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The
Wounded
Storyteller

BODY,
ILLNESS,
AND
ETHICS

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tinguishes itself from other body types. By specifying the communicative body as the undertaking of an ethical task, I hope to orient an ethics of the body. Reflexive monitoring requires an ideal against which the progress of the body-self can be measured.

The next chapter turns to stories, to their role in illness and their context in postmodern times. Chapters 4 through 6 propose three basic illness narratives which most actual stories exemplify. These narratives are not presented as linguistic structures, but as objectifications of the bodies that tell them. The narratives are shown to be media for body-selves to express and reflexively monitor themselves.

My thesis is that different bodies have “elective affinities” to different illness narratives. These elective affinities are not deterministic. Bodies are realized—not just represented but created—in the stories they tell. This realization can and should be reflexive: by telling certain stories, ethical choices are made; the choices in turn generate stories. Common sense understands people as having some responsibility for their stories and for their bodies. Common sense is less accustomed to the possibility of exercising that responsibility for bodies *through* stories.

One road to the achievement of the communicative body is through storytelling. The final chapters, on testimony and ethics, develop the communicative body as an ethical ideal for living with illness.

Three

Illness as a Call for Stories

“We are forever telling stories about ourselves,” writes the psychoanalyst Roy Schafer.¹ Schafer’s work is seminal in understanding how selves are perpetually recreated in stories. Stories do not simply describe the self; they are the self’s medium of being. Where the last chapter emphasized the body part of the body-self, this chapter emphasizes the self. In particular, it considers selves and stories from the perspective of illness: how is illness an occasion for stories; what needs do the ill address in their stories? The chapter concludes by inquiring into the affinity between illness stories and postmodern times.

NARRATIVE WRECKAGE

Becoming seriously ill is a call for stories in at least two senses.² The first is what Judith Zaruches implies when she writes of losing her map and destination. Stories have to *repair* the damage that illness has done to the ill person’s sense of where she is in life, and where she may be going. Stories are a way of re-drawing maps and finding new destinations.

The second and complementary call for stories is literal and immediate: the phone rings and people want to know what is happening to the ill person. Stories of the illness have to be told to medical workers, health bureaucrats, employers and work

associates, family and friends. Whether ill people want to tell stories or not, illness calls for stories.

The spring when I was writing this book I had a routine chest X-ray that showed enlarged lymph nodes; the chest is the expected recurrence site for the cancer I had. The inflammation turned out not to be cancer, but in the course of medical tests and finally surgery, I had to tell and repeat versions of my story to family with their interests, work colleagues with theirs, and to medical workers who required still different stories. One day I recorded I had told a version of my illness story eight times.

These stories are told in conditions of fatigue, uncertainty, sometimes pain, and always fear that turn the ill person into what Ronald Dworkin describes as a "narrative wreck," a phrase displaying equal wit and empathy.³ Judith Zaruch's metaphor of losing her map and destination suggests illness as a shipwreck. Almost every illness story I have read carries some sense of being shipwrecked by the storm of disease, and many use this metaphor explicitly. Extending this metaphor describes storytelling as repair work on the wreck.

The repair begins by taking stock of what survives the storm. The old map may now be less than useful, but it has hardly been carbonized. Disease happens in a life that already has a story, and this story goes on, changed by illness but also affecting how the illness story is formed. I once spoke to a young man the night before he began chemotherapy. He talked about the high incidence of cancer in his family, his father's recent death, and his memories of relatives' deaths. At least on that particular night as he recalled his life, he told a story of having waited for cancer; a story of illness was already in place before his disease occurred. Cancer had long been on his map as a possible destination.

Yet he was a narrative wreck for at least two reasons. However cancer may be anticipated in fantasy, the reality is differ-

ent. When I was told about the lymph nodes on my chest X-ray, I was amazed at what a narrative wreck I was: I who spend my life telling stories about illness, my own as well as others. Somehow the stories we have in place never fit the reality, and sometimes this disjunction can be worse than having no story at all.

My friend was also a narrative wreck because he, like anyone facing serious illness, had suddenly lost the central resource that any storyteller depends on: a sense of temporality. The conventional expectation of any narrative, held alike by listeners and storytellers, is for a past that leads into a present that sets in place a foreseeable future. The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable.

Recall Malcolm Diamond's questions about whether he should have dental work done or buy shoes. These questions are not only about desire but about temporality: Diamond has lost any stable expectation of a relation between what he does in the present and what will happen in the future. Even if death is not an immediate concern, what tomorrow may have in store for the body is unknown. At least I can make known what happened to the young man with so much cancer in his family: the chemotherapy was successful, and in remission he is moving to new destinations.

The way out of the narrative wreckage is telling stories, specifically those stories that Schafer calls "self-stories." The self-story is not told for the sake of description, though description may be its ostensible content. The self is being *formed* in what is told. The quotation from Schafer that began this chapter continues: "In telling these self-stories *to others* we may, for most purposes, be said to be performing straightforward narrative actions. In saying that we also tell them *to ourselves*, however, we are enclosing one story within another. This is the story that there is a self to tell something to, a someone else

serving as audience who is oneself or one's self. . . . On this view, the self is a telling."⁴

The self-story is told both to others and to one's self; each telling is enfolded within the other. The act of telling is a dual reaffirmation. Relationships with others are reaffirmed, and the self is reaffirmed. Serious illness requires both reaffirmations, and Schafer's insight is describing how they proceed mutually. The ill person needs to reaffirm that his story is worth listening to by others. He must also reaffirm that *he is still there*, as an audience for himself. Audre Lorde's expression of her need to write after her surgery for breast cancer begins, "In order to keep me available to myself. . . ." ⁵ Illness is a crisis of self in the specific sense of an uncertainty that one's self is still there as an audience; the reaffirmation of this self as "available" is crucial.

