

**Step by Step** - A Personal Approach to Managing Fibromyalgia



TERRY SPRINGER

# Your Fibromyalgia Treatment Guide

Treating Fibromyalgia Through the Development, Validation and Utilization of an Individualized Self-Management System.

Brought to you by: <u>Fibromyalgia-Treatment.com</u>

## **Table of Contents**

Chapter 1: Go	etting Started: From Confusion to Knowledge	10
	Associations and Internet Resources	13
	Magazines and Journals	14
	Doctors, Care Providers, and Therapists	15
	Support Groups	16
	Support Groups and Accountability	17
	Primary Focus	18
Chapter 2: R	eviewing Fibromyalgia	
_	History and Introduction	19
	Demographics	20
	Symptoms	20
	Fibromyalgia Triggers	27
	Diagnosis	27
	Causal Theories	29
Chapter 3: F	ibromyalgia: The Elusive Fiend	30
•	General Confusion	30
	A Tough Nut to Crack	32
	Symptom–Cause Interplay and Confusion	
	Negative Feedback Loops	
	Medical System	
	"Magic Pill Syndrome"	
	Effective Treatment - Overwhelming Options	38
Chapter 4: Se	elf-Management: Basis for Effective Treatment	
•	Taking Responsibility	
	Education - Laying the Foundation for Success	
	Defining Your Fibromyalgia	
	Building Your Team	
	Take Action	
	Setting Goals	
	Become a Problem-Solver	
	Evaluating Treatment Options	
	Self-Empowerment	
	Self-Management Conclusion.	
Chapter 5: T	reating Fibromyalgia: What you need to know	
	Medical Specialists	
	Create a Partnership with your Physician	
	FDA-Approved Pharmaceuticals	
	Antidepressants	
	Prescription Sleep Medications	
	Anti-Anxiety Medications	
	Pain Management.	
	Coping Strategies for Pain	
	Dietary Supplements	
	<b>→ 11</b>	_

Diet	66
Exercise	67
Therapies	68
Chapter 6: Pulling it all Together: A Systematic Approach	70
Tools	75
Tracking Symptoms	77
Tracking Causal Relationships, Events, and Triggers	
Tracking Your Treatments	
"Intelligent Trial and Error" – A Concept and a System	
The Key to Success	
Chapter 7: The Future: "FibroTrack"	
FibroTrack: Internet Enhanced Self-Management	
Disclaimer	

\_\_\_\_\_

#### **Introduction**

I am not a doctor, nor a research scientist, medical professor, nurse, therapist or medical practitioner in any sense. There are no fancy plaques on my wall that project some aura of authority over me on this subject (my degree is in History.). I do not have fibromyalgia. So why am I writing an ebook on this subject - and why should you pay any attention?

Fibromyalgia has undermined my life. It is working to destroy my wife and wreak havoc on the lives of my 2 children. Experts always stress that writers and business people should focus their efforts on something they are passionate about. Am I passionate about fibromyalgia? Absolutely! I passionately hate it, to be precise. I love my wife and I have watched her suffer to extremes as we both fought feelings of helplessness and hopelessness for years. I qualify as an expert in how fibromyalgia can destroy.

My wife and I chased a dream together. Not a small dream, not a typical sort of dream but something extraordinary (at least to us). We got it into our heads that we could move our family aboard a sailboat to live full time, home school our kids and live a lifestyle of freedom and discovery spending quality time with each other and our kids. We read, studied, learned and planned and in 2008 we began to make this dream a reality. I purchased a 47' sailboat and poured all that we had into building the boat into a home and restructuring our lives to make this huge change a reality.

Through all of this - we fought fibromyalgia. My wife Michele was diagnosed with fibro in 2003 after the birth of our daughter. She exhibited some symptoms before the pregnancy (her 2nd) but it was only after the c-section birth of our daughter that the fibro began its assault in earnest. The <u>diagnostic process</u> was typically confusing, frustrating and long. We suffered through multiple misdiagnoses, more medical tests than we can recall and a long list of "treatments" - none of which really achieved anything more than draining our bank account.

After being diagnosed with fibromyalgia and learning about the difficulties in treatment, Michele began focusing her attention on researching and implementing treatment options while my focus remained on running our business so we could pay for the expensive treatment efforts she needed. (Self-employed with a very small company - our insurance paid for essentially nothing). We went through many doctors and tried different drugs and combinations of drugs and listened to many specialists. Through it all the fibromyalgia waxed and waned but it was

always there. At times things got better and we were deluded into believing a corner had been turned only to feel crushed again when things got worse. But - we maintained our dream.

