

*Faces of CFS*  
*Case Histories of*  
*Chronic Fatigue Syndrome*

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**Cover Design: Zachariah Lieberman**

**Dedicated to  
Dr. Elaine DeFreitas**

Her friendship, scientific work, discoveries,  
compassion, and continuing aid to those  
with chronic fatigue syndrome

**Dedicated to the Memory of  
Skye Kristina Dailor  
January 28, 1976 - September 12, 1990**



## Forward

There are many persons who have helped me greatly with this manuscript and to whom I am grateful. Firstly to Elaine and Tom, friends and colleagues, whose contributions to the study of CFS have been largely ignored. To David Lieberman whose friendship and insights have been invaluable; particularly the technical discussion at the all night supermarket where we argued adrenergic receptor hypersensitivity to the amazement of the check out people. To my friends Jean Pollard, Paula Corser, and Debbie Schmitt who keep me functioning during my day job and encourage me in my writing hobby. And to the many people who have helped me with the manuscript: Hillary Johnson, Beth Schuman, Jill Booth, Mary Robinson, and others. And mostly to my patients, some of whom have permitted me to invade their privacy and relate their stories. And to all my other CFS patients, all of whom have their own important stories to tell. I have learned so much from them, particularly from their courage to persist despite this illness.

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## Introduction

Clinical descriptions of diseases have a way of protecting those of us who are doctors from the intensity of suffering our patients actually experience. I have always wished that doctors could learn about disease directly from patients, but a rift has long existed between the patient and the “objective” physician. Personal accounts of illness mean little to the modern clinician. Doctors consider personal stories and testimonials to be virtually meaningless, the subject of waiting room magazines, not medical literature. If pain or fatigue, for instance, cannot be proven, it can hardly exist, although some doctors generously concede that pain or fatigue may exist as an imagined, or perceived, reality.

Chronic fatigue syndrome (CFS) is more than just a clinically interesting phenomenon. It is also more than fatigue, or daily headache, or the constant feeling of having the flu. It is even more than the crushed hopes and dreams that inevitably accompany any chronic illness. It is human

suffering compounded by the skepticism of doctors, friends, and, often, family. Because the precise mechanisms of the disease - it's nature, so to speak - are not yet fully understood, the medical establishment has yet to accept its reality as a bona fide illness.

I would be happy if CFS were like leprosy or smallpox, or any other malady that is easy to describe according to color, size, and shape of lesion; the ravages of the illness photographed for medical journals. But CFS sufferers rarely come to their doctors with visible wounds. Moreover, CFS, like many of the most severe chronic illnesses, integrates itself deeply into it's victim's physical and emotional being to the degree that merely describing the array of symptoms is inadequate. Worse than inadequate - such descriptions create a false perception of the disease.

It's hardly an exaggeration to say that the controversy surrounding CFS stems primarily from the reluctance of doctors and scientists to look below the surface of a name. The by-now well

accepted term, “chronic fatigue syndrome,” given to the disease in 1988 by the federal Centers for Disease Control and has taken root in our society, but is highly misleading. In part because the mental and emotional exhaustion of CFS goes far beyond our common understanding of the word “fatigue.” Since we all - even doctors - experience fatigue, we assume CFS must be a modest variation of normal, even perhaps some neurotic quirk peculiar to hard driving Yuppies. I hear the comment from skeptics among my colleagues, “I’m tired all the time, too....” Few of them really understand that the fatigue in CFS is not *that* kind of tired. The fatigue of CFS is so different, it is off the scale; it departs from universal experience of fatigue so much, the term does not apply.

I have spent a good deal of time thinking about ways to explain a patient's experience of this illness to the ivory tower academic doctors who rarely see patients, or to busy clinicians, most of whom can allot ten minutes or less to each patient. I wonder what I might say to these physicians, even if they

were to listen, that would convince them that CFS is a real disease.

My most obvious option would be to find an aspect of the disease that healthy people never experience, some symptom that would separate the suffering of CFS from the every day suffering of humanity, a symptom that had nothing to do with fatigue.

Lymph node tenderness could be one such aspect, as could vertigo, or dizziness, sensitivity to light, numbness in hands, feet, or face. But, this wouldn't work. These symptoms do not make the illness wholly unique, because otherwise healthy people experience some of these symptoms on occasion, and because some of the symptoms are present in other diseases, and as well.

In fact, many of the most prominent symptoms of CFS are seen in several other debilitating chronic diseases. What makes CFS significantly different - what defines the illness - is its astonishing litany of often ordinary symptoms that are simply out of proportion. Unfortunately, this issue of proportion, of medical extremes, is precisely what makes CFS

such a difficult illness for medical science to come to grips with. If, as doctors, we can come to an understanding and acceptance of the reality of CFS, however, that knowledge may lead to a better understanding of several other diseases such as migraine, irritable bowel syndrome, multiple chemical sensitivity syndrome; diseases that are definitely real but have symptoms that are difficult to measure with our current medical technology.

At bottom, in order for doctors to fully comprehend CFS, they are going to have to understand the complex mechanisms of brain physiology. That's because, for those who have studied the disease for many years, it is apparent that the most serious issue in CFS is a kind of brain malfunction that may be caused by an infectious agent, or some other source that is, so far, poorly understood. But for most practitioners who can barely keep up with their schedules, it is vastly easier to dismiss an illness as imaginary than to grapple with brain physiology.

Initially, I saw CFS as a simple, straightforward illness that could be defined by its symptoms. I

listened to several hundred people in my town describe something that was affecting them, and the descriptions of their symptoms were virtually identical. In my nine years of medical training, I had never heard of an illness quite like this one.

Sadly, most doctors have been reluctant to put aside their passion for lab tests and simply listen to their patients with CFS. When the illness began to be prominent in the population during the early to middle-1980s, doctors were perplexed because all the simple blood tests they ordered on these patients turned out to be normal. When doctors saw the normal results, disbelief took root. Now, with the passage of years, well-documented laboratory abnormalities abound in CFS, but skepticism somehow persists.

The descriptions of the disease given me by my patients - people who are able to articulate with some precision exactly what they are experiencing - has solidified my belief in the reality of what the government calls chronic fatigue syndrome. These consistent descriptions have come from people with

no reason to fabricate a complex illness. Frequently, my patients have inadvertently offered insights into the meaning or importance of a specific symptom, providing a defining principle that seemed to apply to all patients with this illness.

A few of these defining principles became obvious fairly quickly. Both men and women had the same pattern of symptoms, for instance. If someone were to suggest that only women developed CFS, I could see the faces of Martin, William, and other men, and know this suggestion was dead wrong. Both adults and children were affected, another defining principle. I would see the faces of thirty or forty children - all of whom are now adults - and know that children, too, got this terrible disease. In short, the people I saw every day over a period of years defined the illness for me. Importantly, it wasn't the other way around.

My understanding of CFS is really no more than the sum of these and several other principles I have learned over the years. What follows is my attempt to tell the stories my patients have told to me, the

stories that provided my understanding of CFS, the principles that define the illness.

Describing the suffering of my patients comes close to violating their privacy. For this reason, I have changed names, dates, and irrelevant details. Again, it's the defining principles of an illness that I am seeking to impart here, and for that reason I have in some cases used composite characters in order to best illustrate the principles. They constitute the clinical entity that is chronic fatigue syndrome, and moreover, offer important clues to its pathophysiology - its natural course in the body.

The case histories that follow may seem disparate initially. However, when I see the faces of these people in my mind's eye, I see the many threads that tie each of them to the diagnosis of CFS. I see the shared, defining details of an illness - details that are woven into a common fabric, but one that is also unique to each person who wears it. Everyone experiences chronic disease in their own way, bringing to their ordeal their own particular methods of coping emotionally and practically.

As a group, CFS patients have something vast in scope and vitally important to teach all of us. Doctors, in particular, who are unfamiliar with the faces of CFS, will never really understand the disease from reading a scientific article. They can, however, learn a great deal from simply talking with someone who suffers from it. By allowing me to tell their stories, my patients may help me to teach a dangerously complacent public about this complex and important disease.

## **Outbreak in Lyndonville**

Lyndonville, NY. was a dream come true. My wife and I had struggled through medical school in Boston, then years of post graduate training in other big cities. We specialized, as all up-and-coming doctors do, because we shared the trainee's perception that to be a good doctor, it is important to be narrow and confined to a particular specialty. I spent five years undergoing training in pediatrics. During two of those years, I sub-specialized in pediatric chronic disease and family therapy. However, there was one little detail that our teachers never told us: if you sub-specialize you get very good at what you are doing but you are also confining yourself to a lifetime of working in inner city teaching hospitals. I think I hate the city.

Lyndonville was the first truly rural area I had ever lived in. I quickly realized that the people were unusually kind and refreshingly straightforward in their manner. In the first weeks after we moved into our decrepit farmhouse, welcoming neighbors from all over brought us vegetables from their gardens,

apples from the many fruit orchards, and the occasional homemade cherry pie. In the beginning, we avoided mentioning to anyone that we were both doctors. We needed time to paint our house, fix its plumbing, and figure out what to do with our lives.

In October of that first year, our money ran out, and I had to get a job. I did not have the \$100.00 you needed then to get a medical license in New York State. In order to earn the money I needed, I picked apples along with the migrant workers who labor every year in the fruit orchards of Orleans County. I can report, even today, that picking apples was the best job I've ever had. After my first year in Lyndonville, the thought of going back to the big city was out of the question.

The demand for subspecialists of any stripe in rural communities is minimal when there isn't even a general practitioner in town. So, I thought: what the hell - I would practice general medicine. I rented a tiny building on Main Street, a former pizza parlor, and started to fix it up. My first patient crawled into the office late one night while I was painting the

walls. I mean she literally crawled in, and collapsed. She was covered with a hemorrhagic rash that signified a bleeding disorder. The ambulance arrived, she got to the hospital, and she recovered.

It took me two weeks to recover. No one had ever crawled into my office during my training in the city. They either saw their family doctor, or went to the emergency ward. Because I was a specialist-in-training, I would see them after someone else had diagnosed them, and the drama had passed. I discovered in Lyndonville that the old fashioned family doctor, the one the specialists always make fun of, saw the real action. So this was rural medicine, I realized a simple and primitive concept, with something approaching wonderment, that medical school never taught me: sick patients needed care. I almost packed my bags and left. I had never actually been required to be a doctor before.

In the beginning, upstate New York seemed like the end of the world. Rochester and Buffalo were an hour away in either direction. Choppy waters from Lake Ontario lapped a shoreline that was just barely

past my front lawn, an old apple orchard. The drama of thunderstorms ripping across the lake took my breath away. Every time I turned around outside our old farmhouse I would discover some new wonder - like blueberries. I had thought those old, sagging bushes were of no consequence. That first summer, I overdosed on blueberries and raspberries, too, but there was always plenty left over for the birds. Coyotes howled at the tree line in the evenings, although you never saw them. In the winter you could follow their tracks in the snow, but it was abundantly apparent that they didn't like us very much. The nighttime sky was littered with stars, stars so bright you could take a walk on a moonless night. I had never seen so many stars. Did you know that stars really do twinkle? I hadn't known that until our move to Lyndonville.

The winters challenged us. On windy nights that first year, the temperature inside the house rarely rose above 45 degrees. We had a wood stove because the furnace wasn't very good. It turns out that the farmer who had lived there before us had not considered insulating the walls. The structure

was big and drafty. In November, we had a chimney fire, and when I called the fire department I had to first call the long distance directory operator to get the number. When my call got through, all our neighbors in the volunteer fire department rushed to our house and the flames were quickly doused. It was an unnerving way to meet many of our neighbors. They stayed and had coffee.

My practice was wonderful - slow enough that I was able to chat with my patients, and learn about their day to day existence, including their work and their families. That may seem unimportant, but I think it is the only way to really understand a person's medical complaints. I aligned my treatment with the particulars of their lives. I realized their medical problems were part of a larger pattern, one more complex than isolated symptoms on a medical chart. When Mr. Smith told me he had a cold, I knew he was really sick; Mr. Smith didn't come in for little stuff. In Lyndonville, I began to learn a new type of medicine: I began to learn that it is important to understand the environment of an

illness when you treat the patient who suffers from it.

This is really no big deal. It's a fundamental matter that all rural doctors acquire with enough experience, but it's not taught in medical schools because the teachers there are all specialists in narrow fields. They really know little about their patients. To doctors in urban medical centers, the notion of a house call is a relic of nineteenth century medicine; I think they assume house calls ended in the last century. In cities, patients are evaluated in the sterility of the hospital setting, and they put on their "good citizen" faces. In the country, patients have the luxury of being themselves. Sometimes it isn't always good for their health, but at least they are honest. In the city, I think people lie about their smoking habits and low cholesterol diets.

Five years passed in Lyndonville, the best of my life. In those years, I learned something invaluable: I learned how to be a doctor. I worked hard and, in time, I knew my patients well. Then, on a day when an early snow fell and enveloped the region in

white, one of my young patients in town fell ill with the flu. Shortly afterward, her two sisters and a few neighbors came down what with seemed to be the same bug. Nothing much, I remember thinking. At least, it looked like a standard flu.

One of the sick children had an enlarged spleen, so I ran a test for mononucleosis, one of the infectious illnesses that can cause swelling of the spleen. The results were negative. I confess that, initially, I paid little attention to the matter because these were tough kids and I was confident they would get better. Except, they didn't. And their disease wasn't flu at all. It was the start of an outbreak of CFS in Lyndonville and surrounding regions.

Several months passed without improvement in any of my young patients. They had fevers, malaise (that sick, achy-like tiredness), pain in their joints, and headaches. In time, my adult patients began to come in with the same constellation of symptoms - symptoms of a severe flu, one that just wouldn't go away. When the large spleen I had felt in the first child began to return to normal, I rejoiced. But her

lymph nodes remained swollen, and stayed that way for nearly a year. A constant in each patient was their profound exhaustion, a fact that I ignored at first, since everyone with the flu feels exhausted. But this exhaustion lingered, and eventually, began to dominate the other symptoms. The children were unable to attend school that year, nor could the adults return to work. The patients were, in effect, completely disabled. Something was terribly wrong.

My wife, Karen, and I began to study these patients intensively. We tested them for tuberculosis, yersinosis, Ehrlichea, and even Q fever, rare diseases not normally searched for. Staff people in the laboratory at the local hospital were bewildered, as well as annoyed, because we asked them to perform tests they had never even heard of. For the first time in my life, I read a voluminous medical textbook on infectious diseases from cover to cover, searching for an infectious agent that could explain this seemingly intractable disease. Within months, in our little region, there were more than a hundred people who were sick.

In an attempt to make sense of the malady, I compiled an elaborately detailed list of symptoms I had observed in the first one-hundred patients I had seen. By 1987, two years later, 214 people, adults and children, were ill with the “Lyndonville mono” - as we were calling it then - within a fifty mile radius of my clinic.

Epidemics are outbreaks of a particular disease that occur at a rate far higher than would be expected. To qualify as a bona fide epidemic, all the cases must be relatively close in time, and localized geographically, as well. To this day, the Centers for Disease Control in Atlanta, a federal agency charged with monitoring and controlling the spread of infectious diseases, has never evaluated this worrisome outbreak in Lyndonville and the surrounding region. At first, my wife and I called staff in Atlanta and discussed the outbreak. We described what we had observed, offered our shaky theories, and waited for the disease detectives in Atlanta to help us figure out just what had leveled so many of our patients, young and old. The federal scientists ran a few Yersinosis tests (an obscure

infection) for us using blood we sent to them from our patients, which were negative. Next, they suggested that we perform lymph node biopsies on the earliest victims, the children from two families who had become ill soon after that early snowfall the year before. The federal investigators suggested to us that if the biopsies failed to give us a clear result, they would come to town and study the outbreak.

Lymph node biopsies are not much fun; it requires surgically opening the skin and removing the lymph node tissue. With an effort, we created a little lymph node biopsy assembly line. Six children queued up and, one by one, submitted to the painful and frightening procedure whereby surgeons took lymph nodes from their armpits.

While these children were in the hospital for these operations, I noticed another child across the hall who had been admitted by a doctor from a neighboring town. This child had been suffering from fevers, an enlarged spleen, and disabling exhaustion for weeks. He was in the hospital for

tests, too. One of the remarkable ironies of this illness that the doctors could not diagnose: The boy's parents quickly saw that he had the same illness as the children we were treating. He was still sick two years later.

All the lymph node biopsies were negative for known illnesses. Over the years, in collaboration with other scientists, I have continued to do tests on the children's lymph node tissue that we preserved in paraffin, and I have almost run out of tissue. I still have a small, secret stash, however. One day, when the cause of this disease is known, I will be able to see if the pathogen was present in the lymph nodes of these children when they fell ill in 1985.

Scientific investigators from the Centers for Disease Control chose not to come to Lyndonville after the lymph node biopsies were completed. Instead, they left the outbreak in the hands of the state health department, but the state failed to investigate, as well. My wife and I got the powerful sense that both state and federal health officials thought our outbreak of disease in Lyndonville was all hooey.

Hillary Johnson outlined those awful days in her elegant book, Osler's Web, a historical narrative of several outbreaks of CFS around the world during the 1980s.

The children of Lyndonville, and especially their parents, hold a bit of a grudge against the Atlanta-based health agency for its failure to help us. I reign in my temper by telling myself that, even if they had come, the government scientists would not have been unable to solve the puzzle of CFS. I continue to believe, however, that they could have made one worthy contribution: they could have prevented the skepticism that now rules supreme in the medical profession at large. All they needed to do was admit, "Yes, these people are ill." That's all. But that opportunity has vanished, and the entire nation lingers in a kind of paralyzing doubt and skepticism that cripples any concerted research effort into this disease.

Even now, I find there is just one thing for which I cannot forgive the CDC, however. The same government scientists I was talking to in 1985 were

also discussing a strange form of suspected mononucleosis in Incline Village, Nevada with internal medicine specialists Dan Peterson and Paul Cheney. These two doctors were struggling with what clearly sounded like the same illness at the same time in a small town 3,000 miles away. At the time, Peterson and Cheney were seeking to persuade scientists at the Centers for Disease Control, who had sent investigators to look into the Incline Village outbreak, that the malady affecting approximately two out of every one-hundred people in their region could have been related to mono. The virus that causes mono is called Epstein-Barr virus, and many of the Nevada patients had evidence of being infected with it. But Epstein-Barr is one of the viruses that can linger in a person apparently without causing damage, and we now believe that it has little to do with causing CFS.

I, too, had looked at the possibility that Epstein-Barr virus could be the cause of the outbreak in Lyndonville, but because half of the sick children had tested negative for the virus, I threw out the idea. But I would have loved to know that someone

else in the country was studying this clinical illness. We could have shared notes, come up with better ideas....It would have been so helpful, if only the CDC scientist had said, “By the way, you might want to call....”

More than a decade has passed, and it is now the turn of the century. My children complain that I have grown old and cranky. The “Yuppie flu” publicity of the Eighties has passed, of course, but that was something that never even affected us here. There aren’t any Yuppies in Orleans County - we live in one of the poorest counties in all of New York State. The sensational, if superficial, talk shows about the disease came and went, too. I was invited to appear on Good Morning America; the interviewer gave me ninety seconds to explain chronic fatigue syndrome.

There has been some scientific progress, of course, but it has not yet resulted in effective or curative treatments to my patients in Lyndonville. Perhaps treatments will soon come from the studies showing abnormal immune function, hormone function, or

decreased brain blood flow. But the scientific progress is slow. And clinicians who see patients every day are impatient.

Lyndonville has not changed much. The winters are still harsh, the summer gardens still produce far too many zucchinis. I planted a big garden this summer and it was a wonderful experience. I now understand why farmers keep their shotguns handy. I may have to take bold action against the zucchinis that are marching toward the house. Many of the things I have done with my life confuse me. I hate zucchini, for instance. I have no idea of why I planted them in the first place.

Several of those first young patients have recovered. Overall, about 80 percent of them are leading productive lives, although some of them still have more symptoms that they would like. They have tried to put their ordeal behind them. Sadly, they have learned not to mention their years of illness to anyone, particularly doctors. There exists a strange kind of medical discrimination against patients with CFS. If they sprain their ankle, for instance, doctors

will think its psychosomatic if they had mentioned CFS. Perhaps it would be considered the excessive complaint of a wimp.

At least twenty percent of the original two-hundred and fourteen patients remain ill, and some of them are bed-ridden. For them, the hope of living a normal life once more has nearly vanished. Fortunately, there have been only a few suicides in my practice, but the suicide rate among people with CFS may be quite high. Like many other important areas, it has not been studied.

Nearly every patient with CFS thinks of suicide at one time or another, but rarely can the impulse be blamed exclusively on mere physical pain and disability. I have discovered that most people learn to tolerate those things, particularly the tough breed of people who live out in the country. Instead, CFS sufferers are driven to suicide by loneliness and self-doubt, which arrive part and parcel with the disease itself. Although they are ill with a debilitating flu-like illness every day of their lives, neighbors and even friends and family insist they

look “just fine.” It’s an unfortunate fact that our culture has yet to accept the harsh reality of chronic disease; often, its ravages are invisible to the naked eye. But CFS carries a terrible stigma, the burden of which weighs more heavily on them even than the burdens borne by most victims of chronic disease. The world seems to believe that people with CFS - a population the medical profession has yet to stamp with its imprimatur of “bona fide” - could “snap out of it” if they really wanted to. This utterly false perception of the disease is so widespread that, eventually, most patients with CFS, especially those who become increasingly isolated, have periods when they begin to suspect: "maybe I am just crazy".

And the symptoms persist, year after year, eating away at self-confidence, hope for recovery, and the very foundations of personality. The luckiest patients learn to make peace with their illness, and develop immunity to the snide innuendoes and skepticism that follow them everywhere. But not every patient can reach within themselves and find that degree of strength.

Research into CFS creeps along at a pace commensurate with the pace of the tiny insects nibbling at my zucchinis. New studies that show abnormalities in immunology, brain hormones and brain blood flow go unnoticed. Doctors, like the public, need explanations to be simple, they need a “sound bite,” something that can be explained in ninety seconds on Good Morning America.

