

**Recovery from Chronic Fatigue Syndrome:  
One Person's Story  
By Bruce Campbell, PhD**

I came down with Chronic Fatigue Syndrome (CFS) over a few days in 1997, dropping from fully healthy to 25% of normal. Over four years, I gradually returned to the same level of health I had before becoming sick and have remained healthy now (2018) for more than a decade and a half.

I share my story in the hope that others may find in it both encouragement and practical strategies. The story reflects a my belief that how we live with chronic illness can change its effects and even its course.

Bruce Campbell

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**Bruce Campbell, PhD**, founded the CFIDS and Fibromyalgia Self-Help Program, a non-profit organization that offers a suite of low-cost and free self-help courses over the Internet, plus two websites that contain more than 700 pages of resources for people with CFS and fibromyalgia. The organization was founded in 1998 and has conducted more than 550 self-help classes and groups. Dr. Campbell is a graduate of Stanford University and holds a PhD from the University of California.

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# Recovery from Chronic Fatigue Syndrome

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## 1. Keys to Recovery

Before I tell you my story, here's an overview of the five keys to my recovery.

### 1) Pacing

The single most important part of my program for improvement was pacing.

Why is pacing so important with CFS? Because the way we live our lives with CFS has a big effect on our symptoms. If we go outside our limits, we experience an intensification of symptoms called Post-Exertional Malaise or PEM. The key fact about PEM is that it is always out of proportion to the overdoing. Even the smallest transgression can result in an extended period of time in bed.

When I realized that how I lived had a big effect on my symptoms, my first reaction was to feel devastated: I had unknowingly been creating a lot of my own suffering.

My next thought, however, was more hopeful and gave me the path that led to my recovery. I told myself, "If the way I lead my life has such a direct effect on my symptoms, this effect should work in both directions. If living one way increases symptoms and leaves me feeling that my life is out of control, living a different way should reduce my symptoms and might help me regain control."

So I set out to find that way. You'll read about what I learned in upcoming chapters. For now, let me underscore the importance of self-management in general and pacing in particular by quoting from well-known CFS specialist Dr. Charles Lapp: "*Your doctor can help you cope with CFS/FM, but your success in regaining control will likely depend more on what you do than on anything a doctor does for you.*"

### 2) Stress Management

It took me more than a year to recognize my second key to recovery: managing stress. Stress presents a double challenge to people with CFS. First, the condition adds new sources of stress beyond those we had when we were healthy, such as the ongoing discomfort of symptoms, uncertainty about the future, and financial pressure. In addition, CFS makes us more vulnerable to stress; the effects of a given level of stress are greater than they would be for a healthy person.

In sum, a double whammy: your stresses are multiplied by CFS and stress takes a heavier toll if you have CFS.

As I'll explain in a chapter below, I discovered some simple principles for stress management. The first was to recognize that because there are so many causes of stress and the effects of stress are so strong, I was best served by using a variety of strategies to manage it. The second was to think in terms of two categories: stress reduction and stress avoidance. Stress reduction included using relaxation techniques and getting out of the house for a walk every day. The second approach meant taking measures to use order and routine to avoid stressful circumstances.

### **3) Acceptance with a Fighting Spirit**

I quickly discovered that there was no cure for CFS and spontaneous recovery seemed rare, so I struggled with what attitude I should adopt. I sought one that included both a realistic acceptance that my life had changed and hope for improvement. I settled on the formulation “acceptance with a fighting spirit.”

Acceptance meant that I acknowledged that CFS was a long-term condition. Instead of living as if I were well or searching for a miracle cure to restore me to health, I acknowledged that my life had changed for an extended period of time, possibly for the rest of my life. At the same time, I had the conviction that I could find ways to feel better, even if I was not able to restore my old life.

### **4) Experimentation & Record Keeping**

I came to view living with CFS as a series of experiments that I called being my own "CFS scientist." Like a scientist, I formulated hypotheses (“I can walk 20 minutes a day without increasing my symptoms”), then gathered evidence by testing the hypothesis (what effects do I experience from walking that long, both during and after). I hoped that some experiments would work, but I was sure that others wouldn't. In any case, I believed I could learn from my experience.

Keeping records was crucial to being a CFS scientist. Having systematic notes enabled me to see patterns and to identify links between my actions and my symptoms. I used a variety of logs, most requiring only a few minutes a day to fill out. There is a chapter on logging below and you can find logging forms and instructions on keeping records on the [Logs, Forms and Worksheets](#) page on the website of the self-help program for CFS and fibromyalgia that I founded. (Note: All my work for the program has been as a volunteer. Just as this site is free, I am not paid for my work at the program.)

Logging was also a good tool for motivation. After noticing that some days were better than others, I focused on trying to find what I was doing that created good days so I could expand them. I also used my records to chart my progress over time. Seeing written evidence of improvement reinforced my sense of hope.

### **5) Support**

Support from others was the final key. My doctor was understanding, and my family and friends were supportive, so I didn't have to fight many of the battles others with CFS have.

In addition, I experienced wonderful support from others with CFS. First in local support groups and later in the self-help program I created, being part of these groups gave me a sense of being connected to others at a time of confusion and isolation. Also, fellow patients were tremendous sources of information, experience and perspective. Their successes were a source of both strategies and inspiration. The self-help program, with its emphasis on learning how to manage CFS, enabled me to surround myself with positive people who were also working actively to

improve.

With that overview, we turn in the next chapter to how I made the decision to use self-help to treat CFS.

## **2. I'm *Really* Sick, Now What Do I Do?**

My CFS began as a flu-like illness in the summer of 1997. My doctor told me that my illness was probably caused by an unidentified virus and would run its course in a few weeks. As the weeks passed, however, my symptoms continued and I began to worry. I was puzzled by the bizarre set of symptoms I experienced: exhaustion, waking up tired after many hours of sleep, difficulty concentrating, a generalized aching throughout my whole body, tender lymph nodes in my neck and a puzzling sensitivity to noise and light.

I was confused further by the fluctuation in my symptoms. On some days, the symptoms were low, giving me hope that the illness was ending. But a day or two later, they were back in full force. The overall trend was downhill and I gradually cut back on my hours at work, eventually stopping work altogether.

For four months, I experienced symptoms without having a name for my suffering. I lived with tremendous uncertainty, wondering what was wrong with me and what my future would hold. Finally, my doctor and I came to a tentative diagnosis of Chronic Fatigue Syndrome or CFS. (The illness has also been called CFIDS [Chronic Fatigue and Immune Dysfunction Syndrome], ME [myalgic encephalomyelitis or myalgic encephalopathy] and ME/CFS.) Getting a diagnosis was both a relief and a shock. I was grateful to have a name for my strange and debilitating symptoms, but staggered by the recognition that I had a long-term illness.

### **Choosing Self-Management**

To gain perspective, I spent a few hours later that day reading about CFS in the local health library. That amount of research was enough to convince me that medical resources for CFS patients were very limited. There was no medical cure for the illness and no drugs available to treat the condition.

Rather, patients were advised to try a variety of different treatments in the hope of finding something that reduced symptoms modestly. What one person found helpful might be ineffective with another. Treatment focused on partial reduction in symptoms rather than addressing the cause. It seemed that the best course the medical world had to offer was a series of experiments with different medications in the hope of finding one or more that would reduce symptoms only slightly.

Further, the likelihood that effective treatments would be developed in the near future seemed dim, because there was no agreement on the cause of CFS and very little money was being put into research. I figured it would be at least two or three decades before effective treatments for the condition were available.

Since I wanted to get my old life back, I decided to forego that approach. Rather than experimenting with many medical treatments in the hope of achieving minor symptom improvement, I decided my best chance for getting better was to observe myself and make changes in the way I lived. I felt confident I could find things that would help me.

## **Earlier Experience with Self-Help**

Previous experience helped shape my decision. One important element in my past was work at the Stanford University Medical School for a program that developed self-help courses for chronic conditions. These classes were offered as supplements to regular medical care. Seeing how people had been able to help themselves when living with illnesses like arthritis, cancer, heart disease and stroke had convinced me that how one lives with chronic illness can change its effects and may even change the course of illness.

Perhaps the greatest benefit of my time at Stanford was the idea to ask two questions when faced with a medical problem:

- 1) What help is available from the medical system?
- 2) How can I help myself?

With CFS, the answer to the first question was “not much.” What about option #2? If a self-management approach had been proven to be useful for conditions with well-established medical treatments, it should be all the more important for a condition with no standard or widely effective medical treatment. I asked myself: “where is the self-help class for CFS?” When I couldn’t find one, I started what became the CFIDS and Fibromyalgia Self-Help Program. The initial groups led over time to a set of seven different courses and three websites, and provided me with the supportive environment that led to my recovery.

## **The Medical System and Me**

When I decided to respond to CFS by using self-help alone, forgoing experimentation with medical treatments, my decision did not imply a rejection of my doctor. I checked in with him monthly to keep him apprised of my progress and continued to see him for other medical problems. He was supportive of my approach to CFS.

My response was not a rejection of modern medicine in general. When I had cancer earlier in my life, I chose surgery and radiation, and did so for the same reason that I adopted lifestyle change as my treatment for CFS: I thought the path I chose provided the best option under the circumstances. Proven medical treatments were available in the first case, so I used them. Self-help seemed the most promising approach to CFS.

In describing my approach, I do not mean to imply that others should follow the path of exclusive reliance on self-help to treat CFS or that I would have done so in different circumstances. Had my symptoms been more severe, I might have combined a self-help approach with a medical one. In that case, the possibility of partial symptom reduction using medications might have been strong enough that I would have used them as a supplement to behavior change. But under the circumstances I found myself in, I judged that using self-help exclusively offered me the best chance to control symptoms and improve my quality of life. In the chapters that follow, you will read about the things I found that helped me.

### **3. Understanding My Situation**

Each person's experience of CFS is a unique combination of factors that include the severity of CFS, the pattern of symptoms, presence or absence of other medical issues, and the person's individual life circumstances. Each of these factors can either help promote improvement or make it more difficult. I was very fortunate; my situation was favorable in several ways, each of which supported my efforts to get better.

#### **Illness Severity and Other Illnesses**

Perhaps the most important factor affecting a person's chances for improvement is the severity of their CFS, which varies greatly from person to person. On one end of the spectrum, there are people who have relatively light cases and are able to continue working full time; on the other end, some have very severe cases and are bedbound, with many people in between. The average (median) of people entering the self-help program has been about 25% of normal. I was fortunate to have a moderate case of CFS, one that put me right about at the median.

Another aspect of my medical situation was also favorable. I had only CFS, uncomplicated by other illnesses. Since 1997, I have known several thousand people with CFS and fibromyalgia, most of them through the self-help program. The majority have both CFS and fibromyalgia, or one of them in combination with one or more other serious medical issues, such as sleep disorders (especially apnea), chemical sensitivity, food-related issues (e.g. celiac disease, lactose intolerance) or orthostatic problems (e.g. neurally mediated hypotension). I was lucky to have only one condition to manage.

#### **Finances and Stability**

A third significant factor is a person's financial situation. I was in my 50's when I got CFS, old enough to have created a financial cushion for myself. Having financial reserves allowed me to focus on getting better. Also, as a single person with no children, I was financially responsible only for myself. The result of this combination of financial and family circumstances was that I was not stressed by the money pressures that many people with CFS face. Having financial reserves made it easier to do something that my health was forcing on me, namely to quit work and focus on getting better.

