Fibromyalgia

This booklet provides information and answers to your questions about this condition.
Fibromyalgia is a condition that causes widespread muscular pain. It’s not life-threatening or progressive but it can still have a major impact on your quality of life. In this booklet we’ll explain the symptoms and possible causes and look at how fibromyalgia can be treated. We’ll also suggest where you can find out more about living with fibromyalgia.

At the back of this booklet you’ll find a brief glossary of medical words – we’ve underlined these when they’re first used.
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What is fibromyalgia?
Fibromyalgia is a common condition that can cause widespread pain in the muscles, tendons and ligaments. It’s thought that as many as 1 person in every 25 may suffer from it. More women than men are affected and the condition varies a great deal from one person to another and from day to day.

What are the symptoms?
The symptoms of fibromyalgia can include:
• widespread muscle pain
• tiredness (fatigue) or lack of energy
• sleep disorders
• headaches
• irritability, feeling low or weepy
• irritable or uncomfortable bowels
• forgetfulness or poor concentration
• increased sensitivity (to cold, sound, knocks and bumps).

What causes it?
The exact causes of fibromyalgia aren’t known, but anxiety, physical or mental trauma, and sleep disturbance are thought to play a part.

People with fibromyalgia experience increased sensitivity to pressure or minor knocks that wouldn’t normally be painful, which may be related to chemical changes in the body’s pain pathways. The pain isn’t caused by inflammation or degeneration (progressive deterioration), and it doesn’t cause any lasting damage to the body.

What treatments are there?
A team of healthcare professionals could be involved in your treatment and may be able to offer:
• medications to ease muscle pain and improve sleep
• muscle relaxants
• drugs to treat the pain
• physiotherapy.

At a glance
Fibromyalgia

Although fibromyalgia isn’t life-threatening, it can have a major impact on your daily living.
How can I help myself?

Try these self-help tips to help ease your symptoms:

• Learn about and understand your condition.
• Pace your daily activities.
• Exercise (for example swimming, walking or cycling).
• Share your experiences with other people.
• Tackle any stress or unhappiness at home or at work.
• Avoid tea, coffee (and any other forms of caffeine) and alcohol close to bedtime.
• Eat a balanced diet and keep to a healthy weight.
• Stop smoking.
What is fibromyalgia?

Fibromyalgia is a long-term (chronic) condition that can cause widespread pain in the muscles, tendons and ligaments. It’s quite common – up to 1 person in every 25 may be affected.

In the past, other terms were used to describe the condition, including muscular rheumatism and fibrositis. The condition may even have been misdiagnosed as degenerative joint disease. More recently, research has provided a much clearer picture of what fibromyalgia is and how it can affect your life. For example, we now know that, in spite of the pain, fibromyalgia isn’t inflammatory or degenerative. Evidence from long-term studies suggests that it’s not progressive, so it won’t cause permanent damage to your muscles, bones, joints or organs. Although the pain can be very bad and can affect different parts of your body, it’s important to remember that, unlike arthritis, fibromyalgia doesn’t cause any change in the structure of bones or joints.

Fibromyalgia isn’t an autoimmune disease but it’s much more common than most of these conditions, so by chance alone some people with autoimmune diseases such as rheumatoid arthritis and lupus could have fibromyalgia as well. Symptoms such as pain and tiredness can occur in either fibromyalgia or autoimmune diseases so often people with fibromyalgia are worried that they may have an autoimmune disease. As development of fibromyalgia is promoted by factors such as tiredness, poor sleep and depression, people who have those features due to an ongoing autoimmune disease can get fibromyalgia later.

What are the symptoms of fibromyalgia?

You can’t normally tell that a person has fibromyalgia by looking at them – usually there are no outward signs of the condition. Widespread muscle pain, fatigue and sleep disturbance are the main symptoms of fibromyalgia, but the effects of these symptoms varies from person to person and from day to day. Many people have flare-ups from time to time when the symptoms become suddenly worse. People with fibromyalgia often say that the fatigue is the worst part of the condition and that they can’t seem to think clearly or remember things properly (sometimes this is called ‘fibrofog’). The pain may feel as though it affects your whole body, or it may be particularly bad in just a few areas. Some people find that the pain is worse in extremes of temperature such as very hot, cold or damp weather.

