



# Understanding fibromyalgia

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## Fibromyalgia

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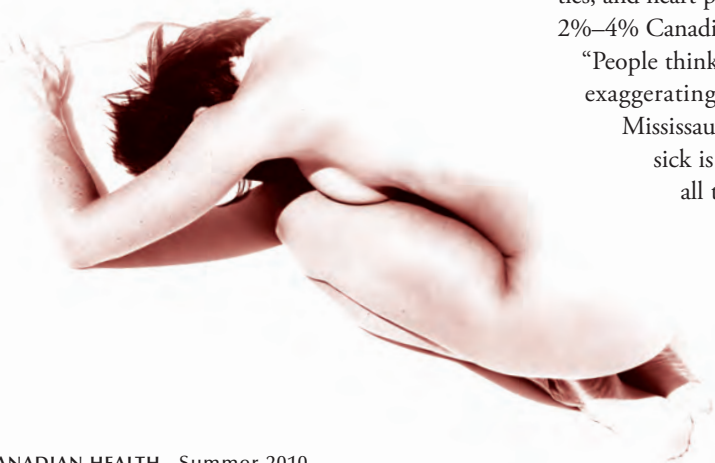
The name “fibromyalgia,” translated as “fibrous tissue muscle pain,” is misleading. While it was once believed that the condition involved the muscles and tissues of the body, scientists and doctors now know that it is actually related to how the brain perceives pain. The preferred description for fibromyalgia today is “chronic widespread pain.”

**F**ibromyalgia can strike out of the blue, and the pain, fatigue and depression associated with it can be debilitating. While treatment options were once limited, research holds new promise for people living with this mysterious and often misunderstood condition.

Fibromyalgia is a central nervous system disorder characterized by pain which seems to be in the muscles, ligaments and tendons throughout the body, accompanied by tenderness to the touch and fatigue. People with the condition may also have trouble sleeping and experience mood disorders. Other associated symptoms can include the following: memory and cognitive difficulties, headaches, weight fluctuations, abdominal or bladder complaints, ear-nose-throat complaints, allergic symptoms, morning stiffness, hearing, vision and balance abnormalities, and heart palpitations. The condition affects about 2%–4% Canadians, most of them women over age 40.

“People think that I’m just lazy or selfish and that I’m exaggerating,” says Susan Monaco, 56, head of the Mississauga Fibromyalgia Support Group. “Being sick is bad enough without having to prove it all the time.”

Monaco’s illness first manifested itself in 1989, following a minor car accident. “I wasn’t hospitalized and looked okay... until things started happening with my immune system. First it was



constant congestion and colds, then earaches, sore throat, infections and loss of voice,” says Monaco. Then there were the body-wide pain symptoms, which Monaco describes as a “dull, constant throbbing—like a toothache only worse.” The severity of the pain fluctuated from day to day, but was constant and overwhelming to the point where she would have difficulty concentrating.

After feeling dismissed by doctors and a series of tests that failed to find any medical cause for her symptoms, Monaco was eventually diagnosed with fibromyalgia, then a relatively new concept. “I had never heard of it, but it had a name. It was real, even if no one understood it,” says Monaco. “And they still don’t.”

This is only partly true, according to Dr. Mary-Ann Fitzcharles, a rheumatologist and pain specialist at the Montreal General Hospital who has been treating fibromyalgia for more than 20 years.

There is no objective clinical test for fibromyalgia, so physicians make the diagnosis by evaluating a patient’s symptoms and ruling out other conditions that may present with widespread body pain. Dr. Fitzcharles notes, however, that differences between fibromyalgia patients and those without the condition have been observed in the research setting. A number of changes have been noted through the use of specialized neurophysiological tests including a hypersensitivity of peripheral nerves to a painful stimulus, pain signals to the brain that are exaggerated, changes in molecules that affect pain perception in the spinal fluid, and defective natural inhibition of pain that is mediated by messages moving down the spinal cord from the brain.

Substance P is a chemical that signals pain and has been found to be elevated in the spinal fluid of persons with fibromyalgia. Lower levels of two different neurotransmitters—serotonin and norepinephrine—are also believed to play a role in the condition. Among their various functions, these two chemicals play a role in pain, mood and sleep regulation.

