

FIBROMYALGIA

An Information Booklet



Committed to curing arthritis

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About this booklet

This booklet is written for people with fibromyalgia and their families and friends. It explains how fibromyalgia affects people in different ways, and how doctors diagnose it. We then explain what can be done to help with the symptoms, and offer tips and advice on living with it more easily. Near the end of the booklet you will find information on how to contact the Arthritis Research Campaign (**arc**) and other organisations which can provide information, and a few suggestions for further reading. Terms that appear in *italics* when they are first used are explained in the glossary at the back of the booklet.

What is fibromyalgia?

Fibromyalgia is a name for widespread pain affecting the muscles but not the joints. It will not cause permanent damage to tissues but the symptoms may last for months or years. There are no outward signs of the condition and people with fibromyalgia often look well but feel awful. Because of this, other people may not appreciate the pain and tiredness you are suffering and this can cause additional distress. Fibromyalgia is a common condition and is sometimes so severe that it affects your work and your personal and social life. In fibromyalgia the *tendons* and *ligaments*, or fibrous tissues (**fibro-**), and the muscles (**-my-**) are affected by pain (**-algia**) and tenderness. The pain may feel as though it affects the whole body.

There are usually tender points in certain areas of the body. These help the doctor to make the diagnosis. If enough pressure is applied to these places most people will find it uncomfortable, but in fibromyalgia there is a change in the threshold at which pressure causes pain and many of these points can be extremely tender. Tenderness at individual sites sometimes occurs and

this can give rise to localised conditions such as tennis elbow. In fibromyalgia, however, there is tenderness at a number of points.

In the past fibromyalgia was often diagnosed as muscular rheumatism or fibrositis, or it was misdiagnosed as degenerative disease of the joints (signs of wear and tear are very common on spine x-rays as we get older, whether there is pain or not). Research in the past few years has led to a clearer picture of what we mean by fibromyalgia, and the diagnosis is being made more often by rheumatologists and general practitioners (GPs).

What are the symptoms of fibromyalgia?

Pain, tiredness and sleep disturbance are the main symptoms of fibromyalgia. Most people feel the pain of fibromyalgia as aching, stiffness and tiredness in the muscles around the joints. It may feel worse first thing in the morning, or as the day goes on, or with activity. It may affect one part of the body or several different areas such as the limbs, neck and back.

Sometimes tiredness (fatigue) can be the most severe aspect of fibromyalgia. There may be overall tiredness and lack of energy, or muscular fatigue and loss of stamina. Either way, it can be difficult to climb the stairs, do the household chores, go shopping or go to work. Becoming less fit makes matters worse. Waking in the morning feeling unrefreshed is common.

Less frequent but still troublesome symptoms include:

- poor circulation – tingling, numbness or swelling of the hands and feet
- headache, irritability or feeling low or weepy
- forgetfulness or poor concentration
- feeling an urgent need to pass water
- irritable bowels (diarrhoea and abdominal pain).

Of course symptoms like these can have other causes, and your doctor can help decide whether any further tests or advice are needed. The severity of the symptoms and the effects of fibromyalgia can vary considerably, and this range of severity can cause problems in diagnosing the condition and lead to varying medical opinions. A particular feature of fibromyalgia is the need to have the symptoms recognised and to be taken seriously.

Is fibromyalgia similar to chronic or postviral fatigue (ME)?

The symptoms described in myalgic encephalomyelitis (ME) are often very similar to those in fibromyalgia except that ME sufferers can often recall a viral infection before symptoms appeared, and may have less pain. Many doctors use the term ‘chronic fatigue syndrome’ rather than ME. More needs to be known about these conditions before we are able to say whether they are the same thing.

What causes fibromyalgia?

There is now a clearer understanding that illness is not easily divided into physical or mental, and that there is an interaction between them. Fibromyalgia is an illness involving both the mind and the body. Sometimes this is called a functional disturbance.

Research into fibromyalgia has been stimulated by the finding of specific tender points and the discovery of sleep disturbance. Brain wave studies (*electroencephalography*, or *EEG*) during sleep have revealed that people with fibromyalgia lose deep sleep. Deep (non-dreaming), ‘restorative’ sleep is repeatedly and excessively disturbed by lighter, dreaming (*rapid eye movement*, or *REM*) sleep.

In an experiment, some healthy people who were woken up in each period of deep sleep suffered the typical symptoms and tender points of fibromyalgia.

Several things could cause the disturbance of deep sleep that can produce fibromyalgia. More than one cause may be affecting any particular individual. Pain or stiffness in the neck may disturb sleep. There may be the pain and stress of an injury or of another disease like arthritis. Emotional pain and the strain of anxiety or depression brought on by events or relationships at home or at work may also be important factors, as may abuse in childhood.

