

Fibromyalgia

This booklet provides information and answers to your questions about this condition.



What is fibromyalgia?



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 in the booklet.

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At a glance

Fibromyalgia

Although fibromyalgia isn't life-threatening, it can have a major impact on your daily living.

What is fibromyalgia?

Fibromyalgia is a common condition. 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 pain in the muscles
- tiredness (fatigue) or lack of energy
- sleep disorders
- headache
- 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 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 – this may be related to chemical changes in the body's pain pathways. The pain has no inflammatory or degenerative (progressive deterioration) cause, and there won't be any lasting damage to the body.

What treatments are there?

A team of health professionals could be involved in your treatment and may be able to offer:

- low-dose antidepressants, which can relieve muscle pain and improve sleep
- muscle relaxants
- drugs to treat the pain
- cognitive behavioural therapy (CBT)
- physiotherapy.

How can I help myself?

There are a number of things you can do in addition to help ease your symptoms:

- Pace your daily activities.
- Exercise, such as swimming, walking or cycling.
- Share your experience with other people.
- Tackle any stress or unhappiness at home or at work.
- Avoid tea, coffee and alcohol close to bedtime.
- Eat a balanced diet and keep to a healthy weight.





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 or 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 – so it won't cause permanent damage to your muscles, bones or joints.

What are the symptoms of fibromyalgia?

Usually there are no outward signs of the condition. Widespread pain in the muscles, tiredness and sleep disturbance are the main symptoms of fibromyalgia, but the severity of 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 tiredness (fatigue) is the worst aspect of the condition. 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 feels 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 appreciate 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 a bit down
- forgetfulness or poor concentration
- feeling an urgent need to urinate, especially at night
- irritable or uncomfortable bowels (diarrhoea or constipation and abdominal pain).

How is fibromyalgia diagnosed?

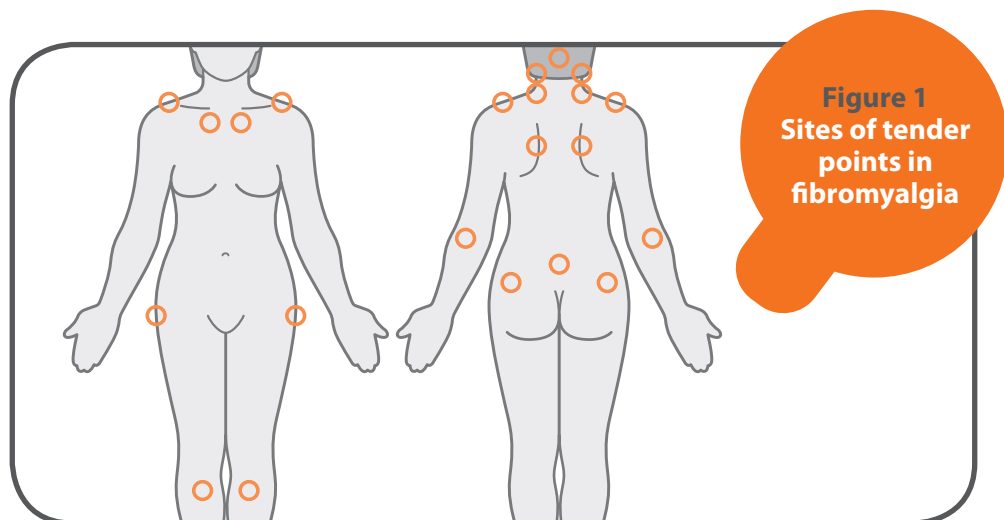
Fibromyalgia is often difficult to diagnose as the symptoms vary considerably and could have other causes. They can be similar to the symptoms of other conditions, for example an underactive thyroid gland (hypothyroidism). There aren't any specific blood tests, x-rays or scans that can confirm a diagnosis of fibromyalgia, but your doctor may suggest blood tests to rule out other conditions.

The diagnosis of fibromyalgia is based on the presence of specific tender points in certain areas of the body (see Figure 1). These areas can be tender even when pressed very gently. While tenderness can occur at individual sites in other conditions, for example tennis elbow, in fibromyalgia there is tenderness in many different parts of the body – usually 11 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 seem worse. At the same time, being in pain can lead to stress and anxiety. Many fibromyalgia patients 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. The pain people with fibromyalgia feel doesn't have a physical cause but is something to do with the way the brain processes pain. This doesn't mean that the feeling of pain is any less real, but because there's no physical reason for the pain, fibromyalgia doesn't cause any permanent joint damage.



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 could be related to chemical changes in the pain pathways in the body.

