

More Light

Research and Experience with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia and Environmental Sensitivities

Introduction

It took me two years of almost daily work to write and edit *Let Your Light Shine Through*. It was hard work and I had no intention of ever updating it or writing another book. However, as I have continued to read the medical literature, I have been energized by new ideas that can help my patients. I have shared my enthusiasm in the form of newsletters, which can be found on my website, www.eleanorsteinmd.ca/blog. You can browse these at any time anonymously and for free.

In 2018, I realized that in the group sessions I facilitate I was increasingly referring to the new material more than to the material in the manual. Slowly and reluctantly, I concluded that if I wanted to share the new information with a wider audience, the best way was to write a new book. I call this book *More Light*. It is a sequel that builds on, but does not duplicate or replace, the contents of the first book. To get the most out of *More Light*, I recommend first reading *Let Your Light Shine Through*. It is fine if you don't do this, but you may wonder why certain topics are left out.

For example, in *Let Your Light Shine Through* I have sections at the end of several chapters listing the drugs I commonly use for sleep problems, orthostatic intolerance, pain and emotional symptoms. These treatments have not changed much since 2012 and so there is little mention of drugs in *More Light*. A reader of *More Light* may jump to the false conclusion that I don't value drug treatment or am against it. In reality, when working with patients individually, I often recommend medications for various challenging symptoms. I have chosen not to repeat information, so drug information in *More Light* is limited to things I do differently now.

The astute among you will notice a change in terminology throughout this book. Instead of Multiple Chemical Sensitivity (MCS), I now refer to Environmental Sensitivities (ES). This is an umbrella term that refers to conditions in which people become sensitive to substances or phenomena in their everyday environment at levels well below what would be noticed or problematic for most people. ES includes MCS, electrohypersensitivity (EHS) and sensitivity to light and sound. Although EHS is still poorly understood, I will include it wherever appropriate to the discussion, particularly in Chapter 8: Environmental Exposures.

The primary focus of my first book, *Let Your Light Shine Through*, is symptom management. Symptom management is a combination of self-management and management requiring the assistance of a health-care professional. Professional-assisted management could include medications, physiotherapy, kinesiology, occupational therapy and more. The goal of symptom management is to achieve the best possible quality of life despite having an ongoing chronic disease. Symptom management is the bedrock of treatment for all chronic health conditions, even those for which diagnostic tests and medical treatments exist.

If I were to rewrite *Let Your Light Shine Through*, I would make some changes in emphasis or order but the content remains an accurate reflection of the management strategies I have observed to be most effective in my practice. Self-monitoring, improving sleep, pacing activity, managing stress, paying attention to diet, minimizing toxic exposures, and addressing pain and emotional symptoms are all necessary. Sadly, self-management improves and stabilizes health but is rarely sufficient for a full or substantive recovery. Even fastidious attention to symptom management is rarely sufficient to ignite full recovery from ME/CFS, FM or ES. Despite their best efforts, many with these conditions remain severely ill and experience limited lives with considerable suffering. **There is an urgent need for effective therapeutic options.**

For the past six years, my attention has turned toward the science around how the brain and body change and can be changed to achieve therapeutic goals. I am increasingly meeting and hearing about people whose health is improving substantially using strategies informed by this science. Since I try most things before recommending them to others, I have been studying and practicing these strategies daily since 2014. Whether related or not, my health has improved significantly. After 30 years of illness and unremitting limitations to my life, some symptoms are substantially improved.

These strategies are new and not yet research tested. Nevertheless, I cannot in good conscience write a new book without sharing what I know. The research could take decades to catch up and people need help now. An attractive aspect of these new approaches is that they are accessible through books, YouTube videos, and online and in-person courses. Some of the resources are free of charge or the cost of a book. They do not appear to cause any serious side effects (based on systematic reviews recently submitted for publication). So, in *More Light* I will explain, where possible, how self-management can change biology.

Some readers may feel that by focusing on self-management, I am being dismissive of or invalidating the serious biomedical reality of ME/CFS, FM and ES. Nothing could be further from the truth. ME/CFS, FM and ES are biomedical conditions with measurable biological abnormalities. In *More Light* you will learn how changing thoughts, emotional states and behavior can rewire the brain and the body and change our biology.

Scope of the Manual

Like *Let Your Light Shine Through*, *More Light* does not exhaustively review all research or management strategies available. I find books that take this approach deadly boring. The encyclopedic approach doesn't differentiate between effective interventions and ineffective ones.

More Light is written through the lens of my personal and clinical experience. In it I share the clinical approaches I have found most useful in my practice with real patients and the information that seems most promising in the field. The emphasis remains on interventions that are accessible to most patients. I have personally tried most of the strategies I write about and I only include things that "make sense" to me.

Because I rarely see the most severely ill patients (they are too ill to attend appointments), these ideas may not be as relevant to house- and bed-bound individuals whose energy and cognitive function are below 30% of their function before they became ill. Self-management can still help these individuals, but most will need a caregiver to be their surrogate to learn and assist.

New information I will be sharing in *More Light* includes:

- Emphasis on building strengths
- Research relevant to ME/CFS, FM and ES
- New science-based interventions based on neuroplasticity, genetic expression and the microbiome
- More links and references to summaries or commentaries on research rather than the original papers. These are more accessible for the average reader.
- Questions at the end of each chapter to get you thinking about the ideas presented. My discussion of these questions can be found in Appendix A.

Although there is much unknown regarding ME/CFS, FM and ES, there is also a lot we do know. I do not expect most of you to read the medical references. They are provided to show serious readers that I did not make this stuff up. There is a substantial evidence base for the ideas I am sharing. If you share information from *More Light* with your health-care team, please show them the reference lists so that they too can see there is evidence that ME/CFS, FM and ES are real conditions with measurable abnormalities and that research is increasing.

Keep in Mind

If I have learned anything over the past 20 years, it is that **each patient is an individual and no recommendation works in every case**. Just because I am excited about a new research publication or management strategy doesn't mean it will work for you. Likely there are many subgroups of ME/CFS, FM and ES. For this reason, there is

unlikely ever to be a single test or treatment that will be universally effective. Please use your common sense and consult your health-care professionals before undertaking any change in management of your condition.

Disclosures

I do not benefit in any way from any of the recommendations contained in *More Light*.

I became interested in ME/CFS, FM and ES because I contracted these symptoms in 1989. It has taken me 30 years of reading, attending conferences, extensive personal experimentation, persistence in the face of apparent failure and learning from my patients to optimize my own health. My experience with these illnesses has been a strong motivator to find what works, regardless of who came up with the ideas or the school of thought from which they are derived. I have tried many approaches about which I was highly skeptical. Some have helped, while some things that seemed to make sense have proven useless. There is nothing like failure to open the mind to new possibilities.

My own health has improved enough that I no longer consider myself defined by the terms ME/CFS, FM or ES. I have written *More Light* in the hope that you too can reach that goal.

Acknowledgements

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- *Working toward the day when every patient with ME/CFS, FM and ES in Canada receives prompt, respectful and effective health care and social support.* -