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Under the Medical Gaze

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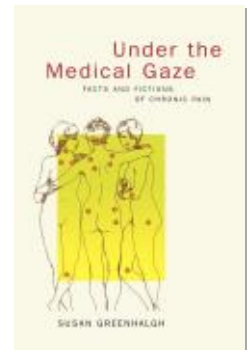
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Preface

An epidemic of chronic pain stalks America today. Nearly half of all Americans suffer from one or more chronic conditions, including illnesses and impairments, and the number is growing.¹ Even as tens of millions struggle with such established chronic diseases as arthritis, diabetes, hypertension, and heart disease, millions more are afflicted with the new chronic conditions of late-twentieth-century civilization.² The past two decades have brought a dizzying number of such ailments: chronic fatigue syndrome, repetitive strain disorder, Gulf War syndrome, environmental hypersensitivity, and, among the newest entrants, fibromyalgia. Although the symptom mixes vary, these disorders share many features. All lack a known organic basis and are difficult to diagnose. All lack a recognized cause but are worsened by stress. All are syndromes of related symptoms rather than true diseases. All are chronic and treatable to a certain extent, but incurable. Most target women in larger numbers than men.

In a culture that worships science, it is to scientific (or conventional) medicine that we first turn for help. Women desperate for someone to acknowledge and alleviate their suffering go to their doctors to name and ease their new pains. Professionally obligated to heal and motivated by humanitarian impulses, our doctors try to live up to our expectations. Although the treatment of chronic pain is one of scientific medicine's most visible failures, in a time of shrinking resources, medical specialists are only too happy to have a new domain in which to apply their skills. Research scientists develop diagnostic criteria for a new syndrome, clinical scientists work out treatment protocols, and a new group of specialists emerges with a guaranteed stable of patients for life. Before long, a bona fide new disease has entered the medical and cultural mainstream. In this way, distress is transformed into disease, and the "diseasing" of social life moves ineluctably forward.

Most of us think that medicine can reveal the truth of our bodies because medicine is a science that claims to have direct, privileged access

to the truths of nature. But does scientific medicine convey The Truth or only *a* truth of our bodies? In recent years growing numbers of scholars in the humanities and social sciences have maintained that medicine's truth is only one truth. Moreover, they contend, it is a partial, interested, and value-laden truth that conceals these weaknesses in the discourses of scientific objectivity and in the rhetorics of physician heroism.

These limitations of the scientific approach to healing matter, because scientific medicine wields prodigious power over our lives. This power is produced by the workings of the "medical gaze," a term coined by the French philosopher Michel Foucault.³ Through the knowing gaze of the physician, medicine claims to "see" diseases that lie deep within the body, bringing them into being as objects of consciousness and intervention. This distinctive way of seeing permits the doctor to know and label our diseases and, on those grounds, to orchestrate interventions in our bodies, with effects that spill over into our lives. How medicine works—what it can and cannot do—affects every one of us, and some of us deeply.

In the medical profession today, there are encouraging signs of greater openness to criticism and growing willingness to address the shortcomings of the scientific, or "biomedical," approach to illness. There is more talk than ever of holistic approaches to healing, partnership relations with patients, and open disclosure of medical mistakes. Yet change has been late and limited. Today medicine at large remains aloof from the more radical critiques of the humanists and social scientists. For good institutional, economic, and legal reasons, most physicians remain inside the discourses of scientific medicine, unable or unwilling to see that their scientific worldview is but one among others. The public actively participates in the mythmaking. We marvel at medicine's high-tech "breakthroughs," while readily forgetting its low-tech mistakes—the wrong leg amputated, the wrong part of the brain excised, and so on. We are awestruck by its promises to overcome human biology and reengineer our genes, neglecting the social, economic, and cultural costs involved. We know the larger system is troubled, but we trust our individual doctors because they have taken the Hippocratic oath—above all, do your patient no harm. And we trust because we have little choice in any case. Many forces have begun to chip away at the power and authority of biomedicine, but its mystique retains a powerful hold on the public and the profession alike. The need for critique remains great.