Another significant factor is the degree of stability in a person's life. And once again, I was lucky. Some people are forced to move or have other forms of instability. In contrast, my life was very stable during the first several years of my illness, helping me to avoid stresses faced by some patients whose lives are more turbulent. My financial position enabled me to continue living in my home of 20 years. My most important relationships were stable for some time.

The timing of my illness was also fortunate. In the summer of my fourth year with CFS, my mother was hospitalized twice for major surgery and my father died unexpectedly. As their only child, but having no spouse or children myself, I was their primary caregiver. I had improved enough by then that the stress from these events did not cause a relapse, as it might have a couple of years earlier.



## **Support**

The fifth significant factor for people with CFS is support, from doctors, family, and friends. Again, I was fortunate. I received a diagnosis after having symptoms for four months and my doctor supported my approach of treating CFS using self-management. I also received understanding and support from my family and closest friends. They all accepted my illness as real and agreed with my decision to pursue self-management. Again, I was lucky. Many people with CFS struggle to find understanding and support, and it often takes years even to get a diagnosis.

My living situation also supported my efforts to improve. I lived alone. Although it could be frightening on the days when I was too sick to get to the grocery store, living alone gave me the freedom to organize my life in the way I believed would maximize my chances for improvement. I did not have to coordinate my daily life with that of others, nor did I have to balance daily responsibilities to others with my desire for improvement.

## **More Good Luck**

Finally, I was lucky in two additional ways. First, I adopted a self-help strategy very early. I have met many people with CFS who tried to ignore their illness, sometimes struggling on with their old lives for years, until they collapsed. I took a different approach. As my symptoms worsened in the first few months I was ill, I reduced my time at work in several steps, then stopped working entirely. As I learned later, listening to my body and giving it what it needed was perhaps the most effective strategy possible for responding to CFS, but I did not know that when I made my decision.

Second, I had a case of CFS that allowed for recovery. I have known many patients since 1997 and have observed many different patterns of improvement. Some patients are able to control symptoms by making lifestyle adjustments, but don't improve their activity level or do so only modestly. Their cases of CFS seem to place a ceiling on how much they can increase their functional level.

My situation seems to be different and reminds me of the experience of gay men in San Francisco during the 1980s. Some never became ill with HIV or AIDS, even though their sexual practices were similar to those of other gay men. After ten or fifteen years, researchers found these disease-free men had a difference in their immune systems that enabled them to avoid infection. Perhaps I had a variant of CFS that allowed for recovery.

In all these ways, my situation supported my efforts to improve. Talk about lucky. It's as if I had flipped a coin eight times and got eight heads.

## 4. Using Multiple Strategies

Having settled on using self-help, I asked myself: where should I begin? I decided to start by developing a set of strategies to deal with my most persistent and disruptive symptom: fatigue.

### Treating Fatigue

From my work at Stanford, I knew that fatigue could have multiple causes, each of which might be addressed by one or more different strategies. I identified eight possible causes for my fatigue besides my illness.

Activity Level	Being active beyond my limits
Inactivity	De-conditioning from having a lower activity level
Poor Sleep	Sleep was not restorative, leaving me feeling tired
Pain	Pain can lead to muscle tension, which is fatiguing
Stress	Stress produces worry and muscle tension
Depression	Low spirits produce a sense of listlessness
Poor Nutrition	Lose energy if don't get enough food or lack right foods
Medications	Drugs can cause fatigue as a side effect

### Activity Level

Activity level seemed the most crucial, because there was an obvious relationship between the number of hours a day I was active and my fatigue, though the effects were sometimes delayed a day or two. If I was active for more than about four hours a day, I later experienced elevated fatigue. Rest produced a reduction in my exhaustion. Ironically, I found hope in this push and crash pattern. If the connection between activity and fatigue was so direct, then I might be able to gain some control if I found a level of activity that my body could tolerate.

As I'll explain in upcoming chapters, finding my limits, adjusting my life to live within those limits, and expanding my limits very gradually using experimentation became the heart of my self-management plan.

### Inactivity (Deconditioning)

The other factor that seemed especially promising was inactivity. I knew that highly-trained athletes become deconditioned if they stop exercising for even a brief time, so I was sure that part of my fatigue was due to my lower activity level. If my aerobic capacity had diminished, then I would become fatigued more easily by activity. I thought the way to fight this was through exercise. But how much? If I strayed outside my limits, I would intensify my symptoms.

My solution was to experiment to find the length and intensity of exercise that would produce an aerobic workout without increasing my symptoms either during my workout or later. Initially, that level was about 20 minutes of walking a day at a pace that raised my heart rate to 90 to 95 beats per minute. I found that by staying within those limits I could recondition myself to some

degree, thereby reducing inactivity as a source of fatigue. (See chapter 11 for more on my experiments with exercise.)

### **Poor Sleep**

Improving my sleep also seemed worth pursuing. I knew that sleep is often nonrestorative for people with CFS, but I thought I could help myself to some degree by maintaining good sleep-related habits. My reasoning was that even if CFS was the major reason for nonrestorative sleep, I could probably reduce my morning sluggishness if I maintained regular hours and avoided things like late nights on the computer. So I made it a rule have a wind down period before going to bed, starting at 9 pm by turning off the TV and my computer.

### **Pain**

The final factor that I thought might be affecting my fatigue was pain. To the extent that I responded to pain by tensing up, I might increase my fatigue. Using relaxation was helpful, as described in the chapter on rest.

### **Stress & Emotions**

In the first year or so, I focused my efforts on the areas described above. What about stress? Didn't I say earlier that stress management was the second most important key to my recovery? True, but it took me some time to recognize the effects that stress, and also emotions, had on my symptoms. When I recognized their effects, I adopted strategies that addressed both of them, seeing them as two more areas providing opportunities to reduce my symptoms.

### **Poor Nutrition & Medications**

I assumed that the final two factors on my list of possible causes of fatigue didn't apply to me. Since I had decided not to take medications, I was not worried about fatigue due to drugs. And I thought my nutrition was probably adequate, because I had eaten a low-fat, mostly vegetarian diet for many years and I hadn't experienced intestinal symptoms. I didn't rule out looking at my diet, but I decided to focus my initial efforts elsewhere.

### **Should I Use Additional Strategies for Other Symptoms?**

In thinking about fatigue, I had discovered an important principle that I was able to use many times. Because a symptom can have multiple causes, it is often helpful to use multiple strategies in response.

Once I developed my approach for addressing fatigue, I asked myself whether I needed additional strategies for my other major symptoms, unrefreshing sleep and pain. I recognized that sometimes a person is prescribed more than one medication if he has multiple symptoms, so I wondered whether I needed separate strategies for brain fog and pain.

After observing the effects of my efforts to control fatigue, I concluded that all three symptoms (fatigue, poor sleep and pain) were responsive to the same strategies, so that, by and large, I didn't need separate strategies for each symptom. As I'll describe below, taking regular rests, limiting my activity level, and reducing the stress in my life worked on all three symptoms and also seemed to improve my mood as well. Just as important, I came to see the presence of any of my symptoms as a sign that I needed to cut back. For example, if I felt cranky or depressed, I took it as a sign I had gone outside my limits and needed to rest.

## **Interactions**

The interactions between symptoms and emotions proved to be another fruitful area to explore. I'll give a couple of examples here and more in the chapter on emotions. Although it took me a while to recognize, I eventually saw a relationship between worry and my symptoms. I noticed that if I reacted to an increase in symptoms by feeling anxious, that reaction would make the symptoms even worse.

I dealt with this vicious spiral in several ways. Probably the most helpful was the combination of rest and meditation. Just lying down helped me to calm down. Beyond that, however, doing a meditation procedure during my rests helped even more. I developed a technique that involved focusing on my breathing.

I also discovered the power of self-talk to reduce symptoms. I found that if I experienced anxiety, I could calm myself down with reassuring words. When an intensification of symptoms led to thoughts like "I bet this is a big relapse starting" or "I'll never get any better," I countered with phrases like "Remember how things always look worse when your symptoms are bad" or "Think about how you've improved in the last six months."

I was surprised to find that the relationship between emotions and symptoms applied even to positive emotions. I remember a time when I was moved to tears by the positive comments about the class from people in one of our early self-help groups. I was confused by my response, which was a combination of joy and brain fog. The fog dissipated gradually over a period of about half an hour. That experience helped me to realize that any experience, whether positive or negative, that produced adrenaline would trigger brain fog. The same principle applied in situations that made me anxious: any experience to which my body responded caused muddled thinking.

I have to admit that sometimes I wished for a simple solution, a single pill to take rather than the behavioral approach, which involved the use of many strategies. But I decided that I needed multiple strategies because I had several symptoms, my symptoms had several causes, and CFS affected so many parts of my life. From that perspective, my challenge was to understand all the inter-relationships and to find those strategies that produced the greatest effect on my symptoms.

## 5. Is Recovery a Realistic Goal?

I struggled for several years with the question of whether I should aim for recovery. Even though I knew that recovery was unusual for people with CFS, I had trouble letting go of the hope that my old life would return. But aiming for recovery created problems, too. By having recovery as my goal, I lived on an emotional roller coaster, buoyed by signs of progress but devastated by my setbacks, of which there were many.

Wrestling with these issues helped me to understand the distinction between things I could control and those I couldn't. It was clear that my actions and attitudes had an effect on my symptoms. If I did too much one day, I suffered increased symptoms the next. If I responded to stress with worry, that too would make my symptoms worse.

I didn't remember having such an effect on my symptoms in previous illnesses. When I had cancer, my recovery depended on the stage of the cancer and the skill of the doctors. But with CFS, my choices and habits were important. My attitudes and actions affected my symptoms. But affecting symptoms is not the same as creating recovery.

### Insight and Inspiration

Reading an [article](#) by Dean Anderson, a recovered CFS patient, provided both insight and inspiration as I was struggling with this issue. Writing in the *CFIDS Chronicle*, he described his successful eight-year struggle with CFS. The article outlined a path much like the one I had adopted, turning away from medical treatments and instead figuring out what he could do to make himself better through changing his attitudes and behaviors.

He wrote that after trying various approaches, he had come to believe that the key to his recovery was a certain kind of acceptance. He described it not as resignation, but rather "*an acceptance of the reality of the illness and of the need to lead a different kind of life, perhaps for the rest of my life*" [my emphasis]. He went on to say that "the 'effort' required to recover from CFIDS [his term for CFS] is an exercise in discipline and hopefulness, not determination and striving."

I found inspiration in his ability to combine acceptance of being ill with hope for a better life. That seemed the right balance. On the one hand, I felt I had to accept that my life had changed and that my old life might never return. On the other hand, however, I found comfort and hope in the belief that there were things I could do that would bring improvement.

I finally concluded that whether I recovered was out of my hands. In reading about CFS and meeting other patients, I decided that possibly as few as 5% of patients recovered. (Note: I'm not sure anyone knows the true recovery rate for CFS, but from knowing several thousand people with CFS, I believe only a small number return to their previous level of health, but many improve to varying degrees.) I believed that there was a limit on how much I could improve, but it was impossible to predict what that limit might be. To avoid likely disappointment, I decided to assume I was part of the larger group who didn't recover and to focus on finding ways to control symptoms and improve my quality of life.

Reminding myself periodically that I was unlikely to recover served me well. Ironically, my symptoms seemed to decline whenever I told myself that I had a permanent illness. So acceptance of the illness as my reality was crucial. But, also, I believe that hope, too, was crucial to the improvement I experienced. I told myself that even if I couldn't recover fully, there must be things I could do to improve my life. That conviction was confirmed many times. For example, I had a belief that I could find the cause of all my relapses and use that knowledge to prevent future relapses. Over a period of a year and a half, I significantly reduced and then eliminated my relapses, as you'll see in chapter 12.

