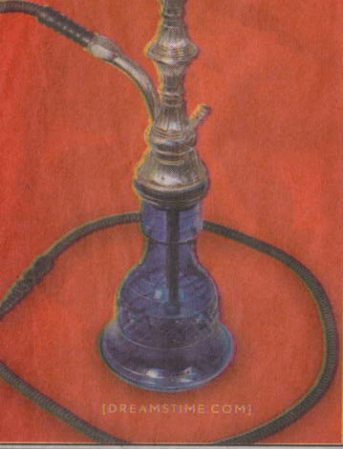


HEALTH & SCIENCE



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(DREAMSTIME.COM)

Smokers

Support for men with MS

Local MSfits group founded for males suffering from disease

BY JOANNA F. SMILEY
(SPECIAL TO THE SUN)

Four years ago, Kurt Clodfelter's legs gave out while he was mincing onions in his restaurant. Next thing he knew, the room swallowed him up and — smack — his 230-pound body hit the floor.

Three months later, he learned why: he had relapsing/remitting multiple sclerosis — a well-known diagnosis but one long considered, in his words, “a chick’s disease” because it strikes three women for every man it devastates.

The degenerative neurological condition, which affects 400,000 Americans and up to 2.5 million worldwide, can produce a wide variety of symptoms. They include loss of strength, numbness, vision problems, tremors and depression. Victims may look and feel fine one day, but be virtually incapacitated the next.

MS took its toll on Clodfelter, a 26-year-old Severna Park resident who attended the Culinary Institute

SUPPORT AND INFORMATION

• The first meeting of MSfits will be held at 7 p.m. Monday at the Columbian Center, 335 Ritchie Highway, Severna Park. For information, call 443-618-9018.

• For information on multiple sclerosis, go to the National Multiple Sclerosis Society Web site at nationalmssociety.org. Links to local chapters are on the home page.

of America, once worked as a strip club bouncer and now manages the wine section at a spirit and catering business in Arnold.

“I hate to say it, but there’s an expectation in society on men that we’re strong enough, big enough to do anything,” he says. “There’s times when my left leg is dragging, when I don’t look that strong. I had to give up my career as a chef because of the uncer-

tainty of the disease.”

He also worried about the aftermath of the treatment, which resulted in two bouts of optic neuritis that cost him the vision in each eye for up to six months. He worried about the ultimate effects of the disease on his new marriage — including his sex life. And he worried about maintaining his self-confidence.

“I still want to be that macho guy, a man’s man,” he says. “The type of guy that you always looked at in a room and asked for help fixing something.”

That’s when he started doing his research and noticed a giant hole in the Maryland MS support group network — there were no signs of meetings geared solely to men.

“Why isn’t there a group out there just for me?” he asked his wife, Kristi, a cosmetologist he married shortly before he was diagnosed.

So seven months ago, he decided to create his own MS support group — called the “MSfits.”

“We’re the frequently forgotten minority,” he says

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of how he came up with the group’s name.

The MSfits will hold its first support group meeting for Maryland men battling MS on Monday at the Columbian Center in Severna Park, where he expects to have a fully stocked bar.

“Yes, it’s stereotypical that guys get together and need a beer, but at the same time, to foster the fellowship it wouldn’t hurt,” Clodfelter says.

Derrick Jeanmarie, 41, also sees a good reason to keep in touch with other men with MS. He was diagnosed in 2002 when he checked himself into a hospital one morning after bumping his head and snapping his neck on his way home from work.

“They found lesions in my brain,” says the 6-foot, 2-inch, 230-pound uniformed Secret Service officer from Hughesville.

The first few years after Jeanmarie’s diagnosis were a tough time. Like Clodfelter, he developed optic neuritis. His short-term memory started to fade, his legs wobbled without warning and he says his wife noticed that he was depressed.

The Air Force veteran, former boxer and active long-distance runner longed for the days when he had full control over his body. “My wife tells me I have a sense of denial about my MS,” he says.

Although he frequents the gym and works night shifts at the White House, Jeanmarie has noticed he can’t run like he used to. “I would think that mentally there’s things I still have to deal with,” he says.

Ed Duggan, 61, an institutional research analyst at Goucher College, has been dealing with MS for decades. Forty years ago, at his Army physical, he was diagnosed with a rapidly progressing form of the disease. “If it weren’t for the MS, I would’ve been drafted,” he says, joking.

