

PHOENIX RISING

A CFS/FMS/MCS NEWSLETTER

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By Cort Johnson

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The Phoenix is a Mythical Bird That Rises Rejuvenated From the Ashes of its Own Destruction

Phoenix Rising is a monthly newsletter committed to elucidating current CFS/FMS/MCS research, describing important events, telling patient stories, suggesting treatments for CFS patients, etc. Please send submissions, comments and/or clarifications to Phoenixcfs@gmail.com).

SPECIAL EDITION - THE DOROTHY WALL INTERVIEW

Dorothy Wall is a longtime CFS patient and writer who has written the best book on CFS I've ever read. This is not a 'how to' or 'get well' book but an intimate exploration of both the private and public aspects of CFS. First we have a review of the book and then an extensive interview with the author.

'ENCOUNTERS WITH THE INVISIBLE'

Unseen Illness, Controversy, and Chronic Fatigue Syndrome

by Dorothy Wall

Southern Methodist University Press
Price: \$22.50/ISBN: 0-87074-504-2

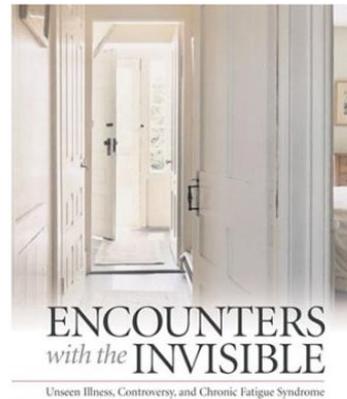
A Book Review by Cort Johnson

Stricken with CFS as a young adult in 1980, Dorothy Wall's has been through it all; the uncertainty of dealing with an unknown disease, the attempts to hold it all together, the relationship problems this disease causes, the isolation it engenders, the uncomprehending friends, the clueless doctors, the small steps forward, the occasional big steps back, the bit by bit resumption of her career.

These are difficult subjects but this is not a depressing book. Nor is it a get well story or heroic epic, instead it is a look at how an articulate and intelligent woman has confronted and still confronts the vicissitudes of having a difficult chronic disease. As we watch her struggle with the aftermath of a terrible relapse she suffered in the midst of a business trip in

1995 she takes us through a range of topics; the disease's history, its strange name, its effects on relationships, its many manifestations, its central nervous and immune system complications, the ups and downs of the advocacy movement, the clash between patient and doctor, advocate and agency, etc..

The chapter on neurasthenia - the name for CFS a hundred years ago – was fascinating. CFS has primarily been a women's disease throughout history and women have borne both the brunt of its effects both physically and psychologically. It was heartbreaking to read the eloquent stories of women's struggle with both the prejudices of their time and their disease. This disease, largely hidden throughout history has caused a countless amount of suffering over time.



Another intriguing aspect of CFS she brings out are its many manifestations of invisibility; how the name has masked the public's understanding of it; how the normal test results mask its severity, how the isolation and silence this disease brings thwarts its public articulation, how its mysteries have thwarted its effective treatment. Along the way she also illuminates the ways CFS is steadily becoming more visible; how the central nervous system and immune findings and others are slowly giving CFS more and more recognition in the medical community.

DOROTHY WALL
Afterword by Nancy Klimas, M.D.

As one follows Dorothy's path one goes through the entire gamut of emotions, dismay, fear, excitement, frustration. One celebrates Dorothy's triumphs and fears for her losses - at one point I was so worried about her I skipped to the end to find out how it all turned out. CFS patients will find their own concerns echoed and their problems illuminated and at all times they will enjoy her rich, poetic prose. Dorothy was a creative writer and editor before she came down with CFS (and still is) and it shows; 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.

One shouldn't forget the wonderful afterword by Nancy Klimas, one of our top CFS physicians and President of the International Association of Chronic Fatigue Syndrome. This is a book that should resonate throughout the CFS community for years to come. We are very lucky to have it.

BECOMING VISIBLE

An Interview with Dorothy Wall

Q. Writing a book is not easy even for a healthy person. This book, in particular, seemed like a huge task to take on. Not only did you have to retrace your dreadful collapse in 1995, you had to do a lot of research and conduct interviews, etc. Doing something this large could exert a real physical cost, yet you seemed almost compelled to do so. At one point you state that, "to have to leave the intricacies of this disabling illness

unarticulated, unexplained, is to become once again invisible." Why did you feel the need to make CFS visible?