People with fibromyalgia often look well even when they’re in a lot of pain. As a result, other people may not understand the pain and tiredness you’re experiencing.
Less frequent symptoms of fibromyalgia include:
- poor circulation – tingling, numbness or swelling of the hands and feet
- headaches
- irritability or feeling miserable
- feeling an urgent need to urinate, especially at night
- irritable or uncomfortable bowels (diarrhoea or constipation and abdominal pain).

**How is fibromyalgia diagnosed?**

Fibromyalgia is often difficult to diagnose as the symptoms vary considerably and could have other causes. They can be similar to the symptoms of other conditions, for example an underactive thyroid gland (hypothyroidism). There aren’t any specific blood tests, x-rays or scans that can confirm a diagnosis of fibromyalgia – in fact, characteristically, all these tests will be normal. Your doctor may suggest you have blood tests to find out whether the results are normal, which can help rule out other causes of your symptoms and confirm that you have fibromyalgia.

Until recently, the diagnosis of fibromyalgia was based on the presence of specific tender points in certain areas of the body (see Figure 1), which can be tender even when pressed very gently. Many people find that other areas are also painful. Guidelines released in 2010 recommend that healthcare professionals should now consider fatigue, waking up...
unrefreshed and cognitive symptoms (problems with thought processes like memory and understanding) when they make their diagnosis, as well as a history of pain lasting for three months or more.

What causes fibromyalgia?
We don’t yet know exactly what causes fibromyalgia, but research suggests that there’s an interaction between physical, mental and psychological factors. The pain we feel is often affected by our emotions and moods – depression or anxiety can make the pain feel worse. At the same time, being in pain can lead to stress and anxiety. Some people with fibromyalgia report that their symptoms started after a viral infection, physical or mental trauma (like a car accident or bereavement), or following a period of stress and anxiety, for example in a relationship. But in other cases, no particular event leads to the development of symptoms.

Usually people feel pain when an area of their body is damaged (as in arthritis) or suffers a physical injury, like stubbing a toe or pricking a finger. The pain people with fibromyalgia feel is different because it’s not caused by damage or injury to the area that’s hurting. Instead, there’s a problem with the way the brain and nervous system process pain from that area. This doesn’t mean that the feeling of pain is any less real, but because it’s not due to damage or injury that can

Figure 2 The cycle of pain and sleep disturbance

localised muscular/joint pain

SLEEP DISTURBANCE

disease, illness

anxiety, life crisis

insufficient deep restorative sleep

functional disturbance, fatigue, widespread muscular pain and tenderness
be healed, there’s no easy way to stop the pain. This is why fibromyalgia pain is long-lasting (chronic), even though the structure of the parts of the body that hurt remains normal and undamaged.

Research has also shown that people with fibromyalgia are more sensitive to physical pressure. This means that what would be a relatively minor knock for most people could be extremely painful for someone with fibromyalgia. While this increased sensitivity isn’t fully understood, it’s thought that it’s also related to changes in the way the nervous system processes pain. In fact, some researchers have shown using special brain scans that these processes are altered in people with fibromyalgia.

Sleep disturbance may also contribute to this increased sensitivity. Brainwave studies show that people with fibromyalgia often lose deep sleep. A number of things may lead to sleep disturbance, such as:
- pain from an injury or another condition such as arthritis
- stress at work or strain in personal relationships
- depression brought on by illness or unhappy events.

Simple painkillers like paracetamol can help to ease your symptoms.

In an experiment where healthy volunteers were woken during each period of deep sleep, a number of them developed the typical signs and symptoms of fibromyalgia.

Not surprisingly, a combination of pain, sleep disturbance and anxiety or depression can turn into a vicious circle (see Figure 2). A poor sleep pattern will contribute to the severe tiredness that often goes with fibromyalgia.

