

BEFORE STEP 1: THERE IS HOPE

You Can Heal

What is stopping you from healing? What will help you believe that you can heal? Most likely, you still have some hope and an inner belief that you can get better, or you wouldn't be reading this.

I am writing this book because you need a clear, simple approach to Chronic Pain Syndrome ("CPS") Fibromyalgia Syndrome ("FMS") and Chronic Fatigue Syndrome ("CFS"). Many of the books already published are excellent as references, but do not provide a method to organize or implement a plan.

The hard part of writing this handbook was writing less. This handbook will summarize the essential ideas so you can see the big picture. You need a map to review before and during your journey.

CPS/FMS/CFS is not one condition, or two, but is a box where people are placed when their long list of symptoms cannot be placed anywhere else. This book is the results of over 20 years of experience with chronic symptoms.

Let me begin by briefly describing the most common patterns I've seen, so that you can feel hopeful that I understand your situation.

Who You Are and Why You Need to Read This Book

People with CPS/FMS/CFS have many of the following features to their "story":

- CPS/FMS/CFS began long before it was "diagnosed" (may have even begun in your childhood)
- Going from practitioner to practitioner

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- Being told that the pain or diagnosis is not real
- Lab tests may be normal
- Neurological, orthopedic and other examinations are often normal
- Been told that you are just depressed or are suffering from childhood abuse
- Family and friends are putting up with this, but are not sure how real this is
- Employer may have begun with some understanding, but now wants you to get back to work or go out on disability.
- Have had to fight with the disability company or SSI if they have gone down that path
- The orthopedist, rheumatologist, or neurologist tells you that "you must live with it".

What makes this syndrome so confusing is that many people with CPS/FMS/CFS push themselves through a normal day. And so, to someone from the outside, you look OK. When people don't understand, there is a tendency to blame the patient—you. Though adding emotional pain to your physical pain, these responses are not malicious. They're simply ignorant. They are a product of our society's very limited model of wellness and dis-ease.

Your CPS/FMS/CFS is real, as are your myriad of symptoms, the worst usually being severe pain and/or fatigue. In addition, there are often problems with concentration and memory ("fog"), irritable bowel or chronic constipation, poor immune function, numbness, tingling and weakness in your extremities. You are probably feeling guilty, shamed, and perhaps depressed. The feelings of helplessness and hopelessness are just waiting for an opportunity to pounce.

The way I know that CPS/FMS/CFS is real is that I have encountered too many motivated, intelligent, balanced

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people who are seeking help. I have personally struggled with them, learning with each success and each failure. I can say, in some way, everything I know about CPS/FMS/CFS I have learned from my patients. Clearly, I could not have learned it from my medical training, or the medical literature, since they still have insufficient and blatantly incorrect information about CPS/FMS/CFS.

Who Am I

Let me tell you about me, how I got into this, and why I have been able to learn about and treat CPS/FMS/CFS more than other physicians.

I Understand Your Frustration, Disappointment and Alienation

As a little boy, I was always fascinated by the power of the mind. I saw a demonstration of hypnosis and quickly recognized that we all have amazing potentials right under the surface. Literally, in a matter of seconds, we have physical and mental talents available to us in the hypnotic state. In the dream state, we are capable of complex imagery that in regular consciousness is only available to the most talented of artists. I spent years when younger, and while a medical resident, studying and utilizing hypnosis in its various incarnations. To this day, we don't know what hypnosis is, we can't scientifically define or measure the various altered states of consciousness, and our understanding of dreaming is rudimentary at best. I ultimately turned to yoga as a more integrated mind-body training method, 25 years ago. I will discuss yoga in Step 7.

When I applied to medical school, I applied for the MD-PhD. programs to enable me to study more about the nervous system. As I was only 20 years old when applying (I went to college from ages 16-20), I was not permitted into the program. However, after my performance in my first year of medical school, where I aced the most difficult

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courses—neuroscience, biochemistry and physiology, I was invited to re-apply to the MD-PhD program. However, I was no longer interested in doing lab research. By that time, I had become interested in dance and other movement methods, having concluded that the dancers, over hundreds of years, knew more about the human body and nervous system, working from the inside, than scientists sitting in their labs.

