

Recovery from Chronic Fatigue Syndrome:

One Person's Story

By Bruce Campbell, Ph.D.

Introduction

When I became ill in 1997, I functioned at about 25% of my pre-illness level. Today (March 2004), I have returned to a normal life and consider myself to be recovered. The path I followed was an unusual one. Instead of seeking a medical cure, I adopted a self-help strategy that excluded medications and focused on changing my habits and behavior.

My improvement was gradual, about one or two percent a month, but today I have an activity level comparable to that of other people of my age. I no longer experience CFS symptoms, except very mildly on occasion. In some respects, I seem to be better than before. For example, I recently did 55 miles of hiking on a three day trip and on another occasion walked 25 miles in one day.

You'll find in this book a detailed description of what I did to feel better. In telling my story, I am not advocating that you forego medical treatment and I am not offering medical advice. In fact, I suggest you work with a physician. Medications can be helpful for many patients with CFS and many patients have additional problems best addressed through a medical approach. I hope, however, that you find encouragement in my story, which I believe suggests that there is much patients can do to help themselves when faced with a major health challenge, things are safe, inexpensive and have a high likelihood of helping.

Bruce Campbell

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Preface

When I was diagnosed with CFS in 1997, I functioned at about 25% of my pre-illness level. Over a period of several years, I gradually returned to a normal life and consider myself to be recovered. I have an activity level comparable to that of other people of my age and no longer experience CFS symptoms, except very mildly on occasion. My improvement was gradual but steady, about one or two percent a month until I got back to 90%, with further improvement since.

The path I followed was an unconventional one. Believing that there was little help available from the health care system, I adopted a self-help approach that excluded medications and instead focused changing my habits and behavior. Believing that my body wanted to get better and that it was my responsibility to create the conditions that made improvement possible, I began a process of observation and change. I studied my experience to find those things that helped me feel better and then changed my life to live more consistently in a way helpful to my body.

My approach combined two factors that might seem incompatible at first glance: acceptance and hope. By acceptance, I mean that I acknowledged that my life had changed for an extended period of time and perhaps permanently. Acceptance did not mean resignation, but rather a recognition that the illness forced me to lead a different and more limited life, perhaps for the rest of my life.

At the same time I had hope. I was confident that through changing my daily habits and routines I could find things to help me feel better. I did not know whether it was possible to recover, but I believed that I could reduce my discomfort, reduce uncertainty and regain some control over my life. I did not expect a quick solution. Rather I recognized that self-management was a way of life. I believed that listening to my body and responding to its needs gave me the best chance for improvement.

My path was one of trial and error. At the beginning, I didn't know my limits or what would help. Everything I did felt like an experiment. Some things I tried helped me, but others didn't. But I believed that whatever the outcome, I could learn from my experience. And I often learned more from the experiments that turned out differently than I hoped. Keeping records, which took only a few minutes a day, helped me to recognize connections between my actions and my symptoms, thus making my experiments more efficient. Once I understood my limits, my records helped me live more consistently within them by documenting the price I paid when I lived outside my "energy envelope."

I also recognized that my approach had to address the complexity of my illness. Not only did I have several symptoms, those symptoms each had multiple causes. Also, my illness affected, and was affected by, many other parts of my life. For example, my illness created more stress, and stressful situations worsened my symptoms. Becoming aware of these interactions showed me that I would have to think comprehensively about my life and use many strategies.

I offer this account of my use of self-help and lifestyle change in the hope that others might find both encouragement and practical strategies in this description of how I used behavioral change to recover from illness.

1: I'm Really Sick, Now What Do I Do?

I came down with a flu-like illness in the summer of 1997. My doctor told me that the illness was probably caused by an unidentified virus that would run its course in a few weeks. As the weeks passed, however, my symptoms continued and I began to worry about what was happening to me. 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 might be lifting. 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, going from 25 to 20, then 15 and eventually 12.

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 is also called Chronic Fatigue and Immune Dysfunction Syndrome or CFIDS.) 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. What should I do?

Choosing Self-Management

Later that day, I spent a few hours 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. It was clear that there was no medical cure for the illness, and 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. It was also discouraging to read that there was no standard treatment, that is, no commonly prescribed medication given routinely to CFS patients. Rather, patients were advised to try a variety of different treatments in the hope of finding something that reduced symptoms slightly. 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 modestly.

Since I wanted to get my old life back, I decided to forego that approach. Rather than experimenting with many 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, to adapt to the illness and the limits it had imposed on me. In contrast to an approach with a very uncertain outcome, I felt confident I could find things that would help me improve.

Earlier Experience with Self-Help

Previous experience had a big effect on shaping my decision. One important element in my past was work as a consultant to medical self-help programs at Stanford University. These programs 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. The example offered by patients I met taught me to ask two questions when faced with a medical problem: 1) what help is available from the medical system? and 2) how can I help myself?

In addition to my observation of others, my own prior experience had shown me the value of self-help. Two years before coming down with CFS, I had a mild fatigue which reduced my energy by about 20%. (Looking back, I wonder if the fatigue may have been a mild version of CFS.) In trying to decide how to address the fatigue, I asked my doctor whether he thought my having blood tests would produce a diagnosis and, if it did, whether that would lead to a treatment. He said that the chances for

diagnosing my fatigue through the tests was about 10% and that there was a 10% chance that a test result would suggest a treatment. Given the 1% probability that blood tests would lead to a helpful treatment, I told him I wanted to follow a different path. I felt confident I could find things that would help me if I kept some records. He encouraged me to follow that path. I began a simple health journal, which took about one minute a day to fill out. I quickly learned that I could reduce my fatigue greatly by reducing my activity level by about 15%. I did so and the fatigue went away in a couple of months.

Me and the Medical System

When I decided to respond to CFS by using self-help alone, foregoing experimentation with medical treatments, my decision did not imply a rejection of my doctor. I checked in with him monthly by phone 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 that course provided the best chance for recovery. Proven medical treatments were available in the first case, so I used them. Self-help seemed the most promising approach to CFS. I felt confident I could find things to help me improve.

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 eschewed medicine under all 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.

2: Adopting Multiple Strategies

I began by asking myself how I would address my symptoms. The main symptoms I experienced were fatigue, brain fog and pain. I decided to begin by developing a strategy to deal with fatigue, my most persistent and disruptive symptom.

Treating Fatigue

I remembered from my work at Stanford that fatigue could have multiple causes, each of which might be addressed by 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 is not restorative, leaving me feeling tired
Pain	Tensing muscles because of pain or being pre-occupied with symptoms can intensify fatigue
Stress	Stress produces worry and muscle tension
Depression	Low spirits produce 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 seemed the most crucial to me. 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 in 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. (For more, see [Chapters 7](#) and [8](#) on the energy envelope and pacing.)