## **Acceptance and Hope**

So for me the combination of acceptance and hope was the key. Acceptance meant acknowledging that I had a serious illness and needed to lead a different kind of life, perhaps for the rest of my life. But acceptance was not resignation. I also had confidence that there would always be things I could do to improve my situation, even if I didn't recover fully.

Combining acceptance and hope enabled me to resolve the dilemma of how to have a goal that was both realistic and positive. My approach was based on a kind of faith, the belief that my body had an innate drive to reestablish good health.

I thought I had two roles in support of my body: 1) to discover what conditions best supported my body's recuperative powers, and 2) to live consistently in a way that allowed these powers to be expressed. I call this faith because I had to proceed with little or no reinforcement that I was doing the right thing. My progress was very slow, at best perhaps one or two percent a month and there were periods of several months when it was hard to see any improvement at all.

Another factor in my recovery strategy was discipline. Like Dean Anderson, I taught myself to live consistently within my limits, extending my activity level gradually as permitted by the illness. Just as an alcoholic must learn to abstain from alcohol and a person controlling his weight must learn to live in a different way, I assumed that my ability to improve depended on my changing my habits so that I lived consistently in a way conducive to improvement.

## **6. Pacing vs Crashing**

I experienced tremendous frustration in the first six months I was ill. I felt that I was living on a roller coaster, swinging between times of intense symptoms and periods of rest. When I felt an increase in my symptoms, I went to bed. When the symptoms subsided, I resumed activity, but no matter what I did, I couldn't seem to escape the cycle of push and crash.

Even when I lowered my activity level to half of normal and then to a quarter, it was still too much and I soon found myself back in bed. I was caught in a demoralizing cycle of overactivity and rest. Living in response to my symptoms, my life felt out of control.

I didn't have the words to understand my experience at the time, but I later recognized that my activity was triggering Post-Exertional Malaise (PEM), the intensification of symptoms caused by overdoing. As I mentioned earlier, the key fact about PEM is that the intensification is out of proportion to the overdoing. All I knew at the time was that punishment for activity felt so unfair!

### **Pacing as an Alternative**

At some point, I heard about the idea of pacing, which involved living according to a schedule that combined similar levels of activity every day with planned rests. Pacing held out the promise of stability as an alternative to repeated cycles of push and crash, and it gave me a way to understand the cycles of intense symptoms followed by rest. They were due primarily to overdoing, which triggered PEM, which in turn forced me to rest.

Understanding this cycle of push and crash led to a depressing realization: I had unknowingly created a lot of my own suffering by being more active than my body could tolerate. But then I realized that if my activity level affected my symptoms so directly, that effect should work in both directions. If living one way intensified symptoms, living differently should enable me to reduce my symptoms.

Pacing offered the possibility of a more stable and predictable life, a way to live life according to a plan, rather than in response to symptoms. The benefits of pacing as I understood it included:

- Lower symptoms
- Less suffering
- More stable and predictable life
- Sense of control
- Less time spent resting (because less PEM)
- More productive use of time (because less PEM)
- Chance for improvement

### **The Three Parts of Pacing**

Over time, I came to see pacing as having three parts, which you'll read about in detail over the next several chapters:

### **1 Finding My Limits or Energy Envelope**

CFS imposes limits and exacts a punishment if a person goes outside those limits. There are limits on physical activities and also limits in other areas, such as mental activity and socializing. The challenge in this part is to define those limits.

### **2 Adapting to The Limits**

The second part of pacing is adjusting your life to live within limits in order to avoid Post-Exertional Malaise (PEM). I realized that learning to live within my new limits would be a gradual process, likely involving the use of multiple strategies. Over time, I came to see that this part also meant learning how to minimize relapses and how to manage non-routine times, such as travel, which often trigger relapses.

### **3 Expanding My Limits**

My hope was that by treating my body well and avoiding overdoing, I would be able to expand my limits over time, doing more without intensifying my symptoms. As you'll read, I found that the keys to expanding my Envelope were to extend my limits a little bit at a time and to be willing to return to my previous level if the extension increased symptoms.



## 7. Finding My Energy Envelope

The key facts about CFS were the combination of the tight limits it imposed and the high cost of exceeding those limits. Here's an example. Before getting sick, I enjoyed hiking, up to 20 miles a day. In the early months of my illness, I could walk for only 15 or 20 minutes a day on my good days and, even on good days, 30 minutes might send me to bed for an hour.

CFS felt like a rigid and unyielding force, a feeling that initially gave me a sense of powerlessness. But the more I fought my limits, the worse I felt. Like many other people with CFS, I learned that if I tried to ignore my body, my symptoms were intensified greatly. After a while, I concluded that my best hope lay in adjusting to my limits. Ironically, yielding to the illness gave me some power. By listening to my body and honoring its limits, I was able to achieve some stability and to begin regaining control of my life.

But what were my limits?

### Overall Limits: The Energy Envelope

My transition to a more productive way of living with CFS was aided greatly by two ideas. The first was the concept of the Energy Envelope, which I found in an article in the *CFIDS Chronicle*, the magazine of the CFIDS Association of America (since renamed Solve ME/CFS Initiative). Titled *Think Inside the Envelope*, the article suggested that people with CFS have limited energy, but that they can gain some control over symptoms by keeping the energy they expend within the limits of their available energy. The authors called this "living inside the energy envelope."

For some time, I used this idea in a general way and found it very helpful. I would ask myself whether doing something would take me "outside the envelope" or whether I was living "inside the envelope." I used this idea in combination with monthly evaluations using a 0 to 100 [Rating Scale](#) I developed.

My self-ratings changed only a few points at most each month, suggesting that my improvement would be slow. Rating myself was like looking in a mirror. It showed me how far from normal I was and reminded me that I could be active only a few hours a day if I wanted to avoid increasing my symptoms.

The other idea from my early reading was the Fifty Percent Solution, a concept I found in the book *Recovering from Chronic Fatigue Syndrome*, by William Collinge. He suggests that people with CFS estimate each day how much they can accomplish and then aim to do half of that. Rather than repeatedly stressing your body by trying to do more than it can tolerate, you aim to limit yourself to a safe level of activity. The unexpended energy is a gift to your body.

I appreciated his giving permission to do less and his reframing a lower activity level as something positive. Over time, I also came to think that his idea was based on the recognition that those of us with CFS often had an unrealistic idea of our capabilities and thus might be helped by a strategy that lowered our expectations .

## Developing a Detailed Understanding: The Little Envelopes

Using the term Energy Envelope was a reminder both of my limits and of my ability to control my symptoms to some degree by staying within those limits. After a while, however, I decided to try to define my limits in detail rather than thinking in terms of the overall term Energy Envelope. This change was triggered by some people in the self-help program pointing out that mental activity and stress could be just as draining as physical activity.

So I began to ask myself a series of questions in order to get a fix on my limits and needs in different areas of my life. I asked myself: how much mental activity (reading or computer work, for example) can I do in a day without worsening my symptoms? how much in a single session? what are the stressors in my life? how much sleep do I need at night? how much daytime rest? how long can I drive safely? how long can I stand at one time without intensifying my symptoms? how far can I walk?

I was also concerned to find my limits in other areas. In addition to those just mentioned, I included activity limits (which I defined as how long I could do various activities like housework, shopping, driving, and spending time with people), food sensitivities, sensitivity to light and noise, and emotions.

In the self-help program, we have come to call these specific limits the Little Envelopes, with several to many specific limits in six different major categories:

- Physical activity
- Mental activity
- Social activity
- Sensory limits
- Stress
- Emotions.

During my recovery, I focused on a dozen areas that I tracked on a form called “My Energy Envelope.” It took me at least a year to develop this more detailed understanding, but I felt rewarded all along the way because every limit I defined helped me gain more control. I filled out the form once every several months and found it a helpful way to assess how I was doing in some detail.

Here's a sample of my Energy Envelope from the second year of my illness.

Sleep            7 1/2 hours, starting by 11 pm

Daytime Rest 10-30 minutes on most days, sometimes more

Activity        4 hours a day. Activities like errands & housework OK in moderation

Exercise       30 minutes walking OK on level ground

Reading & Computer Reading OK most of time, but must limit time on computer, especially at night

Driving Limit about 2 hours, sometimes tired after 30 minutes

Standing Limit 1 hour, whether walking, shopping, cooking

Socializing Usually OK with one person or small group but respond strongly to some people and vulnerable to stressful encounters

Other Illnesses Make CFS symptoms 30-50% worse. Secondary illnesses are more severe now than before

Emotions More easily upset than before. Strong emotions trigger CFS symptoms

Stressors Life mostly stable at present, thankfully

Food Haven't found any food sensitivities so far. Diet same as before

Sense Data Noisy settings and loud noises are very bothersome, e.g. restaurants

Later I added a section that had three parts, one summarized my abilities and limits, the second noted my greatest vulnerabilities (for example, stress, secondary illnesses, and travel) and the third used for short-term goals. This section was a helpful summary of my current situation and also suggested where work might give the biggest payoff in reduction of symptoms.

In studying my envelope, I was surprised to find that my limits were more restrictive in some areas than in others. For example, when I thought I had recovered back to about 60% of my pre-illness level overall, I could do only about 30% as much exercise.

I found it very helpful to share my envelope definition with family and close friends. Getting other people's views of my situation helped me to be more realistic in my self-assessment and also helped others to understand me better.

(For more on the Energy Envelope and the Little Envelopes, see the series of articles [Pacing: What It Is and How to Do It](#), the articles in the [Pacing](#) archive, and the success story [How I Manage My Many Energy Envelopes](#), all on the self-help program website.)

## **Learning Through Experiments**

One way I found my envelopes was by trying experiments and keeping records. Experimentation was such an important part of my approach that I devote all of chapter 11 to it. For now, let me give a few examples of experiments and the lessons I learned from them.

By walking at different times of day, I discovered that exercising in the afternoon was much less likely to lead to higher symptoms than exercising in the morning. The realization led to the

conclusion that time of day was crucial: *when* I did something could be as important as *how much*.

When I tried extending my walks, I observed that I sometimes felt fine during the walk but experienced strong symptoms afterwards or had to take a nap later in the day. That experience helped me to realize that the effects of activity might be delayed, so to understand my limits I had to be attentive to how I felt later as well as during and right after an activity. I also observed that sometimes the effects of activity were cumulative, so that I might feel tired after several days of exercise at the same level.

### **In Sum...**

Overall, the idea of the Energy Envelope was very useful, perhaps the most important idea in my recovery. It motivated me to understand my limits in detail as the foundation for regaining control. And it inspired me to develop the many pacing strategies you'll read about shortly which gave me the ability to adapt to my limits and thus escape from push and crash.

## **8. Life Inside the Envelope**

The second part of pacing is learning to live within the limits imposed by CFS. This is a gradual process that requires patience and discipline, and brings rewards only a little bit at a time.

Since I believed that pacing offered my best chance for long-term improvement, I developed and used many strategies to help me live consistently within my limits. (We teach about two dozen strategies in the self-help program.)

### **Planned Rests**

If there was one secret to my improvement, it was taking two brief planned rests daily. It's so important that I've given it the whole next chapter. Scheduled rests, taken no matter how I felt, reduced my symptoms, brought stability, and actually reduced the amount of time I spent resting (because of avoiding the out-of-proportion price for overdoing).

