**Potsdam Fibromyalgia Support Group**

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# February, 2014

# What Can Supporters Do?

 Fibromyalgia is a difficult disease for many reasons. It is essentially invisible: you cannot see how much pain a person has, nor can you see what other symptoms they have, such as fatigue, trouble concentrating, irritable bowel, headaches, and the list goes on. The following list includes things supporters can do to help people with having FM.

1. Really listen to people with FM and believe what they say. Because there are no outward signs of FM and the symptoms may vary from day to day, you may find it difficult to believe all their complaints. But the pain is real, and it is important to them that you believe them.

***The challenges and rewards of***

***being a supporter***

***for someone with fibro* –**

February 24th (6:30 pm) meeting topic.

**Bring your supporter(s)!**

1. Learn about FM. This will help you understand and believe their fluctuating symptoms. It also shows them that you care enough about them to learn about their chronic condition.
2. People with FM often grieve for the loss of who they used to be and things they used to do. They might have once been an athlete, an artist, or have worked a high-intensity job. People with FM are sometimes unable to continue activities that were once very important to their self-image and they grieve for that loss. Again, listen and understand what this loss means to them.
3. Find activities you can enjoy together in spite of their illness. This is especially true if you are unable to do things you used to enjoy together. Board and card games may be easier than skiing or dancing. Short, local vacations may be easier than long, cross-country trips. Brainstorm ideas that appeal to both of you.
4. Pain and fatigue can sometimes make people with FM crabby, depressed, frustrated and angry. Understand this and avoid silly arguments, which just amplify stress and pain.
5. Try to stay positive, even though they may be very negative at times. Chronic pain saps both physical and emotional energy, so people with FM are often depressed or anxious. But these negative emotions amplify pain. So, it helps if you can maintain a positive attitude and encourage them to avoid negative thinking.
6. Encourage them to be as active as possible, but understand when they are unable to do things. Research shows that remaining as active as possible (both doing exercise and daily tasks) is important in managing chronic pain. Go for a walk or bike ride together. However, people with FM can’t do everything they used to. Help them find a balance.
7. Recognize when they crash and give them the space they need. They might need to go to bed or take time to care for themselves (such as doing meditation, relaxation, or exercises). Don’t take it personally, as they already feel badly about crashing.
8. Take advantage of the good days and do things you enjoy together. It can be difficult for people with FM to plan in advance because they don’t know whether they will feel well when the time comes. Be spontaneous and do things when they feel well.
9. Communicate openly but kindly. FM may change your lives together and it is important to talk about how this affects you. But realize that the person with FM is already stressed and may feel guilty about what they can’t do, so be gentle and supportive.
10. Realize that intimacy can be difficult for people with FM. See the resource at the end of this article for ideas about how to address this.

# What Do Your Supporters Need?

 It can be difficult supporting someone who has a chronic illness. That challenge can be compounded if the supporter feels guilty for being frustrated, overwhelmed or angry. You, the person, with FM, need to help your supporters take care of themselves. The following is advice for your supporters:

1. If you put a lot of time into doing things for your partner with FM, make sure you take time to do things for yourself, to maintain both your physical and emotional well-being.
2. Don’t give up all your hobbies and interests. If there were activities you used to do together, either continue to do them on your own or find alternate activities. People with FM don’t want loved ones to give up enjoying themselves.
3. Avoid becoming isolated yourself. Don’t eliminate all your social activities because your loved one can no longer participate. Don’t feel guilty about having your own friends.
4. Have a support system, someone to talk with about the challenges of supporting someone with FM. While it can be helpful to vent, try not to get overly negative. If there are serious problems in the relationship, discuss those problems directly your partner/friend/relative.
5. Find ways for the person with FM to communicate how they feel without feeling like they are constantly complaining. Create your own (preferably humorous) scale or dial, such as the one shown on this page.
6. You may need to grieve your losses, just as the person with FM may also grieve. Your partner is not the same person he/she used to be, and your lives are not the same as they used to be or might not be what you had planned for the future. One patient is quoted as saying “ I lost my health, but my husband lost the woman he married.”
7. Create new shared interests rather than bemoaning past interests that are no longer practical. Consider this an opportunity to do new things together.
8. People with FM need to realize that their supporting partner may sometimes feel frustrated, exhausted, depressed, confused or angry. People with FM should not take this personally – it is the FM that is frustrating, confusing, etc. People with FM should encourage their supporters to take care of themselves, using the suggestions above.
9. Find ways to keep intimacy in your relationship. Use the resource at the end of this article to start a conversation about ways intimacy can be a good experience for both of you.

**Useful resources:**

# Living With Someone Who Has Fibromyalgia or Chronic Fatigue Syndrome: Bridging the Gap Between Your Old Life & Your New One. By [Adrienne Dellwo](http://chronicfatigue.about.com/bio/Adrienne-Dellwo-30128.htm) at: <http://chronicfatigue.about.com/od/forfriendsfamily/a/lifeafterfmscfs.htm>

## Ten Tips For Communicating With A Person Suffering From Chronic Pain. <http://overcomingpain.com/ten-tips-for-communicating-with-a-person-suffering-from-chronic-pain/>

* Tips for the Caregiver of Someone with Fibromyalgia. By [Bruce Campbell](http://www.cfidsselfhelp.org/about-us/bruce-campbell-bio), available at: <http://www.cfidsselfhelp.org/library/tips-caregiver-0>
* Maintaining Intimacy Despite Fibromyalgia. *by* [*Sherron M. Stonecypher,*](http://legacy.lclark.edu/~sherrons/author.htm)<http://legacy.lclark.edu/~sherrons/intimacy.htm>

# February Support Group Meeting:

The February topic will be **“The challenges and rewards of supporting someone with chronic pain.”** *We hope to have many spouse, family or friends who are supporters come to this session. Invite your supporter(s) now!* This meeting will be **Monday, February 24th, at 6:30 pm to** allow more supporters to attend.

# Special Guest Lecture in April:

Save the date: Monday April 28th, 6:30 pm. **Paula M. Youmell, RN, MS, CHHC, Certified Holistic Health Counselor, will talk about some aspect of nutrition and pain or fibromyalgia. See her website for more info about her expertise:** [**http://wholefoodhealer.com/**](http://wholefoodhealer.com/)

This newsletter is a joint effort of Clarkson University and Canton-Potsdam Hospital. If you would prefer to receive these newsletters electronically, please send your email address to lnrussek@clarkson.edu. You can access current and previous Potsdam Fibromyalgia Support Group Newsletters on our web site: [www.people.clarkson.edu/~lnrussek/FMSG](http://www.clarkson.edu/~lnrussek/FMSG).