

Eight *The Wound as Half*
Opening

SUFFERING AND RESISTANCE

The unspecified topic of this book has been suffering. My early chapters told how the body's suffering during illness creates a need for stories. The middle chapters described narrative structures in which these sufferings become stories. Stories were then understood as a form of testimony: testimony is initiated by suffering, and suffering comes to understand itself by hearing its own testimony. Finally, an ethical practice based on narrative was proposed.

At the center of narrative ethics is the wounded storyteller. What is ethical is found in the story, and the story depends on the wound. Thus my meta-story returns to the wound itself, to suffering.

The most complete definitions of suffering to be offered recently for clinical purposes are by Eric Cassell and Arthur Kleinman. Cassell makes three points with respect to suffering. First, suffering involves whole persons and thus "requires a rejection of the historical dualism of mind and body." The subject who suffers is, in Kleinman's phrase, a body-self.

Second, suffering takes place when a "state of severe distress . . . threaten[s] the intactness of person." This distress can be immediate or imminent, real or perceived: "Suffering occurs," Cassell writes, "when an impending destruction of the person

is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner."

Third, and still emphasizing the person as a whole of mind and body, Cassell argues that "suffering can occur in relation to any aspect of the person."¹

To Cassell's three conditions of suffering a fourth and fifth can be added. Resistance is the fourth condition. Kleinman writes that suffering "is the result of processes of resistance (routinized or catastrophic) to the lived flow of experience." To suffer, a person must not only perceive a threat but must resist that threat. The perception of threat is already a weak form of resistance, since the lived flow of experience is disrupted. But Kleinman's emphasis on resistance opens inquiry to more active resistances than Cassell suggests. Telling stories is a form of resistance. In the story, the flow of experience is reflected upon and redirected; resistance through the self-story becomes the remaking of the body-self.

The fifth condition of suffering is its social nature; the prior four all depict suffering as personal, taking place within the body-self. But Kleinman further argues that suffering is "both an existential universal of human conditions *and* a form of practical and, therefore, novel experience that undergoes great cultural elaboration in distinctive local worlds."² As I wrote in the first chapter of this book, people tell uniquely personal stories, but they neither make up these stories by themselves, nor do they tell them only to themselves. Bodies and selves are, in Kleinman's phrase, culturally elaborated.

All illness stories share a common root in suffering as "an existential universal of human conditions"; this commonality of suffering cuts across worlds of race and gender as well as types of disease. Audre Lorde's story has metaphoric parallels with Robert Murphy's (see chapter 6, "Quest as Self-Story"), but the storylines that elaborate these parallel metaphors reflect

the differences in the two authors' "distinctive local worlds." Similarly, the difference between Lorde's prophetic indignation and Alsop's patrician resignation is hardly accounted for by different personalities, a term that only requires another question. Their stories are the respective products of the worlds each moves through, though these local worlds are also formed anew with each act of interpretation of every story the community recognizes as theirs. Distinctive local worlds elaborate stories, but stories and their interpretation also integrate local worlds.

The story that the local world elaborates may be written or oral. Women organizing themselves in breast cancer activism have found Audre Lorde's book to be a point of mutual recognition. Families recognize what they share as they elaborate oral stories of members' illnesses and deaths. These elaborations become powerful sources of present solidarity as well as models, whether recommended or cautionary, for others' future illnesses. Thus stories are elaborated in local worlds, but stories also elaborate those worlds.

Stories of suffering have two sides. One side, reflecting Cassell's emphases, expresses the threat of disintegration. The chaos narrative is overwhelmed by this threat; disintegration has become the teller's encompassing reality. The other side, reflecting Kleinman's emphasis on resistance, seeks a new integration of body-self. The quest narrative recognizes that the old intactness must be stripped away to prepare for something new. Quest stories reflect a confidence in what is waiting to emerge from suffering.

The resources for creating a new body-self seem uniquely at hand in postmodern times. To be bombarded with stories also means having a variety of stories at one's disposal. Reclaiming has a popular availability. The road of trials can become a journey because the journey motif is available as a self-definition. Postmodern ill people thus live simultaneously with both

the threat of disintegration and the promise of reintegration. The body-self whose foreground is dominated by threat is unmade, but unmaking can be a generative process; what is unmade stands to be remade.