Once fibromyalgia sets in there is a vicious circle of pain and sleep disturbance (see Figure 1). This can be enough to cause depression even if this was not a problem initially. When fibromyalgia is obviously associated with another condition like arthritis or depression it is called 'secondary' (i.e. caused by the other condition). When it seems to be occurring alone it is called 'primary'.

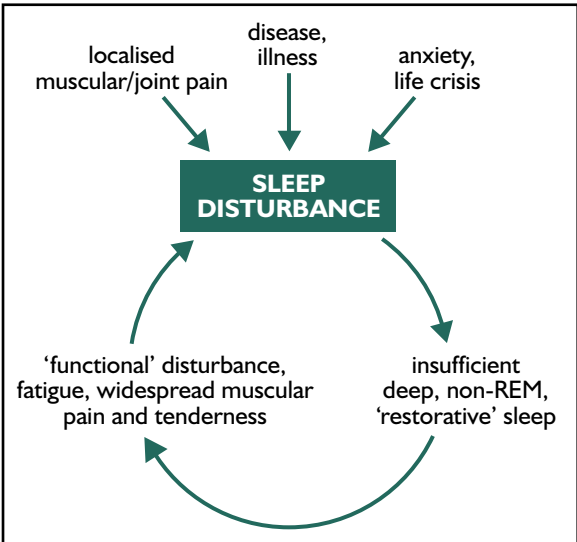


Figure 1. The cycle of pain and sleep disturbance

Research is being carried out to find out whether chemical changes in the nervous system might cause increased sensitivity (known as sensitisation) to pressure or relatively minor knocks which would not normally be painful.

How can fibromyalgia be treated?

There is no overnight cure for fibromyalgia but with the help of your doctor and family it is possible to find ways of managing your symptoms so that you can continue with your normal activities. Fibromyalgia may settle down by itself, but this can take weeks, months or even years. Your doctor may be able to help you by making the diagnosis of fibromyalgia and reassuring you that despite all the pain you don't have a condition that will cause permanent disability. You are no more likely to develop arthritis later on than anyone else. Your family can also help with understanding and encouragement.

Your doctor can prescribe a variety of medications which may help with the pain. These include painkillers such as paracetamol and *non-steroidal anti-inflammatory drugs (NSAIDs)* (of which there are many). A steroid injection in the affected area may give temporary relief if one or two places are particularly painful.

Your doctor can also try to help with the sleep disturbance. Sleeping in a soft collar can help some people sleep better, particularly if the neck is uncomfortable. There is no harm in you trying this for a week or so, providing you do not get into the habit of wearing it during the day. Ordinary sleeping tablets are best avoided because they are often habit-forming and eventually lose their effect.

Many people with fibromyalgia can also be helped by an antidepressant drug. Some of the older antidepressants

(e.g. amitriptyline) have been found to be effective for long-term (chronic) pain. They may also have a sedative effect and help to restore a sleep pattern. This can be helpful even if you do not have the depression which is often associated with fibromyalgia. The benefit may not be immediate, and you may notice side-effects – usually drowsiness during the day – before the benefits, so it is worth trying for at least a couple of months before deciding if they are helpful. Your doctor will gradually raise the dose to an effective level.

Your doctor may also refer you to a physiotherapist, an occupational therapist or a counsellor for further information and advice about fibromyalgia. However, the most effective therapist will be you, yourself.

How can I treat my own fibromyalgia?

It is worth facing up to the fact that fibromyalgia can be severe, and may last for several years. The good news is that many people have learnt to control their condition so that they can continue to live their lives enjoyably. People with fibromyalgia tell us that the following advice does work and will help if you persevere.

1. Learn more about fibromyalgia (from this booklet and from other sources) and find out if there is a local support group in your area. Sharing the frustration of having this condition and knowing that other people out there have similar problems can help some people enormously.
2. Ask your family to read this booklet and, if you want to, encourage them to discuss your condition with you. Your illness will be affecting their lives as well and they will need to know how and when to help you.
3. Try the medication your doctor has to offer and then decide if you want to continue taking it.

4. Don't drink alcohol, tea or coffee late at night, as these may disturb your sleep. Relaxation and gentle exercise can help you sleep.
5. Learn to take time out for yourself. Reduce muscle tension. Learn to relax your mind and your muscles. Playing music or an audio tape about relaxation techniques can also help.
6. Find more effective ways of communicating feelings such as anger. Counselling or *cognitive behavioural therapy* may help and your GP may be able to refer you.
7. Try to sort out any unhappiness or difficulties at home or at work.
8. Eat healthily and keep your weight down.

What about exercise?

Research has shown that aerobic exercise improves fitness and reduces pain and fatigue in people with fibromyalgia. This needn't mean joining an 'aerobics' class (unless you want to). Aerobic exercise means increasing the circulation of oxygen through the blood, so any brisk exercise which gets you breathing heavily and your heart beating faster can be aerobic.

