



THE COMEBACK
Rem Murray takes a moment before the 2006 Stanley Cup playoffs to relish his return to professional hockey after cervical dystonia nearly ended his career.

Home on Ice

After getting treatment for cervical dystonia, Rem Murray is back where he belongs.

BY TODD FARLEY

Given that his professional hockey career was prematurely ended by the sudden onset of a rare brain disease, you might be surprised to hear that Rem Murray considers himself a lucky guy. Murray's eight-year National Hockey League career was cut short in 2004 when he was beset by a debilitating case of cervical dystonia, but he was at least fortunate enough to have his condition assessed correctly. In fact, an immediate diagnosis and treatment eventually allowed Murray to return to the NHL. But such happy endings are a rarity in the annals of this disease due to the historical difficulties in diagnosing it. While some researchers estimate that as many as 300,000 people in the U.S. have cervical dystonia, the exact numbers are not known.

Cervical dystonia (also known as spasmodic torticollis) is a neurological movement disorder characterized by involuntary muscle contractions of the neck that cause tremors and repetitive twisting movements.

For Murray, the first indication that something was wrong occurred in October 2003, when he noticed his head shaking after games. Playing for the NHL's Nashville Predators, Murray thought the tremors resulted from dehydration or hunger, a normal response for a professional athlete pushing his body to its limit. But as the tremors occurred more frequently, Murray began to worry.

"The tremors became constant," Murray says. "It was embarrassing, like something an older person would have, not me." Hoping to save his pregnant wife from worry and eager to maintain his spot on the Predators' roster, Murray told no one about his symptoms. Long a stalwart player in the league (he played an NHL-record 85 games in the 2002-2003 season), Murray tried in November and December of '03 to grit his teeth through the tremors, the increasing pain, and his head's constant pull to the left. "You never want to let down your teammates," he explains. "I wanted to stay on the ice."

His symptoms continued to worsen, however, and the contractions of his neck muscles began to affect the posture of his head. "Normally when I went into the corner to check someone I would look over my right shoulder," he says, "but now I had to spin around two-hundred and seventy degrees to see where the player was going."

By January, Murray knew "something had to be done." While interviewed on live television between periods of a game in Detroit, Murray "couldn't even look at the camera pointed at him" because his head was pulling so far left. After revealing his symptoms to the team's medical staff, Murray followed the trainer's suggestion to make an emergency room visit at the team's next stop in Toronto. It was there that Murray got his lucky break.

The doctor on call at the Toronto hospital was a neurologist, and he almost immediately diagnosed Murray with cervical dystonia, a judgment that left the player baffled. Murray had read Michael J. Fox's memoir *Lucky Man* and thought he might have Parkinson's. "I'd never heard of [cervical dystonia]

The pain of dystonia can be crippling, even for a pro hockey player. “Some days I wanted to put my head through a wall,” Murray says.

in my entire life,” he says, “but the doctor was quite certain.”

Because there are no blood tests that can detect it, a correct diagnosis hinges on the ability of doctors to recognize the physical features of the disease. Unfortunately, that has led to numerous incorrect diagnoses over the years. “Cervical dystonia has been poorly understood, underappreciated, unrecognized, and undiagnosed,” says Mahlon DeLong, M.D., professor of neurology at Emory University in Atlanta, GA. “It was often thought to be wry neck [stiff neck usually due to injury], bony abnormalities, or a ‘hysterical’ problem—the emotional manifestation of mental disturbance.”

“It is only in the last 10 or 20 years that it has been seen as a neurological condition, not a psychiatric one, which is very important,” says Cynthia Comella, M.D., professor in the department of neurological sciences at Rush University in Chicago, IL. “Patients don’t need psychiatrists for help, they need neurologists.”

And the pain can be crippling, what Murray—a professional athlete noted for his durability—calls “the worst part” of his ordeal. “Some days I wanted to put my head through a wall,” he says of the pain. “The only comfortable place to be was lying down.”

While most neurologists believe the disease results from abnormal functioning of the basal ganglia—a part of the brain that helps control movement—no one knows why. “I believe that, like many neurological conditions, patients who come down with dystonia likely have a genetic predisposition, with maybe some environmental factors involved, too,” says Dr. DeLong. “Unfortunately, we don’t really know any of the environmental factors yet.”

Murray’s hockey career was put on hold as team doctors tried to deal with what was described in newspapers as “neck cramps.” Eventually the crippling pain and worsening symptoms made Murray give up the game he loved, and in March 2004, he signed his retirement papers, believing his NHL career was over.

Eventually he began a four-week course of oral muscle relaxants that had no noticeable effect. Murray next tried injecting botulinum toxin type A directly into his neck muscles (type A is called Botox, type B Myobloc), a treatment that alleviated the symptoms of his dystonia by inhibiting muscle contractions in the affected areas. The injections produced positive results within seven days.

“It was a godsend,” Murray says. “That first shot reduced my pain and slightly increased the mobility in my neck.”

Other treatments have proven to be effective for some patients, including partial denervation surgery (in which overac-

tive nerves are surgically snipped) and deep brain stimulation (in which an electrode is implanted into the brain to block the signals that cause loss of motor control), but Dr. DeLong says injections of botulinum toxins have become “the primary form of treatment for many, many patients.”

Retired from hockey, Murray didn’t skate for a year, but his improving symptoms allowed him to consider getting back on the ice. In March 2005, he started to skate recreationally, and by the summer he even began to consider a return to the game. Murray was unwilling to risk the steady improvements he had made, but when doctors assured him that his chosen sport would not jeopardize his recovery, he decided to give professional hockey another chance.

Although Murray’s comeback attempt did not land him an NHL roster spot for the ’05-’06 season, he did earn a job with the Houston Aeros of the American Hockey League. With his symptoms controlled by the combination of regular injections and physical therapy, Murray suffered few adverse effects. “I missed no practices or games that year because of my neck,” he says.

By the end of the ’05-’06 season, Murray’s solid play and good health earned him a return to the NHL: The Edmonton Oilers signed him to a contract in March 2006. Murray, who spent his first six NHL seasons with the Oilers, became a regular

contributor for the team that then made a dramatic run through the National Hockey League playoffs. Although the Oilers ended up losing a decisive Game 7 of the Stanley Cup Finals, Murray found his NHL return an unmitigated success.

“It was a dream come true,” Murray says of playing in the Finals, “especially after all I’d been through.”

Today, Rem Murray’s dystonia is under control. His head still shakes occasionally, and he needs botulinum injections every three months, but neither stops him from playing professional hockey (for HIFK Helsinki in the top Finnish league) or living happily with his wife and four young children. Murray also established the “Reaching Your Goals” campaign with the Dystonia Medical Research Foundation (dystonia-foundation.org) to raise awareness of cervical dystonia. Having met doctors who had never heard of the disease and patients who went undiagnosed for as many as 15 years, Murray realizes just how important that is. NN

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YOU'RE NOT ALONE

That’s the message Howard Thiel sends to those suffering from cervical dystonia, also known as spasmodic torticollis (ST). “We believe hundreds of thousands of people are suffering in pain and they don’t know where to turn,” Thiel says. Contact the association for help and to give them a better idea of the prevalence of ST. Call toll free (888) 445-4588 or email info@spasmodictorticollis.org.