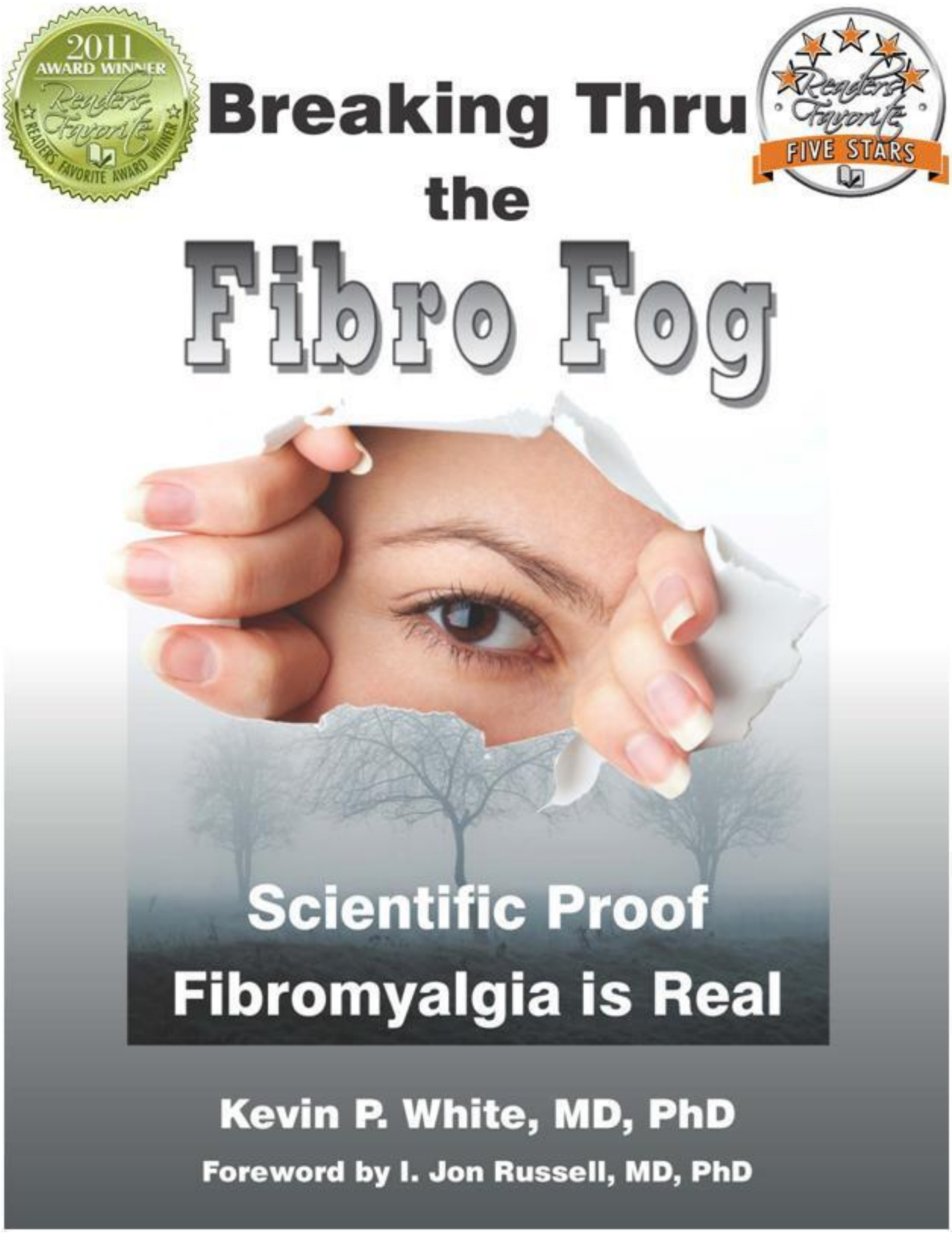

Breaking Thru the Fibro Fog

Scientific Proof Fibromyalgia is Real

Kevin P. White, MD, PhD

Foreword by I. Jon Russell, MD, PhD

Breaking Thru
the Fibro Fog

Scientific Proof
Fibromyalgia is Real!

Kevin P. White, M.D., Ph.D.

With a foreword by Dr. I. Jon Russell

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How many ears must one man have
before he can hear people cry?

Blowin' in the Wind
Bob Dylan

ENDORSEMENTS OF
Breaking thru the Fibro Fog

"God Bless You, Dr. White!"

Ardith Heller (fibromyalgia sufferer)

"BRAVO!!!!!! and there is a lot of clapping going on. For all Fibromyalgia patients, families, physicians, lawyers and researchers, this is a Proverbial Masterpiece. I feel that this book "Breaking Thru the Fibro Fog" is an antidote in itself. BRAVO!"

D. Steele (author, and fibromyalgia sufferer)

"Dr White is an excellent advocate for fibromyalgia and to be commended for this excellent, thorough book to help patients with pain and other debilitating symptoms of fibromyalgia."

Janice Sumpton (pharmacist, fibromyalgia sufferer
and support group leader)

"This book presents, in a clear, and comprehensive fashion, the contemporary scientific evidence on fibromyalgia . It will be of great service to patients and their health care providers; it should become "must reading" for interested third parties, such as insurers, who often need much help in understanding what fibromyalgia is.

Dr. Manfred Harth (Rheumatologist and Professor
Emeritus, University of Western Ontario, London)

"If you have been belittled and ridiculed by family, friends, physicians, employers or attorneys who do not believe your fibromyalgia symptoms are real, this book is for you. Kevin P. White, M.D., Ph.D. restores the credibility and image of fibromyalgia by using scientific logic and examples of other well-known medical conditions to prove that you have a serious, life-impacting disease. White draws on his experience as a researcher in the field and treating physician to give you the ammunition you need to defend yourself against hurtful comments. Everything he states is backed by research. He offers tactful ways to get others to understand your symptoms and respect your physical limitations."

Kristin Thorson (President, American Fibromyalgia
Syndrome Association (AFSA); Editor, Fibromyalgia
Network Journal)

"I LOVED THE BOOK. It is long overdue. Dr. White's dedication and concern for the FM community show in EACH and EVERY word he writes."

Jackie Yencha, Vice President
National Fibromyalgia Partnership (NFP)

"If you have ever been told by a doctor, friend, or family member that FM does not exist and that your symptoms are not real, then this is the book for you. It is one of the best books I have ever read on fibromyalgia, written by one of the most qualified doctors in the field.

The book is expertly written with superb examples and analogies to explain complex scientific points, making the text user friendly and fully accessible to anyone with no medical knowledge. He tackles all the arguments that critics throw at fibromyalgia and all his statements are well supported by scientific research. It brings together the wealth of knowledge we now have about FM and moulds it into a strong argument to legitimise what FM patients around the world have been saying for years. Fibromyalgia is real!

With this book on your shelf you will have the ammunition to defend yourself against any onslaught from any person who says FM does not exist. It will certainly be taking up a space on my bookshelf."

Kathy Longley (Chief Editor, Fibromyalgia
Association of the United Kingdom)

"This insightful book is a valuable tool for lawyers who are prosecuting personal injury actions and long-term disability claims based on a condition that remains poorly understood by both the bench and bar. The detailed index and glossary make it a useful resource to bring right into the courtroom."

Ann Marie Frauts (personal injury lawyer; senior
partner, Frauts & Dobbie Attorneys at Law)

"Great strides have been made in the science of fibromyalgia during the past two decades, yet a great many people, both lay and medical, still fail to understand the breadth and significance of discoveries made. With his own impressive track record in FM research, Kevin White, M.D., Ph.D., is uniquely qualified to make an articulate and authoritative case for the legitimacy of FM. White's new book, *Breaking Thru the Fibro Fog*, is a must-read for anyone with a serious interest in fibromyalgia."

Tamara K. Liller
President & Director of Publications
National Fibromyalgia Partnership, Inc.
[a 501(3)(c) non-profit organization]

“A very well-written user-friendly book that effectively refutes the anti-fibromyalgia critics and gives much needed legitimacy to these long-suffering patients.”

Fred Friedberg, PhD
President, International Association for Chronic Fatigue Syndrome

“Who should, or will read this book? Clearly, patients with fibromyalgia will wish to read it; but others on that list might include those who argue against the validity of this condition, family members who now perceive unexpected cracks in their shields, employers faced with an illness which they fear could affect the bottom line, politicians who are recognizing an illness that affects a large proportion of their constituents, lawyers on either side of controversial issues, and judges required to weigh the arguments in order to make decisions which fairly meet the dictates of law.

It is yet to be seen how history will view this book, but the first step in that process is for history to read its pages and digest its thoughts.”

I. Jon Russell, MD, PhD
University of Texas Health Science Center at San Antonio Faculty
Retired Master, American College of Rheumatology
Editor, Journal of Musculoskeletal Pain
Coauthor, Fibromyalgia Helpbook

DEDICATIONS

This book is dedicated to the millions around the world who have fibromyalgia and have had to suffer in silence. May you now be heard!

And it is especially dedicated to my sister, Barbara.

ACKNOWLEDGMENTS

I have many to thank.

A sincere *thank you* goes to the countless people who helped me by reading this book prior to its publication to provide valuable feedback. Thank you especially to Dr. Manfred Harth, who has been a mentor to me throughout my professional career, and whose undying support of fibromyalgia patients helped me to develop mine; and to Dr. Jon Russell, another tireless FM advocate and researcher, whose assistance has been pivotal to this book being published.

Thank you to Darlene Steele, whose successful fight against fibro can serve as an inspiration to all. Thanks to Kristin Thorson and the American Fibromyalgia Syndrome Association, who have supported me in so many ways throughout the latter stages of this book's preparation, and to Tammy Liller and the National Fibromyalgia Partnership. Thanks also to Jim Asher, Joseé Lemay, and (at Ink Tree Marketing) Denise Hamilton for your continuous guidance in the publication of this book. And thanks to my wife and children for putting up with me throughout the countless hours I spent at my computer over the past 18 months as this book came to fruition.

ABOUT THE BOOK

Did you know that fibromyalgia is more common in Bangladesh and Pakistan than in any country in North America or Western Europe?