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

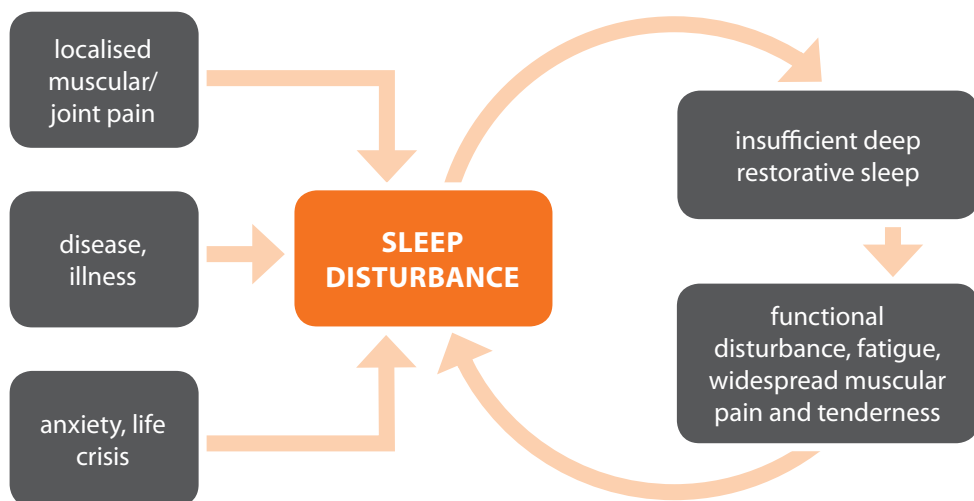
- depression brought on by illness or unhappy events.

i 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.

i See Arthritis Research UK booklets *Pain and arthritis; Sleep and arthritis.*

Figure 2 The cycle of pain and sleep disturbance



Simple painkillers like paracetamol can help to ease your symptoms.

What are the associated conditions?

Some people who have fibromyalgia also report being affected by some of the following conditions:

- chronic tiredness (fatigue)
- headaches
- joint pain in various parts of the body
- restless leg syndrome – spasms in either or both legs (a few people report having spasms in the arms as well)
- 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 myalgic encephalomyelitis (ME), or ‘chronic fatigue syndrome’. People with ME 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. However, there are ways of managing your symptoms and 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.

Paracetamol can help to relieve pain.

Drugs such as low-dose amitriptyline and dosulepin can reduce muscle pain and improve sleep patterns in people with fibromyalgia. These drugs need to be taken 2–3 hours before you settle at night. The benefit may not be immediate 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. A period of 6 weeks is required to assess whether these drugs are helpful.

Duloxetine can help with pain and sleep disturbance.

i See Arthritis Research UK leaflet *Drugs and arthritis*.

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.

