

EXERCISE FOR RELAXATION: Tai chi class at South Miami Hospital gets Delores Longo, center, and Andres Viamonte moving.

NURI VALLBONA/HERALD STAFF

FIGHTING YOUR HEALTH CHRONIC PAIN

Therapy, massage and tailor-made exercise offer respite from the nagging torment of fibromyalgia

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Shedding a tear at the movies may not seem so strange, but imagine breaking down crying while watching a health video. That's what happened to Delores Longo when she saw a tape that described the chronic pain she'd been living with most of her life.

Finally she had found the answer to her suffering. "It took me 30 years to find out I have fibromyalgia. I tried just about everything," says Longo, a Miami business consultant. "Suddenly, I just cried and cried."

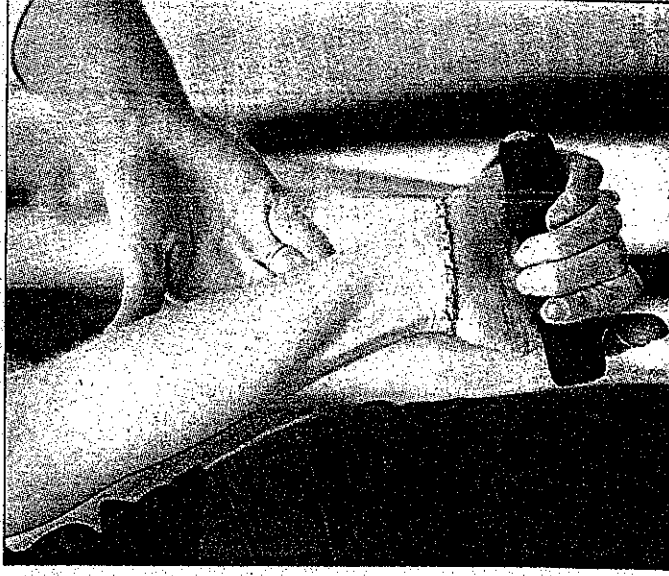
Fibromyalgia is a condition without a known cause and without a cure. It's been called the invisible disability, the irritable everything, supermorn syndrome and even whining women's disease.

Dr. Trumane Ropos calls it "the bane of the rheumatologists' existence, of every physician's exis-

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FOR STRENGTH: Delores Burke exercises her arm with help from physical therapist Nancy Croughwell.

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Relieving the nagging t

► FIBROMYALGIA, FROM 1E

tence.”

“There’s no anatomic abnormality, no concrete physical cause,” says Ropos, a rheumatologist at Cleveland Clinic in Weston. Yet patients present a wide range of symptoms, including chronic, sometimes excruciating pain.

Longo’s pain began when she was 18: First, her knees ached so much while on an errand for her first employer she thought she wouldn’t be able to go on. After about a week, the pain migrated to her hands, then her wrists. Doctors gave her arthritis medication, but it didn’t do any good.

The pain persisted for about 10 years before moving into her back and neck, sometimes incapacitating her to the point she couldn’t walk at all. Soon it was ankles, elbows, shoulders — “just about everywhere.”

And still no remedy.

“It was awful because a lot of people around me thought it was all in my head, and I ended up believing that. How could I be hurting in a different place every day? I couldn’t make plans, couldn’t volunteer in school because how would I know if I’d be able to walk that day?” says Longo, now 50.

“You doubt yourself and you wonder whether you’re losing your mind.”

Ropos treats patients for the condition, but like all physicians, can’t diagnose it until tests have ruled out several other diseases.

An estimated 4 million to 10 million Americans, 80 percent of whom are women, of all ages and all races, have fibromyalgia, doctors report. And sufferers often have other conditions as well, such as migraine headaches, irritable bladder and bowel, chronic fatigue, multiple chemical sensitivity, anxiety and depression — a long list of tension- and stress-related ailments that pile up to create a miserable way of life.

“It’s a product of our society,” Ropos says.

“It’s pretty frustrating when you have pain and you know you’re hurting, but even the doctors will not take you seriously. You’ve got to find a doctor that will listen to you,” says Delores Burke, who visited



PHOTOS BY CANDACE WEST/HERALD STAFF

WORKING MUSCLES: Above, physical therapist Nancy Croughwell steadies Delores Burke’s arms as she works out in Davle. Right, Burke, who at one point could not get out of bed for two weeks, gets a massage from Croughwell.

