



HCSP FACT SHEET

• EXTRAHEPATIC MANIFESTATION OF HCV •

Fibromyalgia

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Foreword

It is estimated that about 4 to 10 million people in the United States and 3-6% of the world population have fibromyalgia (fibro or FM for short), and, while a direct link between fibromyalgia and hepatitis C hasn't been established, there are more people living with hepatitis C who are also living with fibromyalgia than in the general population. Hepatitis C and fibromyalgia also share many symptoms such as fatigue, depression, cognitive issues and muscle/joint pain.

Fibromyalgia is a condition (rather than a disease) which causes widespread muscle pain, fatigue and multiple tender points in specific parts of the body. The pain is felt all over the body and it been described as aching muscles and burning tissues. The exact cause of fibromyalgia is not known, but some experts believe that it may be caused by the malfunction of certain neurotransmitters in the brain and spinal cord. Fibromyalgia affects people differently and the symptoms or severity of symptoms can not be predicted. FM is more common in women than in men. Fibromyalgia is a chronic condition – that is, it is a life-long condition for most people, but it is not a progressive disease and it is not thought to shorten normal life expectancy. It can, however, greatly reduce the quality of life of those who suffer from this condition.

Fibromyalgia is sometimes referred to as an arthritis-related condition, but FM is not considered a true form of arthritis because it does not cause inflammation or damage to the muscles, joints or other tissues involved. It is, however, considered a rheumatic condition that impairs the joints and/or soft tissues and causes chronic pain.

The HCV Connection

The association or direct link between hepatitis C and fibromyalgia has not been discovered, but most experts believe that HCV may act as a trigger to the onset of fibromyalgia. Of interest, one study found that people with fibromyalgia and HCV exhibit symptoms, such as inflammation around a joint, bursa (sac containing fluid for lubrication of joints) and/or tendon, and vasculitis (blood or lymph vessel

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The information in this fact sheet is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.

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HCV – Fibromyalgia

inflammation), that are not seen in FM in people without HCV.

The prevalence of fibromyalgia in people with hepatitis C has been found to be much higher than in the general population – 15 to 19% compared to approximately 2% of the general U.S. population.

Symptoms

The symptoms of fibro vary from person to person. The most common symptoms and conditions associated with FM include:

- *Fatigue* that can range from mild to severe
- *Sleep disturbances* such as trouble falling asleep, staying asleep and/or waking up feeling exhausted (non-refreshing or non-restorative sleep)
- *Restless legs syndrome*, a disorder of the nervous system that affects sensation and movement in the legs and causes a strong urge to move the legs. Restless legs syndrome can also interfere with sleep since the symptoms are usually worse at night
- *Stiffness* when waking or after remaining in one position for a prolonged period of time
- *Irritable bowel syndrome*, a condition characterized by stomach pain and bloating and frequently alternating constipation and diarrhea in the absence of any disease
- *“Fibro Fog”* symptoms, including difficulty concentrating, forgetfulness and mixing up words when speaking or reading (similar to HCV “Brain Fog”)
- *Headaches* that are usually caused by tight neck and shoulder muscles or from the pain associated with fibromyalgia
- *Hyper-sensitivity* to light, noise, touch and temperature
- *Hypotension and reduced heart rate*
- *Numbness or tingling* of the extremities (legs and arms)
- *Anxiety, depression and irritability* due to pain, isolation and the unpredictability of the symptoms

- *Painful menstrual periods* in the absence of an infection
- *Light-headedness and balance problems* such as trouble with balance while standing and difficulty in visual tracking
- *Pain described as burning or aching* from knots in various muscle and tissue areas that can vary in intensity from mild to severe
- *Hyper sensitivity to pain*—in other words a person with Fibro might feel more severe pain than normal

Causes of Fibromyalgia

The exact cause of fibro has not been established, but it is believed that fibromyalgia may be triggered by a physically or emotionally stressful or traumatic event, repetitive injuries, illness (such as HCV?), rheumatoid arthritis or by an autoimmune disease. Fibro may also be influenced by a person’s genes and may run in families. There is evidence that fibromyalgia is caused from one or more of the triggers above and that it affects the way that pain is processed by the central nervous system. In the past, it was believed that fibro was a disease of the muscles and soft tissues, but researchers have documented brain and central nervous system abnormalities. Another theory is that people with fibromyalgia may have a gene that causes them to react strongly to certain stimuli that others might not perceive as painful.