No pretense can be made of reviewing the massive literature bearing on Schafer's thesis that "the self is a telling."⁶ But I can suggest certain themes from this literature that seem most pertinent to hearing illness stories.

INTERRUPTION AND PURPOSE

In the beginning is an interruption. Disease interrupts a life, and illness then means living with perpetual interruption.⁷ Nancy Mairs writes that calamities "have a genius of their own."⁸ Mairs's life has been interrupted by her own mental and physical illnesses and her husband's recurring cancer, by children and their needs, and by the needs of strangers and her sense of obligation to meet those needs. Finally, as her self-story is about to reconcile belief in God with the indignities of having multiple sclerosis, she writes that "the lid just popped off my daily Thirstbuster, dumping about a quart of Diet Coke onto the floor." Mairs is too disabled to clean up the mess and

will "have to continue working on this passage with my feet in a sticky brown puddle" (184).

Mairs interrupts her story in order to display the constant interruption of her life. Her story not only describes these interruptions; it is an interrupted story. The passage also illustrates how metaphor often works in illness stories. The spill is a metaphor for Mairs's interrupted life, but the sticky brown puddle is literal. Thus with regard to metaphor I find most useful Schafer's observation that metaphor establishes a storyline: "What is called unpacking a metaphor is in certain respects much like laying out the kinds of story that are entailed by the metaphor." Between storyline and metaphor, Schafer finds the former to be "the more inclusive term."⁹

The lid popping off interrupts one storyline in order to establish another. The digression is a reminder that her story is about interruption, or, in Schafer's terms, interruption is the story entailed by the metaphor. Mairs's body is equally entailed: her story is a body-self-story. The popped lid jerks the reader back into awareness of the physical conditions that are both the topic of Mairs's writing and the means of performing that writing. Her metaphor is her story of what it is like to live in a body so disabled that she can only sit in the sticky brown puddle until help arrives. She is not helpless: her work can continue. But the condition of that work's embodiment is perpetual vulnerability to interruption.

The Thirstbuster lid may have had a genius of its own, but other interruptions are explicitly part of the territory of being ill. The ill person as medical patient is one who, having been interrupted by disease, is now considered infinitely interruptible in speech, schedule, sleep, solvency, and anything else. When Richard Selzer, writing of his recovery from a coma caused by Legionnaires' disease, is asked by his physician why he wants to be discharged from the hospital, Selzer replies that

he wants not just privacy—he already has a private room; he wants “solitude. A condition that does not include people like you coming in here whenever they feel like it and asking me what else I want.”¹⁰ Even the most benevolent interruption remains an intrusion when it is uninvited. Selzer’s irony suggests that he interprets the interruptions to be benevolent; others may not share this understanding.

The medical redefinition of conversation between physician and patient as a clinical task, for example, as “history taking,” works to suspend normal conventions of politeness and thus to legitimate interruptions. Physicians’ interruptions of patients are well-documented.¹¹ The physician and sociologist Howard Waitzkin interprets these interruptions as “basically attempts to curtail storytelling by patients.” Waitzkin suggests several reasons for this curtailment: “The story may not contribute to the doctor’s cognitive process of reaching a diagnosis; the patient’s version of the story may be confusing or inconsistent; telling the story may take more time than is perceived to be available; or parts of the story may create feelings that are uncomfortable for the doctor, the patient, or both.”¹² Times are changing. A senior surgeon wrote to me that he is finally learning the difference between taking a history and hearing the patient’s story; until recently, the medical history was considered to be the story.

Telling an interrupted life requires a new kind of narrative. Mairs cuts to the inconsistency between interruption and conventional storytelling: “Narratives possess the shortcoming that they drive toward ends, preferably tidy ones.”¹³ Interruptions divert the narrative from such ends; they give stories the “confusing or inconsistent” quality that Waitzkin observes physicians and patients find uncomfortable in patients’ stories. The stories are uncomfortable, and their uncomfortable quality is all the more reason they have to be told. Otherwise, the interrupted voice remains silenced.

The illness story faces a dual task. The narrative attempts to restore an order that the interruption fragmented, but it must also tell the truth that interruptions will continue. Part of this truth is that the tidy ends are no longer appropriate to the story. A different kind of end—a different purpose—has to be discovered. The result is rarely tidy: “Even as I write about it,” concludes Fitzhugh Mullan on his cancer, “I can feel a kind of terminal ambivalence about the entire experience.”¹⁴ Many illness stories do discover purposes in suffering, but even these are rarely without some ambivalence.

Interrupted narratives find many different purposes, and these will be considered in the following chapters. The most general terms of purpose are suggested by Genevieve Lloyd, describing Nietzsche’s concept of the eternal return: “It is a matter rather of seeing everything that happens—whether it be grand or unbearably petty—as integral to the being of a self which, if it were to recur at all, could do so only in its entirety.”¹⁵ Nancy Mairs interrupts her meditations on God to describe the Thirstbuster spilling: the lesson of her interruption is that the grand is never far from the petty.