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 trained too hard, 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. (For more on my experiments with exercise, see [Chapter 11](#).)

Improving my sleep also seemed worth pursuing. I knew from other patients that sleep was often nonrestorative for people with CFS, but I thought I could help myself to some degree by maintaining good sleep-related habits, often called “sleep hygiene.” My reasoning was that while CFS might be the major reason for nonrestorative sleep and not directly responsive to quick fixes, 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 to turn off the TV and stop using the computer at 9 p.m.

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. (See the [Chapter 9](#) on rest.)

In the first year or so, I focused my efforts on those four areas. Because it took me some time to recognize the effects of stress and emotions, I addressed them later.

Lastly, 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.

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, I may need to use multiple strategies in response.

Additional Strategies for Other Symptoms?

Once I developed my approach for addressing fatigue, I asked myself whether I needed additional strategies for my other major symptoms. 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 were responsive to the same strategies, so that, by and large, I didn’t need separate strategies for each symptom. 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. Further, the presence of any of my symptoms was a sign that I needed to cut back. For example, if I felt cranky or depressed, I took it as a sign I was outside my energy envelope and needed rest.

Comprehensive, Two-Way Effects

There were two other reasons for adopting multiple coping strategies, in addition to the fact that each symptom might have multiple causes. First, the effects of CFS were comprehensive, touching many aspects of my life: my ability to work, my moods, my finances, my relationships, my hopes and dreams for the future, and my sense of who I was as a person. Second, there was an interaction between my illness and these many factors; my illness was affected by many other things and in turn affected them. I have tried to suggest something of this complexity in the diagram below, with arrows pointing both both directions.



One obvious interaction was between activity and symptoms. My CFS limited my activity level (arrow pointing out: illness limits activity). But the opposite was also true; if I tried to do more than my limits allowed, I experienced higher symptoms (arrow pointing in).

I also observed other relationships. 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 using several techniques. 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 tried various techniques, finding that I worked well with verbal descriptions but not with imagery. I eventually developed a technique of my own using counting of the breath.

I also found that 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 heartfelt comments of people in a group I led. I was confused by my response, which was a combination of joy and brain fog. The fog dissipated gradually on the ride home. (Thankfully, someone else was driving.) That experience helped me to realize that any experience that triggered the production of adrenaline, whether positive or negative, would trigger brain fog. The same applied in situations that made me anxious, any experience in which my body responded caused muddled thinking.

I think the relationships between illness and other aspects of our lives are probably even more intricate than the diagram suggests. Sometimes one factor from the rim of the illness wheel can affect another factor from the rim, which in turn affects symptoms. For example, illness makes relationships more difficult. Not feeling understood or worry that you’ll be abandoned creates stress, which in turn can exacerbate symptoms.

I sometimes wished for a simple solution, an alternative to my behavioral approach, which was so complex. 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 things that would produce the greatest effect on my symptoms

3: Understanding My Unique Situation

In addition to the idea of multiple strategies, I was helped by understanding my unique life situation. I came to believe that each person's experience of CFS is different. The pattern and severity of symptoms vary from one person to another, and each has his own individual life circumstances. Each of these factors can either help promote improvement or make it more difficult. I was very fortunate. In many different ways, my situation was favorable, supporting my efforts to recover.

First, I had a moderate case of CFS. Though significantly limited by the illness, I was slightly better off at my worst than the average patient I have known in the severity of my symptoms. Because of that, I had a shorter road to recovery than those who were more severely affected.

Another aspect of my medical situation was also favorable. I had only CFS, uncomplicated by other illnesses such as fibromyalgia, chemical sensitivity or Irritable Bowel Syndrome (IBS). I have known more than 1,000 patients, most of them through the self-help course I will describe in [Chapter 6](#). The majority have both CFS and fibromyalgia, or one of them in combination with one or more other long-term illnesses. I was lucky to have only one illness.

In addition to these aspects of my medical situation, several aspects of my life circumstances were favorable. The first was my finances. I was in my early 50's when I got sick, old enough to have created a financial cushion for myself. As someone who had been self-employed, I had set aside money for a "rainy day," savings I could draw on when I became ill. Also, as a single person with no children, I was financially responsible only for myself. The result of this combination of financial circumstances was that I was not stressed by the money pressures that many CFS patients face. Having financial reserves allowed me to quit working and attend to the needs of my body.

Third, 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 after two surgeries. 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.

Also, I received understanding and support from my family and closest friends. They accepted my illness as real and agreed with my decision to pursue a self-management approach. The support of a close friend was particularly helpful. We talked frequently about my illness. Every month, both of us rated my progress on a 0 to 100 [Rating Scale](#) I developed. The discussions helped me to be more realistic about my progress. Also, her interest in helping me communicated that I wasn't alone in my efforts to improve.

Another positive element in my life situation was that I lived alone. Although I felt frightened 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.

Finally, I was lucky in two other respects. First, I adopted a self-help strategy very early. I have met many patients 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 much 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.

Lastly, I had a case of CFS that allowed for recovery. I have known many patients over the last several years 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 1980's. 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 there is something in my system that enabled me to bounce back from CFS.

In all the ways just described, my situation was helpful to recovery. I had only CFS, uncomplicated by other medical problems. My illness was moderate in comparison to that of some patients. My life circumstances were much less stressful than those of some patients. By chance, I adopted an approach that was well suited to my illness. And I had a case of CFS that permitted recovery. I had no control over most of these factors, but I was grateful for them, thankful for circumstances that allowed for recovery.

4: Is Recovery a Realistic Goal?

Another issue that all CFS patients face is what goal they should aim for. I struggled with this question for several years, giving different answers at different times. Even though I knew that recovery was unusual for CFS patients, I had trouble letting go of the hope that my old life would return. But aiming for recovery created problems, too. With recovery as my goal, I lived on an emotional roller coaster, buoyed by signs of progress but devastated by the inevitable setbacks. What was the alternative to hoping for recovery: resigning myself to a lifetime of suffering?

Wrestling with these questions helped me to understand the distinction between those things I could control and those things 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 illness 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.

Reading an [article](#) by Dean Anderson, a recovered CFS patient, provided both insight and inspiration as I was struggling with this issue. In an article in the *CFIDS Chronicle*, he described his successful eight-year struggle with CFS. Dean had followed a path much like the one I had adopted, turning away from medical treatments and instead focused on figuring out what he could do to make himself better through changing 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.” 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.” The discipline he used was the opposite of the discipline of striving. It was the discipline “to recognize and adhere to one's known limitations and to follow a strict regimen without periodically lapsing.”

