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Diagnosing Fibromyalgia: What You Need to Know

What is fibromyalgia?

Fibromyalgia (say: fi-bro-my-al-gee-uh) is a syndrome (a set of symptoms) that causes pain on both sides of your body, and above and below your waist. Areas called “tender points” may be especially painful when pressure is put on them. Common tender points are the back of the head, the elbows, the shoulders, the knees, the hip joints and around the neck.

Fibromyalgia affects about 6 million people in the United States. It is most common among people between 35 and 60 years of age. Women are more likely than men to have fibromyalgia. This syndrome might be hereditary (which means it runs in families). You may have family members with similar symptoms.

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What are the symptoms of fibromyalgia?

Symptoms of fibromyalgia can include the following:

- Increased sensitivity to pain
- A deep ache or a burning pain that gets worse because of activity, stress, weather changes or other factors
- Muscle stiffness or spasms
- Pain that moves around your body
- Feelings of numbness or tingling in your hands, arms or legs
- Feeling very tired or fatigued (out of energy), even when you get enough sleep
- Trouble sleeping

People who have fibromyalgia often also have one or more of the following:

- [Anxiety](#)
- [Depression](#)
- [Irritable bowel syndrome](#)
- [Restless legs syndrome](#)
- Increased sensitivity to odors, bright lights, loud noises or medicines
- Headaches, migraines or jaw pain
- Dry eyes or mouth
- Dizziness and problems with balance
- Problems with memory or concentration (sometimes called the “fibro fog”)
- For women, painful menstrual periods

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Fibromyalgia is real

Fibromyalgia is a condition that is often misunderstood. But your symptoms aren't "all in your head." Scientific research has shown that fibromyalgia is a real syndrome that causes real pain. Don't let anyone discourage you from getting a diagnosis and treatment for your symptoms.

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How will my doctor diagnosis fibromyalgia?

At your appointment, your doctor will ask about your personal and family medical histories. Be sure to tell your doctor whether any members of your immediate family have ever had similar symptoms or have been diagnosed with fibromyalgia. Your doctor will also need to know what medicines, vitamins or supplements you are taking.

He or she will ask about your symptoms and how long you have had them. It's very important to give your doctor a clear, detailed description of your symptoms. Before going to your appointment, write down a complete list of the problems you've been having. Be sure to describe exactly what type of pain you have (for example, whether the pain is dull or sharp) and where you have been feeling pain. Tell your doctor whether your pain comes and goes, and what makes you feel better or worse.

If you have had any trouble sleeping or fatigue, tell your doctor how long you have had this problem. Your doctor may ask whether you have been feeling anxious or depressed since your symptoms began.

Your doctor will also perform a physical exam. This may include applying pressure to the tender points on your body. Your doctor may run tests (for example, blood tests) to be sure you don't have one of the other conditions that have symptoms similar to fibromyalgia. Your doctor will also want to be sure that there isn't anything else causing your pain.

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Is it hard to diagnose fibromyalgia?

Unfortunately, it can take years for some people who have fibromyalgia to get a correct diagnosis. This can happen for many reasons. The main symptoms of fibromyalgia are pain and fatigue. These are also common symptoms of many other health problems, such as chronic fatigue syndrome, hypothyroidism and arthritis. Currently, there is no laboratory test or X-ray that can diagnose fibromyalgia.

It may take some time for your doctor to understand all of your symptoms and rule out other health problems so he or she can make an accurate diagnosis. As part of this process, your family doctor may consult with a rheumatologist (a doctor who specializes in pain in the joints and soft tissue).

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Managing Fibromyalgia: Tips to Help You Feel Better

What is fibromyalgia?

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Fibromyalgia affects about 6 million people in the United States. It is most common among people between 35 and 60 years of age. Women are more likely than men to have fibromyalgia. This syndrome might be hereditary (which means it runs in families). You may have family members with similar symptoms.

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I’ve been diagnosed with fibromyalgia. What should I do now?

