



The Carousel Network

**Chronic Neuroimmune Disease
Information and Support for Sonoma County**
122 Calistoga Road, #216
Santa Rosa, CA 95409
www.cndsinfo.net

It's a Guy Thing: Men with CFS/FM

The relationship between Chronic Fatigue Syndrome/Fibromyalgia and gender has been a source of confusion and controversy among researchers and patients alike. Although CFS/FMS is clearly more prevalent among women, both illnesses do afflict men as well.

The Carousel Network (TCN) offers information on the various diseases and disorders associated with chronic neuroimmune diseases, such as chronic fatigue syndrome, fibromyalgia, multiple chemical sensitivity, autoimmune thyroid disease, etc. The information is intended to help patients and caregivers make informed decisions about the patient's health, diagnostic testing, and treatment in conjunction with their health care practitioners. TCN does not diagnose patients nor recommend specific medical or palliative treatments.

**The Carousel Network is a 501(c)3 nonprofit supported by memberships and donations.
Membership is \$20/year; make checks payable to The Carousel Network, POB 366, Fulton CA 95439-0366.**

C-5 / Rev. 09/04

It's A Guy Thing: Men with CFS/FM

Lisa Lorden

The relationship between Chronic Fatigue Syndrome/Fibromyalgia and gender has been a source of confusion and controversy among researchers and patients alike. Although CFS/FMS is clearly more prevalent among women, both illnesses do afflict men as well.

Estimates vary widely as to the proportion of male versus female patients with CFS/FMS. A four-city surveillance study by the U.S. Centers for Disease Control & Prevention (CDC) identified a CFS population that is 85% female overall. However CDC's Seattle study found that only 59% of the CFS patients were women. A well-publicized study by Jason et. al in the *Journal of the American Medical Association* revealed about 64% of CFS sufferers are women. The estimates of male fibromyalgia sufferers are even smaller. Studies suggest that women make up between 86% and 90% of FMS patients.

The gender gap goes beyond the numbers. Research has shown that FMS symptoms differ between men and women. A recent study in the *Journal of Rheumatology* found that men with Fibromyalgia seem to have fewer and milder symptoms than female patients, including number/severity of tender points, fatigue, and irritable bowel syndrome. However, an Israeli study that compared 40 men and 40 women with FMS, matched by age and educational status, found that men reported *more severe* symptoms than women, in addition to decreased physical function and lower quality of life.

It's clear that more study is needed before the true nature and prevalence of CFS/FMS in men will be known. But what's a guy with this illness to do in the meantime? It seems obvious that a man's experience with this disease would be quite different from that of a woman, if only because of the sheer numbers. One man with FMS writes, "at times I do feel isolated being the only male in most support groups. I try to keep my sense of humor."

It's A Man's World?

A common debate within CFS/FMS discussion forums and support groups is whether male sufferers have it better or worse than their female counterparts. On the one hand, men may have a more difficult time getting diagnosis or treatment since CFS/FMS is generally perceived as a "woman's disease." Balancing this, perhaps, is the widely publicized gender bias in physician's attitudes toward their patients. One recent study in the *New England Journal of Medicine* found that women complaining of chest pain are less likely than men to receive important cardiac testing. Research has also shown that doctors perceive female patients as more likely to make excessive demands on their time, which may be due to women's real tendency to voice more complaints and ask more questions than men do during a typical visit. The same study also found that women's complaints were judged more likely to be influenced by emotional factors.

Still, while the loss of function and quality of life imposed by CFS/FMS is devastating to both men and women, males with this illness may face some additional burdens. Though gender roles are gradually changing somewhat, men have long been expected to "hunt, feed, and protect the family." Societal roles and expectations strongly influence perceptions of success and self-worth. Many men may base their self-worth on their ability to work, their income potential, or their employment position. Once afflicted with CFS or Fibromyalgia, men often can't meet these expectations and must suffer even greater feelings of failure or letting others down.

Furthermore, males are socialized from a young age not to reveal or express their feelings and fears. The well-known fact that men are less likely to seek counseling or attend support groups suggests that men may experience even greater isolation. One young man with Fibromyalgia explains, "I think it is important for people to know how hard it is for men with FMS. Growing up you are taught to be tough, have a job, support a wife and two kids which is very hard to try to achieve. It is much more difficult for a man to maintain a relationship or explain his condition to friends."