This book deepens the critique of the humanists and social scientists by moving into the inner sanctum of scientific medicine, the examining room, to discern how medicine does its work in a real-life clinical encounter

between physician and patient. My vehicle is the auto-ethnography. The working tool of anthropologists, *ethnography* interweaves fine-grained description with close analysis to create a compelling portrait of a small but closely observed slice of social life. In *auto*-ethnography, the writer is also a participant in the domain of life observed. (I say more about this genre in the next chapter.) The ethnographic core of this book is a case study of one intense doctor-patient encounter that lasted for more than eight months in 1996. This medical encounter carries special interest, because it had all the ingredients of a medical success story—an able doctor, an eager patient, goodwill on both sides—but instead turned into a medical nightmare. In a nutshell, it is a story of a passionate specialist who, through creative interpretation of the diagnostic criteria for a newly emerging chronic disease, convinced both himself and his patient that she had a painful, essentially untreatable lifelong muscle condition called fibromyalgia. Events later proved that she did not. The story traces the effects of this simple idea—that the patient “had fibromyalgia”—on the patient’s inner world, bodily health, and overall well-being. To give away the end of the story at the beginning, the effects were nearly ruinous: the patient began to think of herself as a seriously sick person, she grew morbidly depressed, her physical condition worsened, and she started to slip into a mental fog until, nearing the edge of the abyss, she consulted another physician who discovered the mistake and urged that she take steps to undo the damage. When faced with these facts, the diagnosing doctor would acknowledge neither that his patient’s life had come undone nor that he had contributed to her deteriorating state.

One might be tempted to tell this story as a medical morality tale of a bad male doctor doing evil to a good female patient. (Indeed, a female doctor even comes to the rescue.) This book strenuously resists this temptation. Whose behavior deserves praise and whose condemnation is far from clear. Not only did the doctor do some good, but the patient actively (if unwittingly) participated in the near destruction of her life. In the end there are no heroes or villains in this story. Quite the contrary, everyone in it was trapped in the same larger systems of power, which for a very long time no one could see and no one could undo.

In this book I try to unravel the tangled threads that led such a promising medical relationship to produce such catastrophic effects. Part of my task is to write a medical whodunit—to sift through the technical details of multiple disease entities, a multifaceted treatment plan, and a panoply of prescription drugs, all with complicated side effects and in-

teractions, to figure out how things got so far off track. In particular, I need to solve the mystery of how the patient could manifest so many symptoms of a disease she didn't even have. (Clue: she had another disease. Second clue: the treatments for one disease had mysterious effects on the other.) As an avid reader of Patricia Cornwell, Amanda Cross, Sue Grafton, and other women mystery writers, I take up this task with relish, albeit with less writerly skill than these popular authors.

As a student of culture and politics, however, my major concern is to show what this case reveals about the workings of power and culture in the biomedical domain. Although I do not claim that one episode can reveal the workings of a whole culture, I do maintain that some of the most subtle seductions and dangers of our hypermedicalized culture can be grasped only through meticulous attention to the minutiae of specific doctor-patient relationships such as the one described in this book. In trying to understand how things could go so awry, I looked closely at three dimensions of contemporary medicine that are highlighted by the critiques of the humanists and social scientists: the workings of science, gender, and popular cultures of illness. I posed three sets of questions of the case material. First, what is the work of scientific medicine, how does it do this work, and what are the effects for the patient who is the object of medical attention? Second, how does gender affect the power dynamics and outcomes of the biomedical encounter? What exactly goes on in the examining room when the physician is male and the patient female? And third, what alternative discourses on the suffering body and its healing are available in the cultural repertoire? Do the alternative and New Age medical discourses that saturate our culture today help the person in pain or do they only worsen the suffering? Or is the answer perhaps some of both?

