

‘Right Lifestyle’ – the Ken Friedberg Interview by Cort Johnson (Feb 2009)

Dr. Friedberg is not your typical psychologist; a clinician, researcher and IACFS/ME board member and author he's also had chronic fatigue syndrome (ME/CFS) for over twenty years. For much of that time he did what most people with this disease do; he spent a lot of time and money trying every treatment he could. About five years he stopped trying to overcome the disease and began to focus on how he could interact skillfully with it - how he could manage it - and as he did that it lessened its grip on him. His book below relays the insights he gained during that process.



First the book review and then the first part of the interview.

Fibromyalgia and Chronic Fatigue Syndrome: 7 Proven Steps to Less Pain and More Energy. Fred Friedberg, Ph.D. 2006. A Book Review by Cort Johnson

‘7 Proven Steps to Less Pain and More Energy’ doesn’t promise what most CFS patients understandably want – a cure. In fact Dr. Friedberg believes that the need for a cure (when one isn’t present) and the demand to be well (when that probably isn’t possible) only makes things worse and possibly, given the nature of this disease, much worse.

Dr. Friedberg is not talking off the top of his head; as a long-time chronic fatigue syndrome (ME/CFS) patient himself, he notes he wasted a good deal of time, money and energy struggling against the confines of this disease and that substantial improvements came only when he learned how to interact more skillfully with it. Dr. Friedberg still has ME/CFS but his quality of life and his ability to function are much improved. While he is no longer the long distance runner he once was he can now play vigorous games of volleyball without relapsing.

With no new treatments looming on the horizon Dr. Friedberg proposes that the most effective thing patients can do is to learn how to ‘cope’ effectively with this disease. Coping sounds like the kind of palliative term medical professionals trot out when they’ve exhausted everything else; you should learn ‘good coping skills’ as if poor coping skills got you into this mess to begin with.

But Dr. Friedberg means something very different from what’s usually associated with the word. Instead of tinkering around the edges of this disease the program he’s created has the potential to mount a real assault on it. Even if his program doesn’t get you well

Dr. Friedberg asserts that the vast majority of patients who do give it a try will feel better and lead fuller and richer lives.

The Seven Steps are not new; they include relaxation strategies, sleep strategies, pacing, identifying negative emotions and getting support and involve doing breathing exercises, making activity logs, doing mindfulness exercises, etc. What's different about this book is the attention given to each and by the fact they're presented in a package by a medical professional who's successfully used them on himself and his patients.

The book is short and easy to read and Dr. Friedberg does an excellent job of explaining each technique and why it's relevant to ME/CFS. I would have liked a bit more text than Dr. Friedman provides; a deeper exploration of the different meditative techniques, more on the scientific underpinnings of the 'mindfulness stress reduction' approach as well as worksheets patients could use to organize their efforts but the book covers the basics.

It's important to realize that Dr. Friedberg's behavioral approach is more complementary to the march of research than adversarial to it. If the stress response is out of whack, as an increasing amount of research suggests, and the post-exertional malaise in the disease implies, then Dr. Friedberg's recommendations to engage in activities that can help to rebalance it only make sense.

In the modern 'take a pill' and see me tomorrow era of medicine Dr. Friedberg's program stands out in its emphasis on lifestyle management. It's not sexy and it doesn't provide the 'big' answer that will make ME/CFS go away tomorrow but it may very well provide the most good for the most people at this juncture.

[Dr. Friedberg's Website](#) / [Get his Book and a Relaxation CD](#)

“Right Lifestyle” An Interview with Dr. Ken Friedberg: Part I by Cort Johnson

You've had ME/CFS for over twenty years. You've tried many different therapies and seen many different practitioners and even moved twice in order to get into cleaner environments. Your book, on the other hand, focuses on relatively simple (if not easy) things ME/CFS patients can do themselves to improve their health. How much improvement did you get by the first versus the second approach?

