

ENCOUNTERS *with the* INVISIBLE

Unseen Illness, Controversy, and
Chronic Fatigue Syndrome

by
DOROTHY WALL

Afterword by Nancy Klimas, M.D.

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“Encounters with the Invisible is a beautifully written book and probably the best personal account of living with a chronic illness I have ever read....Wall is gifted with extraordinary descriptive abilities. You don't just read about her illness; you experience it with her....You will relate to it equally as well if you have fibromyalgia, Gulf War Syndrome, multiple chemical sensitivity, or any one of a number of chronic and controversial illnesses. If you're looking for a book that will offer you comfort, encouragement and hope, this is the book for you.”

—KAREN RICHARDS, About.com

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“I cannot imagine a more eloquent or honest depiction of what [CFS/ME] is like. [Wall] understands and describes all the bewilderment, denial, confusion, fear, anger, acceptance, frustration, above all, the constant unrelenting presence of the illness itself that all of us have experienced. Dorothy Wall is above all else a writer. The beauty of the words, description, language in this book took my breath away....If you have a friend, or a coworker, or a boss, or a family member, who doesn't believe this is a “real” and very serious disease, you could not find a better book for them to read....I was enchanted, and could not stop reading until I finished.”

—MARY SCHWEITZER, PHD, www.co-cure.org

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“Dorothy Wall has written the best personal exploration of CFS I've ever read....CFS is not an easy disease to describe, but her ability to tease out its manifestations – to make it come alive for the reader – is stunning....This is a book that should resonate throughout the CFS community for years to come. We are very lucky to have it.”

—CORT JOHNSON, Phoenix-cfs.org

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“An important addition to the literature on this controversial subject.”

—*Library Journal* (STARRED REVIEW)

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“An important investigation of a little-understood illness with much to teach doctors and patients alike. General readers will find Dorothy Wall's personal story compelling as well as beautifully told.”

—LYNNE SHARON SCHWARTZ, novelist and author of *The Fatigue Artist*

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“Not only a wonderfully readable, beautifully detailed account of Dorothy Wall's experience of chronic fatigue syndrome (CFS), but also an intelligent review of the history, science, and politics of the illness.”

—KATHRYN MONTGOMERY, Director, Medical Humanities and Bioethics Program at Northwestern University's Feinberg School of Medicine

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“A remarkable book. Dorothy Wall shares her illness experience without self-pity in a way that could help huge numbers of persons. This book imparts knowledge and comfort to those who suffer from CFS and helps to remove society's blinders to this very real, yet invisible, illness.”

—DAVID BELL, M.D., author of *The Disease of a Thousand Names*

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“I want to shove a copy of this book into the hands of every person with CFS and their families and friends—as well as every doubter and detractor, those who have failed to grasp or chosen to ignore the gravity of the illness and the profound life-altering difficulties it creates.”

—KATRINA BERNE, clinical psychologist, author of *Chronic Fatigue Syndrome, Fibromyalgia, and Other Invisible Disorders*

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“A heartfelt book about life-changing illness. Wall’s portrait of the medical community’s failures in responding to the mysteries of patient experience is a harrowing one.”

—FLOYD SKLOOT, author of *In the Shadow of Memory*

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“Dorothy Wall’s riveting account of her experience of chronic fatigue syndrome (CFS) will provide companionship for those afflicted and serve as an eye-opener for those who are not.”

—ANNE HUNSAKER HAWKINS, Director, The Doctors Kienle Center for Humanistic Medicine at Penn State’s College of Medicine, and author of *A Small Good Thing: Stories of Children with HIV and Those Who Care for Them*

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“Wall is a tour guide, leading us through the mysterious grottos of illness. Seamless prose carries the reader along the twists and turns of the body’s mutiny. This book is for doctors, patients, and indeed all readers.”

—DANIELLE OFRI, M.D., Editor-in-Chief of the *Bellevue Literary Review*, and author of *Incidental Findings: Lessons from My Patients in the Art of Medicine*

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“Wall’s intimate disclosures, wise observations, and eloquent style shed light on an astonishing variety of topics—cultural, historical, anthropological, personal—and deliver a satisfying intellectual and emotional experience. The hopeful conclusion celebrates Ms. Wall’s achievement—in writing the book and recovering sufficiently to embrace the simplest of life’s pleasures.”

—K. KIMBERLY MCCLEARY, President & CEO,
CFIDS Association of America

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“A fascinating personal account and an intriguing view of the politics and science that influence how we perceive those with this illness. An important and vivid story.”

—LEONARD A. JASON, Professor of Psychology at DePaul University,
and Director of the Center for Community Research

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While news stories tout the successes of molecular science, gene mapping, and high-tech interventions to treat disease, there's another, untold story within today's medical landscape. It is the story of the growing number of chronic, controversial illnesses—chronic fatigue syndrome, Gulf War syndrome, fibromyalgia, multiple chemical sensitivity—poorly served by today's biomedical, pathogen-oriented approach to disease.