THE SELF UNMADE:
EMBODIED PARANOIA

→ Los'ng My Mind

Illness has always threatened the intactness of mind and body, but in postmodern times this threat takes the particular form I have called *embodied paranoia*.³ The clearest epigram for embodied paranoia is the phrase heard often at public symposia on euthanasia: "I don't want to die on a machine." In postmodern times people fear for their bodies not only from natural threats such as storms or disease and from social threats such as crime or war. People are also threatened by institutions ostensibly designed to help them.

Becoming a victim of medicine is a recurring theme in illness stories. The incompetence of individual physicians is sometimes an issue, but more often physicians are understood as fronting a bureaucratic administrative system that colonizes the body by making it into its "case." People feel victimized when decisions about them are made by strangers.⁴ The sick role is no longer understood as a release from normal obligations; instead it becomes a vulnerability to extended institutional colonization.

I use the term embodied *paranoia* to suggest the internal conflicts that attend this fear of colonization; what is involved is more complex than simple fear for one's body. Even war and crime are "natural" threats in the sense that they are intended to harm and fear of them is natural. Fearing institutions that are designed to help is not natural. This fear is *reflectively* paranoid in its self-doubt about whether it ought to be afraid or has a right to be afraid. The inner conflicts of this reflective para-

noia are evident in the troubling analogy between torture and medical treatment.

Some of my deepest, even haunted, discussions with other members of the remission society have been attempts to sort out whether chemotherapy is a form of torture. We know that in most "objective" respects the two situations differ, and we seek only to make sense of our own memories and fears, not to appropriate the far greater suffering of torture victims. But chemotherapy fits with disturbing ease into Elaine Scarry's definition of torture as "unmaking the world."⁵ The realization that obsessed me during chemotherapy was how easily every strength I thought I had could be reduced to weakness. I was unmade as my mind sought to hold onto the promise that this treatment was curing me, while my body deteriorated: my intactness, my integrity as a body-self, disintegrated.

"I never thought of myself as ill with cancer," says Marcia in her story. "I was never sick before or after the mastectomy. . . . Not true of chemo; chemo was hell. Chemo was not therapeutic; it produced illness. I hated it. I cried every time I had it and did not trust it at all. I felt so vulnerable."⁶ The voice heard here is someone undergoing a kind of torture. In chemotherapy, Marcia's body becomes what Scarry calls "the agent of [her] agony."⁷ Her body is, in the treatment, "made to be the enemy" (48). Physicians believe chemotherapy will cure Marcia; she does not. As Scarry writes of torture, "the body belongs to a person other than the person whose body is used to confirm [the belief]" (149). Yet people in chemotherapy also believe that they are being *cared for*. Or they believe they ought to believe this, or they have given up believing but still confront others who insist that their treatment is care. The self is unmade in the opposition of the mind's message of care and the body's message of pain.

Chemotherapy is hardly the only occasion for comparing medical treatment to torture. Intensive care residents ob-

served by Zussman describe their work as torture and feel tortured themselves by what they believe their work requires.⁸ Zussman, Klass, and Quill all report the “cheechee” story as standard medical black humor that illustrates physicians’ attempts to neutralize the grim realities of their work.⁹ The point of the “joke” is to make its telling as grotesque as possible; without those flourishes, the basic plot describes two or more explorers captured by savages. The first explorer is offered a choice of death or cheechee. Not knowing what the latter means, he chooses it and is horribly tortured to death. The second explorer is given the same choice and chooses death. The chief is puzzled at his decision. “All right,” he says, “but first, a little cheechee.”

Surrendering one’s body to the medical world of “limited liability” is frightening: cheechee does happen. The fear of cheechee is complicated, and conflicted, because the high-tech medical world remains the perpetual source of the hope that keeps restitution stories going.¹⁰ Marcia lives to tell her story, although even years later she does not give much credit to chemotherapy. High-tech medicine offers real hopes, and resistance to “dying on a machine” is itself resisted by wanting what that machine might offer. The resistances that Kleinman places at the core of suffering are resistances within and against other resistances.