See Arthritis Research UK booklets: Pain and arthritis; Sleep and arthritis.

What are the associated conditions?
Some people who have fibromyalgia also report being affected by some of the following conditions:
- chronic tiredness (fatigue)
- depression and anxiety
- headaches
- joint pain in various parts of the body
- restless leg syndrome – spasms in either or both legs
- irritable bowel syndrome (IBS)
- temporomandibular joint disorder (TMJD) – problems with the joint connecting the jawbone to the skull, causing pain in the jaw and areas nearby
- hypothyroidism.

The symptoms of fibromyalgia are often very similar to the symptoms of chronic
fatigue syndrome, which was previously known as ME. People with chronic fatigue syndrome can often recall a viral infection before symptoms appeared and may have less pain than people with fibromyalgia, but we need to know more about the conditions before we can say whether they’re the same thing.

**What treatments are there for fibromyalgia?**

There’s no cure as yet for fibromyalgia, but there are ways of managing your symptoms. Your doctor will be able to suggest treatments to tackle specific aspects of the condition.

**Drugs**

Your doctor can prescribe a variety of medications to help with pain, sleep disturbance or depression associated with fibromyalgia. However, most of these drugs can cause side-effects, particularly the stronger painkillers. They don’t cure fibromyalgia and don’t usually get rid of all the pain. It’s important to discuss the best balance between pain relief and side-effects with your doctor.

**Paracetamol** can ease pain. Where paracetamol isn’t strong enough, some people find drugs like co-codamol or co-dydramol useful. These contain paracetamol plus a stronger painkiller such as codeine, but they can cause side-effects such as constipation.
There are things you can do to manage the symptoms associated with fibromyalgia. Research has shown that exercise reduces the pain and fatigue.

Exercise can also improve your sleep and general well-being.
Opiate drugs include tramadol, codeine and buprenorphine or fentanyl patches. They’re very strong painkillers with many side-effects and it can be difficult to stop taking them once they’re started. Doctors, especially in pain clinics, may offer these if the pain is seriously affecting your quality of life but they don’t always work in fibromyalgia and should be used as sparingly as possible due to the risk of long-term side-effects.

Capsaicin gel or non-steroidal anti-inflammatory gels rubbed into the painful areas may help you, but there’s no convincing evidence that they’re effective in most people with fibromyalgia, especially as many different areas of your body can be affected at the same time.

Drugs such as low-dose amitriptyline and dosulepin can reduce muscle pain and improve sleep patterns. They need to be taken two to three hours before you settle at night. They may not work straight away, so you may need to try them for a few months to see whether they help. Your doctor will gradually increase the dose to an effective level.

Antidepressants, such as fluoxetine or paroxetine, can help with both pain and low mood.

Drugs such as pregabalin and gabapentin have been used to treat pain. It takes six weeks to assess whether they’re helpful. They can cause side-effects such as dizziness and weight gain.

Duloxetine can help with pain and sleep disturbance.

See Arthritis Research UK leaflets Amitriptyline; Drugs and arthritis; Painkillers.

Physical therapies
Your doctor may refer you to a physiotherapist or occupational therapist for further treatment and advice.

Physiotherapy
Physiotherapy can help you to improve your posture, stretch and relax your muscles, and gradually become more active. Physiotherapists can also advise you about relaxation techniques.

Occupational therapy
Occupational therapy can help you to manage your everyday jobs without increasing your pain or wearing yourself out. Your occupational therapist may suggest pacing yourself, changing the way you work or using labour-saving gadgets.

See Arthritis Research UK booklets Occupational therapy and arthritis; Physiotherapy and arthritis.

Self-help and daily living
Many people with fibromyalgia have learnt to manage their condition so that they can continue to live their lives enjoyably.
despite their symptoms. The following sections look at some of the things that might help.

**Exercise**

If you have fibromyalgia your muscles will often feel stiff and tense, making them more prone to sprains and strains. It’s important to reduce this tension by stretching your muscles regularly.