I found inspiration in Dean's description of how he combined acceptance of being ill with hope for a better life. That seemed the right balance. On the one hand, I felt I had to acknowledge that my life had changed and that my old life might never return. To live as well as possible, I had to live differently than before. 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 don't think the recovery rate for CFS has been determined scientifically, but from knowing more than 1,000 patients, I believe only a small percentage recover fully although many improve to some degree.) I believed that there was a limit on how much I could improve, but that 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 lead a meaningful life.

I was certain that there were many things I could do to improve my quality of life. At the same time, I believed that those things that helped me feel better also could lead to recovery, if that proved possible for me. In other words, I came to believe that recovery was out of my hands. All I could do was to create conditions conducive to it. By suspending expectations about recovery, I could focus on what I could do to make my life better.

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 was crucial to my coping with CFS and to the improvement I have 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.

So, for me the combination of acceptance and hope was crucial. Acceptance meant acknowledging that I had a serious illness and needed to lead a different kind of 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 of CFS with hope for improvement enabled me to resolve my 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 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 recovery.

The combination of acceptance and hope was the solution to another problem as well, the grief brought by CFS, as described in the next chapter.

5: Responding to Loss

There is one more central issue to discuss: 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 but rather the central fact around which my life revolved. Much of what I considered “me” had been taken away. The losses brought by the illness created one of my greatest challenges in living with CFS.

One of my responses to the loss of my old life was denial. I think denial helped me for a period of a year or more, as I told myself 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 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 in the last chapter, 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 as 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

CFS stripped away most of what I viewed as myself. 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.

I did two things to cope with my losses. The first was to publicly acknowledge the loss. 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. And 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 more profound effects were on 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. And I continued to believe that there were many things I could do to help myself. I believed that even if I didn't recover, I could find things 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, one from each group. Both were very generous with their time, spending many hours talking to me about the medical, psychological and political aspects of CFS. They were tremendous sources of information and perspective, helping me to understand CFS much more quickly than I could have on my own.

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 CFS patients to be 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.

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 sense of new 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.

6: Starting a Self-Help Program

Another key element in my approach to CFS was knowing and working with other patients through a self-help program I created. Given my professional experience with self-help for chronic illness, 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 a self-help course for people with long-term illness could be a powerful complement to medical care, offering coping techniques and support from fellow patients in a positive, problem-solving setting. Working as a consultant to medical self-help programs, I had seen people gain some control over diseases like arthritis and cancer by using self-help strategies. I saw many people improve their quality of life and sometimes even change the course of their illness by taking responsibility for those things under their control.

I thought that a self-help program for CFS could be even more valuable than the ones I had known for other illnesses. I reasoned that if self-help could be useful for illnesses with well-established treatments, it should be even more helpful for a condition with no standard or widely effective treatment. When I couldn't find any such groups for people with CFS, I decided to start one. I thought that by getting together with other patients to talk about what each of us had found helpful and by supporting one another, we could gain some control over our illness.

The first version of the course was based on three foundations. One was Cognitive Behavior Therapy or CBT, which I was familiar with from my previous work and which was then gaining attention because of its use in England as a treatment for CFS. The second was the self-help programs I had known at Stanford, especially the Arthritis Self-Help course. Like our program, the arthritis course is taught by trained volunteers, most of them patients. The third was another program at Stanford, Dr. David Spiegel's breast cancer support groups, which became famous because participants lived twice as long as controls. I tried to combine elements from these three approaches. We used concepts from the CBT program, tools and ideas from the arthritis class, and also tried to provide a strong element of support.

The content of the course focused on three key ideas, ones that have remained central to the course ever since. The first was the idea of self help: the belief that how one lives with chronic illness can change its effects and perhaps its course. The second was the energy envelope: the idea that illness limits energy, but that patients can reduce symptoms and the severity of relapses by accepting the limits imposed by the illness (living "inside the energy envelope"). The third was the idea of using multiple coping strategies. Because patients usually have more than one symptom and each symptom may have more than one cause, it may help to employ a variety of techniques.

In the first year or so, we called our program the CFIDS Self-Help course and offered the class in several locations in the San Francisco Bay Area and then over the Internet. When many people with fibromyalgia started taking the course, we changed our name to CFIDS/Fibromyalgia Self-Help. The course went through many versions during the first several years, but the focus was always the same: patients sharing what worked to help them feel better and improve their quality of life.

At the same time the program was expanding, my health was improving. Using the ideas and techniques described in this book, I gradually got better. The course was not just a summary of what worked for me. It couldn't have been that, since I began the course just after being diagnosed, when I was searching for things that might help. Rather, the groups were a place where I thought people could learn from one another and share support. The content of the course went through many revisions, as I learned more about the illness and what helped people gain some control. At the start, I was as much a student as anyone else, using the course to understand CFS and develop a strategy for living with it.

Looking back, I think I was trying to create a community of healing for myself. I knew that people respond in many ways to serious illness and wanted to be around others who shared my belief that a positive approach would bear fruit. I knew that not all patients responded in the way I wanted to. Some look for a miracle cure; others spend their time focusing on their losses. 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.

As the program developed, it had some important unintended consequences. 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 that served me well. I took CFS patients to be my peers, not healthy people. That meant that I measured myself in comparison to them, not to my peers from work. That comparison took a lot of pressure off.

Another consequence that I didn't recognize at the time was that leading the class helped me deal with loss. As I mentioned earlier, illness stripped away many of my roles and activities. Developing the self-help program allowed me to create new relationships and find new meaning. By replacing my old goals with different ones, and by focusing on what I was still able to do, I found a way to be useful even when previous roles had been taken away.

7: The Energy Envelope

CFS imposed tight and seemingly inflexible limits. Just as frustrating, I experienced a disproportionate increase in my symptoms whenever I went outside those limits. For example, in the early months of my illness, I could walk for 15 minutes most days without intensifying symptoms, but 25 minutes might send me to bed for an hour. The restrictions seemed unfair, but, after a while, I realized that there was no one to complain to. CFS felt like an inflexible and unyielding force. I concluded that my best hope lay in adjusting to the limits it had imposed on me. Ironically, yielding to the illness gave me some power. If I listened to my body and honored its limits, I could re-gain some control. I have since heard this approach called “looking at illness from the body’s point of view.”

