



inforME Magazine

InforME Magazine is an informal publication for people concerned with ME, CFS and CFIDS.

(ME: *myalgic encephalomyelitis*; CFS: *chronic fatigue syndrome*; CFIDS: *chronic fatigue & immune dysfunction syndrome*)

Autumn 2008

My Fibromyalgia Story

by Mary Brownscombe

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My Fibromyalgia story is similar to many others. In the weeks and months following four surgeries in 1989 to 1991, instead of decreasing pain and increasing energy, I grew more and more fatigued, and the pain worsened and spread throughout my body, even though I very carefully followed my physiotherapy routines!

After many lab tests and visits to specialists, I met with Dr. Von Westarp, an Endocrinologist, in hopes that perhaps my 35-year-old autoimmune thyroid disease had flared up and was responsible for the overwhelming fatigue and pain! After a long discussion and a review of my lab tests, the doctor gave me a physical examination. He pressed on quite a few spots on my body; some felt normal, while others were astoundingly painful! He explained that these tender points were a part of the diagnostic criteria as defined in 1990 by the American College

of Rheumatology, and showed that I had something called Fibromyalgia Syndrome. This was over 15 years ago; I had never heard of FMS. During his explanation, we discussed pain medications and he recommended a low dose of an antidepressant. I was somewhat alarmed!! I'm not depressed, I said! He explained that FMS is NOT depression, the antidepressant helps with sleep, as sleep disorders are a major part of FMS! He continued to tell me that unfortunately there was very little information available about this illness, but strongly recommended the Victoria FMS Group and told me how to contact them.

My own GP was pleased and relieved that I, at long last, had an answer to my Mystery Illness! Perhaps this diagnosis might apply to some of his other patients who looked fine but felt terrible, whose lab results always came back perfect. Unfortunately, lab

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Publication Disclaimer

The purpose of InforME Victoria is to offer a wide variety of information about coping strategies, research issues and possible treatments for ME, CFS and CFIDS. There is yet no agreement in the scientific and medical communities with regard to the causes and optimum treatment for the conditions. We make every effort to use only responsible sources, but some information may only be speculative. We recommend that readers consult with a health professional with regard to their own treatment plan.

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Congratulations to Maxine Rogers: she won the \$25.00 gift certificate donated by the Blue Fox! If you remember, we had a draw at the garden party this June. How exciting for Maxine!

I truly hope that you had a grand summer.

Kindest regards,

Gloria Gray
Editor

Hello friends, thanks for joining me. Was your summer too busy? I keep hearing this over and over again. In the summer there seems to be this influx of extra people in our lives, some you know and the others might be tourists. The over-stimulation of "others" can be a challenge because you expend what little energy you have accommodating others just so we can fit in and this can, of course, exacerbate all the many symptoms that we have to deal with. It can be tough when we are with others and when we are experiencing weird symptoms that don't make sense. When we are feeling beyond tired and pushed to our limits, how do we explain our invisible illness to the less fortunate that have not been educated about M.E.? Or do we? How will I respond if I am not heard and, even worse, belittled because we look perfectly fine? Somehow, all I can hear is: *stop your whining*. I know my story is credible, I wish they knew. Feelings get hurt and we might feel invalidated. Does any part of this ring true to you? Living with M.E. IS NOT FOR COWARDS. Do you have a story to share? Well I'm listening, feel free to share.

I am only halfway through the summer and I have decided that I would feel much safer if I were bubble-wrapped. People hug too hard and give very firm handshakes on the premise that a firm handshake makes them a person of good character or something like that. Ouch! Today I was getting up to greet someone and they pushed me on the head as a way of telling me, don't get up on my behalf. Mega ouch! He didn't get it. He didn't get that his little push injured my neck and my shoulders. I was in a crowd and I didn't want to make a scene and I felt confident that whatever I would say would not be respected, so I pressed on and said, "Thank you for your blessing." It sounds like a strange thing to say, but it did get him thinking.

By the time you read this letter, summer will likely have passed. The family will have gone home, the tourists will have left and there will be less noise, less smog and a whole lot more room in this city. I love September! It is still warm and it's the best time to go boating or enjoy the beautiful surroundings of Victoria without the crowds. The gardens are starting to fade, but it is like a new beginning, where everything changes and all becomes normal again.

I am pleased to report that all is well with the M.E. Victoria Association. The Board of Directors have all found where they fit as leaders. Bravo to you all! They are doing an excellent job. I want to thank you not only for your contribution, but also for your positive attitudes. You are a happy, spirited bunch, and I love that you are in my life. Thank you for making such a big difference in the lives of our members.

Our summertime events were a huge success. We had 20-plus come and go throughout the afternoon in June and in August. Loads of yummy things to eat and friendships were made. If you have any questions about your health, disability or any other concerns, please bring them up at the events. There are all types of people with many life experiences that may be able to help you.

Thanks to Krissoula who hosted our August event! She is a graceful, caring hostess. Thank you for welcoming us into your lovely home. Thanks for making the day so special for us.

Continued from front page

tests were of no help in diagnosing FMS.

