The Wounded Storyteller

Body, Illness, and Ethics

SECOND EDITION

Arthur W. Frank

The University of Chicago Press
Chicago and London
Still to my parents,
Jane and Arthur Frank,
now in their seventy-second year of marriage.

All they had was mine,
and they are with me always.
I wrote the outline of *The Wounded Storyteller* in early spring 1994, while I still had stitches from the biopsy that determined I was not having a recurrence of cancer. Enlarged lymph nodes on my lungs and diaphragm had caused the suspicion of recurrence. To everyone’s great relief, these were attributed to another disease—sarcoidosis, which I had not heard of. I never could take sarcoidosis seriously; all that mattered was not having cancer again.

Writing *The Wounded Storyteller* was as much a work of self-healing as of scholarship. I needed to gather around me voices that shared what I had been through during the previous years of illness. I had written about my own experiences in a memoir, *At the Will of the Body*, but I needed the insights and articulations of other ill people to assure myself I wasn’t crazy. I needed others’ thoughts in order to become fully aware of my own. That is the book’s consistent message about why suffering needs stories: to tell one’s own story, a person needs others’ stories. We were all, I realized, wounded storytellers.

The wounded storyteller is anyone who has suffered and lived to tell the tale. Suffering does not magically disappear when the tale is told, but the more stories I heard the less space my own suffering seemed to take up. I felt less alone. This book was my attempt to widen the circle, to amplify and connect the voices that were telling tales about illness, so that all of us could feel less alone. The wounded storyteller
the boundaries that segment the flow of time into episodes. Experiences are very much our own, but we don’t make up
these experiences by ourselves.

People tell their own stories about illness, but what seems
worth telling, how to format the story, and how others make
sense of the story all depend on shared ways of narrating illness.
The core chapters of The Wounded Storyteller describe three
narratives that storytellers and listeners use to structure and
interpret stories, respectively: restitution, chaos, and quest.
Each is also a way of experiencing illness. I developed my
descriptions of these three narratives by sifting through my
memories of conversations and notes from memoirs, but in
retrospect, each narrative also expresses a moment in my own
illness experience.

Restitution represents my life as a patient. Health-care
workers expected any experience to be interpreted within
a narrative of movement toward recovery of health. Whatever
happened to me could be understood only as a necessary step toward that achievable goal of health. I wanted
to get well and appreciated reassurance that I would. But
I also needed recognition of my suffering at that particular moment, as well as recognition that my recovery was
by no means assured. I increasingly resented the restitution
narrative, especially how it positioned the physician as the
protagonist and relegated me to being the object of that
protagonist’s heroism. I was certainly part of this story, but
it could never truly be my story.

The restitution narrative had no space for the chaos part of
my illnesses: the months when my rapidly progressing testic-
ular cancer was misdiagnosed, first as a sports injury—muscle
strain—and then as an unknown disease, probably, but not
certainly, cancer. Chaos was in the disconnection between
the increasing pain that was sending my life off the rails and
my physicians’ frustrated insistence that nothing serious was
wrong. Chaos was in the claustrophobia of confronting others’
inability to see what I so clearly felt. Many people with chronic
illness, especially multiple sclerosis, have written about this
diagnostic uncertainty and the relief when some physician
validates how much is actually wrong, as devastating as that
diagnostic news can be.

My own chaos was bad enough, but I never experienced
the chaos in which many people feel trapped, when each mis-
fortune seems to trigger some other collapse: disease leads to
job loss, which creates a housing crisis, and then some other
family member gets sick. However, I went through enough to
recognize that desperation and the silence that chaos imposes.
Those living in chaos are least able to tell a story, because they
lack any sense of a viable future. Life is reduced to a series of
present-tense assaults. If a narrative involves temporal pro-
gression, chaos is anti-narrative.

My period of chemotherapy was bordering on chaos when
my understanding of what I was going through began to
shift. A sequence of experiences brought me out of an ob-
session with my own pain and vulnerability and gave me a
sense that I was participating in something shared.3 Time
spent being ill ceased to be time taken away from my life.
Instead, how I lived with illness became the measure of how
well I could craft a life, whether I was ill or healthy. This
attitude is the basis of understanding one’s story as a quest
narrative. Illness remains a nightmare in many ways, but it
also becomes a possibility, especially for a more intimate
level of connection with others.

Illness as quest is described by Anatole Broyard’s posthu-
mos collection of writings, Intoxicated by My Illness, which
became available late in my work on The Wounded Storyteller.

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3. For these experiences, see Arthur W. Frank, At the Will of the Body: Reflections
Broyard, a writer of some fiction and much literary criticism, presents living with rapidly progressing prostate cancer as a problem of style: "It seems to me that every seriously ill person needs to develop a style for his illness." I understand telling stories as an especially important medium through which we discover what that style might be. Storytelling is less a work of reporting and more a process of discovery.

Broyard then writes the sentence that, in retrospect, defines not only the quest narrative but the core issue of *The Wounded Storyteller*: "It may not be dying we fear so much, but the diminished self." He thus expresses what remains my crucial question: If I become ill again, or when I do, how will I find ways to avoid feeling that my life is diminished by illness and eventually by dying?