I was helped toward this change in view by remembering the distinction between acute and chronic illness. Acute or short-term illnesses are temporary problems, conditions in which the diagnosis and treatment are clear and the outcome is usually predictable and positive. Such illnesses can be cured by medical help or are self-limiting. Chronic illness is different. Instead of interrupting life briefly, it imposes long-term limits and forces patients to adjust their lives to it. Because of limits and uncertainty about final outcome, there is often a high level of frustration and a sense of helplessness.

Like many other patients, I learned that using an "acute illness" approach to CFS didn't work. If I tried to ignore my body and just push through, my symptoms were intensified greatly. I came to believe that my best chance for improvement lay in finding and honoring my limits. I hoped that if I reduced the stress on my body that it could find a way to improve.

The Energy Envelope

I felt encouraged in this approach by two ideas I encountered in my reading about CFS. 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. Titled "Think Inside the Envelope," the article suggested that CFS patients 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 [Rating Scale](#) I developed. (The scale was based on a similar rating system in Dr. David Bell's book *The Doctor's Guide to Chronic Fatigue Syndrome*.) My self-ratings showed me that my improvement would be slow; the ratings changed at most only a few points each month. Knowing that I was at a certain level, say a 45 on the 100 point scale, was a reminder of how many hours a day I could be active without increasing my symptoms.

The other idea from my reading was the Fifty Percent Solution. In his book *Recovering from Chronic Fatigue Syndrome*, William Collinge suggests that patients 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.

Developing a Detailed Understanding

Thinking of my 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 understand my limits in detail. This change was triggered by some fellow patients pointing out to me 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) could I do in a day? 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 define as how long I could do various activities like housework, shopping and spending time with people), food sensitivities, sensitivity to light and noise, and emotions.

Over time, I ended up with a list of about a dozen items that I listed for myself 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 third 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	45 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 to the end of my definition, in which summarized my abilities and limits, noted my greatest vulnerabilities (for example, stress, secondary illnesses and travel) and set goals for myself. This section was a helpful summary of my current situation and also suggested where work might give the biggest payoff in reduction of symptoms.

I learned a lot from studying my envelope. One surprising realization was that my limits were more restrictive in some areas than in others. During a period of time in which I thought that overall I was at about 60% of my pre-illness level of functioning, 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 outsiders' views of my situation helped me to be more realistic in my self-assessment and also helped others to understand me better.

Learning Through Experiments

One way I found my envelope 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 I tried and the lessons I learned, all from the area of exercise.

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 a certain level.

Expanding the Envelope

Even though my envelope expanded very slowly overall, I found some ways I could expand my activity level immediately. I just suggested one: by being attentive to time of day. But I found several others by observing my experience and by listening to other patients.

A student in one of our first groups reported that something she tried at a birthday party had made a big difference in her energy level. At a similar party a year earlier, 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 party held during the course, 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 taught me that if I could respond in a relaxed manner to stressful situations, I could preserve energy that might otherwise be dissipated in tension and anxiety. The net result would be more energy for production use, effectively an expansion in my energy envelope.

The same student also taught me that how we rest can affect the amount of energy available to us. At the beginning of the 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. Her flexible approach enabled her to expand her envelope.

I learned from her that taking a short rest break to re-charge batteries can expand the number of productive hours in the day. The use of planned rests was one of the most powerful tools I found for controlling symptoms and will be the subject of [Chapter 9](#). Let me mention here one way I used the idea, to expand my envelope for travel. I found that if I stopped for a ten to fifteen rest for every two hours of driving, I arrived fresher at my destination and had a lower symptom level throughout my trip. Another way that rest helped me increase my envelope was to take a brief rest as soon as my symptoms became more intense. That strategy enabled me to avoid a long period of "downtime," so that by giving in to my symptoms I reduced my total rest time.

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 scheduled of activity and rest, reducing the surprises and emotional shocks in my life, thereby reducing my stress.

Overall, the idea of the energy envelope was very useful. By emphasizing the idea of limits, it helped me to accept that I had restrictions. Also, the idea motivated me to understand my limits in detail. In both ways, the concept of the envelope helped me control my symptoms.

8: Pacing

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 a higher activity level. But even when I lowered my activity level to half of normal and then to a quarter, it was 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.

At some point, I heard about the idea of pacing, which seemed to hold out the promise of stability as an alternative to repeated cycles of push and crash. I believe I first learned of the idea through Alicia Deale, who shared with me materials she had used in a research project that used graded activity (gradual expansion of activity level) as a treatment for CFS. Since the research seemed to show that a substantial portion of patients who used this approach improved, I was attracted to the system she and her colleagues had developed.

Pacing meant finding the right balance of activity and rest, and applying that balance on an everyday basis. The key was to live a life that was planned, with a similar amount of activity and rest every day, so that I would have a consistent level of activity and a similar amount of rest each day.

I found this idea hard to understand. Her approach required that I view my illness in a new way. Up until then, I had applied to CFS an approach used with previous illnesses, resting when I felt bad. She was suggesting an alternative: living according to a plan rather than in response to symptoms. I was intrigued by the possibility that this new approach would give me some control over my illness.

The idea of pacing fit well with the concept of the energy envelope and gave me a way to understand my cycles of intense symptoms and rest. Instead of thinking that fluctuations in my symptoms were random, I came to see that they were due to variations in my activity level. At first, I felt guilty about the idea that I might be the cause of my symptoms, but then I realized that the idea was also the basis for hope: if my actions could make my symptoms worse, I might be able to gain some control over them by changing the way I acted.

I decided to adopt an approach that combined my old idea of resting in response to intense symptoms with the new idea of living according to a schedule. The use of planned rest was the most counterintuitive part of the new program, but the one that probably had the greatest effect. I believe that my daily planned rests were perhaps the single most important strategy I used to gain control over CFS. Rest was so crucial to my recovery that I have devoted the next chapter to it.

The idea of pacing fit perfectly with the idea of limits. The insights I had about the limits in different parts of my life, as explained in the last chapter, showed me what made symptoms worse and what was safe for me.

Pacing also fit with the record keeping I did. Having written documentation in my health log of the effects of activity and rest both proved the effects of activity and motivated me by showing how I was gaining increased control over time. Record keeping was so important to my improvement that it, too, is discussed in a separate chapter. I wanted to link cause and effect, and assumed that I could document my limits by finding connections between my activity level and my symptoms. Records showed me my limits when I could not trust signals from my body to do that. When I was healthy, my body told me to slow down by creating a sensation of fatigue. But that often wasn't true with CFS. I might feel no increase in fatigue during my daily walk, but then be very tired a few hours later.