Swimming is one of the best forms of exercise for fibromyalgia. Many people who have not learned to swim find the effort to do so is well worthwhile.

Try different activities to find out what helps you and gradually try to do more each day, pacing yourself and gradually increasing your physical activity. You must be prepared for setbacks, and for the fact that activity may cause pain initially. Remember too that what helps one person with fibromyalgia may not work so well for another.

Don't be overambitious about your progress. Slow and steady is better. If you feel that walking down the road is

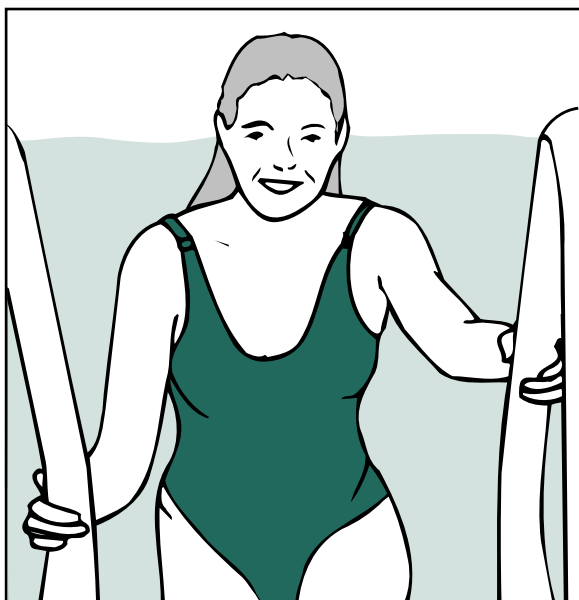


Figure 2. Swimming is an excellent form of exercise.

more than you can manage, start by counting the houses you pass each day and after some time you will find you're counting the streets. If you go swimming (and warmer water is more soothing), start just by standing and moving your arms and legs against the resistance of the water, then go on to lengths, and eventually you could be doing the sort of exercise you used to do.

You must expect exercise to be painful initially and you may also feel tired. Build up your exercise at a rate you can cope with. Start gently and build up to at least 3 hours of exercise each week. It is often better to do 10 minutes and have a break than to do an hour all in one go. If pain and tiredness increase a lot, then don't do quite so much the next day.

Exercising progressively will improve your fitness, flexibility and stamina. Gradually your muscles will become stronger and there will be more muscle fibres to move

your limbs smoothly and avoid jarring of tendons and ligaments. Exercise also promotes sleep and improves your sense of well-being.

Other forms of treatment

No particular diet has been shown to help fibromyalgia, but it is sensible to lose excess weight and to avoid drinking too much coffee and tea. Controlling your diet helps you feel in control of your body.

Treatments like massage, acupuncture, physiotherapy, and manipulation from a chiropractor or osteopath can all soothe pain and improve morale, but the benefits may not be long-lasting. Only you can decide whether the benefits are worth the time and expense.

Exercise, sound sleep and dealing with physical or mental stress are the keys to reducing the pain and fatigue of fibromyalgia. Going to work can help. Until research provides us with better answers you should aim for self-reliance.

Glossary

Cognitive behavioural therapy – a psychological treatment based on the assumption that most of a person's thought patterns and his/her emotional and behavioural reactions are learned and can therefore be changed. The therapy usually focuses on the person's present difficulties rather than the past. The aim is to help the individual to learn more positive thought processes and reactions.

Electroencephalography (EEG) – a technique for recording the electrical activity from different parts of the brain.

Ligaments – tough, fibrous bands anchoring the bones on either side of a joint and holding the joint together.

Non-steroidal anti-inflammatory drugs (NSAIDs) – a large family of drugs prescribed for different kinds of arthritis, which reduce inflammation and control pain, swelling and stiffness (see **arc** leaflet ‘Non-Steroidal Anti-Inflammatory Drugs’).

Rapid eye movement (REM) sleep – light sleep during which brain activity is increased and the eyes move very quickly behind the eyelids. It is thought that most dreaming occurs during REM sleep. A normal sleep pattern consists of several cycles of REM sleep and deeper, more restful sleep, with REM sleep making up about 25% of the total sleeping time. Too much REM sleep can lead to waking feeling unrefreshed.

Tendons – strong fibrous bands or cords that anchor muscles to bone.

Further reading

Living with Fibromyalgia by Christine Craggs-Hinton. Sheldon Press 2000. 159 pages. ISBN 0859698319.

Inside Fibromyalgia by Mark Pellegrino. Anadem Publishing 2001. 348 pages. ISBN 1890018368.

Useful addresses

The Arthritis Research Campaign (arc)

PO Box 177
Chesterfield
Derbyshire S41 7TQ
www.arc.org.uk

As well as funding research, we produce free booklets such as this and a range of many others. Please see the list of titles at the back of this booklet.

