Rare program for multiple sclerosis patients set to grow

A program in the Coachella Valley gives MS patients free access to trainers and physical therapists. Richard Lui/The Desert Sun



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Ken Thompson heads to a gym in a Palm Desert business park twice a week for a onehour workout with a personal trainer.

Because Thompson, 65, has multiple sclerosis and the Coachella Valley happens to be home to a unique program that encourages MS patients to get regular exercise, the sessions are free. Thompson also gets a free therapeutic massage once a month and annual checkups with a physical therapist.

If the neurological disease weren't a prerequisite, it would be a great deal.

It's all the result of the Lynn DeSantis Therapy Program, which valley multiple sclerosis advocates began shortly after founding the nonprofit ACT for MS in 1999. A recent \$368,228 grant from the Desert Healthcare District means the therapy program is prepared for an expansion.

Thompson's workouts at Next Level Fitness aim at improving muscle strength and his two primary concerns: flexibility and balance.

Early on, "I just couldn't hold some of the poses that required balance," he said after a recent session. "Now it's getting better so thank God for that."

Multiple sclerosis leaves people with sometimes unpredictable symptoms such as muscle tightening, fatigue and sensitivity to hot or cold temperatures. Symptoms can gradually progress or suddenly hit hard and then dissipate. Its cause is not fully understood but exercise is recommended as one way to slow its progression.

"One of the misconceptions among some MS patients is that if I exercise, I get hot, and if I get hot I can't do as much ... But that's only a temporary thing," said Dr. Daniel Giang, a professor of neurology of Loma Linda University Medical School.

Giang said there's nothing from preventing someone with MS from exercising and being healthy, but like with many people regardless of their overall health, extra motivation helps.

Giang treated Lynn DeSantis, an ACT for MS supporter who helped start the therapy program and was a longtime participant before she died in November 2012. ACT for MS renamed the program for her soon after she died.

Richard DeSantis, her widow, credits the program with extending his wife's life at least five years.

"It's grown from about six or eight people when we first started to probably 50 or more now," Richard Desantis said. "We're hoping to increase that number to over 100 in the next few years."

A physical therapist evaluates participants when they start the program and continues with annual visits to chart their progress. Giang noted that continued physical therapy like this is not covered by insurance.

Even though regular exercise and physical therapy is understood to benefit MS patients, Giang said he was unaware of any similar program anywhere in the world promoting healthy living for MS patients. This makes the Lynn DeSantis Therapy Program "an interesting side benefit to getting multiple sclerosis in the Coachella Valley," he said.

Overall, people in the program long-term report better strength and flexibility and lower pain, according to an evaluation conducted by HARC, Health Assessment and Research for Communities.

Although the trainers are knowledgeable in working with MS patients, Giang said the workouts aren't different from what others might do at the gym. The program offers group workout sessions and individual attention for people with more advanced mobility issues. Along with Next Level Fitness, the program is available at Zach's Personal Fitness in Palm Desert and through three trainers working in Palm Springs.

Casey Washack, the owner of Next Level, said he and his trainers don't want their MS clients to feel different from any other gym member.

"What we like to say is they're athletes," he said, "but their sport is a little different."

Health and wellness reporter Barrett Newkirk can be reached at (760)778-4767, barrett.newkirk@desertsun.com or on Twitter @barrettnewkirk.

Act for MS

Along with the Lynn DeSantis Therapy Program, ACT for MS offers other help for MS patients such as a free swimming program at the Palm Desert Aquatic Center and utility assistance for low-income patients. More information is available at<u>www.actforms.org</u>. Program particiupants must provide verification of a mulutple sclerosis diagnosis.