The lack of trustworthy signals from my body was one of the chief reasons having a scheduled life made sense to me. In the absence of reliable real-time information from my body, living according to a schedule was a better course than living in response to symptoms. Keeping records gave me a way to determine a safe activity level.

Sticking to Pacing

It was hard to live consistently within strict limits. When I started pacing, I functioned at about 25% of normal. My improvement averaged one or two percent a month, with periods of several months when I couldn't see any improvement at all. But since I believed that pacing offered my best chance for long-term improvement, I developed several strategies to help me live consistently within my limits.

Perhaps the most useful was to visualize how I would feel if I went outside my envelope. Imagining the fatigue and brain fog provided a counterweight to the immediate pleasure I anticipated from doing something that took me beyond my limit. I pictured and felt the consequences of doing too much by imagining myself lying in bed in pain.

Record-keeping also helped me live within my limits. Having written proof of the effects of my actions helped me to hold myself accountable for my actions. 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 as a positive motivator, helping me aim for more frequent no-symptom 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.

A third strategy was routine. Having a regular schedule 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. A related idea is what I call having rules for specific situations. For example, one rule was to avoid noisy places. Having that rule gave me permission to leave noisy restaurants.

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. Learning patience and applying a different standard than that for an acute illness were helpful. It was part of acceptance to acknowledge that the rate of improvement was very slow.

Finally, I tried to be forgiving with myself. I didn't always stay in my envelope. But, instead of beating myself up for failing, I decided it was better to just say "what can I learn from this experience" and move on.

This approach 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 progress, even if it was at a very slow rate.

Special Events

Pacing worked well most of the time, because I lived a predictable life. 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 a number of strategies in response to help me cope better with non-routine events. Most applied mainly to travel.

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, as mentioned in the last chapter.

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 for that time.

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 think it likely that the reduction in stress that resulted from having a stable life helped make my life even more stable. *

9: My Secret Weapon: Pre-Emptive Rest

If there was a secret to my recovery, it was my use of planned rests. As I mentioned in the last chapter, 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 or a whole day in bed was an effective strategy for recovering from periods of doing too much, but my life felt out of control.

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 scheduled rest periods taken no matter how you felt. The goal was to shift away from living in response to symptoms (the cycle 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 if I wasn't experiencing any symptoms. Also, I thought of resting as giving in to the illness, so that rest meant a victory for the illness.

Because other parts of the program from England made sense, I decided to try resting every afternoon, but I wasn't sure what "rest" meant. Was I resting if I was reading or watching television? Or did rest mean lying down? I did some experiments and found 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 rest seemed to help, reducing my symptoms, increasing my stamina and making my life more stable. After a while I added a morning rest as well. Over time, I came to believe that my scheduled rest was the most important thing I did to aid 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 one of the students in our self-help program, I learned the difference between *recuperative rest* and *pre-emptive rest*.

Taking pre-emptive rests enabled me to reduce the time I spent in recuperative rest. The result was that my total rest time was reduced. Resting on a planned schedule greatly stabilized my life, enabling me to get off the roller coaster and giving me a much greater sense of control.

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 often raced from worry to worry, so I experimented with various meditation procedures during my rest time. I learned that techniques using imagery, such as imagining myself lying on the beach or sitting beside a stream, were not effective for me, however helpful they may be to some people. But focusing my attention on my breathing worked. 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. As mentioned earlier, 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, 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 used rests to expand the length of my

walks. If I alternated walking with an equal amount of time sitting, I could walk farther and not affect my symptoms.

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 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, I experimented with the number of rests, eventually replacing planned rests with brief rests in response to symptoms. But this was only after I had recovered back to about 90% of normal. For most of the time I was recovering, pre-emptive rests were crucial. For four years, my planned rests 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: Keeping Records

Initially I didn't know my limits or understand what would help, so I decided to make experiments. I wanted to study my situation as a scientist would, observing and trying things. 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 I wasn't running a true experiment. With only one subject, I couldn't have a randomized controlled trial, but I felt confident that I could learn a lot by systematic 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 be rewarded by 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. Sometimes I went over my logs with a friend.

Looking back, I see that the few minutes a day I spent keeping health records were one of the most important parts of my approach. Certainly the payoff was great for the small investment of time. My records helped in three ways that I will explain below: they documented links between my actions and symptoms; they affected my actions by holding me accountable; and they were a source of motivation.

Linking Cause and Effect

I experimented with a variety of simple logs, usually just one at a time. The log I used the most was similar to the [Activity Log](#), posted on our program's site. 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 the amount of sleep and rest I got, my overall activity level, exercise and stressors (both people and situations). For "effect" I 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. Then I sought to understand what made my days different. Why were some days better than others?

Studying 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. For example, looking at my records for the year at the end of 1998 enabled me to quickly identify the causes of my relapses. It took only a little more time to develop a plan for avoiding them in the future. I began my review by identifying all my relapses during the year. I found eight. (I defined a relapse as symptoms so severe that I had to spend at least one full day in bed.) Then I looked for common causes and discovered that almost all the relapses were associated with either having another illness or travel.

Last, I developed strategies to minimize the impact of each of these factors in the future. 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 ten- to 15-minute rest for each two hours of driving. I think the two hours I spent on that analysis was the most productive time in my experience with CFS: I haven't had a relapse since.

Logging Shapes Behavior

I found that my logs, in addition to being a record of my behavior, 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 twice as active as 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 student in one of our early groups took this principle even farther. 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."

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, I found that the benefits from a few minutes of record keeping a day were great.

11: Experiments with Exercise

As I mentioned in the last chapter, experimentation played an important role in my approach to CFS. 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.

I came to view living with CFS as a series of experiments that I called being my own “CFS scientist.” Because I didn’t know my limits when I started nor did I understand what would help, everything I did was an experiment. I tried to have a willingness to learn from my experience, especially when it contradicted my previous ideas.

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

Finding Exercise Limits

Early on I was able to walk 20 minutes or so a day, with some days missed because of severe symptoms. This represented a big contrast to my exercise before becoming sick, when I took long hiking trips on which I walked an average of 15 to 17 miles a day.

I hoped to expand the length of time I exercised, both because I enjoy exercise and because I thought that exercising would help reduce the fatigue due to de-conditioning. But how much exercise could I tolerate without making my symptoms worse? I tried walking for different lengths of time and at different speeds, keeping notes of how I felt both during and after exercise. I found 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.

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 a higher level of symptoms. 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 was as important as *how much* I did.

This realization led me to ask whether this was true generally. I found that my illness had a pattern. I often woke up feeling tired, no matter how many hours I slept. My symptoms were generally at their peak in the morning, but I had a period of several hours from mid-afternoon through mid-evening when they decreased. I found consolation in this insight. 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.