In addition, the years of controversy have worn down peoples’ interest in CFS. The disease did not turn out to be simple--like Legionnaire’s, or Hanta virus. Even worse, because of the long-standing controversy over CFS, medical journal editors are reluctant to publish treatment studies on the disease, no matter how sound the research. Doctors, and the public at large, will become interested again if a cause is found for CFS. Until then, new treatments can ease symptoms, but few doctors ever hear of them.

I continue to see a great many CFS patients in my practice. Sadly, I find it exceedingly difficult today

to help such patients meet even their most basic needs. The country is in the grip of health maintenance organizations, and HMOs are loathe to perform studies, or even dispense medications, for CFS sufferers. They have little interest in finding out whether CFS is real or imaginary - they just don't want to spend any money on it. HMOs sound really great until you get sick. Yesterday, I argued for half an hour with a twenty-year-old HMO employee who had no medical training whatsoever about whether a patient of mine should have a CAT scan. I think my children are correct: I am getting old and cranky.

Still, I cling to a vestige of medicine that lingers in the memories of elderly physicians - that long-ago era when a doctor was responsible for providing medical care for his patient. In the days before CAT scans and MRIs, when a patient had an illness that defied simple explanation, the doctor studied the problem. When two-hundred and fourteen people have the same illness in a tiny, rural community, I believe a doctor has an obligation to do something about it.

Sometimes, I feel I'm losing the battle. Medicine has moved from an epoch of bold scientific curiosity in the early and middle decades of this century to a period in which money-minded bureaucrats dominate and possibly even retard scientific progress. The modern doctor fills out insurance forms, writes letters that allow little Johnnie to take Tylenol in school, and tries exceedingly hard not to get sued. It makes little sense to me; the caterpillars in my garden do not touch the zucchinis. Both of these events defy logic.

At the risk of sounding overly pessimistic, I must confess that I believe we may have reached the low point in the discovery process that attends this illness. Just last year, a shocking article appeared in a widely read medical journal, *The Annals of Internal Medicine*, that seemed to turn back history. The authors argued that all somatic illnesses, those without a clear explanation of cause, are fake. Such diseases, these psychiatrists argued, are little more than the expressions of unhappy people who are desperate for attention. The authors further stated

that doctors who appear to be “sympathetic” to such patients only encourage these bogus maladies to persist.

I don't know if these psychiatrists had me in mind, but I certainly confess to being sympathetic to my patients with CFS. I don't think they are staying sick just for me, or anyone else, for that matter; they are not stupid. The few doctors who are willing to see CFS patients from day to day, who understand CFS is not a trivial disease, try to find ways to relieve their patients' symptoms, just as doctors are taught to do in training. No doctor I know wants his diabetic patient to stay in poor control of his diabetes, for instance.

Life goes on. And I have always been optimistic about one particular matter: I have always felt that the hard science of CFS will reveal itself given enough time. I am convinced that this disease is the result of a discrete abnormality, a medical aberration that will eventually be defined and understood. But something unique - a specific infection, perhaps an abnormal enzyme or gene. I'm

sorry to break the news, but after more than a decade of studying this devastating disease in several hundred living patients, I can report that CFS is not a psychosomatic illness dreamed up by wimps. There are very few wimps in our town.

In 1950, an epidemic of disease swept through the Royal Free Hospital in London. This epidemic ended the careers of a great many doctors, nurses, and other medical staff who fell ill that year. Careful study of the history of the Royal Free outbreak has revealed that it is identical to the disease our federal health agencies currently call CFS. Several years after this outbreak occurred, however, one psychiatrist wrote that the Royal Free outbreak was just an instance of mass hysteria. This psychiatrist had not been present during the outbreak, nor did he actually interview the people who fell ill. But his opinion of the Royal Free epidemic stuck. In the annals of medicine, it is assumed that the Royal Free outbreak was fake; it never happened. Personally, I feel it defies logic to think that the doctors and nurses who fell ill and subsequently were unable to return to work at the

Royal Free Hospital were just trying to get attention.

## **The Private Detective**

Many who suffer from CFS experience a period of relief at some point in their day. The most severe symptoms seem to ease, and a window opens through which a few rays of sunlight pour into their life. During this period, patients are able to undertake some of the activities that are ordinarily too difficult to manage. For an unlucky few, the shades are drawn and no window exists, or it is very short. But the majority of people with CFS will have one, two, maybe even three, hours during which the window opens, and activity is possible, before total disability claims them again, stealing hope for at least another day.

This “window” of activity is such a common feature of CFS, I have found that I can actually grade the severity of a patient’s case based on the degree of energy a patient experiences during this window. In fact, I believe that its duration on any given day, over a period of months, can predict the likelihood of recovery from CFS.

CFS patients are as impatient as anyone else would be in the same predicament. They have job commitments to fulfill, families to nurture, life to live. When the ravages of the illness wipe out the majority of time available to them each day, they struggle to make the most of their hour or two of improved health. Most CFS sufferers live for this window of time, and typically they will try to accomplish as much as possible when it opens, even though they have learned through experience that any exertion will make them feel even worse when the window closes again. Nevertheless, I have observed that most patients prefer to fly for two hours and then “crash and burn” afterward rather than stay within the confines of the hangar. Eventually, this precious window becomes their life, but their exploitation of it can be dangerous – although not necessarily dangerous to their health. It certainly got Richard Watkins in a lot of trouble.

Richard was destined to be a Lyndonville lifer, constrained by either fate or good fortune to experience life in the comfort of upstate New York. While some young people curse such a fate, and

compare it to being born in the Third World, Richard accepted it gracefully and thrived in the rural atmosphere. In high school, he struggled with Mrs. Carson's English class, but excelled in Mr. Osgood's science class. It helped that Mr. Osgood was also the basketball coach. Richard was competitive and had the good fortune to be tall and very strong. It was rumored that Richard's science grades would have been somewhat less stellar had his athletic prowess been less remarkable.

Richard lived for baseball in the summer and basketball in the winter, as did most of his friends. School work was the obligatory drudgery that afforded him his time on the field or the court. Perhaps not surprisingly, college was a disappointment; academic knowledge for its own sake made little sense to Richard. Eager to get on with life, he paid scant attention to his advisors' counsel to carefully lay out a plan for the next several decades. Instead, he fell in love, married a bright, beautiful girl from a nearby town, and jumped at the first good job he could find: a post at Rochester Plastics. The job required hard labor, but

it also promised opportunities for advancement into management over time. Richard's life was not merely perfect, it was fun. Then, four years after he began work at Rochester Plastics, he developed CFS.

One day he caught the flu. It seemed like your ordinary garden variety flu, probably the same one his cousin and wife had caught at the same time. Richard didn't even come to see me to seek treatment for his fever, chills, sore throat, and aching muscles. He knew what I would say: "Aspirin, fluids, and bed rest." (I hate it when people know what I am going to say, but they are usually correct.) Anyway, Richard felt he could take a few days off to recover; his work record was perfect.

Curiously, this flu failed to resolve in the expected week's time. Two weeks later, I ordered the routine blood tests, all the while not really expecting to find any dramatic abnormality, and I prescribed an antibiotic. I thought the flu might have turned into a sinus infection. The fever subsided, the chills and

sore throat receded to the background, but the exhaustion grew more intense. In addition, headaches and stomach pain joined muscle and joint pain, and he developed an intense sensitivity to bright light. I felt it was time to take a harder look. I ordered more tests: mono, unusual infections like Cytomegalovirus and parvovirus, and tests for thyroid inflammation or new onset arthritis. The tests all came back as “normal.”

Two months later, I was very concerned. Richard had been a vigorous, healthy young man; he should have bounced back by then. After assuring him I was only doing my job, I inquired about HIV infection risk factors, and urged him to sign on the dotted line, permitting me to order a test for AIDS. Richard signed, but that test was negative, too. Perhaps, the problem was heavy metal poisoning, I mused; after all, he worked with nasty chemicals on the job site. Again, the tests were negative. I wondered if he had been affected by insecticide sprays from the nearby farm fields, but no evidence of poisoning turned up. Finally, I sent him to the real doctors in the city.

After six months, hundreds of tests, and three doctors, someone said Richard probably had Epstein-Barr. Richard thought Epstein-Barr was Epstein's Bar, some long-forgotten roadside joint where he might have picked up food poisoning, or worse. I explained that Epstein-Barr was the virus known to cause infectious mononucleosis, but I had my doubts about the diagnosis. Richard's antibody levels to the virus, one measure of a person's degree of infection, didn't seem very high to me. Still, at least mono was a diagnosis, and that was necessary now.

It is hard for a patient to be sick. It is harder still to feel ill and not know what is causing the illness. The added stress and anxiety increase discomfort. Naturally, a patient's thoughts turn to cancer, most people have heard of a relative in whom a cancer lingered without being found. With these thoughts, fear begins to grow, and discomfort increases dramatically. The doctor will reassure the patient that it is not cancer, but this is hardly comforting since the doctor has no idea of what is causing the

illness in the first place. Actually, the problem with cancer is that it is usually silent in the first stages, which is why it is so difficult to find. Whatever was causing Richard's illness was not silent, it screamed many symptoms.

With the diagnosis of mono, Richard was still ill, but he could relax. "It" had a name. It was a wrong name, granted, but at least it allowed him to recognize the enemy. He could begin to separate what was due to his own fear and what was due to illness. Over the next few months, other tests on Epstein Barr virus were run, as it had become clear that this was not the typical mono that would resolve in six weeks. Eventually, the diagnosis was changed to chronic fatigue syndrome, CFS.

An entire year passed, a year during which Richard was unable to go to work at Rochester Plastics. The early flu-like symptoms had remained remarkably constant, but he had new ones, too. He had difficulty concentrating – a sensation he described as a kind of "brain fog," and numbness and tingling sensations in his arms and legs. Those symptoms

came and went, but one symptom was intractable: crushing fatigue. It was not tiredness, not even exhaustion. It was the sick exhaustion of the flu. He would attempt to get up from his bed and move around, even go to work for a day or two, but the fatigue would end up knocking him flat again. Eventually, Rochester Plastics put him on short-term disability leave. Every month, I sent a slip to Rochester Plastics promising the company that Richard would be back to work soon, hoping for the best. All those broken promises led Richard just one place: long term disability leave.

Richard spent his days lying on his couch, watching TV, and talking on the phone. For him, the unbidden lassitude was torture. There would be no summer softball league, no deer hunting in the fall, no winter basketball in the gym. Inevitably, whenever Richard tried to shake himself out of his confinement and try to play a sport, the result was always the same: he would be flattened, and with even more muscle pain and exhaustion than before.

Two years passed. Richard's symptoms weren't getting any worse, and some of them were even beginning to slack off. In my efforts to help, I had prescribed antibiotics, antidepressants, and stimulants. Richard himself explored every conceivable homeopathic option, without appreciable results. I was unable to persuade myself that any of the medications I had prescribed had made a difference, either. It seemed to me that Richard was beginning to get better on his own.

By then, his level of activity during any given day hovered at around forty percent of what would have been normal for him. At the start of his illness, I measured Richard's activity level at about twenty percent. Defining a person's activity level in a scientific manner can be complicated, but not impossible. In 1988, two researchers performed a study in which they asked subjects to keep a detailed daily diary in order to calculate the amount of energy expended for every activity. There is a small amount of energy expended for sleep, more for playing the piano, still more for swimming. Using their method, I might have calculated

scientifically Richard's daily caloric expenditure and come to some highly specific conclusions about his activity levels. But the method is tedious, and I have found CFS patients to be highly accurate and consistent in their estimation of the daily activities pre- and post-CFS. It has always turned out that their own estimates are just as good as the time-consuming scientific measures. Not as fancy, but as reliable over the long term.

In the day's early hours, Richard was rarely able to do more than brush his teeth or drink some juice. His mornings were spent on the couch. "I have been eaten by the couch," he would say. Of course, he wanted to be active every day – but his body refused to respond to his will. Except at two in the afternoon. It was the time when dead muscles seemed to come to life and his brain cleared a little, the period when he did not feel, in his own words, "like a bag of garbage," some invisible infusion of energy got him up and moving around his house, at first tentatively. An hour or two later, he would say, "The plug has been pulled." He could feel the exact moment when the energy source was cut.

When I evaluate CFS patients for their degree of activity over periods of weeks and months, it is apparent to me that they are afforded a relatively constant amount of time each day during which they can stand, walk, and function in a fairly normal manner. Over the short term, however, say over two days, there can often be a surprising degree of fluctuation. Much of the present confusion about CFS is probably generated by this characteristic spurt of increased energy patients experience for extremely brief periods during the frequently years-long course of their illness. In our culture, which rarely examines the day to day reality of chronic (as opposed to acute) disease, you are either sick, or you are well. There can be no fluctuation, no middle ground. If your neighbor sees you at the grocery store, she assumes you're always well enough to shop. She doesn't celebrate the fact that you have managed to dress, put the car into gear, and find your way to the dairy case; nor does she rue the fact that when you return home, you may lack the strength to take the groceries out of their

bags and put them away. The matter is beyond her realm of experience and education.

By the time Richard had been ill for two years, and he had begun to feel well enough in the early afternoons for an hour or two of activity, he was eager to go out into the world. When you have only about 20 percent of your normal energy level most of the time, an hour or two at 80 percent seems very good indeed. Of course, despite his long illness, Richard looked completely normal to casual observers, and when neighbors noticed him outside his house, they assumed he had recovered fully. His wife Jamie, in contrast, knew Richard well enough to notice consistent changes in skin tone and facial expression that heralded the moment when Richard's energy would drain out of him. She described a lifeless expression in his eyes and a gray skin pallor, a color that was almost corpse-like. These changes were too subtle for me to see, but Jamie, like most spouses who know their partners well, was a good observer. I wondered if these marked changes in expression and skin tone would offer insights into the disease itself.

Richard encountered the kind of resistance faced by every CFS sufferer when he tried to obtain full-time disability support from his company. By then, CFS had become a controversial illness, even a notorious one. One side of the debate held that sufferers were either hypochondriacs, neurotics, or scam artists. Perhaps not surprisingly, Richard's company was reluctant to help. I vouched for Richard's honesty and the severity of his illness, but I found it difficult to answer many of the questions posed by the company's disability forms; they simply weren't designed for a disease as complex as CFS.

Most disabilities are fixed or immutable, involving the loss of function of an eye or limb. A typical disability form will ask the doctor, "How many pounds can applicant lift with left hand?" Technically, Richard could still lift forty pounds. He was not confined to a wheelchair, he did not limp, nor was he blind or deaf. He was none of those things, but he couldn't have worked an eight hour day if his life depended on it. In contrast to Richard's day-to-day health status, the disability

forms from Rochester Plastics were inflexible. At a loss, I finally wrote in the bottom margin, "Mr. Watkins is unable to sustain productive activity for more than three hours a day because of fatigue."

My effort on Richard's behalf seemed to help a bit. Rochester Plastics maintained Richard's disability benefits at least for the time being. But the company was far from happy. In fact, Richard's superiors were certain they were being 'had.'

By the beginning of his third year of CFS, Richard began to improve significantly. The array of symptoms remained unchanged; they were simply less severe. His ability to participate in the daily life of his household was expanding. He now experienced several hours each day, instead of one or two, when he could take a walk, go shopping, and generally feel as if he were a member of the human race once again.

I have always encouraged patients to take full advantage of these fleeting hours of better energy. To this day, I remain uncertain as to whether the

increased movement actually stimulates improvement in some way, or whether a patient's ability to function for some portion of a day is a hallmark of spontaneous improvement. As I typically do with all CFS patients, I encouraged Richard to be as active as possible, whenever he could. For him just being able to go outdoors was a sign that he was not really dying, and might actually be getting better; if nothing else, it was important to his mental health.

Some people read books, some people watch television. Before his illness began, basketball had been Richard's life, an essential ingredient of his existence. It's fair to say he lived on air, water, food, and basketball. And when Richard started getting significantly better in his third year of illness, throwing hoops was the first thing he attempted in those early afternoon hours of heightened energy.

A friend installed a ramp under the basket in Richard's driveway so that the ball would roll back toward Richard after he threw it, saving him a few

extra steps. Richard would stand ten feet from the basket, aim, and put the ball through. Most of the time, the ball bounced right back to him; he didn't even have to move. In this way, he could shoot hoops for longer periods. Occasionally, after a miss, he would jog over and pick up the ball. On such days, in his imagination, he was taking a buzzer shot for the New York Knicks in a tie game with the Celtics, and the crowds at Madison Square Garden were going wild. Then he would walk back into his house and crash on his couch for three hours.

As the months passed, Richard slowly improved. He measured his gains by the strength of his shooting arm, the number of baskets he made in a row, and the total number of minutes he could actually shoot hoops. He had even begun taking some shots from the three point line. There was no doubt that he was getting better. The hoop play was exercise and psychotherapy combined. No medicine I could prescribe would help his physical and mental health like basketball.

That summer in upstate New York had been a beautiful one. It stays light in the evenings until nearly nine in the evening. The wind coming off Lake Ontario was cool and pleasant after work and, like Richard, I loved to play basketball. I am a Celtics fan. I could happily abandon nearly everything else about Boston, but not the Celtics. After a day in my Lyndonville clinic, I would sometimes stop by Richard's house and we would play one-on-one. Even if our game lasted just ten minutes, it was always exciting. The former athlete, still hobbled by CFS, and I were a pretty even match. We played like fourteen year olds, but in slow motion. Not uncommonly, I would limp home with a twisted ankle or a pulled calf muscle.

One day I received a call in my office from a man who wanted to set up an appointment to talk with me about Richard Watkins. I made some time for him the following day. His name was John Armstrong. He was accompanied by a tall, gaunt man with sallow features and decidedly shifty eyes. Armstrong failed to introduce his companion, who stood behind him, his eyes darting from door to

window. This mystery man seemed to have stepped right out of a Fifties gangster film. I thought I could make out a bulge near the armpit of his poorly tailored black suit. I speculated that he was Armstrong's body guard, and that the bulge was a holster. For a town the size of Lyndonville, this was really an exciting development.

Armstrong sat in the chair beside my desk; his companion apparently preferred to stand.

Armstrong fixed me in his gaze and began:

"I am the plant manager of Rochester Plastics. Your patient, Richard Watkins, is one of our employees."

"Okay," I said.

"We have papers, signed by you, that state Mr. Watkins is physically disabled with chronic fatigue syndrome."

"Okay," I said.

Armstrong stared at me accusingly.

“Mr. Purtillo here...” and he paused to look at his partner, “is a private investigator. Our company has hired him to investigate this claim.”

“Okay,” I said.

“We do not think Mr. Watkins is sick. In fact, we have videotape of him playing basketball.” As if on cue, Purtillo, still standing, caught my eye and exposed the corner of a videotape he was carrying in his suitcoat pocket. “Now,” continued Armstrong, “I’m sure you may have been convinced that Mr. Watkins is sick, so I thought you would like to know about this videotape.”

I cleared my throat as I tried to collect my thoughts.

“I am aware that Mr. Watkins has been playing basketball in his backyard,” I said finally. “In fact, I have been playing basketball with him – and on a fairly regular basis. Maybe I’m on that tape,” I added in an attempt at humor that fell flat. “If you

had called me about this, I could have saved you some time and money.”

Armstrong stared at me, his mouth open. If Richard Watkins was well enough to play basketball, he was well enough to work, Armstrong insisted. In turn, I tried to explain the subtleties of a disease that left its victims bed-ridden or couch-ridden twenty-two hours a day, but sometimes allowed them a short period of heightened energy, a period during which they might appear to the uninitiated to be perfectly well. I told Armstrong that although Richard often could shoot hoops with me for as much as thirty minutes at a time, he was still too weak to work eight consecutive hours. I added that, not only was I aware of Richard’s hoop shooting, I had encouraged it as exercise therapy because I had hoped it would hasten his recovery.

My words seemed to make no impression at all. Armstrong really wanted me to look at the tape. I assured him that unless he could show me something other than Richard standing quietly for fifteen or twenty minutes in front of a basketball

hoop with a wooden ramp underneath it, I didn't need to watch the video. I told him, too, that I believed Richard was improving, and that he might be able to return to work within the next six months, as long as Rochester Plastics could offer him a job with flexible hours. Armstrong promised me that the matter would be taken up for discussion – in court.

I have few regrets in my life. To this day, I regret my failure to ask Purtillo the question that still haunts me: how many hours did he have to hide in the bushes behind Richard's house to get his fifteen minute video? The sight of the bulging holster caused me to bite my tongue, however. I remained silent.

Months passed without further word from Armstrong and Purtillo. I filled out yet another disability form from Rochester Plastics on Richard's behalf. Under a section called "current treatment," I noted that I was encouraging physical activity for my patient. Although not every CFS patient can boast of improvement, Richard's return

to health continued. Four months after my encounter with Armstrong and Purtillo, he was able to go back to work half-time, with some modifications in his duties. Six months later, Richard went back to work full-time.

Years have passed and Richard has proven to be one of the lucky CFS sufferers: he has recovered completely. He is not only working, but coaching basketball on the side. Sometimes, on warm summer evenings, Richard and I throw hoops together and, afterward, drink iced tea. I'm kind of sorry that we never had an opportunity to see that video played in court.

## **Anna's Identity**

Where does self end and illness begin? When we are ill for years, or for a lifetime, what part of our personality is really our own, and what part has been shaped or even created by disease? These questions are probably nowhere more pressing than in the realm of brain disease, in which the foundation of the personality - the physical brain itself - is under siege. CFS, of course, presents a particularly difficult challenge to its sufferers because, unlike many brain diseases, CFS leaves the brain intact enough to sense its own difficulties. As a result, people who have CFS are forced to cope not only with unceasing physical pain and exhaustion, but with sorting out their real selves from the demon that has attacked their faculties as well as their body.

