

REDBOOK

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You Are Not Alone—Finding a Support Network



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Individuals diagnosed with fibromyalgia face special challenges. Symptoms wax and wane and are often physically invisible to others—sometimes even your family and friends—so unknowingly, they may not always be as empathetic as you'd like nor be able to provide the support you need. And from time to time, your healthcare provider may not be available to answer all your questions. As a result you may sometimes feel isolated or alone. To help you manage these feelings and get the encouragement you need, it's important to develop your personal network of support.

Reaping the benefits

I've been fortunate to observe first-hand the powerful benefits a strong support network can provide to patients, particularly those with chronic conditions such as fibromyalgia. Actually, my first exposure to support groups was as a graduate student when our class examined the dynamics of group counseling. At the time, there was no Internet, so only face-to-face, in-person groups were available. I was so intrigued with the concept that I wrote a term paper addressing the physical and psychological impact of support groups on women with gynecological cancer.

Through this work I learned two quite amazing things: first, research showed women who participated in support groups reported wonderful improvements in their mood and how they felt—*basically, their quality of life improved significantly!* Unfortunately, I also discovered that very few of the women with gynecological cancer had actually joined a support group. Although at the time I didn't have a conclusive answer why this occurred, I did recognize the value that a support group provides its members—a sense of community, compassion and support.

As a psychologist, I've led many support groups over the years for patients with conditions such as multiple sclerosis, infertility, menopausal symptoms, heart conditions, and fibromyalgia. Most participants consistently report a decrease in the frequency and/or intensity of their physical symptoms, and an emotional "lift" to their well-being. Furthermore, they nearly always comment on how much they enjoy this social environment where everyone feels safe sharing their personal experiences: discussing their physical, mental and emotional ups and downs, receiving empathy and support—helping each other through the good days and not-so-good ones—so they don't feel isolated and overwhelmed by their condition. I know my patients believe making these vital social connections is a rewarding experience, even when a group is small in number.

No one really seems to know all the reasons the number of participants is often low. For example, fibromyalgia patients who choose not to participate in a group session may not be feeling well enough to attend or they may worry about how they'll react to other patients whose health status is either better or worse than their own.

Assessing your options

To help you find a support group that fits your needs, consider whether you want to meet with others in person or online. Then, decide if a group led by a healthcare professional or a peer (another fibromyalgia patient specially trained as a group leader) is best for you. Your physician may be your best initial contact to help you find an appropriate support group in your community. Just remember that regardless of the type of support group you select—whether in-person or online—you should examine biases you or someone else may have about a particular type of group before dismissing any options. For instance, you may not regard yourself as a "group person," but think about attending at least one session before ruling out the idea.

Support groups can be an excellent source of information about other local medical resources and experts. And although most groups are very helpful, be aware some can become negative in tone and/or be dominated by one or two individuals. If so, you may want to "visit" several different groups before you select the one that works for you. You'll find too that in a supportive group *you* can have a positive impact on others which helps enhance your own sense of well-being.

Choosing your group

Here are some tips to help you get started with finding a support group that best suits your needs and schedule.

There are several different types of support groups you can join including those led by a healthcare professional or a peer. Personally, I believe a *professionally-led support group* offers many benefits to patients. The group leader generally meets with each member prior to its first meeting. Screening potential members enables the leader to assess who may fit well in the group, as well screen out anyone who may be too hostile or overly narcissistic and could compromise the group's dynamics and productivity. Also having a healthcare professional present at each group session enables members to speak freely and, if any inaccurate information is shared, the leader can gently explain it. This face-to-face live forum gives group members a chance to support one another as they learn effective coping skills.

Peer-led support groups are another option for fibromyalgia patients to consider. These are often led by patients who've previously participated in a group environment and believe in the value this forum brings. Ideally, peer leaders are specially trained to help guide members in productive discussions during each session.

As a patient, you know the Internet is a wonderful resource, available 24/7, for finding vast information about fibromyalgia, including supportive resources. Yet searching for "quality, qualified" *support online* can be tricky sometimes, because some information may be inaccurate. You need to assess the web source and apply common sense in choosing and participating in an online chat or blog. Be sure to look for moderated chat rooms whose content is regularly evaluated for factual accuracy, such as [FibroHugs](#), a site that offers support to patients and their families. Also websites of respected national organizations, such as the [National Fibromyalgia Association](#), the [National Fibromyalgia Partnership](#) and the [Arthritis Foundation](#), offer clinical and practical lifestyle information about the syndrome, as well as guidance to help you locate a support group near you.

And finally, don't overlook your church, synagogue, mosque or other faith-based organization as a resource when you're looking for support. Whether through your faith, family, friends or a combination thereof, seek out the people in your life who understand your needs—physically, emotionally and spiritually—and are willing to provide comfort and support when you need it most.

Give yourself the gift of self-nurturing

As a fibromyalgia patient, you need to take care of yourself *every day*. So be sure to give yourself the gift of "me time" daily. *It's easy*—just select one of these simple exercises, and do it! It's a healthy choice you'll enjoy.

- Every morning when you wake up, spend at least 20 seconds thinking about one *self-nurturing* thing you can do for yourself that day.
- On every to do list you prepare—whether for work or home—add a "to do" just for you! Even better, *alternate things that you have to do with things you want to do*.
- Omit the word "should" from your vocabulary, because it produces feelings of guilt.
- Throughout the day, make a habit of checking in with yourself whenever you look to see what time it is—when you glance at your watch or a nearby clock—think, "*How am I doing? What do I need right now?*" Your needs may range from taking a few, slow deep breaths to a pleasurable walk or giving yourself a mini-neck massage, making yourself a cup of tea or coffee, or eating a piece of fruit.

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