Finding Fellow Fibromyalgia Sufferers

by SARAH BORIEN

Connecting With Other Spoonies

Sometimes it can be very lonely being a fibromyalgia sufferer. Sure, you've got your friends and family around you but no one *really* understands what it's like to have fibromyalgia unless they have it, too.

Today I thought I'd look at ways to connect with other people who share this chronic pain condition.

Social Media

Social media is a great — and easy — way to connect with people with fibromyalgia. As well as following individuals and support groups, you can also follow hashtags. If you know your way around social media then you might want to skip the next couple of paragraphs and jump straight to the recommendations below, but if you need a walk-through of your hashtags and your hyperlinks then read on.

Hashtags are a way of linking conversations on Twitter, and they're starting to be used more and more regularly on Facebook. By using the hashtag symbol (#) you can categorize what you're writing about, which ensures your tweet or status appears when people search for the hashtag.

For example, if I write a blog post and then put the hyperlink on Twitter, I will add the hashtag "#fibromyalgia" which will ensure it appears when people are searching for tweets about fibromyalgia.

If you have a Twitter account, there are a number of relevant hashtags you can search for to find like-minded people who are talking about the same thing you are. Note: don't include any spaces in your hashtag searches, otherwise they won't work.

Common hashtags to search for on Twitter include:

- #Fibromyalgia
- #SpoonieChat
- #SpoonieProblems
- #ChronicPain

These hashtags will take you to conversations the public are having about fibromyalgia, often with links to websites like NewLifeOutlook that can provide you with information or a network of fellow sufferers.

There is a huge number of fibromyalgia-related social media accounts and most people who have a large Facebook following will also have a good Twitter account. It's often a case of having a read and finding a person or group that you feel represents you and your 'voice', but here are some of my favorites to get you started:

Twitter

- Save a Spoon – @Spoonie_Life
- Fibro Facial Gal – @fibrofacialgal
- Juls – @Justagoodlife
- Fibro Babes – @fibrobabes

Facebook

- Beyond Empathy
- Counting My Spoons
- Fibromyalgia Network
- Fibromy-awesome

I am, of course, assuming that you're already following the NewLifeOutlook – Fibromyalgia Facebook page and Twitter account and I (obviously!) recommend my own social media pages for a bit of fibro community spirit; see the A Life Less Physical Facebook page and Twitter account.

Next page: support groups, blogs and forums, and being open and honest.

Be Open and Honest

One of the easiest ways to connect with other people with fibromyalgia is to be open and honest about your condition. Sometimes we get so caught up in the fact that people can't see our pain that we forget to look for the pain of others.

I was talking to someone at work a few weeks ago who had, in passing, mentioned the fact she had "a health condition." She didn't say what it was, but I made an equally blasé reference to my own and then we continued to talk about work. A few days later over lunch, we got back to talking about our health; she mentioned a couple of symptoms and instantly I knew she had fibromyalgia.

We both felt such a relief at being able to talk openly and honestly about our pain — and the impact it had on our work — and our friendship is now very different to the one I have with other work colleagues. We often sneak a few moments to check in on each other and make sure we're coping.

The more you talk to others about your health, the more fellow sufferers you will find.

Support Groups

There is a large collection of fibromyalgia support groups across the globe; the group members meet in person to share their experiences and coping strategies. I've been tempted to attend one of these but never have done, so do leave me a comment if you've attended one and found it useful.

Often the hardest thing about connecting with other fibromyalgia sufferers is making the mistake in thinking that if you share a health condition then you're going to be great friends.

Unfortunately that's not always the case, and even the online comment section of articles like this one show the variety of ways people approach their health. Arguments can start between total strangers when we're debating something as personal as our own vulnerability.

Support groups become challenging because it takes effort and energy to turn up each week and sit with people that aren't as like-minded as you'd hoped. On the flip side, however, if you find a group of strangers that connect with you in the way that you need, then support groups can be a wonderful thing.

Blogs and Forums

Often online fibromyalgia forums are easier for fibro sufferers than physical meet and greets. You can take part from the comfort of your bed and find great virtual friends. Blogging has become insanely popular over the last few years, and there are more and more blogs dedicated to chronic pain.

They're useful to read, as well as to engage with and comment on as a way of finding online support from other sufferers. There's also something really great about reading an article and realizing you're not alone.

Again, there are thousands available but here are a few of my favorites:

- Living Incurably
- Fighting the Fibro
- Spooncast
- Kate the (Almost) Great

And of course, my own blog, A Life Less Physical.

I'd love to hear which blogs you would recommend, and how you connect with fellow sufferers.