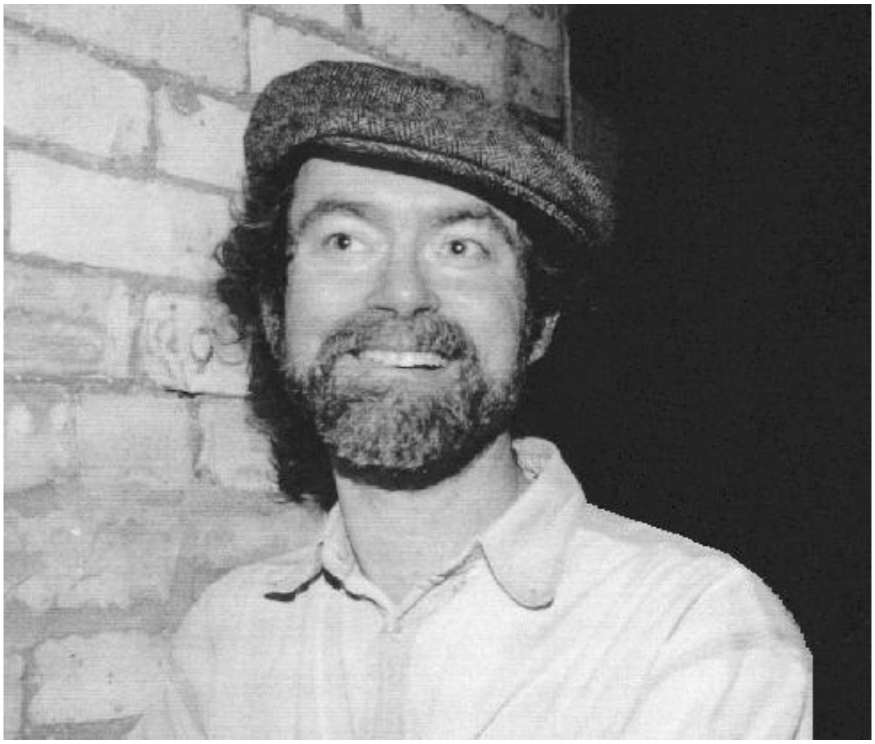
So much for the argument some critics use that fibromyalgia only exists because of wealthy western world insurance and compensation programs.

Fibromyalgia (FM) is a long-term, often disabling disease that affects up to one in ten women and one in sixty males over the course of their lifetimes; and yet many – including many in the healthcare and legal professions – fail to accept that it even exists, or that it can possibly be as disabling as patients say. Over the years, this has led to tremendous hardship for FM sufferers, as they struggle to make others, sometimes their own families and friends, sometimes their employer or own doctor, believe them.

This book is for all of you; and for those who love you; for those who employ you; for all the doctors and lawyers and others who seek to defend you and your rights; and for those who just want to read what the scientific evidence is and then decide for themselves. It contains not only clear, detailed explanations, but scientific references, a glossary of terms, a list of referenced authors, and an index to aid those who really want to explore the science behind this disease.

Fibromyalgia is real. This book should leave no room for doubt.

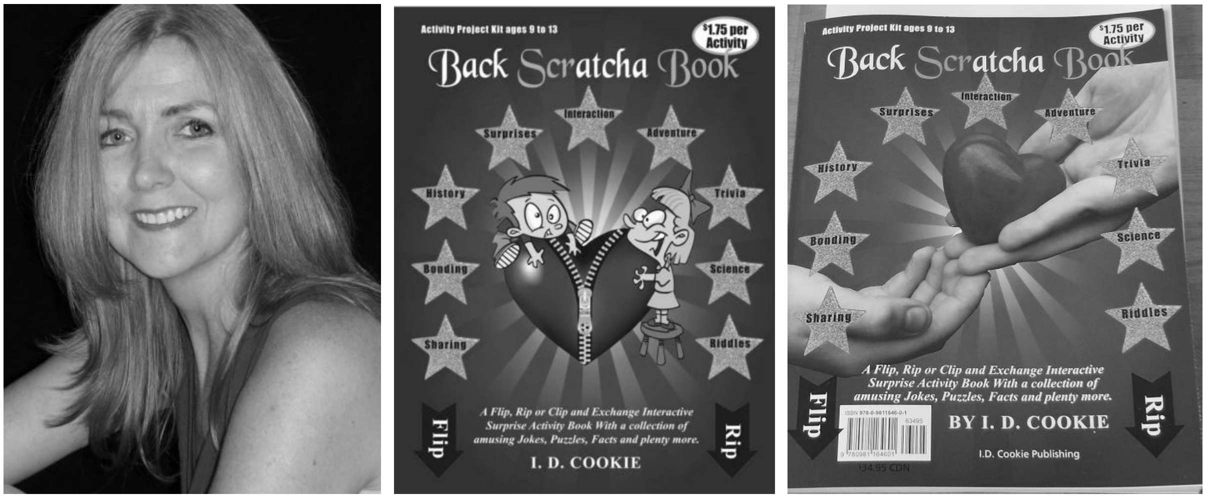
ABOUT THE AUTHOR



With a medical degree, training in two specialties and a further doctoral (Ph.D.) degree in medical research, Dr. White has been an internationally recognized expert in fibromyalgia treatment and research, fibromyalgia patient advocate, and former university Teacher of the Year. Now retired from active practice, he has turned to writing, having already written four novels, nine children's books, a book of inspirational essays and, as a singer-songwriter and multi-instrumentalist, over 400 songs. In this newest book, Dr. White returns to his roots in medical practice and research, trying to help millions of fibromyalgia sufferers with a book that, once and for all, tells all that FM really is real.

ABOUT THE BOOK'S COVER

The cover was designed by Darlene Steele, an amazing woman who epitomizes what this book is all about. She was an extremely busy office manager overseeing dozens of employees and operations while raising two daughters all on her own when, five years ago, she suddenly developed fibromyalgia and became unable to function in the workplace. Instead of giving up she, like Dr. White, turned to writing; and it was through a newspaper article announcing the release of one of her books that Dr. White learned her story. Finding out that she had designed the covers of her own book entirely herself, Dr. White asked her to design the cover to this book; and seeing the result, all his books. Though Ms. Steele still cannot function in a demanding workforce, it is clear that her brilliance and creativity are far too special to be wasted.



Darlene Steele (pen name I. D. Cookie) and one of her own books.
Darlene's books (under the pen name I. D. Cookie) are available at
www.wortleyroadbooks.com and www.backscratchabook.com

FOREWORD

by I. Jon Russell, M.D., Ph.D.

How interesting it would have been to listen in on the conversations of Greek or Roman philosophers as they offered to their students contemporary knowledge gleaned from careful observation and study. Our culture pretends to be so advanced over those that came before us, but the likelihood is that the concerns of those ancient peoples were not very different from our own.

In this book, the reader can almost voyeuristically listen as Kevin White, M.D., Ph.D. explains fibromyalgia to his patients. As he addresses each symptom or finding, the good doctor uses illustrations that he knows will be familiar. The listener is struck by the hominess of the physician’s domestic experience. On one occasion he is folding laundry, while on another, the focus is on the severity of his own pain sustained in an accidental injury.

It should come as no surprise that Dr. White speaks with more than one voice in different parts of the book. In fact, he has at least three voices and he uses two of them in these pages, depending on what is needed. In one chapter, the reader experiences the down-to-earth clinician voice (M.D.) trying to help his patient understand chronic widespread pain or dysfunctional, non-restorative sleep. In another, the reader will encounter the authoritative scientific voice (Ph.D.) describing the meaning of sophisticated research findings. Dr. White's scientific training and experience comes through when he is quoting original sources and teaching through the presentation of research findings. Dr. White knows this material so well because he conducted much of the research himself. It was he who studied the epidemiology of fibromyalgia in Canada. It was he who quieted the critics when they claimed that it is medically harmful to make the diagnosis of fibromyalgia. It was he who discovered the high prevalence of fibromyalgia in the Amish people of Canada.

Dr. White's third voice, by the way, is that of a folk singer who has put to music many interesting vignettes from Canadian history. Look it up on any internet search engine and listen to one of his CD albums. Bet you can't stop with just one.

There are now many books on the market that present the scope of fibromyalgia in the world today. Each offers something unique to the reader. So, why is this book needed and why will it find an important place in the field? To this question, there are many answers. Only a few medical topics have suffered so much from bias and misunderstanding as fibromyalgia, but attitudes are changing. Perhaps for that reason, few fields in medicine are advancing at the rapid rate we now observe with fibromyalgia. Every new research finding must be examined carefully for relevance and importance. All of the new data require expert integration and then explanation.

Who should, or will read this book? Clearly, patients with fibromyalgia will wish to read it but others on that list might include those who argue against the validity of this condition, family members who now perceive unexpected cracks in their shields, employers faced with an illness which they fear could affect the bottom line, politicians who are recognizing an illness that affects a large proportion of their constituents, lawyers on either side of controversial issues, and judges required to weigh the arguments in order to make decisions which fairly meet the dictates of law.

It is yet to be seen how history will view this book but, the first step in that process is for history to read its pages and digest its thoughts.

I. Jon Russell, M.D., Ph.D.
University of Texas Health Science Center at San Antonio Faculty
Retired Master, American College of Rheumatology
Editor, Journal of Musculoskeletal Pain
Coauthor, Fibromyalgia Helpbook

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INTRODUCTION, BY DR. WHITE

WHY I'M WRITING THIS

I was seven years into my medical training towards becoming a practicing pain specialist before I ever heard the term *fibrositis*. Not once did I recall it having been mentioned in medical school or during my residency training in Internal Medicine, until I went to a 3-day symposium in Napa, California, on arthritis and rheumatism. The lecture on fibrositis was the last one given, over the final lunch. Many attending the symposium had already left. I suspect that those who hadn't left mostly had stayed for the fancy lunch, rather than for the lecture. I listened to what this specialist was saying and, I am sorry to say, at some level thought he was some sort of snake oil salesman, trying to sell me on some disease without any physical or laboratory signs, and without any changes apparent on X-ray, CAT scan, MRI or any other imaging technique. It sounded a bit like hocus-pocus to me.

It was almost a year later, months into my own specialty training in Rheumatology (specializing in diseases of the musculoskeletal system, like bones and joints) that I saw my first 'fibrositis' patient, though now the disorder was more often called 'fibromyalgia'. Over the next ten years of training and my own practice, I probably saw two to three thousand more such patients; and though different in some ways, there were so many things they all had in common... the pain everywhere; the extreme fatigue; the poor sleep; the problems with memory.

