



Men with CFS

BY PAMELA YOUNG, DIRECTOR OF PUBLICATIONS

Up against an illness that affects four times as many women as men, males with chronic fatigue syndrome often feel isolated from their families, society and even from their own concepts of what it means to be a man.

Here's what some men with CFS have to share on the subject.

AT-A-GLANCE ▶

- **CFS drastically alters the lives of both men and women, but the male experience is not often represented in the media.**
- **Men with CFS can experience unique challenges, as well as dealing with the universal challenges differently.**

Don Sprayberry is 58 years old, has been married for 36 years and was a senior loan officer at a local credit union before chronic fatigue syndrome (CFS) stopped him cold in his tracks. He went to work one morning feeling perfectly healthy, but before lunch became very ill with what seemed like the flu. For the next two weeks, he took medicine and tried to work, but his health further deteriorated. After months of testing by many doctors, he was eventually diagnosed with CFS. That was 13 years ago, and he hasn't been able to work since.

Sprayberry's story demonstrates similarities and diversity in the CFS experience. Though the way CFS entered and altered his life is not uncommon to the more than one million Americans currently suffering with the illness, the fact that he's a man puts him in the minority of the CFS community. In fact, some would

say that men with CFS constitute an underrepresented segment of an illness that is itself often overlooked by the media and society.

The Centers for Disease Control and Prevention (CDC) estimates that four times as many women have chronic fatigue syndrome as men. That suggests that CFS affects at least 200,000 men. Yet many of the articles on CFS appear in women-oriented magazines, the majority of CFS support group members and leaders are women and even the National Institutes for Health (NIH) trans-departmental working group on CFS is sponsored by the NIH Office of Research on Women's Health.

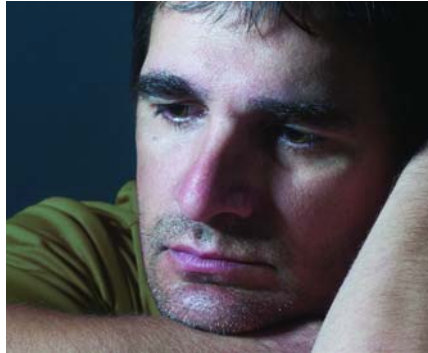
What is that like for the men who have this illness? How do their issues mesh with or vary from their female counterparts? In short, how does CFS affect the lives of the men who have it?

Losing identity

Like it or not, society still molds strong concepts of what a man is supposed to be and do in this world. Provider, protector and competitor are still roles often ingrained in a man's sense of self. When CFS strikes, everything changes and many of the traditional measurements of those qualities crumble. Perhaps that's why, when asked to describe how CFS affects them, many men begin not with the burdensome symptoms they experience, but with how their roles in life have changed.

Loss of work and career status is often one of the first things mentioned by men with CFS when describing their experiences. Says Matt Matherne, a Gulf War veteran, "There's a sense of feeling worthless because you feel like you've let your wife and family down. If I didn't have CFS I would probably still be in the military, supporting my country and my family."

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Sprayberry echoes this sentiment, saying, "I think the most difficult thing for a man is not being able to earn a living. You feel you aren't taking care of your family like you should."

Even for men who continue to work, the career and financial impact weighs heavily. Patrick Venetucci, a corporate executive with a young family, was an international businessman working in Tokyo, Japan, when he became ill. He has since moved back to the States, curtailed his work travels, changed career paths and dramatically reduced his working hours. He shares, "Economically, CFS puts more pressure on the house, especially when the man is the primarily or sole breadwinner. All of a sudden the household income stream is at risk."

CFS often undermines a man's family and social identity as well. Says Matherne, "All the things my wife depended on me to do are mostly no longer possible. It eats away at me." Venetucci agrees, "I did so much more for my wife before I was sick. Now the burden is on her."

Venetucci also describes his changed role as a father. "I have two small children. Right now, I can play with them lying down and they don't realize any difference. But I have to refrain from going to birthday parties and social outings with them to preserve my energy. I worry very much about the future and all the things I won't be able to participate in."

Additionally, many men construct their social network around business, athletics and other physical activities. No longer able to participate in these activities as they once did, their social supports dry up.

In a world where a man often defines *who he is* by *what he does*, this erosion of career, home life and social identity leaves many men with CFS experiencing a profound loss of self—further compounded by struggling with a disease that's considered primarily a women's illness.

And these identity struggles aren't just internal. Other people don't often understand or accept the fact that a man could be so disabled by this illness—especially when there are few outward signs of the physical devastation CFS wreaks on men and women alike. The outside world tends to expect men—sometimes more so than women—to "suck it up" and get going. Sprayberry shares, "I'm six-foot-four-inches tall and weigh 230 pounds. Some people look at me and think I can't be that ill because I look so strong." Other men describe struggling with the same misguided expectations from others (and themselves).

Finding help

Because it's less common to associate CFS with males, many men with the illness are slow to seek medical help as symptoms emerge. They first try to explain away fatigue or pain. As a result, they may enter an extended period of pushing themselves in a way that further compromises their health. It often isn't until symptoms are severe enough to interfere seriously with career and personal activities that a man may bring it up with his doctor. And then, many doctors are slow to consider CFS. This delays the opportunity to begin treating and managing the illness.

Dr. Nancy Klimas, a respected medical authority on CFS, sums it up this way. "Men will deny they're ill longer than many women and not seek treatment until they're unable to do much of anything." She thinks that may help explain why clinic-based CFS studies show so many fewer numbers of men with the illness, because fewer men are seeking help for their CFS.

