Do Men Get Lupus?

by ANNA SCANLON

Lupus in Men: Not as Rare as You Might Think

As a child, lupus was something I always knew about. I can't say I knew exactly what it was, but I knew it was something my grandfather had (amongst a myriad of other illnesses). I had never associated the disease with one sex or the other until I began displaying symptoms and did a little bit of digging.

To my surprise, I found that most people who are diagnosed with lupus are women in their childbearing years. Going to support groups I met a couple of men here and there, but they were far from the majority.

The Lupus Foundation of America states that 90 percent of newly diagnosed patients are women between the ages of 15 and 44. However, this doesn't mean that lupus can't occur in men, children, or women above the age of 44.

Molly's Fund estimates that around 150,000 men in the United States alone have lupus, meaning that it isn't as rare as you may think. This statistic means that there are likely close to a million men worldwide who suffer with lupus. And my grandfather, having been diagnosed as an older man, is one of the few examples of an atypical lupus patient.

Although as a man you may feel less supported in your lupus journey because many support groups and literature are aimed at women, you should be aware that you are not alone — there are many men out there going through the same thing you are.

Additionally, the disease is treated similarly in men and women (although each individual's case of lupus is different), so attending support groups with mixed sexes or with mostly women doesn't mean you won't be able to relate to the issues other patients have.

Differences Between Male and Female Lupus Patients

There are very few differences in how lupus manifests in men compared to women. For one, the Lupus Foundation of America states that lupus actually gets better with age for women as menopause sets in, whilst it can be known to be worse for men as their testosterone levels drop.

Of course, like anything else with lupus, this varies considerably from patient to patient.

Aside from the possibility of lupus worsening in age, there is one other distinct difference for young men with lupus who have not yet had children and who will be undergoing treatment such as chemotherapy.

As chemo for lupus can decrease fertility, or erase it altogether, it is important for the patient who may want to have children in the future to look into options such as freezing the sperm or eggs.

For women, collecting eggs for later implantation can be a pretty invasive procedure, but men can very easily store their sperm for later use. This makes one less thing for a man undergoing serious lupus treatment to worry about.

Next page: combatting feelings of isolation, and the trouble with gender roles.

Combatting Feelings of Isolation

Men with lupus may feel a bit isolated or lost in a world where all of their fellow patients seem to be women. It can feel pretty lonely at times, especially if you regularly find yourself the only male at support groups (which happens quite often).

Because of this, it is important for men with lupus to reach out to each other.

Because it's relatively rare, it may be difficult to find other men in your area to get together in person. However, you may be able to organize a support group online via Skype or Google Hangouts so you can talk about all of the different ways lupus affects you.

The Trouble With Gender Roles

Although physically there are very few differences between male and female lupus, it is important to remember that the societal implication of being a chronically ill man can be very difficult. In a society where men are typically seen as the provider and protector, this can bring about lots of different issues — especially for younger men who are coming into their own as a person with lupus on top of it.

The expected gender role can lead to self-esteem issues, trouble dating and finding a mate and a general loss of self-confidence. Molly’s Fund says the following about lupus in men:

“In general, men seek medical attention less frequently than women. Traditional male culture promotes the 'suck it up,' 'play through the pain,' or 'pain is weakness,' mentality. This simplifies the belief that men are supposed to be strong and any challenge to that belief goes against more traditional ideas of masculinity.

"The fact is, when someone is truly aware of their body, they can determine the difference between normal pain vs. new and different symptoms. They should then be able to acknowledge the need to seek medical attention.”

Seeking Support

Speaking to other men who are having similar struggles can help you feel less alone and supported. The Lupus Foundation of America offers message boards and has several chapters throughout the United States to help male lupus patients find comfort and exchange experiences.

It's important to ensure you have a strong emotional support system as you navigate their illness. Asking your doctor about the possibility of seeing a therapist is a great idea as well if your insurance covers it/you can afford it.

As mentioned previously, the gender roles and expectations for men can be very difficult to navigate without lupus, but adding that layer on top of it can make it seem almost unbearable. It is important to be able to talk to others who can help you find emotional coping strategies so you don’t let lupus get you down completely.

If you are a man who is seeing changes in your body that mimic the symptoms of lupus, don’t hesitate to your doctor and get a referral to a rheumatologist as soon as possible. You know your body best, and you know if something is off with it. Follow your gut instinct.