

When men get MS



It may be time to learn a new way to deal with a diagnosis.

James Townsend

In many settings, we often downplay the differences between men and women. But when it comes to multiple sclerosis, their experiences may be vastly different. For one thing, studies suggest that MS is at least three times more prevalent in women than in men. Theories have emerged, but so far nothing conclusive has explained MS's gender gap. However, what is clear, based on a 2015 review of more than 30 studies, is that there are some real variations in the way men and women deal with MS, many of which may have to do with how men view themselves.

Consider the messages that men often hear:

- Man up!
- A man's job is to provide for and protect his family.
- Be strong; don't show weakness.
- Women are emotional; men don't talk about their feelings.
- Be stoic—big boys don't cry.

For men living with MS, underlying societal attitudes like these can be a major stumbling block to getting the help they need.

We know, for instance, that early diagnosis and treatment is key to living more fully and with less debilitating symptoms. However, according to research published in the **Journal of**

Neurology last year, men take longer than women to report symptoms or get evaluated for MS, start treatment later, and are less apt to adhere to a treatment regimen.

That's in line with men's general health trends. The 2015 literature review, conducted by British researchers Dominic Upton and Charlotte Taylor, and published in **The International Journal of MS Care**, found that women attend to existing health concerns and engage in preventive health behaviors more frequently than men. This is particularly true of young men (ages 16-44), who may not seek help for fear of being seen as vulnerable, weak or lacking independence.

A deep challenge

Many MS symptoms, ranging from fatigue, mobility issues and cognitive challenges to concerns surrounding sexuality or emotions like anger and grief, can contribute to that sense of powerlessness and vulnerability. In short, the MS experience challenges stereotypical ideas about masculinity.



Chris Hill, shown at the World Series last year, has had MS for 20 years. He has found talking to a therapist to be helpful. Photo courtesy of Chris Hill

Chris Hill, 46, of Powell, Ohio, knows about such challenges. "I've had MS for 20 years," he says, "and when my symptoms progressed I was really reluctant to use a mobility device. When I hit my mid-30s, I had a real breakdown when I learned I was going to have to walk with a cane.

“My wife was a real support, though,” he continues. “She said, ‘Who cares what anyone else thinks? You using a cane is no big deal to me.’ She also saw that I was moody and becoming depressed, so she pushed me to go to a therapist, and now we go together. It really helps me to have someone every week to say stuff out loud to about my MS.”

Social support can be critical in helping men with MS better cope with the day-to-day realities of living with the disease. Partners, spouses, family members and friends can be good sounding boards. So too can programs and events offered by organizations like the National MS Society and Can Do MS that involve couples, groups and other people surrounding individuals with MS.

What men talk about

Men often aren’t comfortable discussing such issues, however. Kirk Williams, 63, a Denver-area man diagnosed in 1999, learned that after more than 15 years of participating in groups for men with MS. “You can’t ask a man, ‘How’s your MS going?’ and expect to get an answer beyond ‘OK.’ Sometimes in a men’s MS group, the subject will not come up at all. We’ll talk about sports or jobs, anything else. We just can’t seem to come at it straight on,” he says.

Men’s attitudes about showing emotion or weakness seem to play heavily into this. Williams adds, “One of the groups I’ve been a part of says right on its website: ‘No whining.’ We don’t want to hear any ‘woe is me.’ Men have an unconscious tendency to respond with ‘Come on, pal, man up.’”

However, the benefits of opening up are myriad, says Peggy Crawford, PhD, a Cleveland-based health psychologist who has worked with people with MS for 25 years. “This includes feeling less isolated and alone.”

Even if men don’t share emotions when they get together, they may exchange practical information, Dr. Crawford says, such as recommending a medical professional whom they trust and who understands their issues, especially when dealing with some of the emotional symptoms of MS, like anger or depression. While men may not be comfortable providing one-on-one emotional support, they seem to be willing to provide the resources for others to find it.



Kirk Williams, who was diagnosed with MS in 1999, believes that men need a forum to prevent feelings of isolation.

Photo courtesy of Kirk Williams

Williams has found, though, that information alone doesn't motivate men. "We need to get out of the house, to socialize with other men. We used to hold what we called 'Third Thursday Happy Hour,' where we got together at a bar for an hour or two. We may not have talked at all about MS there, or it may have been all we talked about. Just providing a forum for men to get together helps by keeping us from becoming isolated, and that can go a long way in keeping us as healthy as possible."