Broyard was clear that physicians are often a part of the problem of diminished lives. "Doctors discourage our stories," he writes. I did not include that dig at doctors in *The Wounded Storyteller*, and I am surprised, rereading today, how disciplined I was in depicting health-care professionals only from the perspective of patients and minimizing even that. My intent was to write a book that kept health-care workers generally, and physicians specifically, in the background. Even criticizing doctors makes them central. On rare occasions when I have taught this book, students' biggest initial difficulty is to stop reframing everything ill people say into a question of how some health-care worker might respond. This reframing can be important later for other audiences. But taking the professional perspective undoes what *The Wounded Storyteller* is most concerned to bring about: a view from the ill person's perspective, in which the central problem is how to avoid living a life that is diminished, whether by the disease itself or by others' responses to it.

The professionals in health care and other fields who have communicated with me about *The Wounded Storyteller* all realize that providing treatment should not be equated to offering care, however that distinction is expressed in the respective idioms of different professions. Other readers are working to make sense of their own suffering, struggling to find words and narratives that share their experiences with others. What I appreciate most is when the boundaries between these two types of readers blur. Professionals bring their personal suffering into their work, and ill people discover forms of vocation in illness. The wounded storyteller, ending silences, speaking truths, creating communities, becomes the wounded healer.

*Calgary, Alberta*

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5. Quoted in ibid., 39.
The figure of the wounded storyteller is ancient: Tiresias, the seer who reveals to Oedipus the true story of whose son he is, has been blinded by the gods. His wound gives him his narrative power. The wound that the biblical patriarch Jacob suffers to his hip while wrestling with the angel is part of the story he tells of that event, and it is the price of his story. As Jacob tells his story to those he returns to—and who else could have told it?—his wound is evidence of his story’s truth.

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

The emphasis of contemporary writing is less on the wounded storyteller than on the complementary figure of the wounded healer. For example, Henri Nouwen’s *The Wounded Healer* bases the spiritual vocation on the minister’s acceptance and sharing of her own woundedness.¹ Physicians from Arthur Kleinman to Larry Dossey and journalists like Bill Moyers present the wounded healer as an ideal for medical workers.² Rita Charon writes of the physician’s need “to allow
our own injuries to increase the potency of our care of patients, to allow our personal experiences to strengthen the empathic bond with others who suffer."

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

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

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

In wounded storytelling the physical act becomes the ethical act. Kierkegaard wrote of the ethical person as editor of his life: to tell one’s life is to assume responsibility for that life. This responsibility expands. In stories, the teller not only recovers her voice; she becomes a witness to the conditions that rob others of their voices. When any person recovers his voice, many people begin to speak through that story.

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

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

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

Sooner or later, everyone is a wounded storyteller. In postmodern times that identity is our promise and responsibility, our calamity and dignity. The “theory” I propose here is one tool kit to help fulfill that promise and exercise that responsibility. Twenty years ago when I was a graduate student, theories were proposed with the tag line that they awaited “further research.” I now prefer the idea that this theory awaits further living and the stories of those lives. The theory has been shaped by the stories I have been privileged to live and to hear, and I encourage readers to reshape it in the same spirit.
Finally, because my writing is always an attempt to leave behind traces of myself for my daughters, I thank them for being just who they are: Kate Libbey Frank and Stewart Hamilton-Frank.

"The destination and map I had used to navigate before were no longer useful." These words were in a letter describing chronic fatigue syndrome. Judith Zaruches wrote of how, after an illness that is never really finished, she "needed... to think differently and construct new perceptions of my relationship to the world." 

Serious illness is a loss of the "destination and map" that had previously guided the ill person's life: ill people have to learn "to think differently." They learn by hearing themselves tell their stories, absorbing others' reactions, and experiencing their stories being shared. Judith's story not only stated her need for a new map and destination; her letter itself was an experimental performance of the different thinking she called for. Through the story she was telling me, her new map was already taking shape.

Even though we did not know each other, Judith needed to write to me—she had read my own story of cancer and seen a video tape of a lecture I gave—for me to witness her story and her personal change. As she told me her story, she discovered "new perceptions of [her] relationship to the world." That my response would only come later, in another letter, perhaps made it easier. Seeing herself write, like hearing herself speak, was the major threshold.

Judith's distinctiveness as a storyteller is her illness. Illness
was not just the topic of her story; it was the condition of her
telling that story. Her story was not just about illness. The story
was told through a wounded body. The stories that ill people
tell come out of their bodies. The body sets in motion the need
for new stories when its disease disrupts the old stories. The
body, whether still diseased or recovered, is simultaneously
cause, topic, and instrument of whatever new stories are told.  
These embodied stories have two sides, one personal and the
other social.

The personal issue of telling stories about illness is to give
voice to the body, so that the changed body can become once
again familiar in these stories. But as the language of the story
seeks to make the body familiar, the body eludes language. To
paraphrase Martin Buber, the body “does not use speech, yet
begets it.”  

The ill body is certainly not mute—it speaks eloquently in pains and symptoms—but it is inarticulate. We
must speak for the body, and such speech is quickly frustrated:
speech presents itself as being about the body rather than of it.
The body is often alienated, literally “made strange,” as it is
told in stories that are instigated by a need to make it familiar.

The alternative to this frustration is to reduce the body to
being the mere topic of the story and thus to deny the story’s
primary condition: the teller has or has had a disease. That the
teller’s diseased body shapes the illness story should be self-
evident. Only a caricature Cartesianism would imagine a head,
compartmentalized away from the disease, talking about the
sick body beneath it. The head is tied to that body through
pathways that science is only beginning to comprehend, but
the general principle is clear: the mind does not rest above the
body but is diffused throughout it.  