A. People with CFS don't have visible bruises or injuries, a shadow on an X-ray, a low blood count. When I became severely ill in the fall of 1995, it was difficult for those around me to comprehend why I was too weak to walk across a room, or why I didn't get better within a few weeks or months. My body hurt all over, my throat was so sore I couldn't talk, I had swollen glands, night sweats, light and sound sensitivity, confusion, nausea. Yet doctors shrugged and suggested that Bill and I go away for a weekend or that I see a therapist. The level of misunderstanding was astonishing. As a writer, how could I go through an experience like that and not write about it!



I wanted to pull back the veil from the sick room with its wadded tissues, heating pad and soggy tea bags, and make clear the severity of this illness and the impact on daily life. I wanted the invisible, interior machinations of this illness--the dysfunction in the neuroendocrine system, immune system, autonomic nervous system--to be seen and understood. I hadn't set out to write anything except a few essays, but I soon realized I couldn't tell the CFS story without delving into the science and politics of CFS, and the fascinating and contentious history. I found stories within stories, about the volatile name-change debate, or the prior epidemics of CFS whose history is buried in dusty archives. I was compelled, too, to bring to view all the ill people sequestered in their bedrooms or struggling to maintain a part-time job and some semblance of a life. I wanted the day-to-day efforts of the hundreds of thousands of people with CFS to be recognized and appreciated. I wanted to write a book that those who are ill could hand to their friends, family or physician and say, "Read this and you'll understand."

*Q. Your description of the 1993 session at the CDC to create a new case definition for CFS is almost heartbreaking. In your interview with Kim McCleary, President of the CFIDS Association of America, she said at one point she was so upset that she just "sort of lost it." Obviously things have improved since then, but we still have the terrible name "chronic fatigue syndrome," and physician and public recognition of CFS is still very poor, etc. How much of the frustration in the CFS community do you think comes from CFS patients feeling they still don't really have a voice -- that they are still not **really** heard by their physicians, by the government and by much of the research community.*

A. I think the issue of not having a voice is huge. The CFIDS Association and other patient advocacy groups have done an enormous amount to give a voice to those of us with CFS. Without this large-scale advocacy, we would not be getting the level of attention from federal agencies that we are. But those who are ill, including myself, still go to doctors who know little or nothing about CFS; large portions of the research community still do not regard CFS as a credible area in which to do research; and of some 120 diseases that the National Institutes of Health funds, CFS ranks in the bottom dozen, though the illness affects more people in the U.S. than lung cancer and HIV/AIDS combined. So the

frustration of not being heard, not having a voice, is still a major issue. Individually and as a group, we have to continue to speak out.

Q. You're a very talented writer. Coming out of college you obviously had a bright career ahead of you with many hopes and expectations, many of which you've had to give up. When you look back at what might have been and what did happen, how do you deal with the losses and frustration and anger that this aspect of the disease brings?

A. You know, I've been really fortunate in this regard because I can both write and run my writing consulting business from home. So I haven't lost as much as some people with CFS do. I came down with mononucleosis when I was 30, in 1978, then had an upper respiratory infection in 1980 that started the cycle of continuous illness. Though I was sick and exhausted most of the time for the next 15 years, I was able to continue working, taking walks, and showing up for brunches and parties. I had to adjust my professional life by cutting back on teaching and working instead as an editor, which I could do from home. But I was able to maintain my career, family and social life. By the time I had that huge collapse in the fall of 1995, my writing consulting business was established enough that I could keep it going, even though I now worked in bed and no longer met my clients in person.

So, yes, I've had to stop teaching and going to conferences. I no longer travel or hike or go out to evening events. But I've managed through 28 years of illness to still have the two pillars of work and family. My biggest frustration has been that I've missed out on a lot of fun--parties, vacations, time with friends. That's sad to me. On the other hand, I'm grateful to have a dedicated and committed circle of family and friends. It could be much worse. Many people with CFS really do lose their jobs, their relationships, even their homes.

