social duties resumed. The success of the remedy validates the helper, and a hint of renewed romance may close the story.

To live in contemporary culture is to see such commercials without even noticing them; magazines can condense the plot to a single image, knowing that the reader/viewer will fill in the rest from memory. These advertisements set in place the narratives of the stories that real people tell about real illnesses. Commercials, like the hospital brochure described above, not only condition expectations for how sickness progresses; they also provide a model for how stories about sickness are told.

Here as elsewhere popular culture is most powerful when it reinforces habits of thought acquired elsewhere. The restitution plot is ancient: Job, after all his suffering, has his wealth and family restored, and whether or not that restoration was a later interpolation into the text, its place in the canonical version of the story shows the power of the restitution storyline. Television literally commercializes the Job story: the good person is suddenly struck down, but suffering is bourgeois (for example, a missed party or sports event), the remedy can be purchased, and the only learning involved is where to find relief next time.

Behind the hospital brochure and the commercial lies the modernist expectation that for every suffering there is a remedy. The consequences of this master narrative are complex. When the restitution ending is tacked onto Job, the nature of suffering changes from mystery to puzzle, to use a distinction from William May, who borrows from Gabriel Marcel.<sup>3</sup> A *mystery* can only be faced up to; a *puzzle* admits solution. The restitution ending of Job leaves the reader with the impression that somehow Job got it right, first in dialogue with his three friends and then in the whirlwind. The restitution is his prize for solving the puzzle, even if exactly how he solves it is not quite clear. Without the restitution, his suffering would remain

a mystery, and a troubling one. The mystery cannot be solved, and while a person can seek to measure up to what a mystery presents, one cannot “get it right” because there is no “right” way to get it. This absence of solution makes mysteries a scandal to modernity.

Modernity seeks to turn mysteries into puzzles, which is both its heroism and its limit. Sociology, as one aspect of the modernist imagination, describes illness in its own restitution story, which is Talcott Parsons’s theory of the “sick role,” first presented in the early 1950s but elaborated throughout Parsons’s career until his death in the late 1970s.<sup>4</sup> By a role, Parsons meant action that involves complementary expectations for behavior. Thus the “sick role” describes behavior the sick person expects from others and what they expect from him. These expectations are *institutionalized* in such matters as sick leave from work and medical care; they are validated by *social norms*; they are *functional* for society as a whole; and they are *internalized*, meaning that individuals regard their expectations around sickness as normal and natural.

Parsons makes three assumptions about the social meaning of illness. First, illness is not to be regarded as the sick person’s fault. In an age that understands contagion and infection, becoming ill is not an indicator of moral failure but only the result of some excessive stress, which Parsons perceived as both social and physiological. Second, the sick person is exempt from normal responsibilities, both at work and at home. Sick people can expect this exemption, and others have a reciprocal obligation to offer it. Third, because exemption from normal responsibilities requires social control lest its privilege be abused, the sick person is obligated to place himself under the authority of a recognized professional. Compliance to “doctor’s orders” is fundamental to the social control aspect of the sick role; exemption is balanced by obligation.

Few social science students of medicine accept the sick role

as a definitive description, but its narrative remains sufficiently compelling so that it can never be dismissed. I am not concerned here with the theory's empirical adequacy—for example, *are* most people excused from normal obligations when ill?—but rather with its force as a master narrative of restitution stories.

The sick role is a modernist narrative of social control. People become sick, in Parsons's view, when their normal obligations become overpowering or conflict with each other: Sick-ness is functional for society as an escape valve for excess social pressures. The problem of sickness from this functionalist perspective is how to give people sufficient time to recover without producing dropouts. Exemption must be granted, but it must also be regulated. The physician is explicitly a social control agent. For Parsons, one of the most important aspects of the physician's performance is refusing to "collude" with the patient; medical sympathy is to be limited by the overriding message that the sick person's task is to get well and return to normal obligations of work and family. The physician is there not to pander but to prod, gently but firmly.

Perhaps the central implicit assumption of the sick role, and what I believe provides its narrative force, is that people *do get well*, and many other people who do not get well want to continue to believe they will get well. To those whom I call members of the remission society, the sick role as Parsons describes it has little relevance. These people accept some level of illness as the permanent background and intermittent foreground of their lives. For Parsons, particularly the middle-aged Parsons who formulated the theory, any journey into the kingdom of illness is a limited one, from which return is both expected and possible.<sup>5</sup> The idea that the changing physical capabilities caused by sickness require ongoing renegotiation of social obligations and personal identity is not part of Parsons's theory.

Precisely because getting well is the only outcome Parsons

considers as acceptable, his theory of the sick role both reflects the assumptions of modernist medicine and inscribes the validity of these assumptions in a broader narrative of what society requires to function successfully. Whether or not the sick role describes the *experience* of being ill, and most agree it does not, it remains a powerful narrative of what medicine *expects* from the ill person and what other social institutions expect from medicine. At the core of those expectations is the assumption of restitution: returning the sick person to the *status quo ante*.

Behind the restitution narratives of popular culture and sociology is medicine. So much has been written about medicine's single-minded telos of cure that I will finesse quotation from some definitive clinical source and tell a mundane story. A physician friend told me, with distress, about his patient who is dying of cancer. The physician's distress is not from her dying; everyone dies, and many die too young. He hates watching his patient fall into a world of hospital specialists who refuse to accept that she is dying and continue to perform invasive tests that cannot lead to any viable treatment. Of course, it is his judgment that the treatment is futile, and the specialists might see the case differently.<sup>6</sup> But here was the same story, told so many times, being told again. Obsessed with cure, medicine cannot place the woman's story in any other narrative. Massive resources are expended, and, more important from the perspective of my physician friend, his patient is not being helped to find her way toward her own version of a good death. Medicine's hope of restitution crowds out any other stories.<sup>7</sup>

The restitution story, whether told by television commercials, sociology, or medicine, is the culturally preferred narrative. Nothing less is at stake in the viability of this narrative than the modernist project that Zygmunt Bauman calls "deconstructing mortality."<sup>8</sup> Modernity, Bauman argues, exorcises



the fear of mortality by breaking down threats, among which illness is paradigmatic, into smaller and smaller units. To use May's distinction, the big mystery becomes a series of little puzzles. Medicine, with its division into specialties and subspecialties, is designed to effect this deconstruction.<sup>9</sup>

When my mother-in-law, Laura Foote, was dying from cancer, we all knew she was dying. At least one reason why our family never talked about her dying was that until two days before she died we remained fixed on the incremental remedies that medicine continued to offer. However clear her deterioration, there was always another treatment option. As long as small puzzles could be solved, fixing this or medicating that, the big issue of mortality was evaded. Each specialist carried out his task with some success, and the patient died.