In 1997, Duggan’s MS got the best of his legs, and he now uses a wheelchair. Ironically, he says, his life gets better by the day — with his set of wheels, Duggan is now able to sail, play sports and he



Kurt Clodfelter was diagnosed with relapsing/remitting multiple sclerosis four years ago. After finding no support group in Maryland for men with MS — which strikes three times as many women as men — Clodfelter founded MSfits to fill the void.

JED KIRSCHBAUM (SUN PHOTOGRAPHER)

even plans to start a “competitive MS Olympics team.”

“I only wish I had [a wheelchair] when I was bringing up my kids,” he says. “There were a lot of things I couldn’t do with them. Not being able to play basketball with my son was a big thing for me.”

“Unfortunately, men do fall into certain stereotypes. You want to be able to be a husband, a father, support your family. Obviously, women can do that, too. But still, it was difficult.”

Amanda Culler Glenn, marketing director for the National MS Society Maryland Chapter, says she immediately recognized the value of the MSfits.

“Kurt approached the society

and felt like males needed a specific forum to discuss the kinds of issues that men living with MS may face. The types of issues discussed and the ways that topics are presented can be unique for men,” she says.

According to Glenn, about 1,650 men battle the illness in Maryland, but they’ve never been organized. “In the three or four years since I was diagnosed, I hadn’t met another guy in the state of Maryland with MS, but he’s out there,” Clodfelter says. “That means he’s not getting the support and I’m not getting the support we need.”

At meetings, Clodfelter plans to address many of the vulnerability issues men with MS face, includ-

ing the “ever-present possibility” of losing control of the bowels, and how to deal with “the embarrassment of telling your wife.”

“MS is a great disease in many respects — numbness and paralysis and virtually no pain — but it affects everyone differently. You’ve got to own it. That’s what I want to drive home in my group,” he says.

He takes a strong stance on political issues that affect medical conditions, including funding of embryonic stem-cell research — which the General Assembly approved this year. He hopes that the MSfits will raise awareness and continue to bring these debates to the legislative level.

Public awareness of men bat-

tling MS has gotten a boost lately from two celebrities — talk show host Montel Williams and country singer Clay Walker — both of whom live with the disease.

Walker, a heartthrob with four platinum albums and two Billboard Country Music Singles chart toppers, had a “somber diagnosis” in 1996 when he learned he had relapsing/remitting MS.

“I was playing basketball in Calgary, Alberta, which coincidentally has one of the highest incidences of MS,” Walker said in a phone interview. “I had never even heard of MS. I thought it was muscular dystrophy.”

He said he couldn’t feel his fingers for eight weeks and was “devastated by the news,” along with

the possibility that he might never be able to hold a guitar pick again.

Thanks to daily therapy with Copaxone, a drug that can effectively treat nonrapidly progressing forms of MS, he says his numbness and facial spasms have stopped.

In 2003, he went public with a Web site called Band Against MS (bandagainstm.org), an endeavor that he says is as important as his music. The site includes tips from leading MS researchers, muscle-targeting recommendations from physical therapists and dietitians and “hero stories” intended to help “average joes” manage the illness.

“There are as many as seven or nine types of MS,” he says. “Forty percent of people don’t get treated. If I can help, then my MS has been for a good cause.”

Like Clodfelter, Walker worries that too many people assume MS is still a woman’s disease. “The mental side is crucial for men. [MS] takes away your self-esteem and confidence. I thought for awhile people wouldn’t be able to book me,” he says.

Thanks to his medication, Walker has been able to regain normality in his life. He tours several months a year and released his 13th studio album in April.

Others are doing the same. As long as he doesn’t work extended hours, Jeanmarie still spends most of his evenings guarding the White House. In Towson, Duggan calls his wheelchair “the liberator” and looks forward to weekends of sailing adventures.

On a typical afternoon, Clodfelter says he lifts more than a dozen 45-pound cases of wine. He takes 50 many steps at work that he estimates he’s walking between three and five miles a day.

In the back of his mind, however, he knows the symptoms could resurface at any moment. So he looks forward to a future in which hundreds of Maryland men stricken with MS can meet for a beer, a laugh and maybe even a manly hug.

That, he says, is what the MSfits are all about.