I started taking a very low amount of amitriptyline (the recommended anti-depressant) and MEP 282/s (aspirin, muscle relaxant and small amount of codeine) for pain, and connected with The Victoria Fibromyalgia Group. There I found not only a great source of information but, perhaps more importantly, others who actually understood what I was going through. I researched at the Victoria Library and the Royal Jubilee Hospital Library, but found the FMS Group the best information source. Today there is so much more information available! I realized through reading and talking with others that there is no “magic bullet”/medical “cure” for FMS! I did find many suggestions for help, mostly of the self-help variety.

I've heard many times from people diagnosed with FMS that their doctor has said, “You have Fibromyalgia, there is no cure, so learn to live with it.” – my translation of the doctor's words is: “I don't know how to cure this, go away and don't waste my valuable time...it's probably all in your head anyway!”

Some better words, from Dr. Bruce Campbell, Stanford Univ. Medical School, Head of the CFIDS/Fibromyalgia Self-Help program are: “Medications and self-help strategies may not cure FMS but they can help reduce pain and discomfort, bring about greater stability and improved functionality and decrease suffering. Knowing that we are not powerless while maintaining a sense of acceptance and willingness to adapt...perhaps over and over again with changing circumstances, can bring empowerment and hope for the future.”

From the Fibromyalgia Alliance of America: “A combination of medication, exercise and lifestyle changes to reduce physical, environmental and psychological stress can help improve your quality of life.”

Medications for pain and sleep disorders are

being developed and refined at a very rapid pace; those with CFS/FMS need to work with their medical caregivers as part of this! We need to read and research to keep up and to find products that work well for ourselves! This sounds straightforward and not too difficult, but what if your family, friends and medical support people don't believe in your pain and/or fatigue. It has been well documented that those with unseen and/or unproven pain, especially in females, are notoriously under-treated for their pain. The emotional and psychological toll on someone with FMS can be as difficult a challenge as the direct effects of the disease. It is not easy living with constant pain and fatigue that is pervasive, unpredictable and unrelieved by rest, PLUS the added effect of it being invisible to others – it's no wonder that it's so difficult for everyone suffering!!

While you are working on the frustrating and challenging job of refining your medications, you can do many things on your own, for example...

Exercise - not of the training for a marathon variety, the key words are - gentle, regular, aerobic and at your own level. Start VERY slowly! Easy short walks are a good way to start. Perhaps around your apartment if need be, and then very slowly increase, be firm but very kind with yourself. Consider exercise videos for those with FMS or seniors. Gentle exercise in water is good, if you like being in water. Always use the warmest swimming pool you can find! Hot tubs and saunas are good to relax your muscles in before and/or after exercise. Classes in Alexander Technique and Feldenkreis can increase body awareness and gentle aerobic, and yoga classes can be very helpful. Treat yourself as you would your best friend.

There are many ways to help with sleep above and beyond medications. Some examples are:

use your bedroom for sleep and snuggling only - do a little, very gentle exercise before sleep - have a warm milky drink - take a calcium supplement at bedtime - herbal sleep aids - chamomile tea - listen to a relaxation meditation or soothing music - wear earplugs and a sleep mask, for the best sleep your bedroom should be dark - experiment with different pillows in different positions - have a hot bath (add epsom salts?).

One of the most beneficial things to do for CF/FMS is to find as many ways as possible to reduce stress, both physical and psychological.

Simplify your life, find easier, simpler ways of doing everything in your life. Break jobs up into smaller bits, set aside some prime time for yourself and not just whatever is left over; also find something or things that give you JOY and do them in your prime time!

Train yourself and ask friends and family to help to recognize the early warning signs. Slow down before you “CRASH” (i.e., your worst symptoms of pain, fatigue, etc.).

A crash can be directly related to “overdoing it” or the weather or another health problem or sometimes we need to accept that it can just happen “out of the blue”.

Refine your diet, eat regularly and well, find what works well for you! Many find that vitamins and supplements (e.g., Magnesium) are helpful.

Avoid chemicals and other irritants like excessive noise (and irritating people!!!). Cultivate a positive attitude. Be proactive and read, try courses at the Arthritis Centre, learn from others!

We need to find a balance between “Becoming Cleopatra” (i.e., Living in a state of de-Nile) and “Becoming our Illness” by letting FMS take over and become our entire life.

Living with an Invisible Illness is a big challenge; you can learn many ways to help yourself and you may be able to educate some friends and family members – slowly and

gently, just like your exercise routine. There are a number of excellent printed sources of information that you can ask them to read or introduce them to others with CFS/FMS or ask them to attend a CFS/FMS Group or Arthritis Centre meeting.

As with any illness or disability, ask that people keep an open mind and not jump to conclusions based on what someone “looks like”!

* * * *

Mary Brownscombe is the facilitator of the Fibromyalgia Support Network. They offer information and a support group for people with Fibromyalgia. They meet the first Friday of every month, except July and August, at 2:00pm, in Begbie Hall, at the Royal Jubilee Hospital.

For more information, contact Mary at 250-381-5202.

News Flashes!

The Fibromyalgia Support Network will be presenting Dr. Tom Hickey at 2:00 p.m. on September 5th at Begbie Hall, Royal Jubilee Hospital.