Planned rest is probably the most popular pacing strategy used by people in the self-help program. I estimate that 80% to 90% of people who try it find it helpful. Here are some examples. One person reported: "The results have been incredible. My symptoms and pain have decreased and I feel more 'in control'. My sleep has been more refreshing and even my mood has improved." Another wrote, "I have more stamina and the graph of my days doesn't dip and rise so steeply." And a third commented, "for the first time in the four and a half years I have been ill, I feel that it is possible to manage my symptoms and have some predictability."

### **Record Keeping**

Record keeping, which took just a few minutes a day, helped me live within my limits by showing me what those limits were. Records were a graphic and irrefutable way to prove to myself that doing too much intensified my symptoms and led to increased rest. Also, I used my health log to motivate myself. My records showed me I was improving and my improvement encouraged me to aim for more symptom-free days. Another way I checked on myself was to discuss how I was doing with somebody else, often using my logs for reference. Such discussions helped me to be accountable to someone else.

This strategy was so central to my recovery that chapter 10 is devoted to it.

### **Stop and Choose**

One way that we get pulled outside our limits is by giving in to the temptation of doing something that seems appealing at the moment. A way to avoid such lapses is to stop before you act and realize you have a choice.

I made frequent use of this strategy, which I called "stop and choose." When I was tempted to do too much, I visualized myself lying in bed in pain for hours, with heavy brain fog. I tried to make the image as vivid as I could, feeling the pain in my body and experiencing the guilt about harming myself and feeling the hopelessness that often accompanied my relapses.

The goal was to create an experience that brought to life the consequences of overdoing, thus counteracting the immediate pleasure I anticipated from doing something that would take me beyond my limit.

### **Rules, Routines and Reminders**

I decided that I could reduce the energy expended in pacing if I could ‘automate’ my behavior. I found three ways to do that: rules, routines and reminders. All three were ways to help me to create new habits, so I automatically did the right thing.

**Rules** describe what I would do in particular situations and often had an If/Then structure. One rule was to get off the computer and stop watching TV at 9 pm, to allow for a wind down period before going to bed:

If it's 9 pm, it's time to turn off the TV and the computer

Second, I had rules for my two daily rests:

If it's 11 am, it's time for my morning rest.

If it's 3:30 pm, it's time for my afternoon rest

My third rule was to avoid noisy places. Having that rule gave me permission to leave noisy restaurants.

**Routines** meant having a regular schedule, which enabled me to avoid a lot of decision making. Instead of having to ask whether something was or was not within my envelope, I tried to stick to a schedule I knew was safe.

**Reminders** is a third strategy to facilitate the process of replacing one set of habits with another. For example, I sometimes used a timer to limit the length of my sessions on the computer. Also, I sometimes used objects as reminders. On days I planned to do my weight lifting routine, I often put one weight out where I could see it. And I got out the bread pan as reminder on days when I planned to bake bread.

### **Realistic Self-Talk**

Fourth, I developed ways of talking to myself when I was tempted by the voice that said things like "You don't have symptoms today, so you must be recovered." The best response I could give was to remind myself that, even though I had experienced real improvement, change was very gradual. Increasing my activity level dramatically just because I wasn't experiencing symptoms on a particular day threatened the stability that pacing had brought to my life.

The proof that pacing worked was in my records, which showed far fewer days in bed and gradual progress. Seeing progress helped me accept the slow rate of improvement.

## **Forgiving Myself**

I didn't always stay in my envelope. Initially, I beat myself up for failing, but eventually I replaced that response with two others: a) ask myself "what can I learn from this experience?" and b) then tell myself to move on.

## **Thinking Sustainably**

This one was incredibly simple, once I saw it, and gave a big payoff for a small change.

When I started pacing, I thought of my envelope in terms of what I could get done in a day without intensifying my symptoms. While that was helpful, over time I found that I was often tired by the end of a week, even though I had the same activity level every day. I concluded that the explanation was that the effects of exertion were cumulative.

My response was to ask myself what level of activity I could sustain over a week without worsening symptoms. Through experimentation, I found that to end the week with a same level of symptoms I began the week with, I had to reduce my estimation of the amount of activity I could do in any single day by about 10 to 15%.

## **Minimizing Relapses**

No matter how consistently I lived within my envelope in the first two years I was ill, I would periodically find myself back in bed with symptoms that were so intense that I couldn't do anything but pull the shades, lie down in darkness and wait for a better day. These periods, which usually lasted from one to three days, were greatly demoralizing as well as painful, mocking my attempts to gain some control and filling me with the worry that I would slide permanently downhill.

In discussing relapses with people in the self-help program and through experimenting with different strategies myself, I found there were many things I could do to reduce their frequency, severity, and impact. Learning how to minimize, and eventually to prevent, relapses was such an important part of my recovery that I've devoted chapter 12 to it.

## **Mastering Special Events**

Pacing worked well most of the time, because I lived a predictable life, in which one day looked much like the next. But special events like vacations and holiday celebrations presented a challenge. While I could maintain a routine in my everyday life, some occasions pulled me out of my regular schedule. I developed three strategies in response to help me cope better with non-routine events.

**1) Take Extra Rest:** The most useful strategy was to rest before, during and after a special event. I stored up energy for a trip by doubling my normal daily rest time for a week before leaving. I limited my symptoms by taking extra rest during the trip. And I committed myself to taking whatever extra rest I needed after returning home. I also found that I could reduce the

effects of driving and thus reduce the level of symptoms I experienced while away from home by taking a brief rest break every two hours.

**2) Set Limits with Others:** My trips went more smoothly when, after determining a safe activity level, I discussed my limits ahead of time with the people I traveled with. I found that others appreciated knowing what to expect from me, reducing the chances for surprise or disappointment. When they knew that I would spend part of each afternoon resting, for example, they could schedule an activity that didn't involve me.

**3) Adjust My Expectations:** I was able to replace resentment about not being able to do all that I wanted to by focusing on what I *could* do. I consoled myself with the idea that half a loaf is better than nothing. Even if I weren't able to do everything I did before becoming ill, making compromises enabled me to participate at times somewhat outside my envelope so that I increased my symptoms somewhat but didn't suffer a bad flare-up.

### **In Summary**

Overall, pacing brought a level of stability to my life that I wouldn't have thought possible in the early months of being ill. By following a schedule that balanced activity and rest, I was able to replace a feeling that my life was out of control with the experience of predictability. I believe that the reduction in stress that resulted from having a stable life helped make my life even more stable. In short, pacing was the key to my recovery.

Pacing required a great deal of patience and a kind of faith. To stick with pacing, I needed to feel confident that my approach would pay off in the long run. Although it was very difficult at times to stay within my limits consistently, I resisted the temptation to hope for a quick recovery and I took consolation in my steady, if slow progress.



## 9. My Secret Weapon: Pre-Emptive Rest

When I was first ill, I often experienced the cycle of push and crash, swinging back and forth from too much activity to periods of rest. I would be more active than my body could tolerate, experience intense symptoms, and then use rest to recover. Spending a few hours, a whole day or sometimes several days in bed was an effective strategy for recovering from periods of doing too much, but a frustrating way to live. The experience motivated me to find a different way to live with CFS.

About nine months after becoming ill, I learned that I could use rest for another reason besides recuperation. I found that rest could actually prevent symptoms. This idea was one of the strategies recommended by CFS researchers in England who counseled patients to live their lives according to a plan, one which included similar amounts of activity each day and also daily scheduled rest periods. The goal was to shift away from living in response to symptoms (the cycle of push and crash) toward a consistent, planned life.

I was attracted to the idea of gaining control over the swings in my symptoms and I could accept the idea that a similar amount of activity each day could help me achieve greater predictability. But I resisted the idea of resting each day regardless of how I felt. I couldn't understand why I would lie down voluntarily, even if my symptoms hadn't worsened. Also, I thought of resting as giving in to the illness, so that rest meant a victory for the illness.

### **Rest = Lying Down, Eyes Closed**

Because other parts of the program from England made sense, I decided to try resting every afternoon. After some experimentation, I determined that the most restorative rest resulted from lying down in a quiet place with my eyes closed.

I was surprised at the results from a 15-minute rest. Even that short break seemed to help, reducing my symptoms, increasing my stamina and making my life more stable. After a while I added a similar rest in late-morning as well.

Over time, I came to believe that my scheduled rest was the most important strategy I used in my recovery. Resting everyday according to a fixed schedule, not just when I felt sick or tired, was part of a shift from living in response to symptoms to living a planned life. The experience showed me that rest could be used for more than recovering from doing too much; it could be employed as a preventive measure as well. In the terms suggested by someone in our self-help program, I learned the difference between *recuperative rest* and *pre-emptive rest*.

Surprisingly, taking pre-emptive rests greatly reduced the time I spent in recuperative rest, because I was experiencing much less Post-Exertional Malaise. The result was that my total rest time was reduced.

## **Rest + Relaxation**

I found that my rests were even more effective after I started doing a relaxation practice at the same time. Without the mental relaxation, my mind could race from worry to worry, so I experimented with various meditation procedures during my rest time. I found that focusing my attention on my breathing was the most effective technique for me. By lying down and keeping my awareness on my breath, I could relax both physically and mentally.

I applied the idea of planned rests in other parts of my recovery. For example, I used it to expand my envelope for travel. I found that if I stopped during driving trips for a ten- to 15-minute rest every two hours (tilting the seat back, putting on a sleep mask), I arrived fresher at my destination and had a lower symptom level throughout my trip. Also, as I will explain in more detail in the chapter on exercise, I was able to extend greatly the distance I walked if I alternated walking with sitting down: walk, rest, walk, rest.

The principle I learned from all these experiments was that rest could have a dramatic effect on the energy available to me and on my symptom level. Taking a short rest break to re-charge my batteries expanded the number of productive hours in my day. Also, I found that I could avoid a long period of bed rest by taking a brief rest as soon I felt my symptoms beginning to get worse.

As I improved to 90% and beyond, I gradually phased out pre-emptive rests, but for four years planned rest was crucial. It both reduced my total rest time and helped bring stability back into my life, a big payoff for two brief breaks in my day.

## 10. The CFS Scientist

Initially I didn't know my limits or understand what would help, so I decided to do experiments. As mentioned earlier I thought of myself as a “CFS scientist.” By that I meant trying things and keeping records would generate a great deal of ‘data’ that I could analyze.

Sometimes I conducted explicit experiments, for example trying out a certain level of exercise and then observing the consequences both during the exercise and later. I hoped that some of my experiments would work, but I assumed that others wouldn't. I tried to maintain a willingness to learn from my experience, especially when it contradicted my previous ideas, which was frequent in the beginning. Probably the biggest surprise was to realize that old habits, such as pushing through when my body was hurting, could be harmful.

I knew that what I was doing wasn't truly ‘science’; with only one subject, I couldn't have a randomized controlled trial. All the same, I felt confident that I could learn a lot using self-observation. I believed that the normal events of life would give me lots of experimental data and that I could generate more by deliberately varying my patterns and activities.

Keeping records was crucial to this process. I was confident that having systematic notes about my life would enable me to see patterns and to identify links between my actions and my symptoms.

I experimented with a variety of simple logs, most requiring only a few minutes a day to complete. In fact, I made sure the logs were easy to fill out, because I knew that if they weren't, I wouldn't use them consistently. I wanted to make it likely that the time spent logging would produce insights. I also thought that if I made them too complicated, I wouldn't be able to make sense of all the data I collected. I wrote in my logs daily, then usually spent some time every few weeks analyzing the logs to look for patterns.

Looking back, I see that the few minutes a day I spent keeping health records were one of the most productive aspects in my approach and crucial to learning how to pace myself. The payoff was great for the small investment of time.