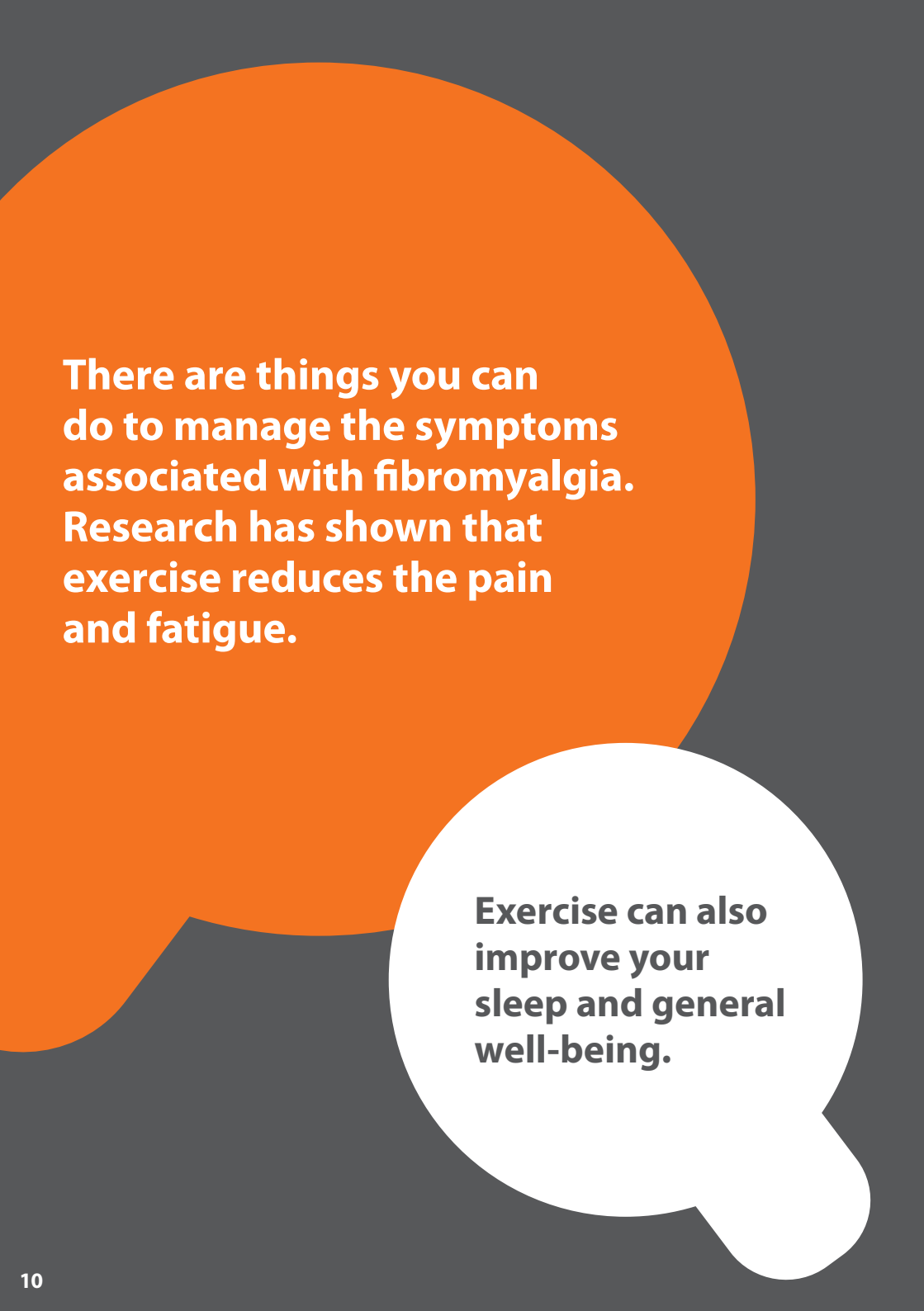
Occupational therapy

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.

i See Arthritis Research UK booklets

*Occupational therapy and arthritis;
Physiotherapy and arthritis.*





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.

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.

i See Arthritis Research UK booklet
Keep Moving.

! 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 or 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 levels.

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.

i See Arthritis Research UK booklet
Diet and arthritis.

Complementary medicines

Treatments like massage, acupuncture, physiotherapy and manipulation by a chiropractor or osteopath may temporarily ease the pain and discomfort for some people with fibromyalgia.

Some trials have shown that capsaicin gel (only available on prescription) and homeopathy may be helpful. However, the evidence is not strong enough for these treatments to be recommended for fibromyalgia.

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.

i See Arthritis Research UK booklet and special report *Complementary and alternative medicine for arthritis; Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia.*

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 ensure you get a better night's sleep:

- avoid alcohol, tea or coffee late at night
- develop a sleep routine, settling down and getting up at the same time each day
- 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.

i 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 lessen 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. 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 medication your doctor has to offer and discuss which ones are helpful.

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Fibromyalgia

- Find more effective ways of communicating feelings such as anxiety or anger. Counselling or cognitive behavioural therapy (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.

i 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 cognitive behavioural therapy (delivered by telephone) and gym-based exercise to determine whether these treatments (alone or together) result in an improvement of symptoms.

Arthritis Research UK is 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 the biological basis of pain in arthritis
- develop new drugs to treat pain more effectively
- improve the effectiveness of currently 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

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.

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.

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

Occupational therapist – a therapist who helps you to get on with your daily activities (e.g. dressing, eating, bathing) by giving practical advice on aids, appliances and altering your technique.

Osteopath – a 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.

Physiotherapist – a therapist who helps to keep your joints and muscles moving, helps ease pain and keeps you mobile.

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 (80-page special report)*
- *Diet and arthritis*
- *Fatigue and arthritis*
- *Keep moving*
- *Pain and arthritis*
- *Sleep and arthritis*

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

Arthritis Research UK

PO Box 177
Chesterfield
Derbyshire S41 7TQ
Phone: 0300 790 0400
www.arthritisresearchuk.org

Related organisations

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

Arthritis Care

18 Stephenson Way
London NW1 2HD
Phone: 020 7380 6500
Helpline: 0808 800 4050
www.arthritiscare.org.uk

Fibroaction

46 The Nightingales
Newbury RG14 7UJ
Phone: 0844 443 5422
www.fibroaction.org

Fibromyalgia Association UK

P O Box 206
Stourbridge DY9 8YL
Phone: 01384 895002
Helpline: 0845 345 2322
www.fibromyalgia-associationuk.org

Fibromyalgia in Wales

Phone: 07885 488288
Email: mail@fibro-wales.com
www.fibro-wales.com

Pain Relief Foundation

Clinical Sciences Centre
University Hospital Aintree
Lower Lane
Liverpool L9 7AL
Phone: 0151 529 5820
www.painreliefoundation.org.uk

Further reading

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

Living with Fibromyalgia by Christine Craggs-Hinton. Sheldon Press 2000.
ISBN 9780859698313.

Fibromyalgia: Understanding and Getting Relief from Pain That Won't Go Away by Don L Goldenberg. Piatkus Books 2002. ISBN 9780749923068.

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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 of our booklet

Please send your views to:
feedback@arthritisresearchuk.org
or write to us at:
Arthritis Research UK, PO Box 177,
Chesterfield, Derbyshire S41 7TQ.

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 clinical nurse specialist Natasha Banya, Brian McFarland and Dr Sarah Ryan. 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, Dr Ben Thompson, 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 gifts from our catalogue

To get more **actively involved**, please
call us **0300 790 0400** or e-mail us at
enquiries@arthritisresearchuk.org

Or go to:
www.arthritisresearchuk.org

Providing answers today and tomorrow



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calls charged at standard rate

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