

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

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

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

## Seven

### Testimony

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

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

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

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

the limits of what its times attend to, is itself another construction of its times. The more that is told, the more we are made conscious of remaining on the edge of a silence. How much remains that can never be told is unknown.

But to observe that testimony is incomplete and only possible at a particular cultural moment in no way diminishes the force of that testimony. To paraphrase the quotation from William James that orients this whole inquiry, no analysis can ever "settle the hash" of testimony. Any analysis is always left gazing at what remains in excess of the analyzable. What is testified to remains the really real, and in the end what counts are duties toward it.

#### POSTMODERN TESTIMONY

Shoshana Felman describes testimony as "composed of bits and pieces of a memory that has been overwhelmed by occurrences that have not settled into understanding or remembrance, acts that cannot be constructed as knowledge nor assimilated into full cognition, events in excess of our frames of reference."<sup>2</sup> The sentence's repeated "that" phrases seem to chase what can never quite be said; Felman's own language seems overwhelmed, especially as I read it aloud. Testimony has that effect: it overwhelms even as it is overwhelmed.

Felman's description evokes what is postmodern in contemporary testimony: even as "truth" is told, we now find uncertainty. Even in testimony, consciousness struggles to gain sovereignty over its own experience. Felman's book is one example of current academic interest in testimony; books like Art Spiegelman's *Maus I* and *II*<sup>3</sup> and films like *Schindler's List* exemplify the popular culture of testimony. But as a form of testimony, the proliferation of Holocaust materials is dwarfed by the self-help movement with its various forms of "recovery."

Recovery, with its paradigm form in the Alcoholics Anony-

mous Twelve Step Program, is based on the popular availability of testimony as a commonsense activity. The different facets of this movement then reinforce the cultural importance of testimony. Published illness stories ride this wave of interest in testimony.

Each of these testimonies presents itself as some fragment of a larger whole that the individual witness makes no pretense of grasping in its entirety. Postmodern testimony speaks not in what Jean-François Lyotard called "grand narratives"<sup>4</sup>—the narratives of church, state, science, and medicine that held earlier societies and lives together; rather, it speaks in Felman's bits and pieces. These bits and pieces are all that an "overwhelmed" consciousness can deal with. A grand narrative is the work of a sovereign consciousness that claims the ability to assimilate experience into what Felman calls "full cognition." This sovereignty depends on experiences fitting into existing frames of reference.

Consciousness loses its sovereignty when the frames of reference that once could assimilate experience have been hauled across the postmodern divide. In postmodern times, events now happen, and are acknowledged to happen, in excess of those frames. This excess takes at least two forms: too many events happen too fast to be fitted into appropriate frames, and some events simply do not fit even when reflective space is available for the fitting. As both forms of excess act together, the old frames no longer contain the pace and breadth of new experiences.

At the root of the overwhelmed memory that Felman finds in testimony is a *body* that is overwhelmed. Audre Lorde hears the nurse's order to wear a prosthesis as threatening "my right to define and to claim my own body." Her body—what it means to define and to claim it—is the point of contest in her testimony. As she writes of her body, Lorde is caught in the same expressive dilemma that Felman, or I, or anyone else

shares. "Define" and even "claim" are still too verbal, too cognitive: the body is the excess of any definitions or stated claims; it is in excess of any language that testimony can speak. What Felman calls "full cognition," the ideal of a consciousness that can be sovereign over its experiences, seems impossible. The body is always "more," which is why desire is always an issue. Bodies want "more," because the body is "more."

What, then, can be said about the testimony of the ill, since this testimony is already an excess of what can be spoken? The post-colonial, embodied self pushes the limits of testimony.

#### THE BODY'S TESTIMONY

The witness in a traffic court speaks on the authority of having been there, on the scene; what counts is seeing. The illness witness also speaks from having being there, but his testimony is less of seeing and more of *being*. Gabriel Marcel expresses this quality of witness: "We are concerned with a certainty which I *am* rather than with a certainty which I *have*." This certainty is realized in testimony: "But how can I *be* a certainty," Marcel asks, "if not in as much as I am a living testimony?"<sup>5</sup>

Marcel's notion of being a living testimony focuses the quality of witness offered by illness stories and further explains how illness stories are not only *about* the body but *of* and *through* the body. The content that illness stories offer is valuable for a variety of purposes: for the teller's reordering of her life story, as guidance to others who will follow, and to provide caregivers with an understanding of what the ill experience. But the body testifies in excess of all these contents.

Illness stories are told by bodies that are themselves the living testimony; the proof of this testimony is that the witnesses *are* what they testify. Others can *have* the story as content, just

as throughout this book I have many stories and retell them. But only the ill person herself can *be* the story, and that being—the excess of any content—is the plenitude of testimony and its demand.

In the previous chapter I quoted a woman called Gail who suffers from chronic pain. Gail's comments, as recorded by Linda Garro, are some of the finest testimony available, while also raising questions of what this testimony is. Gail refers to "people who don't have pain" as "normals," and to "the medical establishment" as "whitecoats":

And all these people in pain . . . all these people with aches and all these people suffering. We walk in different dimensions. We have access to different experiences, different knowledges. And there are so many of us, too. What would happen if we all knew what it really meant and we all lived as if it really mattered, which it does. We could help the normals and the whitecoats both. We could help them see that they're wasting the precious moments of their lives, if they would look at us who don't have it. I'm convinced only sick people know what health is. And they know it by its very loss.<sup>6</sup>

Gail claims different knowledges, but what would her answer be if she were called to account for such knowledge? What if a group of professionals were to examine her and ask, *what exactly* do you have to teach?