MEMORY AND RESPONSIBILITY

The interruption that illness is, and the further interruptions that it brings, are disruptions of memory. The disruption is not of remembering; people’s memories of illness are often remarkable in their precision and duration. I was once on a radio phone-in program. A man called and told a detailed story of having cancer; his wife was hospitalized at the same time that he was, and the details of their visits went on at a length that made the program host nervous. I finally asked the man when this had happened and was told it was thirty years ago. I am frequently amazed at how long ago “present tense” stories have

happened. The disturbance is not of remembering, but it is of memory.

The memory that is disrupted is a coherent sense of life's sequence: what the philosopher David Carr calls "the whole which comprises future, present, and past."¹⁶ I suggested above how illness dislocates the relation of this whole: the present is not what the past was supposed to lead to, and whatever future will follow this present is contingent. Carr points out that even for the healthy person, "the narrative coherence of events and actions" is never "simply a 'given' for us. Rather it is a constant task, sometimes a *struggle*, and when it succeeds it is an achievement" (96, emphasis added).

Illness intensifies that struggle. The past is remembered with such arresting lucidity because it is not being experienced as past; the illness experiences that are being told are unassimilated fragments that refuse to become past, haunting the present. Just as present illness struggles with a past that was not supposed to lead to illness, the present that is recovered from illness struggles with a past that never received its due telling when it was happening.

Disrupted memory—whatever the incoherence in the whole which comprises future, present, and past—is a *moral* problem. Developing arguments from Alasdair MacIntyre, Carr describes this struggle as "a responsibility which no one else can finally lift entirely from the shoulders of the one who lives that life." This struggle has two aspects: "one to live out or live up to a plan or narrative, large or small, particular or general; the other to construct or choose that narrative. The first is constrained by the choice of the second" (96). For the ill, the choice of narrative is equally constrained by a sense of what can be lived out or, in Carr's significant phrase, *lived up to*.

The practical problem of narrative, according to Carr, is to create a story in which "the past is still viewed in light of its

connection to present and future in an ongoing project" (98). In such a narrative, memory is restored as coherent. Because the present of illness is not what was planned in the past, reestablishing the connection of past to present may require an exercise in what psychoanalyst Donald Spence calls narrative truth. Spence and Carr agree that the past cannot be reinvented, but the sense of what was foreground and background in past events can shift to recreate a past that displays what Spence calls greater "continuity and closure."¹⁷ Out of narrative truths a sense of coherence can be restored.

Even the ill person can choose a narrative and create narrative truths. The story expressing these truths must then be *told*. Psychologist Roger Schank is clearest on the need to tell stories to others, although actual telling is implicit in the writing of Schafer and Spence, who both assume psychoanalysis as the scene of storytelling. Schank explicitly links telling to memory: "We need to tell someone else a story that describes our experience because the process of creating a story also *creates the memory structure* that will contain the gist of the story for the rest of our lives. Talking is remembering."¹⁸ Memory is not only restored in the illness story; more significantly, memory is created. If the story being told is what Carr calls something to live up to, then a future is also being created, and that future carries a distinct responsibility.

Paul Ricoeur makes this responsibility central to his concept of *narrative identity*. Ricoeur describes how the self only comes to be in the process of the life story being told: "the *subject* is never given at the beginning" of a narrative. This initial non-giveness of the subject or self is a necessary condition of the story's morality. If the subject were given at the beginning, nothing would be learned. Such an already-given subject would, in Ricoeur's phrase, "run the risk of reducing itself to a narcissistic ego, self-centered and avaricious." Narrative iden-

tity is the liberation from this narcissism of being a narrator who believes he already knows who he is. "In place of an ego enchanted by itself a *self* is born" in stories.¹⁹

This responsibility for narrative identity is directly expressed in illness stories. Tim Brookes, writing about his life with asthma, comes to the realization that "chronic illness in particular challenges us to ask if it is possible to be *successfully ill*."²⁰ The ethicist William May reflects on the response of a recent widow to her husband's sudden death. The question faced by the ill person is not "What are we going to do about it?" May observes; rather, it is "How does one rise to the occasion?"²¹

Briefly, one rises to the occasion by telling not just any story, but a good story. This good story is the measure of an ill person's success. "Narrative truth is what we have in mind when we say that such and such is a good story," Spence writes.²² In chapter 2, I quoted Anatole Broyard describing himself as wanting to be a "good story" for his doctor.

Broyard said this during a speech to doctors; in that context, he is proposing a mutuality of responsibility that is new both to illness experience and to medicine. Broyard claims a role far beyond that of compliant patient. His responsibility is not that defined by Parsons for the sick person, to get well by following medical advice. Instead Broyard claims a responsibility to turn his illness into a good story, to discover the narrative truth in it, and to tell that truth. He is declaring himself a witness to his illness, and he is calling on his audience—members of the medical profession—to become witnesses to his witness. Broyard knew without reading Schank that a story requires listeners; it must be told. As he assumed responsibility for being a good story, he called on his physicians to take the complementary responsibility for receiving this story.

The narrative truth of the good story has to remain truthful to life as it is lived; the question is, which truth of which happenings? In illness stories, truth may be selective, but it re-

mains self-conscious. This accountability of truth is close to the surface of illness stories. One day I met a friend whose adult child is mentally disabled; she was just back from a parents' support group. "We do not tell our own truth," she said to me, describing the group. These parents, my friend told me, were unwilling to tell their disappointments and frustrations. The raw anguish of such talk was rendered unacceptable by unspoken group norms. But telling the truth, as my friend knew, involves recognizing that your life has not turned out as you wanted. What went wrong must be acknowledged and examined; mourning will attend this examination.