Through 2008 as our efforts to make the sailing dream a reality began to pick up steam we also increased the war against fibromyalgia. We began seeing a fibro specialist center, and despite this care being extremely expensive, we went all-in. We both believed that putting forth the effort in a big push to once and for all crush this beast would yield success, and if it didn't, we had a backup plan. The backup plan was simple - If you're going to be in pain, you might as well be in pain in a tropical paradise living aboard a boat. That sounded pretty good at the time.

All of the hard work and effort did pay off. Michele felt much better. In late 2009 we moved aboard our boat full time and began to "live the dream". We had problems (the saying "Going cruising is just repairing your boat in exotic locations" is true). We had adventures and we had fibro. After getting away from the "Big Push" medical efforts the fibro began to slowly build back. After we returned from the Bahamas in June of 2010, fibromyalgia flared with a vengeance, raging like I had never seen before and transforming Michele into a complete wreck.

We were convinced something more was wrong. This flare was different. The pain was overwhelming but it went beyond that to shaking and convulsions and huge migraines coupled with severe anxiety, bowel pains, horrible leg cramping and other symptoms. Was this MS? Could a brain tumor be in play? What could be causing all these new symptoms and in such severity? We were distraught and confused, but one thing rapidly became clear - the "Cruising Dream" was dead. Michele was in serious trouble. We had to seek medical care at once to find out what was really wrong.

This was the worst time of my life. It's bad enough having dreams crushed, but watching my wife suffer was overwhelming. We launched into a whole new endeavor to determine what was wrong. Medical tests flew about like confetti on New Years Eve. Medical bills flowed in on a scale that was shocking. We saw every sort of doctor known to man. The end result, other than insane medical bill totals, was simply this: fibromyalgia.

As we began dealing with fibro on a new level and working to put our lives back in some semblance of order, I began to feel a new sense of mission. I would focus my life on helping my wife overcome this disease and provide my family with the rich

and productive life that they want and need. I had lots of ideas on what form this might take, but the first step was to make myself an expert on fibromyalgia. I set about this task aggressively reading everything I could find. I read books, studied online, delved deep into research reports, contacted research scientists and in general, did everything I could to figure out how to help my wife. I had every expectation that my efforts would yield a magic combination of treatments that would bring complete success.

I no longer have those expectations. Education and knowledge are wonderful things, but in this case, reward was tempered as I began to realize that fighting fibro is a war, not just a single battle.

I also understood that determining what treatments would be most effective for Michele would be an individual struggle. I learned that fibromyalgia manifests itself differently in each patient and that developing an effective treatment strategy would require implementing strong systems in order to effectively manage treatment efforts. I needed to be able to not only research what treatment options were possible, but to quantify results and validate the combined treatment approach that we were developing. I learned that the research data indicated a multi-faceted treatment approach. Such an approach consisting of pharmaceuticals, dietary supplements, exercise, diet changes, therapies and alternative medicine was most likely to yield lasting results, but determining what combination would be best for Michele would be an ongoing individual process.

The more I learned, the more I began to seek out information about self-management programs. Among the very few things I found consistent among the "experts" on fibromyalgia was the call for patients to embrace the concept of self-management. It was clear to me: given the nature of fibromyalgia that a patient-directed, team-focused self-management approach made by far the most sense, but moving from the conceptual idea to implementation proved to be very difficult.

I began to seek programs or systems to utilize in this process. Given that there is so much material out there relative to management of illnesses in general, I expected to find structured online programs specifically aimed at assisting those fighting fibromyalgia in their running of an ongoing self-management program. I searched extensively, but no such program existed. Experts and educational programs exist that are aimed at convincing you that embracing the concept of self-management is crucial to treatment success. However, I found nothing in online systems aimed at

facilitating an ongoing process. Its one thing to learn **what** one may need to do, but it is something else to determine *how* to actually do it. I found no "how."

This need is what has driven both this ebook and the development of the FibroTrack application. My focus is not on telling you specifically what you need to do in order to treat your fibromyalgia. Anyone who purports to tell you what treatments will be effective for you probably does not understand fibromyalgia at its most basic level. The reality is that effective treatment varies from patient to patient and the only way you can tell if any given treatment will be effective for you is to test it. My focus is on this part: the systems and processes required to improve your ability to intelligently test and determine what does work, for you.