In its place, this deconstruction into small tasks can be therapeutic. When I was entering the hospital for my own recent biopsy, I found it mildly relieving to be subsumed in movements from one preoperative test to another; completing each form was a small victory, and I appreciated the distraction from my larger fear. But eventually the reality and responsibility of mortality, and its mystery, have to be faced. Doing so requires a story outside the restitution narrative.

#### THE RESTORABLE BODY

Although belief that the sufferings of illness will be relieved is always the preferred narrative for any body, some bodies show a greater affinity for restitution narratives than others. These bodies can be described using the dimensions of control, body-relatedness, other-relatedness, and desire. Because bodies do not stay put on these dimensions, affinity for the restitution narrative is a *stage in the embodiment process* of illness that every body passes through. When some variation of restitution is in the foreground of the person's story, it will be interrupted

by other narratives, just as restitution interrupts these other narratives when they occupy the foreground.

On the control dimension, the teller of the restitution story wants the body's former *predictability* back again. This predictability is not simply the mechanical functioning that comes with a symptom-free life. What needs to be staved off is the deeper contingency represented by illness itself: the contingency of mortality. Any sickness is an intimation of mortality, and telling sickness as a restitution story forestalls that intimation.

But contingency is not so easily dispelled. The restitution is brought about by an agency outside the body: medicine operating through either surgery or drugs. The body's own contingency is remedied, but only by dependence on an agency that is other to the body. For the teller of restitution stories to consider the paradox—that this dependence institutes its own contingency—would spoil the restitution: in the television commercial the availability of the drug is unquestionable.

The body of the restitution story is fundamentally *monadic* in its relation to other bodies. The disease model of medicine reinforces this conception of each patient "having" a disease, and this disease model articulates well with modernist emphases on the individual as an autonomous entity. The same conception of the individual that makes it sensible to speak of "having" a disease can speak of "having" rights, "getting" an education, or, as will be discussed in the last chapters, "having" empathy. Diseases, rights, education, and empathy are seen as properties of specific persons, not as expressions of persons' relationships to others. Talk about "having" the disease turns the monadic body in upon itself.

The body that turns in upon itself is split from the self that looks forward to this body's restitution. The temporarily broken-down body becomes "it" to be cured. Thus the self is *dissociated* from the body. Both the TV commercial narrative

and the sick-role narrative suggest the presence of a person inside the body who is affected by that body yet remains detached from it. The body is a kind of car driven around by the person inside; “it” breaks down and has to be repaired. The restitution story seems to say, “I’m fine but my body is sick, and it will be fixed soon.” This story is a practice that supports and is supported by the modernist deconstruction of mortality: mortality is made a condition of the body, the body is broken down into discrete parts, any part can be fixed, and thus mortality is forestalled. Sickness as an intimation that my whole being is mortal is ruled out of consideration.

Finally, the body in restitution stories may be “it,” but it wants to be cured; desire remains *productive*. What will cure the body is a commodity, whether that takes the form of a drug or a service, and however it is paid for. The TV commercial is a powerful master narrative not only as it instills the notion that for every ailment there is a remedy, but also because it shows the remedy as a packaged item to be purchased. Restitution is not only possible, it is *commodified*.

Commodification is a crucial aspect of the deconstruction of mortality: as long as I can buy this to fix that, I sustain an illusion of permanence. So long as there is more to buy, whatever needs fixing will be fixed, and I will continue to be. Lest this last mini-plot line seem exaggerated in its simplification, look in any newspaper for what Nicholas Regush, a medical investigative journalist, calls the “gee whiz” stories that pharmaceutical companies regularly send him for publication.<sup>10</sup> Whatever is wrong with the body, these stories describe the imminent development of a high-tech remedy that will cure it.

My sympathy for Regush’s cynicism derives from having to sit through medical lectures that could only be called wildly enthusiastic as they proclaimed impending cures for cancer. If I have cancer again, I might seek these physicians and technologies, but another effect of the technologies—besides curing

some people—is to imply that mortality itself is an avoidable contingency. Amid talk of the advances in genetic screening and manipulation, of drugs that can be delivered to the specific tumor site, and of new diagnostic imaging machines that detect pathology even earlier, amid all this restitution talk, the single certain fact of death has little place. The “gee whiz” news releases and medical self-congratulations are not wrong, but they betray a conspicuous lack of narrative balance: other stories are happening as well, and the restitution story crowds them out.

The body that predisposes choice of the restitution narrative, and the body that this narrative chooses, thus falls somewhere between the *disciplined body* and the *mirroring body*. The restitution story usually demands adherence to some regimen, and this medical (or alternative) compliance demands a disciplined body. But this body is also mirroring because of its emphasis on consumption. The restitution story is about remaking the body in an image derived either from its own history before illness or from elsewhere.

The mirroring body lives principally in what Lacan calls the realm of the Imaginary, where the self comprises images from elsewhere, layered upon each other to become that self. The reliance on images is obvious in the TV commercial: the “bad body” of sickness is juxtaposed with the “good body” of health, achieved after the remedy. The images presented for identification are clear. Identification is equally a central function of the physician in Parson’s sick role. The physician not only cures by his medicine, he also models health in his personal presence. The core of this “health” for Parson is not the physician’s own embodiment but his role performance. The physician is fulfilling the normal work obligations that the sick person has given up as he assumes the sick role. The image offered for the patient’s identification is that of functioning worker.

The language of this last paragraph is filled with terms often used pejoratively: consumption as a mode of activity, identification with images, the primacy of work obligations. Against these pejorative connotations, I reiterate that the Imaginary as a mode of being is essential; self-identification in images only becomes neurotic when the individual lives *exclusively* in the Imaginary. Mirroring and disciplined bodies are perfectly appropriate modes of being; the problem, as with any mode of being, is becoming fixated in one of these bodies. The restitution story may be the first story I tell myself whenever I am ill, but I try to remind myself that other stories also have to be told.

#### RESTITUTION AS SELF-STORY

In the restitution story, the implicit genesis of illness is an unlucky breakdown in a body that is conceived on mechanistic lines. To be fixable, the body has to be a kind of machine. A Nobel prize-winning physician was interviewed in my morning paper. He suggested that for the reporter to understand his work, he should think of the body as a television set, and an elaborate analogy followed.<sup>11</sup> Restitution requires fixing, and fixing requires such a mechanistic view. The mechanistic view normalizes the illness: televisions break and require fixing, and so do bodies. The question of origin is subsumed in the puzzle of how to get the set working again.