In taking up the task of political and cultural analysis I build on the work of many others. Growing scholarly literatures—in gender studies, medical anthropology and sociology, and cultural studies of science and technology—have revealed the complex workings of the discourses and practices of biomedicine and their specific effects on women's lives. But there is still a great deal we do not know. This case takes us into new territories that remain sketchily mapped at best. These include the realm of rheumatological medicine, which treats primarily women but remains unexplored by feminist scholars; the psychological dynamics of patienthood; the intimacies of the doctor-patient relationship; and gendered forms of patient resistance to physician power. We also probe newly emerging “postbiomedical” discourses on the social sources of chronic

pain and psychosocial routes to healing it. I hope this book will have something new to contribute to those bodies of work from which I learned so much.

In writing this book I have a rather large agenda of empirical, theoretical, and political goals. Descriptively, I want to shed light on a darker side of medicine that tends to get lost in the shadows of triumphal narratives of doctors performing medical miracles and of patients achieving personal victories in the face of serious illness. While such stories are inspiring, we need to pay more attention to medicine's failings. When doctors unwittingly produce bad outcomes and see them as good, we have a rare opportunity to see the inherent weaknesses of the larger system of which these doctors are a part.

My second goal is to improve our understanding of the workings and effects of biomedical power. Because I was the patient whose life came unraveled, I came to know in a very immediate way the shortcomings of existing cultural, literary, and feminist critiques of science and medicine. At the time of the medical encounter I was well versed in the critique of science, yet that critique did not protect me when I most needed its help. (Feminist theory did, however, provide crucial tools for resistance.) My experience as a long-term patient amply supports the weight now given to discourse in the cultural critique of biomedicine. At the same time, it suggests that students of the biomedical encounter would gain deeper insight by probing even more fully than they have into the rhetorics of medicine, the inner world of identity or selfhood, and the deep, psychologically rooted limits on women's resistance in face-to-face encounters with male physicians. Without ignoring discourse, this book gives these latter elements increased prominence, in a way that I hope will enrich our understanding of medicine and improve the fit between sociomedical theory and reality. This book also goes beyond the critique of biomedicine to probe the social roots of chronic pain and therapeutic alternatives that rely on neither the body-cure of conventional medicine nor the mind-cure of some alternative medicines but rather on a broader set of strategies that address the sociopolitical sources of the pain.

My aims are also expressly political. Throughout the centuries women in sexist societies have expressed the pain in their lives in the form of bodily ills. From witches to hysterics to fibromyalgics, women have been harmed or incited to harm themselves for deviating from expected gender norms. For this destructive pattern to be undone, women's pain must be politicized. I intend this book as a political intervention on three levels: the plight of the individual patient, the discourse about one partic-

ular chronic pain condition, and the culture of medicine at large. One of my political goals is to alert patients who are unfamiliar with social studies of biomedicine to the power dynamics in their medical encounters. Another is to draw attention to an emerging new domain of power, the “disease of fibromyalgia,” which is now seen by patients and physicians alike as a liberating force for women in pain. A third is to provide elements of a critique of the biomedicine of chronic pain that I hope others will build upon and put to work in the service of creating better and more just forms of medical practice.

I wrote this book for students of medicine, gender, and power in contemporary American life. I also wrote it for physicians and patients. Of all these groups, I most hope to reach the biomedical community. Unfortunately, many physicians are like the doctor described in these pages: they tend to protect themselves from hard truths, to refuse to hear that they might have caused harm while they were trying only to do good. My hope is that other doctors, perhaps some less bewitched by the charms of science, might read this book and find in it a cautionary tale of how powerful is the word of the physician and how biomedicine can go very wrong, *especially* when it is confident that it is unequivocally right.

In the remainder of this preface, I provide some background material to the story that follows. I begin by sketching in key features of the disease that will be featured in these pages, fibromyalgia. (Although technically fibromyalgia is a syndrome, for ease of communication I follow common parlance and refer to it loosely as a “disease.”) Next I introduce the materials that I used in writing the book. Finally, I outline the chapters that will follow and caution against some readings of the story that I hope to discourage.