But actually hearing traces of the body in the story is not
easy. Observing what stories say about the body is a familiar
sort of listening; describing stories as told through the body re-
quires another level of attention. This book attempts to evoke
this other level of attention: How can we make sense of illness
stories as being told through the diseased body?

The ill body’s articulation in stories is a personal task, but the
stories told by the ill are also social. The obvious social aspect
of stories is that they are told to someone, whether that other
person is immediately present or not. Even messages in a
bottle imply a potential reader. The less evident social aspect
of stories is that people do not make up their stories by them-
selves. The shape of the telling is molded by all the rhetorical
expectations that the storyteller has been internalizing ever
since he first heard some relative describe an illness, or she saw
her first television commercial for a non-prescription remedy,
or he was instructed to “tell the doctor what hurts” and had to
figure out what counted as the story that the doctor wanted to
hear. From their families and friends, from the popular culture
that surrounds them, and from the stories of other ill people,
storytellers have learned formal structures of narrative, con-
ventional metaphors and imagery; and standards of what is and
is not appropriate to tell. Whenever a new story is told, these
rhetorical expectations are reinforced in some ways, changed
in others, and passed on to affect others’ stories.  

A first topic of this book is the need of ill people to tell their
stories, in order to construct new maps and new perceptions of
their relationships to the world. A second topic is the embodi-
ment of these stories: how they are told not just about the body
but through it. A third topic is the times that stories are told in:
how the social context affects which stories get told and how
they are told. The central issue of context is the distinction be-
tween illness as experienced in modern versus postmodern
times.
POSTMODERN ILLNESS

The prefix "post" is not quite right; I do not propose any strict periodization of the modern and the postmodern. I do believe that over a period of time, perhaps the last twenty years, how people think about themselves and their worlds has changed enough to deserve a label, and the most accepted label—increasingly diffused in journalism and popular culture—is postmodernism.6 Because of the number of intellectual agendas that employ some version of this label, I prefer "postmodern times." The times that contemporary illness stories are told in, which are also the times I am writing in, have changed fairly recently.

Albert Borgmann's title Crossing the Postmodern Divide7 provides a particularly useful metaphor. Journeys cross divides. Once on the other side, the traveler remains the same person, carrying the same baggage. But on the other side of certain divides, the traveler senses a new identity; that same baggage now seems useful for new purposes. Fundamental assumptions that give life its particular meaning have changed. Postmodernity is such a crossing, occurring when the same ideas and actions are overlaid with different meanings. Sometimes these differences of having crossed the divide are clear, but more often they are subtle: things just feel different. Illness has come to feel different during the last twenty years, and the sum of those differences can be labeled postmodernism. I make no attempt to define postmodernism; the utility of that term lies only in thick descriptions of the feel of the differences.

A useful, if simplified, evocation of the shift from the premodern experience of illness to modernity is provided by a North African woman quoted by Pierre Bourdieu in his anthropological research. That Bourdieu recorded this quotation from a living person is a reminder of the proximity and overlap of the premodern, modern, and postmodern. "In the old days,"

the woman said, "folk didn't know what illness was. They went to bed and they died. It's only nowadays that we've learned words like liver, lung, stomach, and I don't know what."8

Of course premodern people had rich descriptors for disease and its remedies; ethnomedicine was and is highly specific. But I interpret the speaker's closing exclamation as indicating being overwhelmed: she literally doesn't know what. The specialized medical terms that the woman claims her people have only recently learned overwhelm her experience because they come from elsewhere. The shift to modernity crosses a divide into a medical culture that is foreign to this woman's experience of illness.

The modern experience of illness begins when popular experience is overtaken by technical expertise, including complex organizations of treatment. Folk no longer go to bed and die, cared for by family members and neighbors who have a talent for healing. Folk no longer go to paid professionals who reinterpret their pains as symptoms, using a specialized language that is unfamiliar and overwhelming. As patients, these folk accumulate entries on medical charts which in most instances they are neither able nor allowed to read; the chart becomes the official story of the illness. Other stories proliferate. Ill people tell family and friends versions of what the doctor said, and these others reply by telling experiences that seem to be similar: both experiences they have had themselves and ones heard from others. Illness becomes a circulation of stories, professional and lay, but not all stories are equal.

The story of illness that trumps all others in the modern period is the medical narrative. The story told by the physician becomes the one against which others are ultimately judged true or false, useful or not. I will discuss Talcott Parsons's theory of the "sick role" in later chapters.9 What is relevant here is Parsons's observation, made about 1950, that a core social expectation of being sick is surrendering oneself to the care of a
physician. I understand this obligation of seeking medical care as a narrative surrender and mark it as the central moment in modernist illness experience. The ill person not only agrees to follow physical regimens that are prescribed; she also agrees, tacitly but with no less implication, to tell her story in medical terms. "How are you?" now requires that personal feeling be contextualized within a secondhand medical report. The physician becomes the spokesperson for the disease, and the ill person's stories come to depend heavily on repetition of what the physician has said.

Times have come full circle from Bourdieu's North African informant when we read of a patient whose running joke with his surgeon involves reporting his symptoms in an overdone version of medical obscurity. For example, "If you will diligently investigate the pilar projections rising sparsely from the vertex of my cranial ossification, you will detect a macular callosity which may have malignant potential." If modern medicine began when physicians asserted their authority as scientists by imposing specialized language on their patients' experiences, the postmodern divide is crossed when patients such as this one can mimic this language in a send-up of medicine that is shared with the physician. But lay familiarity with medical terms and techniques, even to the point of parody, is only one potential of the postmodern experience of illness.