This disinterest in genesis is typical of modernist thinking. Ernst Bloch wrote that modernists “do not seek legitimization in the original founding act, but in a future still to arrive.”<sup>12</sup> The TV commercial does not consider how the person got sick in the first place; founding acts are effaced. Parsons does consider the forms of strain precipitating the sick role, but he does not discuss any need to change the conditions that gave rise to those strains. That the person in the sick role will return to the

same conditions is not a consideration. As long as there is an infinite future of getting fixed, changing originating conditions seems irrelevant.

The absence of concern with genesis in restitution stories is clearest when other stories provide a contrast. The same morning newspaper that quoted the Nobel-winning cancer specialist also carried a feature on women suffering various ailments that they suspect result from leakage from silicon breast implants.<sup>13</sup> For these women, the “founding act” of having the initial implant is crucial: what they were told about the implants, what their surgeons knew, what the manufacturer knew, and why they had the surgery (“My self-esteem was low”) are all reviewed in detail. But these, sadly, are not restitution stories; the women anticipate being sick for the rest of their lives and even passing that sickness on to their children.<sup>14</sup> When restitution is judged impossible, the founding act becomes crucial; when restitution is possible, the “future still to arrive” is preferred.

This preference for the future also affects how the interruption of illness is interpreted. Both the TV commercial and the sick role focus on sickness as interruption, but this interruption is finite and remediable. Restitution means that if there are any future interruptions, the sick person now knows the remedy that can fix them. The restitution narrative is a response to an interruption, but the narrative itself is above interruption. By contrast, the silicon breast implant story begins with a woman worrying whether her child’s skin rash might be another result of silicon she believes he absorbed during breast feeding. Her worry is presented as an interjection that interrupts the questions the interviewer has been asking, just as the rash interrupts the woman’s train of thought, just as the silicon-induced illnesses present a future of interminable interruptions. Her story is not a response to an interruption, but a narrative that is perpetually being interrupted.

The purpose that restitution narratives aim toward is twofold. For the individual teller, the ending is a return to just before the beginning: "good as new" or status quo ante. For the culture that prefers restitution stories, this narrative affirms that breakdowns can be fixed. The remedy, now secure in the family medicine cabinet, becomes a kind of talisman against future sickness. One explanation for why Parsons does not consider the implication of returning the formerly sick person to the same conditions where he first became sick is that if sickness does return, the remedy can always be taken out of the cabinet, and the person can always go back to the doctor. In the extended logic of restitution, future sickness *already will have been cured*.

Just as the restitution narrative projects a future that will not be disrupted by illness, it also protects memory from disruption. In the restitution narrative, memory is not disrupted because the present illness is an aberration, a blip in the otherwise normal passage of time. The "normal" trajectory remains intact. After I had cancer I saw a colleague who had been on leave during my illness. He was most solicitous about what had happened to me, and finally mentioned that he himself had had cancer once, but it hadn't amounted to much. As we talked it developed he actually had the same cancer I had, a testicular tumor, but while his was found early and operated on immediately, I suffered from misdiagnosis and extensive secondary tumors.

Our diagnostic differences were equally narrative differences. His story had turned into a restitution narrative before he had time to tell it any other way. His memory of cancer was something remembered outside of memory, insofar as memory involves placing experiences into patterns, albeit changing patterns. He remembered cancer, but cancer was scarcely part of any pattern of recollection. For the teller of the restitution story, sickness is not memorable, though restitution may be,

especially if it is exceptional. Restitution makes a good story after the fact only if it was unexpected.

My colleague's cancer experience was over in a couple of weeks. For that incident to have crystallized any significant issues of responsibility would have been unusual, though this also happens. A woman who has made a vocation of her volunteer work for our local cancer society explains her commitment, in emotional terms, by describing a cancer scare she had. She was investigated for a condition that turned out not to be cancer and, so far as I know, has not caused her health problems since. But she was intimate with a family whose lives were determined over many years by the cancer and eventual death of the mother. That intimacy gave her cancer scare a narrative context, and thus a force, that the actual cancer of my colleague never acquired. Her experience left her with a heavy sense of responsibility; she joined Schweitzer's community of those who bear the mark of pain. Even though the medical facts of her case fit a restitution model, her narrative is not one of restitution.

The issue of responsibility suggests one of the crucial differences between types of narrative: the difference concerning what sort of agency the narrative affords the ill person. In the restitution narrative, the responsibility is limited to taking one's medicine and getting well, wellness being defined in contrast to illness. Other narratives understand the experience of illness in a way that makes returning to the same life that was lived before illness impossible as a moral choice. Schweitzer expressed this when he wrote that whoever "has learned what pain and anxiety really are must help to ensure that those out there who are in physical need obtain the same help that once came to him."<sup>15</sup>

Schweitzer is positing a restoration to health, but not within a restitution narrative. Life for the person Schweitzer describes has changed fundamentally, even though illness is



cured. Responsibility is based on an ongoing sense of solidarity with the ill, this solidarity transcending the present health or illness of one's own body.

Is the restitution narrative capable of generating self-stories? No, in the sense that restitution stories bear witness not to the struggles of the self but to the expertise of others: their competence and their caring that effect the cure. In this witness restitution stories reveal themselves to be told *by* a self but not *about* that self. The self of the mirroring body is realized in identifications with images of others; the witness of the restitution story can only be to the validity of those images.

But this "no" must be qualified by recognizing that not every illness story has to be a self-story; even among the seriously ill, many people do not have their sense of coherence disrupted. Little is perceived as having been taken away, so what is there to reclaim? Consciousness has remained sovereign over its experience. The restitution narrative has its proper sphere: images of health can model behavior that many people can adopt and adapt. The problem arises when the ill person does not find restitution, or when someone who can only tell restitution stories encounters another whose health will not be restored.

#### THE POWER AND LIMITATIONS OF RESTITUTION

Restitution stories are compelling because they often are true: many people do exit the kingdom of illness, sooner than later, good as new. The cultural power of these stories is that their telling reflects one of the best impulses in modernity: the heroism of applied science as self-overcoming. Robert Zussman, summarizing his study of medical work in intensive care units, coins the phrase "the banality of heroism." "If [medical house-staff] are heroic," Zussman writes, "they are heroic in

the routine course of doing their jobs, preparing for the future, and getting through the day."<sup>16</sup>

Ill people who tell restitution stories practice their own banality of heroism. They live out illness as a matter of doing their jobs as patients, preparing for the future after illness, and getting through their own days. The restitution story, precisely because it treats sickness as banal, displays a heroism in the face of bodily breakdown. But this heroism of the ill person is invariably tied to the more active heroism of the healer.