Adults have an advantage over children with CFS. Adults have accrued years of personal history; they have a sense of who they are, a personality, against which they may compare their new, unwell selves. Everyone around them may be snickering and

laughing, but the adult with CFS knows he or she is unwell, and that what is happening is anything but normal. Children, on the other hand, lack the requisite life experience and sense of self against which to measure a sudden development like CFS.

I am a pediatrician by training, and I have learned to see the world through the eyes of my youngest patients; I also frequently look into their eyes and see the adult world reflected there. I do not believe I am being disproportionate to state that, for children, CFS is among the very most difficult, if not the most difficult, disease to survive into adulthood. Perhaps the greatest tragedy of CFS in children is that poorly informed adults ascribe a false identity to the child, and that false perception of self is carried by the child into adulthood.

CFS has robbed far too many children of their identities, or more precisely, has robbed them of the chance to develop an identity - to grow into themselves. In the case of at least one patient I know, however, a true perception of self has emerged, despite the odds, but it took thirty-five

years. I am speaking of Anna, who became ill with CFS when she was probably four or five years old.

We often remember of our childhood that which was wonderful and beautiful, but when there has been little joy, memories are dimmer. Anna's memories are cloudy, but she recalls that by the time she was six or seven, she was unable to keep up with her playmates. She could not skip rope because her balance was poor and the slightest exertion left her breathless. The bright sunlight that poured onto the playground left her feeling blinded. She found herself on the sidelines, inexplicably exhausted. Other children seemed to shy away from her.

Anna went to school every day, but she felt sick all the time. She found it difficult to learn skills like reading and math. It was humiliating. She couldn't remember her multiplication tables. Everyone else could, but Anna couldn't. Anna began to devise tricks to help her remember, tricks so complicated she could not have explained them to anyone. For example: eight times seven. Add a zero to a seven,

subtract seven, then subtract another seven. For Anna, visualization was easier than memorizing. She could see numbers in her mind, for instance, and in order to solve the problem, she would look at them. She knew she did not think like other children. The world was a very confusing place.

She had trouble following directions. Her teachers were harsh with her; they believed she was either deliberately ignoring them, or preoccupied with private thoughts. But Anna was simply puzzled and tired. The simple noise of the classroom distracted and perplexed her. It made her ears hurt, too. She had trouble finding words to describe how she felt. She once told her teacher that her brain seemed to “ache” because of the noise, and her teacher dismissed it with a wave of her arm.

“Pooh,” she said, “everything seems to bother you.”

Perhaps Anna’s greatest humiliation was the way her one of her legs would jump without warning, hitting the desk, or even kicking toward the child sitting next to her. Her classmates would burst into

laughter, and her teacher would inevitably become angry, scolding her for being disruptive. Anna had no control over these muscle spasms, but her teacher never believed that. Eventually, Anna learned that if she rested the legs of her desk on top of her feet during class, the weight of the furniture would diminish the force of her jerking legs. The desk was heavy, and hurt her feet, but the technique worked.

Anna wondered why her muscles behaved unlike anyone else's muscles, and why she was unable to memorize facts, and unable to remember what the teacher said to the class from day to day. She wondered why she lacked the energy to run or play games. She struggled to hide these aspects of herself, her deficiencies, from the girls in her class, because like any child she desperately wanted friends. Yet, even though Anna privately wondered every day what was wrong with her, no one believed Anna was sick.

She recalls that during her early adolescence, she was stricken with a remarkable number of sore

throats, fevers, stomach aches, swollen glands, and headaches. As time passed, and she went from child to teenager, her doctor began voicing his opinion that Anna's "illnesses" were an obvious cry for attention. Occasionally, she was hospitalized while a teenager, but the tests ordered by her doctor rarely showed any abnormalities. Her doctor, and eventually, her own parents, began to exhibit increasing frustration.

By the time she was fifteen, no one believed Anna was sick. Her parents' frustration turned to anger. They were poor people, and the medical bills caused by Anna's frequent trips to the doctor were beginning to overwhelm their resources. Eventually, the doctor her parents took her to simply patted her on her head and told her she had a headache every day because she felt badly about doing poorly in school. The doctor told Anna she needed to stop "playing those games."

Anna's response to the anger and disbelief was hardly surprising: she learned not to complain. She recognized that articulation of her sensations of

illness only increased her isolation and actually invited ridicule. She vowed she would hide her symptoms and her feelings however she could from her family, her friends, and her teachers. She even learned to hide these things from herself.

In time, there were two Annas: the one who was sick, and the one who cleaned her room, performed her chores, and attended school every day just like everyone else her age. The first Anna would look at the second with a kind of astonishment; the second Anna was ashamed of the first. Neither Annas found any comfort at school or at home, but they got by.

By the time she became an adult, Anna had hidden her secrets for so long that she barely acknowledged them herself. In fact, by then, she had persuaded herself that her doctors had been right all along: if she had some dreadful illness, she reasoned, her doctors would have identified it, or she would have died. She embraced fully what she had been told throughout her adolescence: she had made up her

symptoms, although her reasons for having done so continued to remain mysterious to herself.

Anna finished high school, married, and began working as an aid in a nursing home. She also had four children. Most of the time, she could keep her secrets hidden, from her husband and children, and even from herself. She was not even being dishonest, because she was in agreement that all the sensations she felt - the weakness, the fatigue, the mental cloudiness - signified nothing at all. There really wasn't anything wrong.

By then, the years of denial had worked their effect; her identity, her sense of herself, had been formed by the opinions of others. The part of her that felt and experienced was shut away from the part that reasoned. She was, she would tell herself, perfectly healthy, but in fact her identity was built on a foundation of silt, and had little to do with Anna's true experience, the reality she lived day-to-day.

By the time she was in her early thirties, Anna skills of self-deception and general deception were finely

honed. She had become a master of covering up embarrassing intellectual gaffes with warm, genuine smiles that would put those around her at ease. No one could be expected to see through her smile to the memory loss, or the peculiar lapses in her speech, lapses in which she would jumble the order of her words in a sentence, or make bizarre mistakes in her choice of words.

She had learned to work despite her daily exhaustion and painful headaches. In fact, she felt weak all the time. But if she had to help lift a patient at the nursing home, she found the strength, proving to herself and the other aids that she was as strong as any of them. Though she often experienced double vision, she never said a word about it to her co-workers. When she stood rapidly, she got lightheaded, and her hands and feet went numb.

She developed a painful stomach condition-- probably an ulcer, she decided. A doctor she consulted prescribed a drug for ulcers, but the pills did nothing to end the pain and Anna quit taking

them. She was disappointed in neither her doctor nor the drugs. Whatever the cause of this particular ailment, she reasoned, it was outside the doctor's reach because, as she knew already, there was really nothing wrong with her. She could get by, she reasoned, just as she had always gotten by. Of course, she never discussed these problems with her fellow workers in the nursing home, and no one around her ever suspected them.

One harsh, upstate New York winter after another passed. Anna acknowledged to herself a certain loneliness, familiar to her from earliest childhood. She had never quite rid herself of that. But her routines were well-established, her coping mechanisms firmly in place, her secrets tucked so deep inside that she barely thought of them. Anna's identity was a fragile construct, however, and vulnerable. One bitter day in March of 1988, it began to break up.

She suffered a seizure while working at the nursing home, an event witnessed by several people. She was taken to a local hospital. When the doctor

informed Anna afterward that she had experienced a seizure, she found it extremely difficult to believe, despite the bite on her lip and the deep gash in her tongue. In fact, she did not believe it - not really. After all, after a lifetime of feeling sick, this was the first doctor who had ever told her with any conviction that she actually was sick. And so she fell back on the opinion of her condition that had been voiced by doctor after doctor from her earliest memories: she was just suffering from a little stress.

When the doctor prescribed medications for seizures, Anna nodded, as if accepting the diagnosis and the treatment. But she did not take the medication. Why should she? She knew there was nothing wrong. There never had been anything wrong.

For three decades, Anna had been able to secret away the ill woman she had been nearly all her life. But things were starting to change. She continued to avoid the prescribed anti-seizure medication, and both her doctor and her husband insisted that she was having convulsions. Anna found their claims

hard to believe. She was unconscious when these so-called seizures were reported to occur; how did she know they were really occurring? It had been a life-long struggle, but Anna had achieved the ability to believe the medical profession, her parents, and her teachers, that nothing was wrong with her. Now her doctors and family were insisting something was wrong. In fact, her doctor arranged for her driver's license to be revoked. Anna couldn't even get to work.

The seizures were exposing the sick side of Anna to herself. They could not be hidden away or covered up with a charming smile and a little joke. The turmoil in her mind was like a hurricane. If she accepted that the seizures were real, she risked opening the long-hidden conflicts about everything concerning her poor health. In short, if the seizures were real, maybe everything else - the exhaustion, the mental foggiess, the numbness in her hands and feet, the pain, the forgetfulness, the endless headache - were real, too.

The bedrock foundations of her assumed identity began to erode. For the first time in years, Anna began to allow herself to acknowledge her physical sensations of fatigue and pain. She realized that she felt awful. But experiencing the pain and exhaustion somehow seemed better than pretending it wasn't there. She answered one question that most people are unable to: is it better to feel suffering than to feel nothing at all?

One day Anna saw a segment on television about CFS. Her mouth hung open as she heard about daily exhaustion, headaches, pain that no one would believe. It was Anna, not a doctor, who recognized at last that her symptoms were characteristic with CFS. In fact, with the exception of seizures, she was picture perfect for the symptom complex that defines the illness.

Anna read everything she could find on the subject. She felt as if she was waking up after lifetime spent cut off from her own feelings and perceptions. She began to remember painful incidents from her childhood - how she had felt, and how she had

learned to deny those sensations not only to those around her but to herself. They were disturbing memories, but Anna, by then thirty-five, was at last beginning to experience her own reality and to recognize herself as she had always been. She was not the healthy, energetic woman she had pretended to be for so long; she was sick.

I met Anna during this period. We talked a lot about these matters in my clinic, and we talked over coffee sometimes in the Tiger's Den Cafe down the street. We both recognized that her identity was in crisis, because she was having trouble distinguishing real illness from false illness. After so many years of believing herself to be "falsely" ill, how could she turn around and be herself? In this, she had no experience.

The perception of pain and illness is very simple from a physiologic standpoint. Primitive animals feel pain in their nerve endings, and struggle to avoid it. Electric probes of one-celled creatures like amoebae show that even these tiniest of organisms feel pain. But advanced creatures, specifically

human beings, have learned mechanisms for denying some of the basics of biology. Nevertheless, our denial hardly changes the mechanical impulses of our nervous systems; our nerve endings continue to be stimulated, and send messages to our brain that are registered as pain or discomfort. Our denial merely creates an emotionally confused response to the pain, or health identity confusion.

Anna's biggest problem, at thirty-five, was her confusion over her health identity. Her confusion had logical origins, but her management of it - to deny her symptoms - put her at risk. She had lost what healthy people would call common sense. Her confusion had cost her the right to drive, and subsequently, her job. She could have controlled her seizures with medication, if only she had been able to believe they were real. But because she had denied her illness for most of her life, she probably would have been hard pressed to believe she was injured if she had been run over by a truck.

As the years passed, Anna gradually began to learn how to feel. She said it was better to feel pain than to feel nothing at all. -It was better to experience the reality of her life, in all its facets, than to deny all of its reality. After decades of pretending, she began to acknowledge to herself the truth of her own experiences, and the place of her identity within those experiences.

I marvel at Anna's courage. She has been one of my teachers in life. And I wonder if I will ever find the same courage to explore the hidden parts of my own soul.

## **The Poison Ivy Treatment**

I had been treating patients in my Lyndonville clinic for ten years when, one day, I happened to pick up the chart of a patient whose name was unfamiliar to me. He was awaiting me in my examining room. I quickly learned that Edwin Maxwell was the man who owned the beautiful farm on the Stillwell road. I had admired this farm every time I passed it on my way to the nearby hospital. The old barns were always maintained with care. I had come to expect an orderly procession of snowdrops, tulips and lilies on tended patches of lawn every spring and summer. I could see that a lovely stream ran through the rear of the property, which looked like a European forest - tidy, but natural, as wonderfully wild as anything could be and still be called a farm.

I also knew whoever tended this farm had a certain mysterious wisdom. If hay had just been cut on the Maxwell farm on a summer day, you could count on three sunny days to follow. Even the weather seemed to respect this farmer; his sixth sense was more reliable than any TV forecast. I observed, as

well, that there was no rush, no great urgency, to this farmer's life. He tended his fields with patience, as if he knew that the earth would unfold its crops the way life unfolds its secrets - all in due time.

I liked the 45-year-old Edwin Maxwell immediately. He began our conversation by letting me know he was Dr. Wilson's patient and would remain Dr. Wilson's patient. He wanted to talk to me about this new disease I was studying, however, because he knew something about it. He allowed as how he had every intention of paying for his visit, but he wanted me to understand that he was there to tell me something about CFS, not to be treated.

I settled back in my chair and waited. By then - the autumn of 1988 - there had been so much publicity about CFS that literally hundreds of people, some of them writing to me or calling me from the four corners of the earth, had already offered me their theories about what was causing CFS. These theories of causation ranged from discarded plutonium at the nearby West Valley nuclear

processing plant, to PCB's in the salmon of Lake Ontario, to yeast in the intestinal tracts of sufferers.

Then, as now, I listened to every one of these ideas with honest interest. I continue to believe that, someday, someone would come up with the correct answer. Nevertheless, even then, these theories were growing pretty thin, sometimes bordering on the weird.

Edwin continued by stating that he, too, suffered from the disease I was studying. He was not looking for confirmation from me; in fact, his expression brooked no argument. He explained that he had been comparing notes on his symptoms with a number of his friends and neighbors who had CFS and were my patients. I confess I was surprised: most people with CFS show up in my clinic in a state of perplexed misery, wondering if I can tell them what is causing their joint pain and headaches and exhaustion. Edwin, in contrast, seemed to have a rare intellectual grasp on the disease.

When I tentatively asked him to tell me about his symptoms, he explained that the fatigue was the worst. Three years before, he said, he could lift six, maybe seven, wagons of hay bales if he had to, and feed them onto the conveyor belt to the barn loft. He could plow and roll seventeen acres of land in one day. Had for years - until three years ago.

He added that he suffered from scratchy, sore throats. He had muscle pain, but he also pointed out that there was no reason, at his age, to have muscle pain. Hell, his father was still baling hay at seventy. He reported with obvious chagrin that he needed to wear sunglasses while he worked, even though he had always disliked sun glasses; they were something city people took to the beach.

So Edwin Maxwell could have CFS, I mused. Okay - now what? I waited.

“This spring,” Edwin said, “I had a lot of fields to plant in a short time.” He was choosing his words carefully. “The winters are okay, because it’s easy to cut the days down and get the extra rest. But not

in the spring. There is so much to be done after the geese leave.”

Lyndonville happens to be on the migration pathway of Canadian geese. These great birds descend on the land for four to six weeks in the early spring, and when the fields begin to dry out from the winter snow, the geese head across the lake toward Canada. It is a time of great excitement in Lyndonville. The days begin lengthening in earnest now, and the geese are incredibly noisy. You don't even mind being woken at five in the morning by two thousand geese in the back cornfield. They leave when the ground begins to dry, the beginning of the plowing season.

“I remembered that the spring before,” Edwin continued, “I got poison ivy on my arm while cutting some brush in the back of the house. The poison ivy was nasty, but I noticed that the fatigue was better. I didn't think much more about it. Then, this spring, just before plowing, I decided to pull up some poison ivy roots and rub them on my arms. Afterward, the itching was horrible, but my fatigue

got better for about two full weeks. I could work just like before I got this disease, and I got all my planting done in time. But I noticed that as the poison ivy wore off, the fatigue came back.”

Edwin Maxwell was a careful observer of not only nature, but of himself, I realized. He asked for nothing in return. He was imparting some information to me, in case I was interested.

I was interested. New concepts about CFS either fit, or they did not fit, based on the selective “principles” I have developed over years of observation, principles framed by my experience. I realized immediately I had just heard a new “principle.” Edwin’s revelation meant that the fatigue in CFS was not fixed; it could be variable. It could come and go, and was just a symptom; perhaps not even a necessary symptom. Theoretically, you could have CFS without being tired!

Consider the implications: if you were shot, or had a broken bone, little would be changed if you also

acquired poison ivy; neither would exposure to the weed impact on your tuberculosis or your depression or your radiation sickness. -Poison ivy was an allergic response generated by the immune system, and localized at the point of exposure. Edwin was suggesting that this immune response - a sharp blip in the day to day functioning of the immune system, resulting from exposure to an allergen - might somehow diminish the fatigue in so-called "chronic fatigue syndrome."

I had already discovered that among my CFS patients who were children, particularly, at least half had early childhood histories of either asthma, or allergies to various common substances. I knew that there were a number of papers already published in the medical literature connecting CFS to medical histories of "atopic" illness, also known as allergies. A history of allergies appeared to be a risk factor for acquiring CFS. In fact, it was one of my established "principles" of the disease that a complex, if poorly understood, relationship existed between having CFS and allergies.

Yet, Edwin was telling me that if you applied an allergen to a small patch of an arm - if you localized an allergic response, in other words - you could make the fatigue in CFS go away while the allergic response lasted.

It didn't really matter to me whether this held true for anyone else in the world. If it was true for one person with CFS, then it provided an hypothesis that could be tested in other CFS patients. The key was to learn whether this phenomenon represented a fundamental physiologic mechanism of the disease, or was just an interesting fluke. If consistently true of all CFS sufferers, then any theory of the cause of CFS would have to hold an explanation as to why a poison ivy attack gave Edwin Maxwell an energy boost.

Sometimes when you think a great deal about something, you get so used to your own thoughts that they begin to seem dull. It takes someone else's ideas to wake you up again. Edwin watched me as I struggled mentally to fit these new pieces of the

puzzle together. He could see that I was taking his comments seriously.

I was ready to accept that fatigue need not be present for someone to have CFS. I knew several people who lived in families where one or more member was thoroughly debilitated with full-blown CFS, and who suffered from severe intellectual problems along with other symptoms highly suggestive of CFS, even though they lacked the accompanying exhaustion. In fact, they had no more than ordinary fatigue.

Could you jettison fatigue from the definition of the disease? I think you could, although this view would be unlikely to be published in a medical journal, especially since, even today, members of the scientific establishment are unwilling to agree that any of the symptoms of CFS are “real” and not psychiatric in origin. To persuade this same community that you can have what they call “chronic fatigue syndrome” without having “fatigue” would be next to impossible.

Nevertheless, the variability of fatigue - the idea that some people could have the disease without being tired - had become for me a defining principle. In truth, if this principle proved true, then the margins of CFS would begin to blur with the margins of attention deficit disorder (ADD), and other learning disabilities, especially in children. That was the population in which I most commonly saw patients with all the symptoms of CFS, minus one: fatigue.

Edwin Maxwell's story got me thinking more intensively about the cause of the fatigue in CFS. I was intrigued that a natural substance, one manufactured by the body, called interleukin, might be the culprit. While it may seem naive to look for a single substance responsible for fatigue, it did not seem a hopeless task.

Scientists have been experimenting with one type of interleukin, interleukin-2 (or IL-2), as a therapy for several kinds of cancer. What researchers inevitably find, however, is that it doesn't take very much IL-2 to induce symptoms in cancer patients that are

almost as bad as the cancer. Amidst the numerous side effects that include confusion and mood changes, IL-2 also causes profound fatigue when it is administered as a drug therapy.

Some months before Edwin Maxwell's visit to my clinic, I had published a scientific paper with a collaborator, internal medicine specialist Paul Cheney, in which we reported that children and adults with CFS had startlingly high levels of the receptor molecule for IL-2. These levels were so high that it implied that the chemical IL-2 could be causing the fatigue and other symptoms of the disease. I realized that Edwin - if he was willing - could help me test my nascent theory that measuring IL-2 levels might be a way to quantitate the fatigue in CFS in a laboratory.

He was willing. I told him we would take blood samples from him when he was exhausted and measure IL-2 receptor. Then, we would apply poison ivy to his arm and wait until the fatigue improved. When the poison ivy kicked in and the fatigue went away, we would draw more blood. I

suggested we do this three times, to be sure of our results.

Edwin liked my idea. It made sense to him. One sunny afternoon at the end of July that summer, I drew blood from Edwin's arm during a "normal" period when the farmer's exhaustion was pretty severe. I asked him to maintain a kind of symptom severity journal, as well, which required him to rate the severity of fatigue and eleven other symptoms on a scale of one to ten, with ten being the worst.

After I drew his blood, Edwin himself rubbed poison ivy on his arm. A week later I met him in the emergency room where they kept a camera and photographed the rash on his arms. A few days later, Edwin's fatigue had subsided substantially, and I drew another sample of blood. We waited for the good effects of the poison ivy to wear off. Then we repeated the entire process. We did not get to the third trial because by then Edwin had begun to dread the effects of the poison ivy as much as he had grown to dread the fatigue. He begged off, and I respectfully complied with his wishes. I already

thought him very brave to offer himself up to medical science as he had done. Also, the emergency ward staff was beginning to look at me in a funny way because I kept photographing the poison ivy someone was giving himself. Ah, science.....

Ours was never anything more than an informal experiment, one that ended somewhat prematurely, but its results were provocative. Just as Edwin had reported, his fatigue, as well as his other symptoms, were diminished when he was suffering from acute poison ivy. Somehow, this classic allergic response mitigated his most debilitating symptoms: fatigue, compromised intellectual capabilities, and physical pain.

However, the results failed to confirm beyond all doubt my theory about the relationship between IL-2 levels in the blood and fatigue. The results did suggest that fatigue severity was not just a coincidence, the normal ups and downs of CFS symptoms. It was intriguing to speculate that this relationship could even be someday turned into an

effective treatment of the symptoms. Unfortunately, the options are not that good. Edwin preferred the regular CFS symptoms to severe poison ivy symptoms. Maybe its not such a great treatment. Medical science is cumbersome. Hints, such as the hints produced by this experiment, cannot be published in medical journals without real proof. And to conduct a proper experiment takes a great deal of time, money and paperwork, all of which are in short supply for the clinician. But the most frustrating part is the inability clinicians to communicate to those able to do real experiments that CFS is real and must be taken seriously.