To my surprise, moving to a different, presumably cleaner environment (rural, so less auto exhaust, I reasoned) did not help at all. Actually, my condition worsened. The second approach (on which my book is based) involved doing more pleasurable, but less exhausting things and getting more socially connected. These new involvements have helped considerably. I'd say I'm 40-50% improved, but I still cannot do the regular

exercise (running) that I loved to do. Instead, I play volleyball, which lessens my fatigue and makes me feel better physically and emotionally — and the improved feeling is sustained over long periods. Part of the benefit comes from the sense of camaraderie and excitement I get from the team I play on. Perhaps because it's an anaerobic activity, I don't get symptom flares from playing the game.

Your approach, which you call a 'lifestyle balance program' suggests many ME/CFS patients lifestyles are out of balance; that is given their disease, they have an inappropriate lifestyle. What do you mean by this?

People with ME/CFS, before they became ill, and even afterward, have led high-activity and high stress lifestyles. This may include full-time work, family responsibilities, regular exercise, volunteer work, and too little sleep. And usually people take little time for themselves. So your life is out of balance in that you almost exclusively focus on being productive and caretaking of others. I call this “helping and hard driving.” Although you may find satisfaction in being so active (and receive admiration from others) you may also feel stressed and pressured to continue this treadmill existence.

This high activity, high stress lifestyle in combination with other vulnerability factors (e.g., genetics, immune defects, stress hormone depletion, past trauma) leads to a collapse into illness. Bodily signals of stress and exhaustion which have been ignored now trigger collapse. Of course, there may be more obvious triggers, such as a car accident, a serious flu, a change in medication, or any stressful major life change.

Once ill, many individuals may stay relatively active, but others may become disabled and homebound. So, the unbalanced life can go in both directions – continuing to do too much or doing too little. Even within an individual—push - crash cycles can lead to a pattern of both doing too much or doing too little. The idea is to find a healthy balance between these two extremes.

After you got chronic fatigue syndrome (ME/CFS) you slowly (18 years!) figured out that lifestyle imbalances that were really affecting your health. They didn't before – prior to getting this disease you were able to tolerate a less than optimum lifestyle without consequences for your health. For instance, your tendency to overwork and isolate yourself didn't stop you from going on your long distance runs. For you relaxation/meditation efforts, increased social contacts, seeking out more pleasurable activities has really helped. For someone who's a 'social butterfly' I assume different changes would be helpful. Is the 'recipe' for lifestyle rebalancing going to change much from person to person?

Yes, what constitutes lifestyle balance depends on the individual. In general, incorporating more low effort pleasant activities and more emotional support as well as fewer high stress, high effort activities moves lifestyle toward balance. But what activities are pleasant and what is high stress is defined by the individual. And yes, my life was out of balance for some time before I became ill.

Your book doesn't promise a cure; it promises seven proven steps to 'less pain' and 'more energy'. My gut response when I look at a technique that promises benefits but not necessarily a cure is that a) the benefits are probably small and b) that what I really want is to be completely healthy so I'll keep looking for 'the cure'. You suggest, though, this is probably not a profitable way to approach ME/CFS?

Yes, Cort, I think you're right on track with the reactions I sometimes get about the book. I was looking for a CFS cure for 18 years. Nothing less than total health was acceptable! My search for cures led me down the path of alternative remedies of all kinds. The result: little illness change and a depleted bank account. I completely understand the desire to be restored to full health. But we just don't have the means right now, medical or otherwise, to get there.

So I ask people if they're willing to accept half a loaf, if full recovery is not possible now. I think the more flexible you are about how well you need to be, the greater the chances of finding a path to improvement—through your own personal efforts.

While it doesn't promise a cure your book is not about cleaning up around the edges either. The goal of this 'self-help' manual for chronic fatigue syndrome (ME/CFS) and fibromyalgia is to use lifestyle adjustments and these seven stress reduction techniques to substantially improve one's health. How far can ME/CFS patients go using these techniques? Can they become well?