My records helped in three ways: they documented links between my actions and symptoms; they affected my actions by holding me accountable; and they motivated me to continue pacing by showing me that it was working.

### 1) Linking Cause and Effect

The log I used the most was similar to the [Activity Log](#), posted on the self-help program's website. My goal was very simple. I sought to understand the fluctuations in my illness by linking events in my life, which I thought of as *causes*, with my symptoms, which I thought of as *effects*.

The list of items that might be causes changed over time, but included things like my overall activity level, the amount of sleep and rest I got, exercise, and stressors (both people and

situations). For effects, rated each day from '+2' (very good) to '-2' (very bad). Sometimes I made two or three sets of ratings each day to see whether there were patterns within a day. Overall, my goal was to understand why some days were better than others, so I could do more of what helped me.

What did I learn? Many things; here are a few. My records helped me to recognize fluctuations in symptoms by showing me that my CFS was worse in the morning and better in the evening, and that the effects of exertion were cumulative during a week. Also, logging showed me the connection between standing and symptoms, documented how much exercise was safe, and showed me my vulnerability to stress.

I also used my records to help me understand patterns over longer periods, such as a year. As I describe in chapter 12, reviewing my records for 1998 and acting on what I learned led to my eliminating relapses.

## **2) Shaping Behavior**

I found that, in addition to being a record of my behavior, my logs also came to shape it. Sometimes, when I was tempted to think that increased symptoms were just part of the illness, my records showed that I had been more active than usual in recent days. Seeing the evidence in black and white helped me to stick to my pacing routine. I could see how much better I felt when I was consistently within my energy envelope and how my symptoms increased when I went outside my limits. So my logging was also a way to hold myself accountable.

A member of one of our early self-help groups took this principle even further. She kept an elaborate calendar with a color rating for each day. She used green to note a minimal level of symptoms ("Go"). Yellow designated an increased level of symptoms and meant "warning, time to cut back a little." Red meant "stop, time to cancel commitments and rest."

## **3) Records as Motivators**

Logging was also a good motivating tool. My records documented that some days were better than others. Seeing this motivated me to search for what I was doing that created good days so that I could increase their frequency. I also used my records to chart my progress over time. At the end of each month, I rated myself using the [Rating Scale](#) I mentioned earlier. Seeing written evidence of improvement gave me hope. It also motivated me to stick to my pacing routines. Each month, I totaled up the number of good days I had. Wanting to expand the number motivated me to be more consistent in staying within my energy envelope.

For all these reasons, the few minutes I spent each day keeping records produced a tremendous set of benefits.

(If you are interested in keeping records, you can find logging forms and instructions on keeping records on the [Logs, Forms and Worksheets](#) page of the self-help program website.)

## 11. Experiments with Exercise

The ideas of the energy envelope and pacing gave me hope that I could improve my quality of life if I could find and honor the limits that illness had imposed on me. I also hoped that I might be able to extend those limits gradually by making small changes. Because I didn't know my limits when I started and did not know what would help, everything I did was an experiment.

One area of experimentation was exercise. I tried different forms of exercise, different lengths of time, and different intensities in order to determine how much exercise was both safe and helpful. In the process, I learned many lessons about CFS in general.

### Finding Exercise Limits

I wanted to exercise to reduce the fatigue caused by deconditioning, but initially didn't know how much exercise could I tolerate without making my symptoms worse. My response: experiment. I tried walking for different lengths of time and at different speeds, keeping notes of how I felt both during and after exercise. The initial answer was that if I walked for about 20 minutes at a speed that pushed my heart rate up to but not beyond 95 beats per minute, I could get some aerobic value without making my symptoms worse. A small triumph from experimentation.

I later learned how important controlling heart rate can be for people with CFS. For why, see the article [Pacing By Numbers: Using Your Heart Rate to Stay Inside the Energy Envelope](#).

### Time of Day

Through experimenting with walking at different times of day, I discovered that exercising in the afternoon was much less likely to lead to increased symptoms than exercise in the morning. If I walked in the morning, 20 minutes was likely to tire me out, but the same amount done in the afternoon did not produce much, if any, increase in my symptoms. So one lesson I learned from experimenting with exercise was that *when* I did it could be as important as *how much* I did.

This realization led me to ask whether this was true generally. Using self-observation, I found that my illness had a pattern. I often woke up feeling tired, no matter how many hours I slept, but I had a period of several hours from mid-afternoon through mid-evening when they decreased. If I could get through the morning, I knew I had some good hours coming. Also, if I had something important to do, it was better to schedule it in the afternoon.

This experience is one of many in which I was able to draw a general conclusion (here that time of day is important) from an experiment in a particular area (in this case, exercise).

### Delayed Reactions

There were days when I felt so good during my walk that I decided to extend it beyond my usual 20 minutes. Sometimes I went as long as 40 minutes, without any increase in symptoms while I

was walking. I soon realized, however, that when I walked longer than usual I had a higher level of symptoms later that day or even the next day.

The realization that the effects of exercise might be delayed prompted me to ask whether this was true of activity in general. After some record keeping, I concluded that it was and, more disturbingly, that I could not trust the signals sent from my body. As a healthy person, I had used fatigue and other clues from my body as a way to tell me to slow down or take a rest. But with CFS, the signal was delayed, sometimes by hours or even days. So I was faced with the question: how can I control my symptoms if I can't trust my body to warn me when I am overdoing?

My solution was to keep records of my activities and symptoms, correlating activity level with subsequent increases or decreases in symptoms. Over time, I discovered my safe activity level, enabling me to control my symptoms by staying within the limits my logging showed were safe.

### **All Activity Is Exercise**

On some days, I felt quite tired even when I walked my usual amount. I wondered whether it might be due to poor sleep the night before or because of stress. While those factors explained some periods of heightened fatigue, I decided that a more frequent explanation was that my total activity level on some days was higher than on other days.

Checking my records, I discovered that times of increased symptoms were often associated with days I did laundry, housecleaning, grocery shopping, cooking or some combination of those activities. All of them required that I be physically active while standing. This led me to state a rule for myself: "All physical activity is exercise." My energy level was so low when I first got CFS that I needed to be aware of all my activity. For several years, I noted household chores and shopping in the "exercise" column of my health log.

### **The Body Is In Control**

It felt unfair to be able to walk 20 minutes and feel fine afterwards, but to have to spend an hour in bed if I walked 40 minutes. The difference was so small in comparison to the length of hikes in my pre-CFS life, that it seemed I was being punished disproportionately by CFS for going only a little outside my limit. Poor me!

Painful as it was to realize how little 'cushion' I had, how tight my limits were, the discovery led to the recognition that there was no way I could argue with my illness or persuade it that it was being unfair to me. I learned that I couldn't expect a "free day" when I could do whatever I wanted as a reward for being good for a week. It was more helpful to see my illness as harsh and unyielding, a force that could not be tricked or persuaded.

The recognition that my body was in control, not me, was a crucial part of acceptance: like it or not, that was my situation. In other circumstances earlier in my life, I might have been able to ignore my body by staying up late and just pushing through to finish a project. But CFS had reversed my relationship to my body. Now my body was in charge and there was a big price for

overdoing. The only way to regain control was by staying within the limits that CFS had imposed.

### **Exercise and Rest**

I was able to extend the length of my walks only slightly in the first several years I was sick. My practice was to make small extensions (no more than a few minutes at a time), but to return to my previous level if symptoms increased. I made little progress. After two years, I was walking about a half hour a day, not much different from the 20 minutes or so when I was first sick.

I was finally able to expand my exercise in a significant way when I incorporated rests into my walks. In retrospect, I am surprised that it took me so long to recognize that rests could help my exercise endurance, given the big benefits I experienced from my two daily pre-emptive rests. As explained in chapter 9, I believe that scheduled rests were perhaps the single most important strategy I used to aid my recovery.

I discovered how I could apply rest to exercise when I went walking one day with another person with CFS, a woman who had a more severe case than mine. She stopped frequently, about once every five minutes. At the end of our hour-long walk, I was surprised that I wasn't at all tired and there were no consequences the next day either. Experience had taught me to pay attention to surprises, so I asked myself whether my lack of fatigue could be explained by the frequent rests. If so, I might be able to extend the length of my daily walks by incorporating rest into them.

So the next day I tried an experiment. I walked for 20 minutes, then sat on a bench for a 20 minutes, then walked another 20 minutes. Result: no increase in symptoms either during the walk or after. What a revelation! In two years I had increased the length of my daily walk by 10 minutes and I extended it an additional 10 minutes in one day just by including a rest in the middle.

For some time, I extended gradually the distance I could walk by alternating periods of walking with equally long periods of rest. Eventually I returned to taking long hikes with only occasional rests, no more than before CFS.

### **Uneven Recovery**

Continuing to experiment, three years after becoming ill, I was able to walk on occasion as much as seven miles. This was a big improvement on 20 minutes a day of the first two years, but roughly a third of what I could do before CFS. I felt discouraged when I compared myself to the past, but was helped by noting that my recovery overall put me back to about 75% of normal.

The experience helped me to see that my recovery was uneven, better in some areas than in others, with exercise tolerance lagging the most.

## **Exercise and Loss**

The final lesson that exercise taught me was about the power of emotions in CFS. I took most of my walks along a part of San Francisco Bay close to my home. For a while, I looked longingly up at the mountains I used to hike in and wondered whether I would ever be able to walk there again, on trails with elevation gain and for times longer than 20 minutes or half an hour. I found it so painful to look at the mountains that I forced myself to keep my gaze on the bay.

The strong emotions triggered by looking at nearby mountains helped me to realize how big a part loss played in my experience of CFS. Acknowledging loss and focusing on what I could still do were the solution, as I explain in chapter 15.

## **Back to Normal and Beyond**

My discipline and patience paid off over time. On a trip to the mountains in my fourth year of illness, I took a hike of 15 miles. The next year, I had a trip on which I averaged almost 15 miles a day over four days. The year after that, I hiked about 90 miles in six days.

Late in 2003, I had a trip on which I was able to walk even greater distances than before I became ill: 18 miles a day. To celebrate my 65th birthday in 2009, I hiked 162 miles in 12 days and I did a similar trip when I turned 70.

By extending my exercise very gradually, as allowed by my body, I was able to return to a level of exercise equivalent to or perhaps even better than my pre-illness level.



## 12. Minimizing Relapses

No matter how consistently I lived within my envelope in the first two years I was ill, I would periodically find myself back in bed with symptoms that were so intense that I couldn't do anything but close the shades, climb into bed, and wait for a better day.

These relapses, which usually lasted from one to three days, were greatly demoralizing as well as painful, mocking my attempts to gain some control and filling me with the worry that I would slide permanently downhill and become bedridden.

Relapses represented perhaps the greatest psychological challenge I faced from CFS. They were so frequent and so devastating that I decided that I had to develop a separate set of strategies to combat them.

### Minimizing Setbacks

The first challenge was to determine what I could do to reduce the length and severity of my relapses. The #1 answer was to get lots of rest. Staying in bed until I felt better was the quickest and surest way to improve. Stating that obvious truth to myself was helpful because it gave me permission to acknowledge that at times I was powerless over my illness and the best strategy was to give in to it.

I also found that what I told myself during a relapse was important. Lying in bed for hours on end, many negative thoughts would swirl through my head, things like "you'll never get better" or "you have no control over your illness."

Knowing that worry made relapses worse and that relaxing helped me recover, I spoke reassuringly to myself, saying things like "you've recovered from all your other relapses, so just relax" or "you've been doing well lately, this is just a temporary interruption of your progress." And I reasoned with myself, saying things like "all your previous setbacks have responded to rest, so this one will probably end too."