The postmodern experience of illness begins when ill people recognize that more is involved in their experiences than the medical story can tell. The loss of a life's map and destination are not medical symptoms, at least until some psychiatric threshold is reached. The scope of modernist medicine—defined in practices ranging from medical school curricula to billing categories—does not include helping patients learn to think differently about their post-illness worlds and construct new relationships to those worlds. Yet people like Judith Zaruches express a self-conscious need to think differently.

Both the divide that was crossed from the premodern to the modern and that from modern to postmodern involve issues of voice. The woman reported by Bourdieu seems to perceive that medicine has taken away her voice: medicine assails her with words she does not want to know and leaves her not knowing what. But this woman does not perceive a need for what would now be called her own voice, a personal voice telling what illness has imposed on her and seeking to define for herself a new place in the world. What is distinct in postmodern times is people feeling a need for a voice they can recognize as their own.

This sense of need for a personal voice depends on the availability of the means—the rhetorical tools and cultural legitimacy—for expressing this voice. Postmodern times are when the capacity for telling one's own story is reclaimed. Modernist medicine hardly goes away: the postmodern claim to one's own voice is halting, self-doubting, and often inarticulate, but such claims have enough currency for illness to take on a different feel.

Voices tell stories. Stories are premodern; Bourdieu's informant suggests that the coming of modern medicine took away a capacity for experiencing illness in her folk's traditional stories. In the modern period the medical story has pride of place. Other stories become, as non-medical healers are called, "alternative," meaning secondary. The postmodern divide is crossed when people's own stories are no longer told as secondary but have their own primary importance. Illness elicits more than fitting the body into traditional community expectations or surrendering the body to professional medicine, though both community traditions and professional medicine remain. Postmodern illness is an experience, a reflection on body, self, and the destination that life's map leads to.
The Remission Society

The possibility, even the necessity, of ill people telling their own stories has been set in place by the same modernist medicine that cannot contain these stories. At the end of the story that I wrote about my own experience of having cancer, I used the term “remission society” to describe all those people who, like me, were effectively well but could never be considered cured. These people are all around, though often invisible. A man standing behind me in an airport security check announces that he has a pacemaker; suddenly his invisible “condition” becomes an issue. Once past the metal detector, his “remission” status disappears into the background.

Members of the remission society include those who have had almost any cancer, those living in cardiac recovery programs, diabetics, those whose allergies and environmental sensitivities require dietary and other self-monitoring, those with prostheses and mechanical body regulators, the chronically ill, the disabled, those “recovering” from abuses and addictions, and for all these people, the families that share the worries and daily triumph of staying well.

Cathy Pearse writes in middle-age about having a bleeding cerebral aneurysm—a stroke—when she was twenty. During the operation, a cranial nerve was damaged. She still suffers from double vision, which she reports is “an ever present reminder” of her near-death experience. Her body is now beginning to feel the long-term effects of muscle asymmetry and favoring her “good side.” But her illness history would be invisible to most people she meets, and she is long since considered “cured” by medicine. Cathy is a member of the remission society. Years after her hospitalization and treatment, she can still describe what happened in exquisite detail; she recalls the hurt caused by a nurse’s casual comment as if it had been spoken yesterday. She refers to being a “recovered stroke patient” as one aspect of her “ethnicity,” a word suggesting an irrevocable identity.

The physical existence of the remission society is modern: the technical achievements of modernist medicine make these lives possible. But people’s self-consciousness of what it means to live in the wake of illness is postmodern. In modernist thought people are well or sick. Sickness and wellness shift definitively as to which is foreground and which is background at any given moment. In the remission society the foreground and background of sickness and health constantly shade into each other. Instead of a static picture on the page where light is separated from dark, the image is like a computer graphic where one shape is constantly in process of becoming the other.

Parsons’s modernist “sick role” carries the expectation that ill people get well, cease to be patients, and return to their normal obligations. In the remission society people return, but obligations are never again what used to be normal. Susan Sontag’s metaphor of illness as travel is more subtle than Parsons’s sick role. We are each citizens of two kingdoms, Sontag writes, the kingdom of the well and that of the sick. “Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.” Sontag’s notion of dual citizenship suggests a separation of these two kingdoms. The remission society is left to be either a demilitarized zone in between them, or else it is a secret society within the realm of the healthy.

To adapt Sontag’s metaphor, members of the remission society do not use one passport or the other. Instead they are on permanent visa status, that visa requiring periodic renewal. The triumph of modernist medicine is to allow increasing numbers of people who would have been dead to enjoy this visa status, living in the world of the healthy even if always subject to expulsion. The problem for these people is that mod-
ernist medicine lacked a story appropriate to the experience it was setting in place. People like Judith Zarubes were left needing a new map for their lives.

The postmodernity of the remission society is more than a self-consciousness that has not been routinely available to the ill. Many members of the remission society feel a need to claim their visa status in an active voice. Those who work to express this voice are not only postmodern but, more specifically, *post-colonial* in their construction of self. Just as political and economic colonialism took over geographic areas, modernist medicine claimed the body of its patient as its territory, at least for the duration of the treatment. "When we're admitted to a hospital or even visiting a doctor," writes Dan Gottlieb, who as a quadriplegic has extensive experience with such visits, "the forms ask for 'Patient Name.' We stop being people and start being patients.... Our identity as people and the world we once knew both are relinquished; we become their patients and we live in their hospital." Gottlieb's anger reflects a widespread resentment against medical colonization.