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 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 it? I decided to keep careful records of my activities and symptoms, correlating activity level with subsequent increases or decreases in symptoms. Over time, I discovered my "safe" activity level. But this was a process of analysis and deduction, not awareness of my body in "real time." I found I could control my symptoms by staying within those limits.

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 of my fatigue, I decided that a more frequent explanation was my total activity level. 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." By that I meant that because my energy level was so low when I first got CFS (about one quarter of my pre-illness level) 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 or so and feel fine afterwards, but to have to spend an hour in bed if I walked 40 minutes, which sometimes occurred. The difference was so small in comparison to the length of my hikes in the past that it seemed I was being punished disproportionately by CFS for going only a little outside my limit. Painful as it was to realize how little "cushion" I had, how tight my limits were, the discovery led to a 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" if I had been good for a week. I saw 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 the body was in charge.

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 my use of daily rests at home. As explained in [Chapter 9](#), I believe that scheduled rests were perhaps the single most important thing I did to aid my recovery.

I discovered how I could apply rest to exercise when I went walking one day with another CFS patient, a person who had a more severe case than mine. She stopped frequently, probably every five minutes or so. I noticed that I wasn't at all tired at the end of our hour-long walk, and asked myself whether I might be able to extend the length of my walks by incorporating rest into them.

So I tried an experiment. The next day I walked for 20 minutes, then sat on a bench for a 20 minutes, then walked some more. It worked! I was able to walk significantly farther than before by including a long rest in the middle. This was a big psychological breakthrough, as it opened the possibility of longer walks without increases in symptoms. I was able to extend gradually the distance I could walk, as long as I alternated periods of walking with equally long periods of rest. Planned rests during exercise also enabled me to begin walking again in areas with uphill stretches.

Uneven Recovery

Three years after becoming ill, I was able to walk on occasion as much as seven miles, a big improvement on 20 minutes a day 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 still had were the solution, as I explained in [Chapter 5](#).

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, walking at a speed comparable to that on similar trips when I was 10 to 15 years younger. 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. By extending my exercise very gradually as I could tolerate it, I have returned now to a level of exercise equivalent to or perhaps slightly 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 pull the shades and hope 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. Especially if I had experienced consistently low symptoms for a while, these setbacks created the frightening thought that perhaps improvement wasn't possible after all. Relapses represented perhaps the greatest psychological challenge I faced from CFS. They were so frequent and so devastating that I decided that having strategies to combat them had to be an important part of my overall strategy.

Minimizing Setbacks

The first challenge was to determine what I could do to reduce the length and severity of my relapses. The number one answer was to 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." Two strategies that were helpful at these times were to speak reassuringly to myself and to connect with other people. Knowing that worry made relapses worse and that relaxing helped me recover, I spoke consolingly to myself, saying things like "you've recovered from all the 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 talking to other people on the phone helpful in calming me down. We didn't even have to talk about my relapse or even about me. I think just having a sense of connection with another person was reassuring and 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. I motivated myself to take the extra rest by visualizing what I would feel like if I didn't take the extra rest.

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 three hours rest 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, remembering how many times such an approach had led to several hours’ rest, 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.

Prevention

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. Believing I caused my relapses gave me hope that if I could change how I lived, I could bring setbacks under my control.

I explained in the chapter on [record keeping](#) how I used my logs to identify the two causes of my relapses (secondary illnesses and travel), and then developed strategies to prevent future setbacks. By taking extra rest for several days after the symptoms of a secondary illness had ended, I eliminated relapses triggered by colds and other short-term illnesses. I used several strategies to minimize travel-related setbacks. First, I limited my travel to destinations that were only a few hours’ driving distance from Palo Alto. Second, I scheduled extra rest before, during and after my trips. Third, I added a ten to 15 minute rest stop for every two hours of driving.

Initially I resented having to give in to my illness so much, but then I told myself that by giving in a little I could have a good trip. Being two-thirds as active as a healthy person was much better than spending my whole vacation in bed, which had happened on a number of trips before I adopted these strategies.

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 keep honor my plans.

Lastly, I sometimes adopted a compromise between strict adherence to my envelope and ignoring the envelope. There were occasions on which I went somewhat outside my envelope so that I increased my symptoms somewhat but didn't suffer a bad flare-up.

Personal Guidelines

A final strategy I developed to prevent relapses was what I called “personal guidelines.” I remember well the day the idea came to me. 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, some things I could write on a 3 x 5 card, which could guide my daily life and be my reference in times of confusion. Here’s what I came

up with (the words in italics went on my 3 X 5 card):

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. This strategy includes: a) taking scheduled rests daily no matter how good I feel; b) keeping daily records of activities and symptoms to help me define my limits and to hold myself accountable for staying within them; c) returning only gradually to my normal routine after a relapse or illness; d) avoiding stressors (people and situations that trigger strong reactions).

Extend the envelope gradually: I will take prudent risks to expand my activity level. “Prudent” means 5% to 10% more at a time. I recognize that not all my experiments will work, and I acknowledge that this approach takes patience. The illness is in control and dictates the timetable and amount of improvement.

When all else fails, go to bed: There are times when the best course is to surrender to the illness. This guideline gives me permission to acknowledge that at times I am powerless over the disease and the smartest course is to give in to it.

Accept that I may not recover: I believe I can create the conditions for recovery but can't control whether I recover. Thus, I try to focus on feeling better, which I believe *is* under my control to some degree.

Gaining (Partial) Control

Gaining control over relapses was a psychologically-significant 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.

I never felt that my control over CFS was complete. I knew that ultimately the illness was in charge and dictated how much improvement was possible. But it was empowering to see my life improve when I discovered and learned to play by the rules that illness had imposed on me. •

13: Stress

I knew from my work at Stanford that long-term illness increases stress. In addition to whatever stresses a person had before becoming ill, sickness adds new ones, including the discomfort of symptoms, isolation, financial pressure, strains on relationships and uncertainty about the future. It took me a while to realize that in addition to these factors usually associated with long-term illness, there seemed to be something special about CFS that made me 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.

Any kind of conflict set off my symptoms and often things as simple as making decisions felt overwhelming. 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 sensitivity had to be a big part of my effort to manage CFS. I would say that, along with pacing, controlling stress was one of the two most important things I did to cope with CFS.

