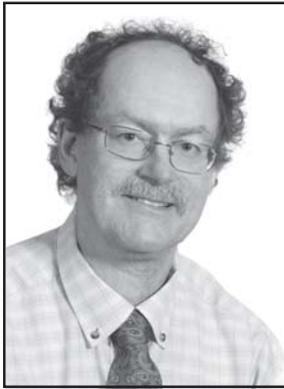


© 2012, Kevin P. White, MD, PhD



by Kevin P. White, M.D., Ph.D.

FIBROMYALGIA

Myth Buster File #1

(The myth: men don't get fibro)



© 2012, Olga Vasemski | Dreamstime.com

I've come up with a new title for fibromyalgia: *the disease of a thousand myths*. There are just a ton of mis-statements and erroneous beliefs about this sadly misunderstood condition. Here are just a few of them:

- It's called a non-fatal disease. But did you know that in a Danish study suicide rates were increased 10 times over the general population?
- It's called an old woman's disease, even though perhaps 10 to 20 percent of cases start in childhood, and 4 to 5 percent of 30 year old women already have it (compared to roughly 10% at its peak at age 60).
- It's called an invisible disease, even though we now have the technology to see it.
- And it's called a housewives' disease, even though people in every field of work get it, including doctors, lawyers, judges, actors/actresses and, yes, even athletes.
- There are plenty more.

Here, I want to go back to the myth that fibromyalgia is an old woman's disease and point out that, in addition to young and adolescent girls and young and youthful middle-aged women getting it... boys and men get it too. In fact, one in roughly 60 to 100 men will get fibromyalgia over the course of his lifetime. To put this in perspective, this means that somewhere between 1½ and 2½ million boys and men currently living in the United States will develop fibromyalgia at some time in their life. If you put all these men in one city, that city would be somewhere between the size of Milwaukee and Denver, including all their suburbs. And I don't think anyone could pass through either of these cities without noticing them.

So why is it that so many people, doctors included but also insurers and employers, seem not to know that men get fibromyalgia, or at least that it is not a rarity?

There are many reasons for this, but perhaps the #1 reason is that almost all the early research that was done on fibromyalgia was done in women seen in specialty clinics. Add to this the fact that men are less willing to go to doctors and less willing to admit to pain (men are taught from boyhood "to be tough"), and the problem is compounded.

Back in 1999, I conducted a general population study of 3400 people living in the Canadian city, London, Ontario, in which we were looking for fibromyalgia as it exists, not in our clinics, but out in the community. Among the 100 people we identified as having fibro, 14 were men. This meant that there was one male with fibro for every 6 females, which was considerably higher than the one in ten or less rate reported in clinic studies. More recently, estimates are that up to 30% of fibromyalgia cases might be males, with most of them never diagnosed.

Here are some of the things I have learned about fibromyalgia in men, both from my own research and the research of others. First of all, it is not at all rare. In fact, in the U.S., an estimated one to 1½ million men *currently* have fibromyalgia. Around the world, this number is probably between 15 and 20 million. That's a lot of men with fibro.

Secondly, males, like females, can develop fibromyalgia at any age, including childhood and adolescence. In our study, though we didn't study children, roughly 0.5 percent of all men had it by age 30. Again, this may not seem like a lot, but it translates into roughly **750,000 boys and young male Americans with fibromyalgia**.

Thirdly, the symptoms of fibromyalgia in men and women are virtually the same. In my own study, we found that women tended to have slightly more fibro-related problems, but only slightly. Widespread pain, severe fatigue, non-restful sleep or frank insomnia, headaches, and a host of other symptoms were ram-

pant in both sexes. And, in both sexes, the severity of symptoms ranged from mild and non-disabling to severe and quite disabling. Our results comparing men and women are consistent with those of another study, published just this summer in July of 2012, in which men and women with fibromyalgia were very similar.

Note that I said similar... not identical!

The Bad News

There are certain sad realities of being a male with fibromyalgia that are frequently overlooked. To begin with, as hard as it sometimes is for a woman to be believed, it's typically harder for men, because many doctors, and others, still think of fibro as a woman's disease. Men with fibro, therefore, are often stigmatized as being wimpy, or whiney, or lazy and opportunistic, or worse. I remember one man who came to me who felt extremely stigmatized. His own doctor thought all he wanted was drugs; his family just thought him lazy; and friends? What friends? They'd all left. No one supported this guy.

Because of this stigmatization, and because men tend to avoid doctors and other health care professionals more than women do anyway, men with fibromyalgia often remain undiagnosed for longer periods of time than usual. Maybe this is why men in a recent Spanish study were worse than women in terms of the overall impact of fibromyalgia on their life.

Another problem concerns work, in particular because the most physically demanding jobs are typically performed by men more often than women. Not only does physical labor aggravate pain, but ultimately it can make it impossible to continue working. How does someone continue in heavy manual labor when they hurt all over and are exhausted all the time? And do you really want someone driving trucks on the highway or handling heavy machinery if they are exhausted? Yet employers often deny men their disability claims because they either remain undiagnosed with fibromyalgia or their doctors remain equivocal about it. Even insurers and caseworkers who buy into the fibromyalgia and disability concept want strong support from a patient's doctor before they will approve disability applications. Many men with fibro lack this support.

If men with fibromyalgia are less likely than women to receive disability payments, another even wider problem arises. In many households, men still either provide the sole financial support for the family

or they are the *primary* provider since society has sadly not yet achieved gender parity in the workforce, and men still tend to get paid more than women. What this means is that disability in a man with fibro can be especially disastrous for the entire family if disability claims are denied, since the majority of income that the family has, and sometimes ALL of it, can be lost. Now it's the entire family who is hurting from financial ruin and poverty.