In effect, I am not trying to tell you *what* you should do for effective treatment - I am suggesting to you *how* to proceed toward effective treatment. What is a self-management program? How do you develop, implement, and manage one on an ongoing basis? **This ebook answers these questions.** 

The concepts and processes that I present in this book are not new. I have not been engaged in new conceptual research and the processes discussed here are not revolutionary new developments. What I have done is take existing research data and treatment process suggestions from many different experts and combine them into an overall strategy that can be implemented and managed by those struggling with fibromyalgia.

I hope this ebook helps you to improve your fight against fibromyalgia. You will find references to the FibroTrack application throughout this ebook and I do firmly believe that FibroTrack can help any patient improve their self-management efforts. But you do not have to utilize FibroTrack in order to put the concepts and systems outlined in this ebook into action. I urge you - please - make the effort to implement what you learn here. Knowledge without action never yields success. Please take what you learn and put it into action.

I also need to point out that a great deal of relevant information about fibromyalgia is <u>not</u> in this ebook, but is available on my website. The following 3 main sections of the site have expandable menus to the left through which you can navigate to hundreds of detailed articles, all based on medical research with most including references to source research materials. My goal for our website is simple: To provide the largest and most accurate repository of fibromyalgia information on the Internet.

Click these links to learn more!

What is Fibromyalgia? Fibromyalgia Treatment Fibromyalgia Symptoms

Also - Please follow my **Blog.** 

Finally - THANK YOU. Thank you for downloading this ebook and taking the time to read it. I truly value the trust you have placed in me by taking the time to read the information I have put together for you.

If you have any suggestions, questions, concerns or problems that you feel I may be able to help with, I urge you to contact me. Email: terrycspringer@yahoo.com

-----

## **Chapter 1:** Getting Started: From Confusion to Knowledge

Fibromyalgia for most patients begins with pain and confusion. Pervasive and persistent pain appearing with no apparent cause and not responding to typical treatments can leave the patient and care providers frustrated. Diagnostic parameters of this disorder are poorly defined due to its inherent nature. Diagnosis frequently boils down to the elimination of other possibilities, a process that can be both long and confusing. No specific medical tests apply, and no established set of symptoms exist that provide a definitive diagnosis. Confusion and doubt have been central to fibromyalgia throughout its history.

This is our purpose: To develop an individualized treatment approach, confusion must be replaced with understanding so that specific actions can be focused toward the reduction of symptoms.

There is no shortage of information about fibromyalgia and its many different treatment options. Books, websites, magazine, associations and organizations abound on this topic.

Much of the information available online is, unfortunately, of dubious quality. The problem is so pervasive that it triggered a research study of its own, a study that concluded that the majority of fibromyalgia websites are deeply flawed (Click **HERE** for an article on this research study). This is one of the primary motivations behind our website at <a href="http://www.fibromyalgia-treatment.com">http://www.fibromyalgia-treatment.com</a>. Our goal is provide an online source for definitive research based articles and information related to fibromyalgia - so of course we urge readers to use this resource.

In addition to our website, many others provide a wealth of information. We urge those fighting fibromyalgia to use the internet as a source of knowledge and a resource for their own research and education. Step one in any effective treatment effort is going to be replacing confusion with knowledge. This process will of course be ongoing, but simply initiating it is a positive action aimed in the right direction.

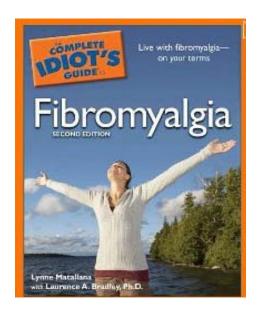
#### <u>Books</u>

There have been hundreds if not thousands of books published on fibromyalgia. Below are brief reviews of 4 favorites:

The Complete Idiots Guide to Fibromyalgia By: Lynne Matallana with Laurence A. Bradley

Ph.D. Stuart Silverman MD, Muhammad Yunus MD

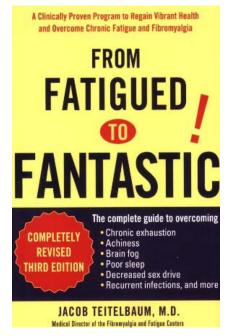
This is a great book. It covers a diverse battery of information and stresses the critical importance of developing and implementing a self-management program. This book also covers many treatment options, the building of a care-provider team, and details on actions you can take to move your treatment efforts forward.