Fibromyalgia is a chronic condition. This means that it affects you over a long period of time – possibly your entire life. There will be times when your fibromyalgia may “flare up” and your symptoms will be worse. Other times you will feel much better. The good news is that your symptoms can be managed.

It’s important to have a health care team that understands fibromyalgia and has experience treating it. Your team will probably include your family doctor, a rheumatologist (a doctor who specializes in pain in the joints and soft tissue) and a physical therapist. Other health care professionals may help you manage other symptoms, such as mood or sleep problems. However, the most important member of your health care team is you. The more active you are in your care, the better you will feel.

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How do I take an active role in my health care?

There isn’t currently a cure for fibromyalgia. Your care will focus on helping you minimize the impact of fibromyalgia on your life and treating your symptoms. Your doctor can [prescribe medicine](#) to help with your pain, but there are other things you will need to do to ease your symptoms. This is called “self-management.”

An Important Note about Your Care

You will need to follow your doctor’s recommendations carefully. Making changes in your lifestyle and daily habits can help you feel better. Remember, your treatment won’t be as effective if you don’t take an active role in your health care.

Self-management means that you take responsibility for doing what it takes to manage fibromyalgia effectively. It's important for you to be responsible for your health. The treatment recommendations your doctor makes won't do any good unless you follow them. He or she can't make decisions for you or make you change your behavior. Only you can do these things.

In self-management, you and your health care team are partners in care. Your health care team can provide valuable advice and information to help you deal with fibromyalgia. However, there isn't one treatment plan that works best for every person who has fibromyalgia. You'll have to work with your care team to create a plan that's right for you. After all, nobody knows more than you do about your feelings, your actions and how your fibromyalgia symptoms affect you.

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How can self-management help?

The following are some ways you can take an active role in managing your fibromyalgia symptoms:

Maintain a healthy outlook

Work with your health care team to choose realistic, short-term goals to manage your symptoms. Focus on what you can do today to feel better. Tell your doctor if you have been feeling depressed or anxious. These feelings are common among people who live with the pain and frustration of fibromyalgia. Your doctor may suggest cognitive behavioral therapy, which helps you replace negative thoughts with positive thoughts.

Find support

Don't be afraid to ask for the help you need to deal with fibromyalgia. Support can come from your health care team, as well as friends and family members. For example, you could ask a friend to be your exercise buddy. There are also support groups specifically for people who have fibromyalgia.

Take medicines exactly as prescribed

Your doctor may prescribe medicines to reduce your pain, improve your mood and help you sleep better. Ask your doctor or pharmacist about each medicine and why you're taking it. Be sure to take all medicines according to your doctor's instructions.

Exercise

One of the best things you can do if you have fibromyalgia is engage in moderate [exercise](#) on a regular basis. Exercise can reduce your pain, give you more energy, reduce stress and help you sleep better. If you're not used to exercising, be sure to talk to your doctor before you start. If you have a physical therapist on your health care team, he or she can help you develop an exercise routine that's right for you. It's usually best to start with low-impact aerobic exercise (for example, walking or water aerobics) for a short period of time a few days a week. As your pain decreases and your energy increases, you can gradually increase the intensity and frequency of your exercise.

Recognize stress and take steps to reduce it

Because stress makes the symptoms of fibromyalgia worse, it's important to recognize when you're feeling stressed. [Signs of stress](#) may include a feeling of tension in your shoulders or neck, an upset stomach or a headache. Unfortunately, there isn't a way to completely get rid of stress in your life. However, you can focus on [changing the way you react to stress](#). For example, you might set aside time each day to [practice deep-breathing techniques or meditation](#).

Establish healthy sleep habits

Lack of sleep can make your fibromyalgia symptoms worse. And increased pain makes it hard to get restful sleep. To avoid getting caught in this cycle, try to [have healthy sleeping habits](#). Avoid caffeine and alcohol before bedtime, go to bed and wake up at the same time each day (including weekends), and limit naps during the day.