Q. You had a difficult decision to make in 1995: you had an important trip to New York scheduled involving a book deal, and you had already canceled the trip once. As it turned out the trip led to a horrific collapse, one that you are still recovering from. Balancing their need to act with the possible costs to their health is something CFS patients do all the time. Looking back on it, did you have any signs that you were possibly stepping into really dangerous waters when you took that trip?

A. Oh, absolutely. I came down with a severe virus three weeks before my planned trip to New York. The night the virus hit me, I had a vasovagal syncope, a sudden drop in blood pressure, that left me on the floor, with my daughter bending over me in alarm. Over the next couple of weeks I went to the doctor several times to have him look at my infected ears and throat to see if he thought I could get on an airplane. He said he thought I could, and I kept telling myself I could muscle my way through this trip and then rest. Yet just the trip to the airport was exhausting for me. Had I listened to my body, I never would have gotten on that airplane. It's amazing how well trained we can be to ignore or override our body's signals, to keep soldiering on.

Complicating matters, I didn't realize that another major infection could plunge me into a more devastating phase of illness. I didn't know that I could become much more severely ill than I already was. Without this larger framework of understanding, I couldn't interpret my body's warning signals accurately. I assumed I'd be wiped out from the trip, but would

recover in a few months as I always had in the past. The physicians I saw didn't understand my illness, and in an odd way, I didn't fully understand it either.

Q. You have really felt the cost of pushing too hard, and yet you write that you "still feel a restless chafing and frustration, an inner struggle...as my spirit and desire strain against the reins of my body...body urged on by spirit, that exuberant child." At one point you state, "I'm still wandering...trying to find my way, through a strange amalgam of surrender and striving." Do you think this problem -- the need to continually learn and relearn how to negotiate between the desires of the mind and needs of the body -- ever ends for CFS patients?

A. I don't know that it ever ends, but I think we can learn to moderate this tension. I hope I've learned to do that. I know I'll never again make the kind of mistake I made in 1995, trying to maintain a level of activity that was way beyond my capacity. But I still struggle in a more day-to-day way to stop when I need to and not do too much. Of course, the desire to carry on, to be engaged with friends, family and work, is a good thing. In fact, I think desire, even for such simple things as reading a book to my grandson or having lunch with a friend, is critical to recovery. But finding a balance, yes, that's the challenge.

Q. You've taken some valuable lessons from Tai Chi and its focus on "yielding" rather than overcoming. You note that with CFS one really needs to learn when to "stop relying on strength in order to gain strength." This is a disease that does not reward "heroic" efforts to overcome it or that one can gain mastery over using will-power. It's more a matter of intelligently adjusting to it and its limitations. This is not the kind of disease that our society trains us well to deal with, is it?

A. No, it's not. The message of our society is to overcome adversity, to not give in, to fight back. We admire people who say they're going to fight their illness and beat it. I wrote a chapter called "On Determination" because I was so struck by the way chronic illness turns on its head this idea of combating and overcoming disease. Living with a chronic illness requires acceptance, adjustment, adaptation. We tend to think of these qualities as defeatist, but with a chronic illness, acceptance and adaptation can help reduce disability and lead to a better life. Sometimes we need to be determined *not* to keep pushing or fighting. Still, it's a hard lesson. Our cultural myths are strong and it's hard to rewrite them.

Q. After your collapse in 1995, it was two years before you were able to start writing even small amounts again. You write how even for you, who have a real mastery of language, "the storms of the body [can] blank out language." You must have wondered during those first years if you had lost your special ability to communicate.

A. No, I knew that I was slowly improving and that I would get back to my writing at some point. In fact, I was doing client work just three months after I became so ill in the fall of 1995. I could only work half an hour a day, in bed, and a critique letter that previously would have taken me an hour took me four days, but I was able to put my thoughts on paper for my writing clients. What kept me from my writing initially was that I had to put client work first, to keep my business going and pay the bills, and it was two years before I had the additional energy to do my own writing. Writing about my illness was probably too radioactive for me in those first couple of years anyway, when I was in so much pain. Focusing on my clients' writing for a few years was probably best.