The Biomedicine of Fibromyalgia

The last two decades have brought growing interest in fibromyalgia, the name given to a painful disorder of the musculoskeletal system. Arthritis affects the joints of the human skeleton. Fibromyalgia, by contrast, affects the muscles and other fibrous tissues, creating sensations that range from nagging to burning to agonizing pain throughout the body.⁴ “My body is screaming!” is how some patients describe the feeling. A syndrome of related symptoms, fibromyalgia, known also as fibromyalgia syndrome (FMS), is often accompanied by severe fatigue, disturbed sleep, morning stiffness, headaches, irritable bowel syndrome, and other de-

bilitating symptoms.⁵ Fibromyalgia is similar in many respects to chronic fatigue syndrome; indeed, it has been called the CFS of the 1990s. The two conditions differ in one major regard, however: in sufferers of chronic fatigue syndrome lassitude is the dominant symptom, whereas in sufferers of fibromyalgia pain predominates. In some patients fibromyalgia is only mildly disruptive, but in others it is incapacitating, forcing them to scale back their lives and abandon careers to take care of their bodies. For these people the illness experience can be one of “absolute devastation.”⁶ Although fibromyalgia is not progressive, with no cure in sight it is considered a chronic condition likely to last a lifetime.⁷

Fibromyalgia is a puzzling disorder whose cause remains unknown. Researchers are continuing their search for an organic basis for the symptoms, but so far efforts to discover a distinctive physiological or psychological pathology have brought little success. Currently, research covers a wide spectrum of possible factors, from metabolic dysfunction, viral infection, immune system dysfunction, and genetic disorder to injury, trauma, victimization, and prolonged stress.⁸ With so little known about causation, effective treatment for the condition has remained elusive. Although there is no consensus on the optimal “management” of fibromyalgia, current thinking stresses the use of medications for sleep and pain, combined with exercise and behavioral therapies such as restriction of activities that exacerbate the pain.⁹

Specialists in the condition estimate that a significant minority of American adults—2.4 percent of the general adult population and 10 to 20 percent of rheumatological patients—suffers from fibromyalgia.¹⁰ People of Caucasian descent are more likely than others to be diagnosed with the condition. The disease is seven times more common in women than in men: overall, 3.4 percent of women but only 0.5 percent of men are diagnosed with fibromyalgia. While women of all ages suffer from the symptoms of the disorder, fibromyalgia tends to strike middle-aged and older women the most. The highest rates are found among women who are fifty or older; in this group between 5.6 and 7.4 percent of women are diagnosed as fibromyalgic.¹¹

Fibromyalgia in its current configuration is a young disease. Although the condition was named as early as 1927 (*fibro* for fibrous tissue, *my* for muscle, and *algia* for the condition of pain), for most of the twentieth century fibromyalgia scarcely existed as a clinical or research entity. In 1977 two Canadian researchers published a seminal article proposing diagnostic criteria.¹² This article revived interest in a condition, fibrositis, that had been known for centuries but had languished in biomedical

obscurity. The term *fibromyalgia* is now preferred to *fibrositis*, since inflammation (*itis*) is generally not present. For proponents of the syndrome, a key step in the growing recognition of the disease occurred in 1987, when the *Journal of the American Medical Association* published an editorial describing fibromyalgia as a common cause of pain that is marked by a constellation of characteristic symptoms.¹³ A committee was then formed to define it. Gaining the endorsement of the American College of Rheumatology, the committee published its working definition of the syndrome in 1990.¹⁴ Since then, clinicians and researchers have shown growing interest in the condition. Yet some remain skeptical about whether it really is a new disease—or even a disease at all.¹⁵