For those whose diseases are cured, more or less quickly and permanently, medical colonization is a temporary indignity. This colonization becomes an issue in the remission society when some level of treatment extends over the rest of a person's life, whether as periodic check-ups or as memories. The least form of treatment, periodic check-ups, are not "just" monitoring. "The fear comes and goes," writes Elizabeth Tyson, a breast cancer survivor, "but twice a year, at checkup time, it's ferocious." For the person being checked, these check-ups represent the background of illness shading back into the foreground. Even for those whose visa is stamped expeditiously, the reality of lacking permanent citizenship is reaffirmed.

Colonization was central to the achievement of modernist medicine. Claudine Herzlich and Janine Pierret describe the "sick person" emerging as a recognizable social type in the early modern period, during the eighteenth century. The condition necessary for the emergence of this type was that "the diversity of suffering be reduced by a unifying general view, which is precisely that of clinical medicine." This reducing of the particular to the general provided for scientific achievements, but the clinical reduction created a benevolent form of colonialism.

The ill person who plays out Parsons's sick role accepts having the particularity of his individual suffering reduced to medicine's general view. Modernity did not question this reduction because its benefits were immediate and its cost was not yet apparent. The colonization of experience was judged worth the cure, or the attempted cure. But illnesses have shifted from the acute to the chronic, and self-awareness has shifted. The post-colonial ill person, living with illness for the long term, wants her own suffering recognized in its individual particularity; "reclaiming" is the relevant postmodern phrase.

In postmodern times more and more people, with varying degrees of articulation and action, express suspicion of medicine's reduction of their suffering to its general unifying view. Members of the remission society, who know medicine from the inside out, question their place in medical narratives. What they question can be clarified by drawing an analogy to people who were politically colonized. Gayatri Chakravorty Spivak speaks of colonized people's efforts "to see how the master texts need us in [their] construction...without acknowledging that need." What do the master texts of medicine need but not acknowledge?

I met a man who had a cancer of the mouth that required extensive reconstructive surgery to his jaw and face. His treatment had been sufficiently extraordinary for his surgeon to have published a medical journal article about it, complete with pictures showing the stages of the reconstructive process.
When he told me about the article and offered to show it to me, I imagined the article might actually be about him: his suffering throughout this mutilating, if life-saving, ordeal. As I looked at the article I realized his name was not mentioned. Probably the surgeon and the journal would have considered it unethical to name him, even though pictures of the man were shown. Thus in “his” article he was systematically ignored as anyone—actually anything—other than a body. But for medical purposes it was not his article at all; it was his surgeon’s article. This is exactly the colonizing that Spivak speaks of: the master text of the medical journal article needs the suffering person, but the individuality of that suffering cannot be acknowledged.

Most ill people remain willing to continue to play the medical “patient” game by modernist rules without question, and almost all do so when required. But post-colonial members of the remission society are demanding, in various and often frustrated ways, that medicine recognize its need for them. Refusing to be reduced to “clinical material” in the construction of the medical text, they are claiming voices.

Because illness, following medicine, is effectively privatized, this demand for voice rarely achieves a collective force. Feminist health activists are a major exception. Susan Bell writes about the attempts by members of the Cambridge Women’s Community Health Center (WCHC) to change the role played by women who were recruited by Harvard Medical School to serve as paid “pelvic models” for medical students to learn to perform gynecological examinations. Bell tells of the women’s escalating demands to participate in a full teaching role rather than serve as inert bodies to be taught upon. Women negotiated for their own class time with medical students, they sought to demonstrate how women could perform their own gynecological examinations using a mirror, and they injected political issues into the medical curriculum.

The medical school finally rejected WCHC demands that teaching be limited to women (since the experience of being examined should be, in principle, reciprocal), that non-student hospital personnel and other consumers be included in the teaching sessions, and that more political discussion contextualize the medical teaching. The specifics of the WCHC demands are less important than their basic post-colonial stance: women wanted to have their necessity acknowledged in the construction of medical knowledge and practice. They claimed an active voice in that knowledge and practice.

Post-colonialism in its most generalized form is the demand to speak rather than being spoken for and to represent oneself rather than being represented or, in the worst cases, rather than being effaced entirely. But in postmodern times pressures on clinical practice, including the cost of physicians’ time and ever greater use of technologies, mean less time for patients to speak. People then speak elsewhere. The post-colonial impulse is acted out less in the clinic than in stories that members of the remission society tell each other about their illnesses.

The post-colonial stance of these stories resides not in the content of what they say about medicine. Rather the new feel of these stories begins in how often medicine and physicians do not enter the stories. Postmodern illness stories are told so that people can place themselves outside the “unifying general view.” For people to move their stories outside the professional purview involves a profound assumption of personal responsibility. In Parson’s sick role the ill person as patient was responsible only for getting well; in the remission society, the post-colonial ill person takes responsibility for what illness means in his life.
POSTMODERN RESPONSIBILITY

Anthony Giddens describes the contemporary self as a reflexive project, for which the individual is responsible. The notion of the self as a reflexive project echoes Socrates' advocacy of the examined life, but Socrates was speaking to an elite, and how far he advocated changing one's life as a result of self-examination is debatable. The modernist responsibility that Giddens refers to has its epigram in the famous line of the poet Rilke, "You must change your life." Modernity is premised on people's capacity to change their lives; philosophical self-examination becomes a practical challenge. Giddens's "reflexive project" describes people taking up Rilke's challenge.