### From Fatigued to Fantastic

Jacob Teitelbaum MD

This book should be considered a mandatory reference manual. Fair warning - the amount of information presented is massive. Dr. Teitelbaum goes into great detail on a huge variety of possible treatment options, so much so that it can be overwhelming. This is not the kind of book someone is going to sit down and just read; its presentation is complicated and at times the content can be difficult to digest. Teitelbaum does focus on the need to develop an individualized treatment protocol, but

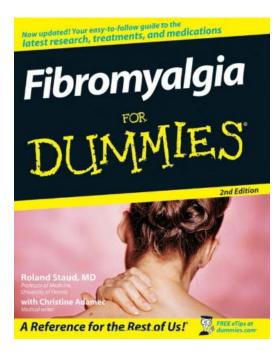


while he is overwhelming in detail relative to what options are recommended, he is a bit short in details on the management process. Despite any shortcomings though, this book has a huge amount of detailed reference information.

#### Fibromyalgia for Dummies

By: Roland Staud, MD with Christine Adamec

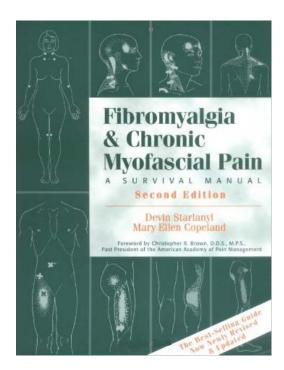
This is both an excellent starting point for beginners and a great reference manual for the seasoned warrior. Much material is covered relative to different treatment options. Much effort is put forth in explaining the history and background related to fibromyalgia, and the reader gains a solid understanding of the struggles those suffering from fibro have faced in having the syndrome accepted by the medical establishment. One shortcoming in this book is its lack of focus on the need for strong selfmanagement processes. The book documents a



wealth of information about treatment options, but it does not delve into discussions about how these efforts should be integrated into an overall plan. Still, it's a worthwhile read and good reference source.

# Fibromyalgia & Chronic Myofascial Pain By: Devin Starlanyl and Mary Ellen Copeland

This is another book that covers a huge amount of content in a largely textbook style manner. Information about Myofascial pain is covered in detail, and it's very helpful given the level of comorbidity between these two syndromes. This book goes into more detail concerning possible causes and triggers, and it discusses the relationships between causal factors at length. The authors discuss the interactions and complications associated with different treatment approaches and the need for the patient to strive to integrate treatments into a comprehensive management strategy, but little detail is provided



on any related processes. Despite this lack, the huge amount of relevant content and excellent supporting graphics are excellent.

#### **Associations and Internet Resources**

Considerable resources are available to fibromyalgia sufferers, all of which provide a multitude of information on living with and treating the disease. Several professional associations have devoted themselves to increasing awareness of fibromyalgia and advocating for those who suffer from it. The National Fibromyalgia and Chronic Pain Association (NFMCPA) joined forces with the now inactive National Fibromyalgia Association (NFA) to become the leading nonprofit organization dedicated to the support of individuals with fibromyalgia and other chronic pain illnesses. Their mission is to educate patients, the medical community, the public, government, and scientists regarding the importance of timely diagnosis and appropriate treatment for fibromyalgia and overlapping conditions. NFMCPA is donor-supported, and members have access to a wealth of information on their website (www.fmcpaware.org), including e-newsletters, Fibromyalgia and Chronic Pain LIFE magazine, online discussion forums, general information on fibromyalgia and overlapping conditions, as well as research and advocacy updates. The NFA website also remains available to fibromyalgia patients (www.fmaware.org) with a number of online resources still available. Other organizations that can provide information and support to fibromyalgia sufferers include the American Pain Foundation (www.painfoundation.org) and the American Academy of Pain Management (www.aapainmanage.org). In addition, a yearly conference on pain, known as PAINWeek, is held each September as an educational opportunity for medical professionals who have an interest in pain management.