Dr. Hickey specializes with those suffering with FM symptoms; he also has his own support group for these patients. He is a man of good humour and you might find his approach refreshing.

This time would be beneficial to anyone suffering with ME/CFS/CFIDS or FM

* * * *

Dr. Theresa Clarke will be coming to Campbell River Thursday, October 2, 1:00 – 4:00 p.m. at the Anchor Inn, 261 Island Highway.

For more information, call 1-866-414-7766.

I Have My Life Back

by Maxine Rogers

The number one desire that I have heard in our community, and have frequently expressed it myself, was a desire to get one's life back. In truth, our lives did seem to be snatched away by some malign spirit.

I have my life back. I have recovered. I believe that my recovery is complete.

I didn't want to write about this until I was positive. Many times I seemed to have recovered, enough to behave as a well person, but then I would get over-tired and crash horribly. I have been fully recovered for almost a year now.

I can bike, push heavy wheelbarrows up hills, scythe heavy grass for hours and scuba dive four times in one day. None of these activities caused me to have a chronic fatigue meltdown. I do get tired, but a good night's sleep sees me waking up perky the next morning, ready for more adventure.

What happened? I began to recover some years ago when an exceptionally kind physician took a good case history and decided that I had all the symptoms of thyroid deficiency. Despite tests indicating that I had a low-normal level of thyroid. The drugs he gave me perked me up from a near-death state to a walking-wounded level. He did tests and settled my dosage in the mid-range of normal.

This wonderful physician changed provinces, causing near hysteria in his patients, but he insured that I went to a physician that he liked and trusted. This physician continued my treatment with thyroid and helped me with additional therapies, mostly natural such as diet and exercise. I chugged along at about one-seventh of my former self.

The autumn before last, I became quite ill and went to see my physician for a routine check-up. He asked if I wanted to experiment with

thyroid treatments to see if it would help me. I said I most certainly did, and he increased my dosage. I got better real quick. He did tests that saw me go up to the high end of normal. I felt great.

Six months later, I had been making steady improvement in strength and stamina and went for a routine check-up. We did a test for thyroid to make sure that it was still where he wanted it.

A couple of days later, I got a panicky call from the receptionist to get into the office as fast as possible. My thyroid results were sky-high. I assured my physician that I had no symptoms of too much thyroid. In fact, I had plenty of symptoms of low thyroid. Low thyroid symptoms are exactly as the same as Chronic Fatigue Syndrome. I was getting better, and I had hoped to increase my thyroid as it was the only thing that had ever helped me.

We decided to lower the dosage and test again. Same results; another panicky call to get in the office. Despite taking much less thyroid, my blood level of the stuff were higher still. Remember, it is quite normal for the CFS and M.E. patients to not excrete drugs from our systems.

I was examined thoroughly and was found to have no symptoms of hyperthyroidism. According to my physician, any person with thyroid levels as mine should look like a crack-cocaine addict after a three-day tear. I was fine. I begged to continue treatment as it was helping me so much. We agreed to keep on with the treatment, but I was to report any signs of hyperthyroidism.

I went to Israel for six months and continued on with my treatment. During this time, I lost most of my CFS symptoms and became amazingly healthy. While I was away, I did some research on Victoria's Dr. Derry. He was an old physician who had practiced much medicine before the current method of testing thyroid came out. He thought that the test was bunk and treated all patients with thyroid if they had

symptoms of low thyroid, regardless of what the test said.

He had a multitude of CFS and ME patients, some coming from as far away as Alberta for his treatments. He said, “that it was a wonderful thing to watch their symptoms disappear in over six months or so as they came fully back to life.” Dr. Derry was barred from practicing medication by the BC College of Physicians and Surgeons. His crime was to cure patients instead of going by the dictates of the new thyroid testing procedure.

The Center for Disease Control in Atlanta recognized CFS and ME as new diseases, about eight years after the current test for thyroid became the established method for determining who got treated for thyroid deficiency. Considering my own experiences, and those of Dr. Derry’s patients, I think I have found the malign hand that stole our lives. Pretty disgusting, isn’t it.

It was explained to me that the College of Physicians and Surgeons is run by lawyers who don’t care if the patients improve. They only care that the usual tests were administered and the resulting treatment accorded with the standard procedure. This protects the Colleges from being sued. It all boils down to money and who cares if people suffer.

I eventually started to experience symptoms of too much thyroid, so we backed off the dosage. I am now sailing on an even keel. I feel great! I love my physician! I have my life back!

I urge you all to try at least talking to your physicians about getting your thyroid levels up to high-normal. I don’t believe we all have the same illness. It is my opinion that CFS and ME are what doctors say you have when they are baffled. However, I do think that you need some thyroid and you will buck up like I did. There is hope. Seize it!

From the Desk of Lorraine Huntley

I am reprinting a short excerpt from this article in order to discuss it. This excerpt is from ImmuneSupport.com and is titled: “Treating chronic fatigue states as a disease of the regulation of metabolism.” Prior to this excerpt, William Bains explains he is discussing just one of many causes and ongoing factors affecting CFS.

William Bains suggests: “that patients with CFS have a reduced ability to increase mitochondrial energy production (mitochondria are tiny energy generators in each cell) when exertion requires it, with fewer mitochondria that are each more efficient, and hence nearer to their maximum energy output, than normal.”