Stress Reduction

My first effort at controlling stress was through stress reduction. I used two formal stress reduction practices, Jon Kabat-Zinn’s body scan and Herbert Benson’s relaxation response. (Kabat-Zinn's program is offered at many hospitals in the US and is explained in the book *Full Catastrophe Living*. Benson's method can be found in his book *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. The relaxation response is a form of meditation that uses a focus on a word or image. I had started using the body scan several years earlier when I did Kabat-Zinn’s stress reduction program. I found it a helpful way to relax and it also helped me to fall asleep at night. Surprisingly, it became less effective as the years went on. Through that disappointment, I learned that sometimes a practice that is helpful for a while “wears out” and needs to be replaced.

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 decided to try meditation during my rests. I hoped that by quieting my mind, I could achieve a deeper quality of rest than by just lying down. The relaxation response 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. I found I did better if I combined focusing on the air coming into and out of my nose, while counting from one to ten. When I concentrated, I found myself 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. Benson describes this as a pleasant state similar to the feeling you might have lying on the beach on a warm summer day or the sense of detached relaxation you feel just before falling asleep. Relaxing my mind while relaxing my body had a dramatic effect on my anxiety level, thus reducing my tendency to over-produce adrenaline.

The other traditional stress reduction technique I found helpful is 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.”

I was aware of the power of thoughts to increase stress from my study of cognitive therapy, which focuses on the effects that our thoughts can have on our emotions. According to this view, negative thoughts can actually make us feel bad. If we say things like “I’ll never get better” or “It’s hopeless,” we are likely to feel anxious, sad and helpless. I observed this effect in me and also found that such thoughts created a vicious spiral. The negative thoughts intensified my stress, which made my symptoms worse, which in turn triggered another round of negative thoughts. I was able to apply the principles of cognitive therapy to cut short this negative 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 tell myself that my health came first and nothing bad would happen if I postponed my chores.

Stress Avoidance

Stress avoidance proved to be just as helpful as stress reduction. I learned that I could prevent stress by avoiding those things that caused 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, that is 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 had adopted routine as a pacing strategy, but 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 I sought out quiet areas in public places like airports.

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 to keep up but not to immerse myself 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 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.

14: Emotions

I knew from my work at Stanford that it is normal to feel strong emotions in reaction to having a chronic illness. Serious illness turns people's lives upside down, upsetting their hopes and goals, and creating frustration and uncertainty. So I knew intellectually that managing emotions could be just as challenging as managing the physical aspects of the illness. I don't think this background prepared me, however, for the strength of the feelings associated with CFS and their apparent connection with the physiology of the illness. I felt less in control of my emotions than at almost any time in my life; they seemed to be independent forces.

I developed a number of strategies in response to my new emotional state, all based on recognition that I was much more emotionally vulnerable than usual. 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 symptoms.

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, as I mentioned before, I found it helpful to fight my negative "self-talk" by saying soothing things to myself when symptoms were strong. I observed that I had an exaggerated initial reaction to relapses, often seeing them as evidence I would never improve. So I learned to talk in reassuring tones to myself. I consoled myself by saying things like "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. Perhaps the most helpful idea in the book was the suggestion to incorporate a relaxation procedure into my daily rests. Learning more positive and reassuring self-talk was helpful for anxiety, just as it helped depression. Exercise or just getting out of the house helped, too, perhaps because being out distracted me from my problems. Finally, talking with others, especially fellow patients, was calming.

I trained myself to mute my emotions after observing the toll from strong emotions, whether positive or negative. 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 held 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. Now that I am better, I am allowing myself to feel again.

While I was ill, I tried to observe myself when I experienced 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, that I could choose whether I would act. I have gone through this sequence enough now that I think I've established a new habit, freeing myself from some needless anxiety.

I 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.

I experienced another emotion, one that took me completely by surprise. I was shocked when, soon after becoming ill, I developed a mild paranoia. Part of me was convinced that people on the board of directors in my condominium complex were out to get me. I tried telling myself that this didn't make sense: I was current in paying my dues and hadn't insulted the president, etc. But a part of me wouldn't believe that. I was very confused by this until I read in Hallowell's book (*Worry*, page 62) about children who developed OCD (obsessive-compulsive disorder) when they had strep infections. The symptoms started when the infection began and disappeared after the children were treated. 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, I did not act on it and the final result for me was similar to the children's experience. My paranoia faded as my CFS symptoms declined.

15: Support

Support is another one of the key ingredients to living well with long-term illness. Again, I believe I was very fortunate.

I see support as having three elements. One is practical help, such as grocery shopping, housecleaning or driving. Luckily, I did not need help of this kind very often. Even though there were times when I was so sick I could not go out of the house, for the most part I could provide for myself.

Acceptance from Family and Friends

Another kind of support is acceptance and again I felt 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. Since I lived alone and was financially responsible only for myself, other people were not affected directly by my decision, but I was still appreciative others' acknowledgment that I was seriously ill and their agreement with my approach.

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 situation 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 meetings communicated that I was not struggling alone with my illness, but rather that there was somebody who cared about me and wanted to help me get better. I think the sessions also helped reduce the sense of helplessness often experienced by people close to those who are seriously ill.

In other places, I have called this having a confidant, a person to whom you can turn for emotional support and an objective view of your life. That person could be your spouse, a good friend or a fellow patient. In any case, I was fortunate to have such a friend.

Support from Fellow Patients

A third kind of support is understanding and that perhaps only fellow patients can provide. One of the first things I did after receiving my diagnosis was to join two local CFS support groups. Based on my experience at Stanford, I thought that fellow patients would be great resources for understanding my illness. Since patients live with chronic illness on a full-time basis, they are often more knowledgeable than doctors or other healthcare providers.

As I mentioned in the chapter on [loss](#), 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. It was they who 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.

A few months after getting my diagnosis, I started the self-help program I described in [Chapter 6](#). As

the program developed, it provided rich contact with fellow patients and became a major source of support.

Models

I experienced a powerful type of support from two fellow patients, neither of whom I met. I knew them through their published writings and, in the second case, via email as well. They provided me with models of living successfully with CFS.

The first was Dean Anderson, who described his successful eight-year struggle to recover from CFS in an [article](#) in the *CFIDS Chronicle*. 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. I thought that if I was following a course similar to his, maybe I was on to something. His improvement was a symbol of hope to me.

In reading and re-reading his article, I focused especially on some memorable passages. He wrote that after trying various approaches, he had come to believe that recovery might depend solely on his own efforts (“I don’t believe any of the remedies, medicine or food supplements I tried helped me one bit”) and 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.”

I found inspiration in Dean’s description of how he combined acceptance of being ill with hope for a better life. That seemed the right balance. For me, acceptance meant acknowledging that my life had changed and that my old life might never return. To live as well as possible, I had to live differently than before. On the other hand, however, I wished to live in hope of better days and assume that there were things I could do that would bring improvement.

