



# FIBROMYALGIA

## What it is and How it differs from ME/CFS

ME CONNECT HELPLINE: **FREEPHONE 0808 801 0484**

by **Dr Charles Shepherd**

Hon Medical Adviser to the MEA

### INTRODUCTION

Fibromyalgia (FM) is the name given to a fairly common condition that causes widespread pain and tenderness in the muscles (-my = muscle; -algia = pain), fibrous tissues (= tendons and ligaments) and sometimes the joints.

FM is believed to affect around 4% of the population, whereas ME/CFS has been estimated to affect 0.4%.

FM onset is often linked to some form of physical or mental stress such as infection or injury; childbirth, surgical operation, or bereavement. In other cases there is no obvious trigger.

FM is similar to ME/CFS in a number of respects:

- It commonly causes fatigue, sleep disturbance and other shared symptoms but the main symptom is pain.
- there is no diagnostic blood test and no curative treatment.
- management is based on pacing and the careful use of activities, with drugs to provide relief from pain.
- it is far more common in women than men (approx. 7:1 ratio).
- it can affect more than one family member but no genetic links have yet been identified.

The first symptoms tend to occur between the ages of 25 and 55. FM is uncommon in children and adolescents.

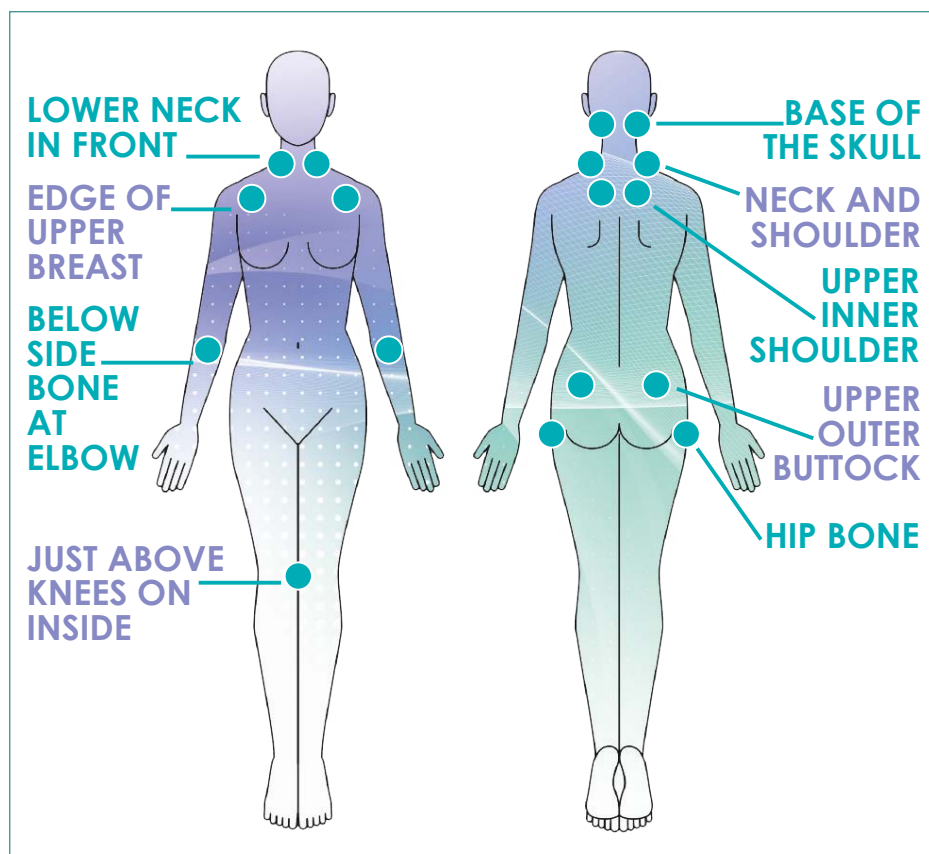


**Fibromyalgia – What it is and How it differs from ME/CFS** was written by Dr Charles Shepherd (pictured above), Trustee and Hon Medical Adviser to The ME Association.