This is old news in itself, but the title suggests a treatment that would increase energy so I read on.

“A range of indirect evidence suggests that the renin-angiotensin system (RAS) stimulates mitochondrial responsiveness and reduces mitochondrial efficiency: Chronic under-stimulation of this system could contribute to CFS etiology. (Renin, an enzyme produced in the kidney, acts on angiotensinogen produced by the liver to form angiotensin. Angiotensin causes blood vessels to constrict/raises blood pressure.)”

It would be helpful to know what causes “the under-stimulation of this system” which may be giving me low blood pressure which, if it leads to low perfusion of blood in the brain, could cause my brain fog.

William continues: “If correct, this means that CFS can be successfully treated with RAS agonists (e.g., angiotensin mimetics), or adrenergic agonists. It also suggests that there will be a positive link between the use of adrenergic-

and RAS-blocking drugs and CFS incidence, and a negative link between adrenergic agonist use and CFS. (An RAS agonist or mimic would stimulate renin-angiotensin system activity. A blocker would reduce it.)”

Okay, obviously he is referring to using a drug to reverse the original effect. Although this may be very helpful in furthering research in this area and checking out his hypothesis, I don't like the idea of treating a symptom with a drug. Since all drugs are toxins by definition, I would rather see an approach which would have a better chance of returning me to health. There is a good clue here, though. Something is clearly not working right in the kidneys and/or liver.

Since the function of kidneys and liver is to clean our blood of toxins, then doing what we can to help them makes sense, but taking more medication does not.

I have taken liver-cleansing herbs many times, and I always give up after a few days because of headaches, irritability and a worsening of my symptoms. This year I seem to be progressing, though. I think it has to do with several factors.

First, I have cleaned up my environment by eliminating as many symptom triggers as I could. That included diet and household changes. This was not simple, and in my case took a couple of years to sort out.

Next I had to build up my body enough that I could tolerate doing a cleanse. I did this with homeopathy, supportive herbs, yoga and meditation.

Then I started a very gentle approach to detoxing. My naturopath started me on very specific cleansing herbal preparations. Presently I am taking one to cleanse the body of formaldehyde. I have tolerated these very well and my symptom triggers have weakened, which means I am winning. I have had three colonics which helped me a lot, but I don't think I was strong enough to do them last year. Timing is very important. I am now continuing with simple herb prepara-

tions, avoiding blends and sticking with the most gentle herb alone first. I have help with this from Simple Remedies, my ND, herbalist/medical intuitive Stephen Austen and, most importantly, my own intuition.

I have decided not to suffer my way back to health; if I can't do it comfortably then it isn't benefiting my life today. Today is my life and I intend to enjoy it.

With many wishes for a joyful life,
Lorraine

For Belonging

by John O'Donohue

May you listen to your longing to be free.

May the frames of your belonging be generous enough for your dreams.

May you arise each day with a voice of blessing whispering in your heart.

May you find a harmony between your soul and your life.

May the sanctuary of your soul never become haunted.

May you know the eternal longing that lives at the heart of time.

May there be kindness in your gaze when you look within.

May you never place walls between the light and yourself.

May you allow the wild beauty of the invisible world to gather you, mind you, and embrace you in belonging.

What Is Cortisol?

by Gary Brandstadt

Cortisol is the primary culprit. Cortisol is produced by the adrenal glands, and is primarily responsible for the ‘balance’ of other biochemicals, the workings of the body’s organs in smooth interaction with one another. In a person who feels well, okay, safe, these interactions will be smooth and, hopefully, harmonious.

Stress can cause an increase in the production of cortisol: it puts the whole organism into a somewhat heightened state of arousal, to help manage the stress.

The key part of the brain that affects this production of cortisol is the hypothalamus, located at the top of the spinal column, in the **very centre** of the brain. I have heard it described as the ‘reptilian’ remnant of our central nervous system, whose primary function is to detect **danger**, to then send out messages to prepare the body to fight or to flee from the danger. It tells the adrenal glands to produce an increase in cortisol, and also its sister-biochemical, adrenaline.

Cortisol is felt inside the body as a wave of mild anxiety. As it heightens, it can cause physical sensations, such as agitation, sick stomach, a somewhat prickly sensation in the skin, perhaps a skin rash. The severe, heart-pounding anxiety is caused by adrenaline. These two chemicals together cause all kinds of changes to the body: digestion is shut down, and blood is shunted away from the digestive system to the muscles (including the heart muscle), to prepare one to run. Blood pressure goes up, to prepare one to handle the emergency situation. In Highly Sensitive People the muscles that tighten up are the hips and the shoulders, because their B-I-S system encourages the protective ‘freeze and go into fetal position’ response.

Many other biochemical changes occur in the body. Over time the Immune System becomes compromised.

All of these physical reactions will hang around the body, come and go, as long as there is a sense of distress or unsafety.