Q. You bring up several times how often it is lay people think they know what to do about CFS. They have their tips, to take this or that supplement, do this class, think this way, don't think this way. For some reason they seem to think that they know enough to manage this disease. This, of course, can put the CFS patient in something of a bind. One appreciates their caring but is appalled at the hidden message, that CFS is not really a serious problem. This doesn't happen with people with diabetes or heart disease or other serious illnesses. Why do you think this is with CFS?

A. Partly it's because of the terrible name, chronic fatigue syndrome, which makes people think this illness is about being a little extra tired. People think, 'Oh, when I'm tired I take such and such and it helps me.' They don't realize that CFS is a severe and disabling illness that has nothing in common with ordinary fatigue.

I was really taken aback when all the suggestions started pouring in. I kept thinking of what Thoreau said: "If you see someone coming at you with your best interests in mind, run for your life!" I have a list now of more than forty different suggestions people have given me, everything from a blood transfusion to magnets to Udo's oil. Naturally, people want to help, want to offer something that you can *do*. But you're right, an illness like CFS that is misunderstood and for which medical science has few answers seems to garner a longer suggestion list than other illnesses. I've resigned myself to it, and among the laundry list, I'm happy to report, I've found a few suggestions (dietary changes and yoga) that have actually helped.

Q. Maybe the most difficult and least talked about aspect of this disease is a feeling that people have that they just aren't themselves anymore. They don't think well, they are forgetful, they have difficulty communicating, etc. In some of your more beleaguered periods you stated that you could easily feel that CFS was "an assault on the basic construction of self." You write that with CFS a new you has appeared, one that is "teary and labile and weak and distracted," and you wondered, after one incident, "Who was this person [so] vulnerable, undignified?" You wrote that returning to health constitutes not just feeling better but a "reappearance of someone familiar." Indeed, as you get better you note that "I am feeling more recognizable to myself." How disturbing for you has been this facet of the disease? Has it affected your relationships with others?

A. I'm glad you asked about this. When I was terribly ill, I did feel as if someone had snatched my personality and replaced it with something rather scary. I think it's hard for healthy people to imagine what it's like to be so ill that you're literally deadened. At my most ill, I was so weak I couldn't laugh, talk or be animated. I could barely write a cryptic note. I remember the first time I had the energy, when talking on the phone, to infuse my voice with a little gaiety, to laugh or sound animated for a moment. It was only for a moment, but in that instant I felt connected to an old self that had seemed lost. It was very important to me to feel that I could still conjure up that person, and as I got better and had more energy, that happened more often. I remember the first time I was able to put on a blouse and earrings and go out shopping. The brief trip was exhausting, but to assume that public persona was a thrill.

The other thing people often don't realize is that CFS is a brain disease. My brain had been severely injured by viral infection, and this injury affected not only my cognitive function (I couldn't do things that involved more than one step, couldn't do two things at once, had trouble with word recall), it also affected the emotional centers of my brain, the limbic brain. I was anxious and emotionally fragile. I didn't completely lose a sense of inner strength and

calm, but it was certainly buried or displaced a lot of the time. To be so discombobulated was upsetting to say the least, to me and everyone around me. As I've healed, it's been a relief to be back in balance and to feel that old self return.

Q. For many CFS patients the trip to the doctor's office is almost like running a psychological gauntlet of frustration, anger, humiliation and fear. You note that while the treatment options of 100 years ago were poorer, at least the doctor's office was probably a much more congenial environment then - at least doctors really listened to the patient. Now, although physicians understand more about the body than ever, they seem less well suited mentally and psychologically to deal with diseases they don't understand. You've spent much of your time with CFS being treated at an HMO. Have you found any physicians there that were really knowledgeable in CFS? Lacking that, did you at least find physicians that treated your problems with respect? Do you think things have gotten better in this regard?

A. Yes, things have gotten better, but we're still a long way from where we need to be. I still can't find a physician at my HMO who is knowledgeable enough about CFS to help with my treatment and care, and believe me I've tried. But at least physicians no longer dismiss my complaints or tell me, as one doctor did, "We know of no organic basis for CFS." Doctors want to be helpful, but most don't understand post-exertional fatigue, or the fact that a person with CFS may not recover normally from infection, so their suggestions are usually off-base. I still know more about how to handle my various symptoms than they do. And you're right to note that as medical technology has become more sophisticated, doctors are likely to give more credibility to test results than to a patient's report of symptoms. If a standard blood test, for instance, doesn't readily confirm an abnormality in CFS patients, that test result can be used to dismiss patients. We have to hope that medical technology will ultimately help unravel the enigma of CFS, but in the meantime, technology has sometimes kept the medical profession from taking our illness seriously.