In my second year of medical school, my beloved grandfather became ill with lung cancer. It was the first serious illness in my family, and I was quite upset and involved with his illness. My grandfather died during our mid-term period, and it turned out that his funeral was the same exact time as my mid-term exam in pathology. The pathology instructor wanted me to miss the funeral to take the exam. I saw red. I also learned that another student in my class, a mediocre student at best, had been excused from the mid-term all together because he had his appendix out weeks before. He was well healed by the time of the exam. I saw bright red. I of course went to the funeral and got into a whole administrative mess to defend my humanity. Ultimately, I also was excused from the mid-term, but the damage was done. I hated the professor, the course, and school. This crisis, horrible at the time, was, through the retro-spectro-scope of 25 years was one of the most important things that ever happened to me. It forced me to question the humanity of the medical profession and myself. It also caused a strong skepticism about the principles and methodologies of modern medicine.

My third and fourth years of medical school, where I rotated through clerkships in the various specialties of medicine (pediatrics, surgery, internal medicine, etc.) just confirmed my concerns about how medicine is taught and practiced. I designed a unique internship in family practice and psychiatry, trying to compensate for the weaknesses that

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I saw in my training, based on the concept that the family and the whole person are the basis of health. The boards of Family Practice and Psychiatry couldn't agree on the curriculum, so after my internship, I had to choose either Family Practice or Psychiatry. Neither felt right. I decided to take a year off, to give myself a chance to regroup, and to more intensively study the dance and other movement methods that were teaching me so much about the mind and body.

There's lots more to this story, but the reason I tell it is that I want you to understand that I experienced (and continue to feel) the frustration, disappointment and alienation from the medical profession that I'm sure you have felt at times, if not all the time.

The good news is that it made me a more compassionate doctor, and that there are other doctors like me who are frustrated with the status quo, who are compassionate and dedicated to your healing.

My Non-Medical Training

My year off from medicine became three, during which time I restored myself. I studied ballet with the Joffrey six days a week, studied acting with George Morrison, studied the Linklater method of voice training, several movement forms, including tap and jazz dance and Feldenkrais with Bob Chapra and Alan Questel. I started to compare the information I had learned in medical school with the experiences that I was having with these different training methods, in some ways using myself as a guinea pig. My general conclusion was that scientists don't know enough about the arts and that the artists don't know enough about science. I began to develop a model of the mind and body, integrating what I learned from dance, yoga psychology, psychiatry, actor training, Feldenkrais and neurophysiology. I began to develop training tapes, based

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on this new model, to teach movement to dancers and actors—to enhance their performance and decrease their chance of injury.

During this time, I also noted the similarity between what I was doing and classic hatha yoga. I started practicing yoga every day for at least three hours, and again integrated this experience into my model and training method.

About PM&R

In my third year "off", with no clue about how or if I was going to return to a medical career, I learned about a specialty of medicine called Physical Medicine and Rehabilitation ("PM&R", Physiatry). This specialty works with physical disabilities and utilizes the same information about the nervous system and movement I had been studying on my own. I enrolled in a residency program and had a wonderful time learning to be a doctor the way I thought I should, taking care of the whole person.

After residency, I looked for a research position to study the effects of music and movement on the rehabilitation of neurological and orthopedic disorders, including stroke and chronic pain. This search, and the promise of a research lab brought me from New York City to Temple University in Philadelphia. However, the research opportunity did not materialize, and so I moved into a private practice, where I could have a better chance of doing this work.

In PM&R, we see lots of people with chronic pain, and we have one of the best success rates of all the medical specialties. Since we are not surgeons, our expertise is in using medications, exercises and therapies (physical, occupational, speech and others) to heal.

However, in a large percentage of patients coming to PM&R with chronic pain, these conventional modalities did not achieve the healing patients were seeking. Out of

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desperation, I began to resort to teaching these patients yoga and other methods. To our very pleasant surprise, their healing was enhanced. I didn't feel comfortable calling it yoga until 1997, when I started a yoga class at my hospital. I then began to explore other modalities, such as acupuncture and nutrition since I needed as many tools as possible to help my patients heal. I subsequently became Board Certified in Pain Management, Spinal Cord Medicine, and Electrodiagnostic Medicine. I also received training in Acupuncture (which will be discussed later).

Without a doubt, the CPS/FMS/CFS patients were the least responsive and most challenging to these methods. With my background in psychiatry and alternative medicine, I was seeing a growing population of patients with CPS/FMS/CFS, sharing their desperation and frustration. I would constantly seek more information from the medical and non-medical literature for clues to why they were sick and why they didn't heal. As I said before, my patients often gave me the best information about what did and didn't work, and why. What were the best books, the best and worst supplements, the best and worst web sites. I began to assemble an organized approach based on this experience, as well as the “best” that the sciences and arts had to offer.

