Learning About Fibro Sensitivity and Pain

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Tactile Allodynia: Fibro Sensitivity to Touch

Fibromyalgia is well-known for causing widespread pain. This comes in the form of joint, muscle and even nerve pain. What some may not realize though, is these different types of pain have different triggers.

Nerve pain specifically is very different from the other types of pain. It is nerve pain that causes sensitivity to touch, which is known as tactile allodynia.

Tactile allodynia is not quite as common as joint and muscle pain, but it can be very difficult to live with for those who do experience it. As with most of the symptoms of fibromyalgia, this sensitivity to touch can vary in severity from person to person. I personally suffer with it, but not as badly as others I have talked to.

For some, myself included, things like being poked or bumping into a table causes pain, much more than it should. However, for others it is so bad that being lightly touched by another person and even the pressure of their own clothing causes extreme pain.

What Causes This Type of Pain?

Imagine you are talking to a friend, someone who you know to be emotionally sensitive. You make a completely innocent comment, but they take it the wrong way and suddenly burst into tears. You stand there trying to figure out what you said or did wrong.

That overly sensitive friend we are referring to is actually your nervous system. Something seemingly innocent happens, such as brushing your arm against the door post as you walk by, and suddenly you are in horrible pain.

You are thinking to yourself, “What did I do?” The problem is your nerve endings completely overreacted and sent signals to your brain that something has gone terribly wrong. What should have registered in your brain as light pressure has instead registered as intense pain.

The word allodynia itself means "other pain." It refers to any pain that results from something that should not normally be painful. The skin feels bruised to touch or sunburned, where even the lightest touch can be very painful — except there is no sunburn or bruise present. And the lack of a visual reminder may cause others to forget about it, or even doubt that the pain is actually real.

What Are Some of the Issues This Causes?

Things others may consider as being playful or affectionate can be painful for us. Some people think there is no harm in a playful slap on the arm, and your response of "ouch!" may be answered with, "That didn't hurt you, stop being dramatic!"

Even things like shaking hands, pats on the back or hugging can cause great pain. This may be difficult for the average person to understand; it may even lead to hurt feelings or resentment. But as with any other aspect of this illness, it is important to remember it is not our fault, and we should not let ourselves feel guilty about it.

Treatment Options

There are a few medicines that specifically help with overactive nerve endings, and may offer relief from the intensity of tactile allodynia. As with any other medication, talk with your doctor and weigh the pros and cons of the medication to decide if that is the right course for you. Pain medications may be helpful when the pain gets to be too much.

There have been some who have benefited from acupuncture, and others experienced relief when they had botulinum (Botox) injections in an area that was a specially affected by nerve pain. But again, these are things that should be discussed with a trained specialist, and should be thought out very carefully.

Talk to Friends and Family

It would also be helpful to have an open and honest discussion with your family and close friends. Explain to them what hurts and why it hurts.

If you only have allodynia pain at certain times, request they inquire before hugging you so you have the opportunity to let them know if it's a good day for you or not. At the very least, ask that they be sure to give very gentle hugs.

Do your best to be kind and considerate in the way you explain these things to them. Ensure they know you understand they do not have bad intentions — this can go a long way in preserving the closeness of the relationship and hopefully avoid any hurt feelings.

When dealing with acquaintances, kindness and graciousness is generally the best course. Different cultures have different customs; if the custom is to shake hands when greeting someone, try offering your left hand, this may throw the other person off enough to where they don't squeeze your hand as much as they normally would. If the custom is to give hugs in greeting, you can stand a distance apart from the person to keep from being squeezed too hard.

Perhaps standing away from others and receiving them with a friendly smile, a wave and a warm greeting might be enough to get you out of these common rituals. If it's not, and even gentle handshakes and hugs are still too painful for you, have something ready to say that conveys to the other person you are unable to be touched, but it is not personal.

Maybe try something like: "I would love to shake your hand, but mine are very sore right now."

I think it is important for those of us with chronic illnesses to accept that there will always be people who do not understand our limitations — and may even blame us for them. This is not a pleasant thought, I know it is something I struggle with.

But the constant reminder that you can in no way control the way fibromyalgia affects you, in addition to the knowledge that you are doing your best to preserve the relationships you have, can certainly help ease the guilt we may at times feel.

I wish there were more suggestions I could offer to help with dealing with the sensitivity to touch many of us experience, but as usual this terrible illness doesn't offer a lot of options. However, by being mindful of our limitations and doing everything we can to work within them, we can hopefully reduce how much tactile allodynia affects our lives.