Reaching Out Across Gender Lines

There is support out there for men and women alike. Online support venues may help in bridging the gender gap, because the relative anonymity of online communication means that an individual's gender is not so readily apparent. In addition, men can more easily connect with other men like them, since they have access to the global community rather than just their local support group, where encountering another male may be less likely.

Most men seem to find that even though online support networks may consist predominantly of women, these groups are extremely welcoming to members of both genders. Says one male patient, "All the women online readily accept me and are amazed that I am 'brave' enough to openly speak with them

and not be intimidated by being the only male."

The society we live in tends to associate self-worth with an individual's ability to be "productive." As CFS/FMS sufferers, our old expectations simply become unrealistic. Continuing to judge ourselves and our lives by unrealistic standards can only lead to discouragement and hopelessness. As with any major life challenge, we need to find new measures of meaning and unique definitions of success. Managing our own and others' expectations is a challenge that everyone, with or without CFS/FMS, must face.

Tips for Men (And Women, Too)

For all individuals who suffer from CFS/FMS, but especially males, the following guidelines are helpful in managing the impact of chronic illness:

1. Do not attempt to push yourself beyond your present physical capacities. Accept and work within your present realm of abilities.
2. Set immediate, realistic, and obtainable short-term goals which can be achieved on a daily basis.
3. Talk, talk, talk. Express your feelings and fears--allow others to assist you in seeing yourself from a more realistic perspective.
4. Attend area support group meetings. Try to connect with other individuals that share your background or unique concerns.
5. Throw out "old lessons" about expectations that one must meet in order to be of value. Write "new lessons" for your life.
6. Realize that change does not necessarily produce negative results or consequences. Look for the gains which can be achieved by and through the changes.
7. Accept that you may not be as powerless as you feel or fear. While you may not have power over your own physical abilities now, or how others may perceive you, you always have absolute power and control over how you view yourself.

Adapted from material compiled by Dr. Dennis G. Cowan, M.D., and provided by the National Chronic Fatigue Syndrome and Fibromyalgia Association

References

- Surveillance for chronic fatigue syndrome – four U.S. cities, September 1989 through August 1993. Reyes, et al. *MMWR, CDC Surveillance Summaries*, vol. 46, pages , 1997. Available online
- A community-based study of chronic fatigue syndrome. Jason, et al. *Arch Intern Med* 1999 Oct 11;159(18):2129-37. Available online <http://www.anapsid.org/cnd/diagnosis/depaulstudy.html>.
- The London Fibromyalgia Epidemiology Study: the prevalence of fibromyalgia syndrome in London, Ontario. White, et al. *J Rheumatol* 1999 Jul;26(7):1570-6
- Expert Commentary: The Puzzle Of Fibromyalgia. Harvard Medical School's Consumer Health Information. October 2, 1997. Available online <http://www.intelihealth.com/>
- Fibromyalgia in men: comparison of clinical features with women. Yunus, et al. *J Rheumatol* 2000 Feb;27(2):485-90. [Abstract included in this packet.]
- Fibromyalgia syndrome in men. Buskila D, et al. *Semin Arthritis Rheum* 2000 Aug;30(1):47-51
- The effect of race and sex on physicians' recommendations for cardiac catheterization. Schulman, et al. *N Engl J Med* 1999 Feb 25;340(8):618-26.. Published erratum appears in *N Engl J Med* 1999 Apr 8;340(14):1130.
- Physicians' attitudes toward female patients. Bernstein B, Kane R. *Med Care* 1981 Jun;19(6):600-8 [Abstract included in this packet.]
- The dynamics of help-seeking in men and women: a national survey study. Veroff JB. *Psychiatry* 1981 Aug;44(3):189-200
- Gender and cancer support group participation. Krizek, et al. *Cancer Pract* 1999 Mar-Apr;7(2):86-92

Fibromyalgia in men: comparison of clinical features with women.

Yunus MB, et al. Inanici F, Aldag JC, Mangold RF

Department of Medicine, University of Illinois, College of Medicine at Peoria, 61656, USA. yunus@uic.edu
J Rheumatol 2000 Feb;27(2):485-90

OBJECTIVE: To describe possible differences between male and female patients with fibromyalgia syndrome (FM) in their clinical manifestations.

