The Wounded Storyteller

Body, Illness, and Ethics

SECOND EDITION

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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 postmodern times. Many physicians seem less interested in being heros, 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 Hilfiker, in his life as well as his writing, is another.[23]

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.[1] 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 Charmaz. 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.[2]

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, whatever has happened: "Even if I'd gotten sick from the chemo, I wouldn't remember."[3] 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."[4] 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 myalgic 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."[5] 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.[6] 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."[7]

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."[8]

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.[9] Note that for most mortals this gesture requires limits: even the Samaritan goes on about his business, paying the inn keeper 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."[10]

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.[11] 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."[12] 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.[13] 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.[14] 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 retrospectively, 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.[15]

What is needed, specifically in clinical work and more generally 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.[16] 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 naivete informed modernity from its inception? The immediate relevance of this question is that the same naivete 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 reinstitute 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: Hilfiker writes of the poorest sections of Washington, D.C. that "health is not so much a question of disease."[17] Hilfiker 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.[18]

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. Hilfiker 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. Hilfiker 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."[19] 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."[20] 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 quested 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-

workers can engage in serious communicative play (185). To borrow terms used by Elliot Mishler several decades ago, within the creative space of borrowed stories, the voice of medicine can be expressed in the voice of the lifeworld, and those whose ears are attuned to the lifeworld become able to hear medical speakers.[16]

Adults borrow more diversely and subtly than children, but whether they borrow any less significantly is an open question. I return to my epigraph from Northrop Frye: even the king must acquire his imagination of kingship from poets. Most people's poets are the creators of mass media stories. If I feel tempted to think that only children indigenize cartoons and their characters, I remind myself of visiting a distinguished academic colleague who was dying. Among the objects that he and his wife brought to his hospital room was a cartoon action figure. I commented on it and they said, laughing, that yes, it was important to them. I wish I had pursued why, but the conversation went elsewhere. We could find a creative space for interaction without that resource, but the resource was waiting, in the background, for when it might be needed.

Most people's stories, I have come to believe, are only rarely narratives in the fullest sense of having an identifiably coherent plot, character types that have recognized roles within that plot, a dramatic tension, a predictably consistent emotional tone, and an expected or desired ending. The stories people enact remix borrowed fragments that are retrofitted as resources for individual expression and dialogical interaction. Buzz Lightyear accoutrements are, in adult terms, conversation pieces that provide entry points into a common space in which people can relate to each other when relating

16. Elliot Mishler, *The Discourse of Medicine: Dialectics of Medical Interviews* (Norwood, NJ: Ablex, 1984).

is hard to do. Their stories emerge from the shifting pattern of those relationships.

Broken Narratives

When I speak about illness and storytelling I am often asked how to include people whose physical or mental capacities make it difficult or impossible for them to tell the sort of stories that fill *The Wounded Storyteller*. The health psychologist Lars-Christer Hydén, with various collaborators, has expanded our ability to recognize how much storytelling is done by people who seem incapable of telling stories.[17]

Narratives become broken because tellers' bodies are somehow broken, lacking capacities essential for storytelling, such as speech or memory. The difficulty of storytelling in the face of such incapacities reminds us that bodies are not only the topic of illness stories. Bodies tell stories, and stories enact imaginations of how to be different bodies—young or old bodies, fit or ill bodies. *The Wounded Storyteller* emphasizes the embodiment of stories; listening to stories requires "hearing the body in the speech" (27). "People telling illness stories do not simply describe their bodies," I write. "Their bodies give their stories their particular shape and direction" (27).

Telling broken narratives requires someone else's collaboration. This co-constructed storytelling is not unique to broken narratives. Any storytelling involves more than the storyteller's body. *The Wounded Storyteller* argues that storytelling is a medium through which "dyadic bodies" recognize that the

17. Lars-Christer Hydén and Jens Brockmeier, eds., *Health, Illness, and Culture: Broken Narratives* (New York: Routledge, 2008). Among Hydén's many articles, see especially Hydén and Eleonor Antelius, "Communicative Disability and Stories: Towards an Embodied Conception of Narratives" *Health* 15, no. 6 (2011): 588–603; and Hydén, "Narrative Collaboration and Scaffolding in Dementia," *Journal of Aging Studies* 25 (2011): 339–47.

other's body "*has to do with me, as I with it*" (35, original emphasis). But in most of the actual stories retold in this book, the "other" of the dyadic relationship is a generalized other, not a specific person. Stories are not presented as collaboratively co-constructed.

Hydén provides transcriptions of orally co-constructed storytelling in which the body of one participant—the person suffering from dementia or brain injury—is a trouble that other participants must constantly accommodate. The stories that are co-constructed most often focus on shared memories. One partner, a well spouse or a health-care worker, leads the ill person through a story by means of a sequence of questions and cues that can be responded to in short segments of speech. The well person connects the fragments of the ill person's speech into a recognizable story. The work of witness here lies not in the content of the story; the story is not about illness. Rather, the act of co-constructing the story witnesses the continuing narrative capacity of the person who is severely incapacitated.