In postmodern times the reflexive project of self can yield two different sorts of identities, contrasted by Zygmunt Bauman to suggest developments that are either more or less responsible. The line of self-development that I understand as less responsible gives rise to what Bauman calls "momentary identities, identities 'for today', until-further-notice identities." Such a self is primarily responsible to itself; its responsibilities are limited to the sphere of its own perceived self-interest. This sphere may include others, but these others are included "until further notice."

The alternative form of postmodern self—though it is hardly unique to postmodern times—is described in Bauman's summary of the moral philosophy of Emmanuel Levinas: "I being for the Other, I bearing responsibility for the Other." Since defining the self in terms of responsibility for the other is the core ethical impulse in most religions, the parable of the Good Samaritan being one of the most succinct examples, what news is there in Bauman's and Levinas's revival of this idea? One response is that so long as practice continues to fall short of the ideal, the ideal must be reaffirmed in the idiom of each age.

A stronger response is that Levinas means something different from how the Samaritan ideal is conventionally interpreted. Living for the other is not, as Levinas describes it, an act of exemplary goodness. Persons live for others because their own lives as humans require living that way. The self is understood as coming to be human in relation to others, and the self can only continue to be human by living for the Other. Bauman concludes his book with a discussion of the ethics of dying for another person, the self that is willing to sacrifice itself for another could not be further removed from the "until-further-notice" sense of responsibility.

For present purposes, however—and I return to Levinas in chapter 9—the importance of Bauman and Levinas is that in secular modernist culture the ideal of living for the other has been sufficiently lost that redefining it does constitute news. Bauman demonstrates how the sense of responsibility for the specific other person—as opposed to collective others—was a casualty of modernity. An understanding of why modern medicine has limited the concept of responsibility as it has, and of how sociology has justified this limitation, can be derived from his work.

Parsons's sick role articulated the modernist requirement that ill persons delegate responsibility for their health to physicians; illness responsibility is reduced to patient compliance. Physicians as described in Parsons's sociology are in turn responsible more to professional codes than to individual patients. According to modernist universalism, the greatest responsibility to all patients is achieved when the professional places adherence to the profession before the particular demands of any individual patient.

Such professionalism—paradigmatic of modernity—is responsible less to individual people than to truth, understood on several levels: the factual truth of medical science, the beneficent truth of institutional management in the hospital, and
ultimately the political truth of administering people’s welfare, which Michel Foucault calls biopolitics. Modernity accepted these truths, and this acceptance required the patient’s narrative surrender to medicine.

These modernist truths remain the basis of professional practice even on this side of the postmodern divide, and popular demand for that practice increases. The prospect of economic necessity requiring explicit rationing of health care provokes fear in many people. The ambivalence on this side of the divide is that, simultaneous with increased demand, confidence in the possibility of truth delivering on its promises has faded. The same people who one moment are fearful that their health care will be rationed may, in the next moment, attend a pro-choice meeting on euthanasia and speak of their fear of “dying on a machine.” People still need their specific professionals, but professions as a group are regarded with increasing cynicism. Strains in lay/professional relations reflect not only conflicts of expectations between these groups, but conflicts within each group’s expectations as well.

Ill people still surrender their bodies to medicine, but increasingly they try to hold onto their own stories. Refusing narrative surrender becomes one specific activity of reflexive monitoring, and thus an exercise of responsibility.

The status of personal responsibility is a central moral issue for postmodernity. Bauman’s description of the momentary identity that holds itself to no particular standard expresses the cynical response to the demise of truth. An alternative was expressed at the beginning of the century by William James, whose prescient modernism may already have crossed the postmodern divide. One of James’s letters is the finest epigram I have found to the particular assumption of responsibility that is equally a potential of postmodern times:

I am convinced that the desire to formulate truths is a virulent disease. It has contracted an alliance lately in me with a feverish personal ambition, which I never had before, and which I recognize as an unholy thing in such a connection. I actually dread to die until I have settled the Universe’s hash in one more book...! Childish idiot—as if formulas about the Universe could ruffle its majesty and as if the commonsense world and its duties were not eternally the really real.

Like a good postmodernist, James rejects truth, but he does so on moral grounds that other aspects of postmodernity often negate.

James is concerned about his own corruption by the “unholy” alliance of truth and personal ambition. His rejection of the attempt to state universal truth—the stuff that could settle the Universe’s hash—seems a necessary prerequisite to an enhanced sense of responsibility. In place of universal truth James affirms the “really real” of “the commonsense world and its duties.” I read that last word, duties, as the strongest in his confession.

Ill people’s storytelling is informed by a sense of responsibility to the commonsense world and represents one way of living for the other. People tell stories not just to work out their own changing identities, but also to guide others who will follow them. They seek not to provide a map that can guide others—each must create his own—but rather to witness the experience of reconstructing one’s own map. Witnessing is one duty to the commonsensical and to others.

The idea of telling one’s story as a responsibility to the commonsense world reflects what I understand as the core morality of the postmodern. Storytelling is for an other just as much as it is for oneself. In the reciprocity that is storytelling, the
teller offers herself as guide to the other’s self-formation. The other’s receipt of that guidance not only recognizes but values the teller. The moral genius of storytelling is that each, teller and listener, enters the space of the story for the other. Telling stories in postmodern times, and perhaps in all times, attempts to change one’s own life by affecting the lives of others. Thus all stories have an element of testimony, and the particular testimony of illness stories will be developed in later chapters.