Once men are diagnosed with CFS, some express having trouble identifying with the information they find on the illness because it so often speaks from a female perspective or is covered in predominantly women-oriented media. As Sprayberry explains it, "Very little is ever mentioned about men and CFS, and it can make you have doubts about your experience." Venetucci describes feeling like "a mutant among mutants"

reading about an illness that's marginalized to begin with and then not seeing any male experiences reflected in the media.

For Andrew Mosmiller, a 29-year-old Maryland man, seeking help from established CFS support groups has proved challenging as well. He shares, "My method of coping seems different from most of the support group members I've encountered, which places me on the outside of such circles in many ways."

This experience appears to be reflected by other men with CFS as they attempt to take advantage of support group networks, which often consist largely of women. It suggests that the nature of support for a man may be somewhat different than it is for a woman. Data shows that many women utilize support groups to address the significant emotional



strain and personal isolation brought on by CFS. Yet many men are more interested in exchanging experiences about ways to function better. The two desires aren't mutually exclusive, but they tend to align poorly when seeking and receiving support.

Mosmiller explains, "The group in my area is very caring and responsible. But when I post a comment about having trouble with a specific situation in my life, I'm looking for support that includes some practical suggestions. What I often get instead is lots of compassion but few recommendations. I appreciate this response, but I'm still left wondering what I can do."

While a handful of CFS information lines and support groups are led by men and some have active male members, currently no U.S. support groups or websites are principally geared toward men with this illness.

Clinically speaking

It's common to hear stories from both genders about misdiagnosis and lack of assistance by the medical community. People are often sent from specialist to specialist and given a battery of tests—or worse, told there's nothing wrong with them—before finally reaching a diagnosis of CFS. With men, this problem again is compounded by the perception of CFS as a women's illness. Doctors may not initially think to explore the CFS diagnostic criteria with their male patients. Anecdotal feedback also suggests that physicians may not be as responsive to men's complaints of fatigue, though evidence suggests that gender bias may exist in a man's favor when it comes to specific pain.

Overall, though, the medical community doesn't benefit from significantly more or better information than the general public when it comes to men with CFS. Dr. Lucinda

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Bateman, who has focused her practice on the diagnosis and care of CFS and fibromyalgia, explains, “We have a lack of information about CFS in general terms. Combine that with the fact that men make up a smaller percentage of patients diagnosed and that leaves us with very little knowledge on the subject.” Klimas agrees about the shortage of gender-specific information. She says, “I’m surprised to see how little we know in this area.”

So how do CFS-experienced physicians address the illness in their male patients, and do they perceive any physiologic differences?

Bateman expresses seeing more similarities than differences. Klimas observes the most disabling features, like profound fatigue, exercise-induced relapse and cognitive dysfunction, as being shared by both genders. And Dr. Charles Lapp, a CFS pioneer, describes the clinical approach to men and women with CFS as being “very much the same.”

But without drawing broader references, all three physicians have observed occasional differences. For example, Bateman reports that some of her most challenging cases of severe, widespread postviral pain have been in men with CFS. Klimas has noted some gender differences in response to certain medications.

Prostatitis, an infection of the prostate gland, has also been observed in men with CFS and may parallel the recurrent urinary infections reported by women with the illness.

Because of the neuroendocrine effects of CFS, all three doctors describe looking closely at the hormone levels in both groups. Says Lapp, “Many men with CFS develop low testosterone levels. This is frequently overlooked by primary care doctors, but replacement can improve libido, energy and quality of life.”

THE “OTHER” MEN WITH CFS

A discussion of men with CFS wouldn’t be complete without addressing the many men whose wives or children have the illness. With something as debilitating as CFS, everyone in the family is affected, and spouses in particular begin their own journey of adjustment, limitations and new roles. Some husbands (as well as some wives of men who are ill) aren’t able to make the transitions this illness demands, and marriages suffer or are lost in the process. But for the husbands who persevere, CFS is a permanent part of their world.

David Fiorito, whose wife has had CFS for many years, says, “We do not experience life as one healthy and one sick spouse. The burden is shared. It’s never easy, but that’s what it takes to be married and share a life with anyone suffering from a chronic illness.”

As with men who have CFS, these husbands are forced to let go of many fundamental plans for the future and drastically change the way they function in the family. With that, old notions of roles and duties often have to go. However, in the cases of husbands whose wives have CFS, this often results in having to increase financial and household responsibilities to help compensate for their wives’ limitations.

Isolation is another issue in common. Not many people truly understand the special needs and sacrifices required to deal with chronic illness. And, of course, even fewer people understand the CFS experience. This can leave husbands dealing with some of the same lack of understanding and support as men who *have* the illness.

In the end, CFS alters a marriage and a family in some of the same ways it alters individual lives. Says Fiorito, “This illness is an invader into a marriage.” His advice for survival? “Always focus on supporting each other.”

The essence of a man

CFS drastically changes lives. That much is clear for both men and women. The panoply of symptoms, the isolation, diminished roles, frustration with the medical community and hope for improved treatments and a cure are all characteristic of the CFS experience. Yet for men, these dynamics may exact a different type of toll.

When asked to convey to the world what it’s like to be a man with CFS, Mosmiller offers a perspective many men with the illness seem to share. He says, “It’s a constant exercise in dealing with frustration. This

is probably true for women as well, but men with CFS have to adjust to things that go very much against the grain of what a man thinks and feels he should be. It’s as if it takes away some of the essence of what it is to be a man.” ■