Embodied paranoia is not knowing what to fear most, and then feeling guilty about this very uncertainty. The patient knows full well that most of those inflicting the torture are sincerely trying to help; thus he cannot hate them, but neither can he offer them the gratitude that the intensity of their efforts seems to demand. Max Lerner reports being mildly reprimanded by his student-physician son for his ambivalent gratitude toward the physicians who administered his chemotherapy. Lerner takes the point but retains his ambivalence: “I

wish however that those who came up with Adriamycin and Cytoxan for my advanced large-cell lymphoma might have hit upon a less bruising mixture,” he writes.¹¹

The other source of Lerner’s ambivalence is that, in chemotherapy, medicine appropriates his healing to itself. Lerner’s healing is *his* story, and he wants it back: “We don’t know how much of the healing was due to the chemical, how much . . . to the patient who was fighting not only the tumor but, to a degree, the doctors and even the chemotherapies addressed to the tumors” (57). Lerner’s embodied paranoia is not fear of medicine, yet his reflection on his need to fight his doctors shows a profound resistance. How he fights is not specified; I would say Lerner needs to keep the fight his own. Even someone so secure in his own voice senses an appropriation he must resist. Other post-colonial selves hear the medical narratives that claim to tell their stories for them as reflecting the interests of corporations, bureaucracies, and hyphenated “industrial” complexes of different kinds: medical care becomes the health care industry.

But if the post-colonial self no longer wants itself to be told in narratives from elsewhere, neither does this self have substitute narratives of its own immediately available. In postmodern times subjection to colonizing narratives—the oppressive side of Keen’s condition of being bombarded by stories (see chapter 3)—can never be fully escaped.

Disease and treatment happen to a body-self that is already substantially unmade by a combination of embodied paranoia and post-colonial skepticism. With respect to Cassell’s main condition of suffering, postmodern times place the embodied self in a *perpetual* condition of multiply threatened intactness. Disease is all too effective as a journalistic metaphor for social problems—crime, poverty, drug use, inflation—because disease metaphors tap the intuitive connection between internal

threats to the body and external threats. Embodied paranoia reflects a blurring of internal and external: everything has potential to threaten.

When illness happens, the disease carries a metonymic overload that compounds suffering. The disease is fully real in itself; the tip of the iceberg is still real ice. *And* the disease is a part standing for a larger whole, the external threats. Some of these threats, like fear of "cheechee," are related to the disease, while other fears of being made a victim have no necessary relation but are summoned up nonetheless. The losses brought by the disease open up extensive fears that one's intac-tness has always been more imaginary than the self has wanted to believe. *critical text*

Selves truly are unmade in these complex fears, but the same unmaking processes can elicit different responses. If one cannot control what happens, these events can still be lived in different ways. Paul Ricoeur intimates a sort of resolution when he writes of "becoming the narrator of our own story without becoming the author of our life."¹² In the context of Ricoeur's biblical hermeneutics, his statement seems to refer to faithful acceptance of divine authorship. In postmodern times, becoming a narrator of one's own life implies an assumption of responsibility for more than the events of that life. Events *are* contingent, but a story can be told that binds contingent events together into a life that has a moral necessity.

REMAKING THE BODY-SELF

Remaking begins when suffering becomes an opening to others. Emmanuel Levinas presents perhaps the darkest vision of suffering as what I have called monadic self-enclosure. Because pain "isolates itself in consciousness, or absorbs the rest of consciousness," suffering is, literally, a dead end: "useless, 'for nothing' . . . this basic senselessness."¹³ Yet these

very depths seem the precondition for a new impulse. Levinas describes this remaking:

Is not the evil of suffering—extreme passivity, impotence, abandonment and solitude—also the unassumable and thus the possibility of a half opening; and, more precisely, the possibility that wherever a moan, a cry, a groan or a sigh happen there is the original call for aid, for curative help, for help from the other ego whose alterity, whose exteriority promises salvation? . . . For pure suffering, which is intrinsically meaningless and condemned to itself without exit, a beyond takes shape in the inter-human. (158)

The orientation that Levinas calls the inter-human becomes possible—or as I suggested in the first chapter, once again becomes news—at a precise historical moment, "the end of a century of nameless suffering" (159). Levinas enumerates "two world wars, the totalitarianisms of right and left, Hitlerism and Stalinism, Hiroshima, the Gulag, and the Genocides of Auschwitz and Cambodia" (162), and since he wrote the list goes on. At this historical moment when consciousness is overwhelmed with "unjustifiable" sufferings, the sense of suffering splits.