Telling stories of illness is the attempt, instigated by the body’s disease, to give a voice to an experience that medicine cannot describe. This voice is embodied in a specific person, but it is equally social, taking its speech from the postmodern times we live in. The voice of the ill person is made possible by modernist medicine, but it cannot be contained within modernist assumptions, particularly those about medical professional dominance and the narrative surrender this dominance requires. A divide has been crossed into new territory, the postmodern, and we know this crossing by the new voices that are heard.

As a post-colonial voice, the storyteller seeks to reclaim her own experience of suffering. As she seeks to turn that suffering into testimony, the storyteller engages in moral action. The themes of body, voice, and illness culminate in the ethics made uniquely possible in postmodern times. Postmodernity is not often described in ethical terms, and when it is, the assessment is usually that “postmodern ethics” is an oxymoron.

In a chapter entitled “The Post-Modern Void,” Alan Wolfe summarizes the intellectual trends of postmodernity as indicating that “nothing is eternal, all value is relative, meaning is self-referential, and the sacred is little more than an ideological construct imposed by those who hold power over those who lack it.” Wolfe certainly assesses one aspect of postmodernity correctly. But in postmodern times, to seek the eternal, the valued, and the sacred in intellectual trends is to look in the wrong place.

Postmodernity has its distinctive ethics, but these must be sought in the everyday personal struggles of people like Judith Zaruches, Cathy Pearse, and Dan Gottlieb, who are trying to make moral sense of their own suffering and who are witnesses to sufferings that go beyond their own. William James’s direction to attend to the commonsense world and its duties still informs the task of the intellectual in postmodern times. The circle of witnesses includes not just ill persons and those who care for them, but the intellectuals who observe these people and their struggles. In these observations, postmodern intellectuals can affirm what is eternal, valuable, meaningful, and sacred.

Wolfe’s observation of “the post-modern void” is a welcome reminder of the risk of our times. Just as James felt personally at risk from his “feverish personal ambition,” the postmodern intellectual is at risk. James feared his ambition to settle “the Universe’s hash.” To settle the Universe’s hash is to place oneself outside the vulnerability and contingency that being in the Universe involves. The intellectual infected with such an ambition ceases to think of himself as a body, thus disclaiming the vulnerability that bodies share. Ceasing to think of oneself as a body severs a connection that is fundamental to thinking of oneself as a person who exists for other people. Social science—or any academic and professional discipline that observes and attends the ill—must accept responsibility for its observations as acts of witness that commit the scientist as a person.31

The premise of this book is that responsibility begins and ends with the body. Both observation and witness begin with a body, and both commit that body. I concluded an earlier review article by calling for an ethics of the body.32 Such a project is too large for one lifetime, much less one book. No one can settle the body’s hash, but I hope the present book begins to
make good on that call. Postmodern times are a void only if people cease to fill those times with meaning.

ABOUT THIS BOOK

A constant theme of social theory is contingency, interpreted as the problem of how stable a course of action can be when this action depends on, but cannot control, some other action. I have made the body’s contingency—how much any of us can depend on our bodies—a major theme below. So perhaps it is fitting that the materials forming the basis of this book were collected through contingent circumstances.

I began academic life as a medical sociologist and then gave it up because I had trouble gaining access to what interested me most, the direct experiences of ill persons. After a decade of pursuing other topics, I returned—or was returned—to illness experience. In 1985 I suffered a heart attack (ventricular tachycardia) as a result of a viral infection. It was a highly contingent heart attack, I was told, dependent on a virus that might have acted otherwise. Just over a year later I was feeling fully recovered when I began to notice the symptoms that eventually proved to be testicular cancer (a seminoma tumor). A year after I had ended treatment myself, my mother-in-law, Laura Foote, came out of cancer remission for the last time.

In 1989 I wrote about these events in what might be called an analytic memoir, At the Will of the Body: Reflections on Illness, published in 1991. Since 1992 that book has been the basis of continuing personal encounters, letters, phone calls, conferences, and lectures that have kept me in contact with individual ill persons and support groups, as well as nursing, chaplain, administrative, and medical groups.

I have tried to tell medical residents what it is like to be seriously ill, my talks usually taking place during the lunch break while they gulp down the pizza, soda, and cookies provided by
drug companies expressing their usual commitment to health. I have listened to what medical students hope to become as physicians and to what they fear may happen to them in practice. In other hospitals, in what seems like another world, I have listened as a support group of parents began their meeting by each saying the name of their child who had died and adding, if emotion allowed further speech, what the cause of death had been. When I was introduced as the evening’s speaker, I wondered what I could possibly tell them about suffering. These personal experiences frame this book.

My direct experiences in the world of illness are complemented by reading many published and unpublished illness stories. The published works are particularly important to this book because, being published, they are easily quoted: readers can reread the stories for themselves. Published stories also have a particular influence: they affect how others tell their stories, creating the social rhetoric of illness. But published materials have their problems. There can be no pretense of a “sample” of this writing, both because there is so much written and because illness figures variously in many different memoirs. What counts as an illness story is by no means clear.

A more substantive problem is the appropriate suspicion about how any published account may have been shaped by editorial forces that the author might have wanted to resist. I know this shaping occurs; I know that even when I have talked to a book’s editors I can never be sure how any particular account was shaped; yet I continue to believe that published stories are “true.” The truth of experience is malleable.