Two weeks ago I attended a neurology conference and CFS was dismissed by the lecturer as a minor psychosomatic nuisance for which there were no tests. The real problem is that academics and governmental public health personnel refuse to put aside their biases and look for the proofs. They seem content to criticize experiments like Edwin's as incomplete. And of course they are correct. But Edwin's poison ivy treatment was over ten years ago, and still nothing has come from it. This minor

test is one of hundreds that prove to me that CFS is real and can be studied. From a scientific perspective, the relationship between the debilitating symptoms of CFS and allergic response is fascinating. I have been naive to think that it would be fascinating for others. The misperception that CFS is psychosomatic comes only from scientists' inability to look beyond their psychosomatic biases and look for the proofs.

Edwin doesn't care, and in this respect he is unique. He gets on with his life, tends the springtime garden with care, manages to get the hay in every summer. He is able to accept the presence of symptoms as he accepts hail which damages the apple crop. And he is lucky, his symptoms are relatively mild and he can ration his time. If he worked in a factory assembly line with rigid hours, he would not be a lucky.

I rarely see Edwin now. Sometimes, while driving by his beautiful farm on the Stillwell road on my way to the hospital, I wave to him in the flower bed, or when he is putting the tractor into the barn. He is

busy getting on with the business at hand, he doesn't  
have time to feel sick.

## **The Prisoner**

Those of us in good health rarely appreciate our good fortune. We live our lives ravenously, devouring the minutes of the day with work, play, love - ever eager for the next course. We charge ahead, assuming life will go on as always. In order to accomplish this, we allow ourselves to be oblivious to the suffering of others. We push their pain to the deep recesses of our subconscious, and remain blind to the fact that around the corner may lie an event that will change the foundation of our lives with similar finality.

Gary Burns was just like the rest of us. There was nothing malevolent about his view of life; he harbored no evil intentions. Yet, he was as unaware of the suffering of others as the rest of the world was about to be of his own suffering.

Like most patients, Gary's ordeal began with a bout of what he assumed must be flu. He was thirty-seven, robust and active, a husband and a father. This "flu" announced itself to Gary one day in

October of 1986. The course of Gary's illness, and the eventual dissolution of everything that he had once taken for granted, was typical for an adult who experiences what we doctors call "sudden onset" of CFS. Initially, he was offered a month's sick leave by his company, a nearby factory. He tried to go back to work when his sick leave ended, but often he felt in a state of collapse by noon, and had to leave the jobsite. He took an extended leave of absence, hoping for recovery. If he could just "catch up" on his sleep, he kept telling himself and others, all would be well.

Gary had moments during the day when he found the strength to shower, wander through his house, and ponder the possibility of returning to his job. But, soon enough, "it" would return, and he would tumble onto the sofa and sleep the day away. Gary still had no idea what "it" was, and his doctor hadn't a clue, either. Gary had been ill for six months when his doctor announced that he had been unable to discover a medical explanation for Gary's symptoms. He advised Gary to "snap out of it," to get more exercise, and to see a psychiatrist. Like a

lot of people, Gary trusted his doctor and believed what his doctor had told him.

With some embarrassment, and worry over the expense, Gary arranged an appointment with a psychiatrist. After all, he was desperate, and willing to try anything. The psychiatrist probed for information about Gary's life, and Gary answered the psychiatrist's questions honestly. He said he was in the process of being fired, and that he was going broke. He confessed he had been unusually irritable, chastising his kids for creating noise and havoc in the house, and sulking whenever his wife tried to comfort him. In a revelation that was somewhat difficult for him, Gary admitted he was depressed.

The doctor prescribed an antidepressant, and invited Gary to continue therapy in order to resolve "emotional conflicts" - conflicts that the psychiatrist suggested were the cause of Gary's disabling illness. The following day, however, when Gary took the first pill, he rapidly deteriorated, feeling as if he had been hit full force by a freight train. He slept for two days, and when he was finally able to

stay awake, he felt hung over, as if he had drunk a case of liquor the night before.

Perhaps not surprisingly, Gary decided to cancel his next appointment. The psychiatrist's secretary insisted the antidepressant could not possibly have caused Gary's severe reaction. She also advised him he would be charged for the appointment, whether he showed up or not. "So much for psychiatry," Gary thought, and never returned.

By then, Gary felt as if he was riding a wild and powerful horse, but the reins had slipped from his hands. Desperation was a daily staple, and as he lay in a helpless mound on his bed, or the sofa, he searched his mind frantically for solutions.

His mother, who he had frequently accused of being a "health nut," owned a health food store. Gary decided to sample the assorted vitamins and nostrums available in his mother's shop. He began eating organic food and taking vitamins for the first time in his life, although he noticed no immediate improvement. On his worst days, he wondered if he

had a terminal illness, especially cancer, that his doctor had missed. He decided to read everything he could about cancer; if the doctors were incapable of discovering the cause of his symptoms, he would become a doctor himself.

In the course of his reading journey, Gary came upon an article that described CFS. The stories of the patients in this article resonated with his own experience of the disease: sudden onset; a long, chronic course, exhaustion, headaches, pain; sensitivity to light, night sweats, the sensation - if not the reality - of high fever. He was stunned when he read that patients with CFS are exquisitely sensitive to many drugs, including anti-depressants such as the one he had taken. He felt as if he was reading his own biography. In fact, he was so persuaded that the long-standing mystery of the last year was resolved, he felt incredulous that his doctor had missed the obvious signs, which now seemed so obvious. There was just one small detail of the disease, as CFS was described in the article, that didn't seem to fit: Gary had never really thought of himself as a Yuppie.

Certain of his diagnosis, nonetheless, Gary plunged headlong into health nut-ism, with his mother's encouragement and guidance. He eliminated fat from his diet and took handfuls of vitamins. He waded through lengthy discussions of echinacea, germanium, and zinc. Still, he remained unable to work.

Even though previous attempts to exercise had ended in disaster, Gary next decided work outs might be the solution to his nightmare. He committed himself to pushing past the sore throats and exacerbated fatigue that had followed on the heels of vigorous activity on other occasions. In fact, he gave it everything he had, beginning with a brisk, one-mile walk each day. On day four, however, when he tried to jog, he felt so suddenly weak at a juncture in the road not far from his house, he wondered whether he would be able to make his way back on two feet. He was completely bedridden for the next two weeks.

Gary felt hopeless. He had been fired, and most of his friends had dropped him, seeming to have forgotten about everything they had once shared in common. The medical profession seemed utterly ignorant of his condition. A day rarely passed when he failed to ponder suicide, but the notion of leaving such a traumatic legacy for his children always pulled him up short.

Now, he became exceedingly cautious with his body. He cloistered himself from the noise and activity of his family. He woke at nine, downed his vitamins, and showered, and then he rested. At noon, he ate a health nut lunch of fruits and grains, and then he rested. In the late afternoons, he attempted a few chores and stretched his muscles in the quiet of his living room. His children stayed with neighbors after school until his wife returned from work. Together, the family ate a nutritious dinner. Afterward, Gary rested. At ten, he went to bed, where he lay quietly until he fell asleep at midnight.

Two years of Gary's life passed in this way. Most of what was important to him before the onset of CFS had dissolved in those two years. His children became used to their new father, the one who could not play baseball or take them to the county fair. They began to forget their old father.

And then something wonderful happened: Gary started to get better. The severity of his daily headache lessened, as did the crushing fatigue; he was able to be more active. Gary felt confident that his improvement was due to his adherence to his rigid schedule of the previous two years.

In the third year of his illness, he told me he felt he was functioning at about seventy percent of his pre-CFS activity level. Still, he planned his days with great care, taking a short walk just twice a week, playing catch with his children each day. He told me proudly that he could ride the lawn mower and cut the entire lawn without stopping to rest in the middle of the job. It was apparent that he had finally accepted his new life; his despair was gone.

By the fourth year, Gary complained only of persistent fatigue, muscle aching, and the fractured, disturbed sleep patterns that are common to virtually all CFS patients, and, in fact, are one of the most pervasive hallmarks of the disease. Although Gary's symptoms were less severe than they had been in the past however, he continued his rigid adherence to a reduced level of activity. He believed that his careful attention to what he ate and his meager exercise regime was responsible for his improvement; that he had finally regained control of his destiny.

I became worried - not about the illness, but about Gary's nearly obsessive concern with over-exerting himself. He had become his own prisoner, caught up in self-imposed rules and regulations that severely limited his experience of the world. One day, I voiced my concerns. I told him that he was both his own jailer and inmate. I told him he needed to take some risks. I suggested exercise.

His mouth nearly fell open, recalling his own disaster with exercise two years before. Most CFS

patients have learned through bitter experience that efforts to surmount their disability and engage in the kind of exercise activities they routinely performed before they fell ill is unlikely to have a good result. But the problem is not exercise, it is the assumption that exercise will by definition change the course of the illness. For patients with severe illness, exercise does not change the course and may lead to worsened symptoms. But if CFS is getting better, exercise is great and may speed the recovery.

I suspected Gary was no longer in the severe illness category. In fact, I was uncertain whether his reduced activity level, which continued to hover around 70 percent of what was normal for him, was due to CFS, or due to physical de-conditioning as a result of his fear of exertion. After all, he had been monitoring himself like an organism under a microscope for three years. Granted, he had learned the brutal limits of his disease through suffering, but it seemed to me that he was becoming almost hypochondriacal in his attention to his body. It is so ironic that while most doctors see CFS as hypochondriasis, I feel that hypochondriasis may be

the result of the combination of CFS and the physician ignorance. Patients must sail these waters without guidance, forcing them to make it on their own.

Of course, the only way to find out was to ask Gary to exercise, and he and I both knew the proposition was risky. Which is better: to exist safely in a compulsively rigid way of life? Or try for a full-out, 100 percent return to normalcy - at the risk of initiating a relapse that might turn the clock back for Gary by months or even years? Gary reminded me that it was his life I was risking by making such a request, not my own. Good point. I was asking him to throw away his fear of the pain and suffering of the past years, all the while courting its return. Did I have that right?

I had come to know Gary well by then. My observations and intuition led me to believe that Gary was going to be one of the lucky ones; he was going to beat the illness. All signs pointed to continued improvement. If my suspicions were in error, I thought, Gary would have a relapse, but he

would likely recover from it within a month. And, more importantly, at least we would have our answer. He would still be a prisoner, but he would be prisoner of the disease, not his own fear.

After a great deal of discussion, Gary finally agreed to try. We planned an exercise program that was extremely gentle. Most healthy people wouldn't have considered it an exercise program at all. We planned stretching exercises, then slow walking, then brisk walking, depending upon the progress, if any. When Gary joked that he was dedicating his body to science, his wife frowned.

In the beginning, Gary experienced significant anxiety, and increased muscle aching, as well. But, over a period of weeks, the quality of his sleep began to improve, along with a decrease in the muscle pain. In fact, at the end of two months, it was clear to Gary and to me that he was better. And when his fear began to diminish, he became more willing to venture out into the world of the living. After three months, he had even more energy, and felt confident and enthusiastic about life to a degree

he had not experienced for years. This is not to say his fatigue evaporated. He was tired, sometimes very tired. But, as Gary pointed out, it was “good tiredness,” not a CFS tiredness.

In the complicated realm of CFS, where there remain so many unanswered questions, I am not sure what “recovery” actually means. I often wonder whether the illness vanishes completely, leaving the patient the same as before, or if it simply recedes in the background, becoming mild enough that the patient learns to ignore its nagging distractions. Both probably occur. In a study Mary Robinson did of our patients, twenty percent remained disabled after fifteen years. Of the remaining eighty percent, half persisted with symptoms although they were able to lead relatively normal lives.

Several years have passed for Gary and we continue to stay in touch. He has clearly entered that privileged circle of CFS patients who actually recover fully from the disease. I do not think that his continued recovery can be attributed to exercise,

or even the vitamins, but who knows? I do feel that if Gary had not tried the exercise, he would have stayed in his prison for the rest of his life. Gary recovered for reasons that are mysterious, but he needed to take a leap of faith in order to demonstrate the recovery to himself.

Gary doesn't really think about these issues very much anymore. He is working again, and engaged once more in the lives of his spouse and children. Nevertheless, he has been changed profoundly by his experience. He left his prison of four years, but as a different man. He carries with him an appreciation of his incredible good luck. His suffering now is confined to feeling the suffering of others who are in pain. When he watches the news on television, and there is a story about AIDS or multiple sclerosis or cancer or CFS, he does not rush to change the channel as he once might have done. Instead, his eyes fill with tears.

## **Arnie's Story**

Karl Friedrich Hieronymus Baron von Munchausen was a German “soldier, adventurer, and a teller of tales,” according to one description, who lived from 1720 to 1797. His fantastic lies about his daring and conquests were so notorious that their memory survives to this day as German lore. Medical science has borrowed from this ancient character's name to categorize the patient who engages in equivalently tall tales, all having to do with physical illness. When a parent or caretaker makes up bizarre tales concerning the health of their child, doctors call it Munchausen's syndrome by proxy.

Sometimes the parent intentionally harms their child, by poisoning for example, to create the symptoms. Experts suggest the parent is motivated by a need for attention, and get it they eventually do, one way or another.

Although it was the Baron who proved himself capable of such outrageous falsehoods, women are more vulnerable than men to being suspected as having Munchausen's syndrome. And women are

suspected of Munchausen's syndrome by proxy when doctors are unable to find a simple answer to a child's ills. This is because women typically take the dominant role in helping children through the maze of doctor's visits, hospitalizations, and treatments when children fall chronically ill.

Every year, parents in this country and abroad face court hearings before judges and juries in which they are subsequently found guilty or innocent of intentionally harming their child due to Munchausen's syndrome by proxy. Depending on the circumstances, the prosecutor, representing the state, may add fraud to the charges. Usually, the mother's psychological competence becomes an issue of enormous significance in such a trial. If a child has been judged to have Munchausen's syndrome by proxy by a psychiatrist serving as the state's expert witness, the mother may face the removal of her child from her household, usually into foster care, as well as criminal charges.

The notion of a mother deliberately hurting her child is difficult for most of us to comprehend.

Nevertheless, for some years now, Munchausen's syndrome by proxy has been accepted by the medical profession as bona fide, if somewhat baffling. And there is no question that it occurs. Hidden videotapes in hospital rooms show parents either injuring their children, or doing things that make it appear that a child is ill. What a world....But, because this does occur, physicians have grown suspicious, particularly when confused by symptoms in the patient they treat.

With this in mind, imagine what might happen when a mother whose child suffers from an extremely complex, misunderstood - even overlooked - chronic disease, becomes an outspoken advocate for that child, struggling to explain her son's illness to unsympathetic doctors and suspicious school officials. Imagine the situation from the perspective of the sick child, who can barely articulate to his friends, much less to an attorney or a psychiatrist, what ails him. Imagine how, over time, these quiet struggles can escalate, thrusting mother and child into a firestorm of accusations by authorities of all stripes, as they

attempt to salvage their dignity and even their right to remain a family. A chronic disease robs children of many things, but it should never destroy the life-affirming refuge children find in their home, as it did with a boy named Arnie.

Arnie was ten when he experienced the onset of CFS, but for much of his brief life he had suffered a seemingly endless succession of colds, allergies, sore throats, stomach aches, and headaches. The doctors his parents took him to see somehow failed to notice a pattern of minor infections that, in retrospect, strongly suggested Arnie may have had a medical problem for some time before the symptoms suddenly escalated. Instead it was attributed to an over-anxious parent worried about trivial illnesses. In July, 1990, Arnie's heightened level of exhaustion, hitting him hard after an intestinal flu, heralded the onset of full-blown CFS. By the time school began that September, Arnie was too weak to stand and was confined to bed. His mother took him to see a pediatrician numerous times, but the doctor was unable to explain Arnie's profound fatigue.

Months passed, a period during which Arnie failed to receive either a diagnosis, or an education. By law, school systems are required to provide home tutoring to students who are too sick to come to school, but school systems also require that the child carry a diagnosis before they hire a private tutor using state dollars. Arnie had no diagnosis.

The school year ended, and another began. Arnie was still house-bound because of the exhaustion. In every respect, he was absolutely typical of a child with CFS. He suffered from sore throats, headaches, sensitivity to light and blurred vision, pain in his muscles, joints, and lymph nodes. His ability to learn was diminished because of difficulties with memory and attention. He could not remember what he had read. His attempts to exert himself physically uniformly resulted in relapse, or worsening of his fatigue.

Eventually, doctors ruled out thyroid disease, lupus, multiple sclerosis, rheumatoid arthritis, HIV disease and hepatitis. Some of these doctors did find

immune abnormalities that suggested that Arnie was suffering from an on-going viral infection, but the doctors believed that the abnormalities failed to fit a pattern associated with any particular disease - at least, any disease with which they happened to be familiar.

Neurological tests revealed that Arnie suffered from vertigo and lacked the kind of fine motor control in his hands that might be expected of a boy his age. Other tests of intellectual capability demonstrated that Arnie's short term memory and concentration skills were impaired. All in all, everything about Arnie - his long history of illness, his physical exam, his laboratory tests - were typical of CFS, a disease his doctor did not believe existed.

It was just eight months after Arnie had become severely ill, however, that his parents began arguing about whether or not he was really sick. Arnie's father sided with the child's pediatrician and other specialists, who had suggested that there was nothing medically wrong with the boy. Arnie's father was particularly tired of paying for medical

exams that failed to provide definitive answers. He believed his son needed psychiatric care. Arnie's mother felt differently. She did not believe the doctors. Instead, she began to explore unconventional treatments for her son, embracing, for a time, the "fringe" medicine offered by "ecologists," naturopaths, and acupuncturists, each of whom seemed confident they understood Arnie's problems, yet each of whom had a different explanation for them. Arnie's father thought these alternative healers were a bunch of loonies.

In time, the boy found himself at the hub of an escalating battle between his parents. Large conflicts and petty complaints that had smoldered for years between the two adults erupted in a war centered on their son. Naturally, the boy tried hard to feel better in order to bring an end to the war. When his illness continued, in spite of his best efforts, he became withdrawn. And when Arnie's father moved out of the house, Arnie assumed he had caused the break up. A child sees the world from a simplistic, egocentric point of view. By the age of ten, children are better able to assess the

relationship between cause and effect than they were at five, but the tendency to believe in a magical connection between one's own actions and unrelated events has yet to vanish entirely at Arnie's age.

Arnie's parents made a mistake, too. They were unable to separate their private conflicts from their son's illness, leaving him caught in the crossfire. What followed was probably inevitable: a kind of chain reaction in which a sick child became a battleground, fought over not only by his parents, but by the local school system, and, eventually, the state of New York.

As far as Arnie's pediatrician and his teachers were concerned, the issues were clear. Arnie seemed to be incapacitated with a slew of mysterious symptoms, just as his parents were in the process of divorce. These authorities believed Arnie was suffering a kind of psychiatric meltdown because of his parents' acrimony.

According to the law of the land, if parents are causing a child's illness - whether psychiatric or medical - then the parents are guilty of child abuse. In such cases, the law decrees that the appropriate social institutions intervene on behalf of the child, even removing the child from the destructive environment if necessary. In Arnie's case, the vultures were beginning to swarm.

The principal of his school made several visits to the boy's house during the first year he was absent, acutely aware that neither his parents nor his doctors had been able to offer the school a diagnosis. Each time she visited, Arnie was in the living room, seated, and watching television. He did not look sick to her. The principal assigned a truant officer to the case. The officer saw Arnie in his back yard one spring day, resting in a lawn chair, sipping lemonade. Finally, the school filed a truancy petition with the local court in order to force Arnie to return to classes. In addition, the local social services department launched an investigation of Arnie's parents to determine if they were guilty of child abuse.

At the court hearing on the matter of truancy, the judge listened to the attorney representing the school argue that Arnie had been absent without good cause. Arnie's mother, representing herself, told the judge about her son's medical condition. She called it chronic fatigue syndrome. She also described the holistic-style therapy of vitamins and herbs and acupuncture she had embarked upon to cure her son. In turn, the impassive judge inquired about the impending divorce, as well as the custody hearing. Arnie's parents had begun arguing about which one of them would raise their son after the divorce.

Not surprisingly, the judge, who knew of CFS only as the rather flakysounding "yuppie flu," concluded the hearing by ordering a psychiatric evaluation of Arnie. He also ordered Arnie to return to school. The next day, two things happened, both of which ended in disaster: Arnie went to school, and his mother hired an expensive attorney.

At school, Arnie found to his dismay that his old friends greeted him with poorly concealed contempt. They had heard the rumors: Arnie was faking it. On the second day, the gym teacher decided that Arnie could benefit from exercise; the teacher believed exercise would shake the boy out of his long “slump.” On the morning of the third day of this new regime, Arnie discovered he was once again too weak to get out of bed.

In the meantime, the lawyer hired by his mother had obtained Arnie’s medical records and had read them closely, paying special attention to the variety of opinions from specialists suggesting Arnie’s problem was psychosomatic. The attorney made a unilateral decision: assuming the doctors were correct that family turmoil had caused Arnie’s psychiatric problem, she decided to put her energy into helping Arnie’s parents obtain their divorce.

At the court-ordered psychiatric evaluation, the doctor began by interviewing Arnie and his mother together. Arnie was dizzy, exhausted, and found it difficult to concentrate on the psychiatrist’s

questions. His mother recognized her son's distress, and consequently did most of the talking in order to help conserve his limited energy. Afterward, the psychiatrist asked to talk to Arnie without his mother present. The exhausted child was slumped in his chair. It was flagrantly apparent to Arnie that the psychiatrist had believed very little his mother said, and, after her departure from the room, he became even more withdrawn, even hostile. He responded to the doctor's queries in monosyllables. Finally, the psychiatrist talked to Arnie's mother privately.