With a lyric, incisive voice, Dorothy Wall blends the personal story of her struggles with CFS with a graphic sketch of the CFS terrain: the woeful federal response, patient advocacy politics, medical debates, environmental questions.

Eighteen chapters explore a spectrum of issues. "Listening" conveys the impact on a patient when medical practitioners are deaf to her story, and posits listening as a moral act. "That Name" leaps into the minefield of controversy between and among patient advocacy groups, researchers, and the medical establishment over the power to define, name, and legitimize disease. "The Erotics of Illness" pulls readers to the intimate core of illness, with its upheavals, pain, and tenuous pleasure. "Staying Home" explores the meanings of enclosure for women and the struggle to find purpose and meaning in a reduced, homebound life.

Personal drama merges with literary reflection, reportage, and medical history. An important investigation of what many are calling "postmodern" illness, *Encounters with the Invisible* offers a thought-provoking look at a controversial illness and the challenge to biomedicine it presents.

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On writing *Encounters with the Invisible*:

From the time I was a child, I knew I wouldn't stay home like the traditional woman. I'd come of age in the liberating '60s, knowing there would be a place for me out in the professional world. So it was with a cruel irony that in the fall of 1995 I found myself in bed with chronic fatigue syndrome (CFS), so ill I could barely walk across a room. Overnight I had become housebound, staring each day through bedroom windows at the gangly branches of my neighbor's Monterey pine. My throat was so sore I couldn't talk for months at a time. I was too weak to write a short note. My partner, Bill, and 23-year-old daughter, Lisa, hovered around me, ferrying in soup and hot compresses.

For two years I lay in bed, staring through the plastic skylight above me at the white pinwheel blossoms of our flowering apple tree, while my head spun with the ideas I didn't have the strength to record. It was unnerving to find myself consigned to bed, like some nineteenth-century neurasthenic woman. I'd worked hard to leave home, my mother's world, to have a life of teaching, conferences, parties, speaking engagements. As someone who prized an active, vocal life, I was struck by the way CFS had made me a shut-in, muted and invisible, mimicking the forced confinement of women in earlier times.

The ironies compounded. Everyone around me, anxious and confused, wanted me to get well and rejoin the world, NOW! But I knew that in order to heal I had to stay where I was, studying the pattern of blue sky behind a clump of brown-green pine boughs. In the fall of 1997, when I could finally pull myself up in bed and put pen to paper, I wrote a cryptic, four-page essay, "Staying Home," about what it meant to me to be confined. That was my starting point, but I knew I had more to say, about invisibility, silence, language, and about the terrible lack of understanding of the severity of this disease. Another essay appeared, and another.

I wasn't thinking of writing a book, nor did I want to write only my daily account of CFS. I was grappling with all the implications of having an illness that has been dismissed by the medical community as "all in the head," trivialized by the media and misunderstood by the public, yet is painfully, palpably real to me and hundreds of thousands like me. My limp body, barely strong enough to take a shower or walk downstairs, was at the center of an intense struggle over medical knowledge and authority. Whose story should have priority, the patient's or the doctor's? The more I wrote, the more I realized that I couldn't write about CFS without engaging the medical and cultural issues this illness raises.

