

A Guide for Relatives and Companions

Fibromyalgia (Fie-bro-my-al-gia, or FMS) is a chronic invisible illness that is difficult to understand. It is not a muscle condition. It's a dysfunction of the informational substances such as neurotransmitters, hormones, peptides, and other biochemical messengers which regulate and run the systems of the body and mind. It causes hypersensitivity to all sorts of stimuli, so it can amplify pain. It often occurs with chronic myofascial (my-oh-fass-shall) pain syndrome (MPS), which is a neuromuscular chronic pain condition with trigger points (TrPs) that can cause incapacitating, intolerable pain. MPS also can cause symptoms such as extreme dizziness, migraines, buckling knee, clumsiness and calf cramps. Pains in localized parts of the body--the back, hands, neck and other areas, are a symptom of MPS. Achy, body-wide pain is a symptom of FMS.

One symptom of FMS is dysfunctional sleep called the alpha-delta sleep anomaly. When you reach deep level sleep, alpha brain waves intrude and jolt you back to shallow sleep or wake you. Not only are you denied refreshing sleep, but delta level sleep is when the body does much of its repair and biochemical regulation. The person with fibromyalgia can't recover from exercise, stress and work like other people. They are constantly in a state of sleep deprivation unless they find a combination of medications, lifestyle modifications and diet that work for them.

If people with MPS are immobile at any time, such as during travel or sitting in a meeting or movie, their muscles get stiff and painful. It can feel like you are wearing a wet suit several sizes too small, your range of motion is limited, and your muscles are weak. Morning stiffness with both of these conditions can be severe. Symptoms fluctuate from hour to hour and day to day, and may worsen with changes in barometric pressure, humidity, cold or heat. If you overextend your limits, you often have extra pain for days or weeks. The FMS body is like an engine idling at 35% power, rather than a normal 5%, or like a radio with its volume control stuck on high.

Symptoms can be severe, yet blood tests, X-ray and other common diagnostic tests do not show FMS or MPS. This only means that we presently lack knowledge of how to test for FMS. MPS is easy to diagnose if your medical care provider has been trained to do it. FMS and chronic MPS are two of the most common sources of chronic pain, and the most undiagnosed or misdiagnosed of illnesses. Most FMS patients have memory and cognitive impairments. Doctors often refer FMS patients to psychologists or psychiatrists, yet studies show that psychologically, these patients have no more abnormal psychology than arthritis patients. People with FMS and MPS are often misunderstood and doubted, and this, in addition to the chronic pain and other symptoms, could cause anyone to feel depressed and confused. An American College of Rheumatology study in 1992 found that the impact of FMS on your life is as bad, or worse, than Rheumatoid Arthritis. They listed one major factor in this as "clinician bias". FMS & MPS patients don't look sick, and their symptoms vary, so they are often misunderstood and disbelieved by clinicians, family and friends.

FMS and MPS are not progressive, but symptoms may worsen if the perpetuating factors are not identified and dealt with promptly and adequately. If you have FMS, you have a history of

widespread pain, and wake up every morning feeling like you've been run over by a truck. You may have headaches and loss of balance. Looking both ways when going into traffic can cause dizziness. You can't always find your car in a parking lot. On your best days you feel like you have the flu. You may have short-term memory loss. If you put on weight, and can't get it off, you may have reactive hypoglycemia, a frequent perpetuating factor. Sometimes you get muscle twitches. With FMS, you will probably have 11 of 18 specific "tender points". If these spots are pressed, you will have pain. If you also have MPS, you have Trigger Points. These TrPs are incredibly painful areas that often feel like knots, hard lumps, or taut bands of fibers in the muscles, and they can be everywhere, and often refer pain to some other part of the body. They can trigger irritable bowel syndrome, grinding of teeth at night, dizziness, chronic inversion sprains of the ankle, weak knees, weak ankles, pelvic pain, dysmenorrhea and painful intercourse in women, impotence in men, and many more symptoms. The tightened and rigid myofascia surrounding the muscles can entrap nerves, blood vessels, and ducts. You can have blurring of the eyes, double vision, leg cramps, trouble swallowing, hypoglycemic-like symptoms, sciatica, numbness or tingling--the list goes on and on. The muscles contracted by TrPs can pull bones out of alignment, and lead to osteoarthritis.

There is no cure for FMS & MPS Complex. There are medications and therapies that help some symptoms of FMS and MPS. The key to reducing symptom load is always to identify every perpetuating factor, such as lack of restorative sleep, poor diet and posture, as well as the pain load, and deal with each of them as thoroughly as possible. It takes a commitment on the part of the patient to practice a healthy lifestyle, including good nutrition, a program of gentle stretching and moderate exercise, and avoidance of smoking and other bad habits. There must be recognition by both the patient and her/his companions in life (including the medical care team) that there are real limitations for people with fibromyalgia or myofascial pain syndrome. It isn't easy to find the right balance to optimize the quality of life. Be patient, compassionate, and listen. Ask if there is something you can do to help.

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