A number of Internet-based resources are also available to those who suffer from fibromyalgia. In addition to our website, <a href="www.fibromyalgia-treatment.com">www.fibromyalgia-treatment.com</a>, the online resource Co-cure (<a href="www.co-cure.org">www.co-cure.org</a>) contains helpful information for both fibromyalgia and chronic fatigue syndrome patients, including a daily newsletter, a message board, a list of "good doctors," and a comprehensive review of additional online resources. The website <a href="www.immunesupport.com">www.immunesupport.com</a> is an industry-sponsored patient education site that donates to fibromyalgia and chronic fatigue syndrome research and advocacy initiatives. In addition, it contains a large repository of articles, as well as message boards and support group information. Finally, the Oregon Fibromyalgia Foundation is the website of well-known fibromyalgia researchers Robert Bennett and colleagues (<a href="www.myalgia.com">www.myalgia.com</a>).

#### **Magazines and Journals**

In addition to the education and advocacy these organizations provide, there are a number of magazines and newsletters that provide fibromyalgia-specific information and support to consumers. The NFMCPA publishes their bi-monthly magazine Fibromyalgia and Chronic Pain LIFE, which is available for free to registered members. Back issues are available for download on their website. The Fibromyalgia Network, a member-supported patient-advocacy organization that covers the latest fibromyalgia-related research and treatments, publishes both a quarterly journal (Fibromyalgia Network Journal) and monthly eNews pertaining to topics of interest for both fibromyalgia and chronic fatigue syndrome sufferers. These publications are all free of advertisements. Fibromyalgia Alternative News is an alternative health magazine devoted to exploring the underlying causes of fibromyalgia and chronic fatigue syndrome, and is published quarterly by the nonprofit organization "Fibromyalgia Coalition International." Other periodicals that may be of interest to fibromyalgia suffers include magazines such as Women's Health, which provides information on health, fitness, nutrition, and beauty issues of interest to women, as well as *Prevention* magazine. *Prevention* focuses on providing information for consumers to help them lead a healthy lifestyle and prevent disease.

In the academic world, a number of scientific journals regularly publish fibromyalgia-related information and research. Although fibromyalgia is not a form of arthritis and does not arise due to joint or muscle inflammation (like rheumatic diseases do), it causes chronic pain and fatigue very similar to arthritis, and therefore Rheumatologists are often involved in the diagnosis and treatment of fibromyalgia. As such, many Rheumatology-focused medical journals publish fibromyalgia-related research findings on a regular basis. *Arthritis & Rheumatism* is the official monthly journal of the American College of Rheumatology, and covers information related to diagnosis, treatment, research, and socioeconomic issues that relate to all rheumatic diseases. Other journals include *The Journal of Rheumatology, Clinical Rheumatology, Journal of Clinical Rheumatology*, and *Clinical and Experimental Rheumatology*. In addition, several journals focused on pain management regularly publish findings related to the treatment of fibromyalgia. These include publications such as *Pain* and *The Journal of Pain*.

#### **Doctors, Care Providers, and Therapists**

Fibromyalgia is not a form of arthritis or rheumatic disease in general, however, rheumatologists are commonly consulted during a patient's quest to achieve a diagnosis. This is because the symptoms of fibromyalgia are similar to those of rheumatoid arthritis and other chronic pain conditions of the muscular-skeletal system. Since the diagnosis of fibromyalgia is one of exclusion, these conditions must be ruled out. A rheumatologist is often the most appropriate specialist to do so. In addition to rheumatologists, neurologists are becoming increasingly more involved in the diagnosis and management of fibromyalgia, as our understanding of fibromyalgia as a neurological condition (rather than a rheumatological condition) continues to evolve. General practitioners and internal medicine physicians can also diagnose and treat fibromyalgia. In addition, psychotherapists and psychologists are an important part of a fibromyalgia patient's care plan.

Anxiety and Depression commonly occur with fibromyalgia, and these specialists can help patients address and manage the psychological components of the disease.

In addition to medical doctors, physical and occupational therapists can be of great benefit to fibromyalgia patients. Physical therapy combines therapeutic exercise with other modalities, including ultrasound, electrical stimulation and massage, in an effort to increase flexibility and strength, reduce pain, and improve overall mobility. Physical therapists are licensed healthcare providers specifically trained to administer these therapies. Occupational therapists are also licensed healthcare providers who receive specialized training related to the physical and psychological ramifications of illnesses and injuries. They help patients who have difficulty performing normal activities to regain functioning and independence by modifying the environment to fit a patient's needs.

It is important to note that for most individuals who suffer from fibromyalgia, effective management and treatment is most often achieved through an integrated system of pharmaceutical therapy, complementary and alternative therapies (such as acupuncture, chiropractic, and massage therapy), dietary modifications and supplements, and regular exercise. For those patients who suffer from anxiety and depression, tailored psychotherapy is also crucial.