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Note: Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your doctor. The ME Association recommends that you always consult your doctor or healthcare professional about any specific problem. We also recommend that any medical information provided by The MEA is, where appropriate, shown to and discussed with your doctor.



Earlier diagnostic guidelines produced by the American College of Rheumatology identified 18 specific sites around the body (nine on each side) where tenderness in FM is likely to be found.

The onset is often linked to some form of physical or mental stress such as an infection or injury; childbirth, surgical operation or bereavement. In other cases there is no obvious triggering event.

## WHAT ARE THE SYMPTOMS?

The main diagnostic symptoms are chronic pain and widespread tenderness upon examination.

Pain can occur in any part of the body. Pain in the neck and back can be particularly disabling. It can be described as burning, throbbing, shooting, or stabbing.

Pain is commonly exacerbated by physical activity and exertion, cold weather, and stress. Areas that are painful are often tender to touch. Stiffness can also accompany the pain and may be more prominent in the morning after sleep.

### Key Symptoms:

- Chronic pain.
- Diffuse tenderness on examination.

### Other Symptoms:

- Cognitive dysfunction: Problems with short-term memory, concentration, and attention span (aka 'brain fog').
- Depression and anxiety.
- Fatigue unrelieved by rest: This is very common and may be more disabling than the pain.
- Headaches.
- Irritable bowel symptoms: Stomach pains, bloating, changes in bowel habit, requery, urgency.
- Painful periods (dysmenorrhoea).
- Sensory disturbances: e.g., pins and needles sensations in fingers and toes. Some people also feel as though their fingers and toes are swollen.
- Sleep disturbance: People with FM often report feeling worse in the morning. This can be accompanied by what is called a restless legs syndrome – where there are unpleasant creeping or crawling sensations in the legs, often worse at night.



## THE OVERLAP WITH ME/CFS

There is a considerable degree of overlap, especially in relation to symptoms, between ME/CFS and FM.

Diagnosis is not always simple. Some healthcare professionals (HCPs) still refuse to acknowledge that FM and ME/CFS are different conditions - even though ME/CFS has its own NICE clinical guideline (FM is included in the 2021 NICE Guideline on Chronic Pain).

### 2020/21 Draft NICE Guideline ME/CFS:

<https://tinyurl.com/aatcs5t3>

### 2021 NICE Guideline on Chronic Pain:

<https://tinyurl.com/drfszwxh>

It is possible that HCPs will diagnose ME/CFS and FM together, believing them to be the same, or will talk about them being on the same spectrum.

Neurologists are more likely to diagnose ME/CFS, while rheumatologists are more likely to diagnose FM.

My personal view is that these two conditions are separate clinical entities with clear differences and some symptoms overlap.

If a person meets the diagnostic criteria for ME/CFS and has widespread pain and tenderness, then it is reasonable for a diagnosis of both FM and ME/CFS to be made.

## WHAT CAUSES FM?

Research into FM suggests that the problem lies in the nervous system and not in the muscles, fibrous tissues, or joints – even though this is where the pain is mainly felt.

- There are no pathological abnormalities in the joints so FM is not a degenerative joint disease like rheumatoid arthritis.

As with ME/CFS, there appear to be changes in the levels and activity of what are called neurotransmitters.

Neurotransmitters send instructions from the brain through the nervous system to target cells in muscles, glands or other nerve cells. The brain needs neurotransmitters to regulate essential bodily functions including heart-rate.

People with FM have an increased amount of a specific brain chemical called Substance P in the cerebrospinal fluid, the fluid that surrounds the brain and spinal cord. This finding may help to explain the heightened sensitivity to pain in fibromyalgia.

Abnormalities in the hypothalamic-pituitary-adrenal axis, mitochondrial function and poor perfusion of the tissues have also been reported – as they have in ME/CFS.