The woman tried to "explain" chronic fatigue syndrome to the psychiatrist, who eyed her warily. Struggling to suppress her own feelings of despair, she spoke as enthusiastically as possible about the alternative medical treatments she was continuing to explore. She wanted the doctor to know just how hard she was trying to help her son get well. The psychiatrist concluded the interview eventually, leaving Arnie's mother feeling uneasy.

Afterward, the doctor called her husband, who took the opportunity to tell the psychiatrist that his boy

was fine. His wife was the sick one, he added. A week later, the psychiatrist submitted his report to the court. At the end of a lengthy discussion, he unveiled his diagnosis: Munchausen's syndrome by proxy.

Arnie looked well, the doctor had argued in his report. In addition, Arnie was clearly depressed. He pointed out, too, that neither the boy's father nor the boy's doctors believed Arnie was medically ill, and that the child was at the center of a custody battle between divorcing parents. More critically, the psychiatrist noted, there existed an unusual degree of "enmeshment" between mother and son; Arnie's mother had acted as his spokesperson during their interview. Further, she had appeared enthusiastic, even cheerful. Clearly, she had created an environment of oppressive neediness that had driven Arnie to feign illness, and her subsequent "over-involvement" with her child's illness stemmed from this deviant desire to be needed.

The judge ordered that Arnie be removed from his mother's custody and placed in a foster home. He

ruled that the final determination of Arnie's fate would be decided in the custody hearing. He also demanded, for a second time, that Arnie return to school and receive twice-weekly psychiatric counseling. In a small concession to the boy's claim of illness, the judge ruled that Arnie could be excused from gym class.

One week later, Arnie swallowed a handful of aspirin and several sleeping pills he discovered in his foster mother's medicine chest. He was admitted to a psychiatric hospital immediately afterward. Though it had never been Arnie's specific intent, his suicide attempt had confirmed beyond all doubt the diagnosis of the court's psychiatrist, school officials, and the judge who had presided over his truancy hearing: he suffered from a serious psychiatric illness.

Arnie's incarceration and resulting isolation would have been considerably less had he robbed the corner grocery store. The psychiatric hospital administrators forbade his mother to visit him; after all, she had fostered the imaginary illness in her

son, then encouraged his belief in it. Hospital doctors ordered him to submit to counseling sessions, sessions during which he found it hard to avoid confessing his depression. Such confessions only served to strengthen the prevailing view that his bizarre “illness” was psychiatric in origin. Arnie was given large daily doses of tricyclic antidepressant medications, a class of drugs that often increase fatigue in CFS sufferers. When Arnie complained that the drugs made him feel worse, staff at the hospital simply ignored the complaints. They further demanded that he participate in all the ward activities. Arnie followed the path of least resistance, dragging himself from project to project without comment, but he felt as if he was dying a slow death. In short, Arnie was snared in a trap worthy of Franz Kafka’s imagination: he would remain incarcerated and drugged until he was successfully rehabilitated, which chiefly meant renouncing his absurd belief that he was sick.

Doctors like to solve problems. They like to make people well. Nothing makes them happier. Sadly, when they fail, their universal fallback position

amounts to blaming the patient for his or her own disease. Even when the evidence points in the opposite direction, doctors frequently come up with psychological diagnoses in the absence of clear answers.

Children may be the most vulnerable of all to such treatment. It's hard for them to fight for their rights, or make the case for their own sanity. Pediatricians, when flummoxed by their small patients' complaints, tend to cast a suspicious eye at the child's home environment: If the parents are in distress, pediatricians are provided with a convenient explanation for mysterious symptoms in the child.

As a pediatrician, I recognize the legitimacy of including the status of a child's home life in my differential diagnosis - the decision tree I work from as I search for the correct diagnosis. But I do not automatically exclude the possibility of medical illness in a child because his parents are on the verge of a divorce, or if a grandmother died. Just as it is possible to have child with diabetes living

within a family in turmoil, it is possible to have a child with CFS living within a family in turmoil. Family dysfunction has its own signature; it creates its own particular pattern of difficulties in children, and these problems are very different from the problems of CFS. Demanding that a diagnosis of CFS may be made only in perfect families makes no sense at all.

In truth, family problems are common, and with the additional stress of a chronic illness in a family member, families can even fall apart. In my view, psychological diagnoses need to be made with the same specificity and accuracy as medical diagnoses. It is not enough to pull a psychological diagnosis out of your hat if you are stumped. It is necessary to be a good doctor. Of course, the attribution of the psyche to the cause of physical illness is hardly a new phenomenon, especially in children. Autism is a severe neurologic disease of childhood, but for many years doctors ascribed autism to family dysfunction. We now understand that autism has nothing to do with poor parenting; it is an organic disease.

Like medicine, psychiatry has a spotty history. Perhaps the most classic example of psychiatric miscalculation was the belief, in earlier centuries, that “shock,” the dire condition we recognize today as the result of a dramatic loss of blood, was due to a “shock” to the emotions. Early psychiatric literature stated that the thready pulse, pale face, clammy hands, and drop in blood pressure - classic shock symptoms - are the result of an emotional shock, likely a reaction to the shock of the sight of blood. During the American civil war, however, a doctor noted that this emotional condition called “shock” was quickly followed by death among soldiers who were mortally wounded on the battlefield. He reasoned and later proved that shock was a physiologic abnormality caused by blood loss. Imagine telling someone who has just been shot in the chest to snap out of their blues and pull themselves together.

I am not going to debate the legitimacy of Munchausen’s syndrome by proxy. It exists, a sad commentary on modern society. But the diagnosis

of Munchausen's is made by obtaining absolute proof of a parent inflicting conscious and active harm on their child. Frequently, hospital administrators who suspect a parent of Munchausen's will install a videotape in the room of the young patient in order to acquire irrefutable evidence of a parent committing such harm. In Arnie's case, neither the court nor school officials bothered to offer proof of his mother's intent to cause harm, or even actual harm, no doubt because they had no proof. Their actions were based on conjecture.

Even putting aside medical arguments, common sense tells us that Arnie's the activity limitation is not due to suggestions from his mother. Adolescents are known for being rebellious and not doing what their parents tell them to do. Sometimes I have a hard time getting my son to clean his room. How could a parent tell a child to be tired all the time and stay sitting in a chair? Fatigue caused by Munchausen's syndrome by proxy is a legitimate diagnosis only if the parent is secretly feeding their

children barbiturates or poison, and this can be easily tested.

In my view, the mother's so-called "enmeshment" in her son's illness was an attempt to protect her child from the authorities in the school system, the legal system, and the medical establishment, who understood absolutely nothing about the disease from which he suffered. I believe she should have been guilty of child abuse if she had been indifferent to her son's suffering.

It would be wonderful if I could report here that Arnie's story is a singular one. Unfortunately, these events are becoming increasingly common as more and more children and adolescents fall ill with CFS. The medical establishment and our federal health agencies are digging in their heels, so to speak, hewing with vigor to the mistaken belief that CFS is psychiatric in origin. As a result, more and more children who suffer from CFS are being diagnosed with Munchausen's syndrome by proxy, and the courts are remanding them to foster homes. Arnie's attempted suicide attempt, under such conditions, is

hardly uncommon, either. Too often, children with CFS who have been taken from their homes, told they are imagining their illness, and sent to live in strange homes with adults who refuse to acknowledge their symptoms and disability, find death to be a better option. Like Arnie, these sick children frequently end up in psychiatric institutions, deprived of the comfort of the parent, or parents, who may be the only people who understand they are ill.

Failure to diagnose an illness is, in some circumstances, malpractice. Failure to properly diagnose Arnie resulted in a forced separation from his mother - his only advocate - and his subsequent suicide attempt and incarceration. For Arnie, failure to diagnose had serious consequences.

The existence of CFS has been confirmed by the National Institutes of Health and the Centers for Disease Control. There continues to be legitimate debate as to what causes the illness, but to deny its existence because of a collective failure to understand its cause is inexcusable. The American

Academy of Pediatrics has stated that at least one part of its mission is to act as advocates for children. On the contentious matter of CFS, which afflicts thousands of children and adolescents, however, the Academy has remained silent. I believe the Academy's silence is equivalent to child abuse. Our court systems have an obligation to protect the young and the helpless. Our courts, however, take their advice from the medical profession.

There are many forms of child abuse: neglect, physical abuse, sexual abuse... I would like to suggest that the term "medical abuse" be used when children are directly hurt by apathy or ignorance of health care providers. Not the ignorance expected prior to scientific discovery, but ignorance defined as refusal of accepted fact. We are not talking about a new religion here, CFS has been recognized and studied in this country for nearly twenty years now.

In the villages of ancient Europe, citizens believed that hitching four widows to a plow and forcing them to labor through the night would ward off

epidemics of plague and influenza. Some day, the current apathy, perhaps more accurately, the silence, that veils the existence of CFS, will be considered medical barbarism on a grand scale, and just as ridiculous as hitching widows to a plow.

Arnie is nineteen years old now, and remains disabled by CFS. His incarceration in the psychiatric institution lasted six months, after which he lived in foster care for another several years. He has reunited with his mother, and is at last receiving basic symptomatic care for his illness.

## **The Fruitcake Factor**

When I was a child, I lay in a field one sunny day, puzzling over something that was brand new. Staring at the sky, I noticed what seemed to be an object of unknown identity hovering in my left field of vision. When I turned my head in its direction, however, it seemed to slide away and disappear. I realized I could also see a similar strange shape in my right field of vision. If I directed my gaze ever so slightly away, it might remain still for a moment, delicately balanced, but it slid away, too, when I turned my head to focus on it. They were shy, transparent objects, and they were not really in the sky. I studied the problem for an hour or so, then I fell asleep.

During my medical training, I learned that these curious objects are called “floaters” by neurologists and eye specialists. They are white cells that have collected in the anterior chamber of the eye. Almost everyone will notice them from time to time.

I have decided that floaters are very like CFS since, whenever you try to look directly at them, they skitter off to the periphery and then disappear. If you pretend not to really look at them, they may hold still just long enough for you to get some sense of their shape and size. Certainly, the illness I study in Lyndonville is like that. The harder you look at a specific aspect of CFS, the more whole disease slides off to one periphery or another, hiding itself just beyond your line of sight.

Let me give you an example. Nearly eighty percent of people suffering from CFS will have joint pain at some point in their disease, and many will have it as a chronic symptom. Yet, this pain is by no means a true arthritis. When these painful joints are subjected to X-rays, the image looks normal; there is no joint damage or deterioration. I am able to rule out rheumatoid arthritis, a more severe disease than the common osteoarthritis, in CFS patients, as well, because the blood tests used to diagnose rheumatoid arthritis are negative. I have noticed that the typical rheumatologist seeing a CFS patient may end up - as I did once as a child studying curious objects in

the sky - falling asleep before the patient even comes to the end of his symptom list. Whatever the root cause of CFS, joint pain is some distance away from it.

Still, there are a few symptoms a doctor notices in CFS sufferers that I believe are crucial to understanding the disease.

Amanda Lewis was nearly forty when I first saw her, and she had been ill with CFS for years. She had all the typical symptoms: unending fatigue, joint and muscle aches, headaches, trouble concentrating. As her years of illness wore on, she had learned ways to cope with these unpleasant sensations, but there were a whole category of symptoms, which came under the heading of “neurologic,” from which she rarely found relief or escape, nor could she hide them from others.

Lights hurt her eyes, and certain high pitched noises caused her to experience pain just behind her ears. Sometimes her fingers hurt when she touched objects. Amanda also described a burning sensation

in her arms, as if they were in flames, and occasional episodes of either numbness, or tingling, in her arms. On occasion, she would also experience tremors in her upper arms, which would shake and begin to rise involuntarily. If Amanda had lost consciousness at such times, one could say she was suffering a seizure, but these were not true seizures because she was fully conscious throughout the ordeal. Amanda discovered, too, that on occasion her arm and hand muscles were so weak objects like empty coffee cups would just slip out of her hand.

Most distressing to her, Amanda's intellectual capabilities seemed to have been shattered.

Sometimes she got lost - in her house. When she cooked, she sat by the oven until her food was ready in order to make sure she remembered to turn off the burners. She was utterly helpless when it came to managing two simple tasks simultaneously; she simply lacked the ability to concentrate. She felt her brain's gears had gone rusty.

I was hardly the first doctor Amanda had consulted. Among those few doctors who took her complaints

seriously, a few had suggested her intellectual difficulties were the natural result of aging, a worrisome suggestion as she was young. In addition, although all the symptoms she described to these doctors could be huddled together under the umbrella of neurologic disease, they had been unable to find evidence of muscle wasting or atrophy, nor had they been able to measure any abnormal degree of weakness, using standard neurological tests. -They did detect a slight tremor in her arms and hands, however. In addition, Amanda failed what's known in medicine as the Romberg test, named after its inventor. When she stood in a relaxed stance with her arms outstretched, she wobbled and usually fell backward and to the right.

When Amanda came to see me and described these problems, I decided to test her reflexes. Everyone who has ever had a physical exam remembers the doctor tapping a rubber hammer on their knee, and watching their lower leg jerk forward. That's a normal reflex. When doctors test reflexes, they are checking a "reflex arc," a nerve circuit or pathway

that travels from a tendon in the leg to the spinal cord and back to the leg muscles. Diseases that interfere with the nerves of the leg will suppress that reflex to kick your doctor in the groin.

I was startled when I tapped Amanda's kneecap tendon. She didn't kick me - her whole body shook.- In fact, she almost jumped off the table. I then tested her vibratory sense with a tuning fork, the ability of her leg nerves to detect vibration. Her reaction was more muted, but similar to the first response by being exaggerated. It seemed to me as if Amanda was very much like a set mousetrap that was ready to trip given the tiniest nudge. I think this was the first time I was worried about hurting someone by tapping a tendon with a rubber hammer.

I sent Amanda to a specialist, a neurologist. His diagnosis: Huntington's chorea, a fatal disease of the central nervous system. Amanda was hardly cheered by the news, and I was dubious because her tremor was unlike the jerking motions of "chorea." I arranged for another neurologist to see her in an

effort to get a second opinion. The second neurologist suggested that Amanda might have multiple sclerosis, but seemed unwilling to test his own hypothesis by conducting the standard diagnostic tests for the disease. A third neurologist insisted that all of Amanda's symptoms could be ascribed to depression. He prescribed antidepressants.

When I asked him, in a telephone conversation afterward, about Amanda's remarkable response to tendon tapping, he assured me that her response was phony. Nobody jumps off the table when you tap their reflexes, he noted with a degree of confidence I found chilling. I realized he was telegraphing to me some basic information he believed I needed to know: Amanda was a fruitcake. Amanda's exaggerated reflex response became "the fruitcake factor."

Neurologic symptoms appear to me to be the most direct window into the heart of this illness; they both define and explain CFS. The reluctance of neurologists to be interested in CFS mystifies me.

Perhaps it is too difficult; perhaps it is because they prefer the classic symptoms of seizure, isolated headache, and the shaking of Parkinson's disease.

CFS is a unique blend of numerous neurologic symptoms, none of which are well understood today. The fatigue (not tiredness) must be generated somewhere in the primitive midbrain; the sleep center is nearby and clearly does not work correctly. Cognitive problems, pain, and headache are clearly neurologic. Even the immune system problems of CFS may be neurologic as we know that brain injured patients display immune system abnormalities. But right now it is too complicated. Physicians can be very interested and scientific when it regards any other organ of the body, but the thing that sits atop the shoulders remains the "black box" of medicine and is largely ignored.

I have no problem with not understanding the exact mechanism of the symptoms of CFS. I was never good in the two week neuroanatomy class in medical school. I do have a problem with the lack of respect given patients with poorly understood

neurologic disease. Science has created a false aura of mastery, and if there is an area where mastery does not apply, it is an area to be disregarded, ignored, and even ridiculed. And this injury by the medical profession and society hurt almost as much as the symptoms of CFS. I routinely see patients with CFS that are disappointed when an MRI scan does not find a nice big brain tumor. At least that is real. Ultimately, the neurologic symptoms of CFS will gain a foothold in the thinking of neurologists and garner respect. The brain is the Rodney Dangerfield of medicine.

It was a colleague who first described to me a possible mechanism for the fruitcake factor in CFS. Paradoxically, this symptom is prominent in only a small minority CFS sufferers, always the most severely ill; it may even be the medical marker for the degree of severity. When I look for it however, I can see traces of it, or at least very subtle myoclonus, in up to half of all patients. And here I will reveal my hunch: the fruitcake factor not only represents a fundamental process of the disease, it

probably exists in every patient to some degree, however minor, and expresses itself as pain.

Amanda's violent reaction to tendon tapping was a manifestation of what doctors call "myoclonus." Neurologists define myoclonus as a sudden and generalized jerking contraction of the muscles. You may have noticed your sleeping partner in the early stages of sleep either jump or jerk, sometimes kicking you quite fiercely without once offering an admission of guilt or regret. So called "sleep myoclonus" is sometimes violent enough to wake you just as you're falling asleep. Sleep myoclonus is perfectly normal, but - with few exceptions - it is the only kind of myoclonus that is normal.

Sadly, although myoclonus is a markedly abnormal finding, it is also the ultimate humiliation for the patient with CFS. Although this finding may be one of the most important signs of neurologic disease during any clinical exam, doctors most typically dismiss it as "hysterical" when they are examining CFS sufferers. What they mean by this is that the patient is going for dramatic effect. In my view, this

is like calling an epileptic patient a drama queen when he has a seizure. Epilepsy is not due to “evil humors,” as seventeenth century healers once decreed, and the fruitcake factor - myoclonus - is not hypochondria.

Of course, muscle tension can cause the tendon reflex to be increased, and anxiety certainly increases muscle tension. But an abnormal reflex due to mere muscle tension would never cause someone to jump off the examining table. This response is due to the fact that the reflex travels up the spinal cord, not just the isolated arc back down the leg. Anxiety could not possibly explain Amanda’s reaction. Some experts on the subject consider myoclonus to be a form of epilepsy, because it originates in the brain. But whether myoclonus is a seizure or not, in a sane world, the neurologists Amanda visited should have recognized her abnormal response to their sensory stimulation for what it was: a highly abnormal neurologic sign.

Amanda had seen three neurologists over a one month period. She has been told that she will either die soon, maybe in a while, and that she was a fruitcake and will probably never die. She is in a bit of a dilemma; and I, as her doctor, am also in a bit of a spot. As primary care physicians, we suggest specialty examinations to offer patients the "real doctors", who will solve their problem, perhaps verifying an opinion to instill confidence. However, as a first line clinician, one who sees the patients who walk off the street, I am now in a bad spot. I admit to bafflement at this juncture.

My patient was diagnosed with Huntington's chorea, but if the neurologist who announced that dramatic news had really believed his own diagnosis, he should have conducted additional tests to confirm the diagnosis, as well as offered genetic counseling, since the disease is passed from generation to generation within families. My patient was then diagnosed with multiple sclerosis, but if the neurologist who rendered that diagnosis had really believed Amanda had MS, he should have offered to perform the standard tests that MS

experts use to confirm the presence of the disease, and told Amanda about some of the new MS drugs on the market, which are considered most effective when prescribed early in the disease. My patient was then diagnosed as an hysteric, but if that doctor really believed his diagnosis, he should have written me a collegial letter explaining his theory about Amanda's myoclonus response.

I guess few self-respecting neurologists, especially if they thought she was seriously ill, would call Amanda's disease by its absurdly trivial and unscientific name: chronic fatigue syndrome. As it turns out, this name not only debases the patient who suffers from it, this name also seems to chip away at the self-esteem of the doctor, especially if he is a highly paid specialist with a reputation to protect. I suspect that's why people suffering from CFS are showered with myriad vaguely outlined diagnoses, or no diagnosis at all, despite having prominent abnormalities during examinations and on a number of lab tests.

Very few medical schools teach young doctors about this illness, and as medical students move into specialty training, their opportunities to learn about CFS from senior doctors who have actually studied the disease become even more rare. Publishing scientific papers about CFS has become so difficult in the last decade, a group of researchers decided in 1995 to establish a journal specifically for the disease, one that would afford clinicians and scientists a forum in which to report on developments in the field.

I sat down with Amanda in my office together soon after the third specialist rendered his opinion. We had been offered a less than appealing choice by these men, all of whom were well respected: either Amanda was going to die, or she was a great actress. I suggested to Amanda that rather than arbitrarily choosing one of these diagnoses out of a hat, or choosing the one we liked best, that we throw them all out. I told her that her central nervous system symptoms were part of a disease that none of these highly regarded specialists really knew anything about. I told her she had CFS.

Over the next few years, that diagnosis has proven correct. Her symptoms abated somewhat except for a marked worsening when we tried a mild stimulant drug because of the fatigue. At that time the myoclonus became worse, but, fortunately quieted down when the drug was stopped. She has not gone on to develop Huntington's chorea nor has she developed the typical findings of MS. The symptoms persist; she has good years and bad years. So that means that she has either CFS or is a consistent fruitcake.

How do you go about diagnosing someone as a fruitcake; what, exactly, are the diagnostic markers? Actually, while I know that many of my colleagues consider my patients fruitcakes, I am not really sure what a fruitcake is, exactly. It is a sweet pastry filled with nuts. Neurosis was defined by Carl Sandberg as the denial of legitimate suffering, and therefore most of my patients are surely neurotic as hell. But fruitcakes?

It turns out there is a diagnostic test for the diagnosis of fruitcake: time. I have now known Amanda for several years. I have seen her during crises and during relatively good times, and the symptoms and signs persist. I have shared her sadness and anger; normal, healthy emotions that anyone should have. And as time passed I have come to admire her courage to get by despite the illness and the society's contempt. And I respect her wishes not to be referred for further neurologic opinions.

## **Andrea's Revolver**

Pain is a common problem in CFS, but it is also symbolic of the enormous challenge this illness presents to doctors and to patients. Patients can't prove it, and doctors usually fail to treat it.