Over this time, I had obtained a second doctoral degree (Ph.D.) in medical research, to go along with my M.D. degree, so I had developed into a pretty critical thinker. That critical thinking led me to really look into this condition that I wasn't sure I believed in or not. Over time, I came to believe in it more and more. And, over time, I came to see how fibromyalgia patients were being denied so many rights afforded patients with other painful conditions, like arthritis and heart disease. Many were denied disability payments when they became unable to work. Many essentially were told by doctors and insurance companies and lawyers and judges and friends and family members that they just needed to “snap out of it.” Repeatedly, I read opinion papers – almost exclusively written by doctors who hadn’t done research in the area or, sometimes, in ANY area - that fibromyalgia wasn’t real; that doctors who supported this diagnosis were doing more harm than good. Finally, I wrote an opinion paper myself, called **Fibromyalgia: The Answer Is Blowin’ in the Wind** (Journal of Rheumatology, 2004;31: 636-9), in which I poked holes in every single one of the arguments that I had heard raised against fibromyalgia. Of all the scientific papers and book chapters and other medical writings I have done to date, I consider that one opinion paper the crowning accomplishment of my career. I see it everywhere on the internet. In fact, if you Google search my name, that paper is probably the very first thing that will appear.

This book is that opinion paper expanded, and written in a way such that patients and doctors and lawyers and loved ones of patients and anyone else who wants to find out why fibromyalgia (FM) truly exists can really delve into it. I have included the scientific references on which I base my arguments and conclusions, including many scientific papers I published myself.

Writing this book has been difficult, because of the diverse audience this book is intended for. I have wanted, on one hand, to make it easy to read, even for those with no or next to no medical or scientific background. On the other hand, I also want it to be informative and of use to doctors, lawyers, and other professionals who want to delve more into the science of what I’m writing (hence, the glossary of terms, index, lists of referenced researchers and authors, and a complete list of references to papers and study results that have been published in various scientific journals). I hope that I have achieved that delicate balance, so everyone can read and get something useful from this. My ultimate goal for this book is that it will help those with fibromyalgia get back some of the respect and rights that every single person deserves.

Kevin P. White, M.D., Ph.D.

PART 1

FIBROMYALGIA:

WHAT IT IS

AND

WHAT IT ISN'T

CHAPTER 1

WHAT IS FIBROSITIS/FIBROMYALGIA?

Fibrositis and *fibromyalgia* (FM) are the exact same thing. *Fibrositis* is an older term that was coined in 1904 by Dr. William Gowers(1).[A] This term literally means ‘inflammation in fibrous tissues’; fibrous tissues being, for example, *tendons* that connect muscles to bone, and *fascia*, which is a nerve-rich, thin, sac-like structure that surrounds every muscle, kind of like slippery Saran wrap.

Meanwhile, the term *fibromyalgia* means ‘pain in muscles and fibrous tissues’. The defining characteristic of all fibromyalgia patients, therefore, is pain that, for years, was believed to originate in muscles, fibrous tissues, or both. What all this means is that, if you don’t have pain, by definition you don’t have fibromyalgia as it currently is defined.

But fibromyalgia (which I will abbreviate to FM) is not just pain in your left finger and right knee. People with fibromyalgia have widespread pain, pain that seems to affect their muscles everywhere, or almost everywhere. Roughly half of FM patients say that they hurt all over(2). To some who don’t have FM, this sounds strange: how can someone possibly hurt all over? But to them I ask: have you ever had a really bad flu where you ached all over? Maybe you also had a splitting headache, and felt so wiped out and weak you could barely stand. In a nutshell, THAT is how most patients with FM feel... like they have the worst flu of their life; and, worst of all, it virtually NEVER goes away.

The pain of FM frequently is accompanied by other muscle problems as well, like severe muscle stiffness, especially in the morning, but also after the person does

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[A] The number (1) here refers to a scientific paper or book, listed at the end of the book, in the section called References, where you can find evidence that the statement I have just made is true.

something that they used to do easily, like getting dressed(2), and sometimes lasting all day(3).

Additional sources of pain are headaches, eye pain, sore throat, and abdominal and pelvic pain. A minority of patients have considerable discomfort when they pass urine. Many have regular abdominal (belly) cramps. And so on.

> The bottom line is this: persons with fibromyalgia hurt, seemingly everywhere or almost everywhere.

But, technically, FM is more than just widespread pain. First the pain must be chronic, which means ‘long-lasting’; and, by this, I mean having lasted at least three months. This is to distinguish it from that really bad flu I mentioned earlier.

And, to meet the current medical definition of FM, besides widespread pain, someone also needs to be tender in characteristic areas when a doctor or some other diagnostician (like a therapist) pushes on these points relatively lightly with their thumb. How this is done will be covered in the next chapter.

But FM is even more than chronic widespread pain and tenderness. It also includes a host of other symptoms that may or may not be present in any given patient. This collection of symptoms has led some to call the condition *fibromyalgia syndrome*.

But what is a syndrome? The best analogy I can come up with is that FM is kind of like a city bus. Have you ever ridden the same bus every day at the same time over an extended period of time, for example, to go to school or to work? Maybe this was before you had a car; or after you no longer could afford to keep one.

Pretend, if you will, that you get on the same bus at the same place and same time every day. Next, for the sake of this analogy, let’s pretend that the driver is always the same. Let's also say that there are a few passengers who are VIRTUALLY ALWAYS on the bus at the same time you are riding it: perhaps there's an old woman who always sits in the third row; a middle-aged man with a brief case; and a kid who sits in the back. In addition, there are a few people who USUALLY are on the bus; not every day, but most days; there are some who OFTEN are on the bus, maybe 30% of the time; and finally, there are some you recognize, but who are only on the bus OCCASIONALLY.

Fibromyalgia syndrome is kind of like that. The DRIVER of the fibro bus is chronic widespread pain. If a person doesn't have pain, they don't have fibromyalgia... they must be riding some other bus, because pain is the defining characteristic of fibromyalgia. The passengers who are VIRTUALLY ALWAYS on the bus are the characteristic tender points; occasionally, we see a person who has all the symptoms of FM but who isn't that tender, but this is quite uncommon. In addition, fatigue and poor sleep are almost always a problem. Other symptoms that USUALLY are present are problems with concentration and short-term memory – something that has been called the *fibro fog*(4). And so on. A more complete list of fibromyalgia symptoms is this:

MUST BE PRESENT (for it to truly be FM, as it is currently defined; this will be explained in greater detail in the next chapter)

- Chronic widespread pain
- Chronic widespread body tenderness

VIRTUALLY ALWAYS PRESENT

- Debilitating (disabling) fatigue
- Poor (non-restorative) sleep (you wake up feeling worse than when you went to bed)

ALMOST ALWAYS PRESENT

- Problems with short-term memory
- Problems with concentration
- Headaches

- Migraine headaches

OFTEN PRESENT

- Diarrhoea; constipation; or diarrhoea alternating with constipation (commonly called *irritable bowel*)
- Crampy abdominal pain
- Abdominal bloating
- Pelvic discomfort
- Urinary urgency (having to go immediately) associated with discomfort
- Numbness and tingling, especially in the hands and feet
- Cold-induced whitish discoloration of the hands and feet (something that is called *Raynaud's phenomenon*)

Other less common symptoms can occur too, but it is beyond the scope of this book to go into them all. Suffice it to say that the bus analogy and the list of symptoms given above should give you a pretty good idea of what fibromyalgia is.

Some of the characteristic features of FM - like the debilitating fatigue, the poor sleep, and the fibro fog - have been reasonably well explained by the research that already has been done on FM. The association between FM and certain other symptoms, like the diarrhoea and hand discoloration, seem less intuitive, though our recent understanding of FM as more of a neurological than a musculoskeletal disease makes such connections more understandable. A lot more about this will come in later chapters.

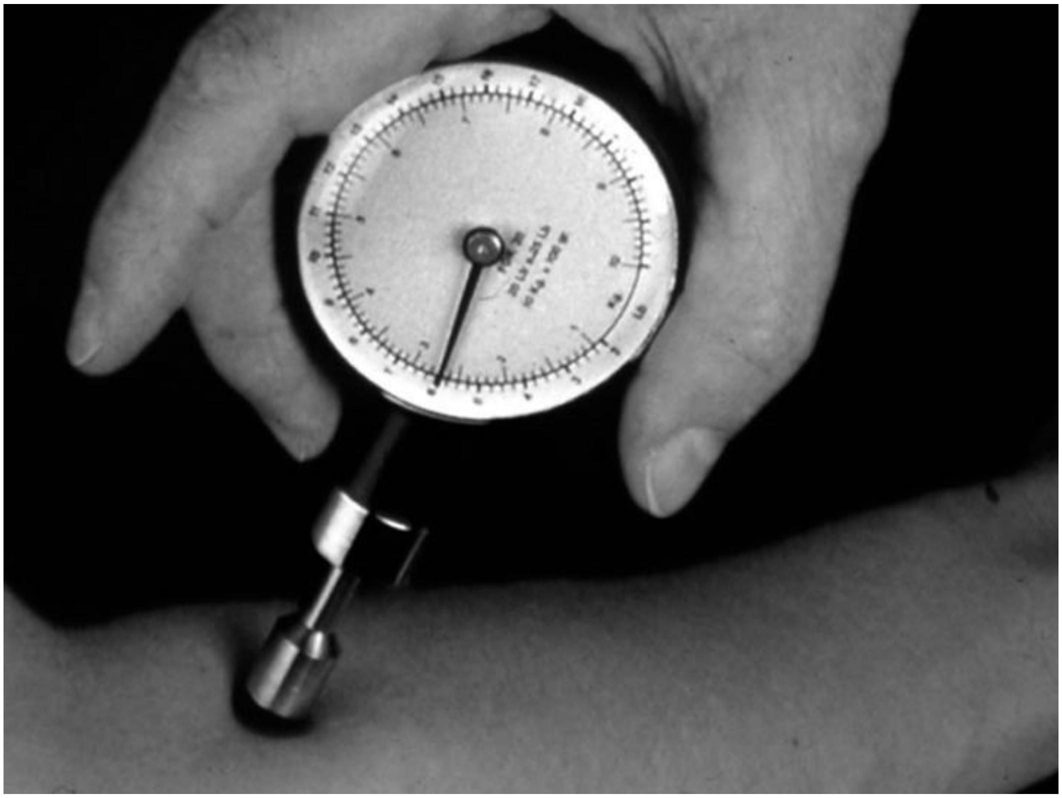
Other Signs of Fibromyalgia

In addition to the characteristic fibromyalgia tender points, there are numerous other things that doctors may find when they perform a physical examination. For example, FM patients characteristically state that their worst areas include their neck and shoulders, and their low back and hips. Understandably, then, patients with FM often are diffusely tender throughout these regions, and many show decreased range of motion of the neck, shoulders and low back.