The respective heroisms of physicians and patients are complementary but asymmetrical. Each heroism is required by the other, but physicians practice an active heroism, while patients accept a passive heroism. This asymmetry is not a problem—it may be the only sensible arrangement—but the ill person who adopts this narrative as his own self-story thereby accepts a place in a moral order that subordinates him as an individual.

This subordination is implied in Zussman's observation that physicians' sense of responsibility is not to patients so much as it is to other physicians. He goes on to refer to house-staff valuing medicine as "an encapsulated intellectual challenge." Zussman is well aware that not all patients will appreciate the physicians' values of collegial responsibility or encapsulation, but these values are nevertheless "of primary importance to the profession of medicine."<sup>17</sup>

Zussman's insightful depiction of medical heroism can be placed in a larger perspective by Bauman's distinction between the modernist "hero" and the postmodern "moral person."<sup>18</sup> The hero believes in a cause that is "nobler, loftier, more worthy than their own self-preservation." What Zussman describes as "the profession of medicine" assumes the stature of such a cause; he makes it clear that the comfort and often the safety of both patients and physicians are worth risking. "The profession of medicine" could easily join Bauman's list of mod-



ernist causes that are “the continuation or promotion or triumph of an idea: that of a nation, of a race, of a class, or a ‘way of life,’ of God, sometimes of ‘man as such’” (209).

Across the postmodern divide and in contrast to the hero, Bauman’s “moral person” takes as his cause “the life or well-being or dignity of another human being” (209). The moral person would risk neither himself nor anyone in his care for such an idea as “the profession of medicine.” If an idea does not respect the value and dignity of any immediate person, if it demands the person be sacrificed, then it is not an idea worth respecting. But that is a postmodern attitude.<sup>19</sup>

Restitution stories inscribe a modernist narrative both in illness experience and in medical treatment. The first limitation of restitution stories is the obvious but often neglected limitation of the modernist deconstruction of mortality: when it doesn’t work any longer, there is no other story to fall back on. Restitution stories no longer work when the person is dying or when impairment will remain chronic. When restitution does not happen, other stories have to be prepared or the narrative wreckage will be real.

Sherwin Nuland, writing as a senior physician who has attended many deaths, evokes the “final sharing” that can snatch “an enduring comfort and even some dignity from the anguished fact of death.”<sup>20</sup> Nuland castigates his medical colleagues whose adherence to an ideal of cure robs dying persons and their families of this sharing. What he calls “the seduction of ‘The Riddle’” (249) is what I call being captured by the exclusivity of the restitution narrative. This narrative leaves no place for stories that will disencumber the dying person of what Nuland describes as “the baggage we shall all take to the grave”: “unresolved, breached relationships not healed, potential unfulfilled, promises not kept, and years that will never be lived” (261). Even the very old, Nuland observes, do not always escape having this unfinished business.

Nuland asserts a stronger version of responsibility than any other medical commentator: “The dying themselves,” he writes, “bear a responsibility not to be entrapped by a misguided attempt to spare those whose lives are intertwined with theirs” (243). The restitution narrative can be just such a trap.

Another limitation, perhaps opposite to the above, is that restitution is increasingly a commodity that some can purchase and others cannot. Imagine the person watching the TV commercial who has the same ailment but no money to buy the remedy. High-tech medicine offers more and more restitutions that fewer and fewer people will be able to afford.<sup>21</sup> Thus the restitution story as a *generalized* narrative of illness can be predicted to become increasingly restricted in its availability.

But even if medical progress will be limited in whom it benefits, this progress is real and remains the ultimate power of the restitution narrative. The ultimate limitation of restitution is mortality: the confrontation with mortality cannot be part of the story. Sometimes what cannot be told is dramatic, as when my physician friend cannot wrest his patient from specialists and discuss her imminent death with her. Other times nothing prohibits talking about death, but something just as strong inhibits this talk.

Zygmunt Bauman, responding to arguments presented by Norbert Elias, describes why the restitution narrative is inadequate to make mortality available to experience. “Perhaps it is not just the delicacy of manner that deprives us of speech [when we encounter the dying],” Bauman writes, “but also the simple fact that, indeed, we have nothing to say to a person who has no further use for the *language of survival*, a person who is about to leave the world of busy pretense that that language conjures up and sustains.”<sup>22</sup>

Professional medicine, on the sociological accounts of Parsons, Zussman, and other students of its practices, and on the practitioner accounts of physicians like Nuland, institutional-

izes having nothing to say beyond the language of survival. Its studied self-restriction to that language is the core of its banality of heroism. This core shows widening cracks in post-modern times. Many physicians seem less interested in being heroes, in Bauman's modernist sense, and more interested in being moral persons. Nuland's self-reflections, and their enormous popular reception, are one indication of this shift; David Hilflker, in his life as well as his writing, is another.<sup>23</sup>

My interest, however, is less in forecasting medical change and more in what happens to ill people. What happens when those who have always spoken their own experience in the language of survival find that language has nothing left to say about themselves, once the viability of restitution has run out? What body-self is left, when the end of survival is imminent? The tragedy is not death, but having the self-story end before the life is over. It is a tragedy if having nothing else to say means that these people have no further use for themselves; if in Audre Lorde's phrase they have lost any language in which they can remain available to themselves. Living can certainly be more than the "life of busy pretense," and stories are available that conjure up these other possibilities. But before describing stories that affirm life beyond restitution, the stories that deny any possibility of restitution must be heard.

## *Five*

### *The Chaos Narrative*

#### MUTE ILLNESS

#### CHAOS AS NON-PLOT

Chaos is the opposite of restitution: its plot imagines life never getting better. Stories are chaotic in their absence of narrative order. Events are told as the storyteller experiences life: without sequence or discernable causality. The lack of any coherent sequence is an initial reason why chaos stories are hard to hear; the teller is not understood as telling a "proper" story. But more significantly, the teller of the chaos story is not heard to be living a "proper" life, since in life as in story, one event is expected to lead to another: Chaos negates that expectation.