The key issue, that we have some control over, is the sense of emergency – the belief that we are in danger, or unsafe. We may be able to keep the flow of cortisol down by ‘mind-over-matter’ techniques that keep us calm and feeling peaceful, no matter what is happening around us. Thus the practice of meditation is encouraged. The example that shows this clearly is the act of dying. Some people are very frightened and agitated at this point in their lives; others are very calm and peaceful. And this attitude depends primarily on two things: a previous mental decision about the process and the sense of support or isolation.

The Courage To Be Imperfect

Before David Burns, a psychologist named Dr. Rudolf Dreikurs, (very influential in the hippy movement of the sixties), tackled the issue of depression, and realized that there was a specific mind-set that kept turning up: the perfectionistic mind-set. That people with a tendency to depression had this ‘Inner Critic’ that was sitting on their shoulder monitoring all their actions, and making judgmental comments about them. They had picked up the habit from somebody in their backgrounds, probably their parents.

Traits Of The Inner Critic

The Inner Critic sits on our shoulder and whispers in our ear.

A lot of you will know about the ‘inner critic’

already, and won't need much explanation from me. But take a look at the following list of its characteristics:

1. It constricts your ability to be creative.
2. It stops you from taking risks because it makes you fear failure.
3. It views your life as a series of mistakes waiting to happen.
4. It undermines your courage to change.
5. It compares you unfavorably with others and makes you feel 'less than'.
6. It is terrified of being shamed and so monitors all your behaviour to avoid this. It digs mind-traps and 'fear-holes' for you to fall into.
7. It causes you to suffer from low self-esteem, and possibly depression.
8. It can make looking at yourself in a mirror or shopping for clothes miserable because of its ability to create such a negative view of your body.
9. It can take all the fun out of life.
10. It make self-improvement a compulsive chore because it bases the work on the premise that something is wrong with you.
11. It doesn't allow you to take in the good feelings that other people have toward you.
12. It make you susceptible, and often victim, to the judgements of other people.

The Inner Critic can also push us into a lesser form of depression: discouragement. (Maybe it's somebody else's Critic.) People who keep high energy and tend not to get discouraged have dismantled the Inner Critic.

Dr. Dreikurs developed a concept that he called 'The Courage to be Imperfect'.

Listen to the following list of ideas and consider building them into your mind-set:

1. (This is from Dr. David Burns) People should be encouraged to pursue **excellence** rather than expected to pursue and reach perfection.
2. **Mistakes are unavoidable**. Mistakes can be regarded as **lessons**, or as aids to learning rather than failures or 'sins'.
3. Too many human relationships are 'mistake-centred' and 'fault-finding', which fosters discouragement, resentment, arguing. Ultimately **perfectionism destroys relationships**.
4. Consider being a **solution-finder** rather than a **fault-finder**.
5. Mutual respect in relationships begins with accepting and **valuing yourself**, including all your faults.
6. Develop a sense of your own **personal strength (courage)** and worth. Develop the courage to cope with the challenges of living.
7. Limit yourself to what you can do. Establish **realistic expectations**.
8. Fierce **competition**, unrealistically high standards, **over-ambition**, and discouragement characterize many ineffective and unhappy human beings. Learn to let go of expectations. That's what weekends and Sundays used to be for.**

** These points have been adapted from a Lesson in the STEP program: Systematic Training for Effective Parenting. Authors: Don Dinkmeyer and Gary McKay, publ. Random House.

Gary Brandstadt, aged 61, is a psychotherapist with fibromyalgia, the slowly developing result of a car accident and back injury when he was 26. He has a Masters degree in Social Work and worked extensively in the areas of disabilities for the first half of his professional life. He states: "As many counsellors will tell you, my professional training really set me up

to be able to sort out and solve my own problems.”

His professional focus has been primarily in two areas: chronic pain and men’s issues. Both of these areas, of course, connect with most other psychological issues: marriage and intimacy, family and child-rearing issues, grief/loss, victimization, stress and PTSD, moods and mood disorders (anxiety & depression). He has run support and psychotherapeutic groups for 35 years.

Gary published the fourth revision of his book ***Chronic Pain Management: 18 lessons in living*** in 2006, and recently published a DVD version of his ***Anger Management Course*** with Pacific Innovations Inc.

Cort Johnson Interviews ME/CFS Victor Martha Kilcoyne

by Cort Johnson*
ImmuneSupport.com
06-15-2008

Martha Kilcoyne is author of the highly rated book [Defeat Chronic Fatigue Syndrome: You Don't Have to Live with It](http://phoenix-cfs.org). This interview is reproduced with kind permission from Cort Johnson's Phoenix Rising website (<http://phoenix-cfs.org>).

Fifteen years ago Martha Kilcoyne had a classic acute onset of chronic fatigue syndrome (ME/CFS), but she didn't end up having a classic outcome.

After enduring one last horrific push/crash cycle as she tried to bull her way through this disease, she and her husband knew what they were doing wasn't working. Martha was on

disability and her husband was trying to raise their two young children mostly by himself. They decided to go back to square one.

Over time, by themselves, this Massachusetts couple ended up producing many of the processes that are now used as a matter of course by many ME/CFS professionals; staying within and slowly building up one's 'energy envelope', maintaining an activity log, focusing on sleep, finding the right physician, etc.

