Taking the mystery out of fibromyalgia

by R.J. Ignelzi

To better understand fibromyalgia, San Diego medical experts answer some frequently asked questions about the disorder.

WHAT IS FIBROMYALGIA?

CHRONIC PAIN - Along with several medications, gentle stretching and meditation have helped Mary Zeigler cope with the fibromyalgia pain and stiffness she experiences daily. CNS Photo by Crissy Pascual.

Fibromyalgia is a chronic pain syndrome or disorder characterized by widespread muscle aches, tenderness, fatigue and sleep disturbances.

"We used to think it was a muscle and tendon (syndrome), but now we think it's a central nervous system disease involving the brain and spinal cord," says Dr. Joseph Shurman, medical director of the Pain Management Clinic at Scripps Memorial Hospital in San Diego.

"A constellation of disorders," is how Dr. Robert Bonakdar, director of pain management at Scripps Center for Integrative Medicine, describes fibromyalgia.

WHAT ARE THE SYMPTOMS OF FIBROMYALGIA?

Fibromyalgia pain has been described as stabbing and shooting, with deep muscular aching. Some patients also complain of numbness, tingling and burning sensations with the pain often worse in the morning and during cold or humid weather.

The pain can be experienced anywhere on the body, but the most common sites include the neck, shoulders, back, hips, arms and legs.

"People who present with fibromyalgia often say, 'I hurt all over,'" Bonakdar says. "There's usually more soft tissue pain with fibromyalgia, but there can also be joint or neurological pain."

Extreme fatigue is another complaint. Patients say they're so exhausted that it interferes with daily activities.

Sleep problems are also typical. Researchers have found that during sleep, fibromyalgia patients are interrupted by bursts of awake-like brain activity, limiting the amount of time they spend in deep restorative sleep.

People with fibromyalgia often report a heightened sensitivity to odors, noises and touch.

Other symptoms may include depression, irritable bowel syndrome, headaches, restless leg syndrome, dry eyes, ringing in ears, loss of coordination and impaired memory and concentration.

"People with fibromyalgia often experience what they call fibro fog. It's a cognitive dysfunction and they have difficulty concentrating or (trouble) with their memory," says Dr. Franklin Kozin, a Scripps Clinic rheumatologist.

WHAT TYPE OF DOCTOR TREATS FIBROMYALGIA?

Fibromyalgia is most commonly diagnosed and treated by rheumatologists, neurologists, physiatrists (who specialize in treating injuries and diseases causing pain and loss of function), pain-management physicians and psychologists.

Shurman often suggests that fibromyalgia patients see all of these specialists to treat all different aspects of the illness.

"It's always best to see a doctor who knows you the best, knows your family history, your social and stress history and your sleep (problems). They are the best ones to understand if it may be fibromyalgia," Bonakdar says.

HOW IS FIBROMYALGIA DIAGNOSED?

There is no lab test for diagnosing fibromyalgia. Doctors must rely on the patient's symptoms, history and physical exam.

The physical exam is based on the standardized American College of Rheumatology criteria. To be diagnosed as having fibromyalgia, the patient must have pain in all four quadrants of the body for a minimum of three months and have tenderness or pain in at least 11 of the 18 specified tender points when pressure is applied.

HOW MANY PEOPLE ARE AFFECTED BY FIBROMYALGIA?

According to advocacy groups and doctors who treat fibromyalgia, about 2 percent to 4 percent of adult Americans, or as many as 10 million people, suffer from the disorder.

WHAT ARE THE RISK FACTORS?

There's a strong genetic predisposition to it, so if your parent had fibromyalgia, you may, too. It's also more common in people who suffer from other illnesses including rheumatoid arthritis, lupus and depression.

For unknown reasons, women are about nine times as likely to have fibromyalgia as men.

Not a progressive or life-threatening illness, it most often begins affecting people of all ethnic backgrounds between the ages of 30 and 55.

"Fibromyalgia is present worldwide and in all cultures, including primitive cultures, not exposed to media that tells them about it," Kozin says.

WHAT CAUSES FIBROMYALGIA?

The most popular theory is that fibromyalgia is a result of central sensitization. This means that the patients have a lower threshold for pain because of increased sensitivity in the brain to pain signals. Researchers believe repeated nerve stimulation causes the brains of people with fibromyalgia to change, involving an abnormal increase in levels of neurotransmitters, the chemicals in the brain that nerve cells use to

communicate and signal pain.

Using functional MRI scans, some doctors have found that people with fibromyalgia have increased activity in areas of the brain dealing with points of pain.

Some medical experts also believe fibromyalgia may be related to physical trauma such as a car accident or an illness. It's also possible that it's connected to an especially stressful or emotional time in their life.

An estimated 50 percent of those with fibromyalgia experience depression or anxiety at some point in their lives. What causes the correlation between fibromyalgia and depression isn't clear, but it may be related to abnormalities in the neurotransmitters, serotonin and norepinephrine.

WHY DO SOME PEOPLE, INCLUDING DOCTORS, DOUBT FIBROMYALGIA IS REAL?

There are no definitive blood tests, X-rays or lab tests to prove fibromyalgia.

"I think some doctors don't like to think of something as a disease unless we have tests or markers to prove it is," says R. Edward Harpin, lead psychologist with Sharp Pain Rehabilitation Program.

He notes that some of the doubt is because fibromyalgia shares some of features of other illness such as depression.

Some people are put off or confused by fibromyalgia's multitude of varying symptoms.

"Fibromyalgia is a moving target. What (patients) present with today is different from what they present with tomorrow. There's a very large continuum of pain for these patients," Bonakdar says.

He notes that patients' symptoms can range from having slight aches and pains to "massive disability," prompting some to ask how the same condition can cause people to feel so differently.

Although some medical experts believe fibromyalgia sufferers may really experience pain, they suspect it may be related to hypochondria, the preoccupying fear of a serious illness.

"We can't prove that it's not hypochondrosis, so that's why you get these controversies," Harpin says.

In fact, doctors who are skeptical of fibromyalgia say the diagnosis can worsen the condition by encouraging people to think of themselves as sick.

WHAT ARE SOME OF THE TREATMENT OPTIONS?

Fibromyalgia patients typically do not respond to conventional painkillers like aspirin and ibuprofen.

Last June, Lyrica (known generically as pregabalin) became the first FDA-approved drug specifically for treating fibromyalgia. Marketed by Pfizer, the drug was already approved to treat seizures, as well as pain from damaged nerves in people with diabetes and shingles. Lyrica may reduce pain and improve function for fibromyalgia patients.

The drug comes with side effects, however. Lyrica can cause sleepiness and dizziness, along with weight gain and swelling of the hands and feet.

FDA approval for two other drugs to help fibromyalgia is likely to come later this year. Both were originally developed as antidepressants, and both work by increasing levels of serotonin and norepinephrine, brain transmitters that affect mood.

Doctors also recommend treating the individual symptoms. A sleep specialist can be consulted to help address insomnia and other sleep disorders. Mild exercise and stretching may help increase muscle strength and endurance. Pool exercises, especially in warm water, can help some patients. Relaxation techniques, such as deep breathing, biofeedback, guided imagery and meditation, may reduce muscle tension and lower anxiety and stress.

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