Chaos stories are as anxiety provoking as restitution stories are preferred. Telling chaos stories represents the triumph of all that modernity seeks to surpass. In these stories the modernist bulwark of remedy, progress, and professionalism cracks to reveal vulnerability, futility, and impotence. If the restitution narrative promises possibilities of outdistancing or outwitting suffering, the chaos narrative tells how easily any of us could be sucked under. Restitution stories reassure the listener that however bad things look, a happy ending is possible—Job with his new family and cattle, basking in God's graciousness. Chaos stories are Job taking his wife's advice, cursing God and dying.

Chaos stories are also hard to hear because they are too

threatening. The anxiety these stories provoke inhibits hearing. Like many people, I saw the chaotic side of illness experience for years before I could acknowledge it. To hear what was being told, I needed the distance of other stories telling events that were not only outside my own experience, but outside the topic of illness. I first began to hear the chaos narrative in Holocaust stories and commentary on them.<sup>1</sup> What cannot be evaded in stories told by Holocaust witnesses is the hole in the narrative that cannot be filled in, or to use Lacan's metaphor, cannot be sutured. The story traces the edges of a wound that can only be told around. Words suggest its rawness, but that wound is so much of the body, its insults, agonies, and losses, that words necessarily fail.

The teller of chaos stories is, preeminently, the wounded storyteller, but those who are truly *living* the chaos cannot tell in words. To turn the chaos into a verbal story is to have some reflective grasp of it. The chaos that can be told in story is already taking place at a distance and is being reflected on retrospectively. For a person to gain such a reflective grasp of her own life, distance is a prerequisite. In telling the events of one's life, events are mediated by the telling. But in the lived chaos there is no mediation, only immediacy. The body is imprisoned in the frustrated needs of the moment. The person living the chaos story has no distance from her life and no reflective grasp on it. Lived chaos makes reflection, and consequently storytelling, impossible.

If narrative implies a sequence of events connected to each other through time, chaos stories are not narratives. When I refer below to the chaos narrative, I mean an *anti-narrative* of time without sequence, telling without mediation, and speaking about oneself without being fully able to reflect on oneself. Although I will continue to write of chaos stories as being told, these stories cannot literally be told but can only be lived.

Yet if the chaotic story cannot be told, the voice of chaos can

be identified and a story reconstructed. What this voice sounds like is captured in an interview fragment reported by Kathy Charnaz. The speaker, Nancy, is a woman with a chronic illness as well as multiple family problems. She describes living with her mother who has Alzheimer's; her mother, she says, "just won't leave me alone."

And if I'm trying to get dinner ready and I'm already feeling bad, she's in front of the refrigerator: Then she goes to put her hand on the stove and I got the fire on. And then she's in front of the microwave and then she's in front of the silverware drawer. And—and if I send her out she gets mad at me. And then it's awful. That's when I have a really, a really bad time.<sup>2</sup>

Hearing the story in Nancy's talk is not easy. First, the story has no narrative sequence, only an incessant present with no memorable past and no future worth anticipating. Second, this anti-narrative contains nothing but life possibilities that anyone fears precisely because almost anyone could end up living in conditions like Nancy's.

Nancy's story displays the chaos narrative in at least two other respects as well. First is the overdetermination of her situation. Nancy is "already feeling bad" from her own illness as she has to contend with her mother. The overdetermination of her problems extends to her troubles with children, dogs, insurance bureaucracies, and, the listener comes to wonder, *who knows what else*. In the chaos narrative, troubles go all the way down to bottomless depths. What can be told only begins to suggest all that is wrong.

The second feature of chaos narrative in Nancy's story is the syntactic structure of "and then and then and then." This staccato pacing of words pecks away at the reader just as Nancy's life pecks away at her. In chaos stories, the untellable silence

alternates with the insistent “and then” repetitions. The personal and cultural dislike for such stories—a dislike that takes the form of simply being unable to hear the story—becomes self-evident.

Gilda Radner’s story of her treatment for ovarian cancer is not a chaos narrative, precisely because it is a narrative. But Radner allows readers some vision of the chaos. Radner is not Nancy; she does have space for reflection; she is writing. The chaos in her life occurs during chemotherapy when the sleeping pills Radner takes cause her to forget, completely, what ever has happened: “Even if I’d gotten sick from the chemo, I wouldn’t remember.”<sup>3</sup> She hates the loss of these days, the literal hole they create in her life. One creative response is to videotape her chemotherapy (169–79). She may miss the world as it goes on around her, but at least she can see what happened to herself. The tape fills in part of the hole in her life; chaos is retrospectively remediated. The story of the videotaping is not the chaos; the story is told around the edges of that hole.

The deeper issue for Radner is the loss of control in her life; time lost during chemotherapy, real enough in itself, also represents this greater loss. “The issue of control plagued me,” she writes; “despite the war I was waging, and my endurance, I couldn’t control the outcome” (181). Control and chaos exist at opposite ends of a continuum. The restitution story presupposes the control that is necessary to effect restitution. The ill person does not have this control herself, but those taking care of her do, which for the restitution story is close enough. The chaos story presupposes *lack* of control, and the ill person’s loss of control is complemented by medicine’s inability to control the disease.

Chaos feeds on the sense that *no one* is in control. People living these stories regularly accuse medicine of seeking to maintain its pretense of control—its restitution narrative—at the expense of denying the suffering of what it cannot treat.

Endometriosis, although recognized as a disease, is often experienced when it cannot be diagnosed. Sally Golby describes her struggle to gain medical recognition of her endometriosis: “The fact the doctors were ignorant about the disease is an excuse, but the fact they battered me emotionally is not.”<sup>4</sup> The present issue is not the difficulty of diagnosing a disease like endometriosis, or the contested reality of conditions like chronic fatigue syndrome (which sufferers prefer to call migralgic encephalomyelitis, in part to display greater diagnostic credibility). The issue is the sense that Sally Golby has of being battered: that emotional battering is fundamental to chaos.

When somehow some part of the chaos is told, no one wants to hear. Lawrence Langer, studying the recordings of oral histories of the Holocaust, observed how interviewers undercut the stories that the surviving witnesses were telling. Very subtly the interviewers direct witnesses toward another narrative that exhibits “the resiliency of the human spirit.”<sup>5</sup> The human spirit certainly is resilient, but Langer forces his readers to recognize that *that is not what the witnesses are saying*. When Nancy tells about her troubles with her mother, we can hear the resilience of the human spirit, but Nancy herself is trying to get recognition of the utter chaos of her life.