METHODS: Five hundred thirty-six consecutive patients with FM (469 women, 67 men) seen in a university rheumatology clinic and 36 healthy men without significant pain seen in the same clinic were included in the study. Data on demographic and clinical features were gathered by a standard protocol. Tender point examination was performed by the same physician. Level of significance was set at $p < \text{or} = 0.01$.

RESULTS: Several features were significantly ($p < \text{or} = 0.01$) milder or less common among men than women, including number of tender points (TP), TP score, "hurt all over," fatigue, morning fatigue, and irritable bowel syndrome (IBS). The total number of symptoms was also fewer among men and approached significance ($p = 0.02$) by parametric test, but reached significance ($p = 0.001$) by nonparametric analysis. All clinical and psychological symptoms as well as TP were significantly ($p < 0.01$) more common or greater in male patients with FM than healthy male controls, with the exception of IBS ($p = 0.03$). Patient assessed global severity of illness, Health Assessment Questionnaire disability score, and pain severity were similar in both sexes.

CONCLUSION: Male patients with FM had fewer symptoms and fewer TP, and less common "hurt all over," fatigue, morning fatigue, and IBS, compared with female patients. Stepwise logistic regression showed significant differences between men and women in number of TP ($p < 0.001$).

Physicians' attitudes toward female patients.

Bernstein B, Kane R

Med Care 1981 Jun;19(6):600-8

The relative impact of a patient's sex and expressivity (expression of a personal problem) on attitudes of physicians toward patients was assessed using case simulations and questionnaires. Eight simulated cases were used that varied by presenting complaint, patient sex, and inclusion or exclusion of a personal problem. Two non-identical cases were read by each of 253 primary-care physicians, yielding 506 questionnaires for analysis. Of the physicians, 25 per cent believed women were likely to make excessive demands on physician time, although only 14 per cent believed this likely of men (p less than 0.01); women's complaints were judged more likely to be influenced by emotional factors (65 per cent versus 51 per cent in men, p less than 0.01), and were identified as psychosomatic more frequently than were men's (21 per cent versus 9 per cent, p less than 0.01). No sex differences were observed for tranquilizer prescriptions. Sex differences persisted when complaint and expressiveness were controlled; however, physicians' reactions to expressivity were strong enough to equalize male-female differences in some items. Although non-expressive women were more likely to receive a psychosomatic diagnosis than non-expressive men (14 per cent versus 2 per cent, p less than 0.01), expressive men and women were almost equally likely to receive psychosomatic diagnoses. Thus, differences in labeling occurred as a function of the patient's sex and expressivity. The effects of these differences on quality of care remain to be determined.

Fibromyalgia in Men: Comparison of Clinical Features with Women

Muhammad B. Yunus, Fatma Inanici, Jean C. Aldag, And Richard F. Mangold

J Rheumatol 2000;27:485-90 February 2000

http://www.jrheum.com/abstracts/abstracts00/feb_abs_31.html

OBJECTIVE. To describe possible differences between male and female patients with fibromyalgia syndrome (FM) in their clinical manifestations.

METHODS. Five hundred thirty-six consecutive patients with FM (469 women, 67 men) seen in a university rheumatology clinic and 36 healthy men without significant pain seen in the same clinic were included in the study. Data on demographic and clinical features were gathered by a standard protocol. Tender point examination was performed by the same physician. Level of significance was set at $p \leq 0.01$.

RESULTS. Several features were significantly ($p \leq 0.01$) milder or less common among men than women, including number of tender points (TP), TP score, "hurt all over," fatigue, morning fatigue, and irritable bowel syndrome (IBS). The total number of symptoms was also fewer among men and approached significance ($p = 0.02$) by parametric test, but reached significance ($p = 0.001$) by nonparametric analysis. All clinical and psychological symptoms as well as TP were significantly ($p < 0.01$) more common or greater in male patients with FM than healthy male controls, with the exception of IBS ($p = 0.03$). Patient assessed global severity of illness, Health Assessment Questionnaire disability score, and pain severity were similar in both sexes.

CONCLUSION. Male patients with FM had fewer symptoms and fewer TP, and less common "hurt all over," fatigue, morning fatigue, and IBS, compared with female patients. Stepwise logistic regression showed significant differences between men and women in number of TP ($p < 0.001$).