Many if not most North Americans share a cultural reluctance to say that their lives have gone badly in some significant respect and to mourn the loss of what was desired but will never happen. Our contemporary version of stoicism borders on denial. The good story refuses denial, and thus stands against social pressures. Waitzkin points out that physicians interrupt patients when their stories become uncomfortable. The interruptions work to silence the telling of what might be, or what might become, truths. What might have become good stories are turned; if not turned bad, then at least turned away from their truths.

What makes an illness story good is the act of witness that says, implicitly or explicitly, "I will tell you not what you want to hear but what I know to be true because I have lived it. This truth will trouble you, but in the end, you cannot be free without it, because you know it already; your body knows it already." In telling this story truthfully, the ill person rises to the occasion.

More needs to be said about the ill person as witness, and a later chapter will return to this theme. Here I only observe that the possibility of becoming a witness makes the coherence of memory the responsibility that Carr calls it. Memory is a responsibility because as it is told it becomes witness and reaches

beyond the individual into the consciousness of the community.

RECLAIMING THE SELF

In postmodern times “reclaiming” has been used to the point of cliché, but like most clichés it carries a significant kernel of truth about the times in which it is so often repeated. Reclaiming suggests that illness stories are doing more than speaking through interruptions; the ill person’s voice has been taken away.

Audre Lorde writes of “reclaiming . . . that language which has been made to work against us.”²³ She expresses a pervasive view among the ill that medical language with its “general unifying view” homogenizes their experience. Students of medical culture find “doctor stories” to be rich in their descriptive nuance,²⁴ but the issue is whether patients experience this side of medicine. Too often the patient experiences a medical rationalization that is epitomized by “diagnostic related groups” (DRGs).

DRGs are detailed statements of what medical treatments some third party insurer will pay for, based on the diagnosis at the time of hospital admission. The DRG is a narrative that sets in place details of the experience of the hospitalization that will follow. I was going to write “countless details,” but the logic of the DRG is that every detail, down to the last paper tissue, can and will be counted. The DRG reduces the general unifying view to bureaucratic proceduralism. Again, to characterize medical narrative culture in terms of DRGs is certainly unfair, but DRGs do epitomize the dehumanizing aspect of “becoming a patient” described by Dan Gottlieb in chapter 1.

The finest statement of the practice of reclaiming is by Audre Lorde: “In order to keep me available to myself, and be able to concentrate my energies upon the challenges of those

worlds through which I move, I must consider what my body means to me.”²⁵ To reclaim a self requires making the self available as what Schafer called an audience to its own self-story. But Lorde’s story, like Mairs’s, is a body-self-story. Her reclaiming begins with her body: the problem of how to regain association with her body after her mastectomy. Her need for self-availability, however, goes beyond her body-self. To be available to herself as a one-breasted woman, she must find a connection to all who share that condition. How the medical world she moves through challenges this connection is described in a later chapter. Lorde must reclaim herself against this opposition.

Lorde echoes William James’s call to the “duties” of the really real. The reclaiming that begins in her body moves seamlessly to the “challenges of those worlds” she moves through. She reminds the ill, and herself, that the worlds any of us move through are challenging, and illness requires an enhanced concentration of energies to meet those challenges. This concentration requires, and in another sense is, what Lorde calls self-availability. She makes herself available to herself in the words the reader reads. Her writing is her struggle for coherence; its truth is her achievement. Not just any story will bring about this coherence. Lorde’s good story is one that concentrates her energies and returns her to the worlds that need her. Lorde’s reader is simultaneously reminded of her own worlds and their challenges; thus the reader is made available to herself.

Lorde’s telling is an act of reflexive monitoring. As narrative practice, reflexivity is described by Jerome Bruner in terms of restoring memory: “our capacity to turn around on the past and alter the present in its light, or to alter the past in the light of the present.”²⁶ Reflexive monitoring is the perpetual readjustment of past and present to create and sustain a good story. Lorde’s narrative practice is exactly what Schafer, Carr, Spence, and Schank all call for: the creation of a coherent self-story, the

re-creation of memory, and the assumption of responsibility. But Lorde emphasizes what none of these theorists include: by calling her narrative work a reclaiming, she attends to its political dimension.

What Lorde believes she must reclaim is suggested by returning to Waitzkin's analysis of doctor-patient communications. Waitzkin characterizes medicine as an ideological system that "calls" the patient to be an identity that medicine maintains for him; the diagnosis is the most prevalent form of this identity. The ideological work of medicine is to get the patient to accept this diagnostic identity as appropriate and moral.²⁷ When the patient accepts this identity, he aligns himself as subordinate in a power relation. Parsons's frequent emphasis on the asymmetry of the professional-client relationship remains forceful because it legitimizes this power relation, endowing it with a certain inevitability. Waitzkin recognizes that for the patient, "the language of medicine leaves few options for action. . . . Periodically, such tensions that derive from troubling social issues erupt into the discourse . . . and create a countertextual reality that cannot be resolved in the framework of a medical encounter" (47). Lorde's reclaiming is such a countertextual reality.