In addition to diffuse (widespread) tenderness in these areas, patients also frequently have something called *myofascial* (= muscle + fascia) *trigger points*(2;5). *Trigger points* should not be mistaken for tender points, though this error commonly is made by physicians and other examiners. A *tender point* is a point on the body surface that, when pushed upon by an examiner's thumb, causes pain directly under the thumb. A *trigger point*, on the other hand, is a point on the body surface that, when pushed upon by an examiner's thumb, causes pain that radiates (spreads) away from the point that is being pushed; for example, pushing on the mid trapezius muscle of the shoulder (half way between the neck and the tip of the shoulder) may cause pain to shoot up the neck and down the adjacent arm. This process of *triggering* is what Kellgren and Lewis described in their experiments in the 1930s(6-9).

Two additional physical findings commonly present in FM patients are skin-fold tenderness (literally, pinching the skin lightly causes severe pain) and something called *reactive hyperaemia*(2). Reactive hyperaemia (*hyperaemia* means: too much blood) most commonly is observed on the patient's back. After the doctor pushes down with his or her thumb and then lets go, the patient's skin becomes very red and warm, and will remain so for minutes or even hours afterwards, as opposed to returning to normal color and temperature within seconds, which is what happens in people without FM. The importance of reactive hyperaemia is that it cannot possibly be faked. Unfortunately, it is not seen in a significant enough majority of individuals with FM and not absent in enough people without FM to be considered diagnostic. Nonetheless, it can be a dramatic finding which often is directly over the patient's areas of greatest reported pain.

A *dolorimeter* or *algometer* (both of which literally mean 'a pain measuring device') is a small tool that doctors and therapists sometimes use to quantify a patient's level of tissue tenderness. It is a spring-loaded device with a rubber end attached to a numerical dial; in essence, it looks kind of like a stop-watch with a rubber stopper sticking out on a short rod (see picture below). The examiner pushes the rubber end into the patient’s muscle at a perpendicular angle, asking that patient to say when the pushing starts to hurt. The examiner then ceases pushing and records the level of pressure that was being applied when the patient first said it hurt. In fibromyalgia, patient pain thresholds are usually very, very low. In other words, even very light touch with a dolorimeter causes the patient to have pain.



An algometer/dolorimeter measures a patient’s degree of tenderness

Decreased pain threshold on dolorimetry testing has been proposed as a more ‘objective’ physical finding than tenderness to an examiner’s thumb, but dolorimetry testing may be less sensitive(2). Hence, most FM experts recommend that doctors use their thumb instead of a dolorimeter when making the diagnosis of FM.

Dolorimetry readings are sensitive to numerous factors, like the size of the dolorimeter's rubber foot plate, the dolorimeter's scale length (for example, can pressure readings be measured just to 5 kg pressure or can they be measured as high as 7 kg or even 9 kg?) and the rate at which dolorimeter pressure is applied(10-12); for example, does the doctor push down slowly or really quickly? What all this means is that any doctor who insists that a patient's previously-made diagnosis of FM is wrong because no dolorimeter was used, themselves are wrong. At this time, the only validated role dolorimeters have, at least with respect to FM, is in scientific research.

Who Gets FM?

Women appear to be more likely to get FM than men, but both genders get it. In our own survey of almost 3300 adults living in London, Ontario, Canada, we confirmed the diagnosis in roughly one in twenty women and about one in sixty men(13). Most had never been diagnosed. In fact, though it hopefully has improved over time, the average duration of symptoms before someone with FM ever even gets to see an appropriate specialist who could diagnose it, has been as long as between 5 and 8 years(3;14-16).

People of all ages can get it, including children(17); but it is most commonly first diagnosed in those who are in their thirties through fifties(13).

Several patterns of disease onset have been described. One pattern is a slow, insidious onset without any precipitating event. A second pattern of onset is much more sudden (acute), often appearing to have been precipitated by something like an injury. There are those who suggest that FM often is caused by some form of injury(18;19). And a small percentage of cases seem to start after some sort of fever-associated illness (presumably an infection), though whether any true relationship exists remains unproven(20;21).

FM may present in association with a variety of psychiatric illnesses. In several studies, FM patients have scored higher than controls (those without FM) on a variety of psychometric scales[B] for anxiety, depression, and hypochondria(22-25). Some have interpreted this as evidence either that psychiatric illness causes FM, or that FM is a psychiatric illness(26;27). Extreme caution must be exercised when interpreting the results of these studies, however. First of all, patients with long-standing (chronic) pain, irrespective of the cause, will score abnormally high on a number of such psychometric tests when compared against those who are healthy(28), which may result in the tests being wrong, particularly when assessing for depression, hysteria and hypochondria(28;29). Second, the majority of patients with FM do not show significant differences in these psychometric scores relative to patients some painful condition like rheumatoid arthritis(22;25). Third, the majority of FM patients seen in rheumatology clinics do not have a psychiatric illness(15;30). And fourth, there is evidence that psychiatric diagnoses in FM patients are related to health care-seeking behaviour, rather than to the illness itself(31). In other words, the ones with FM who are most likely to be sent to a specialist are those who are most psychologically distressed by it; which makes complete sense.

The evidence is as strong or stronger that FM is associated with a variety of other non-psychiatric disorders, with one study finding FM in 15% of 522 hospital in-patients on the Internal Medicine ward at a large Israeli hospital(32). FM frequently occurs in the setting of other rheumatic diseases. Somewhere between about 20% and 65% of rheumatology clinic patients with a very complex condition called primary *systemic lupus erythematosis* (SLE) meet the American College of Rheumatology (ACR) criteria for FM(33-35), and FM appears to be a common component of other arthritis conditions like rheumatoid arthritis(36), osteoarthritis(37), and psoriatic arthritis(38), among others. Men and women who are infected with the human immunodeficiency virus (HIV) that causes AIDS(39) or with human T cell lymphocytic virus type I(40), and women with excessively high hormone levels of either prolactin(41) or thyroid hormone(42) appear to have a significantly increased risk of FM. Women with high prolactin levels have a risk that is fifteen times as great as women without(41). Men with a condition called

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[B] A psychometric scale is usually a questionnaire that asks the patient various questions about their mood, level of anxiety, and so on.

sleep apnea (where people actually stop breathing for very short periods, like several seconds, during sleep) might have an increased risk of FM, though the research is not entirely clear on this (43;44). And, though generally only seen in less than half of FM patients, several studies conducted worldwide over the past 15 years have documented an association between FM and joint hyper-mobility(45-49).

So, if FM commonly is present in people with other diseases, how about the reverse? How common are other conditions in people with FM? Despite the apparent associations between FM and various other illnesses in clinic studies, there have been no studies estimating the frequency of such illness in individuals with FM in the general community. However, since FM appears to be considerably more common than most of these other conditions, it may be that co-morbid (coincident) illness only affects a small percentage of the total FM population. If this seems contradictory to you, think of this analogy:

> Patients with a condition like lupus commonly have FM just like grapes commonly have seeds. Yes, there are seedless grapes; but a large percentage of grapes have seeds. On the other hand, only a small percentage of all the seeds that exist in the world are inside a grape, just like only a small percentage of all those with FM have lupus.

The Course of Fibromyalgia

By definition, fibromyalgia is chronic, since the pain must have lasted at least 3 months for the condition to be diagnosed. But what happens long term? Suffice it to say that, if FM went away relatively quickly – for example, within a year or two – there would probably be no need for a book such as this; patients themselves would be less frustrated; and everyone else – from uncertain family members to employers and insurers – would be more supportive. Unfortunately, however, FM is much more chronic than this, with most patients having continued pain, fatigue, and other symptoms for years, if not indefinitely. The outlook seems somewhat less bleak in children and teenagers; but, with the exception of an Australian study in which 24% of patients had entered into clinical remission within 2 years of their initial assessment(50), at least in adults, complete remission is uncommon(51-57), and the response to treatment often is modest. That is not to say that all patients do poorly. But, as noted in Chapter 17, many become unable to continue working, and most experience major reductions in their activity level. It is the issue of disability that probably sparks the greatest degree of controversy over this condition, even among those who support the FM concept(51;52;58-62). The issue of trauma as a precipitator of FM takes on additional importance given the persistence of symptoms, so it has become a second major source of controversy. And, in response to these two issues, naysayers have flourished, as Chapter 3 will illustrate. One final issue that I will cover briefly here is the controversy over whether FM and chronic fatigue syndrome are the same condition, within the same spectrum of disorders, or quite distinct.

The FM versus CFS/ME Debate

It is not at all uncommon among support or advocacy groups to include both FM and *chronic fatigue syndrome* (CFS; also called *myalgic encephalomyelitis* or ME) in the group name. In Canada, for example, the CFS-FM Action Network provides advocacy, information and patient support to those with either CFS or FM. Similarly, in Australia, the various regional branches of the ME/CFS Society Inc. all provide information and support to those with FM too. This likely is because, in terms of how patients feel, the two conditions seem to have more similarities than differences.

As with FM, there is no single diagnostic test that is useful for diagnosing CFS. The first working definition of CFS that the Centre for Disease Control (CDC) in Atlanta, Georgia endorsed was published in 1988. This definition required that a patient fulfill one major and a number of minor criteria, most of which are very subjective symptoms (for example, joint pain) or non-specific physical signs (for example, fever)(63). Later sets of criteria, published in 1994 and 2005, similarly rely on patient symptoms rather than any hard physical findings(64;65). Although the case definition for CFS also requires that other potential causes of fatigue be excluded, it is very difficult to exclude FM because of the striking similarities between these two syndromes. Profound fatigue often is a major complaint among fibromyalgia patients. Diffuse muscle and joint pain is a frequent symptom of CFS, each being one of the 11 minor symptom criteria in the case definition. In fact, virtually every one of the minor symptom criteria for CFS is a frequent complaint among FM patients. And, although many consider CFS to be transmitted by an infectious agent, like a virus or bacterium, a flu-like or other infectious onset is not required by the 1988 CDC criteria. Moreover, as stated earlier, some cases of FM may begin after a febrile (fever-associated) illness.

Other similarities between FM and CFS are that each has no definitively known cause; there is no highly effective therapy for either syndrome; the symptoms in both tend to be chronic(long-term); and both conditions seem to be more common in women, including young women(66).