I also found it was helpful to talk to other people on the phone. We didn't even have to talk about my relapse or even about me; just having a sense of connection with another person was reassuring. Also, listening to someone else talk about themselves distracted me from my symptoms and worries.

I observed that often a relapse would have two parts. After resting for a day or two, I would feel somewhat better, but then the relapse would resume. Either I was too eager to return to my normal activity level or my body was giving me misleading signals about my recovery. In any case, the strategy I developed to avoid a double dip was to return to normal gradually rather than as soon as my symptoms disappeared. If I took more than my usual amount of rest for a day or two after I *thought* I was OK, I could avoid slipping back into a relapse.

Taking extra rest was also useful for less severe setbacks, ones in which my symptoms were higher than normal but not so severe that I was forced to go to bed. My longest setback occurred

two years after I became sick, when I had gum surgery. I recovered partially in a week or so, but was left with a higher level of symptoms than before the surgery. My symptoms were unusually strong even three weeks after the surgery, so I doubled my usual amount of rest, then tripled it, finally getting up to six times my usual amount: three hours a day in bed.

After only two days of resting three hours a day, my symptoms returned to their pre-surgery level. The experience taught me that often the most useful action I could take to control symptoms was to have additional rest, increasing it incrementally until I found an amount that enabled me to reduce symptoms.

Another strategy I used to minimize relapses was to give in as soon as the first symptoms appeared rather than trying to push through them. By doing this, I found I could stop a minor relapse in its tracks. I stumbled upon this strategy one day when I was cooking chili.

After standing at the stove for 45 minutes, I suddenly felt tired and lightheaded. My first thought was: "If I can just work for another 10 minutes, I can finish this and then go rest." But then I remembered how many times such an approach had led to several hours' rest in the past, and I decided to turn off the heat under the chili and lie down. After about 15 minutes, I felt OK and returned to finish the cooking. I needed no more rest during the remainder of the day.

I was able to use this strategy many times, especially in combination with meditation. When I felt increased brain fog, for example, I found I could eliminate it if I could lie down and get into a deep relaxation for five or ten minutes.

## **Preventing Relapses**

Finding ways to reduce the length and severity of setbacks was good, but I also wanted to know what could I do to prevent them. I decided that to gain control over my setbacks, I would assume that I caused all of them. This was a high standard, especially because one of the hallmarks of chronic illness is symptoms that wax and wane for no known reason. But I wanted to hold myself accountable. Perhaps part of the reason for this approach was that believing I was responsible also enabled me to believe I could gain control.

This assumption led to many helpful discoveries. By avoiding those things that created relapses, I was able to smooth out my life considerably, reducing both the frequency and severity of relapses, and eventually eliminating them.

At the end of 1998, I reviewed my records for the year and found eight relapses. (I defined a relapse as a period in which my symptoms were so severe that I had to spend at least one full day in bed.) Looking for common causes, I discovered that almost all the relapses were associated with either having another illness or travel. I then developed strategies to prevent future setbacks.

To combat relapses triggered by secondary illnesses, I decided to take two days of extra rest after the symptoms of the secondary illness ended before returning to my normal activity level.

To minimize travel-related setbacks, I limited travel to a few hours' driving distance from home, doubled my regular daily rest periods for a few days before a trip, took two or three times as much rest as usual while away, planned for extra rest after returning home, and took a 10- to 15-minute rest for each two hours of driving.

Another travel-related strategy was to plan my trips in great detail, especially how much activity I would have. Making a commitment to myself to stay within a safe activity level helped me resist the temptation to do too much when on the road. Also, I told my travel companions of my limits ahead of time and they helped me honor my plans.

I haven't had a relapse (defined as being forced to spend at least one day in bed) since. I think the two hours I spent analyzing my logs and planning how to handle secondary illnesses and travel differently, was the most productive use of time in my experience with CFS.

### **Personal Guidelines**

A final strategy I developed to prevent relapses was what I called *personal guidelines*. The idea came to me one day when I was unusually fatigued and felt confused about what I should do. I said to myself that what I needed was a few simple rules to follow to guide my daily life and be my reference in times of confusion. Here's the result, which I found immensely helpful:

#### *1) Live within My Energy Envelope*

I believe I can reduce symptoms and lead a more predictable life by living within the limits imposed by the disease if I:

- a) Take scheduled rests daily no matter how good I feel
- b) Keep daily records of activities and symptoms
- c) Return only gradually to my normal routine after a relapse or illness
- d) Avoid stressors (people and situations that trigger strong reactions).

#### *2) Extend the Envelope Gradually*

I will take prudent risks to expand my activity level in small increments, but return to my previous level if symptoms are increased.

#### *3) When All Else Fails, Go to Bed*

There are times when the best course is to surrender to the illness.

### **Gaining Control**

Gaining control over relapses was a big psychological achievement. Eliminating setbacks gave me a belief that I could make my life predictable. I am sure that the reduction in stress that resulted helped create a positive spiral: gaining more control reduced my worry which in turn lessened my symptoms, deepening my sense of control.

It was empowering to see my life improve when I discovered and learned to play by the rules that CFS had imposed on me.

### **13. Expanding the Envelope**

By living within my energy envelope, I was able to reduce my symptoms, regain control, and, over a period of four years, return to my pre-CFS level of health. My progress was slow, about one to two percent a month, and there were periods of several months where it was hard to see any progress. So self-management was not a ‘swallow once’ magic pill.

Based on my experience, I created two rules for myself about expanding my Envelope:

1. Extend your limits a little bit at a time
2. Return to your previous level if symptoms increase

A *little bit* typically meant no more than 5% to 10%. For example, I tried adding two minutes to my 20 minute daily walk. For more than a year, this extension led to greater fatigue, so I returned to 20 minutes. (As explained in chapter 11, I was finally able to expand my envelope for walking significantly and in a lasting way when I incorporated a rest break into my walks.)

The second guideline is based on the recognition that with all experimentation, some attempts work and others don’t, so we need a plan for what to do in the cases where the experiment fails. With failed attempts to expand the envelope, my response was to resume the old, proven-safe activity level.

In the self-help program, we sometimes phrase this third part of pacing as “extend your limits, as allowed by the body” or “increase your activity in small increments, as tolerated by the body.”

#### **Examples of Expanding the Envelope Through Planned Rest**

As described in chapter 9 on pre-emptive rest, probably the most powerful strategy for expanding my envelope was my use of two brief scheduled rests each day. A brief 15-minute daily rest reduced my symptoms, increased the amount of time I could be active safely, and made my life more stable.

One technique I used to expand my envelope was to take a proven strategy and apply it in a new way or a different circumstance. One example is how I used the idea of planned rest to expand my envelope for travel. In the first two years I was sick, I did very little travel and a couple of trips triggered such severe symptoms that I spent the whole vacation lying in pain in my hotel room.

A big breakthrough occurred when I experimented with stopping for a ten to fifteen minute rest for every two hours of car travel. With those rest breaks, I arrived fresher at my destination and had a lower symptom level throughout my trip. This strategy increased my envelope for travel.

Another way that rest helped me increase my envelope was to take a brief rest as soon as my symptoms became more intense. I gave an example in the chili story in last chapter. The strategy

of responding quickly to warning signs from my body enabled me to avoid a long period of "downtime," so that by giving in to my symptoms I reduced my total rest time.

### **Experimenting with Rest & Using Routine**

A member of our first self-help class taught me that it is not the total amount of time spent in rest that is crucial, but rather how the rest is distributed through the day.

When she started our course, she was resting six hours during the day, taking two naps of three hours each. She decided to break up her day into one- and two-hour blocks, taking a 10- to 15-minute rest during each block. Using this strategy, she reduced her total rest time by an hour and a half a day after two months. Four months later she was resting three hours a day, half as much as before the course. By taking frequent short rests, she added three hours of productive time to her day, without increasing her symptoms.

Another way I expanded my activity level without increasing my symptoms was through using routine. In observing myself, I noticed that novelty was a source of stress; it takes more energy to respond to a new situation than it does to something familiar. I found that I could save energy by making my life predictable. I developed a schedule of activity and rest (a daily plan), reducing the surprises and emotional shocks in my life, thereby reducing my stress.

Recent research on habits and routines has demonstrated that they use less energy than one-time events. This is because of 'chunking'. This term means that the mind stores habitual routines as a single set of instructions, which are executed automatically as a set of behaviors.

### **Other Ways to Expand the Envelope**

Also, as mentioned elsewhere, being sensitive to time of day enabled me to do more without increasing symptoms. I first discovered that principle when I tried walking in the morning rather than at my usual time in the afternoon and found I could walk far less in the AM! A member of our program used time of day to study for a professional exam. By experimenting, she found that she could not retain information if she studied in the morning, but if she studied after lunch, she could read for two 45-minute sessions and retain the information.

A final example of extending the envelope illustrates the idea that how we react to events can affect the amount of energy available to us. If we can respond in a relaxed manner to stressful situations, we can preserve energy that might otherwise be dissipated in tension and anxiety.

The example comes from the woman who expanded her envelope by breaking up her daily rests into many short breaks. At her birthday party one year, she took on the role of the good hostess, moving about and worrying whether everyone was having a good time. She found herself tired and cranky after an hour.

At a similar party a year later, she decided to imagine herself as a queen who was observing the situation from a throne. Freed from the self-imposed expectation that she should make sure

everyone enjoyed themselves, she found herself with good energy for more than two hours. By relaxing, she reduced her worry and extended her energy.

Her experience illustrates the idea that mental and emotional activity, not just physical activity, use energy. Stress and any experience that triggers the release of adrenaline are big energy users. Whatever a person can do to lessen stress will also preserve their supply of energy for productive uses.

## 14. Managing Stress

Although it took me quite a while to understand the effects of stress, eventually I came to see that stress was a double challenge for me and everyone with CFS. First, the CFS adds new sources of stress, such as the ongoing discomfort of symptoms, isolation, uncertainty about the future and financial pressure.

Second, there is something special about CFS that makes people much more sensitive to stress than before. It was as if CFS had reset my "stress thermostat," making me sensitive to more types of stress than before and increasing the effects of a given level of stress. Even modest amounts of stress greatly intensified my symptoms, creating a feedback loop in which my symptoms and my response to them intensified one another.

Once I realized how vulnerable to stress I had become, I decided that dealing with stress had to be a big part of my effort to manage CFS. Over time, I came to believe that controlling stress was second only to pacing as the most powerful tool for coping with CFS. By using stress management techniques such as those described below, I learned how to interrupt the cycle in which symptoms and stress reinforced one another.

### Approaches to Managing Stress

Because there were many causes of stress, I decided to use a variety of strategies to manage it. Many of them fit into the category of *stress reduction*. This set of practices involves retraining yourself to respond differently to stressors so that they do not have the same effect as in the past. For example, if you worry in response to an increase in symptoms, you may tense your muscles. Muscle tension can create pain, draining energy and causing fatigue. By learning to relax, you can lessen muscle tension and ease symptoms. This is one example of how to reduce the impact of stressors by changing your response. In the self-help program, we teach people to use 14 different [stress reduction](#) techniques.

The second approach, *stress avoidance*, is preventive, using self-observation to learn how stress affects you and then taking measures to avoid stressful circumstances. For example, you may notice that when you hit a limit, any further activity will intensify your symptoms. In such circumstances, rest can reduce the stress on your body. Having good relationships are a buffer against stress. People with supportive relationships have lower anxiety and depression. The main ways to prevent stress are by avoiding stress triggers and by using pacing, order and routine.