Gail could certainly say this and that about delivery of health care, but her true witness, the witness that "really matters" to use her phrase, is not what she could say but what she *is*. Available language forces Gail to speak of what she is in terms of knowledge, but her "knowledge" is in excess of speech. Her knowledge comes down to this: living as if it really mattered,

which it does, and not wasting precious moments. Everyone knows these things, but Gail, through her years of pain, *knows* them.

Gail wants normals and whitecoats to *look* at her; the necessity to choose one verb limits her, but her choice is important. For testimony in traffic court a written deposition will suffice. The witness of suffering must be *seen* as a whole body, because embodiment is the essence of witness. Gail's knowledge and the difference it could make emanate from the site of her pain, which is the source of this knowledge. Her testimony is her body, and ultimately the body can only be apprehended through all the senses of another body.

A witness such as Gail cannot be *asked* what her testimony is; asking is the least dimension of her demand to be witnessed. Those who would receive Gail's testimony must receive her, because she *is* that testimony. Thus the witness makes a witness of others; a particular quality of the word witness is its movement of outward concentric circles. When someone receives the testimony of another, that person becomes a witness, and so on.

Art Spiegelman's *Maus I* and *II* exemplify this concentric quality. The books' subtitle, "A Survivor's Tale," refers ambiguously both to Vladek Spiegelman, Art's father and a survivor of Auschwitz, and to Art himself, who survives his mother's suicide and a childhood haunted by comparisons to an older brother who died in the Holocaust. The books tell Art's struggle to survive his father's memories. *Maus I* and *II* are as much about the effect of the Holocaust on children of survivors as on the survivors themselves. The books' effect on the next circle of witnesses, the readers, is left open.

One message of Art's survival is that none of us can be detached spectators to others' witness. He comes to terms with his father by eliciting his testimony, recording it, interpreting it, and ultimately presenting it to a broader audience of wit-

nesses. The imperative to receive testimony is postmodern but not distinctively so; the distinctive postmodernism lies in the witness's uncertainty of what is being received. Art remains profoundly ambivalent about his father. Even as he honors his father's testimony, he recognizes his father's less attractive behaviors and questions whether these can be excused as results of wartime trauma. However he attempts to sort out the levels of testimony and responsibility, consciousness will never be sovereign over experience. What is certain is his own inescapable place in the circle of testimony. Testimony is distinct from other reports because it does not simply affect those who receive it; testimony *implicates* others in what they witness.

This reciprocity of witnessing requires not one communicative body but a *relationship* of communicative bodies. Ordinary speech, conditioned by thinking on the model of law courts, refers to "the witness" as if witnessing could be a solitary act. Witnessing always implies a relationship; I tell myself stories all the time, but I cannot testify to myself alone. Part of what turns stories into testimony is the call made upon another person to receive that testimony. Testimony calls on its witnesses to become what none of us are yet, communicative bodies. When Vladek and Art share the testimony of the Holocaust, as survivor and artist respectively, they communicate, and may have their only moments of communion with each other.

In its testimony the communicative body calls others into a dyadic relationship. Testimony as an activity defines the communicative body, albeit tautologically and recursively. Gail becomes a witness to her illness because she is a communicative body, but she also becomes a communicative body through her testimony. The communicative body jumps out of its isolating compartment in my too neat diagram in chapter 2 and requires another body. The dominating body also jumps out of its slot, because it needs the subservience of the other in order to be.

The communicative body needs the other in order to commune.

Testimony like Gail's cannot be called to account because that mode of interrogation isolates her: for others to require her to give them an analytical specification of her "knowledge" is already to destroy the being that is the basis of that knowledge, which is Gail's communicative body. Living like it really matters, which it does, is living in communion with others. The excess of this communion over any verbal account is suggested by Jodi Halpern, defining empathic care as "attuned . . . through preverbal resonance."<sup>7</sup> The only appropriate response to Gail is not, "What do you have to tell me?" but rather, "Let me be with you." The only mode for receiving testimony such as hers is *being with*.

The content of illness stories, the events, actions and responses they tell, are openings to their more fundamental testimony, which is the *presence* of the embodied teller. Illness stories require an interplay of mutual presences: the listener must be present as a potentially suffering body to receive the testimony that is the suffering body of the teller. This presupposition of embodied presence could not be further from the practice of literary deconstruction, with its negation of the author's presence and treatment of the story as "text."<sup>8</sup>

Yet to understand illness stories as testimony is to use them in a deconstructive way. They disassemble what Dorothy Smith calls the "relations of ruling" inherent in the administrative texts—medical charts, financial statements, hospital administrative procedures—that mediate the lives of ill people.<sup>9</sup> The testimony of the illness story asserts the embodied presence that these administrative texts simultaneously rely on and deny, like the colonial texts described by Spivak (see chapter 1). The body of the ill person is the reason medical administration exists, but medicine as scientific, professional activity can only recognize the body as carrier of the disease. The experi-

ence of embodiment eludes official medical discourse, however attuned many practicing physicians are to their patients' experiences.<sup>10</sup>

The change that testimony like Gail's calls for is not some reorganization of "service delivery" or enhanced "communication skills" among physicians. The issue is nothing less than changing the cultural milieu so that people like Gail are *seen* for what their bodies testify to. The demand of her testimony is for other bodies to *commune* with her in her pain, because only through her pain has she learned what really matters. Normals and whitecoats can learn what really matters only through communion with her; in that communion they can stop wasting precious moments. This communion takes place outside the language of survival, which it thus challenges. Communion is not instrumental and not conditional, and so administrative systems have no place for it.