Few illness stories are as self-consciously political as Audre Lorde's, but few are without some motivation of reclaiming. Her statement about self-availability is as good an epigram as I have found to the narrative practice of illness stories, but one significant addition must be made. Just as Lorde specifies the plurality of the worlds she moves through, so also the plurality of the self that is reclaimed needs to be noted. The issue for most ill people seems to be keeping multiple selves available to themselves. Stewart Alsop observes that his book "was written by different mes."²⁸

Alsop's self-observation confirms the generalized significance of what Schafer notes among analysts: the "experien-

tial self may be seen as a set of varied narratives that seem to be told by and about a cast of varied selves. And yet, like the dream, the entire tale is told by one narrator. Nothing here supports the common illusion that there is a single self-entity that each person has and experiences, a self-entity that is, so to speak, out there in Nature."²⁹ What is out there in Nature is, of course, the body. There may be a cast of varied selves, but there seems to be only one body; how many selves can this one body support?

Two sorts of answers are posed by different stories. Sue Nathanson writes about the years following the traumas of an abortion and a tubal ligation. These were elective procedures, fully understood and consented to, and no distinctive medical horrors occurred. But Nathanson could not anticipate how much losing her baby and her fertility would mean to her. She repeatedly tells her readers that her energies had been primarily focused not on her career as a professional psychotherapist but on child bearing and nurturing. Foreclosing that part of her life is a trauma that takes years to resolve.

Part of the resolution is Nathanson's realization that she is not one person but many, and some parts of her have to act in ways that contradict the values of other parts. As she counsels a young woman who has had an abortion, Nathanson articulates her own developing self-awareness: "Women have to . . . accept the consciousness of having the power and capacity to end a life that is also part of their very being," she says.³⁰ Nathanson realizes that her own cast of varied selves includes the destroyer and the nurturer, and these selves can co-exist. The work of telling her self-story is a process of getting rid of what Schafer calls the "exaggerated impression of single and unvarying self-entities."³¹

A different and equally dramatic resolution to the problem of a single body supporting varied selves is found in Reynolds Price's story of surgery, radiation, and recovery from a malign-

nant tumor within his spinal column. Price describes in detail how the paralysis that results from radiation affects his life. His conclusion is that he now inhabits a body that is fundamentally different, and thus he must be a different person. He advises any who suffer similar fates to become “someone else, the next viable you—a stripped-down whole and clear-eyed person, realistic as a sawed-off shotgun and thankful for air.”³² A new body calls for a new self, nothing less will do. Others, especially those who love the ill person most, “will be hard at work in the fierce endeavor to revive your old self, the self they recall with love and respect” (183). Their benevolent efforts must be resisted.

How “new” Price’s self-proclaimed new self is can be disputed, but the narrative truth of his story is clear: in thinking of himself as a new self, he has found the terms to go on living in conditions of embodiment that would have horrified his old self. And he witnesses to others the possibility of creating a “happy” life out of such circumstances (192).

What unites the narrative reclaimings of Lorde, Nathanson, and Price is summarized by Lloyd, writing about the primal teller of self-stories, Augustine. “Reflection on memory makes the self an object of wonder—an astonishment previously reserved for the contemplation of the world.”³³ The good story ends in wonder, and the capacity for wonder is reclaimed from the bureaucratic rationalizations of institutional medicine. Being available to yourself ultimately means having the ability to wonder at all the self can be.

NARRATIVE WRECKAGE AND POSTMODERN TIMES

Illness is one specific occasion for narrative wreckage, but a condition of perpetual narrative uncertainty is endemic to postmodern times. The self-stories that proliferate in post-

modern times are one response to this uncertainty. This proliferation of self-stories includes the analytic self-stories that Schafer refers to and the self-stories that the ill tell from their bedsides. But far more widespread are self-stories as a recognizable genre of popular culture.

Illness narratives as one form of self-story overlap with and are bounded by at least three other forms. These are spiritual autobiographies,³⁴ stories of becoming a man or a woman and what that gender identity involves,³⁵ and finally survivor stories of inflicted traumas such as war, captivity, incest, and abuse.³⁶ As in illness stories, the published examples of these self-stories are only a token of a broader oral discourse. The ways that oral stories are influenced by the rhetoric of published works are undoubtedly as infinite as those stories.

Why is this proliferation of self-stories happening *now*? In terms of published stories, one answer is that a market exists, and this market in turn means readers who find this storytelling addresses their lives. Published self-stories are another ideology, though disputedly a more grass-roots one, that “calls” people to the identities it formulates. But the presence of this market only enlarges the scope of the question, why now?

Each of these self-stories is grounded in some form of narrative wreckage, and each is its own act of reclaiming. Postmodern times both produces the wreckage and provides the resources for the reclaiming. Postmodernity is, in this as in most other respects, contradictory: opposing tendencies happen simultaneously. One side of postmodernity is the hyper-rationalization that subsumes the individuality extolled by modernity. Modernist medicine’s general unifying view was a beneficent rationalization carried out in the interest of a science that had cure as its objective. DRGs are a less-than-beneficent rationalization carried out in the interest of cost-containment and administrative control over medicine. DRGs represent the modernist project turning against itself.

A different side of postmodernity is the presence of self-stories that provide models of reclaiming the self. To see this side, the practitioners of postmodernism are more useful than theorists, though another feature of postmodernism is the blurring of this line. One practitioner is the novelist Clark Blaise. In the preface to his own self-story, Blaise defines the narrative implications of postmodern times as “consciousness fighting to achieve sovereignty over its own experience.”³⁷ Blaise echoes but intensifies Schafer’s observation that experience is “made or fashioned” and not directly encountered, as well as Carr’s recognition that coherence is always a struggle. He also echoes John Lennon’s reported saying, “Reality takes a lot of imagination.” In postmodern times William James’s really real is still there, but where it is and what it is require more work. To experience we have to imagine; imagination is consciousness struggling to gain sovereignty over its experience.

