

FIBROMYALGIA

A PATIENT'S PERSPECTIVE

by Cecil E. Maranville

This is no 'cookie-cutter' disease," said Dr. Frances Nardella, a rheumatologist who spoke at a November 1994 seminar on fibromyalgia in Phoenix, Arizona. He was referring to the puzzling complexity of this common illness. Dorothy Johnson, R.N., Ph.D., the principal speaker at the seminar, said fully five percent of people seen by general practitioners and two percent of the United States population have this disease.

That translates into a total number of 18 to 20 million people in the United States! Yet it seems that few people, other than treating physicians and those who have the illness, know much about it. How amazing that so common an ailment could be so little known in a country with the best healthcare system in the world!

Those with fibromyalgia, along with the doctors who find them by the millions coming for treatment, are hungry for information. Having lived with the disease for about 30 years and researched it for over eight, I've compiled a basic overview of fibromyalgia for this article.

The term "fibromyalgia" literally means pain of the fibrils, the tiny fibers which make up the muscles, although it apparently also affects other soft tissues. Before 1990, the ailment was known by various terms, including "myofascial pain syndrome," "fibrositis," and "fibromyositis." (All information about the knowledge and treatment of fibromyalgia in this article reflects the practice of medicine in the United States. Earlier research and treatments have been done in Europe.)

Fibromyalgia can produce joint pain like arthritis and even "move around" like rheumatoid arthritis. But rather than attack and degenerate the joints as arthritis does, fibromyalgia affects muscles, tendons and ligaments. There is no discernable inflammation or tissue damage. Hence, the derivation of the currently accepted name, fibromyalgia. A diagnosis of primary fibromyalgia means there is no accompanying disease; a diagnosis of secondary fibromyalgia means that there are one or more other diseases present.

Doctors are still debating the cause. Some believe it to be genetic; some lean toward a viral cause; some believe that it is triggered by an accident with sharp trauma to a muscle.

Symptoms in Addition to Pain

Other than pain, common symptoms include chronic fatigue, poor sleep, stiff muscles, and poor circulation. Numerous so-called "tender points" which are extremely sensitized to touch occur in the neck, shoulders, upper and lower back (on both sides of the body) but may also occur in a variety of other areas. The tender points remain painful for months at a time.

These symptoms are not readily recognizable to friends and family, even though the person with the disease may be literally incapacitated. It isn't surprising that depression accompanies the chronic pain in some people.

The average person seeking diagnosis and treatment for fibromyalgia sees eight different physicians, according to Dr. Johnson. Seeking help can be a frustrating and discouraging experience. Since it isn't identifiable by the typical methods of diagnosis-urinalysis, blood sample, biopsy, x-ray, etc. the disease was largely dismissed as nonexistent or psychogenic until recently.

Suffering such pain that one is limited, or unable to work, along with the other debilitating symptoms, a person with fibromyalgia finds no comfort in being told he has "nothing to worry about, as all lab tests are negative." That only means the illness was not identified - not that it does not exist.

The American College of Rheumatology defined diagnostic criteria in 1990 for fibromyalgia, based upon the "tender points" described earlier. Doctors are trained to look for between 11 and 14 identifiable points which are painful to the application of a moderate amount of pressure (pressing with a finger until the nail begins to turn white).

There are also "trigger points" not to be confused with "tender points." The difference is that pain radiates into other areas from a trigger point, but is localized around a tender point.

Dr. Nardella warned in his presentation that these are only working guidelines for the treating physician. There may be more or less tender points in a given person, which may vary from day to day. The physician needs to be flexible with the diagnostic criteria.

Level of Pain

The pain of fibromyalgia can be as intense as the worst possible pain, a '10' on the pain analog, or as little as a "1" merely a "nuisance" pain.

It is common, said Dr. Charles White, a Physiatrist with a practice in Peoria, Arizona, to think of pain in connection with tissue damage. Dr. White presented a lecture on "FMS (Fibromyalgia Syndrome): Diagnosis, Treatment, and Special Problems" in the November 1994 seminar referred to earlier.