Diagnosis

Currently, there is no simple blood test for diagnosing fibromyalgia. Before diagnosis of FM other conditions should be ruled out especially conditions that have similar symptoms. If a physician is not well-versed in fibromyalgia the diagnosis may be overlooked.

Physicians who are familiar with fibromyalgia can make a diagnosis based on criteria established by the American College of Rheumatology (ACR):

- Widespread pain (right and left side body pain above and below the waist) that lasts for more than 3 months

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- 11 or more tender points (out of 18) standard possible sites on the body

The American College of Rheumatology has proposed a new set of diagnostic criteria for fibromyalgia that removes the tender point exam, but they will concentrate on fatigue, a lack of mental clarity and forgetfulness, sleep problems and generalized inability to function doing normal activities. Hopefully, these new criteria will help to increase the diagnosis and care of people suffering from fibromyalgia.

Management and Treatment

Management

There is no cure for fibromyalgia, but there are many strategies to manage the condition including medications to control the pain and wellness strategies to help to make the person with fibromyalgia more comfortable. A comprehensive approach with many different health providers (doctor, physical therapist and others) seems to work best – an approach that includes the person suffering from fibromyalgia is a key element in successfully managing and treating fibromyalgia.

Medications

Pain Management – There are drugs that have been used to help treat fibromyalgia, but they have not been approved by the U.S. Food and Drug Administration for this purpose. Antidepressants have been found to help with managing fibromyalgia. In addition to treating mood disorders, antidepressants are now widely used to manage pain and fatigue. Over-the-counter pain relievers such as acetaminophen (Tylenol), aspirin, ibuprofen and other medications are used to treat mild pain. For more severe pain, stronger medications and narcotics can also be used, but long-term use should be avoided due to the high risk of physical and psychological dependency. Low-impact exercise and stretching can greatly help with pain, stiffness and mood.

Medications used to help with sleep disorders, restless legs syndrome and other conditions associated with

fibromyalgia can help manage symptoms.

Approved Medications

There are currently three medications approved by the Food and Drug Administration (FDA) to treat fibromyalgia—Lyrica, Cymbalta, and Savella.

Pregabalin (brand name Lyrica)

In the studies submitted to the FDA the improvement in pain by dose reported was 68.1% (300 mg dose), 77.8% (450 mg dose), 66.1% (600 mg dose), and 47.5% in the group that received the placebo medication. Some patients reported a decrease of pain within the first week of treatment. The most common side effects reported were blurred vision, constipation, increased weight, dizziness, feeling sleepy and headache. The side effects were generally reported as mild to moderate. The recommended dose of Lyrica is 300 to 450 mg/day. Pregabalin is also approved to treat partial seizures, pain following the rash of shingles and pain associated with diabetes nerve damage (diabetic neuropathy).

Duloxetine HCL (Brand name Cymbalta)

In June 2008 the FDA approved Cymbalta for the treatment of fibromyalgia. In the clinical studies submitted to the FDA, 51% and 55% of patients receiving Cymbalta had a 30% improvement in pain and 65% and 66% reported feeling better. The most common side effects of Cymbalta include nausea, dry mouth, sleepiness, and constipation. Cymbalta is a reuptake inhibitor of serotonin and norepinephrine that is theorized to treat depression and pain by increasing the activity of serotonin and norepinephrine in the central nervous system. The recommended dose of Cymbalta is 60 mg daily. Cymbalta is also FDA approved in adults for acute and maintenance treatment of major depressive disorder, the acute treatment of generalized anxiety disorder, and the management of diabetic peripheral neuropathic pain.

Cymbalta can cause liver problems so people with liver disease should be carefully monitored.

