

Fibromyalgia

David's Story



What if someday you were to wake up and be unable to get out of bed because you were too fatigued or in so much pain that you would contemplate ending it any way you could? If I told you that you might temporarily forget the name of your wife or your child in a moment's notice? And what if most doctors did not know what you have or how to treat you because nothing shows up in blood tests or x-rays so they may possibly even suggest it was all in your head? What would you do?

My name is David Squires and I have primary fibromyalgia syndrome (FMS). Although I did not suddenly wake up with all of the symptoms, I have been dealing with them for the past 50 years. I hope by sharing my story with you that one more person will understand this very complex syndrome.

My experience with FMS started with neck and shoulder symptoms at age 15. Initially, I was diagnosed with “growing pains” and later with juvenile rheumatoid arthritis (JRA). By age 20, the pain spread and involved my low back. By age 30, my whole body was in chronic pain. My joints were unaffected so the diagnosis of JRA was ruled out. At that point, there was no name for my condition. Without a diagnosis, I went through years of unnecessary treatments, spent

thousands of medical dollars, and argued with my insurance companies to cover doctors’ bills. I saw between 30-40 doctors and no two agreed on an effective therapy program.

Some of the therapies I tried included nonsteroidal anti-inflammatory drugs (NSAIDs), pain-killers, hypnosis, TENS, biofeedback, exercise programs, myotherapy, acupuncture, vitamin therapy, yoga, Rolting, a TMJ mouth brace, body cast for six months, chiropractic adjustments, trigger point injections, epidural nerve blocks, ultrasound, electrical stimulation, physical therapy, and, of course, psychiatric counseling. Diagnostic tests included CAT scans, MRIs, blood tests, and over 100 x-rays. Finally, a doctor at the Lahey Clinic in Boston told me I had fibrositis (an early name for FMS), and advised me to find a job with little stress and no physical requirements. At that time in my job as a tool and die maker, I worked 50-hour weeks, always under a contracting deadline. I was too young to retire so I went back to work. By age 37, with great reluctance, I had to stop a career I had spent 15 years exacting. I was in my prime asking myself what the rest of my life would be like if I had to live with this kind of pain.

My story is not unlike so many others with FMS. I thought I had the perfect life. I married my high school sweetheart, bought a home, started a family, and owned my own tool and die business by age 29. I was a good father, husband and provider. Successful at my job, I pushed myself through years of growing pain. Then in 1984, after six months in a body cast, I could not go on.

Life took a radical change for the worse. I could no longer sit or stand for any prolonged period of time without unremitting pain. Unable to understand my condition, my employer thought I could work if I wanted to. When I could not, he cancelled my insurance. My wife of 17 years was not able to cope with the changes and left me. Within the next 18 months, I lost everything – my family, house, and car. I ended up cashing in my life insurance policy and selling my stocks just to get by. I came very close to ending up alone on the street before turning to local social services. A worker there heard my story and went out of his way to help me obtain Social Security disability. Life began to take a turn for the better. In 1985, I remarried and my children came back to live with me. Because of my sensitivity to the cold and damp weather of New England, I moved to Arizona where I live today.

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Although I am still in pain every day, I consider myself one of the lucky ones with FMS. Despite all the wrong diagnoses, the inappropriate treatments, and given all the rejection by doctors, family, coworkers, and friends who thought there was “nothing wrong with me” because I looked “fine”, I survived. There are still some who do not and will not ever know what I go through on a daily basis living with fibromyalgia.

Am I telling you my story to gain sympathy for me or others with FMS? No! I want you and everyone to know to what lengths a FMS person goes through to receive relief and a diagnosis for his/her symptoms. We are struck with an invisible syndrome that makes us look like hypochondriacs, malingerers, psychosomatically ill, or asking for a handout. Nothing could be further from the truth! Given the choice, we would rather work than accept disability, be free from the pain, and certainly would choose to keep our lives intact than have them turned upside down with FMS.

In March of 1993, my wife, Margy, and I started a support group for people with FMS. We wanted to educate as many people as we could about fibromyalgia. Our group, along with three others in the Phoenix, Arizona area, grew to over 1,000 members in a little over 18 months. We held our first Arizona FMS symposium in March of 1994. Since the criteria for the diagnosis of fibromyalgia was written by the American College of Rheumatology in 1990, diagnosis numbers are going up. However, research is still in its infancy. The medical profession is still in disagreement as to the cause and treatment of fibromyalgia.

Although most doctors don't agree on treatment, most will agree on one thing: FMS is not life threatening. However, FMS can be “life shattering”. For the person with fibromyalgia, life goes on, but in a much different way.

It was quite by accident that I learned of a natural way to help my pain. In January of 1993, my doctor asked me to try a topical product with capsaicin. I had tried capsaicin in the past and didn't think it worked on pain but he convinced me to try it again. The doctor explained that because it was a topical and a natural ingredient, it took time to work. The cream had to be put on several times a day and over an extended period of time before I would see results. Capsaicin (cap-SAY-shun) is derived from the hot pepper plant and is believed to interfere with the production of substance P, a chemical which transmits pain signals to the brain. Fibromyalgia patients have up to three times more substance P than the normal person. So I faithfully applied the product for four weeks and was ready to give up again when I felt pain relief for the first time – relief without side effects like stomach upsets, toxicity, or addiction.

Although nature takes longer, people who change their lifestyles and diet, including taking vitamins and herbs, do much better than those on medications alone. I was already on a multi-vitamin mineral program. (I thought since I was in a chronic state and unable to exercise that I could at least keep my body in shape nutritionally.) Knowing that fatigue was a common factor because of un-restorative sleep, I tried valerian, an herb

thought to reduce insomnia by improving sleep quality without that next day morning grogginess with good results. In early 1995, a natural supplement with magnesium and malic acid was found to benefit the muscle tissue of those with FMS. I decided to try that, too. Having so many other therapies fail, I welcomed natural remedies that might help my symptoms. I have not been disappointed. When my wife wanted a career change from the medical clinic where she worked – even after everything she had been through with me – she decided to start a mail order company that would help others like me. Through my personal experiences and her medical educational background, Margy is able to relate to those in chronic pain and offer non-drug answers. Thus, To Your Health was born in July of 1994.



What advice do I have for others with FMS?

Do whatever you can to help yourself. Do not get upset with people for what they think, say, or do. It is what you think, what you say, what you do about your FMS that is important. Remember: Never give up! Millions of fibromyalgia sufferers know what you are going through. Do not be silent with your FMS. Write letters to your representatives to let them know how fibromyalgia has affected your life. Try to stay positive and motivated. Join a support group or start your own, which may be the best thing you can do for yourself. It was for me. Finally, I would like to share a quote from Edward Everett Hale that has helped me, one that I read almost every day.

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“I am only one, but still I am one. I cannot do everything but still I can do something. And because I cannot do everything, I will not refuse to do the something I can do.”

Edward Everett Hale



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