Growing attention to the disease in the medical community has sparked popular interest in fibromyalgia. As word has spread, many women (and some men) are seeing it as the source of their pain. After years of being told they were hypochondriacs or chronic complainers, growing numbers of people are demanding the diagnosis, relieved at last to have a medical name, with its presumption of biological defect, for their suffering.¹⁶ Responding to this demand, a new group of specialists has emerged to treat these patients. The doctor we will meet below—whom I call “Dr. D.”—was one of those eager to serve as an expert in this new disorder. Trained by a prominent specialist in fibromyalgia, this doctor harbored no doubt that fibromyalgia was a biologically based disorder that afflicts countless numbers of women, all of whom would benefit from receiving the diagnosis (“knowing the truth”) and coming under the care of a specialist such as himself. Awed by her doctor’s apparent scientific prowess, the patient we study followed him in believing that fibromyalgia is a true illness and that she “had” it. It was only after the long encounter with the physician was over and she began to read the biomedical literature on her erstwhile disease that she realized that fibromyalgia was a poorly understood, highly controversial, syndrome that lacked even a definitive diagnostic test. “Fibromyalgia” was merely a convenient label for a collection of diffuse symptoms that, had history been different, could have been given a different label or no label at all.

Lest I be misunderstood, I am not suggesting that fibromyalgia is not a real and painful condition. Readers who have, or suspect they have, fibromyalgia know only too well how palpable and debilitating the symptoms of that syndrome can be. As if the physical pain were not bad enough, many if not most have also suffered the psychological anguish of having their complaints dismissed and being told they were simply malingering. The last thing I want to do is to worsen anyone’s distress

by conveying the impression that the pain of fibromyalgia is not real. To the contrary, in writing a book dealing with fibromyalgia, my intentions are not only to underscore the corporeal reality of that syndrome but also to publicize the daily heroism of those who, through no fault of their own, find themselves having to create meaningful lives within physical limits that would strain the endurance of the strongest among us. Although my relation to fibromyalgia is unusual—after all, I was misdiagnosed—I hope that my disturbing experience, once properly dissected, may help those for whom the diagnosis is appropriate to become more savvy and more wary about the process of becoming a “fibromyalgic.”

The historical and clinical features of fibromyalgia noted above make it a fascinating domain in which to study how scientific medicine does its work. The newness of the disease, the still-being-worked-out character of the diagnostic procedures, the lack of effective treatment—these and other aspects of the disease demand resourcefulness on the part of the physician facing a patient who exhibits fibromyalgia-like symptoms. How does he turn the person who finds her way to his doorstep into a patient, someone who has the kinds of problems he is set up to treat? How does he create the scientific facts of the case—diagnosis, prognosis, treatment plan—and knit them into a clinical tale of the nature of the problem and its optimal solution? How does he persuade the patient that his account of her fibromyalgia is true and objective and in her best interest? Finally, how does he get his treatment plan to work? In looking for answers to these questions we will learn much about how scientific medicine works. We are fortunate to have Dr. D. as our clinician. He not only rose to the challenge, he had everything down to a fine art.

A Word on Materials

This book draws on a rich body of primary materials that document the course of the doctor-patient interaction and its daily effects on the patient during the eight months that “S.” was a patient of “Dr. D.” The most important of these materials are a medical diary and a medical chart, both created and maintained by the patient. Although these materials have now become the empirical basis for a critique of biomedicine, the reader must realize that, at the time, the patient’s sole motive in keeping these records was to improve her health. She wanted desperately to get better and spent countless hours every week using her chart and diary in an attempt to reason out how things could be getting worse despite

massive efforts to make them better. Writing about the experience and exposing these shameful parts of her life for all to see was the furthest thing from her mind. The notion of writing a book occurred to her after the long ordeal had come to a close with no sense of closure. It lacked closure because her doctor refused to credit her account of how her life had come undone as a result of his interventions. The desire to speak her own voice and be heard, coupled with the worry that other patients might be suffering as she had, led her to make her story public in a book that I hope will bring wider scholarly and public attention to the problems of doctor-induced illness and medical devastation of the patient's inner world.

