

The Fibromyalgia and Chronic Fatigue
Resource Book
and Life Planner Workbook

Dawn Hughes, Author

Universal Publishers
USA • 2001

*The Fibromyalgia and Chronic Fatigue Resource Book
and Life Planner Workbook*

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Dedication

This book is dedicated to my family.

My mother, Joan Johns, for taking
all the steps to acceptance and beyond
along side of me.

My father, Ben Johns and his wife Jean, for
always watching over me.

My son, Christian Hughes and his wife Andrea.

Special Thanks To:

Dr. Thomas D. Geppert M.D. for finding "My Answer".

To All Fibromyalgia and Chronic Fatigue Patients, Researchers
and Dedicated Advocacy Groups

Together We Will Find A Cure

Acknowledgements

Thank you to:

Anne-Marie Vidal

Article: Why Me, Why Anyone?

Article: Life Changes

Anne-Marie Vidal worked as a systems analyst for 20 years. She was Director Management Information Services for two providers of health care which prompted an interest in delivery of health care in the US. She earned a Masters in Public Administration with distinction specializing in Health Administration from Long Island University. Ms. Vidal was a community activist regarding health, municipal and other services in Brooklyn.

When the combination of Chronic Fatigue Syndrome and Fibromyalgia limited her ability to work full time she became an adjunct professor at several colleges in New York City. The courses she taught included: Understanding Health Insurance, Medical Office Practices, and Introduction to Microcomputers. Although Anne-Marie writes and advocates on issues related to invisible disabilities, Chronic Fatigue Immune Deficiency Syndrome and Fibromyalgia, she and her wonderful, supportive husband Dennis live in Brooklyn, NY, where they provide a home for their 4 cats. She encourages you write to her at:
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Chapter 1 - THE SYNDROMES

Although CFS and FMS are differently defined syndromes, it is likely that patients with Fibromyalgia and Chronic Fatigue Syndrome have the same underlying disease.

What Is Fibromyalgia (FMS) Syndrome?

Fibromyalgia Syndrome (FMS) is a widespread musculoskeletal pain and fatigue disorder for which the cause is still unknown. Over 6 million Americans (alone), 90% of them women in the prime of their life, suffer from FMS. Symptoms usually appear between 20-55 years of age, but children and men are also diagnosed with fibromyalgia syndrome. Fibromyalgia is not deforming, degenerative, or life threatening. It is not a progressive disorder like multiple sclerosis and it is not a mental disorder. Fibromyalgia means pain in the bodies soft tissues (bursa, muscles, joints, ligaments and tendons). This soft tissue pain is often described as aching, stabbing or burning. Severity of symptoms fluctuate from person to person, but chronic pain is the main symptom. FMS patients may have up to 3 times the normal amount of substance P in their spinal fluid. Substance P tells the body how much pain it feels. Patients also have more pain receptors resulting in hypersensitivity to everything. In addition to pain, the sufferer feels fatigue and general malaise or “flu-like” symptoms on a daily basis. Fibromyalgia pain can be manageable one moment and incapacitating the next, therefore, treatment relies heavily on pain management and stress reduction therapies as well as patient and family education to support the emotional needs for living with a chronic illness.

What Is Chronic Fatigue (CFS/ME) Syndrome?

Chronic Fatigue Syndrome (CFS) is a fatigue disorder for which the cause is still unknown. The core symptoms are general pain, mental fogginess and fatigue. The degree of severity differs with each patient and will also vary from day to day. The exhaustion

experienced with chronic fatigue can be completely disabling. Another common name for chronic fatigue syndrome is ME or “Myalgic Encephalomyelitis”, meaning inflammation of the central nervous system and muscles. Many people feel ME more accurately describes the severity of this chronic and debilitating illness.

What Causes Fibromyalgia and Chronic Fatigue Syndrome?