The challenge of encountering the chaos narrative is how not to steer the storyteller away from her feelings, as Langer shows the interviewers of Holocaust witnesses doing. The challenge is to *hear*. Hearing is difficult not only because listeners have trouble facing what is being said as a possibility or a reality in their own lives. Hearing is also difficult because the chaos narrative is probably the most embodied form of story. If chaos stories are told on the edges of a wound, they are also told on the edges of speech. Ultimately, chaos is told in the silences that speech cannot penetrate or illuminate.

The chaos narrative is always beyond speech, and thus it is what is always *lacking* in speech. Chaos is what can never be



told; it is the hole in the telling. Thus in the most hurried “and then” telling, chaos is the ultimate muteness that forces speech to go faster and faster, trying to catch the suffering in words.

#### CHAOS EMBODIED

The chaotic body can be described in terms of the dimensions of control, body- and other-relatedness, and desire, but the resulting permutation does not fit any of the four ideal types suggested in chapter 2, thus showing that while those types illustrate certain parameters of body-selves, they certainly do not circumscribe reality.

On the control dimension, the body telling chaos stories defines itself as being swept along, without control, by life's fundamental *contingency*. Efforts to reassert predictability have failed repeatedly, and each failure has had its costs. Contingency is not exactly accepted; rather, it is taken as inevitable. Denials of the chaos narrative often begin with the listener asserting how, in such circumstances, he would find some way out. Primo Levi describes telling his concentration camp experiences to a group of school children, and one boy responding with a detailed plan of how he could have escaped.<sup>6</sup> My equivalent experiences take place in odd conversations—both strange and mercifully infrequent—when someone who has never had cancer tells me about psychological changes they have made in their lives that are going to protect them from this disease. All of us on the outside of some chaos want assurances that if we fell in, *we* could get out. But the chaos narrative is beyond such bargaining; there is no way out.

Relationships also have a history of failure, and so in terms of other-relatedness, the body is *monadic*. This monadic orientation contributes to the inability to find recognition or support for the body's pain and suffering. A feedback loop is initiated: chaos stories erect a wall around the teller that prevents her

from being assisted or comforted, and the less assistance and comfort she experiences, the more she may feel compelled to breach that wall with monologues that repeat “and then.”<sup>7</sup>

The incapacity to receive comfort both reflects and reinforces the body's *lack* of desire. Whatever desires it once had have been too frequently frustrated. In a world so permeated by contingencies that turn out badly, desire is not only pointless but dangerous, just as relationships with others have become dangerous.

Association with one's own body is also dangerous. The body is so degraded by an overdetermination of disease and social mistreatment that survival depends on the self's *dissociation* from the body, even while the body's suffering determines whatever life the person can lead. But matters are more complex than a “self” dissociating itself from a body. A person who has recently started to experience pain speaks of “it” hurting “me” and can dissociate from that “it.” The chaos narrative is lived when “it” has hammered “me” out of self-recognition. Chaos stories are told at the end of the process that Elaine Scarry calls “unmaking the world.”<sup>8</sup>

Nancy's world is unmade. As her chaos story describes her mother in the kitchen, Nancy herself becomes a null point around which her mother moves. The physical space of the kitchen surrounds Nancy, but what is eerie in her description is that Nancy does not move through this space; instead, she is there only as obstructed. Reduced to being an occasion for obstruction, Nancy's body has lost any agency. She is the disembodied subject of a story that she nominally tells but that contains nothing of her subjectivity. Thus Nancy's story is frenzied but flat; she can no longer express sadness at what her life has become.

The skill of the interviewer, Kathy Charmaz, is to elicit an evocation of Nancy's chaos. The reader hears what can rarely be heard: the unmaking of a person's world. What haunts the



reader is hearing Nancy fade into a voice that speaks only its own interruptions: all the “and then” contingencies that fragment her story and her life.

Contingent, monadic, lacking desire, and dissociated—such is the configuration of traits that typify the *chaotic body*. It is often victim to dominating bodies, which make it the object of their force. It is scandal to mirroring bodies, since it shows how easily the images they use to construct themselves can be stripped away. To the disciplined body, the chaotic body represents weakness and inability to resist. The dominating, mirroring, and disciplined bodies each suppress the possibility that they could become chaotic; the chaotic body is the other against which these bodies define themselves. But they claim no empathic relation to this body; it represents only what they fear for themselves.

For the communicative body, the chaotic body is the traveler whom the Good Samaritan found robbed and beaten by the roadside. The communicative body also defines itself through the chaotic body, but the chaotic body is not other to it. Rather, the communicative body sees itself in the chaotic body, and finds inescapable the gesture of offering itself to that body.<sup>9</sup> Note that for most mortals this gesture requires limits: even the Samaritan goes on about his business, paying the innkeeper to care for the injured man. This chapter, however, is more concerned with the tragedy of the chaotic body: of the one whose world is so unmade that he cannot accept the Samaritan's gift.

#### THE CHAOTIC SELF-STORY

In the chaos narrative, consciousness has given up the struggle for sovereignty over its own experience. When such a struggle can be told, then there is some distance from the chaos; some

part of the teller has emerged. Thus just as the chaos narrative is an anti-narrative, so it is a non-self-story. Where life can be given narrative order, chaos is already at bay. In stories told out of the deepest chaos, no sense of sequence redeems suffering as orderly, and no self finds purpose in suffering.

Nancy is not only too frequently interrupted to be able to write her story down; her story is too interrupted to be susceptible to being written. Gilda Radner, although her disease is terminal, can secure an uninterrupted space—physical and psychological—to write her story. The interruption posed by cancer and each of its recurrences is overridden by the story she tells: cancer can interrupt her life, but as she turns those interruptions into a coherent story, she neutralizes the chaos immanent in them. Radner's ability to keep writing her story, mustering all the resources that writing requires, separates her from Nancy's chaos.

The difference between Nancy and Gilda Radner represents the paradox that a true chaos story cannot be told. The voice that might express deepest chaos is subsumed in interruptions, interrupting itself as it seeks to tell. This self-interruption is the core of the “and then” style of speech, cutting off each clause with the next.