My own experience of publishing my story can serve to illustrate the complex interactions of storytelling and experience. By the time At the Will of the Body was ready for publication, I wondered if I had compromised too much and if the story was still “mine.” I had written every word, but as editorial advice
accumulated, I was less than confident whose voice was being written. Now I can hardly remember what those compromises were: either the book has become my experience, or my experience always was the book. Thus I return to my claim that even edited stories remain true. The truth of stories is not only what was experienced, but equally what becomes experience in the telling and its reception.

The stories we tell about our lives are not necessarily those lives as they were lived, but these stories become our experience of those lives. A published narrative of an illness is not the illness itself, but it can become the experience of the illness. The social scientific notion of reliability—getting the same answer to the same question at different times—does not fit here. Life moves on, stories change with that movement, and experience changes. Stories are true to the flux of experience, and the story affects the direction of that flux.

If calling stories true requires some category of stories called false, I confess to being unsure what a “false” personal account would be. I have read personal accounts I considered evasive, but that evasion was their truth. The more reconstructed the story, the more powerful the truth of the desire for what is being told, as the corrected version of what was lived. Hearing the desire in the story takes me back to the need for a different level of attention to stories.

A final influence on this book is that as I write I am in the middle of my three-year term as editor of the “Case Stories” series in the professional journal Second Opinion: Health, Faith, Ethics.36 My commitment in the series is to publish first-person accounts of illness experience. Each “story” has two commentators who ostensibly write in a “professional” voice, but like many distinctions in postmodern times, the first and third-person voices seem hard to separate. Faced with first-person stories, the commentators tell their own stories. At issue in the commentaries, as throughout this book, is the question of what can be said about a story of primary witness, and to what extent the story has to be left to speak for itself.

My most provocative, and often troubling, editorial task has been requesting revisions to people’s stories. I recognize that in asking authors to revise their stories, I may be asking them to revise their experiences. Recently an author, Richard Morgan, was asked by one of the journal’s manuscript reviewers to provide more medical detail in his story. In response, he subpoenaed and read his medical chart. He told me he then understood, for the first time, what had happened to him during his surgery and hospitalization. Perhaps he did; or perhaps he now has a new story, no more or less true to his experience than his old one, but partially instigated by the editorial machinery. My own experience of reading stories at all stages of editorial review has formed the ideas in this book, not least by affecting how I read published accounts that I have not had an editorial hand in.

My objective with these eclectic materials—stories heard in person, read in print, and watched being shaped for publication—is to develop a practice for doing what I heard an anthropologist recommend while attempting to explain a native oral tradition to a white audience: “You have to learn to think with stories.”37 Not think about stories, which would be the usual phrase, but think with them. To think about a story is to reduce it to content and then analyze that content. Thinking with stories takes the story as already complete; there is no going beyond it. To think with a story is to experience it affecting one’s own life and to find in that effect a certain truth of one’s life. Thus in this book people’s illness stories are not “data” to support various propositions that I advance. Instead, the stories are the materials that I use to model theorizing—and living—with stories.

My project in clinical ethics is to move ethicists and practitioners in the direction of thinking with stories: to help profes-
sionals to recognize ill persons' stories and all they represent. The complementary project in social science might be called a sociology of witness. I seek to situate both clinical ethics and social science within a more general ethics of the body. Such an ethics develops terms of responsibility to the stories told through suffering bodies. Being responsible to these stories, thinking with them, depends on telling certain stories over and over, hearing different nuances of potential meaning as the story is told in different circumstances and at different ages of our lives. Thus in this book I return to comparatively few illness stories.

Thinking with stories is not nostalgia for a premodern oral culture. On our present side of the postmodern divide any thinking with stories carries the baggage of modernity. Thus I retell stories and then, like a good modernist, place them into analytical frameworks. My defense for this procedure is that in times when we have lost the premodern feel for stories, heuristic frameworks can help to hear them. Frameworks can disentangle types of narratives; they can help in recognizing what basic life concerns are being addressed and how the story proclaims a certain relation of the body to the world. The frameworks are not the truth of the stories, which is how modernism often presented its typologies. The frameworks I present are only a means of heightening attention to stories that are their own truth.

Thinking with stories ultimately requires a highly personal sedimentation of experience: living with the stories and having them shape perceptions of various experiences over time. I began reading other people's illness stories just after I was ill myself, and the stories in which I most often anchor my thoughts remain those I read first, just because I have lived with them the longest and had them recur to me in the most varied situations. Some more recent stories may be "better" to make certain points, but stories take time to become mine. My ambition for this book is to facilitate each reader's own sedimentation, but that process can only occur in each reader's own experience, and experience takes time to sediment.

After having cancer I attempted to read some of the professional literature describing the experience I had gone through. I found the language too distant from the immediacy of embodied suffering that I had recently experienced. In Spivak's terms, the professional text needed my body, but it could not acknowledge that need. Now I sense this book about others' stories becoming too analytical, too distant from embodied experience, too modernist in its rationalization of experience. But following James, I seek not to settle the hash of even that small corner of the universe called human illness in late twentieth century North America. Rather I want only to affirm the commonsense world and its duties.

One of our most difficult duties as human beings is to listen to the voices of those who suffer. The voices of the ill are easy to ignore, because these voices are often faltering in tone and mixed in message, particularly in their spoken form before some editor has rendered them fit for reading by the healthy. These voices bespeak conditions of embodiment that most of us would rather forget our own vulnerability to. Listening is hard, but it is also a fundamental moral act; to realize the best potential in postmodern times requires an ethics of listening. I hope to show that in listening for the other, we listen for ourselves. The moment of witness in the story crystallizes a mutuality of need, when each is for the other.