The medical diary is a computerized account of every doctor's appointment and all but one telephone conversation that took place during the eight months of treatment. This was an unusually high-contact medical relationship, involving six office visits ranging from two to five hours in length and twenty-two phone conversations running perhaps from fifteen to forty-five minutes. Doctor and patient spoke by phone two times a week during the first two months and once or twice a month thereafter. In most cases the patient took paper-and-pencil notes during the appointments and conversations, then entered them, along with other observations, into her computer file later in the day. The second major source of information is a ten-item chart in which the patient recorded daily changes in her medical regime and physical and emotional well-being. (This chart is described in detail in chapter 5.) These two sources of information give us a rare opportunity to trace the ethnographic links among physician interpretations and orders, doctor-patient interactions, and patient reactions daily for eight months. In her effort to make sense of her suffering, the patient also created a miscellany of computer files, notebooks, and handwritten notes. Though seemingly trivial, these pencil scribbles and electronic jottings will provide us with crucial evidence of the patient's deteriorating mental state and of what happened to turn things around.

These materials differ from the ethnographic field notes that usually form the basis of anthropological studies. Because in this case the recorder of the field notes was one of the individuals in the ethnographic encounter, the notes and other materials she produced were also active agents in the interaction itself. Like commodities, which, anthropologists have shown, have social lives, these writings were effectively characters in the medical drama, with social lives and social effects all their own.¹⁷ The chart, for example, was not simply a passive record of "physician

inputs” and “patient outcomes.” Quite the contrary, it took on a life of its own, entering into the doctor-patient relationship in unexpectedly lively and contestatory ways. In the patient’s hands the chart served as a technology of knowledge creation and as a weapon in the political battles with her doctor over who could represent her body and what counted as medically relevant knowledge. In the end the chart literally saved her life, and both sets of materials gave her the means with which to write this analysis of what happened.

For Dr. D.’s reading of S.’s case and his medical philosophy more generally, I have relied primarily on S.’s notes on their conversations, but supplemented them with two other documents in which Dr. D. speaks for himself.¹⁸ One is a typed report he placed in S.’s patient file after the initial consultation. The second is a tape recording of a public lecture on fibromyalgia that the doctor gave in May 1996. The views that D. presented in these sources are virtually identical to those that S. ascribed to him in her diary, suggesting the credibility of the diary as a source of information on the doctor’s medical opinions. While I have faithfully recorded everything that transpired in the doctor-patient relationship, to protect Dr. D.’s privacy I have altered certain features of his identity. These changes are relatively superficial ones that have no effect on the medical issues addressed in the book.

In addition to these primary ethnographic materials, I have used three other sets of written materials to illuminate the social, cultural, and biological contexts of the medical encounter. Letters, e-mails, and other communications with family and friends help to reveal the social context of illness. The written items also include a sampling of the rapidly growing number of books written for the layperson in the area of alternative medicine. These include works on stress reduction, meditation, “spontaneous healing,” and sundry other topics. Such books, which can be found in the health, psychology, and self-help sections of bookstores across the country, provide fascinating insight into cultural constructions of health and illness in America today. Finally, I have drawn on technical studies of fibromyalgia to reveal biomedical understandings of the disease and its optimal treatment. I have also mined technical writings for evidence of the social construction and contested nature of the disease within the medical profession. My coverage of the biomedical literature is selective, dealing with aspects of the disease of particular relevance to this project. Encounters with the biomedical community also included correspondence with leading specialists on fibromyalgia; these letters too have become documents for ethnographic use. Like the chart,

these social, cultural, and technical materials were far from inert. Throughout the eight-month episode they actively shaped the patient's understanding of her situation and, in turn, conditioned the way in which the medical encounter unfolded.