Arthritis Care

18 Stephenson Way

London NW1 2HD

Tel: 020 7380 6500

Helplines: 020 7380 6555 (10am–4pm Mon–Fri)

or freephone: 0808 800 4050 (12pm–4pm Mon–Fri)

www.arthritiscare.org.uk

Offers self-help support, a helpline service (on both numbers above), and a range of leaflets on arthritis.

Fibromyalgia Association UK

PO Box 206

Stourbridge

West Midlands DY9 8YL

Helpline: 0870 220 1232 (10am–4pm Mon–Fri)

www.fibromyalgia-associationuk.org

STIFF(UK)

PO Box 1484

Newcastle-under-Lyme

Staffs ST5 7UZ

01782 562366 (as a call-back service 11am–4pm)

www.stiffuk.org

Booklets and leaflets

These free booklets and leaflets are available from **arc**. To get copies, please send for our order form (stock code 6204) which gives a summary of the topics covered in each publication. Alternatively, write to: **arc** Trading Ltd, James Nicolson Link, Clifton Moor, York YO30 4XX **for up to 3 titles**.

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Polymyositis and Dermatomyositis
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DRUG INFORMATION

Drugs and Arthritis (general info.)
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Anakinra
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Cyclosporin
Etanercept
Gold by Intramuscular Injection
Hydroxychloroquine
Infliximab
Leflunomide
Local Steroid Injections
Methotrexate
Non-Steroidal Anti-Inflammatory Drugs
Penicillamine
Steroid Tablets
Sulphasalazine

PARTS OF THE BODY

Back Pain
Feet, Footwear and Arthritis
Joint Hypermobility
Knee Pain in Young Adults
A New Hip Joint
A New Knee Joint
Pain in the Neck
The Painful Shoulder
Shoulder and Elbow Joint Replacement
Tennis Elbow

TREATMENT

Blood Tests and X-Rays for Arthritis
Complementary Therapies
Hand and Wrist Surgery
Hydrotherapy and Arthritis
Occupational Therapy and Arthritis
Pain and Arthritis
Physiotherapy and Arthritis

LIFESTYLE

Are You Sitting Comfortably?
Caring for a Person with Arthritis
Diet and Arthritis
Driving and Your Arthritis
Gardening and Arthritis
Keep Moving
Looking After Your Joints (RA)
Pregnancy and Arthritis
Sexuality and Arthritis
Sports Injuries
Stairlifts and Homelifts
Work and Arthritis
Work-Related Rheumatic Complaints
Your Home and Arthritis

JUVENILE ARTHRITIS

Arthritis in Teenagers
Growing Pains (for children)
Tim Has Arthritis (for children)
When a Young Person Has Arthritis (for schoolteachers)
When Your Child Has Arthritis

Arthritis Research Campaign



The Arthritis Research Campaign (**arc**) is the only major UK charity funding research in universities, hospitals and medical schools to investigate the cause and cure of arthritis and other rheumatic diseases. We also produce a comprehensive range of over 80 free information booklets and leaflets covering different types of arthritis and offering practical advice to help in everyday life.

arc receives no government or NHS grants and relies entirely on its own fundraising efforts and the generosity of the public to support its research and education programmes.

Arthritis Today is the quarterly magazine of **arc**. This will keep you informed of the latest treatments and self-help techniques, with articles on research, human interest stories and fundraising news. If you would like to find out how you can receive this magazine regularly, please write to: Arthritis Research Campaign, Ref AT, PO Box 177, Chesterfield S41 7TQ.

How we raise our funds

We constantly need to raise money by our own efforts to fund our work.

As well as a head office fundraising team we have an extensive network of regional staff, volunteer fund-raising groups and charity shops throughout the UK.



Photo courtesy of the Eastbourne Gazette

Where our money goes

Every year, we raise approximately £24 million to fund around 350 research projects across the whole of the UK.

In addition, **arc** funds the Kennedy Institute of Rheumatology in central London, at a cost of £3.1 million per year. We also set up the Arthritis Research Campaign

Epidemiology Unit in Manchester, currently funded at £1.6 million a year, which collates data on arthritis and its cost to the community.



Please add any comments on how this booklet could be improved.

Feedback is very valuable to **arc**. However, due to the volume of correspondence received, we regret that we cannot respond to individual enquiries made on this form.

Please return this form to: Arthritis Research Campaign, PO Box 177, Chesterfield S41 7TQ

The Arthritis Research Campaign was formerly known as the Arthritis and Rheumatism Council for Research. Registered Charity No. 207711.



A team of people contributed to this booklet. The original text was written by a doctor with expertise in the subject. It was assessed at draft stage by doctors, allied health professionals, an education specialist and people with arthritis. A non-medical editor rewrote the text to make it easy to understand and an **arc** medical editor is responsible for the content overall.



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