What is apparent is that current criteria do not differentiate these two disorders well(67;68). In other words, patients who meet one set of criteria often meet the other. Wysenbeek and his research associates evaluated 33 FM patients and found that 21% met the CDC criteria for CFS, as well(69). Hudson and his research partners similarly studied 33 rheumatology clinic patients with FM, and found that 14 (42%) met the full CDC criteria for CFS, and an additional 9 (27.3%) were within one minor symptom of meeting the CDC criteria(70). Goldenberg has identified similar high rates of concurrence between FM and CFS(71;72). And in our own study of 100 community cases of FM, roughly 60% of the females and 80% of the males with FM also met the case definition for CFS(68). What we also found is that those who met both sets of criteria reported a worse course, worse overall health, more dissatisfaction with health, more non-CFS symptoms, and greater disease impact than those who met the FM criteria alone. In other words, meeting both sets of criteria (for FM and CFS) means that you tend to feel worse and do more poorly; it doesn’t really mean you have two separate diseases.

Of those who strictly meet the FM but not the CFS definition, and *vice versa*, there may be some underlying differences at a causative level. For example, Evengard and colleagues, and Russell and colleagues both found that FM patients, but not those with CFS, had elevated levels of a pain neurotransmitter called substance P in their spinal fluid(73;74). And, though not all research groups have found this, there MAY be an association between the retrovirus XMRV and CFS, an association not yet identified for FM(75). However, especially given the high degree of clinical similarity between the two conditions and how frequently a given person will meet both sets of criteria, it may be some time before the FM-CFS issue is resolved.

So... what is FM again?

FM is a condition in which patients have widespread, long-lasting pain (often everywhere), severe fatigue, sleep problems, and diffuse body tenderness, with other symptoms possible as well. It is fairly common, especially in women, but affects men and children too. It sometimes exists on its own, and sometimes at the same time as other conditions; either way, it can be and often is quite disabling. The next chapter will clarify how it is, or at least how it should be, diagnosed.

CHAPTER 2

MAKING THE DIAGNOSIS

I already have given you a bit of an idea about how fibromyalgia (FM) is diagnosed. The most important additional point that I will make in this chapter is that FM is not a diagnosis of exclusion. In other words, it is not a diagnosis that should be entertained only after extensive examination and testing has ruled out everything else. It is not a garbage pail diagnosis intended for patients whose symptoms doctors just cannot explain (for example, let's just throw it here). Nor should FM be considered just the end of a spectrum of the usual aches and pains we all feel, a suggestion one critic in particular has made repeatedly(76;77); this is a comment that I will address further later in this chapter. FM is a specific diagnosis that is made after the doctor has taken a thorough history and completed a thorough physical examination, looking specifically for the following:

- Chronic (= long-standing), widespread pain
- Debilitating fatigue
- Non-restorative (poor) sleep
- Other symptoms commonly associated with FM
- Diffuse body tenderness.

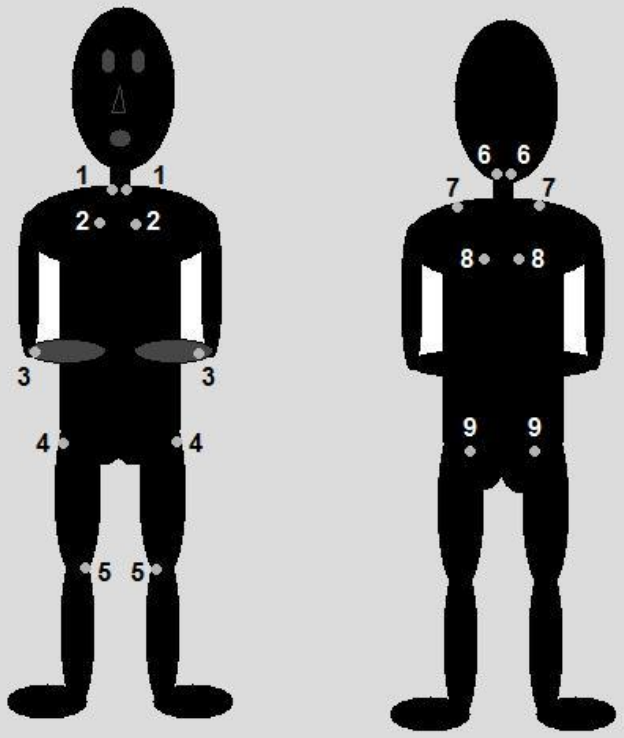
As stated in the preceding chapter, there now are classification criteria that were created largely for research purposes, but which have been widely utilized to diagnose FM in clinical practice. To meet the criteria, a patient must have:

- Chronic, widespread pain.
    - 'Chronic' meaning no fewer than three months of pain; this is to distinguish it primarily from that horrible flu someone might have with which they ache all over.

- 'Widespread' meaning…
1. Above and below the waist, and…
2. Right and left side of the body, and…
3. Involving the limbs and the trunk.

AND

- Tenderness at no fewer than 11 of 18 specific fibromyalgia tender points. The 18 points include 9 points on the right side of the body and the same 9 points on the left side of the body; in other words, 9 symmetrical or mirror-image points.



The 18 fibromyalgia tender points

- Specific locations of the fibromyalgia tender points are:
   1. Near the base of the neck in the front.

2. Along the second rib, just before it joins the sternum (the breast bone).
3. Two centimetres past the elbow on the side of your 5th finger (your pinkie finger).
4. Just behind the bony part on the outer side of the hip (immediately behind the front pockets of your pants).
5. The inner fat pad of the knee.
6. The base of the skull as it meets the back of the neck, where the levator scapula muscle meets the skull.
7. The midpoint of the muscle (called the trapezius) that runs between the neck and the shoulder.
8. The upper, inner angle of the shoulder blade.
9. The upper, outer quadrant of the buttock.

Some have argued that the diagnosis of fibromyalgia should never be made, because there are no objective (visible and measurable) findings, either on physical examination or on laboratory testing, like obvious joint swelling or a marked elevation of some chemical in the blood. However, as I will discuss in several of the chapters in Part 2 of this book, this argument is extremely weak. A brief glimpse of one among many strong counter-arguments is this…

- Have you ever had a headache?
- Prove it.

The fact is: none of us can prove that we have headaches. And yet almost every one of us will have had one, at least once in our lifetime. Many people have headaches on a regular basis. But there is <u>no</u> objective evidence at all that headaches exist. Our technology just has not caught up with reality… we cannot detect headaches, at least not using any routine physical examination or clinical laboratory technique. If we held headaches up to the same level of zealous scrutiny to which some hold FM, we could never diagnose a headache. But does this make sense? Of course not.

But there will be much more on this later.

FM Is Not Diagnosed by Exclusion

I stated at the outset that FM is not a disorder that should be made only when all other possibilities are excluded. There are two major reasons for this. The first reason is:

- FM is a collection of symptoms that is different from that seen in other disorders.

There truly are very few conditions in which a patient says he or she hurts or aches all over, other than that terrible but short-lived flu I mentioned two pages ago. Occasionally, patients with leukaemia will report this; however, it is very rare that leukaemia will be missed diagnostically for very long.

Patients with arthritic conditions like rheumatoid arthritis (RA), osteoarthritis (OA) or lupus (SLE) rarely report aching all over. They may report hurting or having stiffness in multiple joints, such as several fingers, both wrists and both knees. However, it is uncommon that they say they ache all over. The exception to this is when individuals with one or more of these other conditions also have FM. And many patients with these other conditions do, in fact, also have FM. And this is the second reason that FM is not diagnosed when every other possible diagnosis has been eliminated. In short:

- FM can co-exist with other conditions.

As stated in the previous chapter, a significant minority (up to a third) of patients with rheumatoid arthritis (RA) will also meet the diagnostic/classification criteria for FM(36). They generally report more overall symptoms, worse pain, and worse fatigue than their RA counterparts who do not also have FM. Similarly, a sizeable minority of lupus (SLE) patients meet the ACR criteria for FM(33-35). And, as noted in the previous chapter, the list goes on. Having said this, most FM patients do not have RA, lupus or some other disease. This is because most of these other conditions are much less common than FM. For example, FM is approximately 10 times more common than RA, and approximately 100 times more common than lupus(52).

The essential point is that, irrespective of whatever other health conditions a person has, FM is diagnosed based upon whether or not that individual reports chronic, widespread, musculoskeletal pain and has widespread body tenderness. Further work-up to determine whether or not they have some other concomitant disorder or disorders sometimes is appropriate; but the findings of this work-up, whether positive or negative, do not alter the FM diagnosis itself. There may be instances in which the other condition is considered more important, in terms of which disorder to evaluate further and/or treat. But if you have RA and FM, or SLE and FM, or multiple sclerosis and FM, both conditions should be acknowledged.

Some might argue that the fact that FM commonly co-exists with other conditions is proof that it is not a distinct entity unto itself. But two strong counter-arguments to this are:

1. It often <u>does</u> exist on its own; and
2. Many other, well-accepted conditions commonly co-exist with others. Migraine headaches and pulmonary hypertension (elevated blood pressure in the blood vessels feeding the lungs) are two such examples; though both can exist alone, both also are common components of other diseases.

So again, FM is <u>not</u> a diagnosis that is made when you cannot find any other explanation for symptoms. It is diagnosed using scientifically-established criteria, following a comprehensive health interview and physical examination.

What About Control Points?

Some doctors like to use something called *control points* to show that someone doesn't have FM and is just faking. The use of such control points for this purpose is not at all appropriate(78-82), however, as I will explain in much greater detail in Chapter 11.

What About No Points?

Within the last few months, the American College of Rheumatology (ACR) has endorsed preliminary diagnostic criteria for FM that do not rely on a tender point examination(83). In fact, no examination of the patient is required at all. Instead, patients are asked questions about pain and where it is; about fatigue and whether or not they wake up refreshed; about cognitive symptoms like memory and concentration; and then about a whole host of other symptoms and how severe they are. Based upon a given patient's responses, they then are assigned a widespread pain index (WPI) score and a symptom severity (SS) score, and these scores are used to determine whether or not they have FM.

Of course, as with the original 1990 ACR criteria, they must have had symptoms for at least three months, and they cannot have any other disorder that might explain their symptoms. The authors acknowledge limitations of the study they utilized to generate these new criteria, and of the criteria themselves. They even, though clearly discrediting the use of tender points by excluding them in the new criteria, recommend that a tender point examination still be done.