### Stress Reduction

My first effort at controlling stress was through stress reduction. I used two formal stress reduction practices, the body scan and the relaxation response.

The body scan is a relaxation procedure in which you focus your attention on one part of the body at a time. I had started using doing this practice several years before CFS and found it a helpful way to relax. The relaxation response is a form of meditation that involves repeating a word or sound over and over for fifteen or twenty minutes. When your mind wanders, you return

to your chosen word or sound. (For step-by-step instructions for these practices, plus three others, see the article [Stress Reduction: Five Practical Techniques](#).)

I started experimenting with the relaxation response when I noticed that sometimes my daily rests were somewhat stressful because my mind was racing, full of anxious and worried thoughts. I hoped that by quieting my mind, I could achieve a deeper quality of rest than by just lying down and doing the body scan.

I found that meditation put me in a state of deep relaxation, in which I was aware of what was going on around me but detached from it at the same time. Relaxing my mind while relaxing my body had a dramatic effect on my anxiety level, thus reducing my tendency to over-produce adrenaline.

Another traditional stress reduction technique I found helpful was one I mentioned earlier: making mental adjustments or changing my self-talk. Being aware of what I told myself, especially during relapses, helped me to reduce my stress. When I caught myself saying things like "You'll never get better" or "You'll be like this the rest of your life," I countered by telling myself "You've bounced back from all your previous setbacks, so just relax" or "Remember how things always look hopeless when you're at your worst."

It was important to counter the negative thoughts because, unchecked they created a vicious spiral. Negative thoughts intensified my stress, which made my symptoms worse, which in turn triggered another round of negative thoughts. Challenging the negative thoughts enabled me to interrupt this downward spiral.

It was also helpful to be aware of my expectations for myself. If I told myself something like "It's Monday, you have to do the laundry," I sometimes had to remind myself that my health came first and nothing bad would happen if I postponed the laundry.

Lastly, I made good use of exercise as a stress reducer. I took daily walks, as described earlier.

## **Stress Avoidance**

Stress avoidance proved to be just as helpful as stress reduction. By avoiding things that caused stress, I could prevent it.

One cause of stress, I discovered, was novelty. It takes more energy to respond to a new situation than it does to something familiar. My response was to make my life as predictable as I could by using routine, living my life as much as I could according to a plan. Having a daily schedule of activity, rest, exercise and socializing at set times gave structure to my life. With routine I had less pressure, and fewer surprises and emotional shocks. I mentioned routine as a pacing strategy earlier, but I found that it also helped me control stress.

I also learned to identify stress triggers, those situations and even people that set off symptoms. I found, for example, that I was vulnerable to sensory overload, particularly the noise and hustle



and bustle associated with restaurants and other public places. My strategy was to avoid the noisiest places, for example by being selective about what restaurants I visited and when.

My vulnerability to sense overload led me to limit my consumption of the media. I learned to look away from the TV if there were rapid scene changes that would otherwise be disorienting. Also, I limited my exposure to tragic events, such as 9/11. I followed the guidelines suggested for the general public: keep up, but don't immerse yourself for hours on end.

I also experienced a kind of sensory overload around certain people. Some were fidgety, others were animated or highly emotional. Whatever the trigger, I found them hard to be around. My strategies were to limit contact (generally to an hour or less) or, in a few cases, to avoid the person entirely.

### **In Conclusion**

In all these different ways, I took action to reduce the stress in my life. I believe that my successes built on themselves, creating a positive feedback loop. As I gained some control, I'm sure that I relaxed and that my growing confidence further reduced my stress. As I improved, my "stress thermostat" returned to normal.

## 15. Taming Emotions

Serious illness turns people's lives upside down, upsetting their hopes and goals, and creating frustration and uncertainty. It's not surprising that people with chronic conditions experience feelings such as sadness, worry, frustration, guilt, and loss. I was no exception.

### Emotions in CFS

My background didn't prepare me for the strength of the feelings associated with CFS and their apparent connection with the physiology of the illness. I observed, both in myself and in others with CFS, that emotional reactions were stronger than before CFS and harder to control. People with CFS often say they cry more frequently, get upset more easily and have more angry outbursts than before they were ill. As one person in the self-help program wrote, "Just recognizing that emotions are heightened as a result of CFS really helped me. Before learning that, I was quite puzzled by why I got upset about little things."

I developed a number of strategies in response to my new emotional sensitivity, all based on recognition that I was much more emotionally vulnerable than before. First, I observed that the strength of my emotions was often associated with the strength of my physical symptoms. A low mood occurred when I had higher levels of symptoms, usually fatigue, brain fog or both. The strategies I used to control symptoms also helped moderate my emotions. In particular, resting seemed to reduce the intensity of emotions as well as alleviating my physical symptoms.

### Depression & Worry

I found a couple of other strategies helpful for depression. Contact with other people, even if just a phone conversation on everyday subjects, could reduce and even reverse my mood when I felt down. I think that occurred because the sense of being connected to someone else was reassuring and counteracted the stress of isolation.

Also, I observed that I had an exaggerated initial reaction to relapses, often seeing them as evidence I would never improve. In response, I learned to say soothing and reassuring words to myself when my symptoms were strong. For example, I would say "You've always bounced back from other setbacks" or "Remember how life looks better after you've rested."

In addition to experiencing depression from time to time, I also struggled with anxiety. Edward Hallowell's book *Worry* was very useful, showing me many practical ways to reduce anxiety. I also appreciated the author explaining that anxiety often has a physical basis and should not be seen as a character flaw.

I spent time observing myself to see what I could learn about what triggered anxiety. I noticed that when I thought I had a lot to do, I got anxious. The anxiety led to an adrenaline rush and frenetic activity. Observing helped me to detach from the reaction, taking away its inevitable character. Then I began telling myself to be calm when I started to get anxious.

I also used writing to combat anxiety. As I improved, I kept a journal recording my thoughts about resuming a "normal life." I started this exercise when I observed that I was slow to expand my activity level, even when others told me it would be safe. What was the basis for my irrational fears of expanding my activity? By writing about my fears, I was able to recognize that I was carrying around apparently outdated beliefs about safe activity levels.

Other stress reduction tips also helped reduce anxiety. One was the idea to incorporate a relaxation procedure into my daily rests, as I described earlier. Learning more positive and reassuring self-talk was helpful. Exercise or just getting out of the house helped, too, perhaps because being out distracted me from my problems. Finally, talking with others, especially other people with CFS, was calming.

### **CFS and Adrenaline**

It seemed that any event that triggered the production of adrenaline made my symptoms worse. This effect was most noticeable with brain fog. I first noticed this under happy circumstances. I was moved to tears at the last session of one of our first self-help groups, as people talked about the meaning the class had for them. I noticed that my joy was accompanied by a heavy dose of brain fog, which didn't lift until a half an hour or more later. After this event, I noticed that situations that made me anxious also resulted in brain fog.

As a way to avoid symptoms triggered by the production of adrenaline, I tried to cultivate calmness and to construct a life that emphasized routine. I paid a price, of course, losing the enjoyment brought by positive emotions, but for four or five years the trade-off was worth it. Even if I felt like I saw the world in gray rather than in color, it was a price I was willing to pay to avoid brain fog.

### **An Unexpected Guest**

I experienced another emotion while I was ill, one that took me completely by surprise, but thankfully faded away as I improved. Soon after becoming ill, I developed a mild paranoia. Part of me was convinced that some of my neighbors were out to get me. Even though I told myself this idea didn't make sense, a part of me was convinced it was true.

I was very confused by this until I read in Hallowell's book about children who develop obsessive-compulsive disorder (OCD) when sick with a strep infection. The symptoms start when the infection begins and disappear as they return to health. Hallowell wrote that the children's experience showed that "a purely physical event" could cause a psychological syndrome. Seeing my paranoia as a mental distortion caused by CFS, I did not act on it and the final result for me was similar to the children's experience: my paranoia disappeared as my CFS symptoms improved. It has never returned.

## **16. Moving Beyond Loss**

CFS transformed me in a matter of days from a healthy person to someone functioning at 25%. As my symptoms persisted, I came to realize that CFS was not a temporary interruption of my life but rather the central fact around which my life revolved. CFS stripped away most of what I viewed as 'me'. Because of my illness, I gave up work and volunteer commitments, let most relationships slide, lost my ability to be physically active, and replaced an optimistic view of my future with uncertainty.

The losses brought by illness created one of my greatest challenges in living with CFS: who am I if the old Bruce has disappeared and may never return?

I have to admit that my first response to the loss of my old life was denial. I told myself for more than a year that I would be the exception, one of the lucky ones who recovered. This belief enabled me to keep hope alive and to adjust to all the losses and uncertainties. Later, when I accepted that recovery was unlikely, I found hope in the progress I had made and in the conviction that, even if I didn't recover, I could still find ways to bring meaning to my life. Also, gaining some control over the illness helped reduce the amount of uncertainty in my life.

When Elizabeth Kubler-Ross described responses to loss, her end stage was acceptance. I could identify with that in part, but for me the final stage was more complex. As noted earlier, acceptance meant recognizing that my life had changed, perhaps permanently and certainly for an extended period of time. It meant letting go of my past life and also of the future I had envisioned for myself. But it had another component as well, a confidence that I could find things to improve my life. I called the combination *acceptance with a fighting spirit*.

### **Moving through Grief**

One of the ways I coped with my losses was to acknowledge them publicly. In a Christmas letter sent a year and a half after getting CFS, I wrote to friends that I had been living with a disease for which there was no standard treatment or cure.

I concluded: "I am sobered by the realization that it is highly unlikely that I will return to the level of functioning that I had before becoming ill and so probably will have to adjust to living a life with greater limits than before."

Even though I wrote to alert others to expect less of me in the future, I think the most important audience for those words was me. The public declaration helped me recognize the extent of my loss and the possibility that it was permanent.

### **Moving Beyond Loss**

While accepting that my life had changed, I had the conviction that whatever happened, it would still be possible to have a good life. That conviction helped me to accept the losses I had experienced. I continued to believe that even if I didn't recover, there were many things I could do to improve my quality of life. This belief kept me moving forward in hope.

Within weeks of receiving my diagnosis, I joined two local CFS support groups. The experience was especially useful for the friends I made, two in particular. Both were very generous with their time, spending many hours talking to me about the medical, psychological, and political aspects of CFS.

Beyond these two relationships, being a part of the support groups gave me a sense of belonging, an experience of being connected to others like me. I found there is something powerfully healing about feeling understood, all the more so for a stigmatized disease that some people, even some doctors, don't believe is real.

Because I stopped working and dropped out of my volunteer commitments shortly after becoming ill, fellow patients became perhaps my most important community. I think having that source of identification served me well. I took people with CFS as my peers, not healthy people. That meant that I measured myself in comparison to them, not to my peers from work or healthy friends. That comparison took a lot of pressure off.

### **New Sources of Meaning**

I firmly believe that we all need to have meaning in our lives. My way to bring meaning to my new situation was through relationships and from the belief that, even though I had lost much, I could still contribute something. Helping others through the self-help program both provided an opportunity to create many new relationships and gave me a new sense of purpose when previous sources of meaning had been lost.

I told myself that, even though my life might not be the one I expected, it could still be a good life. By focusing on what I could still do, I could shift my focus from loss to possibility. I told myself that even if I was unlikely to return to my old life, I could still create a new life by developing new interests and relationships, and by focusing on what I could still achieve. Ironically, I have been given my old life back, but with a richness and meaning it wouldn't have had without the illness.

## **17. Finding Help**

Support, which can take a variety of forms, is another one of the key ingredients to living well with long-term illness.

