

What is fibromyalgia?

Fibromyalgia, or fibromyalgia syndrome (FMS), is the name for pain and tenderness that affects muscles and tendons over the whole body. The pain continues for more than three months.

It is called a 'syndrome' because it is a collection of symptoms, rather than a disease. It is not arthritis, because it does not affect the joints, although the joints might hurt. But like arthritis, it causes pain and fatigue or severe tiredness.

Fibromyalgia is an illness, which involves both the mind and body. It cannot be diagnosed by standard tests or X-rays. People with fibromyalgia have tender points in certain parts of the body which a doctor will assess to try to make a diagnosis. It can also appear like chronic fatigue syndrome (CFS, or ME).

Though we still do not know what causes fibromyalgia, research is now showing that there may be specific problems with the way people's bodies work. Studies of brain waves show that people with fibromyalgia do not have enough deep sleep. Problems with sleep could be caused by pain or depression, but it might be the poor quality of sleep that is actually causing the pain. Research has also uncovered problems with the central nervous system (the spine and brain) in people with fibromyalgia. The parts of their brain that register pain react differently, so they feel pain where others just feel uncomfortable or stiff.

Around 1 in 25 people will develop fibromyalgia at some time in their life. It most commonly develops between the ages of 30-60. Women are more likely to develop fibromyalgia than men. It is not common in younger adults, and children are not often affected.

REAL LIFE STORY

‘ I was feeling constant pain in my neck, hands, feet, back and knees. My headaches, the tiredness and my inability to remember simple things struck my doctor when he diagnosed me.

The fibro fog is very real and the worse part of it for me is the tiredness as I am unable to sleep for more than four hours. I have to take each day as it comes. If I am tired, I rest. Then, when I feel able, I go out and walk slowly. ’

How will it affect me?

The main symptoms of fibromyalgia are:

- pain in many areas or just in one part of the body. It can feel like your whole body is hurting. The neck and back are most affected
- aching and stiffness, which may change through the day and might get worse with activity

- sleeping badly and waking up without feeling refreshed
- exhaustion, lack of energy or loss of stamina.

Symptoms which some people also get:

- feeling depressed or irritable
- poor concentration and forgetting things (sometimes called 'fibro fog')
- headaches
- restless legs syndrome, where legs are uncomfortable and twitchy, especially at night
- poor circulation, with tingling or swelling in hands and feet
- feeling an urgent need to urinate
- irritable bowels (diarrhoea, constipation or tummy pain)
- painful menstrual periods.

Fibromyalgia can develop by itself. It can also be brought on by something else, such as having a form of arthritis, by being depressed, or after a traumatic event such as an accident or a death in the family.

There are no outward signs of the condition, which can mean people do not understand how bad you are feeling - and that can make you feel more depressed or frustrated.

Fibromyalgia is not life-threatening, and will not cause permanent damage to the joints or muscles. While there is no cure for fibromyalgia, some people may go into remission for months or years.

Who will I see?

See your GP if you think you have fibromyalgia or any other severe constant pain.

The doctor will probably test to see if you have fibromyalgia by pressing on 18 particular points around the body. These points where you are most likely to have pain are called 'tender points'. When these points are pressed, people with fibromyalgia will flinch with pain, unlike someone without the condition. Make sure you tell your doctor about any symptoms you are experiencing, as some of them could be caused by another condition.

The doctor may also suggest referral to:

- a physiotherapist who can give you exercises and relaxation techniques. They may also suggest hydrotherapy

- an occupational therapist for advice on how to carry out daily activities and pace yourself
- a pain clinic to help manage your pain
- a community service such as a chronic fatigue service.

What is the treatment?

There are a variety of things your doctor may give you:

- **painkillers** such as paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen can help with the pain
- a **steroid** injection into a particularly painful part of the body can stop the pain for a while
- a **soft collar** to wear during sleep, which may help especially if your neck is sore
- **anti-depressant drugs.** Tricyclic anti-depressants, such as amitriptyline, can reduce pain and help you sleep. These are given in much lower doses than they would be for depression. They might make you feel drowsy during the day. Some people find taking their dose in the early evening provides a good night's sleep without having a groggy feeling the following morning. SSRI anti-depressants, such as fluoxetine or citalopram can reduce tiredness and depression.
- **anti-convulsion drugs**, normally used to treat epilepsy, may sometimes be prescribed for fibromyalgia. These include gabapentin and pregabalin. Ask your doctor for more information about these medicines and if they can help you.

