

FMS: A disease that's hard to diagnose

Fatigue, muscle soreness symptoms of fibromyalgia

By Kay Murphy Nolan

Freeman Staff

OCONOMOWOC — Imagine playing tennis for the first time in spring. The next day your muscles feel tight and sore.

Now imagine feeling that way almost all the time.

That's life for people with fibromyalgia syndrome, a chronic illness similar to arthritis.

Their muscles ache and feel tight. They have extreme fatigue, yet pain prevents them from sleeping well.

Sore muscles in the back and neck often lead to migraine-like headaches; and for some reason, FMS also causes recurring diarrhea and constipation.

Perhaps worst of all is the frustration felt by patients, who are often made to feel like hypochondriacs.

Yet, the typical person with FMS is a high-achiever, who has a history of robust health, said Debi Marheine, who started a Waukesha area support group for people with FMS after she was diagnosed two years ago.

Marheine is a mother of three and former manager of data administration at Time Insurance Co. of Milwaukee.

"Entrepreneurial types seem to get it," said Jim Schoessow, a member of the support group. Schoessow is co-owner of a farm equipment business near Portage.

The exact cause of FMS is unknown, but often a traumatic event or cluster of events seems to precede it.

Schoessow was driving a semi-truck, which rolled over, injuring his back and slamming his head against the roof of the cab. The injuries healed, but fibromyalgia set in.

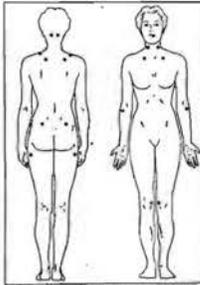
Dr. Jeffrey B. Gorelick, a Waukesha physician who specializes in treating FMS, agreed that trauma such as car accidents commonly triggers the disease.

"Some people, however, develop FMS out of nowhere," Gorelick told a group of about 40 people who attended a six-week workshop on FMS at the Oconomowoc Public Library.

"Seventy-five percent of people with chronic fatigue syndrome may actually have fibromyalgia," said Gorelick.

Diagnosis is not easy, Gorelick said, because no definitive lab test exists. The best guide to diagnosis at this time is whether a patient has certain tender points throughout the body, which are painful to the touch.

Younger doctors may be more likely to know about FMS and its trigger points, as are those



To meet diagnostic criteria for FMS, a patient must have at least 11 of the 18 specified "tender points" and pain in the upper and lower body for at least three months.

trained in rheumatology or physical medicine.

Many patients go from doctor to doctor before they are accurately diagnosed, said Gorelick.

"When I tell them I understand, there's an enormous relief on their faces, and I haven't even started to treat them yet," he said.

Often, patients are referred to mental health professionals.

"That's not bad if the purpose is for a psychiatrist or psychologist to help patients cope with the pain, but if the implication is that it's all in your head, that's devastating to the patient," Gorelick said.

Unfortunately, FMS has no cure, and no amount of treatment can make patients' lives pain-free.

The best known treatment is medication that boosts the body's level of serotonin, a neurotransmitter that helps the brain achieve deep sleep. During this level, the body's healing mechanisms function best.

Other treatments are aimed at easing pain and keeping muscles flexible — FMS patients are prone to "micro-tears" when they exert stiff muscles.

Massage, physical therapy, meditation, stretching exercises, acupuncture, chiropractic manipulation, moist heat and biofeedback have all been tried. Success varies from patient to patient.

Sufferers are also told to alter their lifestyle, to allow for periods of rest.

"My people (at my workplace) know that there are times when I won't be there," said Schoessow.



Deborah Mabeine and her daughter, Amanda, 3, take time on a recent afternoon to share a book in the family's town of Brookfield living room.

Flexibility is key to living with FMS

By Kay Murphy Nolan

Freeman Staff

TOWN OF BROOKFIELD — On a good day, Debi Marheine wakes up with painfully stiff muscles, but they feel somewhat better by 10 a.m.

She is able to clean the house in half-hour increments and perhaps volunteer at Hillcrest Elementary School, a few blocks from her home.

On a bad day, her legs and back ache so much she can barely do anything. As the day progresses, tight muscles in her neck cause a pounding headache and her hands and feet feel numb.

Because the symptoms of fibromyalgia are so unpredictable, Marheine has learned to work her activities around it.

"Flexibility is the key," she said.