Testifying to illness as a communicative body may be an individual moral choice, but this testimony implies a social ethic.

#### THE PEDAGOGY OF SUFFERING

Testimony is complete in itself, but it requires commentary in order to be transformed into a social ethic. Gail's testimony, quoted above, is that the ill offer others a truth. The "pedagogy of suffering" is the phrase I have used in my own earlier writing to describe what the ill have to teach society.

By conceiving suffering as a pedagogy, agency is restored to ill people; testimony is given equal place alongside professional expertise. The pedagogy of suffering does not replace modernist medicine and supporting theories such as the sick role; rather what is opened is the possibility for shifting between frameworks as required by *responding* to the ill. The sick role is useful not only as a lightning rod for criticism of modernist medicine; it retains much explanatory force. The



restitution story remains the most frequently told of illness narratives, and modernist medicine thrives: most discontents are demands for more medicine.

But times change. Modernist medicine has regarded suffering as a puzzle to be "controlled" if not eradicated. Postmodern illness culture, lay and medical, recognizes a need to accept suffering as an intractable part of the human condition.<sup>11</sup> I understand postmodernity as a period of frameworks shifting in and out of foreground and background. Donald Levine has recommended that social theory become "multivocal."<sup>12</sup> Clinical ethics and concepts of care must also become multivocal.

Society needs a pedagogy of suffering. The finest defender of modernity, Jürgen Habermas, also delineates most clearly its dark side: the processes he calls the colonization of everyday, communal lifeworlds of human bodies by administrative systems that are driven by demands for profits and votes.<sup>13</sup> The postmodernity I want to defend is not so different from Habermas's modernity: where he foregrounds the continuing relevance of the modernist project while recognizing problems that require change, I foreground change while recognizing continuities.

The pedagogy of suffering is my antidote to administrative systems that cannot take suffering into account because they are abstracted from the needs of bodies. When the body's vulnerability and pain are kept in the foreground, a new social ethic is required.

The challenge is to state this ethic in terms that remain multivocal. A multivocal ethic does not imply relativism; it suggests the recognition of difference that seems to be the original impetus behind Habermas's work: the need to recognize multiple voices and afford each full legitimacy in reaching a consensus that is not only workable in achieving minimal compliance of all parties, but is also moral in the sense of respecting the values of all whose compliance is required.

The need for a new, multivocal clinical ethic is starkly demonstrated in a quotation reported by Charles Bosk in his research on physicians who are genetic counselors. Bosk asks one of the physicians he has been working with and studying how he "came to grips with all the 'accidents' or 'mistakes' [of medical practice] that he saw." The response should be read aloud to every medical school class as an example of how professional practice can warp an otherwise decent mind:

What you have to do is this, Bosk. When you get up in the morning, pretend your car is a spaceship. Tell

yourself you are going to visit another planet. You say,

"On that planet terrible things happen, but they don't happen on my planet. They only happen on that planet I take my spaceship to each morning."<sup>14</sup>

Robert Zussman suggests the same attitude when he summarizes his research on intensive care units by saying the staff "live in a moral universe of limited liability."<sup>15</sup>

Zussman defends this attitude, at least to some extent. He points out, correctly, that "the impersonality of medicine" and the "disappearance of an orientation to the patient as a person" are the price paid for "the disappearance of a sometimes oppressive moralizing" (29). The limitation of liability at least cuts both ways: drug dealers and patients whose conditions result from their own bad habits get the same care as anyone else, or at least they do in Zussman's observations.<sup>16</sup>

Bosk provides the epigram for what I would call "spaceship ethics," and Zussman adds a reminder that even indifference can have its benefits. What is required in clinical ethics is not a replacement of existing orientations but their displacement within a multivocality that recognizes the respective legibilities of various claims and finds ways to balance these claims, making each aware of the others. In a multivocal medical world, non-medical voices would be heard. Physicians

would take responsibility for their part in creating the "other planet," and others would recognize that physicians do not create the world of medicine exactly as they choose.

The practice of clinical ethics struggles to harmonize a rapidly changing medical practice, pushed in new directions by administrative, technological, and cultural changes, with the older modernist assumptions of professional expertise, administrative rationalization, and the possessive individualism of a capitalist system. I intend no irony in writing that these modernist assumptions are supported by real payoffs: I was lucky to have testicular cancer at the older end of the disease's age range; if I had had it at the younger end, the drugs that treated me successfully would not yet have been in general use.

The payoffs are real, but the tragedies incurred by spaceship ethics are equally real, and popular awareness of the tragic potential in medical treatment grows. The "choice-in-dying" movement is one social indicator of distrust in end-of-life medical care; another is women's discontents and health activism on issues ranging from hysterectomy rates to the safety of breast implants.<sup>17</sup> The problem is that as long as clinical ethics remains grounded in the assumptions of modernity, it is unable to offer an adequate response to such distrust and discontent, as long as limited liability remains the guiding principle governing its vision of the practice of medicine, clinical ethics limits itself to imagining variations in limitation on liability. It keeps on shuffling the same deck.

Nancy Mairs, whose years with multiple sclerosis have given her time to contemplate relationships of mutual giving, proposes a radically different ethic of *extensive responsibility*. Mairs observes that charity "is never nice."<sup>18</sup> People who give in order to be nice do not think of themselves as needy; the needy are others. To be harsher than Mairs is, the "nice" need the needy to be other to their niceness, but—returning to Spivak's argument (see chapter 1) about master texts—the

nice cannot acknowledge their need for the needy. Thus charity turns into domination: the nice make the needy dependent upon them.