This is another critical point. You can definitely improve with lifestyle change, not just cope in a defensive way with unpredictable fluctuations in your illness. I think it is possible to approach near-recovery or wellness by arranging your life so that you allow yourself the time for adequate rest, relaxation and sleep, positive low effort experiences, full expression of emotions, and good social support. Almost anyone who follows these lifestyle guidelines can improve noticeably and sometimes very substantially.

You're a strong advocate of using what you call 'active, extended relaxation strategies' such as meditation, focused breathing, progressive muscle relaxation, etc. and they're

the first step you cover in your book. Are these things any person with a chronic illness benefit from or are they particularly beneficial for ME/CFS/FM patients and if so, why?

The first prescription I give is for home relaxation using a relaxation CD. Many people who I see with ME/CFS are extremely stressed due to frustration over illness limitations. A sudden onset of any poorly understood debilitating condition may trigger strong emotional reactions. Relaxation will ease that stress and generate pleasant feelings. In some cases, perhaps 1 out of 10, relaxation will produce significant illness improvements. On the other hand, some people will not find relaxation beneficial because they are not overly stressed or they just don't care to do the techniques.

Your benefits from doing relaxation/meditation exercises increased dramatically when you began doing them far longer than most people would think to do. At one time I believe you were doing several hours of these exercises a day. This seemed to get you over the hump so to speak and after a time you could attain the same effects by doing much lower levels. What happened here do you think? Were you kind of retraining your central nervous system to calm down? To operate at a slower, less frenetic pace? To burn up less energy?

I did the meditation twice a day, 20 minutes each time. Sometimes I increased it to an hour a day. I once went on a meditation weekend and did 2 hours a day. After that, I felt buffered from stress for about a month. The meditation caused me to react much less to any problem or stress. For instance, I might think angry thoughts, but I only felt slightly angry. Prior to the meditation, I would feel like a pressure cooker when I was angry.

Your program is the opposite of the pop a pill approach that permeates medicine. It takes some time and discipline to get the full benefit. For instance, it appears that the more you put into these 'extended' relaxation strategies the more you get out of them. You noted that an author of a fibromyalgia stress reduction/meditation study stated 'it is only the people that use this technique regularly who show a decrease in the stress response'. How much time does the average ME/CFS/FM patient need to devote to these practices daily to show a significant benefit?

You can see benefits after a single 15 minute relaxation session. But to sustain these benefits requires some level of regular practice over several weeks time. Twice a day is ideal. But once you learn to associate a relaxation technique – say even 20 seconds of focused breathing -- with tension release, then you can use it almost anywhere to dampen stress and generate good feelings. I practiced meditation regularly for 15 years—and I have what you might call a near-permanent state of relaxation. I rarely feel upset or stressed the way I used to be.

Can researchers point to physiological changes occurring in the body as a result of these practices?

Yes. There is a fairly substantial scientific literature on the benefits of relaxation, including improvements in immune function and stress hormones. Both of these physiological processes are implicated in ME/CFS.

Physicians often say that getting good sleep is critical to a chronic fatigue syndrome (ME/CFS) patient's recovery. Given that it's not surprising that many patients at some point turn to and benefit from prescription drugs. You spoke of one patient, though, who found that a combination of a relaxation tape and a progressive muscular relaxation exercise was more useful than drugs in helping her obtain consistently good sleep. Can these types of exercises reduce prescription drug usage or even take their place for a significant number of ME/CFS patients?

The short answer is “Yes.” Deep relaxation before bed programs the body for more restorative, restful sleep. Of course, it's easier to take a pill (assuming it works), but if you want to self-manage your sleep without medications, it can be done. Relaxation can reduce your need for sleeping pills and it will counteract that “tired and wired” feeling that many people have at night before going to sleep. And if formal relaxation doesn't suit you, any personally relaxing activity may work just as well. This could be listening to soft music, pleasure reading, etc. If it leads to a sense of deep calm, you get the sleep benefit.