While the cause remain unknown, research studies support that that FMS/CFS may be hereditary or trauma induced. FMS/CFS may be associated with changes in muscle metabolism, such as decreased blood flow, causing fatigue and decreased strength. Others believe these syndromes may be triggered by an infectious agent such as a virus in susceptible people, but no such agent has been identified. Medical research has produced the following list of possible causes that might play a role:

Environmental

Environmental factors may play a role in developing and/or prolonging the illness.

Genetics

Several studies support the theory that FMS/CFS is an inherited condition. Like other illnesses, it may skip generations or surface in every one.

Hypothalamic-Pituitary Adrenal (HPA) Axis

Multiple laboratory studies have suggested that the central nervous system may play an important role. Medical studies also show hormonal and pain mechanism abnormalities in patients.

Infectious Agents

Due in part to its similarity to chronic mononucleosis, FMS/CFS was initially thought to be caused by a virus infection, most probably Epstein-Barr virus (EBV). It is now clear that FMS/CFS is not caused by EBV. It is unlikely the cause is exclusively from any single recognized infectious disease agent including: Human retroviruses, herpesvirus6, rubella, candida, mycoplasma or other bornaviruses. However, the possibility remains that FMS/CFS may

have multiple causes which means some infectious agents might play a contributory role.

Immunology

It has been proposed that FMS/CFS may be caused by an immunologic dysfunction, for example inappropriate production of cytokines, such as interleukin-1, or altered capacity of certain immune functions.

Neurally Mediated Hypotension

Many FMS/CFS patients experience lightheadedness or worsened fatigue when they stand for prolonged periods or when in warm places, such as in a hot shower, possibly from autonomic regulation of blood pressure and pulse .

Non-Restorative Sleep

Lack of non-restorative deep sleep. Patients rarely reach a deep stage 4 sleep. This is the sleep stage where our bodies heal and release growth hormones which repair muscles and tissues.

Trauma

Statistics show many sufferers experienced a trauma (like a car accident) right before their symptoms surfaced. Whether the gene was latent and the trauma caused the syndrome to surface is unknown.

How Are Fibromyalgia and Chronic Fatigue Diagnosed?

FMS and CFS are difficult to diagnose, because there are no blood test results to show the illness has taken hold. CFS is diagnosed when a patient has severe prolonged fatigue for a period of six months or longer. In fibromyalgia, pain wanders to different parts of the body which often causes people to visit many doctors for the “seemingly” different ailments that they feel. Often, with the onset of muscle and/or joint pain, a sufferer will make an appointment with a Rheumatologist (or other physician) who will make a diagnoses by process of elimination.

Tenderpoints

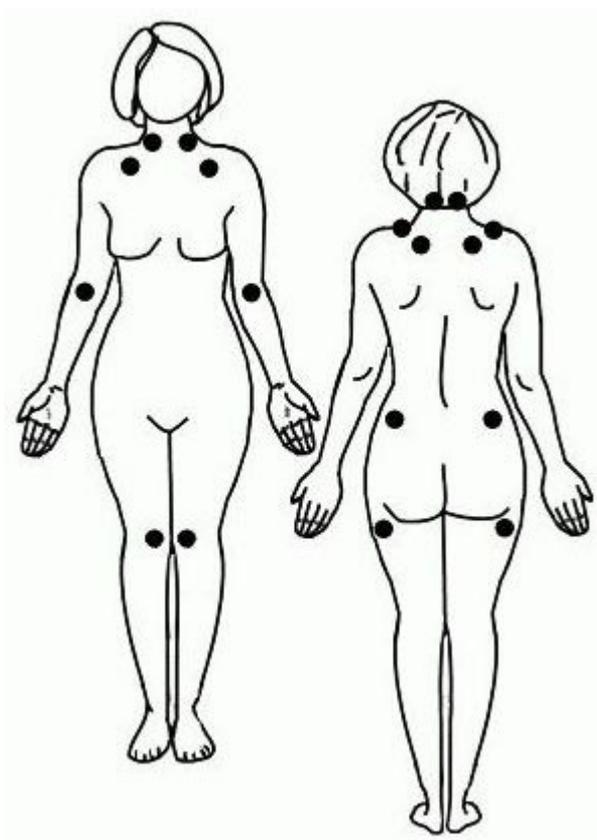
Tenderpoints are very sore and painful nodes that can be located in the muscles, soft tissues, tendons and ligaments. Tenderpoints are found in specific areas and it takes someone very knowledgeable in anatomy to be able to locate them accurately. Sometimes pressing on these tenderpoints causes pain or tingling to be felt in different areas of the body. When this occurs, these points are then called triggerpoints. The radiating symptoms seem to be coming from a different location. Tenderpoint pain may not be obvious to the patient of fibromyalgia until the syndrome reaches an advanced stage. This is another reason why this illness can go undiagnosed for so long.

