10 Things Not to Say to Someone With Fibromyalgia

by SARAH BORIEN

Speaking With Kindness and Respect

Fibromyalgia, like many chronic health conditions, is very difficult to cope with. However, more difficult than that is the wide range of symptoms and the lack of understanding associated with it. It’s therefore not surprising that people struggle to know what to say or, more importantly, what not to say.

Here are 10 things not to say to someone with fibromyalgia.

1. You Probably Need to Get out More

Are you suggesting I’m lazy? Because that’s what it sounds like. We know we need to try gentle exercise and laying in bed all day won’t make things better, but you suggesting we need to get out more implies you think we’re not trying our best. It can sound demoralizing and a bit insulting.

Instead, say: “I’m going for a short walk if the sun’s out tomorrow. I understand if you’re not up to it but if you want to come with me, I thought it might help.” We can be a difficult group sometimes, and it must be difficult for our friends and family to know what’s best. Just be sensitive and keep us involved.

2. I Looked on the Internet; No One Really Knows What Fibromyalgia Is

We appreciate you did some research and it’s true, there are thousands of websites that don’t provide useful information and therefore it can seem confusing. However, some websites articulate this in a way that doesn’t leave people feeling clueless, and trusted health websites or medical books should be where people get their information.

Instead, say: “It must be so frustrating for you with so much information out there. I read that you are coping with a lot of symptoms as well. What can I do?” This shows us that you’re trying to understand and that means a lot.

3. Most Doctors Don't Think Fibromyalgia Is a Real Illness

Actually, that’s not true. Some doctors have doubts about it and those doctors are incorrect and not up to date with modern research. Most doctors know how things have developed in the area of chronic pain, and some specialize in the area and are completely up to date with recent findings.

Instead, say: “Do you have a good doctor?” This makes us feel like you care, and gives us the opportunity to talk about how fibromyalgia is managed by the medical profession if it’s something we want to address. The main thing is that this question puts the emphasis on the GP, not on you.

4. Are You Sure It's Not Just in Your Head?

This is the question we have been fighting since day one. We know stress makes it worse, and we know one of the many symptoms can include depression or anxiety, so we understand the close links between fibromyalgia and mental health. However, that does not mean under any circumstances we are inventing our pain. It’s possible we experience pain in a different way to non-fibro patients, but again, that doesn’t mean we’re inventing it.

Instead, say: Nothing. Even if you believe for some reason that your fibromyalgia friend is imagining a problem that isn’t there, say nothing and just support them. The doctor, the consultant, the pain specialist and the many other medical professionals will help to determine the person’s relationship with pain. Your job is to support your friend.

Next page: six more things not to say, including the one comment ALL fibro sufferers are sick of hearing.

5. It Could Be Worse, It Could Be [Insert Other Illness Here]

This is a tough one, because the people saying this are trying to be helpful. The problem is, it isn’t helpful. You’re right, we could have something that you consider to be worse but for many of us, this is our personal hell. There are many other people with many other health problems, but let’s not rank them from good to bad. They’re all bad.

Instead, say: “This must be so difficult to deal with. I can’t believe how well you cope.” A little compliment about our coping strategies will go a long way.

6. We All Get Sore and Tired

Yes, we do. But ‘sore and tired’ isn’t fibromyalgia. This is different. You might be trying to sympathize with us, and we know that you probably need a rest from your aches and pains because, let’s be honest, we all have them. But this is different.

Instead, say: “My back is so sore today. How do you cope with your back pain?” You can be pretty confident that if it exists as pain relief, we’ve probably tried it and we’ll be happy to recommend what works for us.

7. You Just Need to Rest

Rest helps, there’s no denying it. But remove the word ‘just,’ because resting alone won’t cure fibromyalgia.

Instead, say: “Do you need some rest?” We know when we’ve overdone it, and we know when we’ve had more than enough rest. Pain management is a skill and most fibromyalgia patients are pretty good at it, so leave the ball in our court.

8. What's That Thing You Said You Have?

It’s not a hard word. Fibro-my-algia. Suggesting it’s something *we said* we have implies it has no medical backing. We didn’t make up the condition. It exists, and this question can make us feel like you’re not taking us seriously.

Instead, say: “How do spell your condition? I wanted to look into ways to help but I wasn’t sure how to spell it.” This is all kinds of lovely, and very thoughtful of you. Plus, it doesn’t imply you doubt us.

9. I've Seen You [Insert Activity Here] so I Assumed You Were Fine Now

I walked up stairs, I went to work, I went to a party, I went on holiday — I lived. That doesn’t mean I wasn’t living with chronic pain. Some days will be okay, other days will be terrible, but surviving the day doesn’t mean we’ve been cured.

Instead, say: “How are you doing at the moment? You seem to be having a good day but sometimes it’s hard to tell.” Fact. Sometimes it’s hard to tell. Most of us have gotten pretty good at masking our pain, so it’s okay for you to ask us how we’re doing. In fact, we appreciate it more than you know.

10. You Don't Look Sick

What does sick look like? Do you mean that I’m not in a wheelchair therefore I can’t have a physical disability? Do you mean that I do my hair and wear makeup so I can’t be unwell? What do you mean? This is the single most frustrating thing you can say to someone with fibromyalgia.

Instead, say: “It’s awful isn’t it, my friend has [insert invisible illness] and it’s so frustrating that people assume you can see all health problems.” I am 99 percent sure we are not the only person you know with an invisible illness. In fact, most health conditions are invisible, so we need to stop thinking that if you can’t see then it isn’t there.