Despite the fact that pain occupies nearly all of their working day, doctors have a very poor understanding of it. Although we now have in our arsenal good medicines to relieve pain, we nevertheless try to avoid prescribing them. When a person who has just shoveled the snow off a long driveway complains of back pain, his doctor is likely to prescribe the same pain medications you can readily buy at your local Seven-11. If the snow shoveler's back pain doesn't abate in a few weeks, then the doctor realizes the problem might be worse than suspected. He refers the patient to a back specialist, which gets rid of the problem - for the doctor. Most practitioners tell patients who have unexplained pain to seek help elsewhere.

Doctors are, as a rule, genuinely concerned about doing harm to the patient. This concern merges with another worry: losing one's medical license by prescribing too many narcotics. By law in New York state, doctors are required to write prescriptions in triplicate for narcotics and other potentially addictive drugs, a category of pharmaceuticals that just happen to be the most effective drugs for pain. These triplicate prescriptions help insure that powerful drugs won't be over-prescribed, but the law is both time consuming and expensive - a nuisance for busy doctors. More importantly, we doctors secretly suspect that someone spends their days counting the number of prescriptions we write, and worry that we could lose our medical licenses if there are too many carbons in our waste bins.

Aspirin presents none of these anxieties for us. We never get into trouble from state regulators for offering aspirin to our patients in pain. The great irony is that aspirin may be more likely to kill the patient by causing a bleeding ulcer. But, ignoring that, we urge our patients to try aspirin or

acetaminophen or ibuprofen. And if all of these fail, we usually suggest another mild medication, preferably one that the patient has never heard of.

Cancer pain, of course, is dire, and it is hardly surprising that oncologists (doctors who care exclusively for cancer patients) tend to have the most sophisticated understanding of, and compassion for, pain. They also do the best job of treating pain. When a cancer patient complains of pain, for the most part, the doctor opens his medical chest and says, in effect, take what you need to help with your pain.

Three weeks ago I had a toothache. Like most men, I find this difficult to confess: my toothache hurt. By Friday, two days after it began, my toothache really hurt. On Saturday, it was unbearable. As I hobbled around my house holding my jaw, I found myself thinking, as if silently reciting a mantra: So this is pain....so this is pain.

A friend gave me some serious pain medication, the kind that requires a prescription written in triplicate,

and I was able to fall asleep at last. Even with the narcotic, however, the weekend was horrible. On Monday, I underwent the most wonderful root canal and my pain vanished.

The experience was an important lesson for me. I was reminded of the vast gulf between the subjective complaints of the patient and the objective doctor who listens to these complaints, the difference between hearing about someone else's pain, their toothache, and my own. Most important, I was reminded of the gulf many CFS patients must navigate every day. I was able to see the end of my pain, even when the pain was at its height. I knew that on Monday my dentist would help me, not only because I can afford a dentist and have always paid my bills on time, but because my dentist understood completely that my particular condition was a painful one, and he had been nicely trained to alleviate it.

I see patients with pain every day in my practice. Pain steals in under many guises: the twisted ankle, the stomach ulcer, the spread of a malignant tumor.

I try to respond given my best estimation of the severity of the pain. I have studied CFS for years, and I still am unsure precisely where CFS fits along the spectrum of pain. Some of my colleagues accept as bona fide the pain that often accompanies the disease, and try their best to relieve it with medication. Sadly, most of them tell their patients that CFS is a minor illness; they advise them to get used to the pain until either the pain or the illness goes away. They may suggest aspirin. Despite the fact that pain can be a prominent and even disabling aspect of CFS, it is the rare CFS sufferer who receives adequate treatment for it.

Andrea Thompson had pain, pain that surpassed virtually anything that I had seen before in my practice. By the time Andrea walked into my clinic, she had already seen over thirty doctors. Her story was typical of most of the CFS patients who end up in the village of Lyndonville: each of the doctors she had consulted over the long years of her illness were mystified when she recounted her symptoms, inexcusable now that CFS has been studied in this country for so many years. Some of them performed

studies and offered a multitude of conflicting diagnoses, from the common thyroid disease, which causes fatigue, to the more arcane reflex sympathetic dystrophy, an extremely rare and famously painful nerve disease. All of these diagnoses were wrong, since Andrea had the other symptoms as well: sore throat, headache, numbness and tingling in her legs and arms, as well as a kind of intellectual fogginess that made her feel perpetually “out of it.”

As months turned into years, and her doctors found it increasingly difficult to support their original diagnoses given Andrea’s wide array of symptoms, several of them began to suspect Andrea was a junkie who wanted pain medication to get high. Talking to Andrea for ten minutes displayed the absurdity of these suspicions. Con artists have a certain talent, but Andrea was hardly a con artist. She was in pain.

Andrea was thirty-seven when I saw her for the first time. Before falling ill in 1988, she had worked as an executive in a brokerage firm in New York state.

Her education had been top-notch, and she had a Masters degree in business administration. She was married, had three children, and a nice house in the suburbs. Andrea and her family had been living the American dream - even if they didn't have a Beamer.

Two years after her symptoms began, Andrea's husband was promoted and transferred to Boston. Andrea was looking forward to taking a few months off work to rest, and to settle into her new home in Boston, after which she planned to look for a new job. Once the move was complete, however, Andrea seemed to fall apart completely. In the beginning, at a loss to explain the problem, she and her husband blamed her rapid decline on stress. Yet, the move had been relatively stress-free; her husband's company paid for the packing and unpacking of their possessions, for example.

Andrea's dominant and most crippling symptom was pain, though she was hard pressed to pin-point its source. Pain seemed to migrate through her limbs and even her face. But there were other

symptoms, too. She had migraine headaches that were impervious to medication. She became hypersensitive to light, and took to wearing sunglasses even when she was inside her house. Curiously, odors of any kind made her feel nauseous. Mere sound, too, was often too much to bear. Andrea was an avid R & B fan and had a large library of recordings dating to the 1940s, but she could barely tolerate even the softest music. It was as if every sense she possessed was too finely wired for life on planet earth.

Her first encounter with a Boston doctor ended as badly as her numerous encounters with doctors in New York. Andrea hadn't expected a miracle - she just wanted something to take away the pain. Wearing sunglasses and asking for pain medication at the same time apparently made a poor impression.

She downplayed her pain when she met with a second doctor, with the result that he gave her a complete physical exam, ordered several laboratory tests and an MRI scan of her brain and neck, and

performed nerve conduction studies. The lab tests were normal, and he prescribed mild pain medications and suggested meditation. The drugs didn't touch the pain she felt, however, and Andrea was unable to meditate while in so much pain. She soon gave up trying.

She found some relief when a dentist prescribe codeine after she complained of facial pain, but he denied her additional prescriptions for the drug on the grounds that she might develop an addiction to it. Doctors at a famous Boston pain clinic prescribed exercise and antidepressants, two therapies that simply ended up causing more pain. After two agonizing weeks, Andrea checked out of the clinic.

She had always been an attractive woman, but now Andrea looked ragged. She pleaded with several Boston doctors for more powerful pain killers, but her need for pain relief was proportionate to the degree of skepticism she encountered. In fact, by now, no one she consulted believed she was in pain at all.

Her life was little more than misery compounded by the skepticism of the medical establishment and her friends. Not surprisingly, she began to doubt her own sanity. She became disheveled; her weight plummeted to eighty-nine pounds. She had begun to look like a junkie, even to herself. She felt as if she barely knew her children anymore; they spent much of their time in day-care facilities. Her once-loyal husband began to display frustration and skepticism about her condition. And always the pain - pain that doctors refused to treat. Worst of all, pain with no end in sight.

One day, Andrea loaded her husband's revolver and put it in her mouth. To this day, she has no explanation for why she didn't simply pull the trigger. The following day, she entered a psychiatric unit of a Boston hospital, where she remained for three weeks.

The psychiatrists talked to her about "relocation stress," childhood traumas, and "displaced" anger. Andrea felt she was the only person who saw the

problem clearly: get rid of the pain, she kept telling the psychiatrists, and she would be okay. Finally, her pleas were heard. The psychiatrists prescribed methadone, a synthetic form of morphine that is used to manage morphine addiction, but has the same pain-deadening effects as morphine. The drug worked. Slowly, Andrea began to reconstruct her life.

What was causing Andrea Thompson's extraordinary pain? Usually, pain is associated with tissue damage from injury. The pain sensation serves as a warning, preventing further damage to the victim. This sensation travels on nerve pathways from the injured tissue to the brain. Sometimes, pain is due to damage in the pain receiving areas of the brain itself. In this case, the disease is to the actual pain processing centers, even though the body mistakenly interprets the sensation of pain as if it were coming from somewhere else. Malignancies involving the thalamus, a part of the brain that helps to process sensory impulses, can cause this kind of pain. But Andrea Thompson had no malignancies,

and the MRI scan I ordered of her brain proved to be normal.

A third cause of pain is known as “sympathetically mediated” pain - pain that derives from damage to the autonomic nervous system. The autonomic nervous system controls our breathing, body temperature, blood flow, and heart rate - all those functions we can’t control by sheer will; body functions we barely even notice. One of the diseases associated with this kind of pain, “reflex sympathetic dystrophy,” was the nerve ailment proposed by at least one doctor as the cause of Andrea’s pain. Usually, “RSD” is the a result of an injury to a leg or an arm, or even a single nerve in that extremity. What is most curious about RSD is that the pain may be delayed for months or years, long after the specific injury had healed.

RSD is often accompanied by changes in blood flow, sweating, and, curiously, atrophy of the fingers. In 1988, I heard Dr. Paul Cheney, who had studied CFS among Nevada patients, describe what he called the “disappearing fingerprints” of CFS

sufferers. The surface of his patient's fingertips had grown completely smooth, entirely lacking the normal, distinctive whorls. Dr. Cheney, a true disease detective, even remanded a few of these patients to a police station to find out whether they could be fingerprinted, but their fingerprints left no distinctive pattern. When I heard about this bizarre discovery, I wondered whether it was possible to experience RSD as a body-wide disease instead of one confined to an extremity.

Though it remains controversial, some doctors believe that sympathetically mediated pain can be eliminated by blocking the nerve pathways, or even severing the nerve itself. In truth, doctors argue about the causes - and the treatment - of sympathetically mediated pain every day. Some of my colleagues believe it to be a psychological condition, although new research suggests otherwise.

I began to learn about the relationship between CFS and another puzzling condition called orthostatic hypotension, a failure of the body to adequately

pump blood while standing in the upright position, from Dr. Peter Rowe and colleagues at Johns Hopkins. Soon afterward I began working with Dr. David Streeten, an endocrinologist who had worked extensively with "orthostatic intolerance", the inability of the body to tolerate the upright position. There are only a few truly great doctors who stand out from the thousands of ordinary ones; they are the true masters of medicine. David Streeten is one of these masters. He has both a brilliant scientific mind and the perception and intuition of a superb clinician. If I were thirty years younger and fresh from medical school, I would become his intern and really learn medicine. But working with a master has its drawbacks. When I send my CFS patients to see him for a consultation, they return to my clinic with the news that he was much nicer to them than I ever was.

I met Dr. Streeten for the first time in February 1994 when I accompanied Andrea Thompson to his offices in order to observe his evaluation of her first hand. Until this experience, I was under the mistaken perception that I understood CFS. Dr.

Streeten proceeded to teach me some of the basics that I had overlooked for fifteen years. I had always viewed chronic fatigue as the result of the chemicals released by a viral infection, and had concentrated solely upon looking for the infection that might have caused the condition. Now I was seeing what could be the mechanism, regardless of cause, which might be causing the symptoms to persist. The myriad of symptoms revolving around exhaustion, weakness, lightheadedness, and inability to concentrate were likely due to the inability of the body to circulate blood to the brain when standing, or sometimes even sitting. When the CFS patient is lying down, the symptoms are improved, although not gone entirely. The disability of CFS has to do with the fact that we spend our non-sleeping lives in the upright position.

Dr. Streeten utilized MAST trousers in his experiments. The acronym stands for military anti-shock trousers. These inflatable pants can be blown up like an inner tube in order to create a veritable body cast from the toes all the way to the mid-chest. When paramedics need to transfer trauma patients

suffering from fractured legs, MAST trousers are very handy because they become an instant cast and compress the lower body. Dr. Streeten performed a deceptively simple experiment with his patients. He bid them don deflated MAST trousers, then asked them to stand next to a wall of his examining room. As they stood upright in these somewhat peculiar circumstances, he monitored the patient's blood pressure and pulse. When the CFS patient would become ill during standing, he would inflate their MAST trousers.

Upon meeting Andrea, Dr. Streeten measured the amount of blood in circulating in Andrea's body and discovered that the level was strikingly low. Next, he tested Andrea's blood pressure and pulse for ten minutes while lying down, and they were normal. Blood tests drawn at that time for adrenaline and other "catecholamines" were drawn and later shown to be normal. Then Andrea stood quietly with the plastic MAST trousers around her body but not inflated. Then the problems began. Within minutes she began to feel ill, her pulse began to climb, and the pain began to grow. By ten

minutes of standing her speech was slurred and she appeared a little drunk, swaying back and forth and her feet began to look purple. Her blood pressure dropped and heart rate increased. Then the pain really kicked in. She was confused. All she could do was to say over and over, “The pain...the pain...” While still standing, a second sample of blood was drawn from the line in her arm, again tested for adrenaline.

At that point, while Andrea was still standing, Dr. Streeten inflated the MAST trousers, causing symmetrical pressure around her legs, thighs and abdomen. I had often seen Andrea in this state before, a state where she looked as if she had been on a binge for days. But my teeth nearly fell out seven seconds later she straightened up and looked around and said with a clear voice, “What happened? The pain is gone.”

I was as astonished as Andrea. Even Dr. Streeten was surprised by the magnitude of this response. He hypothesized that the pressure on Andrea’s legs and abdomen by the MAST trousers had forced a more

vigorous blood flow through Andrea's brain, and that this increased blood flow stopped the pain. Andrea wanted to buy a pair of MAST trousers for home use. (Later on we actually tried this, but it turns out to be impossible to walk around with these things on which sort of cancels out the purpose.)

Dr. Streeten was suitably impressed by Andrea's case. He submitted his MAST trouser experiment on Andrea and about twenty other CFS patients to a scientific journal. The editors rejected the paper, initially, because the patients was not sufficiently "blinded" in this experiment. In the world of science, of course, it is optimum for patients in experiments to be ignorant of the researcher's modus operandi. My question to the journal editors is this: how could we sneak Andrea into a pair of MAST trousers without her finding out about it? I can think of only one way: render her unconscious with a general anesthetic. The problem with that, of course, is that it is very difficult for people to describe their pain, or lack of it, while unconscious. Sometimes modern medicine is bewildering.

The temporary stoppage of Andrea's pain in Dr. Streeten's office that day offers up no simple explanations or conclusions, just theories. One simplistic theory is that because Andrea had too little blood circulating in her body, her blood pressure dropped dramatically when she was forced to stand for any length of time. When her blood pressure dropped, so did the flow of blood to her brain, which houses the mechanism that mediates both the sensation of pain and blood flow: the autonomic nervous system. By inflating Andrea's MAST trousers, Streeten was able to rescue, so to speak, blood that was trapped in her legs, and send more to her brain.

Still, the theory has by no means been proven. In the time that has elapsed since Andrea's visit with Dr. Streeten, however, it has become apparent to me and to other doctors who study CFS that problems with blood flow to the brain, and the regulator of that flow - the autonomic nervous system - is responsible for both the exhaustion and the migrating pain of the disease. Of course, myriad questions remain. Might the cause of pain in CFS be

a result of a decreased blood flow through the thalamus? Is there an inherent abnormality of the blood vessels that causes the decreased blood flow through the brain?

A different theory of CFS pain centers on hormones. Studies have demonstrated that a number of different hormones are in insufficient supply in CFS patients. One of these is called growth hormone. The pituitary gland of the brain produces this particular hormone, and besides its primary job of making children grow, it has numerous functions in the body.

Scientists have discovered that there is also a second hormone, called vasopressin, that is deficient in CFS patients. This hormone is essential to regulate the concentration of water in the body, as well as to regulate the size, or diameter, of the blood vessels. I had already determined that Andrea had levels of vasopressin that were much too low to be considered normal. A deficiency of vasopressin could predictably cause excessive thirst as well as an insufficient supply of circulating blood in the body.

As things have turned out, many patients with CFS experience both of these problems.

And this is where the trail leads us to endorphins, hormones produced by healthy people that act as the natural pain killers for the body. Interestingly, vasopressin is a substance that reflects the production of the natural pain-killing endorphins. Could it be that CFS patients have low levels of the endorphins, explaining in part, why they experience so much pain? The fact remains: regardless of why it exists, or what causes it, pain that is both intense and chronic is a daily fact of life for a great many patients who suffer from CFS.

I began testing CFS patients in my office for changes in pulse and blood pressure when they stand quietly, and found that the vast majority have abnormalities. This is the reason that people with CFS may look healthy to outsiders, but they are unable to stand at the check-out counter of the grocery store. In fact, on occasion, some of them faint, or come very close to fainting, presumably

because they cannot maintain good blood flow to the brain.

One day, I showed the blood pressure graphs to one of my best friends, David Lieberman, a substance abuse counselor. I pointed out to him that in addition to their blood pressure abnormalities, these patients often experiences a racing pulse. David made the observation that these physiological signs are picture identical to the body's reaction during withdrawal from narcotics. Could it be that CFS sufferers are in a constant state of narcotic withdrawal because they fail to produce enough of the body's natural pain killers, the endorphins?

I remember a patient with CFS that I had seen almost fifteen years ago. This woman had taken doses of codeine three times a day, every day, for nearly twenty years. She told me it boosted her energy, and provided relief from her symptoms of muscle and joint pain, headache, and trouble thinking. Although she had never increased her dose, I privately suspected she was addicted to codeine. To see if she was addicted, I asked her to

stop taking codeine for a period of two months, and for reasons I will never understand, she actually agreed to do so upon my request. During those two months, her symptoms of pain and fatigue were prominent and troublesome, but she bravely stuck it out. What fascinates me, in retrospect, is that after twenty years of taking codeine, this particular patient displayed absolutely no signs of withdrawal or even a craving for the drug. She never developed tolerance to codeine, where it would become ineffective without increasing the dose. Could it be that for these twenty years she was replacing her own body's deficient endorphins with daily codeine?

Many scientists would tend to dismiss this particular observation. The skeptics among them would probably assume that the woman was sneaking codeine on the side without my knowledge, and, frankly, I would be unable to prove otherwise, since I did not perform regular tests on this woman for the presence of codeine in her system. But, after years of practice, I believe that there is one factor in clinical medicine to which

scientists rarely give credence: the bond of trust between doctor and patient. -I tend to believe what my patients tell me. I may just be gullible.

Andrea has been taking methadone for four years now, and the synthetic morphine provides her with relief from her pain. Curiously, she, too, has not required any increase in her dose, which typically occurs when people take drugs like morphine and methadone over the long haul.

David Lieberman and I often talk about the possibility that CFS patients require narcotic drugs the way a diabetic needs insulin. The myriad symptoms of diabetes are caused, after all, by a deficiency of insulin, a natural substance that healthy people produce in adequate amounts. I have wondered, as well, if blood volumes that are far too low are a clue to the cause of the major symptoms of CFS, particularly pain.

I frankly consider it embarrassing that so little research has been done on blood volume, blood flow, endorphins and other brain hormones in

patients with CFS. If one tenth of the money that has been applied to psychological studies of people suffering from CFS had been used to study endorphins instead, we would have seen some progress in understanding this terrible disease.

One problem, of course, is that CFS continues to be so controversial throughout medicine that earnest investigators eager to study it are often stymied by the failure of government granting agencies to help. This phenomenon is particularly unfortunate when one considers how many CFS patients are in pain each day. According to some researchers, more people in this country have CFS than all the people with AIDS, lung and breast cancer combined. Currently, the disease is approximately fifteen times more prevalent than paralytic polio was at the height of the polio epidemic of the late 1940s. Research barriers have not only impeded my colleagues from understanding the disease, these barriers have prevented doctors from taking a hard look at the pain CFS patients experience, and from treating that pain appropriately.

Eventually, some patients just give up. The foundation of the Hippocratic oath is, "First, do no harm." By failing to treat her pain, doctors caused Andrea Thompson to spend half an hour with a loaded revolver in her mouth.

## **The November Factor**

If robbery is the taking without permission, CFS could be the greatest thief of all. Certainly much has been stolen - the energy to go to work, to play with your children, the ability to enjoy reading a book, the luxury of a refreshing sleep. And, like true, great crimes, the victim sometimes does not even realize that a robbery has been committed. It is as if the thief in a department store steals the surveillance camera along with the jewelry. The thief of CFS steals not only energy, it may rob the victim of the ability to perceive loss. And the mechanism is simple: energy is quietly replaced with guilt. Because the victim feels guilty about experiencing fatigue, the robbery goes unreported. Is it any wonder that this is a controversial illness?

The gift of human nature is the perception of who and what we are. We see ourselves either accurately or inaccurately dependent upon personality and the myriad of factors we call life. We see and feel, relating these experiences to our image of who we think we are. Because fatigue is something to be

ashamed of in our society, it may go unreported. The thief makes off with the priceless essence of our life and replaces it with a plaster statue of guilt. CFS becomes a thief of identity as well as activity.

It is possible to say 'I am an athlete', or 'I am a devoted parent'. When CFS has crept out the back door with energy and hope in a burlap sack, these statements are no longer possible. It makes no difference whether they were accurate to start with. Even if a fantasy, they were a real fantasy for us. With CFS, even fantasies and dreams are stolen. It is like the movie *The Dark Crystal*, where the small victims are placed in an evil machine that sucks out their 'vital essence'. CFS is the thief of the 'vital essence'.

CFS will do to medicine what quantum mechanics has done to physics. The laws, once considered inviolable, are turned on their head. Just as we were comfortable with the simplistic notions of physics before relativity, doctors are comfortable with the simple notions of medicine now. It really makes little difference that these notions are incorrect,

except to those who are not helped by modern medicine. When CFS becomes accepted and understood, the simplistic mechanisms will be replaced by theories that are able to explain what is now considered subtle. And, of course, with this understanding will come effective treatments - not just those to improve the symptoms of CFS - but those that will revolutionize medicine.