Research has shown that aerobic exercise improves fitness and reduces pain and fatigue in people with fibromyalgia. It should also improve your sleep and general well-being.

Aerobic simply means increasing the circulation of oxygen through the blood, so any exercise that gets you breathing heavily and your heart beating faster is aerobic. Swimming is particularly recommended for people with fibromyalgia, but walking and cycling are also helpful.

Build up your exercise at a rate you can cope with, pace yourself and be patient. You may find that the pain and tiredness become worse at first as you start to exercise muscles that haven’t been used for a while. Try and do the same amount of exercise each day so that you build up your muscle strength and stamina.

Increasing your exercise little by little will also improve your fitness and flexibility.

Yoga has been shown to help some people with fibromyalgia.

**Diet and nutrition**

No particular diet has been proven to help fibromyalgia, but we recommend keeping your weight within a healthy range by eating a balanced diet with plenty of fruit and vegetables.

**Complementary medicines**

Some people with fibromyalgia find that complementary medicines help their symptoms. Treatments like massage and acupuncture by a chiropractor or osteopath may temporarily ease the pain and discomfort.

Generally speaking complementary and alternative therapies are relatively well tolerated, although you should always discuss their use with your doctor before starting treatment. There are some risks associated with specific therapies.

In many cases the risks associated with complementary and alternative therapies are more to do with the therapist than the therapy. This is why it’s important to go to a legally registered therapist, or one who has a set ethical code and is fully insured.

If you decide to try therapies or supplements you should be critical of what they’re doing for you, and base your decision to continue on whether you notice any improvement.
Fibromyalgia

See Arthritis Research UK booklet and special reports Complementary and alternative medicine for arthritis; Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia; Practitioner-based complementary and alternative therapies for the treatment of rheumatoid arthritis, osteoarthritis, fibromyalgia and low back pain.

Sleep
Poor sleep is a key symptom of fibromyalgia, so getting enough proper sleep is an important part of the treatment. Not only will it help with tiredness and fatigue but you may also find it helps with the pain. To make sure you get a better night’s sleep:

- avoid alcohol, tea or coffee (or any other form of caffeine) late at night
- develop a sleep routine, settling down and getting up at the same time each day
- try to stop smoking or at least don’t smoke late at night
- avoid watching TV in your bedroom
- keep a notepad by your bed so that if you think of something you need to do the next day you can write it down and then put it out of your mind
• relax and try gentle exercise as this can reduce muscle tension.

Cognitive behavioural therapy (CBT) may be helpful for some people who have severely disrupted sleep.

See Arthritis Research UK booklets Fatigue and arthritis; Sleep and arthritis.

What else can I do to ease my fibromyalgia?

Fibromyalgia varies from person to person. We suggest you try some of the following tips to find out what works for you:

• Learn about fibromyalgia. Understanding the condition can help to reduce any fear and anxiety about it.
• Find out if there’s a support group in your area, or think about joining an online fibromyalgia forum or expert patient programme. Discussing your experiences with others who have fibromyalgia may help.
• Encourage your family and friends to find out more and discuss your condition with you – you could show them this information to help you explain your experiences. It’s especially important that they understand you may be in severe pain even if you look well.
• Learn to take time out for yourself to relax your mind and your muscles.
• Try the medications your doctor has to offer and discuss which ones are helpful.
• Find more effective ways of communicating feelings such as anxiety or anger. Counselling or CBT can help to break the vicious circle of anxiety, depression and pain and has helped many people keep their pain under control – your GP will be able to refer you.
• Unhappiness at home or work can make fibromyalgia pain feel worse. Addressing the causes of this unhappiness could help. Ask for help from people at your place of work, such as a friend, colleague or manager. You can also seek advice from experts such as occupational therapists, a Jobcentre Plus office and the Citizens Advice Bureau. They can work with you and your employer to find the best solution for everyone.

• Some people have found that meditation helps relieve their pain.

**Self-help guide**

A new self-help guide has been launched aimed at people with long-term pain who don’t know where to turn to find the relief they desperately need. *Living with long-term pain: a guide to self-management* has been produced by Arthritis Research UK and aims to offer a lifeline to those people who feel they have exhausted the usual avenues of NHS treatment. See the back of this booklet for details on how to order or download this guide.