The 41-year-old woman said she used to have energy to spare. She worked full-time at a highly-demanding management job in downtown Milwaukee, was married and the mother of two boys,

Joshua and Tim. She and her husband, Bob, a systems programmer for Firstar Bank, were building their dream home.

Naturally, she said, she felt some stress. But a number of additional stressful events occurred in rapid succession for about a year and half, and Marheine is convinced they played a role in her subsequent chronic illness. There were two car accidents, which caused back injuries and whiplash, a miscarriage, and her father and sister were diagnosed with cancer. Marheine became pregnant again, but the pregnancy was fraught with problems.

Her third child, Amanda, was born just three weeks before Marheine's father died.

"A month later, I was overwhelmed with fatigue," she recalled. "At first, I thought it was because I had new baby and had undergone so much stress, so I went for counseling. But my shoulders and back were painfully tight."

After eight months, Marheine

was diagnosed with fibromyalgia. "I was lucky because my family practitioner was familiar with the syndrome," said Marheine. "Many people aren't diagnosed for years."

A rheumatologist confirmed Marheine's diagnosis and prescribed Flexoril, a medication that induces deep sleep. During the day, she may take ibuprofen for pain, but she dislikes too much medication.

Instead, Marheine chose to change her lifestyle. "My husband and I went through a lot of soul-searching," she said. "I finally decided to quit my job."

Although it was hard to give up her career, Marheine said she is glad to be spending more time with her children.

"I'm a room mother now," she said. "I'm a Cub Scout leader. I never did that before."

In addition to running an FMS support group, Marheine also uses her spare time — and good days — to help the visually-impaired.

Support group helps sufferers realize they are not alone

BROOKFIELD — How does a smart, efficient businesswoman and mother cope with the relentless pain and fatigue of fibromyalgia?

Debi Marheine is more than willing to tell others how she maintains a busy life and cheerful outlook with the illness she knows will be a lifelong companion. But she also continuously looks for new information and advice.

That's why Marheine started a local support group for people with fibromyalgia.

She soon found she wasn't alone in her diagnosis or in her desire to learn more about FMS.

More than 60 people have already joined the group. It meets monthly at Elmbrook Memorial Hospital, 19333 W. North Ave.

Marheine met some prospective members at Milwaukee FMS support groups.

Others learned about her new Waukesha-area group by calling the Wisconsin Arthritis Foundation, which trained Marheine as a facilitator.

Marheine distributes the latest information available on FMS to new members. She also includes a "guide for loved ones," which explains in everyday language how FMS feels.

Each month, she tries to get a speaker for the group.

In March, Kris McCormick, a certified massage therapist who also suffers from FMS, demonstrated stretching exercises and played a soothing meditation tape.

Like most support groups, however, an informal exchange of ideas, emotions and words of encouragement is considered as important as expert advice.

Members are asked to each state a "brag" and a "bummer," based on their personal experiences since the last meeting.

Sometimes, the participants' words are as painful as their bodies.

"On Tuesday, I had the best day I've had in 15 years. I felt great. For the first time in ages, I had no pain. But then on Wednesday, the pain was the worst it's ever been."

"My brag is that I made it here today, because within the past week, both of my parents were hospitalized. I stayed at their bedside all day. My number is that I thought maybe I would be able to forget about my own pain for a little while — but it didn't work. It was as bad as ever."

"My brag is that I actually took a train to Chicago and spent all day there. Of course, I rested all week before the trip and I had to rest again afterward."

Members of the group nod with sympathy. The nods are especially vigorous when someone says:

"It's not our imagination!"

"A lot of people with this illness have a hard time having people understand," said Marheine.

"A lot of people don't understand chronic illness. They say, 'What do you mean, you're in pain every day?'"



Certified massage therapist Kris McCormick, at left, speaks to a fibromyalgia support group at Elmbrook Hospital. Above, members of the fibromyalgia support group follow McCormick through a series of stretching exercises.

— Kay Murphy Nolan

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Mrs. Kay Murphy Nolan
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Dear Kay:

Thanks for sending the copy of the articles you did in the Freeman to us. Jim and I sorted out the mailing addresses, with no problem.

You did a magnificent job on the FMS story. I think the three separate approaches were great--you looked at it from three key perspectives, and I think helped readers understand the various problems/aspects/aggravations well.

Just wanted to drop you a note to say how much your professional handling of the story was appreciated.

Sincerely,


Shirley Iwatiw