ImmuneSupport.com Treatment & Research Information

Live Chat with Author Dorothy Wall - April 19, 2007

ImmuneSupport.com

05-02-2007

Welcome to our online chat with CFS patient Dorothy Wall, 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.

***Encounters with the Invisible* is winner of the 2007 "Sand Castles Author and Book of the Year Award" from P.A.N.D.O.R.A., and has been called "the best personal account of chronic illness in general and CFS in particular I have ever read" by ImmuneSupport.com. Dorothy is also coauthor of *Finding Your Writer's Voice: A Guide to Creative Fiction*, and has taught creative writing at several colleges in the San Francisco Bay Area. Her poems and essays have been widely published, and she works as a writing consultant in Berkeley, California. For more about her book, visit her website: http://www.dorothywall.com.**

* * * *

Q: *Dorothy, when did you become ill with CFS - and how is your health now?*

Dorothy Wall: I came down with a severe case of mononucleosis in 1978 at age 30 - at a stressful time of divorce, graduate school, working and being a single parent - and never fully recovered. In 1980 I contracted an upper respiratory infection and became even more ill, with massive brain fog, sore throat, swollen glands, sinus pain, headaches and exhaustion unlike anything I'd known.

From 1980 to '86 I dragged around, ill most of the time, but able to continue teaching, taking care of my daughter, socializing, etc., albeit with difficulty. All the doctors I saw said there was nothing wrong with me, since all blood tests came back normal, but I understood my illness as a "recurring virus," and attributed it to being run-down. From 1986 to 1990 I improved significantly, to the point where I could hike three miles and travel. I didn't have "normal" energy, but I didn't get sick all the time anymore.

But as I'd gotten better, my work life had expanded. I was teaching, writing, attending conferences, and traveling. In the early '90s my health began going downhill again, all my symptoms returning. In the fall of 1995 I took a business trip to New York and had a complete collapse. I came back massively ill, and overnight I was housebound. For the next year I couldn't talk at all because of an intractable sore throat. Since 1995 I have slowly and steadily improved. I was out of bed about one hour a day the first year after my collapse, two hours a day the second year, three the third and so forth.

I'm no longer fully housebound, though I only go out for a few hours a week. I'm able to work at home as a writing consultant, to write, to see family and friends and to walk about six or eight blocks. It's a limited life, but a full one. Given where I was a decade ago, I'm extremely grateful. My book, Encounters with the Invisible: Unseen Illness, Controversy, and Chronic Fatigue Syndrome, is primarily about my experience of severe CFS since 1995, and about the history, science and politics of CFS.

* * * *

Q: *Dorothy - First, thanks for all your insights and compassion! Do you have any ideas about what caused your sudden collapse in '95?*

Dorothy Wall: The collapse may have been sudden, but my CFS had been getting steadily worse since 1990. Overwork, ignoring my body's messages of exhaustion for too many years, and too many previous viral infections all contributed to the sudden collapse I experienced in 95.

* * * *

Q: *Dorothy, did any one particular treatment help you? Or was it all about lifestyle changes?*

Dorothy Wall: For me, rest, stress reduction, good diet and time have been the key, which is to say, lifestyle changes. I haven't found any particular treatment to make a difference. But the minute I recognized my limits and stayed within them I began slowly improving. Dietary changes have been the other thing that has helped the most. I follow a Candida diet: no sugar, no refined foods, no alcohol, no caffeine, no fermented foods. It's helped reduce brain fog, mood swings and allergies.

* * * *

Q: *Have you had experience with doctors who said it is all in your head?*

Dorothy: Oh, for years. I could tell many, many stories of dismissive doctors, and do in my book. More recently, doctors seem willing to acknowledge that CFS is an organic illness, but they often know little about it and have little to offer in terms of help with symptoms. I still find that I turn to the Internet and the CFIDS community for help with managing and understanding my illness.

* * * *

Q: *Do you encourage exercise? I personally tend to benefit from it.*

Dorothy Wall: Exercise is controversial, as you probably know, since exercise intolerance is a main feature of CFS. Like most people with CFS, I get worse if I don't stay within my "energy envelope." On the other hand, if I do as much as I feel able to do, but not more, I do slowly improve. I think being as active as possible is important. I take a short walk every day and do about ten minutes of stretches. But it's also important not to overdo.

* * * *

Q: *Any thoughts on the current study going on at Stanford University in Palo Alto? I can't remember the name of the drug they are using in the study (CFIDS brain thank you).*

Dorothy Wall: I think the Valcyte trial at Stanford is very exciting. I've always felt that what I have is viral in nature, and am delighted that a major study of an antiviral is underway. The preliminary results of a small trial of Valcyte were very encouraging, and I, along with a lot of people, will be eager to hear the results of the larger trial just getting started. [*Note: the drug valganciclovir - trade name Valcyte - is an antiviral often used in treating diseases caused by human herpes viruses. The current Stanford trial of valganciclovir is focused on a subset of CFS patients with viral induced central nervous system dysfunction.*]

* * * *

Q: *Do you believe CFS may be caused by insect bites?*

Dorothy Wall: Nobody knows the answer to that for sure, but chronic Lyme disease, caused by a tick, may shed some light on your question. There's a lot of discussion about whether chronic Lyme is a separate illness, or whether it's CFS, since the symptoms are so similar. It makes sense to me that the micro-organism that causes Lyme disease could cause a postinfective condition that is a form of CFS. But there's lots more to learn in this area.

* * * *

Q: *Do you believe that CFS might be genetic at all?*

Dorothy Wall: There's a lot of new evidence suggesting that there is a genetic component to CFS. I actually have an aunt - the one in the family that I take after - who had a CFS-like illness in the mid-sixties. My thirty-five-year-old daughter has *Candida*, and many of her symptoms are similar to mine. So I certainly see evidence of a possible genetic connection in my family.