See Arthritis Research UK booklet *Work and arthritis*.

**Research and new developments**

Arthritis Research UK is currently funding a three-year trial, called the MUSICIAN study, into chronic widespread pain (which includes fibromyalgia). Its aim is to develop and evaluate new interventions at the general practice level that can be available to a large number of patients and are acceptable, convenient and inexpensive to provide.

Researchers will evaluate the results of CBT (delivered by telephone) and gym-based exercise to determine whether these treatments (alone or together) result in an improvement of symptoms.

Arthritis Research UK are also funding many other projects. Alongside the University of Nottingham and local NHS Trusts, Arthritis Research UK are proud to support the world’s first national centre for research into understanding the mechanisms of pain in arthritis.

The Arthritis Research UK Pain Centre aims to:

• investigate how people experience pain to understand its biological basis in arthritis

• develop new drugs to treat pain more effectively

• improve the effectiveness of available pain-relief drugs

• investigate basic pathways of pain perception to identify new targets for developing treatments.

Experts in rheumatology, neuro-imaging, psychology, neuropharmacology, neurosciences and orthopaedic surgery will all play major roles in realising the ambitions of the centre, funded over five years by £2.5m from Arthritis Research UK and a further £3m from the University of Nottingham.
Glossary

**Acupuncture** – a method of pain relief that originated in China. Very fine needles are inserted, virtually painlessly, at a number of sites on your skin (meridians) but not necessarily at the painful area. This interferes with pain signals to your brain and causes the release of natural painkillers (endorphins).

**Antidepressants** – drugs that are designed to relieve depression. There are many different antidepressant drugs, some of which are also used to relieve pain or to help with sleep disruption. Examples include fluoxetine and paroxetine.

**Autoimmune disease** – a disorder of the body’s defence mechanism (immune system) in which antibodies and other components of the immune system attack the body’s own tissue rather than germs, viruses and other foreign substances.

**Chiropractor** – a specialist who treats mechanical disorders of the musculoskeletal system, often through spine manipulation or adjustment. The General Chiropractic Council regulates the practice of chiropractic in the UK.

**Cognitive behavioural therapy (CBT)** – a therapy based on the assumption that most of a person’s thought patterns and emotional or behavioural reactions are learned and can therefore be changed. The therapy aims to help people resolve difficulties by learning more positive thought processes and reactions.

**Fatigue** – a feeling of weariness that’s more extreme than simple tiredness. It can affect you physically, but it can also affect your concentration and motivation, and often comes on for no apparent reason and without warning.

**Flare-up** – a period where symptoms are worse than normal, sometimes known as a ‘flare’.

**Ligaments** – tough, fibrous bands anchoring the bones on either side of a joint and holding the joint together. In the spine they’re attached to the vertebrae and restrict spinal movements, therefore giving stability to the back.

**Lupus (systemic lupus erythematosus or SLE)** – an autoimmune disease in which the immune system attacks the body’s own tissues. It can affect the skin, the hair and joints and may also affect internal organs. It’s often linked to a condition called antiphospholipid syndrome (APS).

**Nervous system** – the network of nerves that send signals back and forth from the brain to different parts of the body.

**Occupational therapist** – a trained specialist who uses a range of strategies and specialist equipment to help people reach their goals and maintain their independence by giving practical advice on equipment, adaptations or by changing the way they do things (such as learning to dress using one-handed methods following hand surgery).

**Osteopath** – a trained specialist who treats spinal and other joint problems by manipulating the muscles and joints in
order to reduce tension and stiffness, and so help the spine to move more freely. The General Osteopathic Council regulates the practice of osteopathy in the UK.

**Physiotherapy** – a therapy given by a trained specialist that helps to keep your joints and muscles moving, helps ease pain and keeps you mobile.

