



# *Fibromyalgia:*

The Information  
and the Care You Deserve

PATIENT HANDBOOK



*American Chronic Pain Association*



*American Pain Foundation*



**National  
Pain  
Foundation**

## Fibromyalgia: You Need the Facts

Fibromyalgia (fī'brō-mī-āl'jē-ə) affects more than 6 million people in the United States. Most of them are women, but it does occur in men as well.<sup>1</sup>

People with fibromyalgia may experience the following symptoms:<sup>2</sup>

- Chronic, widespread pain all over the body
- Tenderness, soreness and flu-like aches
- Fatigue
- Problems sleeping
- Headaches
- Morning stiffness
- Memory and concentration difficulties
- Difficulty performing daily functions

Many people live with pain for years before fibromyalgia is found as the cause. Now, more healthcare providers are aware of the condition. This means that it can be addressed sooner. And there is a growing list of treatments that may help.

Little is known about the cause of this type of pain, but the central nervous system may play a role.<sup>3</sup> There is no cure for fibromyalgia but there are treatments that can help. Many people have found ways to have a good quality of life in spite of fibromyalgia.

## You Need a Proper Diagnosis

There are no blood tests or X-rays that can detect fibromyalgia. This makes the condition hard to diagnose.<sup>4</sup> But guidelines from the American College of Rheumatology can help you and your healthcare provider figure out if you have the condition:

- History of widespread pain that has lasted at least three months
- Pain in at least 11 of the 18 “tender points” of the body, which are clustered around the neck, elbow, knees and hips<sup>2</sup>

Do you have these symptoms? If you do, your healthcare provider should be able to help you find the causes. Your healthcare provider should know the basics about fibromyalgia. But if he or she does not, you may need to speak to a specialist. Fibromyalgia is often treated by rheumatologists, pain specialists or neurologists. These specialists may help you get a diagnosis. They may also provide you with the appropriate management plan.

People of all ages may have this kind of pain, but it is most common in those between 20 and 50.<sup>5</sup> Some people may have both fibromyalgia and other chronic conditions, such as lupus, rheumatoid arthritis<sup>4</sup> or hypertension.<sup>6</sup> Treating the pain of fibromyalgia can impact the management of other disorders.<sup>7</sup> And treating associated conditions can affect the pain of fibromyalgia. It's important that you and your medical team identify and treat all of your chronic conditions.



## You Deserve to Feel Better

There are a number of ways you can help control your pain and live better. Not all methods may work for you. **Using more than one approach may work best.**<sup>8</sup> It's vital for you to take an *active* role in your care. Taking an *active* role helps you best manage your condition. Among the steps you can take are:

**Exercise:** Staying active is key to maintaining health. This may be tough at first. Try taking small steps. Build up to a program that you can do. Walk, bike or swim to help feel better. These activities don't have to be hard. Any movement will help. Becoming more flexible and maintaining flexibility may help reduce pain. You may want to work with a physical therapist. He or she can design a plan that will work for you. Check with your healthcare provider at the start of any exercise program.<sup>4</sup>

**Sleep:** Getting a good night's sleep is one of the best things you can do. Go to bed and wake up at the same time. Taking naps during the day may interfere with your ability to sleep a full eight hours at night. If you are having difficulty sleeping at night, try not taking naps during the day. Try to get at least eight hours of sleep. Your healthcare provider can give you other sleep tips. He or she may also talk to you about medications that may help.<sup>4</sup>

**Nutrition:** Eating well is central to good health. Drinking lots of fluids also helps. Having a balanced diet means eating plenty of fruits, vegetables and healthy proteins. Don't skip breakfast or other meals. Try to avoid snacks with lots of sugar. Instead, eat healthy snacks such as raw fruits, vegetables and high-protein snacks.<sup>9</sup>

**Stress-relief techniques and complementary medicine:** Research shows meditation can help. It's also a known stress-reliever. Massage may help as well. It boosts circulation and stimulates nerves. Tai chi, acupuncture and chiropractic treatment also may help relieve symptoms.<sup>7</sup>

**Medication:** In some cases, your healthcare provider may suggest medication to treat the pain. Medication may also help relieve other symptoms. Medication is one of the tools to help you better manage your symptoms of fibromyalgia. Talk to your healthcare provider about the best plan for you.



# You Want the Truth

**Myth:** Fibromyalgia is not real

**Reality:** Fibromyalgia is recognized as a medical condition by well-known, expert groups: the National Institutes of Health, American Medical Association, American College of Rheumatology, Food and Drug Administration, Social Security Administration and all major insurers. The American Pain Society (APS) has developed guidelines to help healthcare providers treat the condition.<sup>10</sup> You or your healthcare provider may order these from the APS Web site ([www.ampainsoc.org](http://www.ampainsoc.org)). The cause of the condition is not known, but it can be diagnosed and treated.

**Myth:** Fibromyalgia is caused by depression

**Reality:** Fibromyalgia is not caused by depression. But fibromyalgia patients sometimes feel depressed. Talk to your healthcare provider about treatments that may help you.