The relations of giving that Mairs imagines begin in a *mutual* recognition of need. Mairs's counterintuitive insight is that *all* persons have abundances, and all have lacks: "True, your abundance may complement someone else's lack, which you are moved to fill, but since your lacks are being similarly filled, perhaps by the same person, perhaps by another, reciprocity rather than domination frames the interchanges" (163). Mairs certainly knows that these abundances "may not take a form you much like" (163), such as multiple sclerosis for her or cancer for her husband. Too often one's abundance is suffering. But the recognition of suffering as abundance is one pillar of a charity that is not domination but reciprocity.

The other pillar is Mairs's faith that each person is lacking. Her argument finds a complement in David Hilfiker's explanation of why he took up the practice of poverty medicine, with the loss of income, comfort, and prestige that move entailed. Poverty medicine is an antidote to his own "brokenness."<sup>19</sup> Seeing oneself as "broken" goes against the current of contemporary North American culture, particularly professional culture. The reorientation Mairs proposes is radical. When a person believes, truly, in her own lack, then filling that lack is a matter of need. "Charity" becomes a way of meeting one's own need by drawing on the abundance of others, which happens to be an abundance of need.

Again, this need is certainly not an abundance that the needy want, nor does it make the needy attractive; quite the contrary. Mairs has spent enough time among the destitute to have lost any illusions about the effects of poverty, and Hilfiker struggles constantly with his lack of sympathy for many of his patients. It is precisely the unsympathetic aspect of the needy that makes filling their need into a remedy for brokenness.

Genuine service, for Mairs and Hilfiker, is a matter not of being nice but of recognizing that one's own lack can only be met by the other's abundance of need. Applied to medicine, this thinking displaces Parsons's idea of the physician acting as social control agent to regulate abuses of the privileges supposedly afforded the ill. Instead, what emerges is an image of the physician as servant who understands himself as being served: Jesus washing the feet of his disciples is the appropriate ideal. The paradox that as we serve we are also being served is the core of Mairs's ethic; our deepest human needs can *only* be served in relations created by our service.

If people could believe that each of us lacks something that only an other can fill—if we could be communicative bodies—then empathy would no longer be spoken of as something one person “has for” another. Instead, empathy is what a person “is with” another: a relationship in which each understands herself as requiring completion by the other.<sup>20</sup> The ill person is then no longer the passive patient imagined by the sick role, who receives care against the promise of returning to productive work. The sick-role conception places care within the language of survival: caring is rendered instrumental and contingent.

The pedagogy of suffering means that one who suffers has something to teach, just as Gail claims, and thus has something to give, as Mairs recognizes. Relationships of caring are no longer asymmetrical, even though the real instrumental work of doing care is asymmetrical. When this work takes place in the context of a relationship, however, the asymmetry counts differently.

This ethic of extensive responsibility will encounter objections such as those Joan Tronto has leveled against what she calls “the ‘morality first’ view” of care.<sup>21</sup> Tronto criticizes advocates of care such as Nell Noddings who assert the primacy of moral values over the political realities of “gaining power and

preserving it through force and strength.” She characterizes “morality first” positions as maintaining that only “after moral views are fixed, [should] right-thinking individuals suggest to the state how political life should conform to these moral principles” (7).

Tronto advocates the centrality of care to social life, but she also forces the question of whether a morality of care can ever have any practical currency outside of particular communities that define themselves in “morality first” terms. Her question is appropriate to arguments such as those of Mairs and Hilfiker, which rest on an explicitly spiritual faith. Tronto asks whether such an ideal of care can be “sufficiently broad [as a] moral idea to solve the problems of distance, inequality, and privilege” (158).

Some witness to the practical reality of a “morality first” ideal of care is found in Timothy Diamond's report of working as a nursing assistant in Chicago nursing homes. Here, certainly, is the worst paid, most demanding, most asymmetrical, and physically hardest work of care. Yet Diamond discovers real relations of caring. He quotes one of the assistants he works alongside; she explains to him how she performs the literal “dirty work” she does: “After a while when you get to know these folks, it's like your baby, she said with a smile. ‘You'll find out whose shit stinks and whose don't.’” Diamond calls this remark “framed in a narrative of relationships.” These relationships, he writes, “were not something distinct from the work but integral to how it got accomplished.”<sup>22</sup>

How does this “narrative of relationships” come about? One interpretation is that the communicative body can be heard *even* in the conditions Diamond describes. The alternative is that these conditions—as opposed to higher status intensive care units—are *exactly where* we should expect to hear the communicative body. On either account, idealism about care is justified. Nursing assistants exemplify Bauman's postmodern



moral person. Higher qualified nurses only administer the homes: their orientation is to "the Idea" of keeping charts and state-required accounts of care, such as records of meals and baths (120). The orientation of the nursing assistants is to the well-being and dignity of their patients.

When Diamond asks a fellow worker why she does not get a higher paying job, "her back arched and her eyes blazed. 'This is what I do,' she said indignantly, with a quick glance at the person whose face she was washing" (46). She might also have said that this is who she is: someone who dedicates her body to helping other bodies.

The example of Diamond's nursing assistants does not obviate Tronto's reservations about "morality first" arguments. Nothing the nursing assistants do will *change* the conditions of their work, and their work can only palliate, not change, the degraded lives of the residents of these nursing homes. The oppressive conditions Diamond describes will persist despite the relations of care that take place within them. Ultimately, moral values require a complementary politics with attention to inequalities of power. But improvement in nursing homes—real change for both nursing assistants and residents—can only come when moral views are changed. Diamond's ethnography shows how nursing homes reflect a society with a primary value of warehousing unwanted "others" at minimal cost. He demonstrates that bureaucratic changes—such as increased state surveillance of living conditions—do not improve the lives of residents and those who care for them. Political change without moral reorientation only adds bureaucracy.