As they did so, Martha's health slowly improved and eventually she recovered entirely. Ten years later she returned to explain how she successfully charted her road through chronic fatigue syndrome (ME/CFS).

Her book - *Defeat Chronic Fatigue Syndrome* - is aimed at the ME/CFS patient. It's short, it's readable, and it focuses on the essentials of managing this disease.

This book is not the one to tell you to take X supplement for Y problem (indeed, the short chapter on supplements is weakest in the book) or which treatments to try. In some ways that's the easy stuff. Managing one's disease successfully while being encased in brain fog and being torn by guilt and remorse and frustration - that's the really hard part of ME/CFS, and that's precisely what this book is about.

In *Defeat Chronic Fatigue Syndrome*, Martha grapples with the fundamental issues chronic fatigue syndrome patients have to deal with: How do I balance health and responsibility? When should I say stop? What should my priorities be? How should I manage this disease?

Would Martha's protocol enable you to defeat ME/CFS? That's probably too much to ask. As severe as Martha's illness was, she was lucky in some of the ways it manifested itself. What her advice does do is acquaint (or reacquaint) ME/CFS patients with the basic do's and don'ts of this disease and give them a strong foundation to proceed. It's practical, hard-earned advice, and her message of hope should prove valuable

to ME/CFS patients everywhere. It is a timely reminder, in our ‘supplement of the month’ world, that sometimes the most effective approaches to disease are the most basic. Martha’s book is a worthy addition to any patient’s bookshelf.

A Chronic Fatigue Syndrome Patient Returns: Cort’s Interview with Martha Kilcoyne

Martha, you have such a great story – complete recovery from chronic fatigue syndrome (ME/CFS)! We don’t hear that a lot. Some people are going to think “Well she probably never had CFS,” but it sounded like you were in pretty bad shape. At one point you said, “When I peered around...I was in a dark unfamiliar space. My state of mind at this point was fragile.” How bad did it get?

At one point the exhaustion and pain were so great that I could barely get out of my chair and walk over to another one. I was really almost paralyzed with pain, stiffness and fatigue at the time. I would be so stiff from my shoulder to my fingers that I couldn’t hold a glass in my hands. I was bed-ridden at one point and on disability.

I think like most chronic fatigue syndrome (ME/CFS) patients there were times I was non-functioning and times I was semi-functioning. Every now and then I’d have a good day and feel like I was on the path to wellness, only to collapse two days later.

I think I’m probably not as unusual as you might think. I believe more people probably recover from chronic fatigue syndrome (ME/CFS) than we are led to believe. What’s different about me is that I returned to tell my story.

* * * *

You weren’t getting any help from your MD’s and at one point you decided to bull your way through this disease. I’m sure everyone’s done it. It seems like it was a critical event for you. What happened?

I had done everything I knew to do. The idea that it was “all in my head” was my last option. I didn’t think it was, but I had to give it a try. I decided to try to push past the disease – three days later I was almost comatose. My husband looked at me and said, “Did you get that out of your system?”

After that the lights went on. The traditional ways of battling disease weren’t working for me. The last two years had been misery. I’d had to go on full-time disability. We had two small children and my husband desperately needed me back. Plus we’d been looking at the literature and it looked like this could go on permanently.

We knew - I knew - I had better days and worse days. He said, “This back and forth is not working. You’ve been basically non-functioning for the last two years. We need to figure out what you respond positively to and what you respond negatively to.” We needed to examine everything I did and what effect it had on me.

I started an activity/medications/sleep/symptoms log and began charting everything significant I did; my activities, medications, hours of sleep, etc. It was like going into a laboratory. Over time certain patterns began to emerge. I’d have a bad day and I’d look back and see I did this, this, and this and I’d think maybe I shouldn’t have done ‘this’ and I’d cut back.

For example, on a good day maybe I could handle driving the car to the store, finding the groceries, putting them on the checkout counter and putting them in the car; but taking them inside, putting them on the counter and then putting them away was what put me over the edge.

My goal was to find a consistent pace I could maintain over a period of time without setbacks, and I did.

Before this, life was a series of big ups and downs but no overall progress. When I was feeling well I'd push hard and then collapse. After this it was more about a little up and a little down, but a gradual uptick overall.

It was excruciatingly slow, though. There were times I was ready to jump out of bed and take on the world, but I had to stick to the plan. It was as aggravating as hell at times. I eventually started calling my husband John "my jailor." There were times I would be up doing a little cleaning in the morning and he'd say "No – stick to the schedule."

From that point on, it took me about a year before I started feeling really well. After that there was a year of gathering my strength and then I was well.

I know we don't know what causes CFS and everyone has a different pattern, but I think everybody has consistent patterns they can uncover. [For details, read an excerpt from Martha's book on "Step One: Understand Your Version of CFS."]

* * * *

You had a great story about your encounter with an MD at an infectious disease clinic. When he told you there was nothing wrong you just erupted – telling him that you weren't depressed and telling him to go find someone who could help you – and it worked! That next doctor was able to prescribe you a rather simple set of drugs that did help you. Do you think if most people keep pushing they will find a doctor with adequate knowledge of chronic fatigue syndrome (ME/CFS)?

I think that people should keep looking, if they can, until they find someone who will work with them. When I had chronic fatigue

syndrome there were fewer knowledgeable doctors than there are now.

