

Fibromyalgia



ARTHRITIS CARE

*Empowering
people with arthritis.*

What is fibromyalgia?

Fibromyalgia, or fibromyalgia syndrome (FMS), is the name for pain and tenderness that affects muscles and tendons around 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. But like arthritis, it causes pain and fatigue.

Fibromyalgia is an illness, which involves both the mind and body. Until the 1990s, it was not always recognised by doctors, and it does not show up in standard tests or X-rays. It can also appear like chronic fatigue syndrome (CFS, or ME).

Though we still don't 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 don't 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.

Real life story

I *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. Necks and backs 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
- dryness of the mouth and nasal passages, skin and other parts of the body
- sensitivity to high and low temperatures.



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 don't understand how bad you are feeling – and that can make you feel more depressed or frustrated.

Most people who have fibromyalgia are women, but 10 per cent are men. It usually affects people aged between 50 and 70. Very occasionally, children and teenagers can develop fibromyalgia, sometimes after an illness, accident or shock. Though fibromyalgia can carry on for months or years, it will not cause any permanent damage to your body.

What is the treatment?

There is no cure for fibromyalgia, but you can find ways of coping, so you can carry on normally with life. Sometimes the condition will settle down by itself; although this can take a long time.

Medicines

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 can 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. SSRI anti-depressants, such as prozac or citalopram can reduce tiredness and depression.



Exercise

Research shows that exercise is very important to reduce pain and tiredness in people with fibromyalgia. Exercise will build strength in your muscles, so you can move your arms and legs without jarring. It is also good for sleep, helps you lose weight and generally 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 – don't overdo it. You should aim to do at least three hours of exercise each week, but starting with 10 minutes a day can help.

Who will I see?

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

The doctor will probably test to see if you have fibromyalgia by pressing on 18 particular points around the body. When these points are pressed, people with fibromyalgia will flinch with pain, unlike someone without the condition. The doctor will need to know all your symptoms, because some of them could in fact be caused by something else.

The doctor may also suggest:

- a physiotherapist, who can give you exercises and relaxation techniques
- an occupational therapist who can advise on ways of working to reduce pain or fatigue
- a pain clinic to help manage your pain.

Parents or carers of a child who has fibromyalgia may need to see a paediatrician – a specialist in caring for children – to help manage the condition.

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 another factsheet, 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.
- 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.
- Don't drink alcohol, tea or coffee or eat spicy food late at night, as these can interfere with sleep.
- Keep regular sleeping habits: get up and go to bed at the same time every day; keep your bedroom cool and dark. Avoid exercising within three hours of bedtime.
- Relaxation techniques help relax muscles, calm pain and improve sleep. Get relaxation methods from your doctor, nurse or physiotherapist, or from self-help CDs or books.
- 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', 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.



- An osteopath or chiropractor manipulating the body helps some people.
- Some people find complementary therapies help, but 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.
- 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.
- Acupuncture, where very fine needles are inserted into certain parts of the body, can suppress pain.
- Hydrotherapy to exercise joints and muscles in the support of a warm water swimming pool.



Is it hereditary?

Women who have a family member with fibromyalgia are more likely to have it themselves. But we don't know if this is because it is passed on genetically, or because family members are affected by living in the same environment.

Where can I get more information and support?

- Arthritis Care's helpline 0808 800 4050 (weekdays 10am-4pm) plus website (www.arthritiscare.org.uk) can give you information about adapting your life, treatments and care, or just give you someone to talk to. You can also contact other people with arthritis through the discussion forums on our website.
- The Fibromyalgia Association UK for information and support:
PO Box 206, Stourbridge, West Midlands, DY9 8YL.
Helpline: 0870 220 1232 (10am-4pm).
Email: administration@ukfibromyalgia.com
or visit: www.ukfibromyalgia.com

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Note

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Arthritis Care

Arthritis Care is the UK's largest voluntary organisation working with and for all people with arthritis.

Our publications are just one of the many services Arthritis Care provides. These include a confidential helpline, self-management and awareness training, information for people with arthritis and health professionals, and local activity and support. We also campaign locally and nationally to help change attitudes and laws and to ensure people with arthritis have access to the treatments and services they need and deserve.

Contact us

For confidential information and support, 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

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