



Fibromyalgia:

The Information
and the Care You Deserve

TIPS FOR PATIENTS
AND CAREGIVERS



American Chronic Pain Association



American Pain Foundation



National
Pain
Foundation

Tips for Patients: Getting the Treatment You Deserve

Fibromyalgia affects more than 6 million people in the United States.¹ People with fibromyalgia have chronic widespread pain. They may feel tenderness throughout their body. Flu-like aching may occur. Fatigue and sleep issues also are common.¹ If you have these symptoms, you may have fibromyalgia. It's important that you seek help. The following are some tips to help you do this. There is hope to improve your quality of life and reduce pain when you take an active role in your treatment.

Telling Your Story

No one can feel your pain. Only you can know it completely. It's crucial that you speak up. **Tell your story** and **ask questions** when you visit your healthcare provider. Your healthcare provider needs to listen closely to your concerns. Be prepared so you can make the most of your meeting with your healthcare provider – you will likely have limited time. Write down your thoughts before you go. Take the time to explain how you feel. Place special attention to describing:

- **Pain:** The more you share about the pain you feel, the better. Sometimes it's hard to find the right words to say exactly how you hurt. Below are a few ways to describe the pain of fibromyalgia. Be sure to describe **WHERE** you feel pain.

- Tender
- Stiff
- Dull
- Deep pain
- Achy
- Bruised
- Flu-like symptoms

- **Impact on life:** Pain often affects the way you live every day. Talk with your healthcare provider about how you spend each day. Does the pain keep you from doing any of the things you usually do? Be detailed. It may help to write this information down. Then, you can be sure you don't leave anything out. Take a look at the ACPA Pain Log on the web site listed below. It can help you track your pain, daily activities and well-being. Filling out the log each day will help you describe your pain. It will also help you identify pain triggers. Share it with your healthcare provider at your next visit. It will help him or her get you the help you need. Try to focus on a few questions each day, such as:

- Are you fatigued?
- Does the pain affect your sleep?
How many hours of sleep are you regularly getting?
- Do you have a normal appetite?
- Are you active?
- What is your daily routine?

<http://www.theacpa.org/documents/8%20x11%20Pain%20Log%202-8-06.pdf>



Tips for Patients: Getting the Treatment You Deserve

Telling Your Story

- **Typical daily activities:** Talk to your healthcare provider about tasks you can or can't do. Use the function scale below to determine your level of function. You can take it with you to your next visit:



Adapted from ECOG Performance Status: Oken MM et al. *Am J of Clin Onc* 5(6):649-655, 1982; as part of the American Pain Foundation TARGET Chronic Pain Provider Resource Card.

Tips for Caregivers: Helping Loved Ones Get the Care They Deserve

Friends and family members are vital to people with fibromyalgia. They serve as a support system. It is important that they learn about the condition. No two people feel fibromyalgia in the same way. No two people need the same kind of support. But there are tips that may help you understand and help your loved one:

Ask ... and Listen

- **Take the time to understand:** People with fibromyalgia may not be able to say how the condition makes them feel. Some hurt all over. Others say it's like having the flu that never goes away. Others feel fine one day and bad the next. You won't know if you don't ask. Just because you cannot see their pain, it doesn't mean they are not experiencing it.
- **Don't do it all:** You may want to take care of everything for your loved one. But this may make some people feel helpless. Help when needed. Work to build independence. Check in with your loved one often. Your help may be needed. Or, you may need to give him or her some space. If your loved one does want more independence, don't feel bad. Remember, the goal is for him or her to feel better.



Tips for Caregivers: Helping Loved Ones Get the Care They Deserve

Be an Advocate

- **Attend healthcare providers' appointments:** Join your loved one at office visits and help them organize their thoughts prior to the visit. It can be helpful for them to have an advocate there. You are a part of what your loved one is going through. This means your presence can help back up the information he or she shares. Don't be afraid to speak up – ask questions and make sure the healthcare provider and your loved one are being clear with one another.

Get Educated

- **Read up on fibromyalgia:** More and more groups are focusing on fibromyalgia. They have resources on their Web sites. You can go there to get helpful information. Visit the below Web sites or call to get more details.

– American Chronic Pain Association:

www.theacpa.org,
1-800-533-3231

– American Pain Foundation:

www.painfoundation.org,
1-888-615-PAIN (7246)

– National Pain Foundation:

www.nationalpainfoundation.org,
1-866-590-PAIN (7246)

Please visit our Web sites or call us for more information.

Take Care of Yourself

- **Make sure your needs are met:** Helping your loved one deal with his or her pain can be hard. Don't ignore your own needs. Carve out time for yourself. This will help reduce the stress you may be feeling. Take time to do the activities you enjoy. Share your frustrations with your loved one. You're both in this together! The better you feel, the better you'll be at helping your loved one.

Fibromyalgia can change the lives of an entire family. Remember, your needs are important, too. We hope these tips will help you and your loved one. Together, you can manage fibromyalgia well!



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References

1. Wolfe, F. et al. Prevalence and Characteristics of Fibromyalgia in the General Population. *Arthritis Rheum.* 1995;38:19-28.