Physicians, I have learned, are just as frustrated as CFS patients. The more you can help them figure out what's going on with you the better they can focus on treating it. The log helped a lot with my MD. He loved the fact that it allowed him to focus on certain issues. I could look at it and say I'm doing better here and here and worse here, and he could work on that issue.

* * * *

I think you spoke for a lot of people when you talked about your natural reluctance to take prescription drugs. On the other hand, the natural alternatives just didn't pack enough punch for you, and you noted that your avoidance of them meant that you "wasted a lot of potential healing time."

In the final analysis, how important was it that you found two prescription drugs that helped your sleep and pain?

Absolutely critical. I was very reluctant to take prescription drugs. I told my doctor that I didn't want to feel drugged out - and when he recommended I take anti-depressants, that didn't help either because I knew I was not depressed.

He told me, though, that they were designed to help me with *sleep* rather than with depression and that the doses were very low. The anti-depressant (Elavil, generic amitriptylie) and pain medications (Volataren, generic diclofenac) in combination gave me really good sleep.

After about three months of deep sleep, I could start to feel it when I woke up; that crappy, groggy, exhausted feeling started to lift. After more time the payoff was huge.

* * * *

This book is a lot about giving your body the chance and resources to heal, and you put a special emphasis on getting a lot of sleep.

You say “you must carve out 10 hours each and every night that belong solely to sleep. This time must be sacred!” You’re certainly not alone in this; most ME/CFS physicians emphasize the necessity of getting good sleep. You were getting help from the drugs, but how about practicing good sleep behavior or ‘sleep hygiene’? Was doing that important for you?

Absolutely. I had absolute bed times. Even if I didn’t feel like going to sleep and didn’t feel tired I still had to be in bed at a certain time. I tried to maximize my sleep time. I was basically religious about that. I’d also have a nap from 10 a.m. to 12 noon every day.

I think the pain or fatigue or whatever else you have going in CFS makes sleep really difficult. I noticed I could fall asleep quickly because I was so exhausted, but I’d wake up in pain every couple of hours because of my hip. The pain medications helped with that.

I also had intense low back pain. I had problems with low back pain before chronic fatigue syndrome (ME/CFS), but it seemed magnified. In fact, I think in chronic fatigue syndrome every weak point in your body presents itself more, and that it’s important for CFS patients to identify their weak links and try to alleviate them. My chiropractor recommended I sleep with a pillow between my knees and this helped me sleep better. Now that I’m well I still do this.

I don’t think many people with chronic fatigue syndrome (ME/CFS) realize how much rest they need. I think there’s often a disconnect between the mind and the body in CFS; your mind is racing and telling you to keep moving even when your body is exhausted. There are people who drag themselves around with this disease and try to get away with it. When you’re sick, what does your body tell you to do? – Go home and crash. Be a patient.

* * * *

An important part of your program involves staying within your energy envelope and using your ‘excess’ energy to build your health. You have to be pretty ruthless with yourself for this to work; if the house gets dirty so be it; if the dog needs to get walked – too bad, etc... This program bumps up against our deep need to help out. How do you propose chronic fatigue syndrome (ME/CFS) patients deal with the guilt that stepping back even further brings up?

The ‘could-a’, ‘should-a’, ‘would-a’s were really tough. I had such guilt lying in the bed thinking “I’m not being a good mother/partner,” “I’m not contributing financially,” or “the house is dirty.” The way I stopped beating myself up was to focus on the positive things I was able to do for my family. Besides, being permanently, chronically ill was not going to work. I needed to be a fully functioning partner, mother, worker and person again. I chose to give up one year of my life in order to fully recover rather than spend the undetermined future half sick.

* * * *

One way to combat these problems is to engage in activities designed to instill a calming, peaceful mindset such as active visualization, meditation and exercises.

Did you ever try any of these?

I’m not someone who really uses those methods, but I know that many people find them helpful. Finding ways to be productive within my constraints helped quiet my stress over not contributing. I just had to let go of all that stuff festering about what I wasn’t doing, what I should be doing, etc. That helped a lot. I also made my environment more calming; I’d light a candle or put on some quiet music. I would focus on my gratitude that I was getting better, although slowly, and I held optimistically to knowing that it would eventually pay off.

* * * *

Finding an advocate - someone you can open your heart to and who you can rely on for objective advice - is an important part of your plan. Your husband was your advocate. As you would go charging on trying to ignore/defeat/overcome chronic fatigue syndrome, he'd tell that you were going to be sorry. That's a very enlightened viewpoint! I think having an advocate like that is great, but I'm not sure how many people can find someone like that. What do people do who don't have someone like that in their lives?

I know people are in all kinds of situations. All I can say is, ask for help. So much of what we are taught is to go it alone, to be independent, and there is some pride in that. Lots of times close relatives or friends don't know what you are going through. Try to sit down and talk with them about it and tell them what you need. I know there are people who've been really isolated by this disease and my heart goes out to them. All you can do is try to build a network of support. I think there are more people ready to help than many of us realize.