Location of Tenderpoints

The “signature” 18 tenderpoints are located in 9 areas (both sides) of the body. They Include:

1. The back of the head where the neck muscles connect to the skull.
2. The muscles along the neck.
3. Trapezius muscle. The broad muscle that extends from the neck down to the shoulder.
4. Supraspinatus muscle. The broad muscle at the top of the shoulder blade.
5. The second rib. This area right below the collarbone.
6. Lateral epicondyle. The area frequently referred to as the “tennis elbow” area, located in the upper forearm.
7. Gluteus maximus. The buttock muscle.
8. Greater Trochanter. The part of the thigh bone just below the hip joint.
9. Medial Knee. The tender area above the inside of the knee.

Diagram of Tenderpoints



Fibromyalgia and Chronic Fatigue Symptoms

Central Nervous System Symptoms

Brainfog

Inability to think clearly. FMS and CFS

Chronic Headaches

Recurrent migraine or tension-type headaches are seen in about 50% of patients. FMS and CFS

Decreased Libido CFS

Dizziness and Fainting FMS and CFS

Muscle Twitching FMS and CFS

Sensory Alterations

Hyper or hypersensitivity in smell, taste and hearing. FMS and CFS

Numbness and Tingling in extremities FMS and CFS

Ringing in ears (tinnitus) FMS and CFS

Vision Changes

Prescription changes frequently. FMS and CFS

Emotional Symptoms

Anxiety FMS and CFS

Appetite

Increase or decrease. FMS and CFS

Depression

Any condition which causes chronic pain usually has depression as a symptom. Depression medications are often prescribed. FMS and CFS

Frequent Crying FMS and CFS

Mood Swings FMS and CFS

Suicidal Thoughts FMS and CFS

Equilibrium Symptoms

Balance Problems

Staggering and clumsy walking. FMS and CFS

Dropping Things FMS and CFS

Perception

Distance perception and not being able to clearly see what you are looking at. FMS and CFS

Vertigo FMS and CFS

General Symptoms

Allergies FMS and CFS

Canker Sores CFS

Cough CFS

Dry Eyes and Mouth FMS

Fatigue

This symptom can be mild in some patients and incapacitating in others. FMS and CFS

Flu Like Symptoms FMS and CFS

Frequent Urination CFS

General Malaise FMS and CFS

Hair Loss CFS

Increased Thirst FMS and CFS

Irritable Bowel Syndrome

Alternating constipation, diarrhea, frequent abdominal pain, bloating and abdominal gas. FMS

Low Blood Pressure CFS

Low Grade Fever CFS

Mitral Valve Prolapse (MVP).