Change will only come when people—families, taxpayers, and voters—care about conditions in nursing homes; when residents and nursing assistants are afforded the fullest respect as persons. The pedagogy of suffering is a "morality first" argument, aimed at achieving that shift in moral orientation and thus in political priority.

What is at issue in an ethic derived from a pedagogy of suffering was stated in 1909 by György Lukács, as he meditated on the mysterious reciprocity between creative activity and "the primacy of ethics in life":

Perhaps the greatest life-value of ethics is precisely that it is a sphere where a certain kind of communion can exist, a sphere where the eternal loneliness stops. The ethical man is no longer the beginning and the end of all things, his moods are no longer the measure of the significance of everything that happens in the world. Ethics forces a sense of community upon all men.<sup>23</sup>

The impetus of ethics for Lukács is loneliness; Gail, with her chronic pain that cannot be diagnosed or treated, knows loneliness; so does Mairs, facing both widowhood and complete disability. The nursing assistants confront the loneliness of the residents they care for, and in many cases know loneliness in their own lives as immigrants, and as women of color, who are economically disadvantaged and occupationally marginal. The pedagogy of suffering begins its teaching from a ground of loneliness seeking communion. This communion is the reward of the nursing assistant who cleans the soiled resident and claims it does not stink because of the relationship between them.

The promise of the ethics Lukács recommends is that it lightens the load on people. The ethical person he imagines is "no longer the beginning and end of all things." Being the beginning and end of all things—having to settle the hash of the universe—is the weight modernity puts on its heroes. Physicians feel this weight. Because hospitals and medical offices are run on the assumption that the doctor's mood is "the measure of significance of everything that happens in the world," the doctor has to bear that weight. The danger of imagining ill

people as heroes is putting this same weight on them; the Phoenix as an expectation becomes a burden, not a liberation.

The community Lukács recommends spreads the weight around. Once the moral person has acknowledged his own lack, service is necessary but also easier. All that is needed is to serve the other person. "Not all of us who work with the poor are saints," writes David Hilfker, "but maybe we don't have to be. Perhaps sainthood isn't a prerequisite for the job."<sup>24</sup> This easing of burdens having been recommended, burdens remain. The problem of replacing liability, especially limited liability, with responsibility is burn out. Hilfker reports his own eventual burn out (256) and with characteristic honesty notes that his own "safety net" allowed him to go elsewhere and take time off. The nursing assistants lack that option.

The examples of the nursing assistants and of David Hilfker demonstrate that ill bodies have no special privilege as moral persons; others can become communicative bodies just as well. Illness is *only one form of pedagogy* that can teach the need to become a moral person. What ill people and those who are often the lowest level of their caregivers—whether nursing assistants or practitioners of poverty medicine—have in common is a kind of desperate necessity.

The communicative body is a choice that derives from necessity, and the pedagogy of suffering describes this necessity. When an illusion of oneself as the beginning and end of all things can no longer be maintained, then openness to communion is all that is left. Many faith communities believe in the curious alchemy that whoever engages in that communion thus becomes the beginning and end of all things.

#### NARRATIVE ETHICS

Because the pedagogy of suffering is taught in the testimony of illness stories, the kind of ethic it supports is a narrative ethic.

The question such an ethic poses is the core of what this book is about: how are lives to be affected by stories?

Narrative ethics is a term with some currency in the field of ethics and health care. Describing this work, Rita Charon argues convincingly that "narrative ethics is not an independent method that promises to replace all existing efforts in the field of medical ethics."<sup>25</sup> What Charon calls medical ethics began—as "a project of administering universally applicable principles and adjudicatory rules to health care conflicts" (260). She points out that ethics currently goes well beyond this scope and "increasingly has come to include the search for the meanings of singular human situations" (260), but her concern remains with "the practice of the ethicist" (her subtitle) in resolving "health care conflicts."

Charon suggests how the study of narrative—what I would call narrative sensitization—can contribute to improving the "trustworthiness of medical ethics." Such study would help caregivers:

first, "to recognize the narrative coherence, however obscured, of the patient's life";  
second, to identify "multiple tellers of the patient's story, the several audiences to whom the story is told, and the interpretive community responsible for understanding it";  
third, "to examine contradictions among the story's multiple representations, conflicts among tellers and listeners, and ambiguities in the events themselves";  
and fourth, to help all participants in ethical deliberations to appreciate "the coherence, the resonance, and the singular meaning of particular human events" (261).<sup>26</sup>

Charon is a physician, and her concern—properly for a physician—is with "the patient." For her, the value of "narrative contributions" lies in their ability to enhance medical caregivers' recognition of the complexity of treatment decisions. As such, narrative plays a crucial but ancillary role: by leading

physicians to recognize the moral dimension in *every* medical encounter (264), it helps to ground difficult medical decisions in the concreteness and specificity of each patient's life.

Certainly, the reading of published illness stories can lead to the "narrative contributions" to medical decision-making that Charon imagines. It is, however, in the realm *beyond* clinical medical encounters that narrative ethics becomes a distinct activity. In the chapters above I have interpreted illness stories with the goal of enhancing the hearing of stories that might not otherwise be heard, or might be treated as "just" conversational with no clinical or ethical import. These stories open up moral dimensions of the lives of ill persons when they are *not* being patients.