The modernist autobiographer—still represented by politicians and other “personalities”—presents his story’s ending, the culmination of the status that the author has achieved, as somehow immanent in the story throughout. The postmodern memoirist like Blaise is haunted by the mutual contingency of life and story. Because imagination knows that the story could always be told differently, should the life have been lived differently?

The postmodern memoirist writes to discover what other selves were operating, unseen, in a story that is the writer’s own, but that writer is several selves. As Nathanson tells her story, she is a *writer* telling how she as a *therapist* spoke to her client about what she as a *woman* who had suffered learned about the *multiple sides* of herself. The story she tells the other person, her client, is also a story she is telling herself, thus creating a new memory, possibly for both of them. Here we certainly have Schafer’s cast of varied selves.

The anything-but-tidy conventions of postmodern memoir

—its lack of linearity and competing voices—fit experiences that are interrupted. As I observed earlier, these stories are not only about interruption; they are themselves interrupted stories. Not the least interruption are other stories. Another storyteller, the therapist, group leader, and spiritual autobiographer Sam Keen begins with the commonplace observation that in postmodern times people can no longer participate in some shared communal belief(s) about matters such as “soul” and “guiding principles.”³⁸ The storyteller’s perception that Keen brings to this observation is that in a world without these principles, the narrator becomes “saturated with stories . . . with points of view.” A person who is “bombarded” with so many points of view has to struggle to hold one point of view that can be recognized as her own. The unique perspective that makes the story one’s own constantly breaks up in competing perspectives. “We lose the continuity of our experiences,” Keen writes; “we become people who are written on from the outside” (28).

When I had to repeat the story of the X-ray that led to suspected cancer, I began to feel after multiple tellings that a voice outside of me was talking, and I was listening to that voice. I was not speaking of how *I* felt; I was addressing the interests of particular listeners in rhetoric appropriate to our relationships. I felt written on from the outside, but my own voice was doing the writing.

The postmodern phrase that complements “reclaiming” is “finding one’s voice.” Here also a significant truth underpins the cliché: people who are written on from the outside have lost their voices. Speaking in a voice recognizable as one’s own becomes increasingly difficult, so speech proliferates in search of that voice. Self-stories proliferate.

Amid the cast of various selves, which self can speak the voice that is one’s “own”? The question is not facetious, because the need to speak in a voice recognizable as one’s own is

real. The best answer I have found is offered by Nancy Mairs, reflecting on the question she is always asked when she visits undergraduate writing classes, "How did you find your voice?"³⁹ After some discussion of the invented quality of any voice, Mairs writes: "Whatever I wrote, I wrote out of that pain, and whatever I wrote assuaged the pain a little but never enough" (19). Even in postmodern times, even among the various selves that each of us is, a bedrock of the really real remains. Its name is often pain.

Again I ask, why do self-stories proliferate now? Perhaps because the accumulated violences of modernity are no longer deniable, which is another definition of postmodernity. Terry Tempest Williams tells a story of breast cancer, not her own but throughout her family.⁴⁰ Because so many women are affected in a fairly short period of time, she seeks some environmental cause. Part of any story of illness is genesis: what caused the disease; why did it happen to me?⁴¹ But in Williams's case the question is why cancer is happening all around her.

Near the end of her book Williams tells her father about her recurring dream of a bright light. He tells her this is actually a memory of the family stopping their car by the Utah roadside to watch an atomic bomb test in the 1950s. "The sky seemed to vibrate with an eerie pink glow," he tells her. "Within a few minutes, a light ash was raining on the car." She stares at him as the question of genesis suddenly becomes clear: "It was at this moment that I realized the deceit I had been living under" (283).

The "deceit" is more complicated than atomic testing. It involves her family's Mormon tradition of authority, their relation to the Western landscape, and the "unnatural history" of that landscape, particularly the Great Salt Lake region. When all these complications have been explored, a final mystery of genesis remains: why, among all the women who suffered from the

fallout of that and other explosions, does Williams alone survive?

Williams tells a self-story of memory and responsibility. Her story is multiply interrupted, by floods, deaths, and ultimately by her father's revelation that is not exactly the truth but is at least the end of a denial. Whatever "finding your own voice" means, in ending the denial Williams certainly finds a purpose for her voice: honoring her dead and struggling to preserve the natural heritage that is being destroyed by forces as insidious as that bomb was.

The postmodernism of her story lies in all these qualities, as well as in the anachronism of the atomic testing that seems part of another world, yet has such real effects here and now. "When the Atomic Energy Commission described the country north of the Nevada Test Site as 'virtually uninhabited desert terrain,'" Williams writes, "my family and the birds at Great Salt Lake were some of the 'virtual uninhabitants'" (287). Here the practices of modernity create the language of postmodernism.⁴²

In terms of total pages, most of Williams's book is not about illness but about nature; she is a bird watcher by choice and turns to illness only when its interruption demands response. She struggles for the sovereignty of her consciousness over the events of her life, and she struggles to reclaim what deceit has taken away and still takes away. At the end of the book she describes being arrested for protesting at a nuclear test site. She and her fellow protesters are bused into the desert and left stranded. "What they didn't realize," Williams writes, "is that we were home." Her narrative wreckage is rebuilt; her map redrawn.

medical Ethics from the Perspective of the Sick, Ph.D. diss., Duke University, 1992. Lysaught argues that the exemplar of the communicative body is Jesus, particularly in the crucifixion. This application of my work completely surprised me, and I gratefully acknowledge its importance in my present thinking.