MVP is a condition where one of the heart valves bulge out during a heartbeat. This may cause an abnormal heart rhythm, but is no indication of heart trouble or disease. This valve is mostly connective tissue, which may be affected by fibromyalgia. FMS

Morning Stiffness FMS and CFS

Nightsweats CFS

Shortness of Breath CFS

Soar Throat CFS

Temperature Sensitivity

Feeling hot or cold no matter what the temperature is. Extreme hot or cold weather can worsen symptoms. Also sensitivity to cold, damp or humid conditions. CFS

Tender Lymph Nodes

In the neck or armpit. CFS

Thyroid Inflammation CFS

TMJ - Temporomandibular Joint Dysfunction Syndrome

This syndrome, sometimes referred to as TMJD, causes tremendous face and head pain in one quarter of fibromyalgia patients. Symptoms with this condition may be related to the muscles and ligaments surrounding the joint and not necessarily the joint itself. FMS and CFS

Multiple Chemical Sensitivity Syndrome

Sensitivities to bright lights, foods, noise and medications. FMS and CFS

Pain Symptoms

Abdominal Pain FMS and CFS

Chest Pain FMS and CFS

Chronic Pain FMS

Feeling like arms and legs are tied to concrete blocks FMS

General Body Pain FMS and CFS

Joint Pain

Without redness or swelling. FMS and CFS

Muscle Pain and Weakness FMS and CFS

Tenderpoint (and triggerpoint pain or tenderness) FMS

Sleep Symptoms

Poor sleep is a hallmark for these syndromes. Most patients have an associated sleep disorder that prevents them from reaching a deep (stage 4) sleep level. Stage 4 sleep is when our body releases growth hormones that chemically replenish and repair body tissues. It should be noted that most patients diagnosed with chronic fatigue syndrome have the same alpha-EEG sleep pattern as some fibromyalgia-diagnosed patients. Sleeping aids are a normal course of action for treatment. FMS and CFS

Abnormal Brain Activity In Stage 4 Sleep FMS and CFS

Alternating Sleep and Waking Patterns FMS and CFS

Difficulty Falling Asleep FMS and CFS

Excessive Sleeping FMS and CFS

Non-Restorative Sleep FMS and CFS

Restless Leg Syndrome FMS and CFS

Treatments

The goal in the treatment for FMS/CFS patients is to lead the most pain free lifestyle possible. In addition to medications, lifestyle changes that teach stress and pain relief are essential to minimize pain and fatigue. Many physical activities can cause flare ups and pain. In FMS, moderate activity becomes strenuous, and is likely to result in increased pain. Any body movement that causes the muscles to have a “sustained contraction” will result in pain.

Everyday activities that cause sustained contraction include: Changing a light bulb, computer work, lifting, putting groceries away and virtually any stance that requires reaching up with your arms. Your doctor may recommend therapeutic exercises to improve your physical condition.

Occupational Therapy

Activities of daily living are more difficult. Occupational Therapy helps one become as independent as possible by teaching new ways to perform tasks that minimize pain. Research shows patients take up to 30% longer to complete a daily living task. Daily activities like house cleaning, dressing, and bathing can be performed to better suit the limitations caused by this illness. It is important to remember that changing personal habits and the way daily activities are performed requires repetition and practice. A therapist can help the individual plan goals to build strength, coordination, endurance and cognitive function through activities which are part of his or her daily routine.

Physical Therapy

Patient education usually includes Physical Therapy. Improper exercise will increase pain and cause unnecessary discomfort. Learning how to exercise properly is crucial to pain management. FMS patients have decreased oxygen supply to their muscles, so when muscles contract, less energy is available to sustain these contractions. The combination of decreased oxygen and energy lead to muscle pain. Therapy is designed to condition the muscles and reduce pain. Physical Therapy teaches a wide variety of appropriate exercise treatments including mobility and low impact water exercises. A physical therapist can explain other therapeutic options like massage and hot and cold therapy for patient comfort.

Sleep Treatments

Treatments are geared toward improving the quality of sleep and sleeping aids are commonly prescribed. It is believed that fibromyalgia and chronic fatigue sufferers never reach a deep level of sleep. Because deep level (stage 4) sleep is so crucial for many body functions, such as tissue repair and antibody production, providing the best sleep possible is a priority in the treatment of these syndromes.

Warm Water Therapy

FMS/CFS patients find water means “freedom”. Body weight is buoyed and this reduces stress on muscles and joints. Exercising in water improves the fitness of your heart and lungs, tones the body and reduces fat. The water must be warm, as cold water creates discomfort. You can incorporate every kind of exercise in water therapy: aerobic, flexibility, range of motion and strengthening.