**Myth:** Fibromyalgia is a new and rare condition

**Reality:** Fibromyalgia has been recognized by healthcare providers for a long time. Physicians wrote about “muscular rheumatism,” a condition involving fatigue, stiffness, aches, pains and sleep disturbances back in the 1800s. The current term was coined in 1976.<sup>11</sup> The American College of Rheumatology set out its diagnostic criteria in 1990. Fibromyalgia is one of this country’s most common types of chronic widespread pain.

**Myth:** Fibromyalgia affects only women and older adults

**Reality:** Fibromyalgia strikes both sexes and people of all ages.<sup>10</sup> The condition occurs in about one in 30 women. It strikes one in 200 men. The risk of developing fibromyalgia increases the older one gets.

**Myth:** Fibromyalgia is deadly

**Reality:** Fibromyalgia is not life-threatening. But fibromyalgia can have an impact on daily life. With proper treatment, people with fibromyalgia can see symptoms improve.<sup>12</sup>

**Myth:** It is not possible to have a good quality of life with fibromyalgia

**Reality:** People with fibromyalgia can live full, happy lives. There are tips they can follow to feel better. There are treatments available to help manage the symptoms of fibromyalgia. The future is bright!



## You Need a Healthcare Advocate

No one can feel your pain or understand it completely. Still, your healthcare provider plays a key role in your health. To work with your healthcare provider, you need to ask questions. This helps you get the facts you need. Below are a few sample questions that may help you get started:

- **What is your experience and success in treating fibromyalgia and widespread pain?** Remember, you do have choices. You can work with your healthcare provider to get help. You may require a second opinion. Or you may want to see a specialist. If your healthcare provider wants to learn more, you can also bring in resources you have found. This can help your healthcare provider learn about your kind of pain. There is information at the end of this brochure. It lists groups that have educational materials on fibromyalgia.
- **How do I know if I have fibromyalgia?** The American College of Rheumatology (ACR) has established diagnostic criteria for fibromyalgia. Your healthcare provider may also know about other sources of pain. If your healthcare provider does not know about fibromyalgia, you may want to ask him or her to refer you to a specialist.
- **Do you typically treat patients with fibromyalgia? Should I see a specialist?** Fibromyalgia is often treated by rheumatologists, pain specialists or neurologists. These doctors are specially trained to treat pain. It is OK to ask your regular healthcare provider if a specialist is needed.
  - **Are there activities I can do to lessen the pain or medications I can take to treat my pain?** This handbook offers some places to start. Your healthcare provider should be able to give you advice. This advice may include ways to tackle your pain and other symptoms.



The more information your healthcare provider has, the better. Bring information you've found and discuss it with your healthcare provider. Be specific about the pain you feel. Say where and when it occurs. Tell your healthcare provider whether it is sharp or dull. Mention whether the pain is there all the time or comes and goes. And don't forget to talk about other factors such as your energy level, your sleep habits and your daily activities. All of this helps your healthcare provider understand you better. This aids him or her to help you to feel better.

## You Need a Support Network

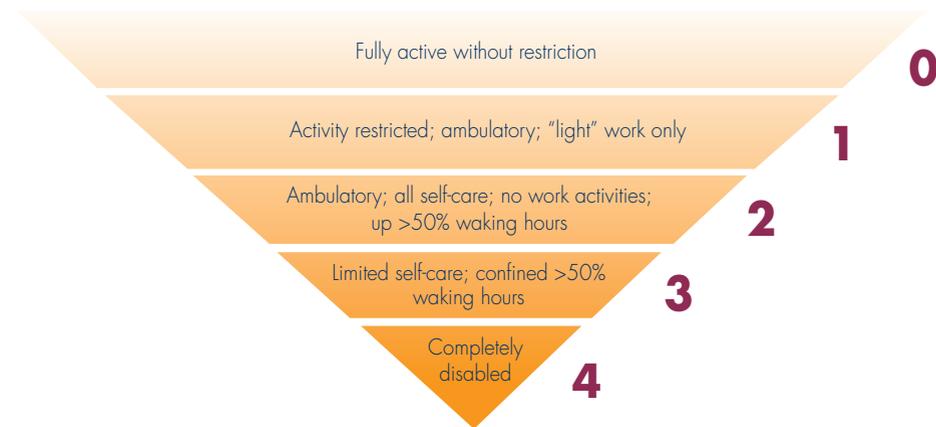
It can be hard to talk about fibromyalgia with family members and friends. But being open with loved ones can give you a vital support network. Your family members and friends gain, too. They get the facts they need to understand your condition and your plan to feel better:

- **Share what you know:** Bring a family member or friend to your healthcare provider visits. Let him or her learn about fibromyalgia with you.
- **Share what you're going through:** Living with pain is very difficult. Being open and honest about how you feel is important. Honesty helps those close to you understand your pain and your needs.
- **Enlist help:** Don't be afraid to ask for help and support. Family members and others close to you can provide encouragement. They can encourage and support your efforts to be active. They can be partners in your progress.
- **Feed on optimism:** There is a great deal of hope. Friends and family members can serve as a reminder of the good side of life. They can hold your hand through the rough days.