Get into a routine

Many people who have fibromyalgia do better when their schedule follows a routine pattern. This usually means that each day they have meals at the same times, go to bed and get up at the same times, and exercise at the same time. Try to keep your weekend and holiday schedules as similar to your weekday schedule as possible.

Make healthy lifestyle choices

By making healthy choices, you'll have more energy, you'll feel better and you'll lower your risk for other health problems. Eat a healthy, balanced diet. Limit the amount of alcohol you drink. If you use tobacco products, stop. Lose weight if you are overweight.

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Fibromyalgia: Overcoming Persistent Barriers to Patient-Centered Care

Collaborators and community resources are vital parts to providing patient-centered fibromyalgia care. Below are some resources to consider in your practice.

Collaborators in Fibromyalgia Management

Healthcare team members should develop an understanding of the experience of the fibromyalgia patient and how to best work with these patients.

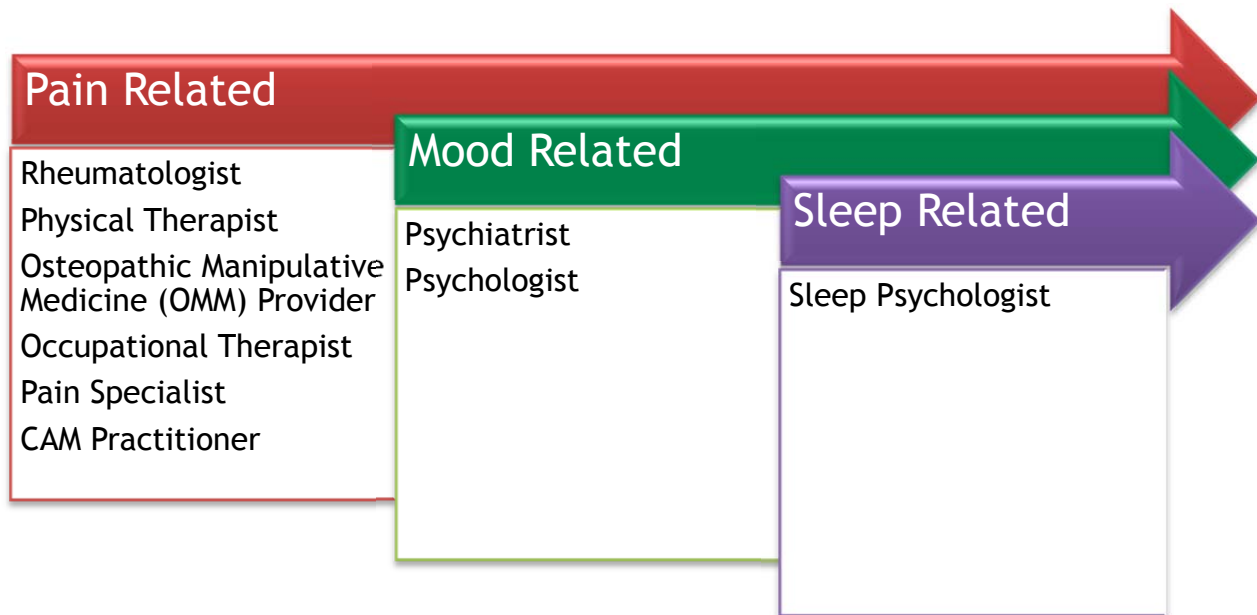
Obtaining tools to support the assessment and management of fibromyalgia patients can not only support improved patient care, but can also serve to increase confidence and empowerment of clinic practice staff, providing support and guidance in working with their patients.

Building a multi-disciplinary network of professionals to support care can be invaluable in expanding the repertoire of skills, knowledge, and expertise available to the primary care practice in caring for fibromyalgia patients.

REFERENCES

Arnold LM, Bradley LA, Clauw DJ, Glass JM, Goldenberg DL. Multidisciplinary care and stepwise treatment for fibromyalgia. *J Clin Psychiatry*. 2009;69(12):e35.