A Look Ahead and a Caution

The book contains twelve ethnographic chapters. These are framed by a *problematique*, a prologue, a conclusion, and an epilogue. The *problematique*, which follows this preface, lays out the book's central questions and the analytic approaches taken to answering them. A central task of the *problematique* is to locate my ideas within the existing scholarly literatures on social and scientific aspects of medicine, women's psychology and gender identity, and the cultures of alternative medicine. Readers who want a better understanding of their own experiences as patients or physicians should find much of interest in these discussions. To make them accessible to a wide range of readers, both scholarly and general, I have tried to avoid specialist jargon and to place all references to the scholarly literature and discussion of strictly academic matters in the endnotes. Nevertheless, some readers may find that there is more than they want to know here about the workings of science, gender, and illness cultures. I invite these readers to bypass the *problematique*, turning directly to the story of the ill-fated medical encounter that begins in the prologue, "Finding Dr. Right." This prologue provides a brief history of the patient's ills before she became a "fibromyalgic" and the social context in which these ailments emerged. This context helps to explain why the patient became so enamored of Dr. D.

The twelve chapters in Parts II–V that form the heart of the book relate the patient's eight-month experience as a "fibromyalgic" and her six-month struggle to recover from it. These chapters move chronologically. They begin in March 1996, when the patient fell under the "gaze" of biomedicine and end in May 1997, when she finally wiggled out from under that gaze and, as her defiant slogan puts it, "quit the body job." The chapters are divided into four parts, each examining a major analytic dimension of the medical encounter.

Part II explores the workings of biomedicine during the initial months of the medical encounter. What happened during those early spring months set the stage for everything that was to transpire during the following summer and fall. Chapter 1 tells the story of the initial consul-

tation. It shows how, in five short hours, a skilled practitioner deployed the discourses and rhetorics of medical science in a way that transformed the patient's bodily identity from "a person with arthritis" to "a fibromyalgic-arthritic patient." Chapter 2 takes the reader into the realm of rheumatological drugs, detailing the doctor's pharmacological discourse—or drug talk—and its effects on patient and doctor alike. The effects on the patient included not only relief from her initial symptoms but also the emergence of a complex of new symptoms that her doctor ascribed to her "fibromyalgia." Chapter 3 traces the rhetorical production of patient compliance, revealing how the patient was both sweetly seduced and blatantly bullied into acquiescing to the medicalization of her body.

Part III probes the workings of gender in the medical encounter. Chapter 4 depicts the patient's relationship-first approach to getting good care and how it led her to create a compliantly pleasant outer self while silencing an inner self that was full of doubt and anger. Chapter 5 documents the silent rages the patient felt and the secret rebellions she mounted in a desperate yet fruitless attempt to resist her doctor's intrusions into her life. Chapter 6 lays out the painful psychological consequence of "fighting like a girl": a deep, enervating depression that became far worse than the bodily disease.

Part IV narrates the consequences of the interlacing of science and gender that unfolded during the summer and fall, with a brief detour into an encounter with alternative medicine. What they add up to is a losing battle to get better. Chapter 7 discloses how, following her doctor's orders, the patient turned her life into an object of medical scrutiny, surveilling herself closely and cutting out all activities that seemed to make the "fibromyalgic" pain worse. During the summer she also dipped into the literature on alternative and New Age medicine in the hope of finding a way to ease the new symptoms. Chapter 8 delves into some of the books she read and some of the mind-cures she tried before realizing that they were making things worse, not better. Chapter 9 describes a life shriveled and shrunk as the patient eliminated all sources of pleasure from her life in a desperate attempt to rid herself of the "fibromyalgia." This chapter also recounts the hair-raising developments of mid-fall, when the patient's mind began to fog up and malfunction, bringing her close to the edge of a psychological abyss.