As to how this causes pain in the muscles, fibrous tissues and joints – when normally there is no evidence of obvious damage to these parts of the body - the current theory is that people with FM develop an oversensitivity to pain signals that are entering the brain. This is called central sensitisation.

There is also some interesting but limited evidence from neuroimaging studies (= brain scans) of structural and behavioural abnormalities in the brain.

In July 2021, an interesting pilot study was published that took antibodies from the plasma of a small group of people with FM and injected



them into mice. The mice were seen to display symptoms similar to those in FM. When the antibodies were removed, the mice returned to normal activities. The authors concluded this may mean FM is an autoimmune condition which could increase the opportunities for effective treatment. It is hoped that larger studies of this nature in FM and ME/CFS can be conducted in the near future.

**Research:** Passive transfer of fibromyalgia symptoms from patients to mice: <https://tinyurl.com/3wfvnyc9>

## CLINICAL DIAGNOSIS

As with ME/CFS, the diagnosis of FM has to be made on the patient's clinical history. In particular, the widespread pain should involve both sides of the body, be above and below the waist, as well as neck, back and pelvic area.

Any 'red flag' or uncharacteristic symptoms – e.g. bone pain, weight loss – should prompt further investigations to rule out other explanations for the symptoms.

There is no diagnostic blood test for FM – so investigations are arranged to make sure other conditions that can cause joint and muscle pain (e.g. rheumatoid arthritis, hypothyroidism, vitamin D deficiency) are excluded.

As with ME/CFS, confirmation of the diagnosis is often based on clinical judgement rather than a strict adherence to any of the published diagnostic criteria.

Where there are any indications from the clinical history or family history (e.g. a family member has rheumatoid arthritis) that the joint pain component could be due to an actual joint disease, an autoimmune screen is advisable.

This is to check for the presence of various antibodies and autoantibodies – e.g. anti-nuclear antibodies (ANA), anti-extractable nuclear antigen (ENA), rheumatoid factor, anti-cyclic citrullinated peptide (anti-CCP) – that are indicative or diagnostic of an inflammatory joint disease.

Physical examination is typically normal but there is often diffuse tenderness, which may be assessed by counting the number of tender points or by palpating several areas of the body – see diagram on page 1. This is a key difference between FM and ME/CFS.

**“The 1990 American College of Rheumatology published a diagnostic criteria that required an individual with FM to have widespread pain (front and back, right, and left, both sides of the diaphragm) for at least three months in addition to tenderness of at least 11 out of 18 designated tender point sites.**

**“More recent criteria do not require a tender point examination and focus instead on identifying widespread pain in combination with fatigue, memory, and sleep difficulties. Although there is not likely to be any single cause, substantial evidence suggests that this is in part a central nervous system-driven pain amplification syndrome.”**

Source: **British Medical Journal Best Practice:** <https://tinyurl.com/2e936tv4>

Diagnosis is highly likely where there are 11 or more tender points. The skin, joints and muscles should also be checked for any signs of underlying inflammation.

## HOW IS FM TREATED?

Management is based on pacing and the careful use of activities, with drugs to provide relief from pain.

## ACTIVITY MANAGEMENT

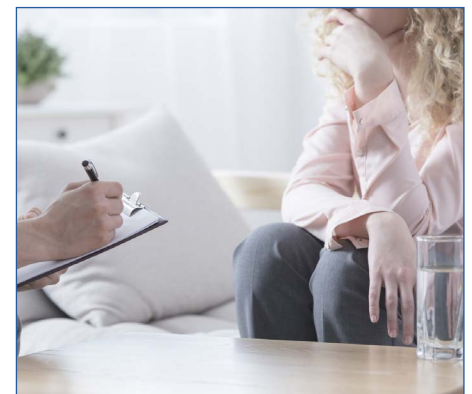
Most people with straightforward fibromyalgia can be diagnosed and managed in primary care. A referral to the local rheumatology department should be arranged if there is any suspicion of an inflammatory joint disease or where further help with management is required.