One kind of support is acceptance, and on this score, I was lucky. My family and closest friends believed that I had a serious medical condition and approved of my strategy of drastically reducing my activity level.

I was especially fortunate to have a good friend who was concerned about me and willing to offer both emotional support and an objective view of my situation. We talked about my CFS often and set aside some time at the first of each month to discuss how I was doing. We each assessed my status using the [Rating Scale](#) I've mentioned, then reviewed my logs for the previous month.

I learned much from the discussions, recognizing patterns I wasn't able to spot on my own. Just as important, the discussions said that I was not struggling alone, but rather that there was somebody who cared about me and wanted to help me get better. I think the sessions also helped reduce my friend's sense of helplessness, which is often experienced by people close to those who are seriously ill.

### **Support from Fellow Patients**

A second kind of support is an understanding that perhaps only fellow patients can provide. As mentioned earlier, one of the first things I did after receiving my diagnosis was to join two local CFS support groups. Based on previous experience, I thought that fellow patients would be great resources for understanding my illness and they were.

I made two good friends, one from each support group. I remember spending many hours with each one on the phone in the first few months I was ill. They were immensely helpful, orienting me to the world of CFS. Talking with them helped me to understand how serious and debilitating an illness I had.

These two people and the CFS support groups gave me a sense of belonging, a feeling of being connected to others at a time of confusion and isolation. I found there is something powerfully healing about feeling understood, all the more so for a stigmatized disease that many don't believe is real. Also, fellow patients were tremendous sources of information and perspective, helping me to understand CFS much more quickly than I could have on my own.

### **Models of Improvement**

I experienced a powerful type of support from two fellow patients, neither of whom I met. I knew them through articles they wrote and, in the second case, via email as well. They provided me with models of living successfully with CFS. As such, they were sources of inspiration and hope, and also offered specific strategies I could use.

The first was Dean Anderson, who described his successful eight-year struggle to recover from CFS in an [article](#) in the *CFIDS Chronicle* titled “Acceptance, Discipline and Hope: A Story of Recovery from CFIDS.” I was inspired by the article the first time I read it and I returned to it often for encouragement. Dean had adopted an approach similar to mine. Turning away from medical treatments, he instead focused on figuring out what he could do to make himself better through changing his attitudes and behaviors. His improvement was a symbol of hope to me. I found inspiration in his description of combining acceptance of being ill with hope for a better life.

The other CFS patient who influenced and inspired me was JoWynn Johns. She was effectively housebound at the time we first came into contact, but she, too, had an inspiring story to tell, which she also shared with the readers of the *Chronicle* in an [article](#) titled "Living Within My Envelope: A How-To Story". Following an approach similar to mine, she had reduced her symptoms greatly over a period of several years. By keeping records, she developed a detailed understanding of what she had to do to control her symptoms. And she believed successful adaptation meant changing one's daily habits and routines.

## **My Doctor**

In addition to all the people described above, my doctor played an important role in my recovery, mostly by being supportive of my approach to CFS. His attitude was consistent with his treatment of me before I became ill. In my appointments with him before I got CFS, he communicated his belief in a partnership between physician and patient. This relation was expressed in his practice of offering various treatment options and then letting me decide.

In the time before CFS, he had also communicated to me a view of the limitations of modern medicine. He said that there were many more illnesses than medicine had names for and not all those with names had treatments. The conclusion I drew was that, in spite of all the advances in recent decades, the realm of ignorance in medicine is probably much greater than the realm of knowledge.

Another part of his approach was useful as well. He had been honest with me about the limitations of lab testing when I had an earlier episode of fatigue. Remembering my doctor's view of medicine's limits and my prior success in using self-help, I felt validated in my conclusion that behavior change offered me the best chance for improvement from CFS.

## **CFS Self-Help Program**

A final source of support came from the people I met in the self-help program I created.

I started looking for a self-help program for people with CFS almost as soon as I was diagnosed. My work at Stanford had shown me that self-help could be a powerful complement to medical care. I had seen people gain greater control, improve their quality of life and sometimes even change the course of their illness by taking responsibility for those things under their control. Not all self-help groups are helpful, but those that are deliver practical tips, counteract isolation, offer

a sense of community, and provide hope in the form of people living successfully with serious illness.

When I couldn't find any such group for people with CFS, I decided to start one. Believing it was important to be around people who were both realistic and positive, I tried to create a setting in which people could share what worked to help them feel better. Because I had stopped working and dropped out of my volunteer commitments shortly after becoming ill, fellow PWCs (People with CFS) became perhaps my most important community.



## 18. Recovery or Just Remission?

Four years after being struck by CFS, I had improved enough to consider myself recovered. I lived a normal life for a person of my age and had resumed taking long hikes (my favorite measure of recovery). But I found myself haunted by new questions: Will my improved health last? Have I truly recovered or am I just experiencing a remission? Will I ever be able to see my improvement as permanent?

The paragraph above was written in 2004. When I re-visited this chapter in 2010, six more years had past and I could still report that I was enjoying good health. If anything, my improvement had continued. Sometimes I was able to do more than I did before CFS came into my life. Pre-CFS, I enjoyed hiking trips on which I walked 15 to 17 miles a day. In the fall of 2003, I had a three-day hiking trip on which I walked 18 miles a day. In 2009, I celebrated turning 65 by taking a hiking trip of more than 160 miles. And I repeated that trip five years later when I was 70. If I can do that, I am a very lucky person. [2018 Update: My lucky life has continued now for more than 15 years.]

On the other hand, I experience mild symptoms of CFS at times, usually brain fog triggered by crowds and noisy places. My response on such occasions is to leave the setting and, sometimes, to take a brief rest. This experience suggests that I have not banished CFS entirely, even if it is dormant most of the time. A good description of me would be a recovered PWC (person with CFS), meaning that CFS is not gone but rather controlled.

What about the future: will my recovery last? I think of the permanence of my recovery in terms of probability, rather than as a yes or no proposition. It is likely that the more time passes without a relapse, the more the odds tilt in favor of permanent recovery, but probability is not certainty. I expect to remain sensitive to my body and responsive to its signals for the rest of my life. And I am very grateful for my second chance to have a normal life.

## 19. What Worked for Me

CFS changed my life, imposing severe limits and bringing great uncertainty. In contrast to prior illnesses, it was not a temporary interruption of my life, but rather the central fact around which my life revolved for several years.

Given the limited medical resources available for treating CFS, I concluded that my best chance for getting better was to rely on myself, accepting responsibility for finding things that would help me and then, step by step, adopting them.

My approach combined two elements which may seem in conflict: acceptance and hope. *Acceptance* did not mean resignation, but rather a recognition that my life had changed and that CFS forced me to live a different and more limited life, for an extended period of time and perhaps for the rest of my life. I believed that listening to my body and responding to its needs gave me the best chance for improvement. Also, I believed that I could exercise some control over my symptoms, but concluded that whether or not I recovered was out of my hands.

In addition to acceptance, I had *hope*. I was confident that through changing my daily habits and routines I could find things to help me feel better. I believed that I could reduce my discomfort, regain some control over my life and reduce uncertainty. I did not expect a quick solution. Rather, I recognized that self-management was a way of life that could bring improvement, but that change would be gradual and involve lots of effort.

### My Approach

I built my approach to CFS on six principles.

**1) Using Multiple Strategies:** Because I had several symptoms and because CFS affected so many parts of my life, I needed a variety of coping strategies. Acknowledging that there was no magic pill or single solution, I realized I would have to think comprehensively about my life and use many strategies.

**2) Experimentation:** I believed I could learn from my experience, gradually becoming more skillful in managing my illness. I assumed that this approach would require discipline and patience, and that some of my experiments would fail. But I felt confident that I could improve my skills over time and that, in any case, there was no better alternative.

**3) Pacing:** Recognizing that CFS had imposed severe limits on me and that how I lived my life could make my symptoms better or worse, I came to believe that defining my limits in detail and living consistently within them offered the best chance of improvement. This meant finding a sustainable level of activity and making appropriate use of rest on a daily basis. Pacing was the heart of my recovery program, providing a path to escape push and crash, and thereby avoid the always-out-of-proportion intensification of symptoms called Post-Exertional Malaise.

**4) Controlling Stress:** Because my illness both increased the stress in my life and magnified the effects of stress, I made managing stress a major focus. I used relaxation and other techniques to

reduce stress and also learned how to control stress by avoiding stressful situations. Managing stress was the second most important part of my recovery program.

**5) Addressing Emotions and Relationships:** I acknowledged the powerful feelings triggered by being ill and adopt strategies to combat them. Also, I found that support, especially the support offered by fellow patients, was crucial to living well with CFS.

**6) Building a New Life:** Another central challenge was coming to terms with loss, finding a way to bring new meaning to my life when so much had been taken away. After much struggle, I decided that while I was unlikely to restore my old life, I could build a new one in its place. Creating and leading the self-help program was a central part of my response.

## Summary

My use of self-management alone, without medications, was different from that taken by most people with CFS. Under different circumstances, I might have combined self-management with a medical approach. But self-help served me well, enabling me to regain my health gradually over a period of four years, using techniques I believed were safe, prudent and effective, focusing as they did on living within limits and extending those limits very gradually, as allowed by my body.

My approach reminds me of the message to patients from CFS/FM specialist Dr. Charles Lapp of the Hunter-Hopkins clinic on [website](#) we created together. He writes:

Your doctor can help you cope with CFS/FM, but your success in regaining control will likely depend more on what you do than on anything a doctor does for you.

Medical treatments can help alleviate the symptoms of CFS/FM and further reduce suffering by treating other medical problems, but *the key to recovery in CFS/FM is acceptance of the illness and adaptation to it by means of lifestyle changes* [my emphasis].

If you adopt [this approach] --which will require discipline, courage and lots of patience-- you can overcome the CFS/FM dragon. You can regain control, instead of your condition controlling you!

## 20. What About You?

I hope that reading my story has shown you that improvement is possible with Chronic Fatigue Syndrome. If you would like to get better, what should you do? Here are five suggestions to get you started, along with some links to articles on the self-help program website. (You'll find more ideas on the Resources page of this site.)

### 1) Get Medical Help

A doctor can confirm a diagnosis of CFS, prescribe medications to treat major CFS symptoms, and help you with other medical issues that often accompany CFS. For more, see the article [How Your Doctor Can Help If You Have CFS/ME](#) by CFS authority Dr. Charles Lapp.

### 2) Focus on Pacing

If there is one secret to improvement, it is living within the limits imposed by CFS using pacing. Pacing takes time to master, but the rewards can start immediately. A good place to begin is with daily rests, as described in the article [Reducing Symptoms with Planned Rest](#). For a detailed explanation of pacing, see the series [Pacing: What It Is and How to Do It](#).

### 3) Manage Stress

CFS both increases stress and makes people more sensitive to stress. This combination makes managing stress crucial. You can begin by working to reduce stress, for example, by setting aside time for yourself to relax every day. Stress avoidance is also very useful. For specific strategies, see the [Stress Management](#) archive and the article [Controlling Stress](#) on the self-help program website.

### 4) Use Patience and Determination

Improvement is possible but usually gradual, so approach living with CFS using an attitude that combines patience and determination. I call it *acceptance with a fighting spirit*, which means accepting that life has changed for now, but believing that there are things to do that will bring improvement. For seven places to start, see the article [The 1% Solution](#).

### 5) Get Support from Other People with CFS

Knowing others with CFS can counteract isolation and depression, and provide information, understanding, inspiration and support. Surround yourself with positive people who are working actively to improve.