Q. There are so many layers to this disease. You tell how in the 1800s and early 1900s, women with CFS (aka neurasthenia) were told, in contrast to men, to refrain from mental activity. Skip forward a 100 years and here you are a liberated woman trying to escape from the home only to be dragged back into it in a big way by CFS. It sounded like at one point you could literally feel the walls closing in on you. CFS mainly strikes women and it seems like there's this extra twist of the knife that it can have for them.

A. Yes. In fact, the issue of being housebound was what first compelled me to write about my illness. I was very struck by the way CFS confined me to the home, much as women in earlier times were confined by social convention. As a woman who had always expected to have a life out in the world, these limits raised all sorts of disconcerting echoes. In the fall of 1997, I penned a short four-page essay called "Staying Home," in which I explored the tensions of being a modern woman who is housebound. That was my starting point for the book, and the essay later developed into a chapter. Once I started writing, I couldn't stop. I wrote a chapter on "Seeing," on "Silence," on "The Erotics of Illness," on "Neurasthenia Revised," and over a dozen more. I wanted to hold illness up like a prism, looking at it from this angle and that, exploring every facet. People tend to think of illness as a bland and boring stretch of days, but as you say, there are so many layers to the illness experience.

Q. I love the Reynolds Price quote you gave suggesting that when faced with a disabling illness, the thing to do is to "become someone else, the next viable you." You got this illness while you were a young adult and spent many years trying to "pass" as a healthy person. Even inside you had trouble admitting to yourself that you

really had problems. A student evaluation that said you had low energy bothered you so much that you tore it up. You didn't so mind students critiquing your lessons, but low energy, that was just too much. Do you know what was going on there?

A. Denial, hope, shame, determination! I write about this complicated issue in the chapter called "Passing." There is such an amazingly strong impulse to hold on to the old, pre-illness self, even when to do so becomes perilous. For many years, I clung to the image of myself as a healthy person. I didn't want others to see my health problems, in part because I didn't want to deal with all the projections and reactions that would follow, and in part because I wasn't ready to accept within myself that I really had to lead an altered life.

Also, CFS can involve a slow downward slide, and when your decline is gradual, it can be hard to identify a point where you have to shift your identity and accept a more limited life. Where that line is is not entirely clear. I wrestled with this issue for many years as my health deteriorated in the early '90s. Only when I had a total collapse in 1995 did I "come out" as an ill person, and even then I balked at doing so until it became absolutely clear I had no choice, that I wasn't going to recover quickly.

It's an enormous relief to no longer have that struggle. I wouldn't have chosen to have such a severe rupture with my previous life, but the positive side is that the more serious phase of my illness forced me to adjust my life and be realistic about who I now am, with myself and with others. That doesn't mean I don't still push against limits. I do, but within a more reasonable zone.

Q. CFS is often very difficult on relationships. We hear time and time again of CFS leading to divorces, breakups and estrangements. You describe the difficulties your significant other, Bill, and your young-adult daughter, Lisa, had adjusting to your debilitation after your 1995 collapse. They didn't understand it and were tremendously frustrated by it, and a few times they said things that were hurtful. At one point you describe Bill being almost wooden with frustration but in the end they both stuck by you. Were you ever worried that you might lose them? How important has your family been in helping you through this illness?

A. CFS, like any serious illness, is very hard on families. My family has been invaluable in helping me through this illness, but that doesn't mean it has always been easy. As you note, there was plenty of misunderstanding, resentment and anger, on all sides. Bill and I spent a lot of years, as my health improved, sorting through what had gone on. I didn't ever feel that my family wouldn't be there for me, but I did feel isolated when they misunderstood what was going on. What was most frustrating to me was the way the cultural and medical misconceptions about CFS impacted the thinking of even those closest to me. Members of my family wondered if I were having a breakdown, or just having a rough time with menopause. When the physical basis of an illness is not well understood, there's lots of room for these kinds of misconceptions. For the ill person, misunderstanding from others creates what is called "secondary" suffering, another level of difficulty to cope with on top of illness itself.