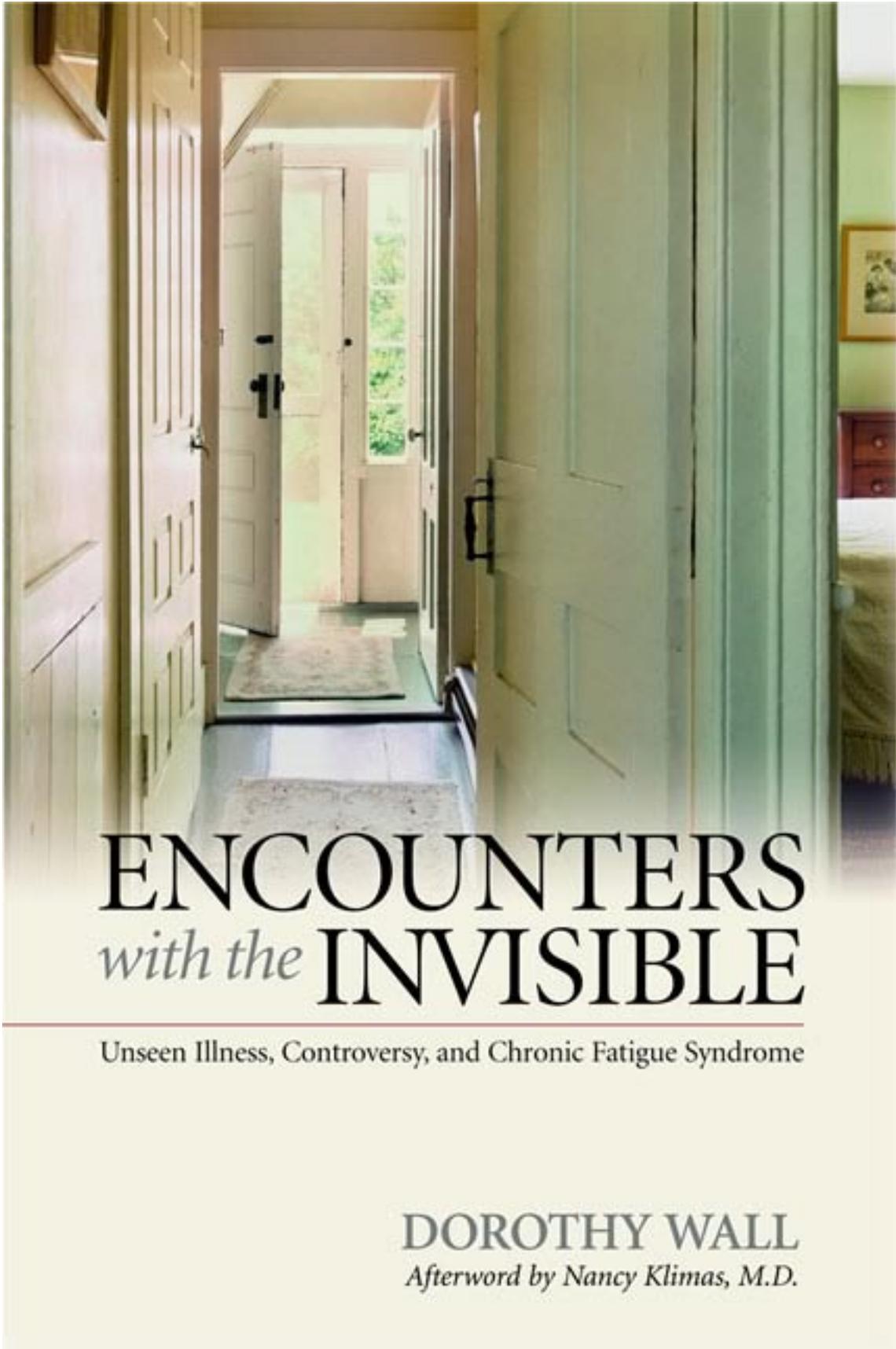
By 2001, as I grew stronger, I began interviewing physicians, researchers and advocates in the CFS community. What they said was surprising and illuminating. Increasingly, I saw the CFS story as a revealing drama of competing needs and interests: of entrenched medical convictions, bureaucratic intransigence, irate patient advocates, of a handful of maverick physicians and whole battalions of very ill patients. I spent the final years of writing linking my personal experience to the fascinating

questions forced by CFS and other controversial illnesses (fibromyalgia, Gulf War syndrome, multiple chemical sensitivity): How are diseases recognized and defined? Who has this power? What are the consequences?

If CFS is a wrench in individual lives, it is also a challenge to our culture's triumphalist ideas about Western medicine: that biomedicine can understand and treat most diseases. CFS is multicausal, chronic and complex. It won't be understood in the laboratory alone. It raises difficult questions about environmental contamination, immune dysfunction and the brain/body interconnection. It reveals the limits of a mechanistic, pathogen-oriented approach to disease, and the importance of valuing the subjective stories of patients as much as test results.

My book was born of inner conflict and frustration, and an urgent need to be vocal, to have a voice. I needed to put on the page the stark details of this illness, and the stories, questions, insights, desires and debates that had careened through my mind for so long. I needed to restore the image of myself as a person in the world, to find my place after having been displaced. If the work of illness is restoration, in the case of a contested illness like CFS, it is also the work of illumination, of making visible what has been unseen: the struggling body, the faulty enzymes and T cells, the medical myths that have erased this illness.

It's easy to think of chronic illness as a bland stretch of days interrupted by a meal or a friend. In fact, the hours spent lying in bed while the body labors to heal are tumultuous and textured, thrusting the ill person face to face with conflicts far beyond the bedroom. I wanted readers to see this complexity, and I wanted to reframe the CFS story from one of problematic patients to one of problematic and limited biomedical orthodoxies. Of the 800,000 people in the U.S. with CFS, only an estimated 10 percent will recover fully. Most will vacillate through cycles of remission and recurrence. Some get worse. The majority heal slowly and venture, as I have, back out to the world with a renewed appreciation for each step along the way.



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Photo by Jane Scherr

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