



Step-by-Step Improvement

On December 26, 2007, I walked to the bathroom for the first time since 1988.

My battle with CFS began in 1984 with a five-week respiratory infection that my roommate and I had simultaneously. After we recovered from that sickness, my roommate stayed well. In January 1985, I got sick again and never got better. Two months later I was unable to work.

Until 1988 I could walk, drive and fix one or two meals, but then I became extremely ill. For the next four years I lay on my back 24 hours a day, getting up only to use the bedside commode. I couldn't talk above a whisper. Conversations of more than a few sentences caused a relapse. I couldn't read, write, walk, listen to the radio, watch TV or sleep on my side or stomach. Being moved by wheelchair from my room every two weeks so the room could be cleaned caused a relapse lasting about a week.

In 1992 the deterioration I'd felt since the beginning of my illness finally ebbed. On a "good day" I could do a little more and get away with it. But the gains were gradual, and I seemed unable to strengthen my

legs. Still, independence was my goal, and I wanted to walk.

I thought I knew how to proceed because I'd already gained some strength for eating by using a gradual approach. Since 1988 I'd eaten only mashed food. Then one day a whole pea appeared in my food, and I ate it without relapse. Within three months I ate almost entirely whole food.

Now I sought the "one pea" equivalent for walking. I tried taking three steps by my bed but the relapse was severe and prolonged. Could I lean my hands on the bed and take one step sideways with one foot? Yes, but at a price. I waited for the perfect time to try again—it seldom came, and I realized this was not the way to progress to walking. Physical therapy didn't seem to help, and for eight years I tried various exercises and strategies. Nothing worked.

Now I see my mistake: thinking that exercise had to be significant and result in a marked gain in strength. Instead, anything moderate backfired, making me sicker and weaker. So I sought an effective exercise that was just consistently doable. Maybe I'd never walk but at least I'd be headed

in that direction without dread or exercise-induced relapses.

I began this strategy with two new guidelines:

1. Find an exercise small enough that I can come out of a relapse while doing it. With something at that level, if I was experiencing a relapse I could continue the exercise because I'd know the relapse wasn't caused by it.

2. Increase the exercise or begin a new one only when my body lets me know that it's all right. Don't get caught up in predetermined schedules of progression.

Then as months and years passed, I expanded on the original two guidelines:

3. Make notes, and carefully describe exercises. Measure and record increases in time or frequency. This allowed me to track expended energy more accurately and avoid doing too much. Also, I could learn the rhythm of my relapses. When do they start relative to overexertion? What are their early warning signs, length and signs of improvement? The answers to these questions changed as I got stronger, so tracking my condition helped me reevaluate.

Further, memory lapses were lessened if I kept careful records. I could isolate the effects of exercises on symptoms by documenting anything relevant to the illness (a visitor, a trip out of the house or exposure to toxins). I discovered that keeping records encouraged me when progress

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was slow. I could look back and see I really had gained in strength.

4. Work on increasing repetitions of the exercise before increasing the load. (I read this advice in the *CFIDS Chronicle*.)

5. Try a new exercise only when reasonably sure the social and physical environment will be stable for a few days.

6. Do a new exercise in the morning. As its repetitions increase, spread them throughout the day. Do the exercise at night only when it has become easy to do during the day. This rule minimized the impact of a new exercise on my fragile sleep.

7. If an exercise is too strenuous, break it down into its component parts and attempt one part at a time. If I can't do any parts, try the next closest thing.

8. When possible, choose exercises that can accompany some activity I must do. I began this new program in early 2001 by, once a day, sliding one knee to my chest while sitting in bed, and lifting one knee to my chest while sitting on the bedside commode, and stretching my feet. After two-and-a-half years I did each activity six times

a day. Over the next two years I added isometric leg exercises and arm and trunk strengthening work.

In late 2005 I began standing while leaning on the bed. After nine months of this activity I was standing for three minutes, eight times a day. I unsuccessfully attempted the sideways step I'd tried in the 1990s. But after a few more months I was taking two of these side steps eight times a day, still leaning on the bed.

Then I started standing unsupported, and four months later I could stand for three minutes eight times a day. I progressively put more weight on one leg and then the other. After almost three months I could stand on each leg for three seconds eight times a day. Now I was ready to walk. I began trying in late May 2007. By June 1, 2007, I consistently walked two steps a day. I took off: The steps taken on the first of the next few months, respectively, were 6, 21, 48, 101, 185, 301!

I'm still sick. All the old symptoms lie in wait. I still take all my old medications plus a few new ones. Exposures to chemicals or allergens can stop my progress. I still spend

most of my time lying in bed with my eyes closed and the radio off. But regardless of the circumstances, I don't stop exercising. Knowing I have done the exercises during a relapse tells me I can safely do them even when I feel terrible.

However, my life has changed enormously. More activity is required to elicit a relapse. Recovery time is shorter. I can do more for myself and, although I may never vacuum the house or climb a mountain, relative independence (with the help of a motorized scooter) now seems possible.

Exercises alone don't account for my progress. In addition to the medications, I needed quiet, freedom from allergens and toxins, help doing things I couldn't do for myself. I also needed the ability to set my own activity level and to say, "This helps," or "That hurts." For those who gave me the accommodations, help and trust I needed—my family, boyfriend, nurse, doctor, caregivers and friends—this is their victory too.

Now on to the kitchen. ■

AFTERWORD

I've passed many milestones since walking to the bathroom that day: walking to the kitchen; cooking all my food; doing the laundry; giving up the use of a scooter; getting my driver's license; taking daily walks in the neighborhood; and driving myself to and from medical appointments and grocery stores. Medications and rest are still essential parts of my life and will probably remain so. A rash restricts my diet, and I still have chemical sensitivities. But there is no sign that the improvement is ceasing. With the exception of heavy housework and gardening, the dream I had in the 1990s is now a reality. I'm independent.



Dianne Timbers has a PhD in sociology. She was working at UCLA on a research project when she became ill with CFS. In 1985 she moved back to Tucson where she now resides.