* * * *

You, in conjunction with your husband and your doctor, put together a way out of chronic fatigue syndrome piece by piece. A lot has changed regarding treatment in the past 10 years. Do you have any comments on the treatments you see offered now?

The emphasis on exercise I see now really floors me. In fact it makes me want to scream sometimes.

Someone who has chronic fatigue syndrome (ME/CFS) has as much reason for doing exercise as someone who's broken their leg. It wasn't until I really started feeling well – until I had extended periods of really feeling good – that I started to do things like ride my bike. Chronic fatigue syndrome patients should identify every-

day activities as exercise, and slowly, without crashing, work up their activity levels before they even think of exercising.

I think nutrition is important and I don't doubt that more helpful supplements have been discovered since I had chronic fatigue syndrome, but I really wonder about people who are taking 20 different kinds of supplements and drugs at once and spending \$200 to \$300 a month on them.

I think some people are probably using up whatever boost they've gotten from the supplements because they're not addressing such fundamental questions as their energy usage and sleep.

I support taking supplements in addition to everything else. I go back to the root of the word: Supplements are supposed to supplement your health, not necessarily fix it.

* * * *

You had a fascinating story with low blood volume. Your reading of literature indicated that blood volume was often low in chronic fatigue syndrome (ME/CFS). At one point, your progress stopped and it turned out that enhancing your blood volume played a big role in your return to health. What happened?

I tend to have low normal blood pressure, but I'd noticed it had gone down. This is not something a physician is going to notice because in our medical culture the emphasis is on *lowering* blood pressure in general.

But when I mentioned it to my physician, he was willing to try to boost my blood volume. Neither Florinef (Fludrocortisone) nor a beta blocker helped, but under my doctor's supervision I started to drink a lot of water and I tried to add a gram of salt a day in order to retain fluids and build blood volume naturally.

Over time it really it paid off. After feeling sick for so long, I began to feel "right" again.

* * * *

I was struck how far ahead of the curve you and your husband were on many of your ideas. You got this disease in 1993. Some of the things you came up with on your own – finding your ‘energy envelope’ and slowly enlarging it, good sleep hygiene, the fundamental importance of sleep in this disease, the activity log – are becoming accepted practice with more knowledgeable doctors.

We weren't really trying to come up with a protocol. But over the course of time it fell into place. When I had chronic fatigue syndrome (ME/CFS), the medical community mostly thought it was all in your head. We knew that was false. So we started to collect data to try and get a handle on what was going on with me. The eight-step protocol came together bit by bit as we “tweaked” along.

I want to emphasize that this is not a short haul. It took me a full year. I've met people who've told me that they tried something for a couple of weeks and quit because they didn't see any benefit. But this is not a normal disease; your time frame should be on the order of months, not weeks.

You have to evaluate yourself on a monthly basis to really see the difference. It's hard to tell sometimes, when you're in the thick of it. That's where the activity log is so helpful. You can look back and see, yes, I have made some progress.

* * * *

Your time with chronic fatigue syndrome (ME/Fibro) was intensely painful; as soon as you got well you said, “I ran screaming from CFS as fast and as far as I possibly could.” Not only did you not talk about it, but you even tried never to think about it. You were afraid that even acknowledging it would somehow give it entry back into your life.

This reminds me of people who've been in war and refuse to talk about it. It really had a hold on you, didn't it?

Your analogy is similar, but the psychological scars left after experiencing the atrocities of war are magnitudes greater than a debilitating illness. That said, I think probably anyone who's been in such an awful situation as CFS runs as fast from it as possible. Plus, people who aren't ill really don't want to hear about it. When you're sick they don't really want to hear about how sick you are, and when you're well they don't want to hear about how sick you were. You gladly get on with your life.

* * * *

Although your life was dominated by this disease for four years it did have some positive benefits for you. Can you talk about those?

CFS (Fibro/ME) truly humbled me. The gratitude that I feel for my good health is so great that it can't be quantified. Every day I am reminded of how healthy I now am. I rarely complain about anything. I live more in the moment than I ever did before and I find that I have more patience for life's bumps and unexpected turns. Each healthy day is a gift that I never tire of opening.

I just wish that everyone can have the success that I've had. I don't expect that everyone can, but I'm an optimist at heart.

**Cort Johnson is an ME/CFS patient who has put his scientific knowledge to work on behalf of others. He offers on the latest ME/CFS research as founder of the website Phoenix Rising: A Guide to ME/CFS, and his Phoenix Rising newsletter. To share Cort's take on the latest treatments & research, read his [expert Q&A with patients](#), held in the ImmuneSupport.com Chat Room, and to learn more about Cort, read the profile [“Cort Johnson: Making ME/CFS Research Readable and Accessible.”](#)*

Upcoming Events!

Hungry for some Thanksgiving Turkey?

Thank goodness! Please join us for this special time as we celebrate all that we have to be thankful for.

October 8th at 2:00 p.m.

Merry Christmas!

You are invited to come and make merry, HO HO HO!
December 10th at 2:00 p.m.

Please bring a new or used item under \$5.00 for a fun gift exchange!

You are welcome to bring guests and snacks to share.

All events will take place at 1908 Stanley Ave.

For more information call Gloria at 250-370-2884 or gmgray@hotmail.com



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