

by Howard Bloom

The Chronic Fatigue Syndrome/Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy (CFS/CFIDS/ME) is something each of us must fight in our own way, based on our own unique symptoms and circumstances. But there are some "self-management" principles that apply to all of us, and that are especially important for newly diagnosed patients to understand. This article is my attempt to share some of the guidelines I have developed over nine years of personally fighting this disease. By applying them, I have been able to achieve a great deal, despite being largely bedridden. With the following advice, I hope that you too can maximize what you are able to achieve within your own constraints.

First, before assuming CFS/CFIDS/ME is the cause of your symptoms, *have you been reasonably tested to rule out other plausible illnesses?*

This is a step recommended in all the literature (and required in the Centers for Disease Control and Prevention (CDC) diagnostic criteria), since many other diseases can mimic CFS/CFIDS/ME symptoms.

A word of caution, however. Doctors' visits and tests can demand a great deal of time and energy—commodities that a person with CFIDS (PWC) lacks. Withdraw more than you have in your energy "bank account," and you will make yourself worse. The "*overdraft relapse*" may not be evident for two days or for two weeks, but you can be sure it will occur

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and it can range from somewhat increased pain to long-term incapacitation. Thus, the best, most well-intentioned doctor can sometimes become your worst enemy

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if you don't communicate your limits (how often you can make it to appointments, what times of day you typically feel best, etc.).

While there is currently no cure for CFIDS, *skillful self-management (and appropriate medical treatment) can allow you to function optimally* within your new, more limited capabilities. Charles Darwin, who suffered from a disease greatly resembling CFS/CFIDS/ME, researched, wrote, and aggressively promoted his theories of evolution while confined to his cottage, unable to attend the meetings of the Royal Society that would determine his brainchild's fate. Florence Nightingale also suffered from a CFIDS-like illness that forced her to do most of her major organizational work while confined to home, and severely limited her social activity (e.g., she allowed only one visitor at a time).

The trick— and it is far, far harder than it sounds—is to "*know thyself.*" Recognize that your illness has created new boundaries that you cannot push through

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and a new set of rules governing behaviors and activities that you previously took for granted. Many of the truths you must learn about your "new" self will be hard to absorb and harder still to accept. Chronic illness often brings with it a virtual reinvention of identity. As with any loss, you may find that you go through a period of mourning for your lost abilities before you can fully face the reality of your current illness. With few exceptions, the basic rule is to learn your new limits and do not exceed them, or you will pay dearly.

Think again in terms of having an energy bank account with very small balance. You must become aware of every *penny* of energy you expend during the day. You have no passbook, so you must determine your balance through continuous self-assessment to ensure you do not over-draw your account.

As you go through your daily activities, *imagine you are wearing a pedometer* and keep a weather eye on it. The "*mileage*

" of seemingly simple activities like walking up the stairs, moving from room to room, carrying and lifting

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and just sitting up

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can add up quickly to more than you can handle. Even talking and listening to others, however pleasurable, are also extremely taxing to persons with CFIDS (PWCs).

Therefore, to reduce your energy expenditure—to keep the mileage as low as possible on your "pedometer"—get others to fetch things for you (and do other chores for you) when possible. Sit when you do things that you might ordinarily do while standing up, such as brushing your teeth.

Take baths rather than showers so you can recline. And, when feasible, shift to the bed or a horizontal couch when doing activities you may have traditionally done sitting up.

One factor an actual, literal pedometer can't measure, but that a CFS/CFIDS/ME pedometer does, is stress. It is now the most draining experience you face: recognize it is your nemesis. Try to identify the circumstances and people that stress you, and minimize or avoid all you can. And maximize the things that reduce stress for you—whether watching comedy films, listening to music, or engaging in a low-energy avocation or hobby (yoga and meditation help many patients).

If you can, keep a daily record or diary of the way you spend your energy (sitting, walking, talking on the phone, meeting with people, traveling out of the house, etc.). Also keep a record of the medications and dietary supplements you take. Look for patterns in what variables correlate with "good days" and which with bad. It will not be easy, but over time you will get a sense of the size of the hidden treasury of energy you have, small though it might be, and what affects it. To repeat: You have new limits of a kind you never imagined before. Get to know them well and *do not exceed them*.

Do not challenge your limits by trying to be your "old" self. This temptation hits every CFS/CFIDS/ME victim, but it can carry you to new depths of illness, crushing you with even more severe limitations and surrealistic symptoms than you ever imagined possible. If you are going to get better —and many people do —it will be through skillful self-management, not through challenging your capabilities. If you are, like so many PWCs, a take-charge, formerly high-achieving person, your new goal is an achievement of a different kind

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to rein yourself in; to gain a gentle self-discipline over your cravings for your former level of activity.

You are still capable of achieving miracles. But you will have to make them happen in new ways.

Finally, if you have insomnia, I highly recommend the following idiosyncratic "*treatment*": Obtain an auto-reverse cassette player, and buy or rent books-on-tape that interest you. (Those available via rental are far superior to those on sale, since the rental versions are unabridged). Place the cassette player next to your pillow so you can operate the controls in the dark. (Use headphones if you live with others so as not to disturb them). As you lie there sleeplessly, listening to the tape and the narrative will keep you from being driven mad by boredom and frustration. If you're lucky, it will lull you to sleep. At worst, just think how "well-read" you'll be!

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