

by Kenneth Casanova

Diagnosis

I had the Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy (CFIDS/ME) for about 4 years before I obtained a diagnosis.

I often felt I was lost wandering in the dark; I spent much time in my mind trying to get a grip on what was happening to me. Identifying a problem, getting a hold of a problem is the first step in determining what one can do to cope and where to start looking for a solution. If one can't identify what is happening to oneself, then one doesn't know what to do or what approach to take.

For the first 3 years I was really sick with an interminable flu, which would get better and then get worse. For those 3 years I was either in bed or shut in my apartment most of the time. I was barely able to struggle out to buy food and do my laundry.

I wanted to know what was wrong—to identify what was happening to me in order to get a grip on it. After about a year of thinking I probably had a virus, my doctors began telling me my illness was all in my head, there was really nothing wrong with my body, or with me, at all. (The last refuge of medical ignorance is the patient's mind.) Yet in certain moments it was clear to me that I was really sick; there was something really wrong with my body: I had fevers, chills, muscle-aches, and the weakness of a physical illness. This was a serious, flu-like illness—it was the same as when I had the flu as a child when everyone knew I was physically sick, when there was no dispute.

Now my doctors were telling me, despite my own reality, that I was not sick. In my clear moments I had to fight a two-front war: one front was against the illness—to cope, to fight to keep one's mental balance; on the second front, I had to fight the doctors: to assert my reality and demand and ask for help. In other moments, I was in wavering doubt: could it be psychosomatic, or was it physical, or a combination of both? If only I could try like the doctor's were saying not to be sick. So one becomes confused; and a path, a course of action becomes hard to find and one wanders about in a dark woods .

Then in 1985 I went to a specialist who diagnosed me as having CFIDS. This helped a lot because it helped me *validate my experience*, that I was actually physically sick. It helped me with the wavering doubt about my reality and experience; it helped me at least get a somewhat better grip on my situation and to identify my problem.

Coping

With this illness one has to find a way to accept where one is, rather than digging yourself deeper into the hole, pushing yourself beyond where you're able to be now—because you can only be where you are. Once you accept where you are, then you can find out what you can do within those limits. You can't have control what you can't have control over; you can have control over what you can do within the limits you're given. And I think, given my own experience, that by living this way, you're able to expand your limits—you're able to gradually get control over more things as the limits expand.

But you can't expand those limits if you're constantly overreaching them. So there is a lot to be said about accepting where you are and then setting priorities within those limits.

So you need to do things you know are essential and can be done based on your limits. By saying: this is what I have to do, this I can do, and the rest I have to let go because I can't do it—then I think the limits gradually expand.

Certainly if there is something that you need that you can't do you should seek available help from your family, your friends, your community, or your government.

You do gain more control. One thing I've learned from this illness (or so it seems) is: before I had the illness my mind, in many ways, was dictating to my body or emotions. Finally, somehow, my body broke down. Now my body was saying: "I'm taking over." So the body has to be given its due. The mind, somehow, has to accept this and give in to the body's basic needs; then gradually recovery can begin.

This is not to say that acceptance means becoming an invalid. Don't give up. Keep up as much of your life as possible, but within the limits that keep you from getting worse. Keep up hope, that over the long-run you will get better. (Make a distinction between your limits today and this week, and the long-run when you will be better.)

At first, during the first 3 years, I was very, very sick: either bed-ridden or mostly shut-in. Then, for about another 3 years I was moderately ill: I was able to get out more; I started physical therapy, recognizing that I had to do whatever I could to arrest and reverse the deterioration of my body. I also learned meditation. As part of the meditation I learned to become aware of (my) behaviors that caused my illness to worsen. I then worked to modify or eliminate those behaviors. I also learned which of my emotional patterns and conflicts could lead to behaviors that exacerbated my illness; I was then able to try to seek to resolve past conflicts and find better ways of dealing with present conflicts. The meditation also induced the relaxation response, which autonomically helps to clear the body of present stress and accumulated past stress. Surprisingly, as a result of pursuing these methods, the intensity of my symptoms were reduced by almost 50%.

However, these methods were no cure-all. I remained exhausted and sick much of the time for years. The basic treatment was rest, more rest, giving-into the body's demand for rest as much as possible (Aggressive Rest Therapy, the term coined by Greg Fisher).

As I said, during the second 3 years I began to improve. I had begun physical therapy: slowly, haltingly, testing the limits of physical exercise; very often overreaching my physical limits and paying for it. But slowly, haltingly, I was able to make progress and extend my physical capacities. This has been a process of years.

As I had improved significantly I began to follow the "2 out of 3 parts of the day policy," that is, I could be moderately active for two out of the three parts of the day: either morning and afternoon, or morning and evening, or afternoon and evening. The third part of the day I had to rest if I didn't want to get worse.

Now after 9 years of CFIDS I am moderately active with infrequent relapses—as long as I watch and monitor my activity level. I do have to periodically, during the day, monitor my body for fatigue. If I've done several tasks or activities and I'm starting to feel a little tired, I have to check myself and be aware of how I'm feeling; I then have to assess myself and my condition: can I carry-on with another limited activity or have I reached the cut-off point, that is, if I don't stop what I'm doing and rest, chances are good that I'll have some amount of relapse, that I'll have to pay for not stopping.

I've learned through painful experience that it's better to miss one activity today than six in the next 2 or 3 days. I've learned to be conservative on curtailing activity if I'm starting to get exhausted, because too many times I've ignored my body cues, pushed myself, done the one extra thing and then been in bed for 2 or 3 days. Better to say: I'm going to go home now and take a rest and be sure I can do what I've got planned for tomorrow. This is a trial and error process that I believe many CFIDS/ME patients have gone through.

Now after 9 years of illness I am active working on a number of volunteer projects which keep me fairly active during the day. I also, as part of my continuing physical therapy, work out 3 times a week for about 90 minutes each session at a health club. A short afternoon nap or rest gives me moderate energy for the evening.

I find that making sure I get at least 8 hours of sleep per night is crucial to having energy the next day and for avoiding relapses. Getting to bed after 11:30 is also taking a risk since I may wake up too tired. I also find that eating 3 nutritious meals daily on a regular schedule is important in maintaining my energy level and avoiding relapse. Moderately high doses of vitamin, mineral, and protein supplements markedly increase my energy level and feeling of well-being.

I think it's crucial to note that there are stages to the illness and recovery, though one moves from one stage to another either more or less gradually. For me there were four stages: severe illness, moderate illness, improvement with limited activity and frequent relapses and my present stage of moderate activity with infrequent relapses. It took me years just to move from one stage to the next, others may do so in shorter time periods. Also for me, sometimes I would slip back before moving forward again.

I believe that what a CFIDS/ME patient can do to cope or help himself/herself depends very much on the stage of illness/recovery he or she is in. In the stage of severe illness, it's almost impossible to do much more than rest, except for essential activity like personal care, eating, getting to the doctor, etc. At a later stage, mildly progressive exercise will help rather than hurt; some social activity may give you an emotional lift. A quarter-mile walk may help or hurt depending on the stage you're in.