Part V tracks the patient's long-forestalled rebellion against her doctor and the project of reconstructing the self she launched to heal the wounds that medicine had inadvertently inflicted. Chapter 10 tells the story of the patient's late-fall visit to her previous rheumatologist in which

she discovered that her transformation into a “fibromyalgic” was a huge mistake. Chapter 11 narrates how the patient found her voice again and staged a final, high-drama meeting with her doctor in which she mustered the courage to tell him what had happened, only to hear him deny her pain and disclaim responsibility for everything that had gone wrong. Chapter 12 documents the patient’s six-month journey to bodily recovery and the useful if sobering lessons she learned along the way. The book’s conclusion addresses each group of imagined readers separately to tell them—that is, you—what I hope you will take away from the book. An epilogue suggests that storytelling by the ill is one of the most promising paths to changing the culture and politics of chronic pain.

The reader should be forewarned that, because S. was in the process of relocating from the East Coast to the West Coast when the story takes place, the action unfolds in no fewer than four states: New York (where S. originally lived and worked), California (where she found a new job and home), Washington (where D. practiced medicine), and Maine (where S. spent a summer). S.’s numerous moves and complicated communications will be sorted out as the story progresses.

There are two types of readings of this story that I hope to discourage. Some readers who identify primarily with the doctor will see S.’s anger at Dr. D. as excessive, sufficient cause to dismiss this book as “doctor bashing.” *Please do not do this.* The anger displayed in this book is the patient’s anger, which she recorded in her diary at the time of the medical encounter. It is not the author’s anger. My task as author is to make that anger comprehensible. As author, I have taken great pains to distance myself—whom I refer to as “I”—from the patient, known here as “S.,” to portray Dr. D. in the most favorable light possible. My aim here is not to criticize the doctor but to understand why the sort of medicine he practices too often falls short of its goals. This book challenges physician readers to see beyond the training that taught them to discount patients’ ideas and feelings to a recognition that patients possess valid knowledge and legitimate emotions that might prove useful to them in their efforts to create more humane and effective forms of medical practice. Moreover, unlike most patient accounts of medical errors, which blame the doctor and exculpate the patient, in this book the former patient takes full responsibility for her part in the undoing of her health. Physician readers should welcome this more balanced approach to understanding medical mistakes.

Other readers who identify primarily with the patient may be frustrated and angry at S. for her persistent passivity in the face of threat and

her staying sweetness in the face of abuse. These readers will be tempted to dismiss her as having too many faults to speak for the plight of the ill. *Please do not do this.* Of course S. had faults; everyone has faults. I, the author, am also angry at S., my former self, for “allowing” her life to come undone. I actively dislike—and hope I have now jettisoned—those aspects of her personality that caused her to write patient “love letters” to the doctor who was unknowingly devastating her health. My task as author is to step outside this patient’s personality to show that its passivity and pleasantness were not so much individual flaws as products of the conditions of gender and chronic illness in American culture. It may be painful to acknowledge this, but in our culture women are too often confined within psychological prisons that make them greet their abusers with smiles. What is unusual about S. is not that she was pleasant, but that she escaped from the prison of pleasantness to recount how it felt to be locked up. And she escaped because that passivity and pleasantness were mostly on the surface; when we peer inside we will see that S.’s inner world was home to a titanic struggle for agency and voice. Indeed, there were two S.’s; fortunately, the more politically aware and assertive one won the struggle.

S.’s be-nice-and-obliging approach to her doctor was equally a product of the conditions of chronic illness. Unfortunately, it is hard to convey a sense of those conditions to people who have not endured this kind of debilitating pain. Words simply cannot describe the brutal realities of unending pain and fatigue. Such pain forces the mind to attend to the body, robbing people of their faculties for rational judgment and blinding them to the structural sources of their distress. Nor are there words to explain how the never-ending problems of chronic illness frustrate family and friends, leaving the chronically ill person isolated from her social network and pathologically dependent on the doctor, who alone in the world holds the hope that things can be made right. In this situation, creating a good relationship with that doctor becomes a life-and-death matter, a desperate attempt to prevent the only lifeline back to the world of the living from snapping in two. This book challenges readers who are sometimes-patients to move beyond their personal experience of illness as something that can be cured to understand how it feels to be sick with an illness that will never go away.