Fibromyalgia

What is fibromyalgia?
Fibromyalgia, or fibromyalgia syndrome (FMS), is a condition where the whole body is affected by pain and tenderness lasting more than three months. People with fibromyalgia usually have other symptoms including poor sleep, difficulty concentrating and problems with their bladder and bowels.

Fibromyalgia seems to be a disorder of how pain signals are processed in the spine and brain. People with fibromyalgia feel constant pain which does not reflect a problem in the joints, muscles or bones. Fibromyalgia is not in the mind, though it does affect the mind. Some features are similar to chronic fatigue syndrome (CFS, or ME). It cannot be diagnosed with blood tests, X-rays or scans. Doctors should make a diagnosis through listening to people’s symptoms, a physical examination (which may include checking for tender points) and perform tests to exclude other causes of persistent pain and fatigue.

It is called a ‘syndrome’ because it is a group of symptoms, rather than a disease where the cause is known. It is not arthritis, because the pain is not caused by swelling or damage to the joints. But like arthritis, it causes pain and fatigue or severe tiredness.

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.

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 worst 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
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● 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, through gradually increasing physical activity levels, with psychological support and sometimes with help from medication, many people can get their life back - even if the pain is still there.

Who will I see?
See your GP if you think you have fibromyalgia or any other severe constant pain.

Make sure you tell your doctor about any physical and psychological symptoms you are experiencing as pain is only one aspect of fibromyalgia. Your doctor will ask you more questions, conduct a physical examination to look for signs of fibromyalgia or other conditions, and may request blood tests or scans to exclude any other causes for your symptoms.

The doctor may also suggest referral to:
● a specialist, such as a rheumatologist, to confirm the diagnosis if it is uncertain and to exclude any other causes for the pain and fatigue
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● a physiotherapist who can give you exercises and relaxation techniques. They may also suggest hydrotherapy
● a clinical psychologist or counsellor who can use techniques such as cognitive behavioural therapy or mindfulness that will teach you ways of controlling fibromyalgia and stopping it controlling you
● an occupational therapist for advice on how to carry out daily activities and pace yourself
● a community or hospital-based specialist pain clinic or chronic fatigue service to help manage your symptoms

What is the treatment?

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.

● Resistance exercise helps strengthen muscles which move and protect joints. Strengthening exercises may be difficult to begin with, but soon become easier. Aim to do at least one session a day. If exercising in a gym, there should be a range of resistance equipment and weights to choose from and instructors are on hand to give advice. If exercising at home you can use household items such as a pair of tights, cans of food, bottles and bags of sugar. Alternatively you can buy specifically designed equipment such as ankle weights. Be sure to begin with lighter items and build up.

● 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.

Psychological Therapies
Psychological therapies such as counselling or cognitive behavioural therapy may be useful to develop techniques to manage the pain, anxiety and depression. They explore the relationship between thoughts, feelings and actions and show you how to turn negative thoughts into positive ones which in turn makes you feel better. One of the aims is for you to be able to use the strategies after the sessions have come to an end.
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There are a variety of medications your doctor may give you:
Up to half of people with fibromyalgia get some benefit from medication which should be taken regularly to be effective, usually for several weeks.

- painkillers such as paracetamol, codeine or tramadol may help with the pain
- neuromodulatory drugs are medications that work on the nervous system to change how pain is processed in the brain and spine. These were developed for other purposes, such as to treat depression or epilepsy. They have since been shown to help many people with fibromyalgia.
- Amitriptyline and nortriptyline taken regularly in the evening can help sleep and reduce pain. Some people find they are groggy the next day and taking these in the early evening may help. Although they are also used to treat depression, the doses effective in fibromyalgia are usually much lower.
- Other medications used in fibromyalgia include gabapentin, pregabalin, fluoxetine and duloxetine. Ask your doctor for more information about these medicines and if they can help you.
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.arthritiscareforum.org.uk).

- 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](http://www.arthritiscare.org.uk)

Other organisations
The Fibromyalgia Association UK for information and support. Studio 3013, Mile End, Abbeymill Business Centre, 12 Seedhill Road, Paisley. PA1 1JS Helpline: 0844 887 2444 (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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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 in England
Tel: 0844 888 2111 or 020 7380 6509/10/11
Email: englandoffice@arthritiscare.org.uk

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Tel: 028 9078 2940
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