In fact, support groups per se may not be the most effective way to help men improve their well-being. Rather, research suggests that efforts to get men with MS to engage with each other must be done in a way that helps them retain a sense of masculinity and belonging. This may be accomplished through mentoring, education or demonstrating self-efficacy (a person's belief in his ability to succeed in certain situations, influence events and be successful), whether through daily tasks or even physical reconditioning. These approaches might help de-stigmatize their need for support.

Learning man-speak

Dr. Crawford points out that unlike women, who often seek someone who will listen and perhaps comfort them, men often want to fix things.



Evidence suggests that men feel more supported when they engage with each other in ways that help them retain their sense of masculinity.

For that reason, Dr. Crawford sometimes encourages male clients to problem-solve their concerns during counseling sessions. She recalls how one became depressed when, physically, he could no longer do the job he loved. She asked him, “What else are you passionate about?” and he told her that he loved to read. “He became a tutor at a grade school, and the kids absolutely loved him. What he thought was just a pastime became a whole new way of finding joy.”

Loved ones can help men with MS problem-solve their concerns, too, and may find that doing so gets men to open up more. “For instance,” Dr. Crawford says, “coming up with options for helping him get to the kids’ sporting events, or getting up and down stairs, as opposed to talking about emotions.

Working together like this can be good for family members, too, and it doesn’t have to become highly emotional.” That’s a good thing, says Dr. Crawford. “Men think, ‘ Why would I talk if I know she’s going to get upset?’”

Dr. Crawford suggests setting up any potentially emotional conversation almost as if it were a date, with certain parameters. “For instance, set a time limit on the discussion so it has a beginning and an end. Agree to a signal, whether verbal or nonverbal, that lets either partner call a time out when things get too frustrating or when anger flares up.”

The center of a man

When men do begin to confront emotion, their work often begins with anger they feel, Dr. Crawford notes. “MS can impact so much of what men feel is their core value, whether it is their work or ability to do the things that have formed their identity,” she says.

Admitting they no longer possess the physical functionality to do something can be frustrating and devastating for men. This can lead to them taking dangerous risks in their workplace, or even around the house, to prove to themselves or others that they are still capable.

Williams concurs. “My work was in building security design and required certain dangerous activities like climbing ladders. I finally got a functional capacity evaluation and the occupational therapist didn’t even finish the last test before she said, ‘You can’t do this anymore.’ I needed her to tell me that. My work ethic wouldn’t have allowed me to quit otherwise.”



Joe Grubbs, right, with friend John Haegele, has been living with MS since 2010. Men with MS who start talking about feelings often have to confront anger, psychologist Peggy Crawford, PhD, says.

Adding to men’s frustrations are the role reversals that can sometimes occur. If men were previously responsible for household chores that required physical strength and are now

finding that they're better suited, say, to folding laundry or cooking, they may experience additional questions about their identity and virility.

Says Dr. Crawford: "One of my clients expressed it this way: 'Anger is my way of proving to people that I'm not giving in to MS, not lying down and letting it run over me. I need to feel strong.' They are really talking to themselves so that they don't feel as though they are going down a slippery slope to anxiety or sadness and depression."

But anger, anxiety, sadness and other emotional responses to the disease and the changes it brings are all valid, Dr. Crawford says. In fact, she says, depression is one of the most common—and most treatable—symptoms of MS.

"It is often a physiological symptom of MS, just like weakness and fatigue, due to changes in the brain." Seeking help for any MS-related emotional changes is actually a sign of strength, Dr. Crawford says, and can go a long way toward bolstering relationships with partners, spouses, family members, friends and colleagues.

Treating emotional symptoms can also help men get more effective care for other MS issues. For example, Dr. Crawford explains, "Angry people are tough to be around, so they are often shuffled out of the doctor's office quickly and the patient doesn't even get to ask his questions, much less have them answered." People who are depressed or anxious may face similar challenges advocating for themselves.

Therefore, it seems what men may need is a new take on what's acceptable male behavior. If men can learn from mentors and others with MS that it is manly to be actively responsible for improving their emotional and physical health, they are likely to experience less pain and live better, stronger lives.

James Townsend is a Boulder, Colorado-based freelance writer.

Connect with other men online at [MS Connection](#). Find other social support programs and events at [Can Do MS](#).

For additional support in dealing with physical, emotional or job-related concerns, call an MS Navigator at 1-800-344-4867.

Watch several men discuss their experiences of living with MS in "[Male Voices of MS](#)."