Q. They say we never know what we are made of until we're tested, and you have been sorely tested in so many ways. This disease hit you when you were a young adult and it plunged you into situations that most people never in their wildest dreams contemplate. Looking back, are you ever surprised at a kind of innate resilience that you've had to make it through these trying times?

A. I think almost everyone who goes through hard times rises to the occasion. What other choice is there? We all muddle along and do the best we can. In retrospect you might call it resilience, but at the time all you're thinking about is whether you can make it downstairs to get your oatmeal. And I'm not sure the only effects of severe illness are to make one stronger. The trauma of serious illness can make a person more aware of vulnerability, more anxious or fearful. Resilience is something we're more apt to feel when healthy than when sick. I often felt that I was going on faith when I was terribly sick, going on the belief (sometimes shaky) that the future would be better--though I suppose faith is partly what undergirds resilience.

Q. At the end of the book you state that you don't think there will be an end to your story with CFS, that this disease is not going to go away, that your health is probably never going to be fully restored to you. Your expectations and hopes at this point are not on getting well but simply on getting better. Was this realization -- that, given the way things are, this illness is most likely going to be with you for life -- difficult to accept? Was it helpful in any way?

A. Good question. The realization that I had what might be a permanent, serious illness was very hard to accept when I first began to face that fact in the early '90s. In the early '80s, I didn't know there was any such thing as chronic fatigue syndrome since the Centers for Disease Control didn't officially recognize and name this illness until 1988. By the late '80s my health had improved and I was able to lead an almost normal life. I thought those days of being run-down and having "that recurring virus" were behind me. It wasn't until my health started worsening in the early '90s that I saw a doctor outside my HMO who delivered the shocking news. He was a character, with a streak of the dramatic, and I later learned he left his medical practice to go to film school. I can still see him leaning against the wall of the exam room, with the rolled up computer print-out of my test results in his fist, saying, "You'll always have this illness." I was stunned and angry, and didn't want to believe him.

As I became more ill, and then when I became suddenly bedridden in the fall of 1995, I had a hard time adapting to this new reality. I hung on to visions of myself teaching again or speaking at a conference. The realization that those days are behind me sank in slowly, and probably that was best, as it gave me time to adjust. Is it helpful to accept the reality of my illness? Sure, because I take better care of myself and don't do anything truly foolish. And I don't have the constant stress of trying to carry on a life that really is too much for me. But I think it's natural to strain against limits. I haven't stopped trying to cram a full life into a part-time schedule.

Q. I always have to ask about treatment. We know that CFS patients are a heterogeneous bunch that can have wildly varying responses to treatments. Still, are there treatments that have been particularly beneficial to you that you want to pass on?

A. What has helped me most, besides time and rest, has been dietary changes. Six years ago, I went on a candida diet (no yeast, no sugar, no fermented foods, no alcohol, no caffeine), and it has greatly reduced my brain fog, allergies and hormonal swings. But life isn't all renunciation. You can still find a chocolate truffle or two in my refrigerator.

Q. We left you in the book back sometime in 2005 in a state of very slow but steady progression and perhaps on the edge of a trip to the Sierra's for the first time in many years. Did you make it to that trip and if so, how did it go? How are you doing now?

A. Bill and I didn't end up going to the Sierra's, but to the coast. We've gone away for a couple days each of the last six or seven years, and each year I've felt a little more "normal," a little stronger, less brain-fogged and achy. Six years ago when we went to Pt. Reyes, the hour-and-a-half car ride was exhausting, and I spent most of our vacation resting in our room. This fall Bill and I headed to Pt. Reyes, and I was able to make the drive, go out to eat (amazing berry pie a la mode at the Station House Cafe), take a half-mile hike on Bear Valley Trail and still play a short game of pool in the evening. It took me four days to recover, but the difference from earlier years is enormous. Bill and I were delighted. At the moment, I'm feeling the best I've felt in over eleven years.

You can visit Dorothy's website at <http://www.dorothywall.com/index.html>

[You can find Dorothy's book at Amazon.com by clicking here.](#)