If a unique sphere can be claimed for narrative ethics, this sphere is illness outside patienthood. Clinical ethics is concerned primarily with professional and institutional obligations to patients. But with the increasing proportions of chronic and degenerative diseases, more ill people spend more of their time not being patients; what I call "the remission society" grows. The ethical questions for members of the remission society are not adjudications of health care conflicts but *how to live a good life while being ill*. The cornerstones of this "good life" involve those same decisions that I identified with respect to living in a body, especially desire. The core ethical questions concern what the ill person should want for herself and for others. As ethical questions, desires become responsibilities: what is it *good* to want for oneself and others?

Medical and other professional caregivers are hardly excluded from this narrative ethics, but neither are they involved in their core professional capacities. As professionals, their concern is closer to what Charon describes: helping *patients* live good lives with the aid of appropriate treatments. Medical work, however, has another side, when the professional-patient relationship becomes a relationship of two persons.

Arthur Kleinman describes being asked by a patient who had suffered multiple losses and was seriously ill, "Can you give me the courage I need?"<sup>27</sup> The question is not a request for medical information or treatment; Kleinman hears himself being called to a moral relationship in Levinas's sense of being *for-another*. However he responds to this question, his medical expertise is minimally relevant. The woman is asking Kleinman if he, as a person, can be *for* her, as a person. The ethic of his response involves not a health care conflict—the paradigm occasion for clinical ethics—but the assumption of a profound moral commitment.<sup>28</sup> Narrative ethics guides people, whether ill or healthy, lay or professional, in the moral commitments that illness calls them to.

Thus I am less concerned with the significant narrative contributions to ethics that Charon describes so well. Nor am I concerned with narrative ethics as ethicists' practice of "thick description" of cases.<sup>29</sup> My concern is with ill people's self-stories as moral acts, and with care as the moral action of responding to those self-stories. The *ethics* in narrative ethics is best suggested by Barry Hoffmaster: "The crucial test of a story might be the sort of person it shapes."<sup>30</sup>

Hoffmaster intends this test as a limitation on narrative ethics which he, like Charon, views as incomplete by itself. His valid argument is that this test "presupposes that one already knows the difference between good and bad, or virtuous and non-virtuous persons" (1161). My response, perhaps more postmodern, is that because one *never* knows these differences in advance or even in retrospect,<sup>31</sup> narrative ethics has no inherent limitation that is not shared in any other ethical inquiry. The advantage of narrative is to confront this uncertainty head-on. Narrative teaches that being human is the perpetual finding out of what is good and virtuous, whether the process of that moral inquiry is called the examined life or reflexive monitoring.

The moral imperative of narrative ethics is perpetual self-reflection on the sort of person that one's story is shaping one into, entailing the requirement to change that self-story if the wrong self is being shaped. Thus awareness of the general type of narrative one is telling or responding to—restitution, chaos, or quest—is a crucial beginning.

Narrative ethics is complete, within its sphere. This sphere is not clinical adjudication but personal becoming. Narrative ethics is an ethics of commitment to shaping oneself as a human being. Specific stories are the media of this shaping, and the shaping itself is the story of a life.



Thinking *with* stories is the basis of narrative ethics. The physician may take her patient's story seriously, but only to hear a truth that the patient himself cannot tell. The corrected story becomes the "case." Cases are objects of professional scrutiny. In presentations of cases, professionals talk *about* people's stories; the story is an object of analysis, and professionals believe themselves to be the only ones qualified to carry out this analysis.<sup>32</sup> If Kleinman had heard his patient's question, "Can you give me the courage I need?" exclusively as a professional, his response would have been to wonder about possible medication for a diagnosable depression. He would have missed the opening to a relationship.

Thinking with stories means joining with them; allowing one's own thoughts to adopt the story's immanent logic of causality, its temporality, and its narrative tensions. Narrative ethics seeks to remain with the story, even when it can no longer remain inside the story. The goal is empathy, not as internalizing the feelings of the other, but as what Haberm calls "resonance" with the other.<sup>33</sup> The other's self-story does not become my own, but I develop sufficient resonance with that story so that I can feel its nuances and anticipate changes in plot.

But the primary question is not how to think with the other's story; it is how to think with your *own* story. Or, how is narrative ethics a practice of reflexive monitoring for the ill themselves? As I hear Native Canadians speak of their stories and what it means to live in an oral culture, I am struck by their *retelling* of stories. When stories are retold, the point is not what is learned from their content, any more than the point of Gail's experience can be stated in so many analytical points. The point is rather what a listener *becomes* in the course of listening to the story. Repetition is the medium of becoming. Professional culture has little space for personal becoming. Young doctors are not trained to think of the careers ahead of them as trajectories of their own moral development, which is one reason why they have trouble with an expanded notion of service.

Professionals understand stories as something to carry a message away *from*—as in, "What did you learn from that history?" The professional, as paradigmatic modernist, is always moving on, the sooner to get to the next thing and move on from that. The danger for ill people is that they are often taught how to be ill by professionals. Illness is not presented to the ill as a moral problem; people are not asked, after the shock of diagnosis has dulled sufficiently, what do you wish to *become* in this experience? What story do you wish to tell of yourself? How will you shape your illness, and yourself, in the stories you tell of it?

The first lesson of thinking with stories is not to move on once the story has been heard, but to continue to live in the story, *becoming* in it, reflecting on who one is becoming, and gradually modifying the story. The problem is truly to *listen* to one's own story, just as the problem is truly to listen to others' stories.