Alternative Therapies

Alternative therapy means an approach to solving a health problem that's different from those used by conventional practitioners of western medicine. It would be more accurate to call some of these therapies complementary, since they complement - rather than replace - conventional medical practice. Following are complementary therapeutic options that promote general wellbeing, mentally, emotionally and/or physically. Many people with chronic pain seek alternative therapies to obtain relief from their pain, in their effort to lead the most comfortable life possible.

Acupuncture

Is a Chinese medicine. Most people picture acupuncture as a therapy that uses thin needles, but there are several different methods that can be used to stimulate the more than 300 acupuncture points that lie along the meridians. Some methods used include : Heat, herbs, magnets, pressure and laser. Acupuncture treats pain, and maintains health by stimulating points located on channels of energy running along the body (meridians).

Each channel carries Chi (life force) and is linked to a specific organ and different emotion. If these channels become blocked or stagnated then pain and disease occurs. The stimulation used, unblocks the meridians and restore the flow of Chi. Patients are treated as a whole with the understanding that all symptoms and signs within one person interrelate and influence each other.

Chiropractic Care

Is a branch of the healing arts which is concerned with human health and disease processes. Doctors of Chiropractic are physicians who consider man as an integrated being and give special attention to the physiological and biochemical aspects including: Structural, spinal, musculoskeletal, neurological, vascular, nutritional, emotional and environmental relationships. Chiropractic treatment is geared toward, dietary changes, nutritional enhancement, postural changes, physical therapies (heat, ice, light massage, etc.), spinal manipulation and stress management.

Massage Therapy

Massage relaxes muscles which improve circulation and decrease pain. Massage stretches muscle fibers and increases flexibility. It is one of the most soothing and comforting treatments for mental and physical relief.

Common Medications

Antidepressants

Aventyl
 Elavil
 Endep
 Fluoxetine-Prozac
 Doxepin Adapin
 Paroxetine-Paxil
 Sinequan Nortriptyline Pamelor
 ProzacRemeron-mirtazapoin
 Sertraline-Zoloft
 Sinequan-doxepin
 Zoloft

Anxiety

BuSpar
Klonopin-clonazepam
Xanax-alprazolam

Headaches

Imitrex (sumatriptan)
Maxalt
Midrin calcium
Migranol
NSAIDS
Tylenol

Irritable bladder

Tricyclics
Urised

Irritable bowel syndrome

Bentyl
Librax

Muscle Relaxants

Cyclobenzaprine
Cycloflex
Flexeril
Zanaflex

Pain Relief

COX-2 Inhibitors
Hydrocodone
Soma-carisoprodol
Ultram

Restless legs

Klonopin

Sleep

Tricyclics:

Elavil

Flexeril

Sinequan

Soma

Trazodone

Sedative/Anxiolytic Medications:

Ambien

Buspar

Support Of Chronic Pain Medications

Pain is a personal experience which means it can not be measured. Pain can be emotionally crippling and is also the cause of many psychological problems, such as feelings of anxiety, fear, depression, hopelessness and low self-esteem. While concern for the long term effects of daily intakes of pain medications is valid, it is also important to understand that chronic pain sufferers have to manage life in a much different way than a person without daily pain. Medications are a personal decision between the patient and doctor, for some, unrelieved pain has many other negative health consequences including, but not limited to: Blood clotting, decreased mobility, delayed healing, increased stress, hormonal imbalances, impaired immune system and gastrointestinal functioning, loss of appetite, nonrestorative sleep, water retention, and needless suffering.

Chronic Pain Medication Resources

ABC News

Website:

http://archive.abcnews.go.com/sections/newsuse/nl_stadol_narc/

Chronic Pain Relief Coalition (CPRC)

Website:

<http://www.fortunecity.com/millennium/hibiscus/152/index2.html>

MARRTC

The only federally funded arthritis rehabilitation research and training center in the country.

