How and Why to Raise Fibromyalgia Awareness

by ADRIEL MALDONADO

Raising Fibromyalgia Awareness

As many of us are well aware, fibromyalgia is a chronic illness that is not readily understood by doctors, much less the general public. Sadly, unless someone has fibromyalgia, or has a close friend or relative with it, they generally don't know what this illness is.

Fibromyalgia is starting to be recognized for what it is: a chronic disorder that causes widespread musculoskeletal pain, tenderness in key areas and fatigue, among other health problems not limited to nerve-related and gastrointestinal issues. But even those who have heard of it or know someone who has it don’t know how all encompassing it is. They are not aware of how it affects every aspect of our life.

If you have fibromyalgia, you may have encountered many people, even in healthcare settings, who deny that such a condition exists. Some people may believe that it’s all in your head, question whether or not fibromyalgia is real, or think you are seeking attention.

It’s not uncommon to hear others make unkind remarks when they learn someone has fibro. Even those who genuinely mean well may make thoughtless comments.

Unfortunately, even when you know the intention is good, it still hurts.

If you are hoping to break through these barriers, build fibromyalgia awareness, and to show fibromyalgia is a very real disease that is recognized by many health professionals, you should become an advocate for fibromyalgia.

The more that the general population knows about this condition, the more can be done about it. It needs to be taken seriously.

Shying Away

These negative experiences understandably make some shy away from discussing their illness openly.

I myself was hesitant to talk about how I felt for a long time. I kept many of the physical symptoms I had to myself.

But more than that, I kept the way it affected me mentally and emotionally to myself. Comments about how others had it worse, or that I needed more faith, felt like stabs to my heart.

However, as the years went on, I eventually realized I could not expect someone to understand what I was going through if I was unwilling to share my experience. I knew that speaking out would inevitably lead to some heartache, but my desire to help others outweighed my desire to protect myself from hurtful words.

I personally find it easier to express myself in written word. It is also easier for me to share such personal information when I am not face-to-face with someone.

So, I chose to start writing my experience. I started a blog and multiple social media accounts to share what my life really was like.

Opening Up

This has been an enlightening experience. Many of the people in my own life are now better able to understand what I am dealing with, as I am considerably more comfortable sharing in this way.

I have gotten in contact with others who are in the same position that I am. There is very little that can compare to finding someone who knows just what you are feeling and experiencing.

But the best is when others with relatives who have fibromyalgia reach out and say they now better understand what their loved one is dealing with. That is why I am here.

I don't speak out to get attention or pity — I honestly do not want those things. I speak out because I know there is a need to spread awareness.

I know how incredibly scary it can be to feel so open and vulnerable. But if we don't speak out to raise awareness, how can we ever expect those we meet to understand?

How Do You Go About Raising Awareness?

Well that all depends on what you are comfortable with!

You may choose to start by being more verbal about how you feel and how that affects you. Or you may feel more comfortable sharing articles about fibromyalgia with your loved ones or coworkers.

If you do not feel you are able to share with those you know personally, why not start by opening an anonymous social media account? You can always work up the courage there.

There are many ways to raise awareness and you have to find a way that you personally are comfortable with. Just keep in mind that any negative experiences you may have will pale in comparison to the many benefits of raising fibromyalgia awareness!

Next page: How to raise fibromyalgia awareness.

How Do You Go About Raising Awareness?

There are many causes out there vying for the world's attention today, including ALS, which was brought to everyone's attention in 2014 with the popular ice bucket challenge. There may not be a hugely successful marketing campaign for fibromyalgia (yet!), but there are other ways to put the spotlight on this illness.

Some things you go do from home to raise awareness:

- **Host a Facebook page –** Setting up a Facebook page is fairly easy and you can opt to reach people locally or in a wider geographical area. The more likes you get, the more you can spread the word! Post articles about that educate about fibromyalgia. Get on your soapbox and tell everyone about it!
- **Join your local fibromyalgia support group –** If there is a fibromyalgia support group in your area, be sure to join! If there isn't any such group, start one yourself. This is a great way to connect with fellow fibro sufferers and pool ideas for raising awareness.
- **Contact your local representative –** Correspond with your local state representative about fibromyalgia.

You may want to lobby for improved care pathways for fibro and chronic pain. Government officials need to be aware of the pain and other debilitating symptoms that make it difficult for you to work or do normal day-to-day activities. The more personal the message from you, the more powerful it is.

Raising Money

Raising money for the organizations that lobby for fibromyalgia or do research to find treatments is another way to help raise awareness while at the same time benefiting these groups. You can donate to American Fibromyalgia Syndrome Association (AFSA), the National Fibromyalgia & Chronic Pain Association (NFMCPA), or the National Fibromyalgia Association (NFA).

There is a variety of fundraising activities you could do — some simple, others huge undertakings. Think about what you can manage before committing to anything — you don't want to end up in the middle of a flare-up as a result of fundraising for fibromyalgia! You could try:

- Sponsoring for a marathon, sporting event, or a non-swearing day
- Going without chocolate, pizza, TV, video games, texting, talking on the phone
- Sell rubber wristbands for the fibromyalgia cause
- Sell arts and crafts or do a craft show
- Organize a car wash or do odd jobs
- Karaoke evening or trivia night
- Bake sale or raffle
- Fashion show
- Charity dance, dinner or wine tasting
- Kids’ carnival

It is best to have literature like pamphlets people can take with them with your message on it. You can also set up a booth at your events that focuses on your message. You can strategically place images and perhaps a video that discusses fibromyalgia awareness.

Speaking Out

When you act as a self-advocate, you are often addressing personal health issues. Try speaking out to the medical community; you will need to encourage them to listen to your concerns and fight to have the condition recognized as legitimate. Once you’ve got their attention, move on to working towards making the changes in medically directed care for fibromyalgia patients.

Speaking out on your own behalf can be intimidating — no matter how passionate you are about your cause. Being surrounding by professionals whose technical knowledge exceeds your own can be daunting. The more often you speak out, the easier it will become. You will learn to communicate with medical professionals in a way that gets your point across.

Here are some points to remember as you begin your journey of self-advocacy:

Your rights, thoughts and needs are just as important as everyone else’s — you deserve to be treated with respect and dignity. Identify what you would like to see accomplished and what obstacles you face in your healthcare as a result of your fibromyalgia.

Be respectful, even if you find yourself upset. But don’t beat around the bush; speak up and be direct about the problems you are facing.

In discussions, you should be an active listener and always ask questions. Try to see everyone’s point of view and clarify with questions. You may have to reach a compromise and there may be disagreements — remain calm and collected when you respond or react.

Discuss your concerns in a way that does not place blame. Rehearsing your speech will help you to feel more comfortable.

Stand up for yourself and confront people who challenge you and your rights. Be assertive, but not aggressive.

Accept criticism, compliments and feedback. Seek to collaborate and form alliances. Keep an open mind for the problems you face.

Be informed about fibromyalgia and relevant information. You need to do your research.

Keep records and document all meetings, and keep any correspondence pertaining to the meetings.