On one side is the suffering that Levinas calls, in the above quotation, "unassumable," which I take to mean the suffering that the individual cannot assume as his own; he cannot give his own suffering any meaning, and no other person can assume this suffering for him. This "*suffering in the Other*" can only be witnessed as "unpardonable" (159). This suffering "solicits me and calls me," eliciting in me "a suffering for the suffering." Thus a second order of suffering begins: "a just suffering in me for the unjustifiable suffering of the Other." This just suffering can "take on a meaning." This meaning is "attention to the Other," which Levinas calls "the very bond of

human subjectivity, even to the point of being raised to a supreme ethical principle" (159).

Out of this profoundest moral darkness, a new light—even if the new light of an old ethic—begins to shine. Suffering becomes "the possibility of a half opening" to the other. As I read Levinas, this opening does not give meaning to the nameless suffering, but neither does that suffering remain useless. The meaning and the just suffering are experienced by the witness. The original, "unassumable" suffering has use in calling the witness to these ethical feelings, but Levinas seems too realistic to believe that it is mitigated.

Levinas's argument suggests a stronger connection between the chaos narrative and the quest narrative. The chaos narrative is the unassumable, nameless suffering. Chaos suffering is "useless" because the chaos story cannot be told, because it is an anti-narrative, a non-self-story. The quest narrative is the just suffering, what Levinas calls "my own adventure of suffering" (159). But the adventure, or journey, is of course not my own. The journey begins as the hero's own, but what the hero learns throughout the journey is that she suffers for others. The boon is a vision of the inter-human. The hero who has returned embodies this "supreme ethical principle." The Bodhisattva and the Christ both return, and their return is the measure of their love of the world.

Most heroes are called to the quest not by their recognition of the suffering of others, which seems to be what calls Levinas, but by their own suffering. The journey is a process of learning that their own suffering touches and is touched by the suffering of others. The "inter-human" opens when suffering becomes the call and response implicating self and other.

One of my conflicts in writing this book was whether to include types of suffering other than illness, particularly whether to include Holocaust sufferings. To discuss these sufferings beside illness necessarily implies comparability or comparison.

There can be no comparison of levels of pain, of the impotence and abandonment, or of the cries, groans, and sighs that Levinas refers to. Comparisons are impossible either between the ill and the nameless sufferings that Levinas enumerates, or among the ill themselves.

Suffering becomes useless precisely because any person's suffering is irreducible: being nothing more than what it is, suffering can have no meaning. Irreducible sufferings can never be compared. But here the argument turns on itself. Once it is understood that sufferings cannot be compared, then it is possible to speak of different sufferings in the same story, because there is no comparison. Beyond comparison, the "existential universal" of suffering requires that different forms be spoken of. Where there can be no comparison, there is metonymic overload. Each suffering is part of a larger whole; each suffering person is called to that whole, as a witness to other sufferings.

I also realize that part of my hesitation to speak of illness and the nameless sufferings in the same text is an aspect of my own embodied paranoia. I have this idea that illness is always cared for, or at least ought to be cared for, and thus it cannot be compared to sufferings that are humanly intended to inflict pain. But body-selves are unmade in all sufferings. If suffering is pain that isolates itself in consciousness, absorbing the rest of consciousness, then the true difference is not between suffering that occurs in a hospital and suffering in a concentration camp. The difference is between suffering that has its cry attended to, and suffering that is left in its own uselessness. Again the argument turns on itself: certainly among sufferings illness is far more often responded to; the cry from the camp is stifled.

Levinas's most important lesson is that for everyone rendered "other" by suffering who speaks, perhaps in that act of witness some nameless suffering is opened. The suffering per-

son is always the other, reduced and isolated. To tell any story of suffering is to claim some relation to the inter-human. Any testimony is a response to the half opening of nameless suffering.