Exercise

Research shows that exercise is very important to reduce pain and tiredness in people with fibromyalgia. Exercise will build strength in your muscles. It will also help you to lose weight, which may help to improve symptoms. It is also good for sleep and generally will help you to feel better.

- Aerobic exercise means getting more oxygen circulating through your blood - any exercise that gets you breathing harder and your heart beating faster. That includes low-impact exercise such as walking. Swimming is especially good because the warm water can soothe and support your body at the same time.
- Stretching exercises are also important, to increase flexibility. You can do these anywhere. Learn how to do them from a physiotherapist, self-help books or CDs, or take up a form of exercise such as yoga or Tai chi. Arthritis Care has a very practical booklet about exercise.

Exercising may hurt at first and make you feel tired. So do a small amount to begin with and gradually build up - do not overdo it.

What can I do to help myself?

- Help your family to understand how fibromyalgia affects you, so they can support and encourage you. Show them this or other factsheets, or refer them to Arthritis Care's website or helpline.
- Share your experiences with others who have similar problems, by joining a support group or online discussion forum such as Arthritis Care's (www.arthritiscare.org.uk/forums).
- Adapt your work to shorter hours, change to something less demanding, or make sure your work station is comfortable. It can be important for your state of mind to keep working if you can.
- Applying heat with a hot water bottle or hot baths or showers can help pain and improve morning stiffness.
- If you have a dry mouth, try a toothpaste based on sodium bicarbonate.
- Eat a healthy diet.
- For 'fibro fog', some people find it helpful to do mental exercises like crosswords or jigsaw puzzles; do as much as you can to stimulate your brain. Pick your best time of day to do anything needing concentration. Explain to others if fibromyalgia affects your memory.
- Some people find complementary therapies help, though evidence is limited. You may have to pay for these treatments - ask your GP first. Before you choose a complementary therapist, check they are a member of a professional body, and beware of anyone asking you to give up your prescribed drugs.
- Careful massage (by a partner, friend, or a professional) can help you relax and may improve muscle tone, improve blood flow and make you feel cared for.
- Some people may find it helpful to talk to a professional counsellor – ask your GP to refer you.
- Learn to pace yourself by breaking up tasks into smaller chunks and allowing time to rest.

Getting enough sleep

A lack of sleep can make your symptoms worse. Making sure you have regular bedtime habits will help you to sleep. Try going to bed at the same time every night, and keep your bedroom cool and dark, without distractions such as a TV.

Avoid exercising three hours before bedtime, as well as any caffeine, to help your body wind down. Relaxation techniques can also help relax muscles; ask your doctor, nurse or physiotherapist for methods they can recommend.

Is it hereditary?

You will have a greater risk of developing fibromyalgia if one of your parents or siblings has the condition. It is thought that a combination of genetic and environmental factors work together to cause fibromyalgia.

Where can I get more information and support?

Arthritis Care is the UK's largest charity working with and for all people who have arthritis.

We are here to help you make positive choices through our information, website, self-management training, and professional helpline. Call the free helpline for confidential support on 0808 800 4050 (10am-4pm weekdays) or email: Helplines@arthritiscare.org.uk

You can find support from others with arthritis by joining our online discussion forums.

We rely on donations to fund our vital work in supporting people living with arthritis. If you would like to make a contribution, please phone us on 020 7380 6540 or you can donate online.

www.arthritiscare.org.uk

Other organisations

The Fibromyalgia Association UK for information and support. PO Box 206, Stourbridge, West Midlands, DY9 8YL. Helpline: 0870 220 1232 (10am-4pm). www.fibromyalgia-associationuk.org

Our factsheets are reviewed every 18 months. Please check our website for up-to-date information and reference sources or call 020 7380 6577.

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Note

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Contact us

For confidential information and support about treatments, available care and adapting your life, contact the Arthritis Care Helpline

Freephone: 0808 800 4050

10am-4pm (weekdays)

Email: Helplines@arthritiscare.org.uk

For information about Arthritis Care and the services we offer, contact us at: **www.arthritiscare.org.uk**

You can also talk to other people who are living with arthritis, through the discussion forums on our website.

Arthritis Care UK office and England regional services:

Tel: 020 7380 6500

Central England email: CentralEngland@arthritiscare.org.uk

North England email: NorthEngland@arthritiscare.org.uk

South England email: SouthEngland@arthritiscare.org.uk

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