Dean’s article validated some specific elements of my approach, as well as the general orientation. First, he defined his activity limits and then adjusted his life to them. Even though his limits were far greater than mine (at his worst, he worked six hours a day), we both believed in the idea of an activity envelope. Second, he learned to stay within his limits by alternating periods of activity with times of rest. Third, he also used record keeping to discover what helped and what hurt his recovery.

The other CFS patient who influenced and inspired me was JoWynn Johns. A CFS patient from Maryland, JoWynn contacted me late in 1998 after the publication in the *CFIDS Chronicle* of my [article](#) about our first self-help groups. Over the following months, we exchanged many emails about our parallel approaches to living with CFS. Her case was much more severe than Dean’s or mine. 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"). Following an approach similar to the one I had presented in our class, she had greatly reduced her symptoms over a period of several years.

A number of her approaches dovetailed with my own. The first was her focus on “feeling better.” After many unsuccessful attempts to recover, she let go of the frantic search for a cure and instead focused on finding things that would improve her immediate quality of life. She took a systematic approach to understanding her illness by keeping very meticulous records. Based on her records, she developed a detailed understanding of what she had to do to control her symptoms. Her records also motivated her, because they documented her improvement.

As someone who had lived with CFS four years longer than me, JoWynn taught me a lot about successful adaptation. She made Dean Anderson's idea about long-term adaptation to illness concrete. She likened living with CFS to adjusting to other chronic medical conditions, like diabetes or to long-term struggles with weight or alcoholism. She believed successful adaptation meant changing one's daily habits and routines. JoWynn also taught me many specific points about CFS that I used in my own life, such as the toll taken by mental and emotional events.

Her experience also forced me to re-evaluate my optimism about recovery and to think more about what promoted it and what made it unlikely. She had been as disciplined and consistent in living within her limits as anyone I knew, yet her functional level did not improve. She was able to control symptoms, but she did not expand her energy envelope by making lifestyle adjustments.

I learned a great deal from both JoWynn's and Dean's experiences with CFS. The fact that they used an approach similar to mine to control their symptoms encouraged me in my path. I found hope in Dean's recovery and felt sobered by JoWynn's improvement, which reinforced the idea of a ceiling or limit on the amount of improvement possible for each person.

My Doctor

Even though I never had another medical appointment for CFS after getting my diagnosis, my doctor played an important role in my recovery. For some period of time, I checked in with him monthly by phone to keep him apprised of my progress and I continued to see him for other medical problems. He was 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. That background may have made it easier for him to accept that I would try behavior change as a treatment for CFS.

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. This left me with an image of a person in a large room carrying a single candle and the implication that the realm of ignorance is probably much greater than the realm of knowledge. Also, as described in a previous chapter, he had been honest with me about the limitations of lab testing when I had an earlier episode of fatigue. So my decision to use behavior change to treat CFS was consistent with my belief in the limitations of medicine. 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.

16: Recovery or Just Remission?

Will my improved health last? That is, can I think of myself as truly recovered, with my old health restored or am I just experiencing a remission of symptoms, with the illness lurking beneath the calm surface of good health? It's a hard question to answer. Just as living with CFS means living with uncertainty, so does living without it.

For most of the time over the last couple of years, I have lived a normal life for someone of my age. Sometimes I am even able to do more than I did before. In my life before 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, running out of daylight before I ran out of energy. I feel very fortunate to have restored so much of my old life.

On the other hand, I have to acknowledge that I experience mild symptoms at times. My response is to take a brief rest. This experience suggests that I have not banished CFS entirely, even if it is invisible most of the time.

It may be helpful to think 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.

As a practical matter, I think it helps me to believe both that I have recovered and that my CFS is only in remission. Believing that I am recovered helps me to be more venturesome than I would be if I feared a relapse was waiting to pounce. Believing that CFS is merely quiet but not vanquished reminds me that I may have still have limits different from those of a healthy person and that I need to remain sensitive to my body and responsive to its signals.

In the end, my attitude is similar to the one I adopted at the start: whether I recover is out of my control. I believe I can reduce symptoms through the way I live and that I can create a meaningful life for myself whatever my circumstances.

17: Lessons

I began my CFS journey with a recognition that the illness had changed my life. Rather than a temporary interruption, CFS had become the central fact around which my life revolved. Its effects were comprehensive, limiting my energy level and my ability to work, changing my emotions and relationships, and creating great uncertainty. So the beginning of my journey was the brute fact that CFS had imposed severe limits on me, changing my life perhaps permanently and certainly for an extended period of time. My focus would have to be on adapting to those limits.

Given the limited medical resources available to me, I concluded that to get better I would have to accept responsibility for finding things that would help me. I tried to combine two elements which may seem in conflict: acceptance and hope. Acceptance did not mean resignation, but rather a recognition that my illness forced me to live a different and more limited life. I believed that listening to my body and responding to its needs gave me the best chance for improvement. I also recognized the limits of my power. I believed that I could exercise some control over my symptoms, but whether 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.

Looking back, I see an approach built on six strategies.

1) **Using Multiple Techniques:** Because I had several symptoms and because CFS affected so many parts of my life, I needed a variety of coping strategies. Rather than thinking I could cope by using a 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 by trying things to find what worked for me. I assumed that this approach would require discipline and patience, and that I would often fail. But I felt confident that I could improve my skills over time and that, in any case, there was no better alternative than experimentation.

3) **Pacing:** I came to believe that defining my limits in detail and living consistently with them offered the best chance of controlling my symptoms and improving my quality of life. This meant finding a sustainable level of activity and making appropriate use of rest on a daily basis.

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.

5) **Addressing Emotions and Relationships:** I had to acknowledge 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 illness.

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.

My approach of using self-help exclusively was different from that taken by most patients. Under different circumstances, I might have combined a self-management approach with a medical one. 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 and prudent, focusing as they did on living within limits and extending those limits very gradually, as allowed by the illness.

Recovery from illness often occurs in one of two ways. Many illnesses are self-limiting and resolve themselves over time. In other cases, medical treatment brings relief. Taking an anti-biotic cures an infection or a surgery repairs a broken bone. I followed a third path in response to CFS, neither assuming that my illness would disappear with the passage of time nor treating it with medications or supplements. Rather, I believed that my best chance for improvement was to use behavioral change. I saw my role as listening to my body and doing those things that would help it find a way to re-establish good health. For me, that was sufficient to produce recovery. I realize that most patients will use medications to treat CFS. But, if you are a patient, I hope you will also explore how you can help yourself by changing how you live with your illness.