No One Should Suffer Alone: The Benefits of Joining a Fibromyalgia Support Group

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Fibromyalgia Support Resources: The Importance of Social and Emotional Support

Being diagnosed with any condition can bring mixed feelings. Some people may feel relief that they finally know what they are dealing with but there may also be feelings of apprehension, sadness, and even isolation.

Nowadays we have the internet as a resource but looking up your condition can prove to be a mistake as humans tend to focus on worst case scenarios.

When I was first diagnosed with fibromyalgia I had never heard of the condition, and as soon as I left the doctor's office, I went online to look it up. It didn't help that I was in the middle of a serious flare-up so I worried that my life as I had known it was over.

I was even worried that my newly-diagnosed disability would result in my children being taken away from me, but thankfully a friend who is a police officer assured me that compared to some of the terrible parenting she saw every day I was like Mary Poppins, even with my disability.

The one thing this conversation with my friend showed me was that support is vital, whether it's from friends and family, your medical team, or support groups.

Why Is Support Important?

Dealing with any medical condition alone can be very frightening and lonely. You might be tempted to battle on without making allowances for your condition which can make fibromyalgia flare-ups worse.

It's vital to tell friends, family members, and co-workers about your condition. They may not fully appreciate what you are going through, but they will hopefully be more understanding about any changes to your routine and any limitations that you may experience.

One problem to overcome as soon as possible is any reluctance to admit your need their support. Don't be a martyr. Ask for their help whether it's for practical assistance or emotional support.

Brain fog leaves me reluctant to drive so I have learned to ask others to drive on days I don't feel up to it. I have one friend who is excellent at shopping with me and reminding me what I came out for. I find even lists don't help in the same way that her verbal prompts do.

Speak to your healthcare team about how your condition affects you and ask them what support they might be able to offer. You might be eligible for healthcare home visits on days when you don't feel able to travel. There may be therapies they can offer as well.

My doctor arranged Cognitive Behavior Therapy (CBT) for me but I soon realized they expected me to travel 40 minutes by car to get to the sessions. I asked for further support, and was able to arrange for the sessions to be over the phone instead of in-person.

Finding Support Groups

When I was first diagnosed, I was keen to meet other people with the same condition. Although you might have friends and family who are supportive, they can never understand what you are going through as well as someone else with the same condition.

Even if we all experience and manage fibromyalgia in different ways, the main issues of pain, fatigue, and fog are generally universal and it can be reassuring to talk to others, especially people who have been living with the condition for a while.

Unsurprisingly, given the nature of fibromyalgia I didn't find any specific fibromyalgia support groups near me (in the UK) where people actually gathered to talk or socialize face to face.

However in the US there is this fantastic resource from the National Fibromyalgia and Chronic Pain Association, which lists support groups across the country. You can find it here.

Facebook and Twitter are also good ways of finding online communities and other people with the same condition. Just avoid anyone trying to sell you a cure.

If you still can't find a group, ask your doctor or therapist if they have any resources, or contact your medical insurance company or your local hospital to see if they can recommend any support groups. It might be that even if there isn't anything specifically for fibromyalgia, a group for people with chronic pain or other similar conditions may still prove beneficial.

Fibromyalgia frequently overlaps with other conditions including IBS, Lichen Sclerosis, and arthritis so if you also have these or other health issues, you can find a support group for that and ask if anyone else there also has fibromyalgia.

Luckily there are lots of online support groups, chat rooms, blogs and websites offering advice and support, and a chance to chat without even having to change out of your pajamas.

Find Your Tribe

When support groups are run well, they are an amazing resource for practical, emotional, and financial assistance.

Unfortunately, depression and anxiety are common alongside fibromyalgia. Pay attention to the conversations in your support group, as negative thinking can occur and easily seep through. I joined one group but quickly became disillusioned and depressed as the main theme seemed to be that fibromyalgia was a prison sentence and a diagnosis signaled the end of work, any social life, and meaningful relationships.

A decade later and I have managed to launch and run my own business from home, have had another child and am still happily married. I have a wheelchair which I use occasionally and have days when I need to adapt my plans but on the whole, I live a worthwhile, happy life.

Fibromyalgia affects people of all ages, genders, ethnicity, and backgrounds so it may take some time to find your tribe. If you find you don't "gel" with one support group keep looking until you find another that offers the kind of support you are looking for.