## Causes of fibromyalgia remain a medical mystery

nne Bell thrived as a pharmaceutical sales representative until the devastating effects of fibromvalgia took over in December of 1991.

"My husband would come home and find my detail bag on the floor, my purse in another place, my jacket thrown down elsewhere, and me crashed out on the couch," she recalls. "I was absolutely exhausted, my chest ached. It was not like what most people associate chest pain to be. Mine was chest wall pain. Constant pain around the muscles of my chest, my ribs."

Today, nearly 11 years down a very long road. Anne is no closer to recovery. The chest pain is gone, replaced instead by unrelenting head pain and exhaustion. Pain that is so constant and severe, she must take a derivative of morphine for relief. Exhaustion so brutal, that if it weren't for methodical pacing and planning, one "good day" out and about could force her to stay in bed for another two or three.

But Anne is not alone. At least 900,000 Canadians suffer from fibromyalgia, a rheumatic-type disease of unknown origin. In fact, Dr. Hugh Smythe, a rheumatologist and expert on the subject, says if you put the number of cases of all classic rheumatic diseases together, fibromvalgia is more common with the exception of osteoarthritis. Women are more than four times as likely to develop the disease and it usually occurs in people over age 50. People afflicted with the condition usually suffer from stiffness and overall joint and muscle pain. They have trouble sleeping and batand lack of concentration.

It's diagnosed through means of elimination, ruling out other diseases like lupus and multiple sclerosis, a process Anne recalls with

"It can be tough to diagnosis," she says. "It depends on which specialists you see, what your presenting symptoms are. At first, I wanted to know what caused this to happen; that it was real and not in my

"But now, my feeling is that you can call it whatever you like. I just what to know what you can do for me, and there is not a lot they can

But Dr. Smythe disagrees. He says that fibromyalgia is curable and not chronic as many people be-

"To make it very simple, fibromyalgia is a mixture of referred pain of skeletal origin and neurological mechanisms which can amplify or which can increase the severity of pain and its persistence." he explains.

To highlight this, Dr. Smythe says that when a person touches a finger to a hot stove, they feel the pain all at once and recognize that the pain is a burn and not a cut, and the person can place the site of injury within a fraction of an inch.

"This happens because humans have a large area of representation of their hands in their cerebral cortex and consciousness. This facility is essential for all of the complex interactions which permit skilled eye-hand co-ordination," he says.

"But none of this is true if the pain arises from a structure deep in the body. We cannot feel the locatle chronic fatigue, poor memory tion of the tip of our spleen, and similarly are unable to feel the fifth Unfortunately, there is no one bone in our neck, or the fifth bone single test to isolate fibromyalgia. in our low back. They are not represented in our cerebral cortex or in consciousness."

Therefore, Dr. Smythe continues. the pain people feel with fibromyalgia is what is called "referred pain," resulting from some sort of neck or lower back injury or irritation.

For people with fibromyalgia, "pain arising in these structures will be misinterpreted as arising from perfectly innocent tissues that share the same nerve supply," he says. "In fact, the perceived location may be at a considerable distance from the unknown site of origin."

Essentially, the brain puts the pain in the wrong place. Depending on the original source of pain, a person with fibromyalgia might feel aching in one place, in an other a sensation of a wearing tight band. They might even feel as though their eyes are dry, gritty or burning.

"If it is in the back of the chest, commonly it feels like a burning in the upper chest or a feeling of heaviness," he adds. "This is often misdiagnosed as asthma"

With referred pain, Dr. Smythe says a person will also get referred tenderness. Referred tenderness is something that one doesn't even know exists until a patient visits his

"They have no idea they are going to be tender until my thumb hits the spot. The location of these sites are quite sharply localized and extremely predictable in location.

"If the source of referred pain is coming from the neck, the pattern of tenderness will be very specific," he adds. "Similiarly, this will happen if the pain is coming from the lower body."

The general principle of fibromyalgia treatment is relatively easy. Dr. Smythe says. The ultimate goal is to achieve a high level of physi-

## **Quick Facts**

What is fibromyalgia? Fibromyalgia is widespread pain in the muscles, ligaments and tendons. It causes people to have trouble sleeping, resulting in constant lethargy. According to the Arthritis Society, although fibromyalgia is a relatively recent term, this syndrome has been known by several other names, including soft tissue rheumatism, fibrositis and non-articular rheumatism.

## Who does it affect?

- 900,000 or three in 100 Canadians
- Women are at least four times more likely than men to develop fibromvalgia
- It usually occurs in people over the age of 50.

- What are the warning signs?

  Stiffness, especially in the morning, and pain in muscles and joints all over the body.
- Trouble sleeping at night and a feeling of being very tired all the
- Numbness in muscles and joints.
- Poor memory and concentration.
- Other warning signs may include depression, tension and migraine headaches, and pain in the jaw.

In addition, fibromyalgia may cause dryness in the eyes. As well, those with fibromyalgia may develop sensitivities to certain foods, medications and allergens. They may also experience depression. an irritable bowel and bladder characterized by pain in the abdomen and a frequent need to go to the bathroom. Developing chronic fatigue syndrome is not uncommon.

cal fitness because "that's what sway-back position." makes you tough and if you are not fit that's what make you vulner-

However, there is real difficulty in achieving this. If a fibromyalgia patient neglects to first look after their neck and back, they don't get

"So, we start by identifying the problems and teaching them strategies to support the lower back throughout sleep and teach them postural strategies to avoid the lower back when it is sagging into a

From there, Dr. Smythe prescribes physiotherapy and exercise. But the process is long.

When a patient returns to him after six months, they will report that they are feeling better, but all "the basic patterns in their symptoms are still there." Frustrating, to say the least. On the upside, when Dr. Smythe performs a physical examination, he will find that their points of tenderness are gone.

And this is where patience on the patient's part is critical. They must

remember, he says, that the tenderness goes before the symptoms do. The process is similar to a person who was in severe pain with a gangerous leg. For as long as a year after the leg was amputated, the person will still feel pain in a leg that is no longer there even though the source of the pain was removed.

"This is due to the changes in the nervous system in response to chronic pain," he adds. "It takes about a year for the nervous system to learn that the vulnerability is gone."

In recent years, some doctors have attributed the cause of fibromyalgia to anything from chronic fatigue syndrome and various viruses. One more recent theory put out by Dr. Richard Bruno in the United States is that fibromyalgia is a result of Post-Polio Sequelae, which is identified as overwhelming fatigue, severe muscle weakness and chronic pain.

Dr. Bruno, author of the book The Polio Paradox, believes that many people with fibromyalgia had a mild, undetected case of polio in their childhood. This would lend itself to the fact that fibromvalgia strikes baby boomers born before the discovery of the polio vaccine.

Dr. Smythe isn't convinced.

"They can say fibromyalgia is due to a virus, infection. I can make up a theory. The medical profession does, but the question is 'does the experimental, controlled evidence put down by others support that or not?" "

"For example, there has been millions spent to see if it is the Epstein Barr virus. The answer is no. It is not a virus. Chronic lime disease was a biggy in the last year. Again, the answer is no."