More detailed information about Doctors and Care Providers is covered in discussions about building your individual care team in Chapters 4 and 5.

Learn more about - Medical Specialists in the treatment of Fibromyalgia.

#### **Support Groups**

Participation in fibromyalgia support groups, whether online or in person, can also be of benefit to patients. Support groups offer an opportunity for fibromyalgia patients to connect with others who have the disease and gain valuable insight that can help overcome challenges and improve their understanding of the lifestyle changes that result from a diagnosis of fibromyalgia. Support groups also offer emotional support, facilitate the exchange of information related to treatment strategies, and provide a safe and understanding environment for patients who can often feel neglected, ostracized, and misunderstood by the medical community.

It is important to understand that not all support groups are the same. Some may be discouraging in tone, with a pervasive focus on the negative aspects of fibromyalgia. Others may unevenly distribute member participation, with one or two individuals dominating the meetings and the focus of the group. Therefore, it is important for you to choose the support group that is best for you and your fibromyalgia. Make sure you choose one that reinforces the positive factors in your life, is constructive and caring, and encourages participation from all members. You may need to try out a few different groups before you find the right fit for you. You may prefer a live support group, or you may wish to test the waters with an online support group first. For some people, using a combination of the two may be most beneficial.

A few examples of the numerous online support communities available include:

- www.dailystrength.org
- www.mdjunction.com/fibromyalgia
- www.fibrotalk.com
- www.livingwithfibro.org

The Arthritis Foundation sponsors fibromyalgia support groups in many locations across the United States. You can find one of these groups by visiting their online support group directory at their website, <a href="www.arthritis.org">www.arthritis.org</a>.

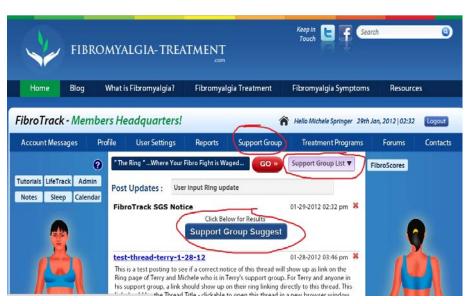
The NFCPA website also offers a directory of support groups (<a href="www.fmcpaware.org/support-groups">www.fmcpaware.org/support-groups</a>), organized by state. Individuals who are interested in starting a support group of their own can also visit the NFCPA website to find information and resources to assist in the startup process, as well as to register new support groups with the NFCPA directory.

#### **Support Groups and Accountability**

Support groups can provide camaraderie for fibromyalgia patients, however they should not be viewed as mere "clubs" where patients convene to commiserate about how terrible they feel. Effective support groups will consist of highly motivated individuals who strive to help each other through the decision making processes that are required to progress toward achieving treatment goals. Support groups should enable members to help each other with goal-setting, review treatment ideas, obtain feedback and opinions on collective symptoms, and maintain motivation during bad times. The KEY to a successful support group is that all members maintain their accountability to each other. Like soldiers in a foxhole, support group members are in this war against fibromyalgia together. They should hold each other accountable, as accountability has demonstrated effectiveness in helping people achieve a variety of goals, and it can also help patients progress toward reducing fibromyalgia symptoms as well.

#### The *FibroTrack*

online selfmanagement system
includes many tools
focused on assisting
those with
fibromyalgia in
building and
participating in an
effective,
meaningful online
support group. This
includes a
sophisticated system



for matching potential support group members based on their demographic data (age, geographic location, work situation, comorbid conditions and Fibromyalgia symptoms). FibroTrack also facilitates support group interaction with social networking functions, contact sharing and rating, symptoms and treatment program sharing, private messaging and forums. The FibroTrack system has been designed from the ground up to promote and support effective support groups.

The information presented in this ebook is merely an overview of the highlights of these topics. Please visit our website, <a href="www.fibromyalgia-treatment.com">www.fibromyalgia-treatment.com</a> for more detailed information, including blogs, articles, webinars, and much, much more.

#### Thank You for previewing this eBook

You can read the full version of this eBook in different formats:

- HTML (Free /Available to everyone)
- PDF / TXT (Available to V.I.P. members. Free Standard members can access up to 5 PDF/TXT eBooks per month each month)
- > Epub & Mobipocket (Exclusive to V.I.P. members)

To download this full book, simply select the format you desire below