The rationale behind these new criteria escapes me, largely for this reason: though many have argued over how accurate and useful the tender point exam is, as I will discuss again in Chapter 11, tenderness is a physical sign that is used for hundreds of other diseases and injuries; why is it suddenly suspect in FM? Numerous other strong arguments supporting the use of tender points have been made by Harth and Nielson(84).

A second issue is this: what advantage do these criteria present over the previous 1990 version? Obviously, there cannot be that much of an advantage if the authors themselves encourage examiners to still check for tender points.

A third point is that these criteria invariably lump together (1) persons with, for example, localized sciatica (pain from their low back into their buttock and thigh) that, in turn, causes them to have severe insomnia that, in turn, makes them wake up non-refreshed and feel profoundly fatigued, with (2) those who hurt and are tender to light touch all over. As an example of a condition where such lumping of extremes does not work, let’s look at scleroderma. Scleroderma is a condition where patients have severe thickening of the skin (so thick it feels like wax). When this skin thickening is localized (for example, on the face or a single arm), it can be disfiguring. But when it is all over, it is associated with a whole host of other problems, like heart, lung, and kidney failure, that can be rapidly fatal. Specialists and researchers have made a point NOT to lump these two extremes of scleroderma together. So why do it now with FM?

Finally, for what other physical illness that is not diagnosed through some gold standard confirmatory lab test or imaging study have physical findings been removed from previously-established diagnostic criteria? None come to mind. My concern is that, by removing the physical exam from the evaluation of FM patients, these criteria run the risk of convincing even more physicians that FM is all in a patient’s head. Although I hate even to think this, it is possible that the absence of any need to physically examine the patient to confirm FM even may be used by some specialists as an argument against them needing to see FM patients at all.

So... do I like the newly-proposed criteria?

In a word: No!

CHAPTER 3

FOURTEEN FALSEHOODS ABOUT FIBROMYALGIA (THAT NAYSAYERS ESPOUSE)

Fibromyalgia (FM) has been called “an illusionary entity(85)” and “a common non-entity(27)”. One author claims that FM is the result of “a long tradition of poor science(26)” and cites the opinion of another who had written: “In no other field have pseudoscientists flourished as prominently as in the field of medicine(86)”. Fibromyalgia critics invariably use one of a number of arguments against its existence, all of which can be easily countered. In this chapter, I will list these so-called arguments against FM, and then go back over each one of them in a bit more detail, while providing brief counter-arguments. The chapters that follow this one will expand on the counter-arguments, providing references to indicate the research that has been published supporting the counter-arguments. It is important to note that **there is almost no scientific evidence supporting any of these arguments against FM.** Nonetheless, here they are:

1. Fibromyalgia is just the usual aches and pains everyone has, expressed in people who can’t deal with them.
2. Fibromyalgia is a syndrome, not a disease.
3. Fibromyalgia only exists because of today’s politically-correct bleeding-heart society.
4. Fibromyalgia only exists because of an overly-generous compensation system.
5. Fibromyalgia only exists because some people are lazy and want society to take care of them.

6. Fibromyalgia only exists because some doctors and researchers profit from its so-called ‘existence’.
7. The way fibromyalgia is diagnosed is inherently flawed.
8. The way fibromyalgia initially was defined is inherently flawed.
9. All the symptoms of fibromyalgia are subjective.
10. Fibromyalgia is 100% subjective; there are no objective physical findings to suggest the disease is real.
11. There is no anatomical or physiological basis for fibromyalgia.
12. None of the objective physical or physiological findings in fibromyalgia are specific to this disorder.
13. No one has fibromyalgia until they are told they have it; if you removed the fibromyalgia label, these people wouldn’t be nearly as ‘sick’.
14. Fibromyalgia is a psychological, and not a physical disease.

Now let’s go back over these fourteen anti-FM arguments in greater detail.

1. Fibromyalgia is just the usual aches and pains everyone has, expressed in people who can’t deal with them.

In essence, this argument is that everyone has aches and pains, but most people live with these and just go on with their daily lives(76); a small percentage, however, just can’t tolerate them. Maybe they have a low pain threshold. Maybe they are psychologically incapable of dealing with them. Maybe they see the opportunity for an easier life, not having to work while receiving compensation for so-called ‘disability’. In the following chapters, I will refute these statements repeatedly. But several counter arguments for this one spring to mind immediately. First of all, you could say the same of conditions like migraine headaches and cluster headaches… I mean, almost everyone has headaches, don’t they? What makes migraine headaches and cluster headaches so ‘special’ that they warrant a special designation, if FM doesn’t? If we use the same logic some have used for FM, since everyone has headaches, aren't migraines and clusters just at the severe end of the usual headaches everyone has?

And what about polymyalgia rheumatica (PMR), a highly-accepted condition in which stiffness is prominent and little else… everyone gets a little stiff from time to time, don't they? Why do we treat stiffness in PMR?

Second, as I will demonstrate later in Chapter 15, several studies have shown that people with FM have no more psychological distress than others with similar levels of reported pain.

Third, studies have shown that people who just have aches and pains but not FM are, in fact, different in a number of both subjective and objective ways (in particular, see Chapters 7 and Chapters 9 through 12).

And fourth, any health care provider who has ever tried to get disability compensation approved for an FM patient will find that it is one of the most arduous, prolonged and demeaning processes any patient will ever have to go through; and the outcome is never certain... many are never compensated and end up living in abject poverty, losing their homes and families and friends and more. It is not, as some have claimed, an easy road at all. Chapter 17 details the many issues and obstacles related to disability in FM.

2. Fibromyalgia is a <u>syndrome</u> and not a <u>disease</u>.
With this argument, critics seem to be trying to make the point that syndromes are just a collection of symptoms, whereas diseases have real pathology. My first argument against this feeble attempt is this: look up the word *syndrome* in any dictionary or on the internet. The Oxford desk dictionary defines syndrome as *a group of characteristic symptoms of a disease*(87). Wikipedia, which tends to be quite exhaustive in its definitions, writes this:

> In medicine and psychology, a **syndrome** is the association of several clinically recognizable features, signs (observed by a physician), symptoms (reported by the patient), phenomena or characteristics that often occur together, so that the presence of one feature alerts the physician to the presence of the others. In recent decades, the term has been used outside medicine to refer to a combination of phenomena seen in association.
>
> The term *syndrome* derives from its Greek roots (σύνδρομος) and means literally "run together", as the features do. It is most often used to refer to the set of detectable characteristics when the reason that they occur together (the pathophysiology of the syndrome) has not yet been discovered(88).

And the 31st (2007) edition of Dorland's Illustrated Medical Dictionary(89) defines syndrome as "a combination of symptoms that either result from a single cause or occur together so commonly that they constitute a distinct clinical picture. See also disease and sickness".

Note that not one of these three sources, not even the two paragraphs supplied by Wikipedia, implies any lack of pathology; and that the first and last definitions actually use the word *disease* within the definition.

A second strong counter-argument to "FM is a syndrome not a disease" is this: look up the word *syndrome* in the index of any standard medical dictionary(90) or general medical textbook. What you will find is a long list of conditions in which the pathology is obvious, but for which the name still includes the word *syndrome*. Among the most common examples are Down's syndrome, Turner's syndrome, and the Syndrome of Inappropriate Antidiuretic Hormone (SIADH), all three of them conditions in which there is blatantly obvious and objective pathology (disease). Again, as I stated in Chapter 1, a syndrome is merely a collection of symptoms and signs that tend to run together like travellers on a city bus: these symptoms and signs can be as obvious and objective as a major deformity or death in infancy, or as ‘subtle’ as a mild headache; the term syndrome is open to both extremes and everything in between.

And the third counter-argument is for critics to read chapters 9 through 12 in this book, where any claim that there is no pathology in FM will be repeatedly and soundly thwarted.

3. Fibromyalgia only exists because of today’s politically-correct, bleeding-heart society.

This is an extension of what I wrote about with the first anti-FM argument. Critics who utilize this line of ill-reasoning essentially believe that FM wouldn’t exist if society just didn’t tolerate it. But, as I note right away in the very next chapter, FM may have existed in biblical times; and certainly has existed since the mid 1900s, if not the mid 1800s, long before bleeding-heart societies with generous compensation systems were in existence (to see how ‘generous’ society used to be in the 1800s, just read Charles Dickens’ famous novels *Oliver Twist* or *The Christmas Carol*). In addition, population studies have found FM to be more common in some very poor countries than wealthier ones, and in one particular population, the Amish, that specifically refuses to participate in ANY compensation system for religious reasons. Read Chapters 4 through 6 to explore all of this further.

4. Fibromyalgia only exists because of an overly-generous compensation system.
5. Fibromyalgia only exists because some people are lazy and want society to take care of them.

These two arguments are very similar, and many of the counter-arguments to the previous two statements apply here. Why, for example, would FM be more common in Bangladesh, arguably the poorest country in the World, than in prosperous and very society-conscious Sweden, if the generous compensation argument applies? And why would FM exist at all in the Amish? As with issue #3 above, the various counter-arguments are especially discussed in Chapters 4 through 6.

6. Fibromyalgia only exists because some doctors and researchers profit from its so-called ‘existence’.

Believe it or not, I had this argument thrown at me by a doctor who was making hundreds of thousands of dollars every year doing *independent medical assessments* for insurance companies, when I often charged nothing for my dictated reports or for filling out forms.

Ask anyone you know in research if the following statement isn’t true: scientific research in an area like FM pays little; in fact, most doctors who conduct such research would probably make much more if they devoted all their time to clinical versus research pursuits. Moreover, grounding one’s research in a controversial area like fibromyalgia might even hurt one’s career. Imagine a young FM researcher applying for a university faculty position at a medical school where the Chief of Medicine or the head of their division happens not to believe in FM.

7. The way fibromyalgia is diagnosed is inherently flawed.
8. The way fibromyalgia initially was defined is inherently flawed.

These arguments come back to the way doctors diagnose fibromyalgia using criteria, instead of a confirmatory blood test or X-ray or other scan. As stated in the first two chapters, FM is diagnosed when a patient has widespread pain and tenderness at specific areas. The way that these two criteria were decided upon was that researchers asked questions of, and examined over 260 patients already diagnosed as having FM by their specialist, and also asked questions of, and examined a similar number of patients with arthritis and other conditions believed NOT to have FM. The tautologic argument (as it is called, meaning a circular argument), is that this was a self-fulfilling prophecy. How did these doctors really know any of these patients really had FM? However, this method of establishing diagnostic or classification criteria is the same scientific method that has been used to develop classification criteria for every other disorder (including SLE and RA) for which they exist. If you find this confusing, rest assured that this argument and counter-argument will be clarified in Chapter 8.