* * * *

Q: *I find myself feeling better when on a course of antibiotics. Has this happened to you?*

Dorothy Wall: I haven't ever suspected that my illness was bacterial in nature. It has always seemed viral to me. The few times that I had a sinus infection and took antibiotics, the sinus infection cleared up but I had no other benefit. But I think it's quite possible that a subgroup of people with CFS may benefit from antibiotics.

* * * *

Q: *Do you believe that a traumatic event like your divorce played a part in your getting sick?*

Dorothy Wall: I think stress in general is a part of the CFS picture, along with genes and an inciting event, in my case, mononucleosis. There's been a lot of focus recently on stress as a contributing factor, but I think it's important to not let that overshadow the fact that the illness begins, for most people, with an infectious illness. Many people are stressed, but most don't develop CFS. A recent study in Dubbo, Australia, has shown that 10% of those who contract mononucleosis go on to have CFS. In other words, for these people, CFS is a postinfective illness. Is excess stress, along with a genetic predisposition, a part of the picture? For some people, probably.

* * * *

Q: *How have you dealt with the conflict between wanting to push yourself to exceed your boundaries and recognizing the limitations and realities of CFS?*

Dorothy Wall: Not easily! So many people with CFS, myself included, enjoy being active and engaged, and have a hard time stopping when they need to or saying "no" to an opportunity. I have learned to set limits the hard way, by becoming so severely ill that I was forced to adopt a smaller, more restricted life. But as I write in Encounters, in a chapter called "On Determination," I hope that I've learned to appreciate the drifting "down time" that illness brings, and to find fulfillment in things other than constant accomplishment or activity. That doesn't mean I don't keep pushing; I do. But in a much smaller way.

* * * *

Q: *Do you believe that Eastern medicine methods are as much if not more beneficial for us than our current available Western ones?*

Dorothy Wall: Until we have effective antivirals or pharmaceuticals based on our knowledge of genetics, yes. The holistic approach of Eastern medicine is well-suited to a complex illness like CFS. Many people find that herbs or acupuncture are helpful. I've found that acupuncture helps to treat my allergies, and that in turn reduces my overall symptoms.

* * * *

Q: *Are you allergic to mold?*

Dorothy Wall: I don't seem to be allergic to mold, though I do my best to have a mold-free environment just as a precaution, and I also stick to a *Candida* diet. I think molds are a serious issue for many people, and I've heard many people say that they get worse in the damp weather and in the spring, when molds proliferate. I think investigating mold allergies is always a good idea for people with CFS.

* * * *

Q: *Being ill for so long, most of the hopes and dreams I had for my life have now passed me by. How do you keep your morale and your hope and spirits up given that you have felt sick for so long?*

Dorothy Wall: I've been so fortunate to be able to continue working at home despite being quite ill, and that's made a huge difference for me. Being able to maintain a professional life and to maintain connections with family and friends goes a long way in terms of keeping up morale. I think over time I've adjusted to a smaller life, and as long as I can keep doing things that have meaning to me, I'm pretty accepting of my other limits.

Finding new hopes and dreams when previous dreams have been lost is always a good strategy, though not always easy.

* * * *

Q: *I still have a problem with some of my friends and family being judgmental about CFS. What is the best way to explain this to your loved ones so that they don't assume you're only being 'lazy'?*

Dorothy Wall: When people don't understand my illness, I always give them some brief information about the organic nature of CFS, such as: "For many people, CFS is triggered by an infection of the central nervous system, and when the brain is affected, it in turn causes dysregulation of other body systems, so that my endocrine system, immune system and autonomic nervous system all don't work right."

I emphasize that my body doesn't work the way a normal person's does. This takes the conversation out of the realm of will-power or laziness.

* * * *

Q: *Did you meet your SO before you became ill? I had an acute onset of ME/CFS that left me disabled when I was in my early 30s. I was housebound for a good 10 years. I feel there's no hope for me to meet someone.*

Dorothy Wall: The challenges of dating and maintaining a relationship while chronically ill are significant, but they can be managed. I write about this issue in the chapter of Encounters called "The Erotics of Illness." I met my SO, Bill, in 1987 when my health was starting to improve. Dating wasn't easy, even then, and I was delighted to learn that Bill wasn't an evening person, either. In fact, he sometimes had lingering body aches and fatigue after a cold or flu, along with exercise intolerance. We often wondered if he had a mild case of CFS. We were lucky to be simpatico in this regard.

I encourage you not to give up on the idea that you can meet someone despite being limited. There are other people out there in a similar situation, and there are also people who understand and will value you for who you are. With the Internet as a way to reach out, it is not impossible to form new relationships.

* * * *

Q: *What do you think of as the single most effective advocacy strategy in light of the CDC's insistence on studying only the "fatigue" component of CFS?*

Dorothy Wall: I'm not quite sure what you mean about the CDC only studying the "fatigue" component, since they have genetic and epidemiological studies underway.

I worry more about all the emphasis on stress, which tends to put CFS back in the "psychological" camp - i.e., it's just a bunch of stressed-out people. In terms of advocacy, I think we need to continue to press Congress and the NIH to increase CFS research funding and to reestablish Centers of Excellence for CFS. A steady source of research dollars is key to drawing investigators to the field and expanding crucial research.

* * * *

Dorothy Wall, in closing the online chat: This has been great! Thanks so much to everyone for your insightful questions and for your interest in CFS and my book, *Encounters with the Invisible: Unseen Illness, Controversy, and Chronic Fatigue Syndrome*. You can find more information about the book on my website: http://www.dorothywall.com. Thanks again and I wish you all many good days ahead!

Related Articles

Related Information Resources