



A Visit with Author *Dorothy Wall*

by Margy Squires

Dorothy Wall describes herself first as a writer and it's this talent that ultimately is the jewel of her book. *Encounters with the Invisible* is a frank exposé of both her personal struggle to find answers to her own illness and the subsequent evolution of chronic fatigue syndrome itself as a valid medical entity. I visited with Ms. Wall in a "chat" via e-mail.

MS: Ms. Wall, Encounters with the Invisible is more than an autobiographical sketch of your struggle or history of Chronic Fatigue Syndrome (CFS). What do you want your book to accomplish?

DW: More than anything, I want my book to convey to readers what this illness is like on a day-to-day basis and why it has been so misunderstood. I wanted readers to come away with a visceral understanding of what those with CFS experience: the cognitive problems, pain and exhaustion, the limits on activities, the struggles with identity, or with work and relationships. And I wanted to place CFS in an historical and scientific context. There's a reason physicians were all too ready to call CFS a psychological illness, and I wanted to illuminate those reasons.

MS: Could you give a short explanation of why CFS is seemingly invisible?

DW: CFS is invisible on many levels. It's been invisible within the medical community because physicians didn't know how to talk about it or understand it. Also, the person with CFS often looks okay despite being severely ill, and this creates another kind of invisibility. And some people with CFS are housebound, so this keeps them out of view as well.

MS: You've side-stepped offering specific treatments that helped you get well, which I think is an important message in itself. How did you learn to "turn off" the other voices to hear your own body talk?

DW: I don't know if it was a matter of "turning off" the voices offering well-meaning suggestions so much as simply learning from experience what helped me get better. Often, when you're ill, those who love and care for you are eager to offer remedies and solutions. But for me, after trying for too many years to keep going despite being ill, the real key to healing has been to listen to my body and to learn to live within limits. Not an easy lesson! I've also been helped by treating sleep problems and allergies with herbs and by adopting a "candida" diet (no sugar, yeast, alcohol or caffeine), which has reduced my brain fog and allergies.

MS: While no one asks for an illness, often there's a rainbow in the storm. What did you find illuminated in your life that might not have been without CFS?

DW: As soon as you slow down, it's amazing what you notice and appreciate that you wouldn't have otherwise. I appreciate every day the changing light in my room or the shiny magenta leaves of our Japanese maple. As I've gotten better, I'm delighted to be able to take a short walk or go out to lunch. When things have been stripped from your life, you appreciate everything you still have with renewed intensity, and this renewed gratitude is a gift in itself.

MS: You write that there's a balancing of what you want to do versus what you can do. You suggest adopting "a smaller life" as one way. Would you clarify what you mean by that?

DW: I don't mean a less full life, simply less physically active. I don't run around the way I used to, going to conferences or parties, teaching, traveling. I largely stay home. Fortunately, I'm able to work at home, and to see family and friends. And the internet connects even those who are housebound to a large network of people. But, as for many with CFS, my life is fairly quiet. If I maintain this kind of balance, I become slowly stronger.

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Author Dorothy Wall

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MS: What is the one question you'd liked to be asked as an author but haven't yet? And what is the answer?

DW: Great question. I guess I'd like to be asked why it is that CFS has been ignored and ridiculed for so long. It's been a fascinating question to explore, and of course there's no easy or single answer. I go into more depth in my book, but basically, I think it was a "perfect storm" of factors, having to do with outdated medical views, the invisibility of the illness, the failure to understand post-infective illnesses adequately, and the complex nature of the illness itself. Read my book for more!

MS: Ms. Wall, a final question. What single piece of advice do you have for others with CFS (besides buying your book!)?

DW: Listen to your body and stay within your energy envelope. Do as much as, but not more than, you feel able to do each day. It's the basic mantra for those with CFS, and it can't be restated enough.

MS: Thank you for visiting with our readers today and sharing. Encounters is an extraordinary study in CFS that I hope others are inspired to read and more importantly, lend a voice for increased visibility.

Dorothy Wall is author of the acclaimed book, Encounters with the Invisible: Unseen Illness, Controversy, and Chronic Fatigue Syndrome, the only book on CFS to blend a vivid personal story with an investigation of the history, science and politics of the illness. Winner of the 2007 "Author and Book of the Year Award" from P.A.N.D.O.R.A., Encounters has been called "...the best personal exploration of CFS I've ever read" by Phoenix-cfs.org. Ms. Wall is also coauthor of Finding Your Writer's Voice: A Guide to Creative Fiction, and has taught creative writing at San Francisco State University and U.C. Berkeley.

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