But can pain occur without tissue damage? Yes, indeed. So-called "ghost pain" in amputated limbs illustrates that fact. Dr. White noted that anyone over the age of six who loses a limb will "feel" pain in it, even though the limb is gone.

Pain without tissue damage is the pain of fibromyalgia.

This pain can manifest itself as an ache or a spasm. Either type may range from minor to so strong that it alone can disable. The spasms may occur in any area of the body, at any time of day or night. They may "fire" for an instant or repeatedly from minutes to hours at a time.

Pain may occur symmetrically or asymmetrically, in the muscles, as well as in tendons and ligaments and around joints. The pain of fibromyalgia is truly a tormenting experience.

Fatigue accompanies the pain, either as part of the disease or as a result of the incessant pain. The fatigue alone can be severe enough to incapacitate. According to Dr. Nardella, 80 to 90 percent of people with fibromyalgia meet the diagnostic criteria for chronic fatigue syndrome. (That doesn't mean they are one in the same.)

The Nature of Fibromyalgia

It has taken me years of experience, as well as the help of knowledgeable doctors and therapists, to learn the undulating nature of fibromyalgia. The pain will cycle, like the rising and falling of ocean tides. Based upon my research and comments of my treating physicians, mine is a typical example.

I have experienced disabling pain sweep over me in a matter of minutes. By contrast, in the early stages of the illness, pain would grow slowly, more like a gradually rising tide. It came on so slowly that I didn't consciously realize what was happening. Eventually a "crest" would strike, leaving me disabled completely.

In the early stages, remission would begin with treatment after six to eight weeks. When the pain began to wane, it went quickly. Since I did not understand fibromyalgia, I resumed all activities and my demanding job as a full-time pastor. The pain cycle would slowly return until another crest of a wave" would flatten me again.

I would be terribly discouraged. I was surprised every time the pain grew so strong that I was out of commission. No one had been able to tell me I had a "syndrome" or "disease," what to expect from it or how to adjust to it. Whenever I experienced a remission, I assumed I was completely well - a big mistake!

Now I manage the pain, rather than seek to eliminate it. Pain management started with keeping a detailed journal of pain levels, activity levels, weather (humidity, barometric pressure, temperature), sleep patterns, and mental outlook. It took only a short period of

time to recognize consistencies in circumstances which preceded flare-ups. That began the long journey of adjusting my work and lifestyle accordingly.

Treatment

The overwhelming consensus of physicians who treat fibromyalgia is managing treatment yourself. Remember the colorful comment "this is no cookie-cutter disease." There are no short-cuts.

To aid a person in reaching selfmanagement, there are a variety of temporary "tools" in common use. No one method seems to be generally superior to any other. What helps one person does not another; what helps a person break one pain cycle may not be able to break the next one.

Drug therapy is a temporary "crutch" used by the majority. Dr. Dorothy Johnson, referred to earlier, told of a study of drug therapy for fibromyalgia which showed that 97 percent of people with the disease take an average of 2.9 prescriptions.

Dr. Nardella gave an open and honest assessment of drug therapy in his presentation on fibromyalgia. Individual body chemistries react differently to medications. There is a widespread difference of opinion among doctors regarding the use of narcotics (whether to use them at all; how much to control exercise versus how much control to leave up to the patient; what types, dosages, etc.). Statutory regulations on narcotic prescriptions must be followed as well.

Some physicians prefer to use antidepressants as a treatment. One type of antidepressants (the tricyclic group) is a sedative able to help restore refreshing sleep; other antidepressants are used to stimulate a person who is often fatigued. Dr. Nardella cautions that antidepressants are complicated and affect a host of neurotransmitters. The exact effect of any one of these drugs is unknown. The potential problems with drug therapy, in addition to its imprecise nature, include the following: some people are intolerant to most drugs; drugs may lose their effect; they may not produce an adequate response; some people are susceptible to addiction.

The direct injections of corticosteroids into tender and trigger points is another application of drug therapy.