9. All the symptoms of fibromyalgia are subjective.

This one is easiest of all to rebut, because all symptoms are, by definition, subjective. If you don't believe me, just do a Google search. Likely, the first entry you'll come to is the Wikipedia definition of symptom, which is as follows:

> A **symptom** (from Greek *σύμπτωμα*, "accident, misfortune, that which befalls", from *συμπίπτω*, "I befall", from *συν-* "together, with" + *πίπτω*, "I fall") is a departure from normal function or feeling which is noticed by a patient, indicating the presence of disease or abnormality. A symptom is subjective, observed by the patient, and not measured(91).

Or, if you would like a more scientific or academic reference, check out Dorland's Illustrated Medical Dictionary, 27th Edition, where a symptom is defined as "any subjective evidence of disease or of a patient's condition, i.e., such evidence as perceived by the patient; a change in a patient's condition indicative of some bodily or mental state."

I'm sorry, but any doctor who uses the "all the symptoms of fibromyalgia are subjective" argument needs to review their first-year medical school notes and/or buy and use a dictionary.

10. Fibromyalgia is 100% subjective; there are no objective physical findings to suggest the disease is real.

The argument here is that people with FM don't have a rash or measurable high fever or anything else that can be seen (actually visualized) and/or measured by the examining doctor. But there are many other highly-accepted conditions for which the same can be said (see Chapters 12 and 13). And, more important, in fact, is that there ARE observable and measurable physical findings in many FM patients. Most doctors don't know about them, so they don't look for them. They also are non-specific (meaning that people with other conditions also can have them); but they still are abnormal, indicating the presence of illness (see Chapter 11). And their lack of specificity for FM also is no argument, as this applies to most physical and laboratory findings in most diseases (see Chapter 12).

11. There is no anatomical or physiological basis for fibromyalgia.

In other words, if you do x-rays and routine blood tests on these patients, they all come back normal or unrelated to the patient's pain. Okay... this is true. However, if you do tests beyond the routine blood-work and imaging that most doctors know of, in fact, there are dozens and dozens of abnormalities that have been documented repeatedly in FM patients. And many of these abnormalities make perfect sense, given the symptoms FM patients report. Chapters 9 and 10 are all about this.

12. None of the objective physical or physiological findings in fibromyalgia are specific to this disorder.

Again, what critics are saying here is that none of the various things you do find wrong in a fibromyalgia patient are unique to fibromyalgia… so they are useless in justifying the condition. But, as I explain in detail in Chapter 12, this is true of almost everything. Virtually none of the physical findings your doctor looks for or routine blood tests your doctor orders are very specific for anything. You have a fever? So what… fevers aren't specific. Neither are 99% of rashes. Does this mean you ignore these signs? Of course not! This argument against fibromyalgia is pretty lame.

13. No one has fibromyalgia until they are told they have it; if you removed the fibromyalgia label, these people wouldn't be nearly as 'sick'.

One particular author seems to really like this one(76;92). He argues that people with FM wouldn't be nearly as sick if you just told them they weren't sick. First, I challenge him to try this, see the patients a second time maybe a year later, and then truthfully report on the results of his approach. And second, this already has been looked at in a large population study… and no, this was not the case at all(93). Read about all this in Chapter 14.

And, finally:

14. Fibromyalgia is a psychological, and not a physical, disease.

In other words, FM patients are just depressed, or anxious, or both… or they are just hypochondriacs. There are numerous counter-arguments against this one (see Chapter 15), including the fact that many patients with FM, when tested, show no evidence at all of depression, anxiety, hypochondria, or any other psychological illness. But the major point to be made here is that NO ILLNESS is 100% physical; and NO ILLNESS is 100% psychological. The physical illness vs. psychological illness dichotomy has been scientifically, thoroughly debunked!

Read on to have all these 14 counter-arguments expanded upon and scientifically justified in Part 2, Chapters 4 through 15. In Part 3, Chapter 16 specifically addresses the issue of post-traumatic fibromyalgia (FM that starts immediately following an accident of some kind), and Chapter 17 the issues of disability and disability assessments in FM. Chapter 18 wraps things up by going way back to the beginning, where it all started for me with a famous song by Bob Dylan.

PART 2

TWELVE
SCIENTIFIC REASONS

FIBROMYALGIA IS REAL

PART 3

TRAUMA,
DISABILITY,
AND
DYLAN

Reference List

(1) Gowers W. Lumbago: It's lessons and analogues. Br Med J 1904;1:117-21.

(2) Yunus MB, Masi AT, Aldag JC. A controlled study of primary fibromyalgia syndrome: clinical features and association with other functional syndromes. J Rheumatol 1989;16(suppl 19):62-71.

(3) Yunus M, Masi AT, Calabro JJ, et al. Primary fibromyalgia (fibrositis): clinical study of 50 patients with matched normal controls. Semin Arthritis Rheum 1981;11:151-71.

(4) Katz RS, Heard AR, Mills M, Leavitt F. The Prevalence and Clinical Impact of Reported Cognitive Difficulties (Fibrofog) in Patients With Rheumatic Disease With and Without Fibromyalgia. J Clin Rheumatol 2004;10(2):53-8.

(5) Wolfe F, Simons DG, Fiction J et al. The fibromyalgia and myofascial pain syndromes: a preliminary study of tender points and trigger points in persons with fibromyalgia, myofascial pain syndrome and no disease. J Rheumatol 1992;19:944-51.

(6) Kellgren JH. Observations on referred pain arising from muscle. Clin Sci 1938;3:175-90.

(7) Kellgren JH. On the distribution of pain arising from deep somatic structures with charts of segmental pain areas. Clin Sci 1939;4:35-46.

(8) Kellgren JH, McGowan AJ, Hughes ESR. On deep hyperalgesia and cold pain. Clin Sci 1944;7:13-27.

(9) Lewis T, Kellgren JH. Observations relating to referred pain, visceromotor reflexes and other associated phenomoena. Clin Sci 1939;4:47-71.

(10) White KP, McCain GA, Tunks E. The effects of changing the painful stimulus upon dolorimetry scores in patients with fibromyalgia. J Musculoskeletal Pain 1993;1(1):43-58.

(11) Smythe HA, Buskila D, Urowitz S, Langevitz P. Control and "fibrositic" tenderness: comparison of two dolorimeters. J Rheumatol 1992;19(5):768-71.

(12) Smythe HA, Gladman A, Dagenais P et al. Relation between fibrositic and control site tenderness; effects of dolorimeter scale length and footplate size. J Rheumatol 1992;19(2):284-9.

(13) White KP, Speechley M, Harth M, Ostbye T. The London Fibromyalgia Epidemiology Study: The prevalence of fibromyalgia syndrome in London, Ontario. J Rheumatol 1999;19(7):1570-6.

(14) Campbell SM, Clark S, Tindall EA et al. Clinical characteristics of fibrositis. I. A "blinded" controlled study of symptoms and tender points. Arthritis Rheum 1983;26(7):817-24.

(15) Goldenberg DL. Fibromyalgia Syndrome: An Emerging but Controversial Condition. JAMA 1987;257(20):2782-7.

(16) Wolfe F, Hawley DJ, Cathey MA et al. Fibrositis: symptom frequency and criteria for diagnosis. An evaluation of 291 rheumatic disease patients and 58 normal individuals. J Rheumatol 1985;12(6):1159-63.

(17) Buskila D, Neumann L, Hershman E et al. Fibromyalgia syndrome in children - an outcome study. J Rheumatol 1995;22:525-8.

(18) Greenfield S, Fitzcharles M, Esdaile JM. Reactive fibromyalgia syndrome. Arthritis Rheum 1992;35(6):678-81.

(19) White KP, Carette S, Harth M, Teasell RW. Trauma and fibromyalgia: Is there a connection and what does it mean? Semin Arthritis Rheum 2000;29:200-16.

(20) Moldofsky H. Nonrestorative sleep and symptoms after a febrile illness in patients with fibrositis and chronic fatigue syndromes.
Moldofsky H. J Rheumatol Suppl 1989;19:150-3.

(21) Rea T, Russo J, Katon W et al. A prospective study of tender points and fibromyalgia during and after an acute viral infection. Arch Intern Med 1999;159(8):865-70.

(22) Scudds RA, Rollman GB, Harth M, et al. Pain perception and personality measures as discriminators in the classification of fibrositis. J Rheumatol 1987;14:563-9.

(23) Uveges JM, Parker JC, Smarr KL et al. Psychological symptoms in primary fibromyalgia syndrome: relationship to pain, life stress and sleep disturbance. Arthritis Rheum 1990;33:1279-83.

(24) Wolfe F, Cathey MA, Kleinheksel SM, et al. Psychological status in primary fibrositis and fibrositis associated with rheumatoid arthritis. J Rheumatol 1984;11:500-6.

(25) Yunus MB, Ahles TA, Aldag JC, et al. Relationship of clinical features with psychological status in primary fibromyalgia. Arthritis Rheum 1991;34:15-21.

(26) Bohr TW. Fibromyalgia syndrome and myofascial pain syndrome: do they exist? Neurol Clin 1995;13:365-84.

(27) Hart FD. Fibrositis (fibromyalgia): A common non-entity? Drugs 1988;35:320-7.

(28) Merskey H. Physical and psychological considerations in the classification of fibromyalgia. J Rheumatol 1989;15(suppl 19):72-9.

(29) Smythe HA. Problems with the MMPI. J Rheumatol 1994;11:417-8.

(30) Mufson M, Regestein QR. The spectrum of fibromyalgia disorders. Arthritis Rheum 1993;36:647-50.

(31) Aaron LA, Bradley LA, Alarcon GS et al. Psychiatric diagnoses in patients with fibromyalgia are related to health care-seeking behaviour rather than to illness. Arthritis Rheum 1996;39(3):436-45.

(32) Buskila D, Neumann L, Odes LR et al. The prevalence of musculoskeletal pain and fibromyalgia in patients hospitalized on internal medicine wards. Semin Arthritis Rheum 2001;30(6):411-7.

(33) Romano TJ. Coexistence of fibromyalgia syndrome (FS) and systemic lupus erythematosis (SLE). Scand J Rheumatol 1992;suppl 94:12.

(34) Staud R. Are patients with systemic lupus erythematosus at increased risk for fibromyalgia? Curr Rheumatol Rep 2006;8(6):430-5.