You also told a similar story of someone who was able to reduce her pain medication and became more pain free rather quickly after starting muscle relaxation exercises. Again, is this a pattern you see often? Is the ME/CFS/FM population as a whole missing some effective, healthy and cheap ways to reduce their pain?

Relaxation can reduce pain in ME/CFS/FM if practiced regularly. And that may be all that some people need. But often, the pain is anchored, at least in part, in an individual's emotional life and that must be addressed as well. Strong, but unexpressed emotions are a big contributor to the type of widespread pain you see in FM. People with FM may be angry at themselves for failing to live up to their own high standards. Also they may be angry at unsupportive family and others—given all that the ill person has done to provide for and help those close to them. But the individual may be unable to identify or express that anger and so it festers internally, creating physiological changes that produce pain.

Learning how to express that anger constructively and ask for what you want (and not doing what you don't want to) is a first important step in managing your life more effectively and reducing persistent pain.

Your discussion of 'longstanding hyperactive patterns' in chronic fatigue syndrome (ME/CFS) really rang a chord for me. It seems bizarre that someone with a fatiguing disease could exhibit 'hyperactivity' but that is my experience. When I walk I tend to walk fast, when I eat I eat fast, and my mind is often racing. Some studies do suggest ME/CFS patients are stuck in a chronic 'fight or flight' stress response. Can calming the mind calm the body down too? Is it possible to turn off this chatter and reduce this underlying nervous tension?

This high activity pattern is very common in ME/CFS. I think that allowing yourself to have personally enjoyable downtime is one way to infuse a little more balance in your life. The balance you're looking for is between activity, rest and leisure. Once the rest and leisure parts are worked into your schedule, then the active go-go part of your personality and all that positive excitement that goes with it can be better maintained.

Also, it's good to allow at least some time to wind down the internal chatter by distracting yourself in some positive way -- so that you're not forcing yourself into a new pattern — but just easing into other things that you may not have normally done or thought about.

Do you think this mental wiredness or nervous tension is a core part of the disease itself or is it more an inevitable buildup of all the frustrations and problems the disease brings with it? Do patients with other chronic diseases display this kind of pattern or is this something you find more in ME/CFS and FM?

The tired and wired feeling that people have especially at night before they go to bed is typical of insomniacs—poor sleepers who may or may not be medically ill. There's an interesting theory of CFS/FM that views a broken up sleep pattern as a primary cause of these illnesses. A study was done by Dr. Harvey Moldofsky about 30 years ago in Toronto where healthy individuals spent 3 nights in a sleep lab. During their deep stage of sleep a low level noise was played that disrupted sleep but did not wake them up. After 3 nights of this, these subjects developed widespread pain similar to FM. And this study had been replicated.

In CFS and FM, we also may find a type of disrupted deep sleep called "alpha-delta intrusion." So unrestful sleep may play a role in causing pain as it does in fatigue. Improving sleep may help to lessen pain as well as fatigue.

You say if you agree with this statement “I do much more when I feel better and much less when I feel worse” you’re engaged in a negative pattern. But this seems like chronic fatigue syndrome (ME/CFS) to me! This is how I operate. What’s wrong with this?

The up and down pattern is certainly the way things usually are for people with ME/CFS. And I don’t think that lifestyle changes can completely eliminate this pattern. There are certain things you want to do that you know will lead to a crash (say a concert you want to attend). But you do them anyway because it’s important enough to you that it’s worth the consequence. Nothing wrong with that.

What I suggest to people is that they try to be more consistent in their daily activities—so they may do only a bit more on a good day and just a bit less on a bad day. What I often see are up and down patterns where if the energy is there, the individual runs out the clock on that energy by doing all of the things that have been left undone until he/she totally collapses—and stays that way for some time. This pattern doesn’t give the body a chance to recharge. With gradual, rather than sudden increases in activity, a daily routine can be developed and energy level can slowly increase because it is not used up all at once.