Alternatives to Drugs

Dr. Clark Hanson, a naturopathic physician practicing in Scottsdale, Arizona, also gave a presentation at the Phoenix seminar. He outlined a program of various herbal and vitamin combinations which he has used successfully in breaking the pain cycle in some people.

There is an entire discipline of treatment known as physiatry, which uses physical therapy in a detailed program to treat chronic pain. Physical, recreational, and occupational

therapists, along with a physiatrist (an M.D.) will work together with the ailing person to bring him or her to the highest possible level of function.

Dr. Charles White summarized the physiatric approach with the comment that most patients respond to some type of treatment, experience remissions, and have recurrent flareups. That's a common comment from treating physicians; they treat a pain cycle, not cure the disease.

Practical Aids

Simple items take on new significance to the person with fibromyalgia, such as having a comfortable chair to sit in, a bed which allows restful sleep, or a back support in a car seat. The obvious aids such as canes, walkers, wheelchairs and electric scooters are useful. Walking posture is important, for as simple a matter as walking with one's head thrust too far forward can put undo strain and stress on the back.

All of these therapies involve recommendations on, if not fully supervised programs of exercise. Exercise in warm water is a good way to begin physical therapy; a person can be guided into or discover more exercises which are comfortable for him or her.

A Blend of Treatments

The approach of a naturopathic doctor and an anesthesiologist in Phoenix illustrates the "combining of forces" to successfully treat fibromyalgia.

Dr. Konrad Kail of the Naturopathic Family Care Clinic in Phoenix, Arizona, is Chairman of the Board of Directors of Southwest College of Naturopathic Medicine and Health, and a member of the board of directors for the American Association of Naturopathic Physicians. He is a naturopathic physician and a Certified Physician's Assistant.

Dr. Kail has successfully helped people break the pain cycle of this disease by using a combination of acupuncture, dietary supplements, prescription drugs, and allergy clearing. Dr. Kail has pioneered methods of discovering and clearing allergies which are common triggers of pain. Dr. Daniel Remen is the head of the Pain Medicine Center at Community Hospital in Phoenix. He is an anesthesiologist and a specialist in pain medicine. He and his brother, Dr. Uriel Remen, treat only people who suffer chronic pain.

Dr. Remen has pioneered methods and the combination of medications in chronic pain treatment. Not limiting himself to drug therapy, he is continuously studying and applying whatever therapy helps his patient manage pain - with the least amount of intervention possible.

Both doctors get to know the patient and his or her particular pain, for everyone's pain is different. They guide the person in learning to recognize what brings on the pain and how

to deal with it, so that the person can continue to function in life. This method requires time, patience and close attention, as well as a willingness for the physician to be flexible.

The naturopathic physician should look at conventional medicine, while the conventional physician should look at alternative medicine. This represents the broad type of program which may well be necessary to successfully treat this complex disease.

Alternative care for Fibromalgia:

Diet and Nutritional – look for allergies (a quick test is to take the pulse at rest, pop a small sample of the suspect food in the mouth and recheck the pulse rate. An increased pulse rate indicates a possible sensitivity). Foods can be "triggers" to a pain cycle. Eat and live healthy.

TENS – an electronic device that interferes with the nervous communication. These can give temporary pain relief but if used extensively will become ineffective.

Exercise – routine stretching and light exercise. Don't overdue it. Let your body be your guide.

Myotherapy – gentle thumb or finger pressure is held on the pain center and held at a tolerable level while the thumb or finger is moved in a circle about the "trigger point".

Light or Shallow Massage – A touch so light you can barely feel it. Concentrate on the known acupuncture points for the area being massaged.

Bio-feed back – many methods let you get in touch with what your body is doing and may provide modification relief.

Temperature control – warm or cold applications. Experiment to see what works.

Acupuncture / Electro – acupuncture – it's proven effectiveness and versatility make it your most powerful tool for self treatment. Small portable devices that use an electronic probe to stimulate the "trigger points" give immediate and long term relief. Not a TENS.