I value Levinas's qualification that the opening is only a "half opening." The quest of finding meaning in suffering can only be undertaken oneself; to prescribe this quest to others is arrogance. Levinas requires us to remember the suffering that remains useless, nameless, and untouched; useless but also, in its call to others, not useless. The tragedy is that such suffering will never hear the response to its call. The chaos story remains monadic in its self-enclosure, even as the quest story—the suffering that has found terms to assume what it suffers—calls out to it.

The call for illness stories is more than what I described it to be in chapter 3. There I wrote of the practical imperative to tell people what was happening, and the existential imperative to find a new map and destination. Levinas requires we hear a third level of call: the opening to the inter-human. The Other who suffers now speaks but cannot hear his own speech, because to be able to hear oneself is already to have found some meaning in useless suffering. But this speech that cannot hear itself remains a call for aid. The voiceless are given a voice.

I also suggested above that the parent for the quest story is Nietzsche, who named his pain and thus gave it a use, making it an opening for himself and to others. I now add a much earlier parent, the biblical patriarch Jacob who wrestled with the angel, was wounded in his hip, and persevered until he received a blessing (Genesis 32:24–30). Jacob's story contains the elements of any illness story that brings suffering out of uselessness.

First, the self is formed through *uses of the body*. Jacob wrestles with all his body, and he is wounded in his body. He leaves the scene with a limp, which is the stigmata of his encounter

with the divine, and with a new name, Israel, which is the boon of this encounter. The boon is purchased with the wound; the self is thus found through the body, hence the body-self.

Second, the body-self is also a *spiritual* being. Jacob's story is about the complexity of resistance to what readers of the story can only call God. God is the mystery of what Jacob wrestles with; this mystery is not named until the end of the story. Whether Jacob knew at first who he wrestled with, who his attacker was, is unclear.¹⁴ Jacob's impulse toward what is retrospectively known as God is curiously expressed as resistance: Jacob contests the divine. What is being contested remains ambiguous: is Jacob wrestling a blessing out of the angel, or is the angel wrestling the petition for a blessing out of Jacob? Or is Jacob wrestling in order to be wounded, since that wound will finally open him to the spiritual aspect of life he has resisted ever since he stole the blessing that belonged to his brother?

Third, the wounded, spiritual body-self exists in moments of *immanence*. Humans are not alone, even if being with God is a process of resistance, contest, and wound. In his embodied resistance and through his wound, Jacob discovers that he has been on holy ground. As he leaves he "called the place Peniel," which is translated as "the face of God." The face of God was not self-evident in the place when Jacob went to sleep there, deeply troubled and as often in his life, running away. The holiness of the ground is created in the wrestling that sanctifies the ground.

Later in Levinas's essay on suffering he takes up the question of theodicy: how can a just and powerful God allow such sufferings? He responds: "To renounce after Auschwitz this God absent from Auschwitz . . . would amount to finishing the criminal enterprise of National-Socialism, which aimed at the annihilation of Israel and the forgetting of the ethical message of the Bible, which Judaism bears."¹⁵ Peniel is a place where

Jacob may have thought God was absent; he learns in his wounding that God is present. In Peniel, Jacob is renamed Israel.

Finally, the spiritual body-self assumes an ongoing *responsibility*. Jacob leaves Peniel to be Israel. The postmodern Jacob describes sanctification as proceeding recursively: resistance is never worked out once and for all; the self must continue to wrestle and continue to be wounded in order to rediscover the ground it now stands on as sacred. *To be is to wrestle with God.*

The illness story accepts what has happened as an ongoing responsibility. Oliver Sacks's claim to be changed is a commitment to continue a process of change. Audre Lorde is a modern Bodhisattva: she commits herself to continue writing until all who are silent are able to speak. Sacks's and Lorde's quest stories are responses to their own moments of chaos; the quest narrative does not stand apart from the chaos narrative but bears witness to it. Nor is the restitution narrative without its responsibility. The call for aid that emanates from nameless suffering is heard by Levinas as "the original opening toward what is helpful, where the primordial, irreducible, and ethical, anthropological category of the medical comes" (158).¹⁶ Cure is life, and life is the fundamental quest.