An example of an illness assumed to be straightforward but is, in fact, bewildering, is the "flu." A person will say, "I was well until a year ago February when I got the flu." Or "In the months before I got sick I kept getting the flu." Or "My immunity must be low because I have had the flu three times this winter." And of course, when the doctor has no idea of what may be causing your symptoms, comes the standard, I think it is the flu." The longer I study medicine the less I understand about the flu.

Jason Ewing was in his mid thirties, and apart from being a little overweight, appeared like many up-and-coming executives that trooped into the

company offices in the morning, brief case swinging at his right side. He had a promising career until two years ago when he developed a typical case of the flu. Actually, like many persons with CFS, there was one minor difference. This flu had more-than-usual exhaustion associated with it. It is a detail frequently overlooked, and it has always been difficult to tell whether there really was more exhaustion with this first flu or whether now, two years later, the fatigue is remembered more prominently.

But at the time Jason took time from work and returned, still not feeling well, a week later. He had not even bothered to see his doctor during the illness because 'it was just the flu.' Two weeks later he had crept almost to the point of recovery, and paid it little attention. He was at work when the flu came back a second time. Jason noted with clarity that this second flu episode was identical to the first. Not just a similar illness, but the same illness. And now we are getting into strange territory.

If a person gets a cold, we assume runny nose, cough, sore throat. But, like ice cream, colds come in many varieties - hundreds in fact - and they are all slightly different. For example, one cold starts off with a scratchy throat, swollen glands, a little nausea and intense sneezing which lasts a day. But this cold is not the same as that of the neighbor down the street, sore throat and headache but no sneezing. We can call them both colds, but the pattern of symptoms is slightly different, and indeed with viral studies we can see that the initiating virus is also different.

But what Jason noticed was that whatever the first virus had been, the second one felt exactly the same. It would be hard to describe the specific combination of twenty symptoms that made up this particular "flu". It would be like trying to describe an unknown ice cream flavor. In the ice cream store drooling Mocha Vanilla from the corner of your mouth, you say, "that's it."

And it was a second one. It was separate from the first because he had recovered, implying that his

body's immune mechanism had conquered the first invader. He had returned to work and nearly forgotten about the flu three weeks before. He went to the doctor and described the course and symptoms, and the exact similarity of the second course to the first. His doctor said that he could not get the same "flu" twice, and that it must be a coincidence that the two were similar. Jason nodded agreement; they had just made a pact to accept a statement, clothed in the language of science, that was obviously wrong.

There are many viruses that cause the illness we call the common cold. In fact the viruses that cause colds are of several different groups. Flu viruses are a little different, but sometimes it is difficult to say by the symptoms if something is a cold or the flu, because they overlap so much. In general a cold is mild, one or two days of feeling crummy, and the flu is a week. The flu can be dangerous to older people because they develop secondary infections. And there is a vaccine to cover many of the strains of flu that appear during a given winter. There is the 'Warsaw' flu, the 'Beijing' flu, the 'Moscow' flu. It

always seemed to me as a medical student that the different strains of flu were named for communist cities as if they were deliberate attempts at biologic warfare.

Each flu strain is distinct. If you had the 'Hong Kong' flu once, you would develop antibodies to this particular viral strain and recover. Then, because of blood cells called memory T-cells, you would remember this strain and not get it again, except in the rare instance after decades when the memory T cells become a little senile. That is why, in general, we get chicken pox or measles once in childhood and then do not get these illnesses again when our children have them.

It is difficult to measure or determine the specific strain of virus during an infection. The government will look for new strains in order to include them into the flu vaccine, but because they take several weeks and are costly they are not routinely done during a flu infection. You go to the doctor and he or she says you have the flu. Please pay at the front desk. As an aside, have you ever noticed that the

first ten visits for CFS are said to be due to a virus, and the next ten are said to be due to depression?

So therefore it is not likely that Jason had the same flu twice in a row. And all of this would not have made any difference if everything got better and resolved. Jason didn't care much about T-cells and strain variation. Unfortunately, as he was recovering from this second bout he had a third, again with identical symptoms. There was a very particular set of discomforts that made up this flu and a particular malaise, and it came back full force. He was treated with antibiotics - maybe it was a sinus infection, and again recovered, only to get it again a fourth time.

Over the next six months the process kept repeating with one significant trend. The episodes of this "flu" began coming closer and closer together and the recovery period shortened. Six months after the initial episode, they were no longer separate bouts, but a constant illness with the symptoms of abdominal pain, flu-like aching, sore throat, joint pain, headache, blurry vision, trouble concentrating,

and, of course, exhaustion. Instead of being thirty five and playing piggy-back with his children, Jason had CFS.

Jason's onset was not the most common for CFS, but then, again, there are many types of onset in this illness. Jason's particular onset, however, raises several important questions. Is the illness due to a flu-like virus? Is CFS due to an unusual virus that plays hide and seek for the first six months? Or does CFS have nothing to do with a virus at all? Can flu-like symptoms be due to something other than an infection with a tiny microbe?

The first time this question ever occurred to me was while an intern, working thirty-six hour shifts in the intensive care nursery. After being up all night and struggling to remember where I parked my car, I would notice that my lymph gland felt swollen and that I was coming down with the "flu." But after a coma-like sleep I would be recovered and ready to hit the next thirty-six hour shift. Another of life's ironies: they have now made it illegal for interns to work those hours because they would prescribe the

wrong medications, put IV fluids in the wrong patients, and make other mistakes due to fatigue. But when a person is disabled with CFS and is constantly in that exhausted state, no one believes them, particularly the former interns.

The most common type of onset in CFS is the flu-like illness that does not resolve. Yet even in this more frequent type, there are parallels with Jason's flu. In the acute onset, there is a flu-like event, which after five days or so begins to resolve, just as one would expect with the flu. But after the initial resolution, almost to good health, the symptoms come crashing back and do not disappear again. This implies that the illness is a little uncertain, it wavers a little at the beginning as if trying to make up its mind. "Shall I come down on Mrs. Peterson or not?" If this is so, it had a really hard time deciding about Jason.

A second unusual detail common to the onset of CFS is the severity of the fatigue during the initial episode of the apparent flu. Again, difficult to differentiate in retrospect, but in the initial illness,

the fatigue seemed to be more severe than usual.

When I observed the outbreak in Lyndonville, I felt that this was one detail which set this flu apart from all the others. In fact I felt that you could even guess which people were destined to not get better - although I never hinted that at the time. The belief I held was that there was a unique infection which caused CFS.

What is it about the flu that causes the symptoms that everyone knows only too well? The conventional explanation is that with an infection, viral or otherwise, chemical mediators designed to fight the infection are released into the blood stream. And it is the presence of these immune substances that actually cause the symptoms. Part of the evidence for this is that when these substances are infused into healthy people they feel rotten, as if they had the flu. They flu virus and many other viral, and bacterial agents stimulate the production of these normal chemicals which causes the symptoms. When the body's immune mechanism destroys the infecting virus or bacteria the

production of these immune mediators shuts down with a return to good health.

With Jason, the onset had begun as a typical viral infection followed by repeat episodes or relapses until a continuous illness developed. His course of CFS was then typical. There were good days and bad days, but no days without exhaustion, brain fog, and muscle and joint pain. There were the usual problems with diagnosis, many specialists consulted, tests run. After fifteen months the diagnosis of CFS was made.

The time when the flu-like events coalesced into a continuous illness was around March of 1995. By summertime the symptoms followed a daily ritual that varied little. He would have four or five hours of up-and-around activity, headaches every other day, and so on. When he had a bad week, his activity would drop down to two to three hours a day and he would feel more ill. On a good week, sometimes coinciding with sunshine and a warm breeze off the lake, the activity could go as high as

six good hours a day. Summer eased on into fall, and into November.

Jason had a severe relapse in November, and felt the same as at the onset of his illness. Exactly the same. His symptoms worsened to the degree that he was confined to bed for two weeks. He saw his physician who, predictably enough, said he had a virus and to take plenty of fluids and aspirin. On the next visit he was given an antibiotic just to be on the safe side. The flavor of this virus was the same flavor that had started his illness nearly two years earlier.

In this detail, Jason is not unique. CFS is an illness of relapses and remissions, and when patients describe relapses, they describe very similar events to those which occurred in their onset. It is not uncommon to hear, "It was like it was beginning all over again." It is because of this observation that the theory of a persistent infection, one that does not resolve, has been a steady thread through the tapestry documenting the history of CFS. Viral and

bacterial candidates come and go, but the proof has been hard to come by.

A second characteristic of Jason's relapse that seems typical of CFS was its occurrence in November. In our office we call it the November Factor. For some reason, people with CFS get sick or sicker in late fall, and our telephone rings off the hook. I believe there is some connection between the unusual onset type and the worsening which occurs in November.

One possible explanation is that the patient has caught another bug. Kids are back in school, a perfect breeding ground for bugs of all sizes. They bring these bugs home, particularly this year's variety and share them with their parents. The relapse is due to a worsening caused by an intercurrent infection, probably viral. This explanation implies that the relapses, and possibly the onset, are random, due to any old virus.

A second possible explanation is that summer is over and winter is setting in. Many persons with CFS feel better in the summer, perhaps because

there is less stress, and more time sitting around on the porch in the warm August air. For young persons and schoolteachers, summer is a time of unsustained activity. That is, instead of eight straight hours of work, school or study, it is an hour here, a couple of hours there with rest in between. Therefore starting back to a day with eight straight hours of work or school can precipitate a relapse. In this theory, the November factor is the resumption of sustained upright activity after a stress-free, relaxing summer. This possibility implies that a critical amount of sustained activity initiates a relapse, a common experience for persons with CFS.

A third possibility has to do with sunlight. Upstate New York, next to Lake Ontario, undergoes a change in November. The days become short with sunset at 4:45 PM by mid December. Worse yet, water vapor from the lake creates a perpetual cloud bank that drifts over Lyndonville and lingers for the next four months. Mid day is gray, bleak and cold, and all sensible adults have left for Florida. Perhaps the lack of sunlight alters the brain's melatonin and

the addition of seasonal affective disorder is the November factor. Nearly everyone around here is depressed all winter, a fact that the chamber of commerce leaves out of the brochures. Our great joy in winter is a good nor'easter storm which blows the clouds up to Toronto and gives us several wonderful days of sunlight in which we can shovel snow. My lack of enthusiasm for winter here is more than compensated for by the arrival of the geese in the spring and the following months of cherry and apple blossoms that blanket the county.

There are other possibilities. With the coming of cold and bleak weather in November, people go into their homes, shut the windows, add plastic sheeting to help insulate the windows and begin breathing more carbon monoxide. Carbon monoxide, despite being a deadly poison, is very interesting. It can cause a flu-like illness and prolonged neurologic symptoms very similar to CFS. Oxygen makes many persons with CFS feel better, at least temporarily. Experiments with hyperbaric chamber treatments, where oxygen is pushed into tissues at high concentrations, have shown improvement in

patients with CFS. High altitude sickness also shares many of the symptoms of CFS, again due to decreased oxygen availability to brain cells. Could it be that the flu-like event is not due to an elusive virus at all, but instead to decreased oxygen availability to the cells?

Medical science is amazing. The technological advances are astounding. We can rescue one pound preemie babies and transplant hearts, livers, and fingers. We can diagnose retroviruses and have made great strides in treating AIDS. Few pediatricians can boast of seeing measles epidemics, and chicken pox will not be seen by the next generation of doctors. But try to explain something as simple as the flu.

Jason did well for the most part. The one time he got really sick was when I tried to treat him with fludrocortisone. He got the same flavor flu-like event initiating the relapse. It was not as severe this time, and it was not in November. He has been the only person treated with this medication who has had a relapse, but it again raises the question of

whether the flu-like symptoms are due to infection or an entirely different mechanism. We stopped the medication, left him alone for two weeks and the relapse ended, albeit slowly. It has now been almost five years since Jason began his journey, and he has improved slowly and steadily. He is up to eight hours of daily activity, and while the symptoms persist, Jason feels grateful that the crushing flu-like malaise has passed.

## Maggie's Panic

Maggie came into my office about two years ago. By then, she had been ill with CFS for ten years. She was fairly classic for the disease: joint and muscle pain; night sweats; a headache that would not end; severe fatigue. Despite the latter, she could barely sleep at night. Naturally, the doctors she had seen in the past were unable to explain the strange combination of symptoms that seemed to possess her like some demon from a haunted past.

Maggie, in fact, had been to so many doctors, including two psychiatrists, that she had lost count. Doctors grow suspicious when patients tell them they already have seen several doctors for the same problems; they assume such patients are looking for a medical opinion they like, as opposed to a medical diagnosis. This is called, in the trade, "doctor shopping." Maggie knew she had been typecast as a shopper, but she was searching for a diagnosis that made sense.

The symptoms that distressed Maggie the most had to do with her heart. If she took a walk, she developed chest pain and become short of breath. Once, she told me, after taking a very long walk, she had seen a doctor the next day. She looked ragged, as if she run a marathon and come in last. Her resting pulse was too fast - 110 beats per minute. She told the doctor that she was afraid she was having a heart attack, but the doctor surprised her with a diagnosis of panic attack, instead. Panic disorder has long been viewed as a bona fide condition in which the patient experiences panic at inappropriate times.

Chest pain and shortness of breath were just part of Maggie's heart symptoms, however. She often had episodes when her heart would race. Her heartbeat wasn't merely rapid, it felt as if her heart was flopping around in her chest, as if she had drunk a gallon of coffee, but she had given up caffeine years ago. Her face would flush and her palms would sweat. Her lips would quiver, her hands would tremble, and one of her eyelids would twitch. Most

doctors, if not all, would diagnose what I have just described as panic disorder.

But Maggie also suffered from a constellation of symptoms that were diametrically opposed; in fact, they were remarkably akin to the state of being comatose. She was exhausted to the point of being unable to walk. She showered seated on a lawn chair because she could not stand, for instance; she slept on the couch in her living room because she was unable, at times, to climb the stairs to her bedroom.

Another coma-like symptom had to do with the way her intellect was dulled. While driving, she sometimes couldn't remember whether green meant stop or go. Nor could she recall the names of members of her family, or remember a seven digit telephone number - even if it happened to be her own. She found the dialogue on afternoon soap operas incredibly confusing, like a foreign language. Everyone spoke so fast!

Her body felt leaden, and curiously toxic; she felt a certain kinship with Chernobyl's radiation sickness victims. Her bowels couldn't decide between coma or panic; they alternated between constipation and diarrhea. In truth, her entire body couldn't decide whether it was in a panic or a coma. At night, when she awoke drenched in sweat, her heart pounding, it was as if panic was awakening her from her coma. There seemed to be no middle ground.

Her doctors told her all these symptoms were due to stress. To one such doctor, Maggie commented that, aside from the fact that she had lost her job and her husband, that she was bankrupt, and that she was often too weak to climb the stairs of her house, she really had no stress at all.

Our bodies respond to stressful events with the release of adrenaline from the adrenal glands. Adrenaline activates the body's primal "fight or flight" response. It is a natural stimulant, resulting in a sudden rush of energy to deal with the crisis at hand. Panic is appropriate in times of danger, and adrenaline will give someone the strength to run, if

that's the best choice, or fight. A cave man confronted by a saber tooth tiger might choose to run; the student faced with final exams might choose to knuckle down and study.

Of course, after the adrenaline rush, we are left exhausted and weak, but the crisis is over and with a little rest we are good as new. This, in fact, is the key difference between panic disorder, and CFS. Patients who have panic disorder may have relatively normal activity and energy when there is no panic. CFS patients never achieve a normal level of activity, no matter how much they rest or what measures they take to relieve stress. Take a person with CFS and put them on a sunny beach for a day, and their fatigue will not go away, nor will their panic-like symptoms.

Doctors and researchers have long experienced difficulty differentiating CFS from simple anxiety. It is true that many persons with CFS experience anxiety. But because CFS patients tend not to have obvious, diagnosable psychiatric illnesses, I suspect that when panic occurs in CFS patients, the cause is

physiological, not psychiatric. Whatever else this disease does to the human brain, it includes agitation in its repertoire.

That first time I evaluated Maggie, I realized her medical history was consistent with both CFS and panic disorder, however. In fact, if I were to follow the strict guidelines that the government has laid down regarding CFS, I would not diagnose Maggie with CFS. That's because research criteria in use today are designed to create a homogeneous population of CFS patients for research purposes. From clinical experience, however, Maggie's tender lymph nodes, sore throat, endless headache, and intellectual difficulties, were not consistent with a diagnosis of panic disorder. From a clinical point of view the most accurate diagnosis I could render for Maggie was both panic disorder and CFS.

Maggie didn't really care about the label; she wanted to get at the basis of her symptoms.

Together, we decided to try some of the newer tests for CFS, tests involving the autonomic nervous system. In particular, we would look at the blood

vessels and the heart's ability to pump blood throughout the body. By the time I met Maggie, I had already learned that many CFS patients had low levels of circulating blood in their bodies, an abnormality sometimes accompanied by pulse and blood pressure changes when standing.

The medical term used for this is "orthostatic intolerance," meaning, simply enough, a worsening of symptoms when in the upright position. In many medical illnesses, the patient will feel ill regardless of whether he or she is lying down or standing up. With CFS, patients will say, "I feel so exhausted I have to lie down." For fifteen years, nearly every patient with CFS has said this sentence, and I, as well as most other doctors, have misinterpreted it. No wonder this illness is so poorly understood. People should not be tired from standing up for fifteen minutes. We have concentrated on the word "exhausted", but the key words are, in fact, "lie down." The terms "fatigue" or "exhausted" don't even really describe the unpleasant sensation experienced. "Collapse" is more accurate. What the patient with CFS is really saying is "If I don't lie

down, I am going to collapse." Medically, the appropriate term is "pre-syncope," meaning the state which occurs prior to fainting.

Maggie agreed to allow me to test her orthostatic tolerance, her ability to function during quiet standing. During a physical exam, she had two abnormalities: fibromyalgia tender points in her muscles and difficulty maintaining her balance standing with her eyes closed, a common finding in patients with CFS. The practical expression of this finding is that patients with CFS are frequently unable to stand for periods in a hot shower. The heat of the water in the shower makes standing more difficult than normal, and often patients will have to go to bed after a simple shower. Sometimes, persons with CFS will put a chair in the shower even though they may be able to walk around the kitchen for ten minutes. A curious, but important detail that Maggie related, implying that heat somehow worsened the process.

The first test we did was very simple, a test of concentration done on two different days, once

while standing for fifteen minutes and once after lying down for the same length of time. One of the most prominent symptoms of CFS is the cognitive impairment; patients will have difficulty with confusion, short term memory, doing simple calculations, and remembering names or telephone numbers. Sometimes this is so severe that concern is raised about dementia or senility. The hardest thing for a patient with CFS is "double tasking."

My son has amazing powers of concentration. He can be in his room doing his homework, listening to rock-and-roll music while the TV, without sound, shows a football game. I made many vain attempts to inform him that it is not possible to do his homework that way, but his grades were good, and studying this way seemed to do little harm. He was able to "multiple task", just like I do when I talk on the car phone, drive, and find a quarter for the toll booth, all at the same time. For my son, he probably used eighty percent of his brain studying, nineteen percent enjoying the music, and one percent watching the football game. Most shows on TV, the sitcoms, can be enjoyed with even less dedicated

brain function. Double tasking is one of the first things to go in CFS.

The test we gave to Maggie was the coding test of the WISC, a standard intelligence test. In this test, a series of simple codes are made for numbers between 0 and 9, the code printed at the top of the page. The test involves finding, or remembering, the codes for a list of numbers, and scoring is done by adding up the correct coding accomplished in two minutes. It is an annoying little test.

After lying down, Maggie did the test, getting fifty five right in two minutes, a normal amount. A week later we repeated the test after standing, and she was able to get only forty correct, a twenty percent drop. We have been testing this with healthy persons, and found that, in general, they do as well standing as after lying down. Maggie's cognitive problems are related to the position she is in before the test. When horizontal, she does well; after standing, she is dull as a melon. This correlates to another curious detail often found in the history taking of someone

with CFS - they read lying down. Most healthy persons prefer to read sitting up.

We measured Maggie's circulating blood volume at a nearby hospital, and like eighty percent of our CFS patients, she was low, or as she would later say, "down a quart." This finding seems to mesh with the difficulty standing; gravity makes it difficult for blood to get up to the brain, and if the circulating blood volume is low, it should affect brain blood flow. And the mechanism of CFS may be that simple: decreased blood flow to the brain. We don't know if animals can get CFS, but if they do, giraffes would be in big trouble.

The next test was the most exciting for me, the most unpleasant for Maggie. We call it "orthostatic testing" and it can be done in any doctors office. It is a simple test, perfected by Dr. Streeten, and described in Andrea Thompson's case. The patient lies down for ten minutes during which the pulse and blood pressure are taken. Then during a half hour of quiet standing the pulse and blood pressure are measures every five minutes along with

observations of what the patient is experiencing. Maggie's blood pressure and pulse were normal while lying down, and she was feeling relatively well - it was a good day for her. We measured the amount of adrenaline in her blood while lying down and it came back at 350, a normal level.

The first ten minutes standing were not bad for Maggie, although she started feeling tired. Then she described pain in her legs, lightheadedness, and spiraling fatigue. Her palms were sweaty, and I saw her grow visibly pale. -Most significantly of all, she became agitated, and, eventually, she became panicked. The pulse and blood pressure measurements began to change. When Maggie said she could no longer stand, we terminated the test, I did not want her to pass out on the floor. Her pulse had risen to 140 beats per minute, eighty more than when she had started, and her blood pressure had skyrocketed, almost to levels that could cause a stroke.