Healing vs. Cure

There is nothing magic here. There is no magic bullet. “Cure” is an illusion based on the antibiotic era, when the model was “one cause, one disease”. However, even in the case of a bacterial pneumonia, only five out of a hundred people get an infection. The bacteria are not really the “cause” of pneumonia—bacteria are present all the time. The “cause” of the pneumonia is the status of the immune system, which is multi-factorial.

Most likely, you've already tried numerous approaches. Maybe all of them. So how can you get better?

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Well, I compare this situation to one where Julia Childs (the famous French chef) and I are in the same kitchen. We have the same ingredients and are asked to make a chocolate cake. Julia Child's chocolate cake will taste a lot better than mine. Why is that? It is because she knows how to put the ingredients together in the proper order with the proper amounts, and then add the magic of love and art.

What I will help you do is put the ingredients together in a logical, meaningful, organized way. Most patients, due to their frustration and desperation, jump from thing to thing, never giving themselves a chance to observe the effects. I am going to help you become a scientist (and artist) where you are the laboratory. You need to take control, become organized, systematic and full of knowledge and inspiration. You cannot afford to waste any more time, money, energy or hope.

People with CPS/FMS/CFS often have a narrow "window" of activity. Too much or too little can make you worse. These Nine Steps will allow you to work within this window, and slowly make it wider, so you will gain more energy, reserve, and overall wellness.

I define "fitness" as the capacity to withstand stress. Stress is not just physical, but also mental, emotional, spiritual and metabolic. As you increase your fitness in each of these realms, you will find yourself on a steady path to healing.

Even with the advances in diagnosis and treatment that will occur with time, these Steps will not change. This is because there are the steps that we all must take in order to optimize ourselves. It's just that you, as a CPS/FMS/CFS patient, have more of an incentive, more motivation to use these steps, now, rather than later. With CPS/FMS/CFS, you have a smaller margin of error, less tolerance for deviation from what is truly healthy.

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Priority Order

The Nine Steps discussed here are discussed in order of priority. It's not that you can't change the order—in fact, individual need may require a change in order. However, if you follow the order, you will increase the efficiency of your healing. Some of you may not get to the later steps for a year or two, due to time, energy, economic, or other reasons. However, the more of this you can do, the better you will do. Oftentimes, out of desperation, CPS/FMS/CFS patients try to do everything at once. That's not an optimal plan either. Go one step at a time. That's why "Education and Plan" is the first step. Once you understand what you need to do and why, it will be easier for you to stay on the path during your exacerbations, which will continue, though hopefully at a lesser frequency and lesser intensity.

Healing Curve and Your Expectations

As a note of warning, the healing curve is not a straight line upwards, but is a zigzag, with ups and downs. However, the overall trend is uphill. As you heal, there are periods of reorganization that require that you go backward a few steps. A bad period doesn't mean you are back to ground zero any more than a good period means that you are "cured". You can tell you are healing because these troughs in your healing won't be as bad, you won't need as much medicine, and you'll come out quicker and better.

I cannot emphasize this enough, because you are guaranteed to have some setbacks, some periods of exacerbations. When you hit these periods, you may lose faith (but hopefully not all of it). You will know you are on the path to healing because the setback will not last as long, and hopefully will not be as intense as before.

In fact, over the years I have used these techniques with my patients (and myself, though I don't have

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CPS/FMS/CFS), I have concluded that periods of setback are necessary; they are essential and are a sign of your healing. As your body and mind re-organize and re-balance, there are periods where re-organization are necessary—when a prior mode of operation is no longer working and a new mode becomes necessary. If you want to upgrade from an old kitchen to a new kitchen, you have to have a period of dust and chaos. During healing, changes are occurring at the neurological, emotional, biochemical, energetic and several other levels. Such periods will feel like you are worse. Just like psychotherapy or surgery, you have to get worse in order to get better. Keep the faith.

If you go away from this path, or have a period of denial, let it happen. Don't push yourself too hard. Be gentle with yourself, and you will be able to return to your path more easily with a sense of lightness and purpose.

Other Resources

In this book, I will only superficially cover the very basic and the very detailed information that is available through many excellent books and web sites. This book is a macro guide that will help you organize the micro level of information. This book should help you avoid getting too over-involved in one set of details or one therapeutic approach. You should use this book as an overview to your strategy, and then use other references to give you more details. Patients who get too involved in vitamins, or medications, body work or inner work, without balance, do not achieve optimal results.

If you feel stuck or overwhelmed, you can always come to Pennsylvania for a consultation. I am working through the complex legalities of doing phone consultations as well.

Congratulations on getting this far, and best wishes for a rewarding journey.