People with FM are often recommended aerobic exercise such as walking on a treadmill, using an exercise bicycle, going for brisk

walks, swimming, yoga, or stretching exercises – but not to the point where this exacerbates symptoms.

The emphasis tends to be a gradual but progressive increase in activity levels. This can be similar to **graded exercise therapy** – a controversial treatment in ME/CFS where increasing aerobic exercise is not recommended.

For people who have both FM and ME/CFS a safer form of activity management should be employed based on pacing and a very careful introduction of non-aerobic exercise only after symptoms have stabilised and/or started to improve.



## COGNITIVE BEHAVIOURAL THERAPY (CBT)

CBT may be helpful for people who are finding it hard to cope with the psychological and social consequences of having fibromyalgia. CBT should be tailored to your needs and provide an opportunity to discuss any problems that relate to living with FM. It is not a curative treatment but can help you learn how to cope with FM.

## PAINKILLERS

Over the counter painkillers such as aspirin, paracetamol and ibuprofen (Brufen) tend to be of limited value in treating FM pain – as they are in treating similar symptoms in ME/CFS.

If these drugs do not help, prescription-only painkillers such as a low dose of amitriptyline





(e.g. 10mg at night) or tramadol may be worth trying.

Pregablin and gabapentin can also be helpful for more severe pain in FM. Strong opiate/morphine painkillers are not normally recommended.

Although sleep is often disturbed and is unrefreshing, sleeping tablets are not normally prescribed.

**ANTIDEPRESSANTS**

The use of an antidepressant drug known as an SSRI (selective serotonin uptake reinhibitor) is another treatment option that can be considered.

**COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)**

There is very little evidence to show that CAM treatments such as homeopathy and aromatherapy, etc. are effective. However, some people find them helpful to reduce stress and cope better with their illness.

**Alternative and complementary approaches:**

<https://tinyurl.com/3uht4d32>

**WHAT ARE MY CHANCES OF RECOVERING?**

Prognosis is variable and not easy to predict. In some cases the symptoms gradually disappear over months or years. However, as with ME/CFS, this condition often turns into a chronic illness which varies in severity over a long period of time. FM does not affect life expectancy.

**Further information:**

Fibromyalgia UK:

<https://www.fmauk.org/>



**ME CONNECT**  
The Support and Information Service for people affected by ME/CFS/PVFS and Long Covid



**Freephone**  
**0808 801 0484**

For opening hours visit:  
[meassociation.org.uk/me-connect](https://meassociation.org.uk/me-connect)

Contact ME Connect  
**3 WAYS TO GET IN TOUCH:**  
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**ME Essential**

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Extract from the new NICE clinical guideline draft:  
*"Do not offer people with ME/CFS any therapy based on physical activity or exercise as a treatment or cure for ME/CFS - by Russell Fleming"*

**THE NEW NICE DRAFT GUIDELINE**  
The new NICE guideline is welcomed with cautious optimism. Russell Fleming reports.

**COVID VACCINES**  
Priorities, safety and making a decision - all in the enclosed leaflet written by Dr Charles Shepherd.

**ME AWARENESS WEEK**  
The most important week in the ME calendar takes place from 10th to 16th May.

**OUR CHRISTMAS APPEAL**  
Your support helped us to raise over £25,000!

**INTIMACY AND M.E.**  
A sensitive discussion regarding the difficulties in coping with intimacy when you have ME/CFS.





**ME Association Literature:**

The ME Association has the largest selection of free ME/CFS information leaflets in the UK on:

- Medical Management**
- Mental Health**
- ME Connect**
- Diet & Nutrition**
- General Information**
- Fundraising Leaflets**
- Benefits & Social Care**
- 'To Whom It May Concern' letters**

Download leaflets from our website here:

<https://meassociation.org.uk/fdwc>