The interruptions undercut any pursuit of purpose, and if there were a sense of purpose, again the story would not be chaos. In his analysis of how interviewers elicit Holocaust stories, Langer notes that one device they use to keep the talk tolerable for themselves is to steer the witness toward what the interviewer takes as the end of the camp experience, liberation; liberation becomes the closest thing to a purpose that can redeem the horror. But witnesses, unlike their interviewers, do not think of liberation as any great dividing line that orders their experience. Most striking is one witness whom Langer quotes. In response to being asked how he felt about liberation

he says, "Then I knew my troubles were *really* about to begin." Langer points out that this statement inverts expectations grounded in "traditional historical narrative."<sup>10</sup>

The witness's statement recalls Oliver Sacks's story about his last night in a London hospital where his badly injured leg has been repaired. Sacks's troubles began when he injured himself in a hiking accident.<sup>11</sup> Surgery on his leg is successful from a medical perspective, but Sacks has no sensation in the leg. The problem is not just failure of the nerves to feel and respond. The deeper problem is that Sacks sees his own leg as not being his. He describes the leg as feeling "meaningless and unreal . . . an absolutely ludicrous artificial leg."<sup>12</sup> Nurses and orthopedic surgeons refuse to acknowledge any aspect of what Sacks is experiencing, and their denial increases his "horrible fears and phantasms" (127). Sacks's chaos is his extreme dissociation from what he knows is part of his body but cannot experience as belonging to himself.

Sacks regains sensation in his leg by listening to Mendelssohn; internalizing the rhythms of the music, he begins to walk again. Eventually he is to be discharged from the hospital to a kind of halfway house for rehabilitation. His moment of deepest chaos would seem to be behind him. His story's narrative has become one of recovery, yet he was, as he puts it, "dead scared of leaving." In his fear I hear an echo, however faint, of "my troubles were *really* about to begin."

The hospital's time and space have come to circumscribe Sacks's world. On his last night in this world he decides to climb up onto the hospital roof, on crutches with his leg still in a cast, to see the view of London at night. Fortunately a nurse stops him before the inevitable accident occurs. Later he learns how many patients engage in similar attempts to sabotage their imminent releases (166). The manic humor of Sacks's tale of this escapade rests on an edge of terror, though terror of *what*?

Too quick explanations of "fear of reentry" trivialize what Sacks faced. He had known chaos and been face to face with his own dissolution. His fear is of reentering a world that cannot imagine, and does not want to imagine, that dissolution. This reentry is a worse trouble than language can readily formulate.

Many people with cancer report a kind of terror when the treatments they have hated finally end, usually explaining this as a fear of recurrence.<sup>13</sup> That explanation, with its emphasis on cure, turns their stories into restitution narratives. Yet Sacks seems to reject restitution in his desire to climb back into darkness: if not the darkness of his original injury, then at least the darkness of the roof with its probability of accident and continued hospitalization.

At various times during my own treatment for cancer I both hated the hospital and found it was the only place where I felt I had a place. Chemotherapy was both the proximate source of my chaos and a sort of solution to the problem it itself generated. That solution was *not* getting to the end of treatment. The solution was being kept apart from a world that could not, and would not, understand. When liberation from the hospital comes, as welcome as it is, one's real trouble begins: the trouble of remaking a sense of purpose as the world demands.

Parsons labeled ill people as seeking a "secondary gain" when they remain in the "sick role" longer than they apparently need to. Gains include benefits such as attention, care, and excuse from other responsibilities. Such an explanation, applied by healthy analysts to ill people, is a bit like the clock that has stopped but is still correct twice a day. Something is explained, but the whole notion of "explaining" requires imposing a purpose on behavior. Much illness behavior can only be understood when the would-be interpreter is able to enter imaginatively into a world *without* purpose. The interviewers described by Langer seek to impose liberation as, if not a goal, then at least a definite end to the stories they hear and the hor-

rors these stories tell. The Holocaust witness who resists this narrative imposition inverts the narrative order by showing the interviewer the inapplicability of finding any ending in liberation.

When Sacks captures his moments of chaos in prose, he writes from well outside a chaos that the Holocaust witness can never leave behind. Sacks's story invokes moments of chaos, but it is hardly a chaos narrative. Sacks tells a series of interruptions—first his accident, then the post-surgical lack of feeling in his leg, then his misadventure on the roof, and so on—but these interruptions are assimilated into a stable pattern of memory. In Sacks's story, one thing leads to another: To the extent that such a narrative ordering can be discovered and told, beginning with a clear *genesis*, that story seems to keep the body out of chaos.<sup>14</sup> A sense of genesis sets in place subsequent narrative order: something early results in something else later on.

The Holocaust stories may have a clear historical genesis, the moment of being transported to the camp, but in the depths of all that happens later, this moment loses narrative force as an explanation. In a chaos story such as Nancy's, the genesis of her troubles is lost in the overdetermination of these troubles: which came first—illness, financial problems, family problems—is impossible to sort out. The lack of genesis in chaos stories has its corresponding lack in any sense of the future. Thus the chaos narrative shows the truth of Carr's observation (see chapter 3) that a coherent whole requires all three: future, present, and past, each depending on the others. In a story such as Nancy's, which lack precedes which—past or future—cannot be told.

Just as a story of chaos cannot be told from within the chaos, the responsibility implied by an experience of chaos cannot be exercised from within the chaos. The person who has lived chaos can only be responsible to that experience retrospec-

tively, when distance allows reflection and some narrative ordering of temporality. The body-self that is immersed in a chaos lives only in immediacy. Whenever events seem to be sorted out, the chaos generates another crisis of survival.

Exercising responsibility requires a *voice*, and the chaotic body has no voice; I imagine Nancy cannot hear her voice as entirely her own. Muteness begins in the body; when Sacks cannot experience a part of his body as part of himself, he cannot speak, at least in the sense of articulating his feelings in a way that gains the recognition of others. His story suggests how speech requires the body that is spoken through: Sacks is unable to speak through his body when it seems only contingently attached to him. The achievement of his writing is to capture the claustrophobic terror of this muteness.

Sacks is awakened from this nightmare by Mendelssohn. Music allows a direct connection to his body that speech can no longer provide. As he learns to turn musical rhythms into movement, Sacks begins—the story does not end here—to rediscover the use of this body and thus reintegrate himself. Eventually he finds a voice to witness his experience—ultimately in his book—but this voice can only speak *about* the chaos, from *outside* that chaos. Being a mute witness, caught within the chaos itself, is a condition of horror.

#### HONORING THE CHAOS STORY

The need to honor chaos stories is both moral and clinical. Until the chaos narrative can be honored, the world in all its possibilities is being denied. To deny a chaos story is to deny the person telling this story, and people who are being denied cannot be cared for. People whose reality is denied can remain recipients of treatments and services, but they cannot be participants in empathic relations of care. The chaotic body is disabled with respect to entering relationships of care; as sug-

gested above, it cannot tell enough of its own story to formulate its needs and ask for help; often it cannot even accept help when it is offered.