HELP FOR FIBROMYALGIA PATIENTS

Several organizations work with fibromyalgia patients and can provide information and support. Here are

some:

- South Miami Hospital Collaborative Medicine Program, (FM, Tai Chi and yoga support groups, 305-662-5130)
- Women’s Health Resource Center of Baptist Hospital (FM support group, 305-598-5981)
- JFK Medical Center (www.jfkmc.com or 561-965-7300)
- National Institute of Arthritis and Musculoskeletal and Skin Diseases (www.nih.gov/niams or 1-877-22-NIAMS)
- National FM Partnership (www.fmpartnership.org)
- Upledger Institute (www.upledger.com)

more than a dozen doctors before finding Ropos and determining that she had fibromyalgia. Her worst point was when she couldn’t get out of bed for two weeks.

“Pain,” says MaryJo McPhail-Brown, director of rehabilitation at JFK Medical Center in Atlantis, “is not a normal condition.” Pain is a signal that you need help.

EASING THE PAIN

The good news is that even without cause or cure, there are successful management techniques that can relieve at least some of the pain of fibromyalgia.

McPhail-Brown offers a customized course, usually about six weeks long, to help fibromyalgia patients deal with all aspects of the condition.

“Besides popping pills, what can you do to manage this? It’s a multi-faceted syndrome, affected by many things —

poor sleep, hypersensitivity to pain, touch, smell, noise, lights, temperature,” she says. “When you don’t reach that deep sleep, you don’t get the restoration of hormones in your body, then it slips into hormone imbalance. That could affect your immune system and your brain, and your muscles don’t act the way they should.”

Fibromyalgia can follow physical trauma — 45 percent to 70 percent of cases surface after an accident or injury — or be brought on by an illness such as osteoporosis, rheumatoid arthritis, or, as in the case of Burke, from lupus, with which she was diagnosed 22 years ago.

The 41-year-old Margate mother uses anti-depressants to ensure a good night’s sleep, an important part of treatment for most fibromyalgia patients. “That and physical therapy is really what got me back on

ment of fibromyalgia



Palm Beach Gardens.

"It's considered an alternative medicine approach that helps to relax the body and relieve some of the pain that these people are experiencing," she says. "I've found it can help them tremendously."

Even after she'd determined the cause of her pain, it took Longo several years to find the proper combination of treatments to achieve a comfortable life. One doctor even treated her for hypochondria when she told him she thought she had fibromyalgia.

'HIGH ACHIEVERS'

"I've noticed in group sessions that the people are always very high achievers, great family people who were giving so much they were forgetting themselves," says Longo, the mother of 9- and 16-year-old sons.

"You need to take care of yourself. You need to assess your life. My life was a continuous deadline; stress is a big trigger for fibromyalgia. I've had to simplify my life quite a bit. I've had to learn that sometimes things will not be perfect."

In the end, she says, "you end up with your own bag of tricks — not everything works all of the time, but there is always something that will help."

Longo uses anti-depressants to help her sleep, and relies on muscle relaxants when necessary. She swapped her desk chair for a giant rubber ball, which keeps her moving while at her desk, balancing with perfect posture. She attends Tai Chi classes at South Miami Hospital twice a week and exercises at home daily for stress reduction, strengthening and stretching. And she maintains a healthy diet.

But her favorite method of treatment is dancing the tango every weekend.

"It's extremely energizing. I think moving to music has an effect on pain. Anything that releases your endorphins is beneficial, and dancing certainly does," Longo says.

"It's also a form of meditation, which is very important when you have pain. The first thing you do is take a deep breath and relax."

track," says Burke.
"When I have a flare-up, the first thing I have to do is exercise. There's a lot of pain, but it's the best thing for you. The muscles become very hard and knotty, especially when you're tense or under stress — that makes it worse."

STRETCHING, WEIGHTS

Burke has a long-standing date with physical therapist Nancy Croughwell, co-owner of OrthoSport in Davie. The routine includes regular paces of stretching and weight training, as well as electrical stimulation to increase circulation and reduce pain, something that patients can do at home with special equipment.

Croughwell conducts assessments to help patients identify whether their symptoms of pain could be fibromyalgia so they can discuss appropriate treatment with their doctors. She says there

are some herbs she might recommend, but that patients should check dosage with their doctors because of possible interactions with medication. Burke says a natural vegetable and juice supplement has helped her tremendously. Acupuncture and acupressure have helped some patients.

Michele Laya, a physical therapist at Parkway Regional Hospital and an instructor at the University of Miami, uses aquatherapy — exercising the patients while they're submerged in a pool of warm water — to help ease the muscle pain and tension of fibromyalgia, with good effects.

"They're going to feel terrible when they first do exercises," Laya says, "but it's worth it if they keep it up."

Another treatment method Laya has used is called Cranio-Sacral Therapy, a cerebral massage technique developed at the Upledger Institute in