29. Broyard, *Intoxicated by My Illness*, 45.

30. Schweitzer, *Out of My Life and Thought*, 104.

3. ILLNESS AS A CALL FOR STORIES

1. Roy Schafer, "Narration in the Psychoanalytic Dialogue," in W. J. T. Mitchell, ed., *On Narrative* (Chicago: University of Chicago Press, 1981), 31.

2. My title phrase comes from Coles, *The Call of Stories* (cf. chap. 2, n. 17). Coles's different emphasis describes how a moral life can be lived as the "call of stories," specifically literary stories that become woven into one's own life story.

3. Ronald Dworkin, *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom* (New York: Knopf, 1993), 211. Dworkin refers specifically to the effects of prolonged immobility on the sense of self and the self's capacity for decision-making in matters such as termination of treatment.

4. Schafer, "Narration in Psychoanalytic Dialogue," 31.

5. Audre Lorde, *The Cancer Journals* (San Francisco: spinsters/aunt lute, 1980), 65.

6. In addition to sources cited below, see in particular George C. Rosenwald and Richard L. Ochberg, eds., *Storied Lives: The Cultural Politics of Self-Understanding* (New Haven: Yale University Press, 1992). A useful bibliography of recent work on narrative with reference to the self is found in Genevieve Lloyd, *Being in Time: Selves and Narrators in Philosophy and Literature* (New York: Routledge, 1993), 176.

7. The editors of the diaries of Etty Hillesum, a Dutch Jew who died in Auschwitz, captured this in their title, *An Interrupted Life* (New York: Washington Square Books, 1983). Recently, Susanna Kaysen calls her memoir of mental illness *Girl Interrupted* (New York: Vintage, 1993).

8. Nancy Mairs, *Ordinary Time: Cycles in Marriage, Faith, and Renewal* (Boston: Beacon Press, 1993), 122.

9. Roy Schafer, *Retelling a Life: Narration and Dialogue in Psychoanalysis* (New York: Basic Books, 1992), 32.

10. Richard Selzer, *Raising the Dead* (New York: Viking, 1992), 95.

11. Candice West, *Routine Complications: Troubles with Talk between Doctors and Patients* (Bloomington: Indiana University Press, 1984), and H. Beckman and R. Frankel, "The Effect of Physician Behavior on the Collection of Data," *Annals of Internal Medicine* 101 (1984): 692–96.

12. Howard Waitzkin, *The Politics of Medical Encounters: How Patients*

and Doctors Deal with Social Problems (New Haven: Yale University Press, 1991), 28.

13. Mairs, *Ordinary Time*, 100.

14. Fitzhugh Mullan, *Vital Signs: A Young Doctor's Struggle with Cancer* (New York: Laurel, 1984), 195.

15. Lloyd, *Being in Time*, 111.

16. David Carr, *Time, Narrative, and History* (Bloomington: Indiana University Press, 1986), 96.

17. Donald P. Spence, *Narrative Truth and Historical Truth: Meaning and Interpretation in Psychoanalysis* (New York: Norton, 1982), 31. See also Schafer: "Experience is made or fashioned; it is not encountered, discovered, or observed. . . . The introspecting subject extracts from the plenitude of potential experience what is wanted" (*Retelling a Life*, 23).

18. Roger C. Schank, *Tell Me a Story: A New Look at Real and Artificial Memory* (New York: Scribners, 1990), 115, original emphases changed.

19. Paul Ricoeur, "Life: A Story in Search of a Narrator," in M. C. Doeser and J. N. Kraay, eds., *Facts and Values* (Dordrecht: Martinus Nijhoff Publishers, 1986), 132.

20. Tim Brookes, *Catching My Breath: An Asthmatic Explores His Illness* (New York: Times Books, 1994), 277.

21. William F. May, *The Patient's Ordeal* (Bloomington: Indiana University Press, 1991), 131, see also 3.

22. Spence, *Narrative Truth and Historical Truth*, 31.

23. Lorde, *The Cancer Journals*, 22.

24. Kathryn Montgomery Hunter, *Doctors' Stories: The Narrative Structure of Medical Knowledge* (Princeton: Princeton University Press, 1991).

25. Lorde, *The Cancer Journals*, 65.

26. Jerome Bruner, *Acts of Meaning* (Cambridge: Harvard University Press, 1990), 109. Bruner is writing about Kenneth Gergen in this passage.

27. Waitzkin, *Politics of Medical Encounters*, 299–300, n. 8. Waitzkin is quoting Theron Britt.

28. Stewart Alsop, *Stay of Execution*, x (cf. chap. 2, n. 18).

29. Schafer, *Retelling a Life*, 26.

30. Sue Nathanson, *Soul Crisis: One Woman's Journey Through Abortion to Renewal* (New York: Signet, 1989), 209.

31. Schafer, *Retelling a Life*, 28.

32. Reynolds Price, *A Whole New Life* (New York: Atheneum, 1994), 183.

33. Lloyd, *Being in Time*, 20.

34. Anne Hunsaker Hawkins, in *Reconstructing Illness* (cf. chap. 1, n. 34), describes illness stories, or "pathographies," as the contemporary form of spiritual autobiography, suggesting the former has displaced the latter. I see the spiritual autobiography as alive, well, and anything but displaced: Malcolm Boyd, Frederick Buechner, Annie Dillard, Richard Gilman,

Natalie Goldberg, Sam Keen, Madeleine L'Engle, Julius Lester, Kathleen Norris, and Dan Wakefield are only some of the many contemporary spiritual autobiographers. Illness stories and spiritual autobiographies seem rather to complement each other. Just as the illness story is a self-story reclaiming the post-colonial self's identity from medical systems, many spiritual autobiographies explore how to restore a spiritual impetus within religions that have ossified into formal systems. Illness and spiritual self-stories overlap in both Madeleine L'Engle, *Two-Part Invention: The Story of a Marriage* (New York: HarperCollins, 1989) and Nancy Mairs, *Ordinary Time*.