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Milnacipran HCl (brand name Savella)

In two large clinical trials, patients receiving Savella reported a 30% reduction in pain compared to what they experienced before they started taking Savella. The most common side effects reported were nausea, constipation, hot flush, hyperhidrosis (abnormal sweating), vomiting, palpitations, increased heart rate, dry mouth and hypertension. Savella is thought to work by blocking certain brain neurotransmitters—norepinephrine and serotonin.

This product is not generally recommended for people with liver disease.

There are other antidepressants and pain medications that are not approved by the FDA to manage and treat fibromyalgia, but they may be prescribed “off-label” to treat FM. Consult with a medical provider for diagnosis, management and treatment.

Vitamin D

In a small study 30 women who had low levels of Vitamin D were given Vitamin D Supplements for 25 weeks and monitored for an additional 24 weeks. The women reported less pain and morning fatigue over time. This study suggests that everyone with Fibromyalgia should have their Vitamin D levels checked.

Note: *Many people with HCV have low levels of Vitamin D. It is recommended that everyone with HCV should have their vitamin D levels monitored.*

Exercise

Research has clearly found that aerobic and flexibility exercises are some of the best tools for managing fibromyalgia. Try gentle exercise like walking. Stretching is also helpful. New research is examining strength training exercises. Physical therapy has also been found to improve the symptoms.

Sleep

Getting the right type and enough sleep is very important. This can be difficult for people with

fibromyalgia since the symptoms of fibromyalgia can greatly interfere with amount and quality of sleep. Talk to your medical provider about medications to treat sleep disorders, pain management and restless legs syndrome to help restore quality of sleep (see the HCSP Fact Sheet Sleep for tips on managing sleep).

Stress

Stress can trigger or worsen the symptoms of fibromyalgia so stress management is another important tool that a person can use to manage the symptoms. Try relaxation, prayer, meditation and other techniques to lower stress.

Work Adjustments

It may be helpful to find out if an employer allows for flexible working schedules, and improving the physical work environment with ergonomically correct equipment such as the chair, desk and computer monitor. If you are unable to work you may be eligible for disability benefits from Social Security or from private disability insurance. People with fibromyalgia have some work place protections. Contact the Americans with Disability office at 1-800-949-4232 for more information.

Complementary Medicine

There are many practices that can help reduce some of the symptoms of Fibromyalgia and to help relieve the stress of living with a chronic condition including:

- Acupuncture: a practice to stimulate and restore energy flows through the body by inserting special slender needles into certain points in the body
- Acupressure: the same principle as acupuncture, but finger pressure is used instead of needles
- Prayer and healing practices
- Deep breathing techniques
- Biofeedback: a technique that a person learns to control bodily functions such as heart rate, blood pressure, and pain
- Relaxation techniques: meditation, healing practices

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Support Groups

People with fibromyalgia, like people with HCV, can greatly benefit from professional counseling and/or a support group to deal with the emotional and physical realities of living with fibromyalgia.

In the past fibromyalgia was not taken seriously and there was very little research conducted to find the cause and steps to manage the condition.

But as we have begun to learn more about the condition and it has been more widely acknowledged additional research is being conducted to learn about the cause, management and treatment of this potentially disabling condition. Until more information and medications are available the best advice is always advocate for the best possible care for yourself and others with this condition.

Related publications:

- **Sleep**
www.hcvadvocate.org/hepatitis/factsheets_pdf/Sleep.pdf
- **HCSP: A Guide to Hepatitis and Disability**
www.hcvadvocate.org/hepatitis/factsheets_pdf/Disability_Guide.pdf
- **An Overview of Extrahepatic Manifestations**
www.hcvadvocate.org/hepatitis/factsheets_pdf/Extrahepatic.pdf

For more information

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| <ul style="list-style-type: none"> • Americans with Disabilities Act
www.ada.gov • Centers for Disease Control and Prevention
www.cdc.gov | <ul style="list-style-type: none"> • National Institute of Arthritis and Musculoskeletal and Skin Diseases, Toll free: 877-226-4267
www.niams.nih.gov • National Fibromyalgia Partnership
www.fmpartnership.org |
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