Missouri Arthritis Rehabilitation Research and Training Center

130 A P Green, DC330.00

One Hospital Drive

Columbia, MO 65212

E-mail: marrtc@health.missouri.edu

Website: <http://www.muhealth.org/~arthritis/marrtc.html>

Mayo Clinic

Reassessing the role of morphine and other narcotics. Call for the location nearest you.

4500 San Pablo Road

Jacksonville, FL 32224

Phone: 904-953-2000

Website:

<http://www.mayohealth.org/mayo/9710/htm/morphine.htm>

The Painful Dilemma

The Use of Narcotics for the Treatment of Chronic Pain

Website: <http://mojo.calyx.net/~schaffer/asap/dilemma.html>

WebMD

Website: http://onhealth.webmd.com/conditions/in-depth/item/item%2C46864_1_1.asp

Prescription Drug Resources**Directory of Prescription Drug Patient Assistance Programs**

It has been a long-standing tradition for pharmaceutical companies to provide prescription medicines free of charge to physicians whose patients might not otherwise have access to necessary medicines. This website provides a list of pharmaceutical companies that participate in programs.

Website: <http://www.phrma.org/patients>

Prescription Website Guide

Online guide to more than 9,000 prescription and over-the-counter medications provided by the United States Pharmacopoeia (USP).

Website: <http://www.nlm.nih.gov/medlineplus/druginformation.html>

Prescription Drug Handbook

Published by The Association of American Retired Persons. AARP has recently revised its Prescription Drug Handbook, which is a guide to medications frequently prescribed for older people. The handbook describes nearly 1,000 brand name and generic drugs, over-the-counter medications and vitamins.

AARP

601 E St. NW

Washington, DC 20049

Phone: 800-424-3410

Phone: 800-456-2277

E-mail: member@aarp.org

Prescription Drug Programs

Free Medication Program (for low income patients).

The Medicine Program

Phone: 573-996-7300

Website: <http://chronicfatigue.about.com/health/chronicfatigue/gi/dynamic/offsite.htm?site=http%3A%2F%2Fwww.themedicineprogram.com%2F>

American Pharmaceutical Association - Pharmacy and You - Online

Information resource on pharmacists, medication and drug interactions.

American Pharmaceutical Association

2215 Constitution Avenue, NW

Washington, DC 20037-2985

Phone: 202-628-4410

Fax: 202-783-2351

E-mail: webmaster@mail.aphanet.org

Website: <http://www.pharmacyandyou.org>

The American Pharmaceutical Association's Guide to Prescription Drugs

Author: Donald Sullivan, Ph.D., RPH

Are the prescription drugs you're taking safe? Written in clear, easy-to-understand language, this book provides the most up-to-date information you need to know about the most commonly prescribed drugs.

The Medical Letter

The Medical Letter on Drugs and Therapeutics is an independent, peer-reviewed, non-profit publication that offers unbiased critical evaluations of drugs - with special emphasis on new drugs - to physicians and other members of the health professions.

Occasionally, the Medical Letter publishes an article on an entire class of drugs, a new non-drug treatment or a new diagnostic aid.

The Medical Letter

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Website: <http://www.dds.nl/~me-net/meweb/web3.3.html>

Research

Researchers have several theories about what triggers these syndromes including, central nervous system injury, changes in muscle metabolism, or an infectious virus agent. Support of fundamental research is extremely important, because it is impossible to know which area will produce the next important discovery. Discoveries can come from research funded in a variety of areas. For example, the National Institutes of Health (NIH) supports pain research at different levels--from the cell, gene, molecule, and organ to the human organism itself. Since not all the outcomes can be anticipated, and it is hard to know where scientific advances will come from, NIAMS strives to support and maintain a diverse research portfolio. This is especially important in fibromyalgia/chronic fatigue, where many areas are being developed simultaneously. Contact FMS/CFS Associations to make research contributions.