For wounded storytellers, the return from illness brings the responsibility to teach others so that not only sick people can "know what health is," as Gail says.¹⁷ Neither Sacks, nor Lorde, nor Gail accept their stories without resistance, but their resistance changes. First they resist the call: the disease, or trauma, or chronic pain that is being forced upon their bodies. As their stories develop and as they develop in their stories, they resist the silence that suffering forces upon their bodies. Finally their resistance finds a voice; they make suffering useful. In the wounds of their resistances, they gain a power: to tell, and even to heal.

A complementary voice to Levinas is Rachel Naomi Remen,

writing as both a member of the remission society and as a physician. Remen describes the wounded healer: "My wound evokes your healer. Your wound evokes my healer. My wound enables me to find you with your wound where you have the illusion of having become lost."¹⁸ The wound is a source of stories, as it opens both in and out: *in*, in order to hear the story of the other's suffering; and *out*, in order to tell its own story. Listening and telling are phases of healing; the healer and the storyteller are one. The healing may not cure the body, but it does remedy the loss of body-self intactness that Cassell identifies with suffering. The sufferer is made whole in hearing the other's story that is also hers, and in having her own story not just be listened to but heard as if it were the listener's own, which it is. The illusion of being lost is overcome.

This chapter has said too much and told too little. In narrative ethics, if the point of a story is not clear, don't explain, tell another story. If what it means to take a place in a story that has been resisted is still not clear, then a final story can be told. Dennis Kaye worked as a logger and freight hauler on the coast of British Columbia until he developed Amyotrophic Lateral Sclerosis, sometimes known as Lou Gehrig's disease. He has lived years longer than doctors predicted and has used those years to become a leading spokesperson for people with ALS. Kaye ends the story of his life and illness by describing himself sitting on his deck, almost immobile in his wheelchair, watching the herring school in the bay below. All the creatures of the sea come to feed on the fish: seagulls and terns, eagles, herons, even an Orca cow and two calves.

Even for someone who has spent most of his life around the water, it was an inspiration. At its peak, the whole scene changed from one of frenzy, greed, and pandemonium to one of harmony and balance. It was spring itself—everything in its place—each

creature keeping time to a universal pulse. Even the unseen carnage below the surface seemed to be part of something perfect, and I felt a part of that perfection. The sea was alive. The air was alive. And sappy as it sounds, I felt more alive than I had in years.¹⁹

The depiction is another metaphor that is actually a storyline. In the story of the herring and the pandemonium of animals feeding on them, Kaye both tells a story, and he discovers his own story.

The carnage in the sea is also taking place in Kaye's body, which he says a couple of paragraphs later is "literally starting to fall apart." But Dennis Kaye's grace is to hear the universal pulse within his own dying. He remains fully alive even to his own destruction because what Buddhists would call his "little mind," his personal ego, dissolves into the "big mind." He is dying sooner than later; he learns that his dying will be part of the same springtime when herring school and are eaten. Like Nancy Mairs, he knows that we will all die, and that is all right.

Kaye is not just sitting on his deck, or perhaps he is able to understand what he sees from his deck because of his other work. He organized a support and advocacy organization, ALS Awareness. In this organization Kaye brought together an interpretive community that could understand each other's stories. His story is the forming of this community, which is local in its shared interpretations if not in its geography. The community then elaborates his story, both within itself and beyond. In this elaboration, the community recognizes what it has in common, and it grows. Witness, here as elsewhere, grows in concentric circles.

Dennis Kaye's story has not become a best-seller; as Mairs could tell him, the subtext is wrong. Like most returning heroes, he finds that others do not want his woundedness; they do

not want reminders of their own wounds. But to those who know they are wounded, to members of the remission society, Kaye's story is an opening that heals. In his epiphany of participation in the perfection of the universal pulse, he reenchants his life. To those who listen to his story, he reenchants all life.

The wounded storyteller is a moral witness, reenchanting a disenchanting world. In the voices of these storytellers William James's really real speaks clearly; we are reminded of the duties owed to the commonsense world. Postmodern times may be pandemonium, but they are not a void. Illness stories provide glimpses of the perfection.