**Rheumatoid arthritis** – an inflammatory disease affecting the joints, particularly the lining of the joint. It most commonly starts in the smaller joints in a symmetrical pattern – that is, for example, in both hands or both wrists at once.

**Tendon** – a strong, fibrous band or cord that anchors muscle to bone.

**Where can I find out more?**

If you’ve found this information useful you might be interested in these other titles from our range:

**Therapies**
- *Occupational therapy and arthritis*
- *Physiotherapy and arthritis.*

**Self-help and daily living**
- *Complementary and alternative medicine for arthritis*
- *Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia (63-page special report)*
- *Diet and arthritis*
- *Fatigue and arthritis*
- *Keep moving*
- *Living with long-term pain: a guide to self-management*
- *Pain and arthritis*
- *Practitioner-based complementary and alternative therapies for the treatment of rheumatoid arthritis, osteoarthritis, fibromyalgia and low back pain (66-page special report)*
- *Sleep and arthritis*

**Drug leaflets**
- *Amitriptyline*
- *Drugs and arthritis*
- *Painkillers*

You can download all of our booklets and leaflets from our website or order them by contacting:

**Arthritis Research UK**
Copeman House
St Mary’s Court
St Mary’s Gate, Chesterfield
Derbyshire S41 7TD
Phone: 0300 790 0400
www.arthritisresearchuk.org

**Related organisations**
The following organisations may be able to provide additional advice and information:

**Arthritis Care**
Floor 4, Linen Court
10 East Road
London N1 6AD
Phone: 0207 380 6500
Helpline: 0808 800 4050
Email: info@arthritiscare.org.uk
www.arthritiscare.org.uk
**Further reading**

The following books may be useful if you want to find out more about fibromyalgia. They're available from bookshops or libraries, not from Arthritis Research UK.


Links to sites and resources provided by third parties are provided for your general information only. We have no control over the contents of those sites or resources and we give no warranty about their accuracy or suitability. You should always consult with your GP or other medical professional.
We’re here to help

Arthritis Research UK is the charity leading the fight against arthritis. We’re the UK’s fourth largest medical research charity and fund scientific and medical research into all types of arthritis and musculoskeletal conditions.

We’re working to take the pain away for sufferers with all forms of arthritis and helping people to remain active. We’ll do this by funding high-quality research, providing information and campaigning.

Everything we do is underpinned by research.

We publish over 60 information booklets which help people affected by arthritis to understand more about the condition, its treatment, therapies and how to help themselves.

We also produce a range of separate leaflets on many of the drugs used for arthritis and related conditions. We recommend that you read the relevant leaflet for more detailed information about your medication.

Please also let us know if you’d like to receive our quarterly magazine, Arthritis Today, which keeps you up to date with current research and education news, highlighting key projects that we’re funding and giving insight into the latest treatment and self-help available.

We often feature case studies and have regular columns for questions and answers, as well as readers’ hints and tips for managing arthritis.

Tell us what you think

Please send your views to: feedback@arthritisresearchuk.org or write to us at: Arthritis Research UK, Copeman House, St Mary’s Court, St Mary’s Gate, Chesterfield, Derbyshire S41 7TD

A team of people contributed to this booklet. The original text was written by Dr Robert Bernstein, who has expertise in the subject. It was assessed at draft stage by rheumatology specialist registrar Dr Laura Connell, RCGP clinical champion for chronic pain Dr Martin Johnson, nurse consultant in rheumatology Sarah Ryan, impact chronic pain nurse Nicola Stanyer and chair of FMA UK Pam Stewart. An Arthritis Research UK editor revised the text to make it easy to read, and a non-medical panel, including interested societies, checked it for understanding. An Arthritis Research UK medical advisor, Prof. Anisur Rahman, is responsible for the content overall.
Get involved

You can help to take the pain away from millions of people in the UK by:

• volunteering
• supporting our campaigns
• taking part in a fundraising event
• making a donation
• asking your company to support us
• buying products from our online and high-street shops.

To get more actively involved, please call us on 0300 790 0400, email us at enquiries@arthritisresearchuk.org or go to www.arthritisresearchuk.org