Thinking with stories also requires attending to how a story is *used* on different occasions of its telling. As the same story is repeated on different occasions over years and decades, people



hear it differently. In its repetition, the story provides continuity between different occasions of the body-self's life.

At some point, however, continuity gives way to unfathomable difference. "In the end, he imagines that he might live a different story and that words have taken him only to the threshold of my story, before the door that opens on my story," writes Martha Nussbaum, quoting Samuel Beckett's *The Unnamable*.<sup>34</sup> What the story teaches is that there is always another story, and other stories have always been possible. One meaning of this lesson is that life is lived in decisions, each setting in place a different way of telling the story. Because these decisions have consequences—the plot cannot be reversed at will at any point—they are moral.

Thinking with stories means that narrative ethics cannot offer people clear guidelines or principles for making decisions. Instead, what is offered is permission to *allow the story to lead in certain directions*. Medical workers need this permission. When physicians in an intensive care unit present a case to me, I can only ask questions about who their patients are, how the present illness fits into the pattern of these people's lives, and where both the physicians and the patients' families see their pattern leading. In intensive care situations the ill person is often mute, as an effect of disease, medication, or life-support mechanisms. But despite being unable to speak to the patient, the medical staff usually have a good idea of the story. I offer them permission to invoke this narrative knowledge to make professional decisions.

Some of the most unfortunate medical decisions are made when there is a breakdown in the continuity of relationship and of story. In his early exploration of narrative ethics, Steven Miles wrote of an elderly nursing home resident whose imminent death precipitated transfer to a hospital where no one knew her. The nursing home staff who did know her wishes were no longer making the decisions, and life-support mea-

sures were instituted that the woman would not have wanted. Physicians who knew nothing of her life could not try to achieve the kind of death that made sense as the culmination of that life.<sup>35</sup>

But ill people do not tell their stories so that medical workers can make decisions. Self-stories are told to make sense of a life that has reached some moral juncture. Nearing the end of his "sort of memoir," Stewart Alsop writes that he is about to turn sixty, after an interval of almost thirty pages he adds that "perhaps this is a good time to bow out."<sup>36</sup> In order to think with Alsop's story, and perhaps to be guided by that story in some future decision, narrative ethics might pose this question: What is said in between these statements to connect them, and what narrative work does Alsop have to do to make the latter follow as a *sequitur* to the former? Other people might consider life to be beginning a new stage at sixty and thus interpret illness differently.

In between observing turning sixty and accepting bowing out, Alsop tells a series of anecdotes from his experiences as a young officer in World War II. He marries an even younger English woman, who is happily still his wife as he writes. They enjoy a honeymoon that was as lawless as London during the bombing could provide; its memory becomes more mythic because of that bombing. Alsop leaves his bride to participate in a failed parachute landing in occupied France, and by a series of remarkably lucky coincidences he escapes being captured. These stories connect turning sixty with bowing out, and they establish a direction for ethical decision-making, by rendering the incoherence of Alsop's disease and imminent death coherent.

Alsop was not supposed to end up dying at sixty; leukemia is a tragic and frustrating imposition on his life. His wartime anecdotes address the incoherence of cancer in at least this way: if Alsop is to die at sixty, he has had an extraordinary sixty years.



He might well have died in the London bombing or in the parachute raid. If he lived through these by a series of accidents, there is no particular injustice to his dying now because of some equally accidental events in his bloodstream. The continuity of Alsop's self is reestablished as the story of someone who has always lived by his luck. If the event of his illness remains tragic, it nevertheless takes on an acceptable level of rightness.

The wartime stories reinforce this rightness in another way as well. These stories have probably been told and retold in the Alsop family. The stories are the core mythology of Alsop's marriage, its touchstone. I imagine them having been used on different occasions for different purposes: sometimes as diversions and entertainments, other times to remind Alsop and his wife who they were together and what they had come through, yet other times to teach children who their family is.

Now Alsop is telling the old stories on what may be his last occasion. The simple fact that they can be told again, that they still fit the present circumstances, places those circumstances within the continuity of the family's lives together and gives illness a sad but acceptable rightness. Dying is *not* a loss of the old map and destination; in the context of the familiar stories, dying is accepting where the map always led.

Alsop follows his remark about bowing out with the last of many anecdotes concerning Winston Churchill that he tells throughout the book. He describes the old Churchill attending parliament for the last time. To the embarrassed hush of his younger colleagues, he slumps over his desk, dozing. Alsop paints a pathetic picture of the hero as relic, adding the fine epitaph that he has already applied to several others: "He should have died heretofore."<sup>37</sup> Churchill as metaphor becomes the storyline that Alsop rejects for himself, better to bow out than to doze off.

Stewart Alsop is not a "case" to be described as "acceptance"

or "denial" or any other reduction of his capacity for moral choice about who he is and how he wants to live. His story, which is really a complex of stories interrupting each other, shows the paucity of such labels. For purposes of ethics, what counts most is that Alsop tells a self-story that gives his dying a sense of rightness for himself and, I hope, for his family as well.

Telling his story is the final discharge of his responsibility. For a caregiver who would enter into a relationship with Alsop, the story invites *becoming the sort of person* who could act within the story in ways that Alsop would appreciate. In terms of the question asked Kleinman, Alsop tells himself how to find the courage he needs, and he shows others where to find the strength to care for him. His story provides for Diamond's "narrative of relationships" between himself and his family and caregivers.

Narrative ethics takes place in telling and listening. There is no such thing as a self-story if that term is taken literally; only self-other-stories. The stories we call "ours" are already bits and pieces we have gathered from others' stories, and we exist no less in their "self"-stories. Ultimately narrative ethics is about recognizing how much we as fellow-humans have to do with each other. As we grope toward some unknowable vision of the good and virtuous, cutting and pasting stories, borrowing and lending along the way, we become communicative bodies.