Hydén turns to the philosopher and bioethicist Hilde Lindemann to show that what is at stake in broken narratives is continuing to uphold the *moral personhood* of people whose limited mental capacities put the recognition of their personhood in jeopardy.[18] Summarizing Lindemann's description of her own childhood with her radically disabled sister, Carla, Hydén and Eleonor Antelius write, "[Carla] became a person through stories others told about her; her personhood and identity came to life and existed through this storytelling activity."[19] Hydén's observations of couples in which one spouse suffers from dementia lead him to describe the well spouse's collaborative storytelling work as a "*deeply moral* activity" that

18. Hilde Lindemann Nelson, "What Child Is This?" *Hastings Center Report* 32 (2002): 29–38; and Hilde Lindemann Nelson, *Damaged Identities, Narrative Repair* (Ithaca, NY: Cornell University Press, 2001).

19. Hydén and Antelius, "Communicative Disability and Stories," 599.

displays "the couple's mutual obligations rooted in a longstanding relationship."[20] In the language of *The Wounded Storyteller*, one spouse creates an occasion that witnesses the continuing moral personhood of the other, when that personhood is threatened by cognitive disability.

In broken narratives the content of the co-constructed stories matters less than the mode of narration. The act of telling the story—telling it against the odds that a story can be told—bears witness to the storytelling capacity of the "broken" person. As far as possible, that person is enabled to speak himself or herself. At the extreme, as in Lindemann's description of her family's life with Carla, the person can only be brought into the story by what others tell about him or her.

Both Hydén and Lindemann begin with the recognition that moral personhood is vulnerable.[21] The boundaries of moral personhood are upheld and contested not only in stories about vulnerable persons. These boundaries are also tested when vulnerable persons participate in storytelling. Their participation is risky. For it to enact moral personhood, the storytelling requires collaboration; that need reflects what is "broken" about the narrative. As Hydén demonstrates in his analyses of collaborative storytelling, what is broken allows levels of repair.

The situations in which broken narratives are told may appear to border on what *The Wounded Storyteller* calls chaos narratives, but the telling is significantly different. The teller of the chaos narrative imagines himself or herself alone; the absence of any possible collaborator is one condition of the

20. Hydén, "Narrative Collaboration and Scaffolding in Dementia," 346. Original emphasis.

21. On the vulnerable moral personhood of disabled people and the need to tell their stories when they cannot speak for themselves, see Michael Bérubé's analytical memoir, *Life as We Know It: A Father, a Family, and an Exceptional Child* (New York: Pantheon, 1996). I discuss Bérubé in *The Renewal of Generosity: Illness, Medicine, and How to Live* (Chicago: University of Chicago Press, 2004).

chaos. Broken narratives presuppose collaboration that enables storytelling. Moreover, chaos narratives and broken narratives involve different temporalities. Chaos narratives are distinguished by an incessant present tense; the repetition of "and then" losses and assaults admits no future, only a perpetual present. The collaborative stories that Hydén reports recollect a past in which both spouses were fully competent storytellers. The storytelling sustains a present in which one spouse, although impaired, remains morally present. In the foreseeable future, stories will have to be told about one of the spouses, sustaining his or her personhood and identity, and that future is being prepared for. Broken narratives represent a degree zero of storytelling, because the real story is the act of telling.

Ethics, Hope, and Courage

At the core of *The Wounded Storyteller*'s conception of ethics is the communicative body. Unlike the other body types that are described (disciplined bodies, mirroring bodies, and dominating bodies), the communicative body is not simply an ideal type—that is, a description of a readily observable, culturally typical way of living. The communicative body proposes a cultural ideal. "Becoming a communicative body is an ethical end, a telos, for a life to aspire to" (163). This statement is preceded by a quote from the philosopher Barry Hoffmaster: "The crucial test of a story might be the sort of person it shapes" (157). I summarize the issue in two non-rhetorical questions for wounded storytellers to ask themselves: "What story do you wish to tell of yourself? How will you shape your illness, and yourself, in the stories you tell of it?" (159).[22]

A person cannot take such questions seriously unless she

22. How people are shaped by stories is the core issue in Frank, *Letting Stories Breathe*.

or he has hope for a possible future. Hope begins with having sufficient confidence that one's life will have a future story. Most hope—other than hope for a miracle—then requires believing in one's capacity to affect how that story unfolds. Beyond those minimum conditions, hope means imagining that life can be at least worthwhile and at best valuable. The person who is hopeful imagines living a life that is, in its own terms, *good*. This life is not as the person wanted it to be. Instead, *good* means life lived in conditions the person did not choose and could not avoid, but this person has discovered value in life lived in those conditions.

Illness support groups like to talk about hope, but I resisted that word in *The Wounded Storyteller*; there is no index entry for *hope*. The talk I heard about hope seemed too often to reflect the most troublesome aspects of restitution narratives. Hope was the specific *hope for* a desired medical outcome, which might be either simply continuing to live regardless of one's physical condition, or the restoration of certain functions and capacities, or regaining the full measure of previous health. I understood such talk as limiting people's ability to find possibilities in a range of potential outcomes. At worst, it set up failure if the specific hope for remission or cure was not fulfilled.

An alternative is to think in terms of what I call *intransitive hope*—that is, hope that has no specified object or objective. Intransitive hope leaves the future open. Cheryl Mattingly describes the form of hope sustained by parents whose children have terminal diseases. These parents require "a kind of flexibility that allows hope for healing even in the face of a grim clinical prognosis precisely because 'healing' itself is not a fixed outcome but *becomes reimagined in the course of illness*."[23] Healing, in this understanding, denotes a range of possible conditions all different from a medical cure. These

23. Mattingly, *Paradox of Hope*, 142. Emphasis added.