

Paul Nelson: Online Erectile Dysfunction Support

FrankTalk.org, an online discussion group for men with erectile dysfunction, is the brainchild of prostate cancer patient Paul Nelson.

Prostatepedia spoke with Paul about his journey and the thinking behind FrankTalk.

Why did you start FrankTalk?

Mr. Nelson: I was diagnosed with prostate cancer the day before my father died of the same disease. I was 46. I had surgery very quickly, because that's what everyone said I had to do given that I was so young. In retrospect, I'm glad it's out and that it's over.

That was eight years ago. I discovered there is a lot of online support for cancer patients. After I had the surgery, I assumed there would be online support for the sexual side effects of cancer. I went online and searched and searched. I just kept coming up with one commercial after another, or one scam after another. Even the medical information sites all said the same thing. It was very vague.

I was frustrated and said to my wife, "There's nothing online about erectile dysfunction!" She's a librarian. She said, "You're just searching for the wrong

terms." One day at work she texted me: "My God! You're right. There is *nothing* online."

There were prostate cancer discussion boards, but they weren't focused on erectile dysfunction. They are for men fighting prostate cancer! I thought that surely there must be a patient organization for men with erectile dysfunction. Wrong again.



"America is uncomfortable with sex."



After I complained about it for several months, my wife told me to shut up and start my own online group. Here we are eight years later.

FrankTalk is a patient support site. We are an online community of men talking about our experiences with erectile dysfunction. We talk about what erectile dysfunction does to your view of yourself as a sexual person and how you cope sexually and emotionally. It is not a medical site. You can get medical information



from other patients—how to do a penile injection or how to use a penis pump—but the heart and soul of the site is men discussing the frustrations, triumphs, and disappointments of dealing with sexual dysfunction.

Do you include only men with erectile dysfunction after prostate cancer?

Mr. Nelson: We now have men with erectile dysfunction who do not have prostate cancer, as well, but we started off with only prostate cancer patients.

When I started the site, I was a patient at Mount Sinai Hospital. Dr. Natan Bar-Chama was the urologist in charge of erectile dysfunction following surgery. When he found out what we were doing, he said, "This is much bigger than prostate cancer. There are millions of men out there with erectile dysfunction who have no resources." And so we opened up to those without prostate cancer.

We still have a huge number of prostate cancer patients on the site, but by no means is it a prostate cancer/erectile dysfunction-only site any more. That's just where it started.

That was actually a big discussion on the site for a long time: it doesn't

matter what your erectile dysfunction comes from, you still need help. No matter what the cause, the pain of having it is still the same.

Do you think men with erectile dysfunction are reluctant to seek help?

Mr. Nelson: America is uncomfortable with sex. The world is uncomfortable with sex. Men in our culture believe their male identity is firmly rooted in the penis. It's tragic.

Unfortunately, most physicians are uncomfortable as well. They get zero training in sexual medicine in medical school. People don't realize that urologists are surgeons first and foremost. They're trained to cut; they do not get classes in human sexuality in medical school. They don't take classes on erectile dysfunction. It really puts them in an awkward spot to have men ask for help with erectile dysfunction. We have doctors who shouldn't be expected to be sexual medicine experts forced into playing that role.

It's a double whammy. We've got a culture of men for whom it's scary to talk about sex and about sexual failure or sexual difficulties. They're then presenting themselves to doctors who really don't have much training in sexual medicine. It's a complicated problem.

What are some of the psychological problems associated with erectile dysfunction?

Mr. Nelson: Depression is first and foremost.

When men can't have intercourse, or the trial and the pain of going through injections or pills is too much, they tend to withdraw. They avoid sex. Men stop having sex. Their wives mostly just want intimacy. But because men are

hardwired in our culture to just want intercourse, they just stop having sex. They stop touching their wives completely, because it makes them feel like a failure or broken or dysfunctional. It's easier to just avoid it completely.

Meanwhile, their partners are thinking, "What happened? He doesn't love me anymore. I'm not attractive. I'm too old."

Women will often say, "It doesn't matter that you can't have an erection." But yes, it *does* matter to men. The man feels stupid that it bothers him. It's really a complex problem.



"It destroys marriages far more frequently than anyone talks about."



Part of the problem is that couples don't know how to talk about it. They don't have the tools to talk about it. They don't have the vocabulary. It destroys marriages far more frequently than anyone talks about. It's tragic.

That's why support groups like ours are important. It's worth seeking help. [Pp](#)