# You Need Tools

Every person with fibromyalgia has his or her own plan to cope with the condition. Here are some steps you can take to help you live better:

- **Start small:** The changes your healthcare provider suggests may seem like a tall order. If you plan well, though, you can make them work in your life. Building new habits should be done in small steps. Set and meet realistic goals. Keep a record of your progress. Some helpful tools to keep track of your progress are the accompanying ACPA Pain Log and the below ECOG (Eastern Cooperative Oncology Group) function scale. Start small and you'll soon be amazed at how far you've come.



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.

- **Peer support:** You are not alone. People with fibromyalgia are part of a community of more than 6 million Americans. A number of resources are available to bring people with fibromyalgia together. This includes online and local support groups. There is power in numbers. Visit the Web sites on the back cover of this handbook to learn more. They will help you benefit from the support of others who know what you're going through. Sometimes, just talking to someone who understands can make all the difference.

- **Stress management:** Stress may increase pain.<sup>7</sup> Everyone handles stress in his or her own way. You need to learn how to lower your stress level. Can you spot the stresses in your life? Knowing the causes of stress that affect you can help you better manage your pain. That can mean an improved quality of life, too. Focus on the elements of life that you *can* control. Learn to let go of the things you can't control. For example, if work is stressful, take a 15-minute break to relax. Your children or household work may be hard to handle at times. Ask a family member, friend or neighbor to help. Or leave the chores for another day when you're feeling up to it. Practice relaxation techniques that can help calm you when your sources of stress are beyond your control.

## Most Importantly, You Deserve Hope!

The understanding of fibromyalgia among the public, scientists and healthcare providers is getting better each day. More and more research is being conducted. New treatments are in development. The future is bright!

Careful attention, a proper diagnosis, a good medical team (including you), self-advocacy skills and education, a thorough treatment plan with necessary lifestyle adjustments and a positive attitude together can lead the way in improving your pain and how you live each day.



# Resources

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

- American Chronic Pain Association: [www.theacpa.org](http://www.theacpa.org), 1-800-533-3231
- American Pain Foundation: [www.painfoundation.org](http://www.painfoundation.org), 1-888-615-PAIN (7246)
- National Pain Foundation: [www.nationalpainfoundation.org](http://www.nationalpainfoundation.org), 1-866-590-PAIN (7246)

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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.
2. Wolfe, F. et al. The American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia: Report of the Multicenter Criteria Committee. *Arthritis and Rheumatism.* 1990; 33:160-172.
3. Crofford, L. Afterward: The Relationship with Fibromyalgia to Neuropathic Pain Syndromes. *Journal of Rheum.* 2005; 32: 41-45.
4. American College of Rheumatology. Fibromyalgia. Available at: [http://www.rheumatology.org/public/factsheets/fibromya\\_new.asp?#3](http://www.rheumatology.org/public/factsheets/fibromya_new.asp?#3). Accessed January 29, 2008.
5. National Pain Foundation. Fibromyalgia Fast Facts. Available at: [http://www.nationalpainfoundation.org/MyTreatment/articles/Fibromyalgia\\_FastFacts.asp](http://www.nationalpainfoundation.org/MyTreatment/articles/Fibromyalgia_FastFacts.asp). Accessed January 29, 2008.
6. Bruehl S, Chung OY, Jirjis JN, Biridepalli S. Prevalence of clinical hypertension in patients with chronic pain compared to nonpain general medical patients. *Clin J Pain.* 2005; 21(2):147-53.
7. Millea, P. MD, MS and Holloway, R. PhD. Treating Fibromyalgia. *American Family Physician.* 2000;Vol 62: No.7.
8. Bennet, R. Fibromyalgia. *Textbook of Pain.* 1999; 4th edition:579-601.
9. National Pain Foundation. Self-Management Strategies. Available at: [http://www.nationalpainfoundation.org/MyTreatment/articles/Fibromyalgia\\_Special.asp](http://www.nationalpainfoundation.org/MyTreatment/articles/Fibromyalgia_Special.asp). Accessed January 29, 2008.
10. American Pain Society. Guideline for the Management of Fibromyalgia Syndrome Pain in Adults and Children: APS Clinical Practice Guidelines. 2005. Series, No. 4.
11. Inanici F, Yunus MB. History of fibromyalgia: past to present. *Curr Pain Headache Rep.* 2004;8:369-78.
12. National Institute of Arthritis and Musculoskeletal and Skin Diseases. Fibromyalgia: Questions and Answers About Fibromyalgia. Available at: [http://www.niams.nih.gov/Health\\_Info/Fibromyalgia/default.asp](http://www.niams.nih.gov/Health_Info/Fibromyalgia/default.asp). Accessed January 29, 2008.