As soon as Maggie lay down, we drew a second blood sample to measure her adrenaline again. I

also gave her an infusion of saline water. Normally, saline is the last thing you want to give someone with high blood pressure, but I already knew Maggie had abnormally low circulating blood volume. The elevation of her blood pressure had to be due to a constriction of the blood vessels, a compensation mechanism that would help circulate the blood to her brain. The fast pulse reflected the same problem: her autonomic nervous system was trying to make her heart beat faster in order to circulate blood. While standing, Maggie began to fall apart because her brain was deprived of blood.

A healthy person has several compensatory mechanisms that automatically keep blood flowing to the brain indefinitely. Maggie might look healthy to a casual observer, and the private disability company she had paid into for many years prior to becoming ill said that she was just fine. But imagine Maggie trying to work an eight hour day when she had such dramatic changes in pulse and blood pressure after just twenty minutes standing. I would definitely not want her to be my bank teller trying to make change after standing for two hours.

Maggie's compensatory mechanisms were impaired. All but one, that is: adrenaline production. The body produces adrenaline to compensate for impaired blood flow to the brain. In fact, it is one of the body's most effective ways of improving circulation, which is why it is called the "fight or flight" mechanism. Perhaps the most significant finding we made that day had to do with Maggie's adrenaline. Her adrenaline level had risen to 1450, way above normal, when she had been forced to stand for twenty minutes. Maggie's body was pumping out adrenaline like mad just to compensate for the crisis of quiet standing.

Adrenaline has one drawback: it causes anxiety. I believe now that Maggie's panic was simply due to elevation of her adrenaline levels in an attempt to compensate for impaired blood flow to the brain. I do not think a hidden neurosis or other psychiatric condition was lurking in her subconscious. Her panic was organic in nature; it came on as a result of physiologic, not psychiatric, factors. Panic is appropriate during a crisis, but not during quiet standing.

The surge of adrenaline has several drawbacks. First, it doesn't work very well. If it had, Maggie would feel wonderful, like the burst of energy after having a cup of coffee in the morning after a good night's rest. It may be that the adrenaline keeps her up longer, but the price is fatigue. A healthy person will notice that after a crisis, a near car accident for example, the surge of adrenaline is followed by profound exhaustion. Chronic stress will leave a person drained and tired, but recovery occurs quickly once the stress is removed and good rest is supplied. Maggie's fatigue is due to a combination of decreased blood flow to the brain and the surge of adrenaline her body produces to attempt to remedy the problem.

Suddenly, there were several medical diagnoses I could give Maggie. Technically speaking, she had chronic fatigue syndrome, fibromyalgia, idiopathic hypovolemia, postural orthostatic tachycardia, orthostatic narrowing of the pulse pressure, orthostatic diastolic hypertension, and hyperadrenergic orthostatic intolerance. Maggie

was not displeased; literally overnight, she had gone from being a hypochondriac to having seven medical diagnoses.

Research into blood volume and brain blood flow is in its infancy. Nevertheless, while we are still in the dark as to what initiates these problems, breaking CFS down into its many parts may allow us to develop specific diagnostic tests for the disease. Moreover, Maggie's testing results inspire theoretical treatment options. If we could somehow increase blood flow to the brain and deliver more oxygen to brain tissue, the symptoms of impending collapse should improve. The need for the adrenaline surge would be removed, so the post-adrenaline exhaustion would also disappear. In concept, that is.

The co-existence in CFS patients of simultaneous coma and panic symptoms is no longer paradoxical. Doctors and researchers who assume panic disorder is caused by psychiatric problems exclusively have been looking at the phenomenon in an overly simplistic way. The same chemical mediators that

are present in emotionally stressful situations are also the same chemical mediators that help circulate the blood. A test would be to find a way to improve the blood circulation in the brain. We started with a drug to expand her blood volume, and Maggie's response to treatment made me so excited that my socks started rolling up and down all by themselves.

Peter Rowe and his colleagues at Johns Hopkins made an important discovery in 1996 after discovering that patients with CFS would faint when tilted upright on a tilt table. They treated their patients with a drug called fludrocortisone (Florinef™), which works by increasing salt and water retention by the body, thus raising blood volume. I had tried Florinef in many of my patients, and it improved their symptoms about one-third to one-half the time. In my experience, adolescents and those with milder illness responded best to this treatment.

The drug helped Maggie: her rapid pulse slowed down, her sleep improved, and she felt slightly more energy. Her panic nearly disappeared. The

concept that a presumably psychiatric symptom - panic - would be helped by a drug which increases circulating blood volume is hard to believe. But it happened to Maggie. Her panic was clearly caused by CFS and its concomitant blood volume deficits, not the other way around. I was encouraged by these changes, but my socks had not yet started rolling, the surprise was yet to come. Maggie and I talked almost every day during this trial, and we decided to push the therapy a little further by adding salt tablets, hopefully to augment the response. Two days after adding salt tablets, Maggie returned to “normal.”

At first, I didn't know what Maggie meant by “normal.” Did she feel a bit better? No, she was reporting complete recovery, normal for the first time in ten years. -It was as sudden as a switch being thrown; she described her transformation as “awakening from a dream.” Her thinking was crystal clear. She walked for two miles that first day, smelling the flowers of spring. The whole feeling of illness, the malaise, was gone.

Unfortunately, her recovery was brief. Thirty-six hours later, she began slipping back to her former state, minus the panic, and she has remained in that particular jail cell since then. We have tried twenty different treatments, raising and lowering doses of this and that, but she has not regained her freedom. In retrospect, the memory of thirty six hours of freedom remains a cruel reminder of how nice it feels to be healthy.

The importance of Maggie's experience to me is a confirmation of a long held belief that CFS is a reversible state, even after ten years. Not just treatable by reducing some of the symptoms, but reversible. Her return to health was short lived, but it occurred. If she had permanent damage to her brain, I do not think the thirty-six hours would have been possible. What is so frustrating is the fact that this state could not be maintained, even though we tried treatments that pushed so much blood into her brain that her skull was ready to explode. Maggie has been a good sport about all of this. Each treatment attempt was discussed in detail and she was eager to take the steps. While disappointed that

we have not been successful, she has not regretted the trials we undertook.

I see the problem a little differently now. By expanding blood volume it is possible to make some improvements, but not all the time. Even with Maggie's dramatic thirty six hours, the response cannot be maintained even if the blood volume is returned to normal or even elevated levels. The problem must be in the blood vessels themselves. They must be constricted so tight in the brain that little blood gets through. Perhaps it is one of the hormones that constricts blood vessels. Perhaps an infection of the blood vessels. Perhaps it is an excessive sensitivity of the blood vessels to adrenaline. Hopefully, this story will soon have a new and more encouraging ending.

CFS is a devastating physiologic process that undermines the body's energy and the brain's cognitive ability, but I believe that full recovery will someday be possible. We await the next step, the step that will make Maggie's precious thirty-six hours stretch into days, months and years. There is

so much to study in this illness, and so much to be gained. Science needs to recognize the importance of CFS, embrace its difficult paradoxes, and get to work.

CFS is not an isolated, rare illness nor is it an illness behavior for lazy people. The consequences of this illness weigh heavily on not only the victim, but also on family, community and society. Its tentacles seem to reach across boundaries, blurring the lines between other neurological and immunological disorders. CFS, and the patients who suffer from it, have a great deal to teach those of us who have made medicine our life. Once researchers unravel the physiologic mechanisms of this illness, the discoveries will help unravel basic mechanisms of unnumbered other diseases.

## **Mary Ann's Transfusion**

Mary Ann was a bold and highly competent nurse in the intensive care unit of our local hospital, and I depended on her. Given that my specialty is pediatric medicine, I was always a little nervous treating adult patients who were in the midst of medical crises. I quickly learned I could count on the vivacious Mary Ann, who was then in her thirties, for the most up-to-date and reliable information about my patient's status. Often, she suggested successful solutions to problems for which I had never been trained in medical school, like constipation. There should be a course on constipation in octogenarians who have suffered heart attacks, but there isn't.

In 1985, when the epidemic of CFS in Lyndonville began, eventually affecting more than two-hundred people in a town of 1,500 (or whatever), Mary Ann got sick, too, although some years passed before her diagnosis was readily apparent. The one constant, however, which began in 1985, was exhaustion. Mary Ann was weighted down with a panoply of

other problems, as well: arthritis-like pains in her joints, sinus infections, allergies, migraine headaches, chest pain, shortness of breath. As the years wore on, these symptoms and many more resulted in her slide from being perhaps the finest ICU nurse I have ever known to little more than - in the eyes of the medical specialists she consulted - a hypochondriac. As a result, she was inhabiting a remorselessly bleak netherworld.

I tried to help Mary Ann, too, over the years. It was rapidly apparent to me, and eventually to her, that she had same disease from which so many of the patients she had met in the hospital in 1985 had suffered. I tried everything I could think of by way of drugs and other therapies to help her, but none of them worked to any appreciable degree.

There was an aspect of her case that I found very interesting, perhaps because it seemed to me to be one of those elusive clues that might lead me to a more comprehensive understanding of the mechanism of the disease. Mary Ann had a remarkable requirement for water. She rarely came

into my clinic without a large container of ice water, from which she sipped continuously. I was pretty sure it was water, anyway; if it was vodka, I knew we were in for some big problems. It turned out not to be vodka, of course. Once, I asked Mary Ann to keep track of the amount of water she drank in one twenty-four hour period. Her consumption turned out to be four gallons a day.

Persistent thirst is a sign of diabetes, and Mary Ann did indeed have diabetes, in addition to all her other problems. She had a rare kind, however, one called “diabetes insipidus,” which is not the “sugar diabetes” with which most people are familiar. In the primitive days of medicine, doctors would actually differentiate between the two forms of diabetes by tasting their patients’ urine. If the urine had a sweet taste, their diagnosis was sugar diabetes, known today more formally as “diabetes mellitus.” In the case of diabetes insipidus, the urine was tasteless, or “insipid.” Recalling this piece of medical history makes me wonder if I really want to return to the good old days of clinical medicine.

What struck me as most interesting about Mary Ann's diabetes is the fact that it is caused by a deficiency of the brain hormone, vasopressin, which, as I have noted, is a common finding in CFS sufferers. Among its many functions, vasopressin helps the kidneys absorb water and maintain the body's fluid balance. When vasopressin is low, or missing entirely, water runs through the body without being absorbed, like a bucket with a hole in the bottom. Usually, diabetes insipidus signals damage to the pituitary gland in the brain, which manufactures vasopressin. Paradoxically, in spite of her gargantuan intake of water, lab tests suggested that Mary Ann was living in a state of perpetual dehydration.

I decided to measure the volume of blood circulating in Mary Ann's body. In case anyone was wondering, it is not a good idea to measure someone's circulating blood by taking it all out at once. Instead, a high-tech system deployed in a hospital radiology department requires only two small blood samples to determine the body's entire circulating blood supply. A normal person has about

five quarts of blood in their system. It turned out that Mary Anne had only 51 percent of the amount of circulating blood that would have been considered normal for a woman of her age and size. This was a startling finding. If a person loses as much as 40 percent of their blood volume suddenly, they will usually die from shock.

In science and in medicine, when one is trying to calculate what is “normal,” and what is “abnormal,” one will always encounter pitfalls. Mary Ann’s radically reduced blood volume caused me to think about what constitutes a true “normal” value for blood volume. Mary had gained weight in the course of her struggle with CFS, for instance, and I wondered if blood volume can be reduced in people who are overweight. I tried to come up with all sorts of explanations for Mary Ann’s radically low blood volume. In the end, I could draw only one conclusion: no matter what the mitigating circumstances of her case, Mary Ann’s blood volume was below normal.

The blood volume assay has been used for almost thirty years, and is considered to be highly reliable. The fact that Mary Ann - no matter how hard she tried - could not possibly fake the results of this particular test, seems especially significant to me given the vast array of medical experts who continue to insist that CFS is a psychosomatic condition. I will give my little finger to anyone who can successfully argue that this finding was psychosomatic.

I must confess that I am not the first doctor to discover that CFS patients have dramatically lowered blood volumes. Dr. David Streeten had been measuring the low blood volumes in CFS patients for some by the time I tested Mary Ann for the condition. Mary Ann just happened to be my first patient in whom I personally observed the phenomenon.

Dr. Streeten and I, being doctors, were excited by these findings and were enjoying our collaboration. Mary Ann, the patient, was enjoying very little about her life. In fact, she told me she was eager to

experiment with therapies. I felt that her informed consent was reliable, in part because of her nursing experience, which had left her well-versed in medical matters, and because she was, in my opinion, entirely rational. Thus, in December of 1997, I decided to attempt to raise Mary Ann's blood volume level by giving her injections of vasopressin. I reasoned that, if she improved, I could reasonably suspect that low blood volume was at the root of her symptoms and might also play an important role in CFS.

Unfortunately, complications with this therapy set in almost immediately. Mary Ann began suffering from "water intoxication," the main risk of this treatment, since vasopressin causes the body to retain water. The newly expanded blood volume causes a dilution of the salt in the blood and Mary Ann's blood sodium levels dropped markedly. Upon measuring her blood sodium, I halted the drug therapy immediately.

I was relieved when I determined that Mary Ann had suffered no physical difficulties because of the

sharp drop in her blood sodium. In fact, curiously, two days after the therapy was stopped, she began feeling better than she had felt in years. However, the risks that accumulate with water “intoxication” and low blood sodium levels, in my mind, failed to justify the treatment, and we abandoned that particular effort.

I found myself unable to sleep at night thinking about why Mary Ann had felt so much better after her vasopressin infusion, even when it had caused complications. I was, and remain, perplexed by this seeming contradiction. Clearly, low blood volume levels are important and meaningful in some way to our understanding of the mechanisms of CFS, but, I am sorry to report, the puzzle remains unsolved at this date. And, soon enough, Mary Ann was just as ill as she had been prior to the vasopressin treatment.

Then, a wonderful thing happened: she developed a bleeding ulcer. I suspected the problem could be blamed on the large doses of ibuprofen Mary Ann routinely swallowed to control her muscle and joint

pain. At any rate, the hemorrhage inside her abdomen caused her so much pain that Mary Ann rapidly found her way to the emergency room of our local hospital. The staff there determined that she was bleeding internally, and they followed standard protocol for such a condition: they gave her a blood transfusion. In fact, they gave her several pints until her stomach quit bleeding, at which point they sent her home. She began keeping a journal the day she came home and called it, “Diary of Lab Rat # 1.”

I always ask my CFS patients to fill out a questionnaire before each visit. I sometimes suspect that they believe these questionnaires, which force them to respond to a great many detailed inquiries about their symptoms and their level of activity, are a kind of punishment. Inevitably, these forms remind them of just how thoroughly rotten they feel. Nevertheless, I have found these questionnaires to be extremely helpful in monitoring their illness. It turns out, in case anyone was wondering, that the secret to interpreting

fluctuating energy levels in CFS is in the fine details.

Mary Ann filled out one of these questionnaires the day after her transfusion and wrote that she was “whoogy and very tired.” I have never demanded of Mary Ann that she define “whoogy” for me, mostly because I can pretty well guess by the sound of it. The following day, however, Mary Ann was able to walk through the rooms of her house and even venture outside to her garden. She also discovered that, for the first time in her recent memory, she was not thirsty.

Before her blood transfusion, Mary Ann typically experienced about an hour a day during which she could be upright. A week after the transfusion, however, Mary Ann’s life began to change radically. One morning, she wrote in her lab rat diary, “Did I get healthy blood--or what???” It seemed to her that virtually every symptom of illness had been muted - dramatically.

One of the most exciting new developments was her newfound sense of mental clarity, something that CFS sufferers inevitably lose when they become sick. Before falling ill with CFS, Mary Ann had been a crossword puzzle whiz; now she began to work the crosswords again. She felt as if she was opening up all the dusty, long-shuttered cabinets in her memory, and was discovering that although they had been closed for a long time, the contents had remained in tact. She found she could keep her focus on the written page, too. She took up reading after a long hiatus. One evening, she set the newspaper down and realized with wonderment that, for the first time in years, she had read the journal from front to back.

She noted in her diary that she had pulled her grandchildren, all of them squeezed together in a red wagon, down the sidewalk. On the eleventh day after the transfusion, she wrote that she had played baseball with her older grandchildren for the first time. Soon afterward, she and her husband drove 200 miles looking for the perfect pair of bicycles -

Mary Ann was anticipating long rides along the country roads. After all, she felt perfectly well.

Mary Ann was even ready to do a TV commercial about her hair. One of the oddest symptoms of CFS is the complaint by many patients that they are losing their hair. Women in the most severe episodes of the disease often report they find clumps of hair in their brushes. My patients, women particularly, get annoyed with me over this particular issue, and not only because it's hard for me to objectively assess this complaint. I rarely consider hair loss to be a pressing concern when there are so many more serious medical matters to face. I suggested to Mary Ann that blood transfusions were not currently the modality of choice to correct thinning hair.

Diary of Lab Rat # 1: "No nightmares like I used to have. I don't feel 'sick' all the time. I'm praying that it will last, but if it doesn't, I pray that I won't get depressed. I know that God could heal me in a minute if He wanted, but He's given me this illness, and now, feeling better, for a purpose. So I guess

my job is to do His will and whatever He has in His plan.”

Whenever Mary Ann came to my clinic during her incredible respite from suffering, I was always reminded of the old Mary Ann who had worked in the ICU at the hospital. She was perky; she looked great. For the first time in years I was able to enjoy that wonderful, relaxed sense of comic timing that was her hallmark. It is incredible what CFS can do to a person.

The scientist in me was at war with the clinician in me over Mary Ann’s case. The scientist was insisting that Mary Ann’s metamorphosis could easily be ascribed to the placebo effect. Finally, I had to tell the scientist to stuff a sock in it. Mary Ann’s come-back-kid status had been precipitated by an event - a transfusion for an abdominal hemorrhage - that was virtually an accident. Still, I asked myself again and again: what was the secret of the blood transfusion? What was it telling me about CFS?

I began thinking about other blood-related clues I had observed over the years. People with CFS typically report they feel much worse after lab technicians draw multiple vials of blood from them for diagnostic tests. In addition, I had observed that by administering IV fluids to people with CFS, I could often generate a temporary improvement in their symptoms. Most significantly, I realized, the constellation of symptoms that make up the entity we know as CFS, particularly weakness, dizziness, and difficulty concentrating resemble the symptoms of shock due to blood loss.

Nevertheless, from my experience with Mary Ann, I had learned that simply expanding a patient's blood volume wasn't the answer. I have since speculated - but it is only speculation - that the answer might lie in the red blood cells themselves or the blood vessels carrying them. Scientists in Australia and England have suggested that red blood cells of CFS patients are misshapen, and appear to be damaged. They have advanced the hypothesis that the capability of red blood cells to carry oxygen around the body is impaired in CFS sufferers. Maybe the

infusion of new red blood cells into Mary Ann's body was what made the difference. Maybe this really was, as my patient had called it, "healthy blood." In other words, normal, undamaged red blood cells, coupled with an increase in general blood volume, might explain Mary Ann's rebound.

Mary Ann's deterioration began six weeks later. "Day 46," she wrote in her diary. "Starting to spiral down." She had to put her crossword puzzles away; her mind was growing foggy and confused. "Fingers keep latching up and dropping and breaking stuff," she wrote a few days later. On another day, she wrote, "Dizzy if I stand up and I have to hold on to something." The following day: "It's been worth it...but if it's over I have to keep from falling apart." And finally, "Quietly starting to panic." She was unable to pull her grandchildren in their wagon.

Months passed. My heart broke whenever Mary Ann came to the office. Searching for a therapy that might help, or at least do no harm, I decided to give her weekly intravenous infusions of a liter, or about

a quart, of saline water, the salty, purified water that is titrated to mimic the salt content of our bodies. I offered the therapy to her on the grounds that we might be able to raise her blood volume simply by administering extra fluid to her blood stream. Mary Ann felt a bit better after this treatment, though its good effects lasted just two days. I continue to provide Mary Ann with this treatment on a weekly basis, because it offers her some relief, which happens to be more than any other therapy can offer.

One might ask: why not give Mary Ann with another blood transfusion? The question goes to the heart of clinical medicine. As doctors, we must err on the side of caution. In fact, my profession and the federal government each has a responsibility to protect us all from medical charlatans. Before the government can approve a new treatment for a disease, for instance, scientists must apply for grant money, submit protocols for their experimental therapy to review boards, and those protocols must be approved by these boards. After all this, the therapy must be thoroughly tested on significant

numbers of patients, and the results submitted to the government for further review. It's a good system, and without it, great harm might be done.

Doctors who work each day in the trenches of clinical medicine cannot undertake this kind of research. We would require sizable grants from the government to begin the work, an enormous amount of free time, and a veritable hoard of interns and residents to carry out the study using real patients. Clearly, a small town doc like me, living near the end of the world, cannot test in an appropriately scientific fashion the effect of blood transfusions in CFS. And it's hard to imagine any medical journal would publish Mary Ann's case history, because it is merely speculative, even if highly provocative.

Sometimes, I feel the only solution for me is to develop multiple personalities or else go mad. When I am wearing my "scientist" hat, I remain skeptical. When I am in my office, talking to Mary Ann, I sometimes think I'm going to go ballistic over the scientific establishment's onerous demands for expensive, lengthy, double-blind studies. Yet,

giving Mary Ann another transfusion cannot be done now, as there is no established protocol for this treatment in CFS. I'm not just worried about going to jail. It is possible that another transfusion might cause Mary Ann harm. I just don't know.

In the old days, patients rarely learned very much about whatever disease had laid them low. There were no support groups, no newsletters, no conferences, and no unscientific books like this one. As a result, patients were rarely frustrated about scientific progress in their particular disease. For the most part, they remained blissfully ignorant about new ideas and new developments that could directly impact their destinies. Most especially, patients did not read about crackpot ideas like blood transfusions as a treatment for CFS.

I remain convinced that CFS is a treatable disease. Perhaps it will be impossible to fully reverse CFS once it has a foothold in a patient, but I believe many of the symptoms will be alleviated, once we learn how. It saddens me profoundly to see Mary Ann as she is today. Only our shared faith that CFS

may someday be amenable to treatment allows me  
to shield her from that sadness.