Goldenberg DL. Using multidisciplinary care to treat fibromyalgia. *J Clin Psychiatry*. 2009;70(5):e13.



Note: These are provided for informational purposes only and each clinician is encouraged to investigate local resources and use their best clinical judgment when making recommendations to patients. Endorsement of organizations, techniques or products is not made nor implied.

Community Resources

In many communities, resources already exist to serve patients with fibromyalgia and supplement the medical treatment with education, support and self-improvement. It may be helpful to develop a list of resources in your community that you can provide to patients when fibromyalgia is diagnosed. Some suggested resources include:

- Pharmacists
- Exercise options (YMCA, fitness clubs, parks)
- CAM resources (specialists and health food stores)
- Family members or other loved ones
- Online support groups
- Weight loss programs (e.g. Weight Watchers, Nutisystem, Jenny Craig)
- Addiction programs

As mentioned in the presentation, a number of Internet resources already exist for patients, including:

- www.FamilyDoctor.org
(American Academy of Family Physicians)
- www.Arthritis.org
(Arthritis Foundation)
- www.FMNetNews.com
(Fibromyalgia Network)
- www.FibromyalgiaSupport.com
(ProHealth)

A Community Support Group Locator: <http://www.fmaware.org>

Participation in support groups can provide an opportunity to reach out to others who have had similar challenges and foster an improved understanding of lifestyle management.

Patient Education

Is Fibro the Cause? Published by the American Pain Society, this valuable toolkit is loaded with helpful tips, resources and vital information on how to recognize fibromyalgia's signs and symptoms as well as guidance on seeking treatment. In this well-researched, easy-to-follow toolkit you will find a worksheet to help track symptoms, nutrition tips to overcome fatigue, ideas for alleviating stress, and essential strategies on coping and living well. Download free at: <http://www.painfoundation.org/learn/publications/files/is-fibro-the-cause.pdf>

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Fibromyalgia Criteria and Severity Scales for Clinical and Epidemiological Studies: A Modification of the ACR Preliminary Diagnostic Criteria for Fibromyalgia

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Abstract

Objective. To develop a fibromyalgia (FM) survey questionnaire for epidemiologic and clinical studies using a modification of the 2010 American College of Rheumatology Preliminary Diagnostic Criteria for Fibromyalgia (ACR 2010). We also created a new FM symptom scale to further characterize FM severity.

Methods. The ACR 2010 consists of 2 scales, the Widespread Pain Index (WPI) and the Symptom Severity (SS) scale. We modified these ACR 2010 criteria by eliminating the physician's estimate of the extent of somatic symptoms and substituting the sum of 3 specific self-reported symptoms. We also created a 0-31 FM Symptom scale (FS) by adding the WPI to the modified SS scale. We administered the questionnaire to 729 patients previously diagnosed with FM, 845 with osteoarthritis (OA) or with other noninflammatory rheumatic conditions, 439 with systemic lupus erythematosus (SLE), and 5210 with rheumatoid arthritis (RA).

Results. The modified ACR 2010 criteria were satisfied by 60% with a prior diagnosis of FM, 21.1% with RA, 16.8% with OA, and 36.7% with SLE. The criteria properly identified diagnostic groups based on FM severity variables. An FS score ≥ 13 best separated criteria+ and criteria- patients, classifying 93.0% correctly, with a sensitivity of 96.6% and a specificity of 91.8% in the study population.

Conclusion. A modification to the ACR 2010 criteria will allow their use in epidemiologic and clinical studies without the requirement for an examiner. The criteria are simple to use and administer, but they are not to be used for self-diagnosis. The FS may have wide utility beyond the bounds of FM, including substitution for widespread pain in epidemiological studies.

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New Clinical Fibromyalgia Diagnostic Criteria – Part 1.