(35) Middleton GD, McFarlin JE, Lipsky PE. The prevalence and clinical impact of fibromyalgia in systemic lupus erythematosus. Arthritis Rheum 1994;37(8):1181-8.

(36) Romano TJ. Incidence of fibromyalgia syndrome (FS) in rheumatoid arthritis (RA) patients in a general rheumatology practice. Scand J Rheumatol 1992;94(Suppl):11.

(37) Romano TJ. Presence of fibromyalgia syndrome (FS) in osteoarthritis (OA) patients. Scand J Rheumatol 1992;suppl 94:11.

(38) Thune O. The prevalence of fibromyalgia among patients with psoriasis. Acta Derm Venereol 2005;85(1):33-7.

(39) Simms RW, Zerbini CAF, Ferrante N et al. Fibromyalgia Syndrome in patients infected with Human Immunodeficiency Virus. Amer J Med 1992;92:368-74.

(40) Cruz BA, Catalan-Soares B, Proietti F. Higher prevalence of fibromyalgia in patients infected with human T cell lymphotropic virus type I. J Rheumatol 2006;33(11):2300-3.

(41) Buskila D, Fefer P, Harman-Boehm I et al. Assessment of nonarticular tenderness and prevalence of fibromyalgia in hyperprolactinemic women. J Rheumatol 1993;20(12):2112-5.

(42) Jurell KC, Zanetos MA, Orsinelli A et al. Fibromyalgia: A Study of Thyroid Function and Symptoms. J Musculoskel Pain 1996;4(3):49-60.

(43) Fiona D, Esdaile JM, Kimoff JR, Fitzcharles M. Musculoskeletal complaints and fibromyalgia in patients attending a respiratory sleep disorders clinic. J Rheumatol 1996;23(9):1612-6.

(44) May KP, West SG, Baker MR, Everett DW. Sleep apnea in males with the fibromyalgia syndrome. Am J Med 1993;94:505-8.

(45) Sendur OF, Gurer G, Bozbas GT. The frequency of hypermobility and its relationship with clinical findings of fibromyalgia patients. Clin Rheumatol 2007;26(4):485-7.

(46) Ofluoglu D, Gunduz OH, Kul-Panza E, Guven Z. Hypermobility in women with fibromyalgia syndrome. Clin Rheumatol 2006;25(3):291-3.

(47) Acasuso-Diaz M, Collantes-Estevez E. Joint hypermobility in patients with fibromyalgia syndrome. Arthritis Care Res 1998;11(1):39-42.

(48) Hudson N, Starr MR, Esdaile JM, Fitzcharles M. Diagnostic associations with hypermobility in rheumatology patients. Br J Rheumatol 1995;34(12):1157-61.

(49) Gedalia A, Press J, Klein M, Buskila D. Joint hypermobility and fibromyalgia in schoolchildren. Ann Rheum Dis 1993;52(7):494-6.

(50) Granges G, Zilko P, Littlejohn GO. Fibromyalgia syndrome: Assessment of the severity of the condition two years after diagnosis. J Rheumatol 1994;21:523-9.

(51) Felson DT, Goldenberg DL. The natural history of fibromyalgia. Arthritis Rheum 1986;29:1522-6.

(52) Felson DT. Epidemiology of the Rheumatic Diseases. In: Koopman WJ, editor. Arthritis and Allied Conditions: A Textbook of Rheumatology, 14th Edition, Volume 1.Philadephia, PA: Lippincott, Williams & Wilkins; 2001. p. 3-38.

(53) White KP, Speechley M, Harth M, Ostbye T. Remission Rate in Fibromyalgia Syndrome (FMS). (Presented in poster format at the XII Panamerican Congress of Rheumatology, June 21-25, 1998, Montreal, Quebec.). 1998.

(54) White KP, Harth M. Classification, epidemiology, and natural history of fibromyalgia. Curr Pain Headache Rep 2001;5(4):320-9.

(55) Bengtsson A, Backman E. Long-term follow up of fibromyalgia patients. Scand J Rheumatol 1992;S94:98.

(56) Forseth KO, Førre O, Gran JT. A 5.5 year prospective study of self-reported musculoskeletal pain and of fibromyalgia in a female population: significance and natural history. Clin Rheumatol 1999;18(2):114-21.

(57) Kennedy M, Felson DT. A prospective long-term study of fibromyalgia syndrome. Arthritis Rheum 1996;39(4):682-5.

(58) White KP, Harth M, Teasell RW. Work disability evaluation and the fibromyalgia syndrome. Semin Arthritis Rheum 1995;24(6):371-81.

(59) White KP. Fibromyalgia: the answer is blowin' in the wind. J Rheumatol 2004;31(4):636-9.

(60) Wolfe F, Potter J. Fibromyalgia and work disability: Is fibromyalgia a disabling disorder? Rheum Dis Clin North Am 1996;22(2):369-91.

(61) Wolfe F, the Vancouver Fibromyalgia Consensus Group. The fibromyalgia syndrome: A consensus report on fibromyalgia and disability. J Rheumatol 1996;23:534-9.

(62) Wolfe F. The fibromyalgia problem. [Editorial]. J Rheumatol 1997;24:1247-9.

(63) Holmes GP, Kaplan JE, Gantz NM et al. Chronic fatigue syndrome: a working case definition. Ann Intern Med 1988;108(3):387-9.

(64) Reeves WC, Wagner D, Nisenbaum R et al. Chronic fatigue syndrome--a clinically empirical approach to its definition and study. BMC Med 2005 Dec 15;3:19 2005;15(3):19(1)-19(9).

(65) Fukuda K, Straus SE, Hickie I et al. The chronic fatigue syndrome: a comprehensive approach to its definition and study. International Chronic Fatigue Syndrome Study Group. Ann Intern Med 1994;121:953-9.

(66) Goldenberg DL. Fibromyalgia and chronic fatigue syndrome. J Musculoskeletal Pain 1994;2(3):51-5.

(67) Demitrack MA. Chronic fatigue syndrome and fibromyalgia. Dilemmas in diagnosis and clinical management. Psychiatr Clin North Am 1998;21(3):671-92.

(68) White KP, Speechley M, Harth M, Ostbye T. Co-existence of chronic fatigue syndrome with fibromyalgia syndrome in the general population. A controlled study. Scand J Rheumatol 2000;29(1):44-51.

(69) Wysenbeek AJ, Shapira Y, Leibovici L. Primary fibromyalgia and the chronic fatigue syndrome. Rheumatol Int 1991;10(6):227-9.

(70) Hudson JI, Goldenberg DL, Pope HG et al. Comorbidity of fibromyalgia with medical and psychiatric disorders. Amer J Med 1992;92(4):363-7.

(71) Goldenberg DL, Simms RW, Gieger A, Komaroff AL. High frequency of fibromyalgia in patients with chronic fatigue seen in primary care practice. Arthritis Rheum 1990;33:381-7.

(72) Goldenberg DL. Fibromyalgia and its relation to chronic fatigue syndrome, viral illness and immune abnormalities. J Rheumatol 1989;19(Suppl):91-3.

(73) Evengard B, Nilsson CG, Lindh G et al. Chronic fatigue syndrome differs from fibromyalgia. No evidence for elevated substance P levels in cerebrospinal fluid of patients with chronic fatigue syndrome. Pain 1998;78(2):153-5.

(74) Russell IJ, Orr MD, Litman B et al. Elevated cerebrospinal fluid levels of substance P in patients with the fibromyalgia syndrome. Arthritis Rheum 1994;37:1593-601.

(75) Lombardi VC, Ruscetti FW, Das Gupta J et al. Detection of an infectious retrovirus, XMRV, in blood cells of patients with chronic fatigue syndrome. Science 2009;326(5952):585-9.

(76) Hadler NM. Fibromyalgia: La maladie est morte. Vive le malade. J Rheumatol (editorial) 1977;24:1250-1.

(77) Hadler NM. "Fibromyalgia" and the medicalization of misery. J Rheumatol 2003;30(8):1668-70.

(78) Granges G, Littlejohn GO. Pressure pain threshold in pain-free subjects, in patients with chronic regional pain syndromes, and in patients with fibromyalgia syndrome. Arthritis Rheum 1993;36(5):642-6.

(79) Khostantine I, Tunks ER, Goldsmith CH, Ennis J. Fibromyalgia: can one distinguish it from simulation? An observer-blind controlled study. J Rheumatol 2000;27(11):2671-6.

(80) Tunks E, Crook J, Norman G, Kalaher S. Tender points in fibromyalgia. Pain 1988;34(1):11-9.

(81) Wolfe F, Smythe HA, Yunus M et al. The American College of Rheumatology 1990 criteria for the classifcation of fibromyalgia: report of the multicenter criteria committee. Arthritis Rheum 1990;33:160-72.

(82) Wolfe F. What use are fibromyalgia control points?
Wolfe F. J Rheumatol 1998;25(3):546-50.

(83) Wolfe F, Clauw DJ, Fitzcharles M et al. The American College of Rheumatology Preliminary Diagnostic Criteria for Fibromyalgia and Measurement of Symptom Severity. Arthritis Care Res 2010;62(5):600-10.

(84) Harth M, Nielson WR. The fibromyalgia tender points: use them or lose them? A bried review of the controversy. J Rheumatol 2007;34(5):914-22.

(85) Ochoa JL. Essence, Investigation, and Management of "Neuropathic" Pains: Hopes from Acknowledgement of Chaos. Muscle Nerve 1993;16:977-1008.

(86) Gardner M. Fads and fallacies in the name of science. New York, NY: Dover; 1957.

(87) The Oxford Desk Dictionary: American Edition. New York, NY: Oxford University Press; 1995.

(88) Syndrome. Wikipedia 2010 March 24;Available from: URL:
http://en.wikipedia.org/wiki/Syndrome

(89) Dorland's Illustrated Medical Dictionary, 31st edition. Philadelphia, PA: W.B. Saunders Company; 2007.

(90) Dorland's Illustrated Medical Dictionary, 31st edition. Philadelphia, PA: W.B. Saunders Company; 2007.

(91) Symptom. Wikipedia 2010;Available from: URL: http://en.wikipedia.org/wiki/Symptom

(92) Hadler NM. The danger of the diagnostic process. Occupational Musculoskeletal Disorders.New York, USA: Raven; 1993. p. 16-33.

(93) White KP, Nielson WR, Harth M et al. Does the label "fibromyalgia" alter health status, function, and health service utilization? A prospective, within-group comparison in a community cohort of adults with chronic widespread pain. Arthritis Rheum 2002;47(3):260-5.