What is still unknown is what causes the condition in the first place. In many cases symptoms begin to appear after a triggering event. Dr. Fitzcharles says, “It can be a psychological stress such as the loss of a loved one, an injury, a severe viral illness or even the birth of a child.” About 40% of patients reported that they were completely well before the onset of the condition, which seemed to occur following the trigger.

Some 80 to 90% of fibromyalgia patients are women, and those with a family history of the condition are eight times more likely to develop it themselves. Dr. Fitzcharles notes that this also points to both hormonal and genetic components at work in the condition.



Many fibromyalgia patients experience mood disorders that develop from the stress of living with this condition. Chronic pain, physical limitations, and feelings of discouragement and isolation can lead to anxiety and depression. In some cases, Dr. Fitzcharles remarks, “depression and fatigue can often be more debilitating than the pain of fibromyalgia.”

After struggling to hold down a job, Monaco, in her words, “had to stop” working. The loss of her status as a “productive member of society” and her inability to be as active and involved in her family life as she once was led to feelings of inadequacy, guilt and, ultimately, serious depression.

She has used psychotherapy to help her cope with her condition, and believes that, as with many fibromyalgia patients, her biggest mental stumbling block has been denial — denial of her limitations and her need to care for herself before others. Accepting her illness and her new reality was a slow process for Monaco, her husband and her children. “It took a long time for them to acknowledge my illness. I still get pressured to try to do things I know I can’t. Maybe my hardest lesson was learning to say no.”


There is no gold standard of fibromyalgia

treatment, but Dr. Fitzcharles advises that many patients benefit from a combination of non-pharmacologic and pharmacologic therapies. First, it is important that the patient become an active participant in her care, and educate themselves and those around them on the condition. They should take care to avoid activities that aggravate their symptoms, and try to follow a healthy lifestyle that includes regular exercise, healthy eating, good sleep hygiene and relaxation techniques.

Monaco assesses her levels of energy and pain throughout the day and paces herself accordingly, perhaps forcing herself to attend a morning aqua fitness class, which helps her to relax as well as build strength.

Certain drugs have proven effective to treat the pain, fatigue and other symptoms associated with fibromyalgia. Analgesics such as NSAIDs can be helpful for treating the pain of fibromyalgia. These are available over the counter; if necessary, stronger versions can be prescribed by a doctor. In selected cases of severe pain, a physician may suggest treatment with stronger painkillers, but these should only be used with extreme caution and with very careful medical supervision.





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Recently, two drugs have been recognized for their effectiveness in treating the symptoms of fibromyalgia. Duloxetine (Cymbalta), part of a class of antidepressant medications called serotonin-norepinephrine reuptake inhibitors (SNRIs) has proven effective in the treatment of pain, fatigue and mood disorders. This is likely because it prevents the rapid reuptake of serotonin and norepinephrine, resulting in higher circulating levels of these pain-regulating neurotransmitters. The antiseizure medication pregabalin (Lyrica), approved by Health Canada specifically for the treatment of fibromyalgia, works differently by calming overactive nerve cells that relay pain. Other drugs such as antidepressants and sleep aids can also be prescribed to treat individual symptoms.

A major source of strength for Monaco over the years has been her 600-member fibromyalgia support group. “People with fibromyalgia depend on each other because we’re the only ones who really understand each other. We all have different backgrounds and situations, but we all face common issues,” she says. The group has guided her through many rough patches over the years, and helped her find alternative therapies, which she has found to be very beneficial.

At the American Academy of Neurology meeting in Toronto this spring, promising results were reported for sodium oxybate, a central nervous system depressant most

commonly prescribed for narcolepsy, a condition characterized by excessive tiredness. This drug significantly reduced symptoms of pain and fatigue and improved overall function in patients with fibromyalgia. It is, however, a highly controlled drug and additional study needs to be done before it can be recommended for routine use in fibromyalgia patients. A simple reduction in symptoms is not sufficient reason to continue with a treatment; improved function in daily activities is the goal of a successful treatment.

Experiences with fibromyalgia vary from person to person, but in most cases fibromyalgia does not prevent a person from staying active and leading a normal life. Though rare, fibromyalgia can go into remission. For everyone else, the key is finding a treatment plan and lifestyle that work.

“Every day is a gift, but it’s also a battle. You need to listen to your body, work with your doctors and find support,” Monaco says. 🍀