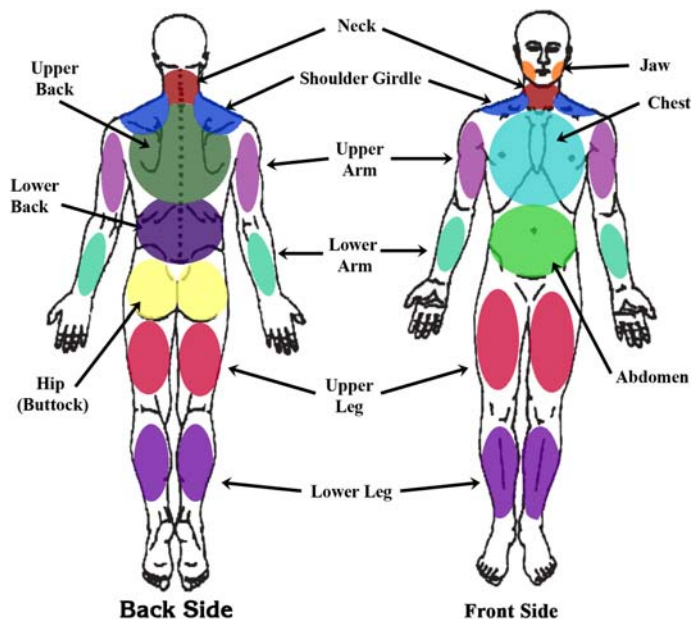
To answer the following questions, patients should take into consideration

- how you felt the **past week**,
- while taking your current therapies and treatments, and
- exclude your pain or symptoms from other known illnesses such as arthritis, Lupus, Sjogren’s, etc.

Check each area you have felt pain in over the past week.

- | | |
|---|--|
| <input type="checkbox"/> Shoulder girdle, left | <input type="checkbox"/> Lower leg left |
| <input type="checkbox"/> Shoulder girdle, right | <input type="checkbox"/> Lower leg right |
| <input type="checkbox"/> Upper arm, left | <input type="checkbox"/> Jaw left |
| <input type="checkbox"/> Upper arm, right | <input type="checkbox"/> Jaw right |
| <input type="checkbox"/> Lower arm, left | <input type="checkbox"/> Chest |
| <input type="checkbox"/> Lower arm, right | <input type="checkbox"/> Abdomen |
| <input type="checkbox"/> Hip (buttock) left | <input type="checkbox"/> Neck |
| <input type="checkbox"/> Hip (buttock) right | <input type="checkbox"/> Upper back |
| <input type="checkbox"/> Upper leg left | <input type="checkbox"/> Lower back |
| <input type="checkbox"/> Upper leg right | <input type="checkbox"/> None of these areas |

Determining Your Widespread Pain Index (WPI)
The WPI Index score from Part 1 is between 0 and 19.



Count up the number of areas checked and enter your Widespread Pain Index or WPI score here ____.

Symptom Severity Score (SS score) - Part 2a.

Indicate your level of symptom severity over the past week using the following scale.

Fatigue

- 0 = No problem
- 1 = Slight or mild problems; generally mild or intermittent
- 2 = Moderate; considerable problems; often present and/or at a moderate level
- 3 = Severe: pervasive, continuous, life disturbing problems

Waking unrefreshed

- 0 = No problem
- 1 = Slight or mild problems; generally mild or intermittent
- 2 = Moderate; considerable problems; often present and/or at a moderate level
- 3 = Severe: pervasive, continuous, life disturbing problems

Cognitive symptoms

- 0 = No problem
- 1 = Slight or mild problems; generally mild or intermittent
- 2 = Moderate; considerable problems; often present and/or at a moderate level
- 3 = Severe: pervasive, continuous, life disturbing problems

Tally your score for Part 2a (not the number of checkmarks) and enter it here ____.

Symptom Severity Score (SS score)- Part 2b

Check each of the following OTHER SYMPTOMS that you have experienced over the past week?