Those living chaotic stories certainly need help, but the immediate impulse of most would-be helpers is first to drag the teller out of this story, that dragging called some version of “therapy.” Getting out of chaos is to be desired, but people can only be helped out when those who care are first willing to become witnesses to the story. Chaos is never transcended but must be accepted before new lives can be built and new stories told. Those who care for lives emerging from chaos have to accept that chaos always remains the story’s background and will continually fade into the foreground.

The exemplary fortitude of Oliver Sacks, the man with the unreal leg, is to refuse to play the role of doctor to himself, even though he is a doctor. Against medical denial that anything is wrong, Sacks sticks with his perception, as fearful as that is. He stays in his body until it finds its own way out of the chaos, which for him begins through music.

The worst thing medical staff can do to someone in the chaos story is rush him to move on. Moving on is desirable; chaos is the pit of narrative wreckage. But attempting to push the person out of this wreckage only denies what is being experienced and compounds the chaos. The anxiety that the chaos story provokes in others leads to the standard clinical dismissal of chaos stories as documenting “depression.” When chaos is thus redefined as a treatable condition, the restitution narrative is restored. Clinical staff can once again be comfortably in control: the chaos can be dismissed as the patient’s personal malfunction. That reality is classified as either amenable or resistant to treatment; in either case it no longer represents an existential threat.<sup>15</sup>

What is needed, specifically in clinical work and more gen-

erally in any interpersonal relations, is an enhanced tolerance for chaos as a part of a life story. Robert Bly cites Norwegian scholars who write about medieval customs of young men dropping out, sometimes for two or three years, to lie in the ashes of the fire pits in the large, communal houses. “Apparently some also chewed cinders,” Bly notes, explaining their name of Cinder-Biters.<sup>16</sup> Bodies living chaos stories are contemporary Cinder-Biters.

I worry that this chapter has already drawn too many analogies between forms of suffering that cannot be compared. Unlike the Cinder-Biters, Nancy is not going through a developmental phase as she attempts to cope with her chronic illness, her mother’s Alzheimer’s, and her other problems. But a society that had an accepted place for Cinder-Biters might show more empathy for Nancy’s condition and be able to provide for more of her needs. Nancy would have a recognized place in such a society, while she has no place in ours. Because contemporaries, whether medical or lay, cannot allow themselves to imagine her chaos—to entertain it as anything close to their normality—they can only pile more sickness labels on her, driving her deeper into chaos.

Here as elsewhere, the clinical problem reflects a larger social issue. Clinicians cannot entertain chaos because chaos is an implicit critique of the modernist assumptions of clinical work. Reconsider that provocative, Zen koan-like line of the Holocaust witness describing liberation, “Then I knew my troubles were *really* about to begin.” What is inverted here are not just the expectations of historical narrative, but the modernist understanding of history, both social and personal, as progress. When interviewers steer witnesses toward liberation, they reinstitute a modernist restitution narrative of progress. The great modernist exemplars of my own youth were the Japanese and German “economic miracles” of rebuilding and, as a kind



of complementary phenomenon, the creation of Israel. After Auschwitz and Hiroshima, these phenomena restored faith in the modernist project.

Many intellectuals—Theodor Adorno, Maurice Blanchot, Edmond Jabes, Jean-François Lyotard—have asked how it is possible to write after Auschwitz. Perhaps the other question that ought to be asked is how it was possible to write before: what naiveite informed modernity from its inception? The immediate relevance of this question is that the same naiveite continues to suppress the chaos story. Clinical caregivers steer patients toward medical versions of liberation: treatment plans, rehabilitation, functional normality, lifestyle counseling, remission. These phrases and the many others like them reconstitute the restitution narrative. My objective is hardly to romanticize chaos; it is horrible. But modernity has a hard time accepting, even provisionally, that life sometimes *is* horrible. The attendant denial of chaos only makes its horror worse.

This horror is a mystery that can only be faced, never solved. Working out treatment plans and seeking to achieve remissions are fine, heroic work, in the perspective of what they are. The serious question is whether the heroic work of modernity, exemplified by Zussman's intensive care physicians, can proceed in concert with the kind of tragic consciousness that affords a normal place to Cinder-Biters: a consciousness that does not see these people as in need of fixing but honors them for what they are being.

Much of postmodernity—haunted by the question of how to write after Auschwitz—is a struggle to work out what aspects of modernity can be preserved while scrapping the modernist telos. In this telos the restitution narrative demands hegemony; it denies chaos and requires chaotic bodies to be “depressed” and thus fixable. There is no modernist clinical category for “living a life of overwhelming trouble and suffering,” yet only this label can describe someone like Nancy being

buffeted about her kitchen, or the Holocaust witness, or Gilda Radner as she goes through recurrence after recurrence of cancer, or Oliver Sacks as he looks at his leg and cannot see it as part of his body.

Sacks's chaos has its macrocosmic analogue when society looks at people in chaos and cannot see them as part of the social body. The difference is that Sacks takes it as his problem to reclaim his leg; society often attributes the problem to these “others” themselves. The most prevalent North American example of these others are the homeless. As ill persons, the homeless present an ambiguity: Hilfler writes of the poorest sections of Washington, D.C. that “health is not so much a question of disease.”<sup>17</sup> Hilfler evokes the inversion of Parsons's sick role: lives of sickness outside medical purview. “The strictly medical factors are rarely the most crucial to healing,” he observes (211). His diagnosis is what I call “living a life of overwhelming trouble and suffering.” Society prefers medical diagnoses that admit treatment, not social diagnoses that require massive change in the premises of what that social body includes as parts of itself.<sup>18</sup>

The very poor and the very sick have only a marginal place in the case load of the professions, which prefer what can be fixed. Hilfler describes how this preference is enforced in medical schools. After a lecture he gives, a “distinguished professor of pediatric surgery, garbed in a long white coat” rises to ask him whether his practice of poverty medicine is not a “waste” of his medical education. Hilfler acknowledges having little opportunity in his conditions of practice to exercise his scientific skills. He also recognizes that the professor is using the question to “persuade his students and residents not to ‘waste’ their own educations by choosing work as ‘useless’ as I do.”<sup>19</sup> I would add that the professor is not only cautioning these specific student physicians. He is upholding, first, the modernist medical project of attending to what is fixable and



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 gested 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. 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 Bodhisattva, 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 disappearingly." 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 healthist, 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 autonomythological 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 autonomythology 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 Dalmoney 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 Schafer (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 this 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 recollect 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 dependant 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.