Another issue that should be raised is that men and women may respond differently to treatment. This relates to treatment effectiveness, tolerance, and safety. Harkening back to my earlier example, does anyone really want to see a truck driver with poorly-controlled fibromyalgia pain and fatigue driving a big rig down the highway? Now put him on any one of the many sedating drugs often prescribed for fibromyalgia. Feel safer? I don't. Men (and women) also work as pilots, firefighters, soldiers, and in other occupations where concentration and quick decision-making affects lives. Doctors and insurers who deny such risks, in either a man or woman, are potentially jeopardizing much more than just the individual patient's health.

Finally, let me go back to the fact that not just men, but boys get fibromyalgia. A 12-year old boy with fibromyalgia who suffers with a lot of pain, tenderness, and fatigue could quite easily fail at his attempts at sports and being physical, (things that often are crucially important to young males), potentially leading to ridicule and frank bullying by peers, who typically will not understand. What could be worse than someone who already hurts everywhere being beaten up every day?

The Good News

What can we do about all this? Fortunately, there is more and more information about fibromyalgia in males on the internet. There are, in fact, several really good websites for men with fibromyalgia to go to for up-to-date information, camaraderie, and support (see Table 1). I recommend that all men with fibro go there, as well as those who want to support them, to learn as much as you can from men who actually have the disease and have found ways to deal with it.

Secondly, and more importantly, fibromyalgia CAN be treated, in men and women. Not cured, maybe... but certainly treated to the point where people feel better than they did. The SECRETS to doing better with fibromyalgia are these:

(1) Learn as much as you can about fibromyalgia, including what it is and what it isn't (do you remember all those myths I told you about at the start?). No one likes to fight in the dark. Truly knowing what you are up against and climbing out from all the lies, misconceptions, and misunderstandings is a HUGE first step.

(2) Educate important people around you, so they can be more supportive. (Some doctors are even open to being educated, if the source is legitimate. True stories: One patient gave her disbelieving doctor a copy of my book and received a letter of apology from him a week later, and a lawyer in England was gifted with one from a woman fighting for disability payments, won the case, and now gives FREE copies to ALL his clients).

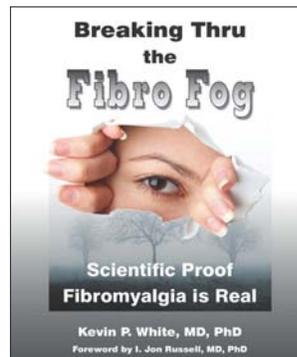
(3) Recognize that the management of fibromyalgia is not usually a single, simple thing, like a little pink pill you take twice a day, or avoiding sugar, or bathing in coconut oil. Long-term results with fibromyalgia usually require a combination of approaches that include things your doctor or other health care professionals can do for you, AND things you must do for yourself, like lifestyle, dietary, and attitudinal changes, as well as carefully increased activity and exercise. In fact, the more you can do for yourself, the more control you have over your own health.

(4) Don't overlook or let others overlook other treatable conditions that often co-exist with fibro, like tendonitis of the heel causing foot pain, which might result in you being unable to walk but can often be treated with a custom shoe insert +/- occupational therapy +/- a short course of an anti-inflammatory drug. This is where having a conscientious and fibro-educated doctor or therapist is a HUGE plus.

And finally...

(5) Keep a sense of humour – this might seem silly, but the fibromyalgia patients I've seen who do best are those who still can laugh, even when they hurt. Perhaps my favorite patient of all time was a man who had terrible fibro but loved to laugh. Every time I saw him, he'd tell me about how the last thing I'd tried with him hadn't worked, and then he would start telling me a couple of good jokes he'd just heard. One day after about a year of trying one thing after another, he came back and something HAD worked. He was feeling better than he had in years. The last time I saw him he was volunteering at a local railway museum 20-30 hours per week and "loving it". This

time, he was doing so well we hardly had to talk about his pain or fatigue at all. But he STILL had a long list of new jokes to tell me.



Kevin P. White, M.D., Ph.D. is a world expert in fibromyalgia research and treatment and a staunch fibromyalgia patient advocate who tours Canada, the U.S., and Europe educating people about the realities of fibromyalgia,. He is also the multiple award-winning author of *Breaking Thru the Fibro Fog: Scientific Proof Fibromyalgia Is Real*. Visit him at <http://thefibrofog.com>. His best-selling book is available as both a printed soft-cover and eBook at <http://amazon.com> and in bookstores.

TABLE 1

Websites for Men with Fibromyalgia

"Men With Fibromyalgia"
<http://www.menwithfibro.com/home.html>

Health.com
[www.health.com/health/condition-article 0,,20354924,00.html](http://www.health.com/health/condition-article-0,,20354924,00.html)

"FibroMen Support Group"
<http://health.groups.yahoo.com/group/FibroMenSupportGroup/>

"Men With Fibromyalgia"
www.fibromyalgia-symptoms.org/fibromyalgia_relieve.html

The Fibromyalgia Research Blog - PTSD & FM Pain in Men: <http://fibroresearch.blogspot.com/2006/11/ptsd-and-fibromyalgia-pain-in-men.html>

About.com
<http://chronicfatigue.about.com/b/2012/02/18/men-with-fibromyalgia-special-problems-symptoms.htm>

* * * * *

Courtesy of the National Fibromyalgia Partnership.
 This list also available at: www.fmpartnership.org/