- | | | |
|--|--|---|
| <input type="checkbox"/> Muscle pain | <input type="checkbox"/> Nervousness | <input type="checkbox"/> Loss/change in taste |
| <input type="checkbox"/> Irritable bowel syndrome | <input type="checkbox"/> Chest pain | <input type="checkbox"/> Seizures |
| <input type="checkbox"/> Fatigue/tiredness | <input type="checkbox"/> Blurred vision | <input type="checkbox"/> Dry eyes |
| <input type="checkbox"/> Thinking or remembering problem | <input type="checkbox"/> Fever | <input type="checkbox"/> Shortness of breath |
| <input type="checkbox"/> Muscle Weakness | <input type="checkbox"/> Diarrhea | <input type="checkbox"/> Loss of appetite |
| <input type="checkbox"/> Headache | <input type="checkbox"/> Dry mouth | <input type="checkbox"/> Rash |
| <input type="checkbox"/> Pain/cramps in abdomen | <input type="checkbox"/> Itching | <input type="checkbox"/> Sun sensitivity |
| <input type="checkbox"/> Numbness/tingling | <input type="checkbox"/> Wheezing | <input type="checkbox"/> Hearing difficulties |
| <input type="checkbox"/> Dizziness | <input type="checkbox"/> Raynaud's | <input type="checkbox"/> Easy bruising |
| <input type="checkbox"/> Insomnia | <input type="checkbox"/> Hives/welts | <input type="checkbox"/> Hair loss |
| <input type="checkbox"/> Depression | <input type="checkbox"/> Ringing in ears | <input type="checkbox"/> Frequent urination |
| <input type="checkbox"/> Constipation | <input type="checkbox"/> Vomiting | <input type="checkbox"/> Painful urination |
| <input type="checkbox"/> Pain in upper abdomen | <input type="checkbox"/> Heartburn | <input type="checkbox"/> Bladder spasms |
| <input type="checkbox"/> Nausea | <input type="checkbox"/> Oral ulcers | |

Count up the number of symptoms checked above.

*If you tallied:

- | | |
|------------|----------------------------|
| 0 symptoms | Give yourself a score of 0 |
| 1 to 10 | Give yourself a score of 1 |
| 11 to 24 | Give yourself a score of 2 |
| 25 or more | Give yourself a score of 3 |

Enter your score for Part 2b here ____.

Now add Part 2a AND 2b scores, and enter ____.

This is your Symptom Severity Score (SS score), which can range from 0 to 12.

What Your Scores Mean

A patient meets the diagnostic criteria for fibromyalgia if the following 3 conditions are met:

1a. The WPI score (Part 1) is greater than or equal to 7 AND the SS score (Part 2a & b) is greater than or equal to 5

OR

1b. The WPI score (Part 1) is from 3 to 6 AND the SS score (Part 2a & b) is greater than or equal to 9.

2. Symptoms have been present at a similar level for at least 3 months.

3. You do not have a disorder that would otherwise explain the pain.

For example:

If your WPI (Part 1) was 9 and your SS score (Parts 2a & b) was 6, then you **would meet** the new FM diagnostic criteria.

If your WPI (Part 1) was 5 and your SS score (Parts 2a & b) was 7, then you **would NOT** meet the new FM diagnostic criteria.

*The new FM diagnostic criteria did not specify the number of "Other Symptoms" required to score the point rankings from 0 to 3. Therefore, we estimated the number of symptoms needed to meet the authors' descriptive categories of:

0 = No symptoms

1 = Few symptoms

2 = A moderate number

3 = A great deal of symptoms

* Wolfe F, *et al.* *Arthritis Care Res* 62(5):600-610, 2010.

For information about Fibromyalgia Network, call our office Monday through Friday, 9:00 a.m. to 5:00 p.m. (PST) at (800) 853-2929 or visit us online at www.fmnetnews.com.

This survey is not meant to substitute for a diagnosis by a medical professional. Patients should not diagnose themselves. Patients should always consult their medical professional for advice and treatment. This survey is intended to give you insight into research on the diagnostic criteria and measurement of symptom severity for fibromyalgia.