#### RECURSION AND RISK

The communicative body, as I wrote when introducing it, is not only an ideal type but an *idealized* one; the ideal of the communicative body grounds criteria for ethical action. Becoming a communicative body is an ethical end, a telos, for a life to aspire to. Because this telos is never fully achieved short of being a Bodhisattva or a Christ, the communicative body is not a

fixed state but a *recursive process*. Recursion is what is involved in “pulling yourself up by your own bootstraps”; gravity-defying as that image is, such processes happen.

The communicative body creates itself, recursively, as an ideal that guides choosing which actions can bring itself into being. The simplest analogy is faith: one must have faith in order to be faithful, and being faithful increases the quality of faith. Like faith, the communicative body is always an incomplete project; recursive processes continuously loop, never conclude. I refer to the communicative body using the modernist term “project.” Modernist projects imagine their endings before they are begun; their object is completion because modernism seeks to move on to another project as quickly as possible. Postmodernity prefers discovering the nature of the project during the activity of carrying it out.<sup>38</sup> Thus what the communicative body tries to do is to become a communicative body.

The nature of the project changes in postmodern times, but people should not give up on projects.<sup>39</sup> When people lose “The Project” that Frederick Franck calls becoming more fully human, then postmodernity is a moral void. Franck asks, “Could the Meaning of being born human be, to become Human?”<sup>40</sup> This question is too practical to be called rhetorical, but it is too vast to provide for an answer. As a project, it is recursive. Like a story, it can only be lived. What Franck calls becoming Human, I call the communicative body.

The illness story begins in wreckage, having lost its map and destination. The story is both interrupted and it is about interruption. In the illness stories what begins as the breakdown of narrative—life’s interruption by illness—is transformed into *another kind* of narrative. I recall one of my great aunts commenting on a piece of popular music. The band was playing the time signature wrong, she said, but they were playing it so consistently wrong that it became their own time signature. A life

with serious illness is out of time, if time is measured by the metronome of social expectation. The illness story creates its own time out of interrupted time, or its own coherence out of incoherence.

One reason I return to Stewart Alsop and Audre Lorde is the jumpy interrupted quality of their writing. In Alsop the interruptions appear seamless; the book transforms interruption into culmination. Lorde gives her interruptions a rougher edge; she wants to preserve the grating immediacy of illness. Both, in their respective ways, are *reclaiming* interruption as theirs to tell.

Only the communicative body can reclaim interruption because only it associates with its own contingent vulnerability. The communicative body makes this contingency the condition of its desire, reaching toward others who share this vulnerability. Here again is recursion: the body grounds the story that in its telling allows the body to realize itself. The body “realizes” itself in the dual senses of gaining self-reflection and of making itself real in action. “Making itself real” figures most significantly in the achievement of character.

The body’s story requires a character, but who the character is is only created in the telling of the story. The character who is a communicative body must bear witness; witness requires voice as its medium, and voice finds its responsibility in witnessing. What is witnessed is memory, specifically embodied memory, a memory of experience now written into the tissues. St. Paul, whose attitudes toward sexual embodiment are not popular, nevertheless expressed the embodiment of witness passionately. Paul knows he witnesses through his body: “In stripes, in imprisonments, in tumults, in labours, in watchings, in fastings” (2 Corinthians 6:5). Paul’s ministry to bring others into the body of Christ, is effected through rendering his own body available to suffering. This archetypal affinity of witness and bodily suffering cannot be evaded: Paul’s unpopular mes-

sage is that the responsibility of some is to find themselves called to the nexus of this affinity.

The same voice of embodied witness is heard in Nancy Mairs's writing. She tells a story about an editor of one of her earlier books, whose enthusiasm she had to dampen. Explaining why her book's sales potential would be limited, Mairs tells her editor, "The subtext here is that we are all going to die, and that that's all right. It's not a message that will attract readers in droves." But like any authentic witness, she had no choice in what she wrote: "I had to risk a messenger's death then and still must do: *We are* all going to die. And it is all right."<sup>41</sup>

The quest story accepts illness as a calling, a vocation. This vocation includes responsibility for testimony, and testimony implies risk: dying a messenger's death, as Mairs calls it. Risking one's body implies an ethic. The value of this ethic, its witness, is to speak outside of the language of survival. Modernity disallows any language other than survival; the modernist hero cannot imagine any other way to be, which is why physicians are often genuinely baffled by criticisms. People in post-modern times need different languages of meta-survival with various messages that death is all right. Clinical ethics needs these messages.

Audre Lorde, who brought a poet's sense of language to the question of witness, wrote that she and other women together "examined the words to fit a world in which we all believed."<sup>42</sup>

Later she writes of translating "the silence surrounding breast cancer into language and action" (61). To make the world she believes in a reality, Lorde must find the words to fit that world.

Lorde expresses most directly the quality of moral humanity that is realized by all those who tell illness stories. At the beginning of her book she writes of her "terror" that if she opens herself to memories of illness, she "might also open myself again to disease." This risk informs her decision to write. Here is the voice of the communicative body, turning interruption

WV

into witness. "I had to remind myself that I had lived through it, already. I had known the pain, and survived it. It only remained for me to give it voice, to share it for use, that the pain not be wasted" (16).

This witness is uniquely that of Audre Lorde, but Audre Lorde could only be who she is in postmodern times, and these times are formed by people like Audre Lorde. Her narrative becomes the ethic of her times.