35. Self-stories of gender and of illness often weave together in AIDS narratives. In the work of Paul Monette, compare his story of gay identity, *Becoming a Man: Half a Life Story* (New York: HarperCollins, 1992), with *Borrowed Time: An AIDS Memoir* (New York: Avon, 1988) and *Last Watch of the Night* (New York: Harcourt Brace, 1994). Paul Zweig's *Departures: Memoirs* (New York: Penguin, 1986) is a gender story interrupted by illness, in his case lymphoma.

36. Incest-survivor stories probably do most to set the cultural threshold for personal writing; see Charlotte Vale Allen, *Daddy's Girl: A Very Personal Memoir* (New York: Bantam, 1981). Thus when Richard Selzer describes the writing in his illness memoir, *Raising the Dead*, as "so open, explicit, so personal" (29), he actually is far within the boundaries that survivor stories have set for open, explicit, and personal writing.

37. Clark Blaise, *I Had a Father: A Post-Modern Autobiography* (Toronto: HarperCollins, 1993), xi. Commenting on his usage of postmodern in his title, Blaise also notes that his reconstruction of his life cannot be linear.

38. Sam Keen, "Our Mythic Stories," in Charles and Anne Simpkinson, eds., *Sacred Stories: A Celebration of the Power of Stories to Transform and Heal* (New York: HarperCollins, 1993), 28. Note the postmodernity of the book's title: in an age of narrative wreckage, an enhanced belief in the efficacy of stories emerges.

39. Nancy Mairs, *Voice Lessons: On Becoming a (Woman) Writer* (Boston: Beacon Press, 1994), 15.

40. Terry Tempest Williams, *Refuge: An Unnatural History of Family and Place* (New York: Vintage, 1991).

41. See Gareth Williams, "The Genesis of Chronic Illness: Narrative Reconstruction," *Sociology of Health and Illness* 6, no. 2 (1984): 175–200.

42. On the need for a postmodern social science as a means of grasping the distortions of language that—however presciently observed by George Orwell—took on a new quantity and intensity during the Vietnam war era, see Charles Lemert, "The Uses of French Structuralism in Sociology," in George Ritzer, ed., *Frontiers of Social Theory: The New Synthesis* (New York: Columbia University Press, 1990), 230–54.

4. THE RESTITUTION NARRATIVE

1. Friedrich Nietzsche, *The Gay Science*, trans. Walter Kaufmann (New York: Vintage, 1974), 249–50. This passage is discussed in detail in chapter 6, section 1.

2. One other type could be called the political/environmental narrative. Here the ill person presents herself as having been made ill by toxins originating usually in some specific industry. Bill's narrative in Williams, "The Genesis of Chronic Illness" (cf. chap. 3, n. 41), would fit this type, as would the stories reported by Balslem, *Cancer in the Community* (cf. chap. 1, n. 20). Investigative reporting on pollution often contains such narratives; see Monte Paulsen, "The Politics of Cancer: Why the Medical Establishment Blames Victims instead of Carcinogens," *Utne Reader*, November/December 1993, 81–89. Susan DiGiacomo proposes one variant of this form, the "victimization narrative." Here identity derives from being a victim of some person, group, or institution, and the narrative telos involves punishing that victimizer (personal communication). Another variant is what Anne Hunsaker Hawkins calls the "ecological narrative" in which the genesis of illness progressively expands in a web of connections that is both extensive and dense (personal communication).

3. May, *The Patient's Ordeal*, 4 (cf. chap. 3, n. 21).

4. Talcott Parsons, *The Social System* (New York: Free Press, 1951). The sick role receives its last and fullest elaboration in *Action Theory and the Human Condition* (New York: Free Press: 1978), chapters 1–3. For the aspects of Parsons's theory that move into postmodernity, see my article, "From Sick Role to Health Role: Deconstructing Parsons," in R. Robertson and B. S. Turner, eds., *Talcott Parsons: Theorist of Modernity* (London: Sage, 1991), 205–16.

5. Late in his life Parsons became diabetic. He suggests this experience did not modify his earlier theory substantially. See *Action Theory*, 19, 20, 25, 27, 29.

6. Or, more curious to the layman, the specialists might agree that treatment was futile but still believe they had to do *something*. For sociological reports on such attitudes, see Charles Bosk, *All God's Mistakes: Genetic Counseling in a Pediatric Hospital* (Chicago: University of Chicago Press, 1992) and Zussman, *Intensive Care* (cf. chap. 2, n. 9). One physician's struggle with his colleagues' obsession to continue treating is told in Harold Klawans, *Life, Death, and In Between* (New York: Paragon House, 1992), 259–70. For a medical ethicist writing on pressures to continue treatment of comatose patients exerted by their families who are caught in a restitution narrative, see Nancy Dubler and David Nimmons, *Ethics on Call* (New York: Harmony Books, 1992), 32–33, 334–37.

7. For a similar story, see Sherwin B. Nuland, *How We Die: Reflections on Life's Final Chapter* (New York: Knopf, 1994), 250–54.